

Little Hearts Matter

Guide for Completing the DLA Form

It is important to remember when completing DLA forms that each child with complex heart disease is different. The following suggestions of information to include in your application are only general ideas. Some children will have a better quality of life, some a more difficult one - you must decide what to say about your child.

These sample answers have been developed to support families completing DLA applications for a child, say from age two or three to teenage years. LHM have a separate form sample form for babies, and are developing a form for teenagers.

Wherever possible, answer each question with four pieces of information:

- Describe the problems your child has with this activity
- Explain what help your child either gets or needs
- Explain why your child can't manage without this help
- Stress what is different compared to their peers.

Don't include the bold sub-headings, just make sure you have thought about each area wherever possible.

Tick yes or no for each section - make sure you read all the ideas in the sample answer box before ticking 'no' to make sure you aren't missing anything.

Complete the numbers at the end of each section as accurately as you can, if appropriate give a range of times.

Please refer to the rest of the Little Hearts Matter DLA pack for other guidance about claiming this allowance.

Phone or email the office (tel: 0121 455 8982 or info@lhm.org.uk) if you have any questions or would like some help.

Disability Living Allowance

Claim for a child under 16

Little Hearts Matter
Guide for completing
the DLA Form

Do not delay in returning this claim form as benefit can only be considered from the date we receive it.

You may find it easier to fill in the questions in this claim form if you read the Notes first. If you need help filling in any part of this form, phone on 0800 88 22 00.

Part I - About the child

Surname of family name

Other names in full

Any other surnames or family names the child has had

Sex

Male

Female

Address where the child lives

Postcode

Previous address if different in the last 3 years

Postcode

The child's date of birth

 / /

Letters

Numbers

Letter

Child reference number if you know it

What is the child's nationality

We may get in touch with you for more information

Part 2 - About the person claiming Disability Allowance for the child

Tell us about yourself here, not the child

Tell us your full name

Mr/Mrs/Miss/Ms

Your date of birth

/ /

Letters

Numbers

Letter

Your National Insurance (NI) number

This helps us arrange payments quickly.

Your address

Postcode

Previous address if you have moved in the last 3 years

Postcode

Daytime phone number where we can contact you or leave a message

Code

Number

Please tick the appropriate box

Home Work Mobile Fax Textphone

What is your relationship to the child?

For example, parent, step-parent (includes civil partner), foster parent, guardian, etc.

What is your nationality?

If you are claiming for a child who was born in the UK but their parents are subject to immigration control, please tell us if the child leaves the UK for any period, even if this is for a short holiday.

We may need to contact you for further information.

Do you receive Child Benefit for the child

No

Yes

If someone else receives the Child Benefit, tell us their name

What is the Child Benefit number for the child?

This is on letters about Child Benefit

Claiming under the Special Rules

If you are claiming for a child under the Special Rules tick this box

You must read the Notes about claiming under the Special Rules before you tick this box.

The Special Rules are for children who have a progressive disease and are not reasonably expected to live for more than another 6 months.

Only for people claiming for a child under the Special Rules

Complete all questions that apply to you or to the child you are claiming for on pages 1 to 5 and pages 28 to 38.

If the child needs help with getting around, read the Notes about claiming Disability Living Allowance. They explain what we mean by help with getting around. Then complete all the questions that apply to the child you are claiming for on pages 6 and 7.

Please check that you have answered all the questions on this form that apply to you or to the child you are claiming for. Check that you have ticked the box above.

Make sure you sign the Consent on page 32 and Declaration on page 38.

Send this form to us. Send it with the **DS1500** report from the child's doctor. Use the envelope we have sent you. It does not need a stamp.

If you cannot get the **DS1500** report in time, send us the claim straight away. Send the **DS1500** report as soon as you can.

Part 3 - About where the child lives

Does the child normally live in Great Britain?
Great Britain is England, Scotland and Wales.

No

Yes

If you live in Wales and would like to receive future communications in Welsh, please tick this box.

Has the child been abroad for 4 weeks or more in the last 12 months?

No

Yes

Tell us the dates they went abroad, where they went and why they went. Please give any additional details on an extra piece of paper and send it with this form.

Tell us when they went abroad.

From

To

Tell us where they went.

Tell us why they went.

Part 4 - About the child's illnesses or disabilities

If you have a spare up to date printed prescription list from the child's doctor, please send it in with this form.

What are the child's illnesses or disabilities?

Just tell us the names of the child's main illnesses or disabilities. We will ask you how these affect the child later in this claim form.

Do not worry if you are not sure how to spell anything.

Put down everything. Firstly explain the heart condition (complex non-correctable congenital heart disease plus name of diagnosis), but then add any other health conditions, however trivial they may seem as they all add to the child's care - e.g. ear problems, asthma, skin conditions, eye problems, learning difficulties, reflux, etc - it all adds up to a picture of your child's total care, so put everything for which your child receives treatment.

If medicines, tablets or other medical treatments are prescribed for the child's illnesses or disabilities, tell us about them here.

This information will be on the printed label on front of the child's medicine bottle. Do not send any type of medication or other personal items with your child's claim form.

Put down everything (e.g. include inhalers, hydro-cortisone cream for skin conditions or frequent use of over the counter cough / cold remedies, anti-reflux medication).

Include non-prescribed medicines and any alternative / complimentary therapies if appropriate.

Include a note about any daily treatments required such as daily physiotherapy exercises or daily speech development activities.

Part 5 - More about the child

Please tick all the boxes that apply to the child. Tell us if the child

is blind or partially sighted Partially sighted means that they have problems with their eyesight even when wearing glasses or contact lenses.

has problems with hearing even with a hearing aid

has problems with speech or language which affects communication with other people

is both deaf and blind To get help because of deafness and blindness the child must have a large amount of loss of hearing and sight. But they do not have to be totally deaf and blind.

has physical disabilities

was born without legs or feet or has had both legs amputated above or through the ankle

has a learning difficulty

has a mental health problem

has both a severe learning disability and severe behavioural problems

has a long term illness

Tick all that apply - definitely physical disabilities and long-term illness. Your child may also have other issues e.g. learning difficulty, mental health problem, etc - if so, tick these boxes also.

has been assessed for things such as disability aids, or do they have a care plan or an occupational therapy report? No

Yes

Please send copies, if you can, of any documents with this claim form.

If you do not want to complete the care or mobility needs on pages 6 to 26 you can ask for a doctor to visit the child. The doctor will normally examine them. See Notes pages 6 and 7.

If you would like a doctor to visit the child, tick this box.

Make sure that you answer all other questions that apply to them.

Part 6 - Walking outdoors

By this we mean walking on reasonably level ground, not up or down hills or slopes. You can only get Disability Living Allowance for help with getting around at the higher rate if the child you are claiming for is 3 years old or over.

You cannot get Disability Living Allowance for help with getting around at the lower rate until the child is 5 years old or over.

Does the child have difficulties walking?

This may be because

- they cannot walk at all
- of an amputation
- they were born with a deformity of the spine, legs or feet, or something like this
- of paralysis, weakness or stiffness
- walking makes them breathless or gives them pain or discomfort
- of a heart condition
- they refuse to walk

No

Go to Page 7.

Yes

Also tick the example statements given e.g.

- walking makes them breathless or gives them pain or discomfort ✓
- of a heart condition ✓
- they refuse to walk ✓

Tell us about the difficulties they have with walking and about any equipment they use to help them.

Tell us here if there is anything about the way the child walks that causes difficulties. For example, if they have poor co-ordination, bad balance or a poor manner of walking. Tell us if the effort of walking might be dangerous for the child and why this might be. Equipment might be crutches, a walking stick or walking frame, an artificial leg, callipers, splints, a rolator, or something like this.

What causes the problem - heart condition, any associated breathing difficulties plus any behavioural problems.
What problems does the health condition cause with walking - discomfort, pain, muscle stiffness, breathlessness, dizziness, fatigue.

How fast do they walk, compared to children of their own age?

How long do they walk for? Do they have to stop and rest before walking again?

Do they move in the same way as their peers?

Are there any after effects - that day or the following day?

Any equipment used e.g. buggy which wouldn't be used by other children of same age, plus social effects of this.

Any phobias e.g. of dogs, any obsessive behaviour, any fear of loud noises?

The child has difficulty in walking any distance. Has weakness in lower leg muscles and joints. Walking on the level ground causes chest pain, headache and breathlessness.

Child becomes sweaty and severely uncomfortable walking only a short distance.

When feeling tired, child's balance is poor.

How many days a week does the child have these difficulties?

7

days a week

How far can the child walk before they have to stop because of severe discomfort?

For example, it may be too painful for them to go on, or they may need to stop and rest

metres/yards

How long does it take them to walk this far?

minutes

How far can they walk - usually a range applies depending on the day (e.g. 0-50m or 0-100m) and depending on how well or otherwise the child is. This used to be the most important part of this question, but now decisions are based on all of the above points. If there are days when your child won't or cannot walk at all, make sure you include this.

Part 7 - If the child needs someone with them when they are outdoors

Does the child need to have someone with them when they are outdoors in places they do not know well?

For example, they may need someone to look after them because

- they are blind or partially sighted
- they are deaf or hearing impaired
- they might fall
- they have behavioural problems or a severe learning disability
- they may forget where they are going, or wander off
- they need a lot of encouragement to walk
- they might put themselves or other people in danger.

No

Go to Page 8.

Yes

This question is all about guidance and supervision, not about physical walking. You may need to watch your child to see if they are exhausted and / or likely to fall.

They may need help with crossing roads, you may need to calm your child down if distressed.

Remember - the child must need more help than a child of the same age who does not have their illness or disability.

Tell us why the child needs someone with them when they are outdoors in places they do not know well.

For example, they may be easily confused or taken advantage of.

Describe problems your child has with this activity and help required

Supervision to ensure no over exertion.

Supervision to watch for signs of cyanosis.

Balance problems leading to falling.

Any non-cardiac issues such as visual or hearing impairments, or behavioural problems (aggression, tantrums, easily distracted).

Upset by loud noises or lots of people - need to be calmed down, especially to keep breathing OK.

Watching out for signs of incontinence

- Tires more quickly and suddenly than a child with a normal heart, and then needs to be carried/buggy

- Suffers badly in hot or cold temperatures, can't stay outside too long in very hot or cold weather. Poor temperature regulation, poor circulation, in cold weather get terribly cold hands/feet, go blue, have to be taken inside. In heat, get sweaty, clammy, become distressed

- At risk of cardiac episode (tired, distressed, cyanotic, sleepy) if over-tired or over-exercised, too hot/cold or ill

- On medication XX times daily [fill out yours] needing supervision

- Need to be reminded/helped to eat frequently or lose energy/get wobbly

-More at risk from skin abrasions because of Warfarin [where applicable] so greater vigilance needed, more at risk of infections through abrasions than child with normal heart

Risks of chest injury.

Any side effects of medication which are relevant to being outdoors such as the need for sunscreen in all weathers.

Additional assistance required such as with carrying bags.

Why can't your child manage without this help

Add information to explain that without help and supervision, child would be at risk of illness, would be too distressed, could get badly injured, could get dehydrated, etc.

What is different compared to peers

Would another child be more likely to walk outdoors in unfamiliar places on their own?

Would another child of this age have less supervision and less adult involvement?

Could other children of their age manage some of these activities by themselves e.g. carrying bags?

Claiming under the Special Rules

Go straight to Part 27

You do not have to answer any more questions until that page

Part 8 - Someone keeping an eye on the child

All children need someone to keep an eye on them to make sure that they are safe. Answer the questions on this page if the child you are claiming for needs more supervision during the day or night than other children of the same age who do not have their illness or disability. By night we mean when the household has closed down at the end of the day.

Does the child need someone to keep an eye on them?

For example, because they

- have no sense of danger and might hurt themselves or someone else
- might wander about
- have behavioural problems
- cannot hear or see or respond to danger signs
- need someone to monitor their medical condition or diet.

No Go to Page 9.

Yes

Why the child needs someone with them.

During the day

To be aware of changes in medical condition, signs of heart failure. Sweating, breathlessness, cyanosis (blueness), vomiting.

To ensure the correct medicine is taken.

Need to monitor food and fluid intake.

To watch for falls and bleeding if anti-coagulated.

Personal/toileting needs, nappy/clothes changes [where applicable particularly if on diuretics]. Monitoring for wet patches which could become sore.

Behave dangerously towards self or others.

May over exert self - which has serious consequences.

Suffering more in cold or heat, need help to regulate core temp (put layers on or off).

Needs to be carried or pushed in buggy when too tired to walk by self.

What is different compared to peers

Do other children of same age need same supervision?

Why the child needs someone awake with them.

During the day

To continue to monitor condition over the night. Do you set an alarm to check your child?

Night-time medication. Overnight feeding. Coughs. Check for wetness. Check equipment (e.g. feeding equipment). Often awake in pain or distress.

Personal/toileting needs e.g. nappy/bed changes.

Core temperature issues, getting too cold/hot at night, vigilance over right temperature.

Getting upset at night - crying bad for heart - can take longer to settle. Do you need to listen out?

Needs more monitoring during bouts of illness, which are more debilitating than normal child.

If the rest of the questions on this page are difficult to answer because of the child's condition, do not worry. You can tell us more about this later.

How many days a week does the child need someone with them?

7 days a week

How many nights a week does the child need someone to be awake with them?

7 nights a week

How much of the day do they need someone with them?

Could be constant

How much of the night does someone have to be awake with them?

How often do you check?

Tell us roughly how long they need someone with them each time during the day.

We know this may be difficult, but please try to tell us in minutes

Constant minutes

Tell us roughly how long they need someone awake with them during the night.

We know this may be difficult, but please try to tell us in minutes

minutes

This is the total time you are up in the night.

Part 9 - About the child's development

We know that all children develop at different rates, but some illnesses or disabilities can have a marked effect on how a child develops. Tell us if the child you are claiming for has suffered a delay in their development.

Has the child's development of physical and sensory skills been delayed?

For example,

- using their hands
- hearing or talking
- sitting, standing or walking.

Or something else.

No

Go to the next question under the thick orange line.

Yes

Tell us about the help they need.

Varies by child.

Physical / sensory - Describe problems your child has with this activity

E.g. difficulties with movement, manipulation, hearing/seeing, eating (esp if NG fed as baby/toddler), picking things up, using pen/pencil, speaking, knowing when bladder needs emptying.

Fine motor skills/gross motor skills delayed?

Difficulties with concentration/completion of tasks owing to poor oxygen levels in blood. Can lead to giving up more quickly if task is physically difficult; can get easily frustrated, child may stop trying.

Explain what help your child either gets or needs

Time and encouragement to achieve tasks.

Help with simple day-to-day jobs because of lack of co-ordination.

[Continued - see continuation sheet, figure (A) on the next page]

If the next 2 questions are difficult to answer because of the child's condition, do not worry. You can tell us more about this later.

Tell us roughly how many times a day the child needs help.

times a day

Tell us roughly how long it takes each time.

We know this may be difficult, but please try to tell us in minutes.

minutes

Has the child's development of learning skills been delayed?

For example,

- understanding the world around them
- following instructions
- developing daily living skills,

Or something else.

No

Go to page 10.

Varies by child.

Yes

Tell us about the help they need.

Learning skills:

Learning everyday skills - washing, dressing, using cutlery. Learning to be safe in traffic. Learning to read, write, maths, etc. Understanding instructions.

May find it difficult to interact with others.

- Put any communications/language/comprehension difficulties here. Particularly indistinct speech and difficulty in comprehension/being understood.

- Put if daily living skills compromised by clumsiness/poor co-ordination.

[Continued - see continuation sheet, figure 9B) on the next page]

If the rest of the questions on this page are difficult to answer because of the child's condition, do not worry. You can tell us more about this later.

Tell us roughly how many times a day the child needs help.

times a day

Tell us roughly how long it takes each time.

We know this may be difficult, but please try to tell us in minutes.

minutes

Part 9 - All about the child's development - continued

Has the child's development of social skills been delayed?

For example,

- interacting with others
- communicating with others or something else.

No

Go to the next question under the thick orange line.

Yes

Tell us about the help they need.

Varies by child.

Social Skills

Child becomes withdrawn, unable to interact with peers and/or adults. Lack of concentration.

Unable to keep up with peers because of reduced physical ability.

Shy or aggressive?

Relates better to adults?

Dominates conversations.

- Restate any communication difficulties and point out how this makes it harder to interact successfully than for a 'normal' child this age.

- Restate any physical/co-ordination difficulties and say again how it makes interactive play harder.

- Is child 'detached' (this could be due to time in hospital/exposure to lots of medical strangers etc).

[Continued - see continuation sheet, figure 9C) on the next page]

If the next 2 questions are difficult to answer because of the child's condition, do not worry. You can tell us more about this later.

Tell us roughly how many times a day the child needs help.

times a day

Tell us roughly how long it takes each time.

We know this may be difficult, but please try to tell us in minutes.

minutes

Does someone need to help the child develop through play?

For example, encouraging

- age appropriate play
- stimulating play.

Or something else.

No

Go to the next question under the thick orange line.

Yes

Tell us about the help they need.

Varies by child.

Develop through play

Preparation for medical treatment.

Help with learning tasks.

Slow at tasks so needs carer's help.

Does child play obsessively or repetitively?

Do they prefer games for younger children?

Do they dominate others?

- For motor skills being behind.

- For linguistic skills being under-developed.

- If your Special Needs advisers have said anything about this, add it in

- If any involvement with portage or Child Development Centre, explain this here.

If the rest of the questions on this page are difficult to answer because of the child's condition, do not worry. You can tell us more about this later.

Tell us roughly how many times a day the child needs help.

times a day

Tell us roughly how long it takes each time.

We know this may be difficult, but please try to tell us in minutes.

minutes

Continuation Sheet

Part 9 - All about the child's development

(A) Physical/Sensory

Why can't your child manage without this help?

Would they become frustrated with no help? Would they not manage tasks without help?
Could they hurt self without help? Could they be in danger if tasks not achieved?

What is different compared to peers?

Do peers also need same help and encouragement?

(B) Learning Skills

- Put if being assessed by Special needs/support needs workers.

Explain what help your child either gets or needs

Need constant encouragement, repetition etc.

More help at home/school to learn skills, one-to-one help, monitoring to ensure they aren't too tired to learn, monitoring to ensure they don't become frustrated, extra help at home with school work.

Why can't your child manage without this help

Would become more frustrated and upset, would find learning new skills even more of a challenge, would fall behind at school.

What is different compared to peers?

Do peers also need same help and encouragement?

(C) Social Skills

Explain what help your child either gets or needs

Help to communicate, strategies to deal with bullying or teasing, encouragement to interact with other children, supervision when with other children e.g. playground.

What is different compared to peers?

Do peers also need same help and encouragement?

Part 10 - Waking, getting up and going to bed

Does the child have difficulties waking, getting up or going to bed?

For example, they may need help with things like

- getting into or out of bed
- settling in bed
- staying in bed

Or help with something else

No

Yes

Remember - the child must need more help than a child of the same age who does not have their illness or disability.

Does someone have to wake the child up, or tell or encourage them to get up or go to bed?

No

Yes

Tell us about the help the child needs to wake up or get up or go to bed.

Tell us about any equipment the child uses and how it helps them.

Describe problems your child has with this activity

Reluctant because of nightmares or fears about condition or pain.

Disturb others.

Need rigid routine.

Resist getting up - don't like school/fears of being bullied..

Added difficulties of managing to maintain routine - cannot leave a cardiac child to cry themselves to sleep, takes extra time to settle them.

These children become lethargic and tired and can be difficult to rouse.

Regular naps are necessary because of fatigue, children often fight sleep.

It is very difficult for parents to hand care over to other people

Any toileting issues

Gets unsettled more often because ill - i.e. get ill more often than child with normal constitution, more prone to bugs and colds, keep them awake more than with 'normal' child.

Explain what help your child either gets or needs

Any physical help?

Spend lots of time with them at bedtime.

Lots of encouragement needed.

Administering of night-time medication.

Changing of bedding.

Repeated help from carer.

Why can't your child manage without this help

Physically can't manage without it.

Extremely distressed.

Would become even more tired, so could become ill.

What is different compared to peers

Do they manage with less help/more quickly/without getting upset/with less encouragement?

How many days a week does the child need this help?

7

days a week

How many times a day does the child need this help?

times a day

E.g. how many naps or rests?

Tell us roughly how long it takes the child to get out of bed or into bed.

We know this may be difficult, but please try to tell us in minutes.

minutes

Part II - Washing and bathing

Does the child have difficulties washing, or having a bath or shower?

For example, they may need help with things like

- cleaning their teeth
- washing their hair
- getting into or out of the bath or shower
- physical support
- coping with periods
- keeping safe

Or help with something else

No

Yes

Remember - the child must need more help than a child of the same age who does not have their illness or disability.

Does someone have to tell or encourage the child to wash or have a bath or shower?

No

Yes

Varies by child.

Tell us about the help or encouragement the child needs washing or having a bath or shower.

If they have bed baths, tell us about this here. Tell us about any equipment the child uses and how it helps them.

Describe problems your child has with this activity

Too tired to wash or bathe.

Need cream.

Need watching.

Have to wash more often.

Help with teeth.

Need routine.

Children on diuretics suffer with urgency and may have accidents requiring baths and clean sheets - need good skin care.

Where applicable, put if water causes any extra care needs; for e.g. for children with skin conditions, or perforated eardrums or anything else.

Put if toileting needs because of any developmental delays.

Explain what help your child either gets or needs

Extra supervision.

Extra help to make sure teeth properly clean, skin clean and dry.

Encouragement.

Why can't your child manage without this help

Teeth cleaning is essential because of the risk of dental decay infecting the heart, subacute bacterial endocarditis.

Care over bathing because children get cold.

Could become unwell without help.

What is different compared to peers

Need washing more often.

Other children manage with less help/less severe consequences.

How many days a week does the child need this help?

7

days a week

How many times a day does the child need help with washing or having a bath or shower?

times a day

Put number of times for different activities e.g. washes, teeth cleaning

Tell us roughly how long it takes the child to have a bath or shower.

We know this may be difficult, but please try to tell us in minutes.

minutes

Part 12 - Getting dressed or undressed

Does the child have difficulties getting dressed or undressed?

For example, they

- have poor co-ordination
- have no control over their arms or legs
- are not able to judge appropriate clothes

They may need someone to help them, or it may take a long time.

No

Yes

Remember - the child must need more help than a child of the same age who does not have their illness or disability.

Does someone have to tell or encourage the child to get dressed or undressed?

No

Yes

Varies by child.

Tell us about the help or encouragement the child needs getting dressed or undressed.

Tell us about any equipment the child uses and how it helps them.

Describe problems your child has with this activity

The children often lack co-ordination and have under-developed fine motor skills (fiddly tasks, like buttons are difficult).

Some children have problems with concentration which means they forget their task.

Put if also impacted on because of poor toileting skills, i.e. more changes of clothes.

Need to change during day due to incontinence.

Takes more time.

Do they prefer loose fitting clothes?

Do you need to alter their clothes for them? (children may be small for their age, it can be hard to find age appropriate clothes).

Do they find it distressing in front of other children due to physical differences?

Do they need help to get clothes in right order?

Are they easily distracted?

Explain what help your child either gets or needs

They are often tired and need great encouragement.

Physical help.

Watching to make sure no bullying.

Help to cope with other children's reactions.

Reminding to keep on task.

Why can't your child manage without this help

Physically unable to do what's required.

Could get cold.

Could get frustrated.

What is different compared to peers

Do peers need same encouragement and help?

How many days a week does the child need this help?

7

days a week

How many times a day does the child need this help?

times a day

E.g. how many changes of clothing?

Tell us roughly how long it takes the child to get dressed or undressed.

We know this may be difficult, but please try to tell us in minutes.

minutes

Part 13 - Help with toilet needs

We know these are very personal questions, but this information will help us to decide about the child's claim.

Does the child have difficulties coping their toilet needs?

For example,

- getting to the toilet and using the toilet
- using something like a nappy, commode, bedpan or bottle instead of the toilet
- using or changing incontinence aids
- catheterisation or bladder expression
- using enemas or suppositories

No

Yes

Does someone have to tell or encourage the child to attend to their toilet needs?

No

Yes

Varies by child.

Tell us about the help or encouragement the child needs and any equipment they use.

Tell us about the help or encouragement the child needs and any equipment they use.

During the day

Describe problems your child has with this activity

Diuretics can cause urgency. This leads to accidents when trying to reach the toilet. It also delays potty training.

Lack of confidence with peers. Lots of nappy changes. Pain, distress or embarrassment.

Episodes of incontinence.

Being more frequently on antibiotics can make for looser bowels and increased discomfort.

Frequent constipation is uncomfortable.

Rashes and skin problems [indicate here any specific treatments prescribed if applicable for dermatitis/eczema etc.]

May still need nappies (cost plus emotional issues), may need extra nappies.

Explain what help your child either gets or needs

Reminding to use toilet. Bathing after accidents. Extra washing of clothes. Lots of support and reassurance. Skincare cream.

Why can't your child manage without this help

Can't manage without adult help. Would be constantly wet. Can get very distressed. Needs carer's support especially if in pain or discomfort.

What is different compared to peers

Can children of this age manage their toileting independently?

During the night

Include the information suggested for During the day.

PLUS

Unsettled sleep.

Lack of confidence with peers.

Changing bed

How many days a week does the child need this help?

7

days a week

How many nights a week does the child need this help?

7

nights a week

How many times a day does the child need this help?

times a day

How many times a night does the child need this help?

times a day

Tell us roughly how long it takes each time

We know this may be difficult, but please try to tell us in minutes

minutes

Tell us roughly how long it takes each time

We know this may be difficult, but please try to tell us in minutes

minutes

Part 14 - Communicating with other people

Does the child need help understanding other people?

For example, they need someone to

- help with lip reading
- explain what people mean
- interpret sign language

No

Go to the next question under the thick orange line.

Yes

Tell us about this.

Varies by child.

Tell us about the child's difficulties understanding other people. Tell us about anything the child needs to help them understand other people, and how useful this is. Tell us if they need to have physical contact or some other sign to attract their attention.

Describe problems your child has with this activity

Linguistic/social development, any delays.

Speech/hearing impairment?

Anxious or aggressive.

If the next 2 questions are difficult to answer because of the child's condition, do not worry. You can tell us more about this later.

How many times a day do they need someone to help them understand other people?

times a day

Tell us roughly how long it takes each time.

We know this may be difficult, but please try to tell us in minutes.

minutes

Does the child need help being understood by other people?

For example,

- because of a language disorder or a physical speech problem
- Someone has to interpret the child's language, signs or gestures.

No

Go to page 16.

Yes

Tell us about this.

Varies by child.

Tell us about the child's difficulties being understood by other people. Tell us about any equipment the child uses to help them, and how useful this is.

Describe problems your child has with this activity

Difficult to understand. Can't manage long complex sentences. Difficult to make self understood. Have vocabulary and style of speech of a younger child.

Get angry if not understood

Easier to talk to adults than children. Lack of trust in adults.

Linguistic/social development, any delays. Speech/hearing impairment? Do they use Makaton or other signing?

Anxious or aggressive? Do they become frustrated if they aren't understood?

If the rest of the questions on this page are difficult to answer because of the child's condition, do not worry. You can tell us more about this later.

How many times a day do they need help to make themselves understood by other people?

times a day

Tell us roughly how long it takes the child to get out of bed or into bed.

We know this may be difficult, but please try to tell us in minutes.

minutes

Part 14 - Communicating with other people - continued

Is the child unwilling to communicate with other people?

For example, because of

- difficult or withdrawn behaviour
- frustration or stress
- a communication disorder.

Or something like this.

No

Go to part 15.

Yes

Tell us about this.

Varies by child.

Tell us about the encouragement the child needs to help them communicate with other people. Tell us about any equipment the child uses to help them and how useful this is.

Describe problems your child has with this activity

Unwilling to communicate.

Withdrawn following repeated hospital visits or treatment.

Explain what help your child either gets or needs

Special or Support needs help, say if being assessed, say if may be delayed.

For 'any equipment or help needed', write about any people helping them - Nursery workers, Special Needs consultants etc.

Speech therapy - how often, what you do at home to practice, whether they respond better in one to one situations.

Do people need to speak in a particular way (slowly and clearly)?

Does child need information presenting in different ways to get understanding?

Why can't your child manage without this help

Won't make progress.

Could become more withdrawn.

May miss warnings of danger.

Can't develop socially.

Would get more frustrated.

What is different compared to peers

Do peers manage to understand without any special help or strategies?

If the rest of the questions on this page are difficult to answer because of the child's condition, do not worry. You can tell us more about this later.

How many times a day do they need help to communicate with other people?

times a day

Tell us roughly how long it takes each time.

We know this may be difficult, but please try to tell us in minutes.

minutes

Part 15 - Eating and drinking

Does the child have difficulties eating or drinking?

For example, they need help

- cutting up food or being fed
- with a specialised feeding method.

Or with something else

No

Yes

No

Yes

Does someone have to tell or encourage the child to eat or drink?

Tell us about the help or encouragement the child needs, and any equipment they use.

During the day

Describe problems your child has with this activity

Children need high levels of energy to run their hearts, therefore they need high calorie content in food. May find it difficult to suck, swallow, chew. May need to eat little and often.

Child takes long time to eat meals and may get upset if others finish first. Fussy eater. Low appetite because of lack of energy.

Only willing to eat a very narrow range of foods.

Special diets - e.g. MCT diet or one for protein losing enteropathy.

Calorie supplements. Precise monitoring of food needed. May associate feeding with pain, discomfort, nausea.

Do they eat in socially unacceptable ways? e.g. use fingers not cutlery.

Late to lose bottle feeds.

Tendency to gag or choke.

Explain what help your child either gets or needs

Lots of encouragement. Lots of patience. Lots of time. Allowing toys at table.

Constant reminders about how important it is to finish. Monitoring of calorie and fluid intake. Preparation of special foods or interesting meals to tempt them to eat. What about at school?

Why can't your child manage without this help

Children with this condition burn calories more rapidly, hence drop in energy levels if not consuming enough calories. If they don't get enough calories they become shaky, cyanotic, lethargic, cross, etc [Whatever applies to your child].

Without enough food, they will come to physical harm - e.g. become ill, even more tired, wouldn't gain weight, no energy.

What is different compared to peers

Feeding is more difficult and time consuming than for other children of the same age.

Others don't need same supervision/same calorie intake/same fluid intake.

Others may eat more quickly. Others don't need same encouragement/coaxing.

Others don't need special foods prepared in addition to normal family meals.

How many days a week does the child need this help?

7 days a week

How many times a day does the child need this help?

times a day

E.g. number of meals and snacks

Tell us roughly how long it takes each time

We know this may be difficult, but please try to tell us in minutes

minutes

Tell us about the help or encouragement the child needs, and any equipment they use

During the night

Overnight feeding may be necessary for some years to maintain weight gain.

Children often wake for milk or food which makes night-time routine very difficult.

How many nights a week does the child need this help?

? 7 nights a week

How many times a night does the child need this help?

times a day

E.g. number of drinks at night.

Tell us roughly how long it takes each time

We know this may be difficult, but please try to tell us in minutes

minutes

Part 16 - Help with medication

Does the child need help with medication?

For example,

- taking tablets or medicines
- having injections
- using an inhaler or nebuliser
- applying creams
- they do not co-operate with their treatment.

No Go to part 17.

Yes Tell us about this.

Tell us about the help or encouragement the child needs with medication.

During the day

Describe problems your child has with this activity

List medications.

List times taken and dosage.

How does the child cope without medication?

Do they vomit when medication given?

Do they need oxygen therapy?

Are they uncooperative/do they get distressed?

Are they angry about having to take medicine?

Do they get upset about side effects e.g. Warfarin?

Do they become angry or distressed when it's medicine time?

Explain how the dose of Warfarin may be different every day, and needs to be checked with the hospital regularly. Explain about either hospital blood tests or home blood testing.

Any extra monitoring required if your child is on aspirin.

Any other side effects of medication e.g. need for sunscreen.

Explain what help your child either gets or needs

Reminding or adult giving medication.

Comfort and reassurance

Do they have any medicine which only needs to be given if you observe certain signs?

Monitoring of dosage for Warfarin

Find ways to make them take medicine e.g. crushed with yoghurt, followed by favourite drink, need for sticker chart or other incentive

What about at school?

Why can't your child manage without this help

Would child take medication without your intervention?

What harm could happen if you don't help them take medication?

What is different compared to peers

Do others take medication without help/encouragement?

Do other children even have similar medication?

Tell us about the help or encouragement the child needs with medication.

During the night

List medications given after the household has gone to bed.

Is it difficult to resettle the child if medications have been given?

Stress if child is uncooperative/distressed, particularly at night.

You may need to repeat some ideas from the box on the left.

How many days a week does the child need this help?

7 days a week

How many times a day does the child need this help?

times a day

E.g. how many doses a day?

Tell us roughly how long it takes each time

We know this may be difficult, but please try to tell us in minutes

minutes

Total time including preparing medicines.

How many nights a week does the child need this help?

? 7 nights a week

How many times a night does the child need this help?

times a day

Tell us roughly how long it takes each time

We know this may be difficult, but please try to tell us in minutes

minutes

Part 17 - Therapy

Does the child need therapy?

Therapy may be done by a therapist or by someone else. It may be at home or somewhere else. It may involve exercises, routines or methods designed to help the child develop. For example.

- physiotherapy
 - speech therapy
 - play therapy
- Or something else

No Go to part 18.

Yes Tell us about this.

Varies by child.

Tell us about the child's therapy.

During the day

Examples could be

- Speech therapy
- Counselling
- Behavioural therapy.
- Play therapy - to help development
- Portage
- Physiotherapist - to help with chest problems, muscle weakness, co-ordination, gross motor delays, appropriate participation in physical activities with peer group, etc.
- Psychotherapy - hospital or needle phobia.

Explain what therapy is required, or has been required in the past, how long it takes, what is involved.

Explain what you then do at home to continue the pre-scribed therapy, and how long that takes, whether your child cooperates, etc.

Tell us about the child's therapy.

During the night

Do you need to do any physiotherapy exercises at night?

Does your child have oxygen therapy?

Has anything been suggested to help with nightmares?

How many days a week does the child need this help?

days a week

How many times a day does the child need this help?

times a day

Tell us roughly how long it takes each time

We know this may be difficult, but please try to tell us in minutes

minutes

How many nights a week does the child need this help?

nights a week

How many times a night does the child need this help?

times a day

Tell us roughly how long it takes each time

We know this may be difficult, but please try to tell us in minutes

minutes

Part 18 - Help with medical equipment

Does the child need medical equipment?

For example.

- colostomy or catheter care
 - tracheostomy care
 - using splints, gaiters or special clothing.
- Or something else

No

Go to part 19.

Yes

Tell us about this.

Varies by child.

Tell us about the help or encouragement the child needs with medical equipment.

During the day

Describe problems your child has with this activity

List everything - syringes, measuring tubes, pill-crushers, bungs, needles, n-g tubes, taking temperature, checking weight gain, need for suction.

Home blood testing (INR).

As my child is taking Warfarin, and will do so for the rest of his/her life, we are trained to check the clotting levels in his blood at home using specialist equipment. This involves a blood test once a week before school followed by a phone call to the hospital and then waiting for information about the new doses prescribed. Every six months the monitoring equipment needs to be checked at the hospital, and my child needs a hospital blood test. Oxygen therapy.

Explain what help your child either gets or needs

What do you do to help e.g. help child use equipment such as feeding equipment or checking weight gain, making sure equipment is being used properly, keeping it clean, disposing of used things appropriately, recording information, supporting your child throughout.

Why can't your child manage without this help

What would happen if you didn't help your child?

Can they manage without your help?

Do they get upset if you don't help?

Could they come to harm if you didn't help them?

Without regular and accurate blood tests to monitor Warfarin dosage, my child is at great risk, either of thrombosis (clots) or of haemorrhage (excessive bleeding), both of which are potentially fatal.

What is different compared to peers

Do peers use any medical equipment?

Tell us about the help or encouragement the child needs with medical equipment.

During the night

Do you have to give medicines at night?

Does your child need oxygen?

How many days a week does the child need this help?

days a week

How many nights a week does the child need this help?

nights a week

How many times a day does the child need this help?

times a day

How many times a night does the child need this help?

times a day

Tell us roughly how long it takes each time

We know this may be difficult, but please try to tell us in minutes

minutes

Tell us roughly how long it takes each time

We know this may be difficult, but please try to tell us in minutes

minutes

Part 19 - Blackouts, fits, seizures or something like this

Does the child have blackouts, fits, seizures or something like this?

For example, because of

- epilepsy
- diabetes.

No

Go to part 20.

Yes

Tell us about this.

Tell us what happens.

We need to know

- what happens before they have a blackout, fit or seizure
- if they get any warning of what is going to happen
- what happens during the fit or seizure
- if they lose consciousness or if their limbs shake, or if they bite their tongue or are incontinent
- what happens after a fit or seizure, if they need to sleep or if they are confused.

Tell us anything that will help us get a clear picture of what happens to the child if they have a blackout, fit or seizure.

Tell us about the help the child needs.

During the day

Explain that your child's heart condition can cause cyanotic spells.

The child needs constant observation to look out for signs of increased heart failure, such as becoming breathless, sweaty or cyanosed.

This would need swift medical treatment.

Add in if they have asthma attacks, or dizziness, or blackouts, or anything else similar.

Give as much detail as you can about the attacks or episodes - how often they happen, if there is a pattern, whether your child knows they are coming, etc.

Explain what help you or another adult must give, and the consequences of it not being given.

You could also add in the dangers of bleeding due to a fall or cut when on anti-coagulation e.g. Warfarin. *Swift response required.*

Tell us about the help the child needs.

During the night

Explain that your child's heart condition can cause cyanotic spells.

The child needs constant observation to look out for signs of increased heart failure, such as becoming breathless, sweaty or cyanosed.

This would need swift medical treatment.

Tell us roughly how often this happens.

Could be 7 days a week

Tell us roughly how long the child needs help each time.

We know this may be difficult, but please try to tell us in minutes

minutes

Tell us roughly how often this happens.

Needs frequent checking

Tell us roughly how long the child needs help each time.

We know this may be difficult, but please try to tell us in minutes

minutes

Part 20 - The child's mental health

Does the child have difficulties because of the way they feel?

For example, they may sometimes

- get anxious or panicky
- get upset or frustrated
- feel someone may harm them
- try to harm themselves
- be verbally or physically aggressive
- try to damage things
- be impulsive or destructive
- feel they cannot cope with even the slightest change to their daily routine

Or something else.

No

Go to part 21.

Yes

Tell us about this.

Varies by child, but likely to be 'yes'

Tell us about the help the child needs and the things the child does because of their mental health problems.

Describe emotional effects of condition on child

Living with many changes, for example, hospital treatment can leave children unsure and easily distressed.

They develop hospital treatment/needle phobias.

Schooling can be disturbed which can lead to fear of peers or teachers.

Behavioural problems - anything and everything, frustration, tantrums, bad sibling relations, all can be made worse by medical time/treatment; or frustration owing to poor ability/concentration because of oxygen deficiency.

List again any communication difficulties, these can make the child more truculent, anxious or withdrawn.

Fearfulness in older children - can be very anxious and fearful, of medical treatments or just of future.

Do they have poor self-esteem?

Are they vulnerable or do they feel vulnerable?

Are they co-operative or not with managing own condition?

If they are small for their age, what emotional effects does this have e.g. feeling even more vulnerable?

Explain what help your child either gets or needs

Lots of care and attention is needed to combat these problems. The child needs lots of comfort and emotional support, and needs his/her self-confidence to be gradually built over time.

He/she needs lots of comfort and emotional support at all times, but particularly at xxx times.

Discuss treatment or care planned to help solve these problems.

Is there a counsellor or psychologist involved?

Is there any special support or are particular strategies used at school?

Why can't your child manage without this help

Would become more distressed.

Could hurt self or others.

Will not be able to fulfil their potential.

What is different compared to peers

Do children without this condition need the same amount of emotional support?

Tell us roughly how often this happens, and how long the child needs help when it happens.

Every child is different, but behavioural problems may happen all of the time, and you may always need to use particular strategies to help, whereas appointments to see specialists may be on a weekly or fortnightly basis, for example.

You may need to give extra emotional support every day, or most days, or just in particularly difficult circumstances.

Part 21 - Movement and co-ordination

Does the child have difficulties with movement and co-ordination?

For example, they

- cannot move at all
 - suffer pain when they move
 - may injure themselves if they move
 - cannot co-ordinate movements of their arms or legs
- Or something else.

No

Go to part 22.

Yes

Tell us about this.

Parts 21 and 22

When children are in gross heart failure they become breathless on walking and unable to walk well. They can suffer with leg pains during the night due to poor circulation. They lack balance and co-ordination. Again, re-state in both of these bits if your child needs to be carried or buggied.

Tell us about the help the child needs with movement and co-ordination.

Explain what help your child either gets or needs

Help from you to move around / exercises to help co-ordination / encouragement / supervision to make sure they don't get hurt / supervision to make sure they don't get over-tired / massage legs at night.

Why can't your child manage without this help

Are they unable to move far without help? Are they unsafe without an adult supervising them? Do they get pain in their leg? Are they at risk from increased strain on their heart?

What is different compared to peers

Do other children of the same age need this sort of help with movement and co-ordination?

Part 22 - Moving about indoors

Does the child have difficulties moving about indoors?

For example, with things like

- getting out of a chair
- walking around indoors
- going up or down stairs
- using a wheelchair or Major Buggy
- transferring from a wheelchair or Major Buggy
- having to be carried

No

Yes

Varies by child, but likely to be 'yes'. Think about school also.

Remember - the child must need more help than a child of the same age who does not have their illness or disability.

Does someone have to tell or encourage the child to move about indoors?

No

Yes

Tell us about any help or encouragement the child needs moving about indoors. Tell us about any ways the child's home has been adapted, or about any equipment they use to help them move about indoors. This could be a wheelchair, a frame, a stairlift, or something like this.

Part 23 - When the child is in bed at night

By night we mean when the household has closed down at the end of the day.

Does the child need help when they are in bed at night?

For example, they may need help with things like

- changing sheets or nightclothes
- getting bedclothes back on the bed if they fall off
- turning over
- resettling to sleep after waking because of night terrors or irregular sleep patterns
- getting back into bed after falling out
- settling and staying in bed.

Or something else.

No

Go to part 24.

Yes

Tell us about this.

This page is really important for determining whether your child is eligible for middle or higher rate personal care DLA. DON'T worry about repeating yourself - in fact go back to what you've put in previous night-time notes for other questions to check you've put everything you put there and remembered every issue. Remember that night-time means after the time that the adults in the house usually go to bed.

Remember - the child must need more help than a child of the same age who does not have their illness or disability.

Tell us about any help the child needs when they are in bed at night.

Describe problems your child has with this activity

Problems with wetting the bed.

The need for night feeds or drinks

Do they become cold during the night because of poor circulation?

Do they often get a high temperature at night?

Cramp like pains (e.g. leg cramps) can wake the child.

Night-time medication or treatments.

Nightmares.

Disturbed sleep.

Distressing coughing leading to breathlessness and/or vomiting.

Does it take a long time to settle the child again after waking (for night-time feeds, medications, or generally)?

Explain what help your child either gets or needs

Need medication.

Need drinks

Need bed/nightwear changing.

Massage legs and feet.

Check on child.

Comfort them back to sleep.

Do you still use a baby monitor?

Respond to coughing or crying immediately so they don't vomit or become distressed.

Why can't your child manage without this help

Unable to sleep without it.

Would become even more unsettled, then would become ill.

Could become overtired, which in turn makes them more restless and disturbed at night.

What is different compared to peers

Do other children of the same age need this sort of support and parental involvement during the night?

How many nights a week does the child need help?

7 nights a week

How many times a night does the child need help?

times a night

Tell us roughly how long it takes each time

We know this may be difficult, but please try to tell us in minutes.

minutes

Part 24 - Help the child needs when they go out during the day or in the evening.

Please tell us in this part about the help the child needs from another person at home or when they go out. For example, this can be help with things like social and religious activities, interests and hobbies.

Remember - they can be helped in lots of different ways. Someone speaking to them can count as help if they

- tell them or encourage them to do things
- tell them how to do things
- tell them if there is danger.

Even someone reading to them or helping them to communicate with other people can count as help. For example, they may need someone to interpret their sign language for other people. Or they may only be able to make themselves understood to someone who knows them well, who needs to interpret what they are saying for other people.

You should tell us about the help they need even if they do not actually get that help. We want you to tell us about each of the different things they usually do or would do if they had the help they need. Use a separate box to tell us about each thing. We have given you three sets of boxes, but you do not have to fill in every set unless you need to tell us about 3 different things. If you want to tell us about more than 3 things, use a separate sheet of paper and send it to us with this form.

What they do or would do if they had the help they need.

When they go out during the day or evening

Think of all the places you normally go e.g. medical appointments, playgroup, nursery, school, swimming, to the park, to church, etc. Put one activity here.

What they do or would do if they had the help they need.

At home

Think of activities such as homework, playing, having friends to visit, etc. Put one activity here.

How many days a week?

? days a week

How many times a day?

times a day

How many days a week?

7 days a week

How many times a day?

times a day

How long do they usually need help for each time?

How long do they usually need help for each time?

What help do they need from another person?

Help with getting to activities, help with toileting, dressing and undressing, staying safe and well, administering medication, feeding, drinking, comfort and reassurance.

Will need adult supervision even when peers don't. Somebody to accompany them e.g. to party when peers may be left without parent/carer.

Some activity groups will not allow a heart child to stay without a parent or carer staying with them.

Constant monitoring.

Supervision to make sure they aren't hurting others or at risk of being bullied.

Constant supervision to make sure they aren't exhausted.

What help do they need from another person?

Constant supervision to make sure they stay safe and well.

You may also wish to add some ideas from the box on the left.

Part 24 - Help the child needs when they go out during the day or in the evening - continued

What they do or would do if they had the help they need.

When they go out during the day or evening

Put a different activity here.

How many days a week?

? days a week

How many times a day?

times a day

How long do they usually need help for each time?

What help do they need from another person?

Same as box on previous page.
Repeat the information that applies to your child.

What they do or would do if they had the help they need.

At home

Put another 'home' activity here.

How many days a week?

7 days a week

How many times a day?

times a day

How long do they usually need help for each time?

What help do they need from another person?

Same as box on previous page.
Repeat the information that applies to your child.

Part 25 - Who would you like to tell us about the child's illnesses or disabilities?

This could be for example

- a teacher
- a nurse, a health visitor, a physiotherapist, a speech therapist, or an occupational therapist
- someone from the Social Services or the Social Work Department
- a carer or any other professional who knows the effect of your child's illness.

Your Cardiac Liaison Nurse could be a good contact here.

We may contact them if we need further information.

Please tell us their name

Their address

Postcode

Their phone number, if you know it.

Code Number

What is their job?

When did they last see the child?

Part 26 - Anything else about the way the child is affected by their illnesses or disabilities

Tell us about any ways that the child's illnesses or disabilities affect them that you have not been able to put anywhere else on this form.

For example, the child may need special help at school or nursery. Or there may be places on this form where the questions have been difficult to answer, and you want to tell us more about the help the child needs. Or you may want to tell us if the child's condition changes from day to day, which means that the amount of help they need varies.

Tell us anything that you think will help us get a picture of how the child is affected by their illnesses or disabilities.

This can be a useful way of painting a clear picture of your child and their needs, and how their heart condition (plus any other needs) impact on their day-to-day life.

Paint a picture of child's needs.

Their diagnosis, treatments and lifestyle.

How does their condition affect the family, school, friends?

How often are they in hospital? What surgery have they had? What is still to come?

Are their needs different on different days?

Do they have special educational needs? Do they have a statement and/or Individual Educational Plan (IEP)?

Do they need support at school (regardless of whether they actually have it)?

Do you give extra support outside school?

Include a diary showing the care and support you give over a period of a few days or a week.

A typical day can be useful to show the difference between lower rate and middle rate DLA (middle rate is granted when a child needs attention "frequently" throughout the day). E.g. list times for help with getting up, encouragement with breakfast and medication, same for lunchtime, throughout school day supervision and learning support, after school pick up and need to rest, help with school work, tea and medication, bedtime routine.

Don't leave anything out! Compare your child with any other 'normal' child you know - or sibling - list absolutely every possible feature in which your child is different.

Some examples from LHM families are included overleaf - always remember that all children are different, so you need to make this appropriate for your child.

Continue on a separate piece of paper, if necessary. Remember to write the child's name and reference number at the top of each page.

Part 27 - About the child's condition

Put your child's date of birth in these boxes - they were born with their condition.

Please note - it may delay the claim if you do not complete this section.

If the child has problems getting around, tell us when they started to have the problems you have told us about.

Tell us the exact date if you can. But if you cannot remember, you must tell us roughly when this was.

If the child has problems with personal care, tell us when they started to have the problems you have told us about.

Tell us the exact date if you can. But if you cannot remember, you must tell us roughly when this was.

Part 28 - About nights in hospital

Is the child in hospital now?

No

Go to part 29.

Yes

When did the child go into hospital?

When will they leave hospital? If you know this.

Please tell us the full name and address of the hospital. Tell us the name or number of the ward if you know it.

Postcode

Hospital phone number, if you know it.

Code	Number
------	--------

While the child is in hospital is the NHS paying for their stay and treatment?

No

Yes

Not sure

Part 29 - About nights in a care home or similar residence

This includes independent hospitals, boarding schools, hospices, residential colleges, children's homes, respite care or anywhere like this.

Is the child in a care home or similar residence now?

No Go to part 30.

Yes

Please tell us the full name and address where the child is staying.

Postcode

Phone number if you know it.

Code	Number
------	--------

When did the child first start to live in a care home or similar residence?

/	/
---	---

Does a local authority, a health authority, an NHS trust, Primary Care Trust or a government department pay any of the costs for the child to live there?

No Yes Not sure

Which authority, NHS trust, Primary Care Trust or government department pays?

--

Part 30 - About nights in hospital and nights in a care home or similar residence

Has the child been in hospital or a care home or similar residence in the past 6 weeks?

No

Yes

Tell us when they went in. If they have come out of hospital or a care home or similar residence, please tell us when this was.

In

Out

Please tell us the full name and address of where the child is staying.

Postcode

Phone number if you know it.

Code	Number
------	--------

Part 31 - For children on kidney dialysis

Tell us about the hospital that arranges the dialysis, so we can contact them.

Hospital Address

Postcode

Hospital phone number, if you know it

Code	Number
------	--------

Hospital record number, if you know it

Part 32 - The child's school or nursery

Name of child's school or nursery

Tell the school/nursery about DLA, and about how important it is to you and your family. Explain that the principle is about your child's care needs. Ask them to consult you when they are contacted by the DWP.

Address

Postcode

Phone number

Code	Number
------	--------

Contact

For example, a teacher

Part 33 - The child's hospital doctor or specialist

Tell us about any hospital doctor or specialist the child has seen in the last 12 months because of their illnesses or disabilities. This might be a doctor at a child development centre. If you want to tell us about more than one person, give us the details on an extra piece of paper and send it with this form.

Please tell us their name

List all the specialists involved.

Their address

Postcode

Their phone number, if you know it.

Code	Number
------	--------

The child's record number, if you know it.

When did the child last see their hospital doctor or specialist?

The child's present illness or disability they are seeing a hospital doctor or specialist for.

Part 34 - The child's family doctor or health centre

Please tell us their name

Their address

Postcode

Their phone number, if you know it

Code	Number
------	--------

When did the child last see their doctor about their illnesses or disabilities?

Part 35 - Consent

We may wish to contact your GP or persons or organisations involved with you for information in relation to your claim. This may include medical information in respect of your claim. You do not have to agree to us contacting those persons or organisations. If you do not, however, agree to us obtaining such information, it may mean that we are unable to obtain enough information to satisfy ourselves that you meet the conditions of entitlement in respect of your claim.

The Department for Work and Pensions or any doctor providing medical services on behalf of an organisation approved by the Secretary of State, may ask any person(s) or organisation(s) for any information, including medical information, which is needed to deal with:

- this claim for benefit, or
- any appeal or other reconsideration of a decision in relation to this claim and that the information may be given to that doctor or to the Department.

Now please tick one of the consent options below.

I agree to you contacting persons or organisations as in the statement above.

I do not agree to you contacting persons or organisations as in the statement above.

Now sign and date below.

Signature

Date

Please make sure you sign and date the Declaration on page 38 of this claim form.

Part 36 - Statement from someone else who knows the child

Please note - completion of this page is optional.

Please ask someone who knows how the child's illness or disability affects them to sign this statement. This could be anyone who knows the child well. For example, a carer, relative, friend, professional health care worker or someone like this. They do not need to look at the answers on this form.

How often do you see the child this form is about?

Please tell us what their illnesses and disabilities are, and how they are affected if you know it.

Our experience suggests that your child's cardiologist is the best person to fill in this section. Ask their secretary for help.

Tell us your job, profession or relationship to the child this form is about.

Your full name

Your daytime phone number

Code	Number
------	--------

Your address

Postcode

Your signature

Date

Part 37 - About Income Support, Jobseeker's Allowance or Pension Credit

Are you getting or waiting to hear about Income Support, Jobseeker's Allowance or Pension Credit?

No

Yes

Is anyone within your household getting or waiting to hear about Income Support, Jobseeker's Allowance or Pension Credit for you?

No

Yes

Please tell us their name

Their National Insurance (NI) number

Their relationship to you

Part 38 - About Tax Credits

Is anyone within your household getting or waiting to hear about Child Tax Credit?

No

Yes

Please tell us their name

Their National Insurance (NI) number

Their relationship to you

Is anyone within your household getting or waiting to hear about Working Tax Credit?

No

Yes

Please tell us their name

Their National Insurance (NI) number

Their relationship to you

Part 39 - Payment Direct into an account

We normally pay your money direct into an account.

You can use a bank, building society or other account provider. Many banks and building societies will let you collect cash at the post office.

How we will pay you

We will tell you when the first payment will be made and how much it is for. Each payment, after the first one should be the same unless there is a change in your circumstances. We will tell you whenever there is going to be a change in the amount we pay into your account.

Finding out how much we have paid into the account

You can check your payments on the account statements. The statements may show your National Insurance (NI) number next to payments that are from us. If you think your payment is wrong, get in touch with the office that pays you straight away.

If we pay you too much money

We have the right to recover any money paid to you, which you are not entitled to. This may be because of the way the Direct Payment system works. For example, you may give us information, which means you are entitled to less money but we may not be able to change the amount we have already sent out. If this happens, we will contact you before we recover any money.

What to do now:

- Tell us about the account you want to use on the next page. By giving us your account details you are agreeing to be paid by Direct Payment and understand the information above about being overpaid.
- If you intend to open an account, please give us your account details as soon as you have them.
- If you do not have an account, please contact us and we will give you more information.

Please continue to fill in the claim form and send it to us now.

Part 39 - Payment Direct into an account - continued

About the account you want us to use

Please tell us your account details below. It is very important you complete ALL boxes correctly including the building society roll or reference number if you have one. If you tell us the wrong account details your payment may be delayed or you may lose money. You can find the account details on your cheque book or bank statements. If you are not sure about the details, ask the bank, building society or other account provider.

About the account you want to use

You can use

- an account in your name
- a joint account or
- someone else's account,
subject to the terms and conditions of the account and as long as you have the other person's permission and authorise them to use the money in the way you tell them.
- If you are an Appointee or a legal representative acting on behalf of the customer, the account should be in your name only.
- To be paid into a credit union account you must provide the credit union's account details. Your credit union will be able to help you with this.

Part 39 - Payment Direct into an account - continued

Name of the account holder

Please write the name of the account holder exactly as it is shown on the cheque book or statement.

Full name of bank, building society or other account provider

Sort code

Please tell us all six numbers
for example, 12-34-56

This is about your bank account; your child does not have to have their own account.

Account number

Most account numbers are 8 numbers long. If your account has fewer than 10 numbers, please fill in the numbers from the left.

If you are using a building society account you may need to tell us a roll or reference number. This may be made up of letters and numbers, and may be up to 18 characters long. If you are not sure if the account has a roll or reference number, ask the building society.

Building society roll or reference number

You may be getting other benefits and entitlements that are not paid direct into an account. To have them paid into the above account, please tick the box.

Part 40 - Declaration

No benefit can be paid, for any time period claimed for, until the declaration is signed and the form is returned to us. Please return the signed form straight away.

- **I declare**

that the information I have given on this form is correct and complete as far as I know and believe.

- **I understand**

that if I knowingly give false information, I may be liable to prosecution or other action.

- **I understand**

that I must promptly tell the office that pays my child's Disability Living Allowance of anything that may affect their entitlement to or the amount of that benefit.

- **I understand**

that the Department may use the information which it has now or may get in the future to decide whether I am entitled to

- the benefit I am claiming for my child
- any other benefit I have claimed
- any other benefit I may claim in the future

This is my claim for Disability Living Allowance

Signature

Date

Please make sure you sign and date the Consent section on page 32 of this claim form.

Part 41 - What to do now

Do not forget to write the child's name and reference number on any additional documents you send us.

If you are sending any documents with this form, please list them below.

Check that you have signed the Consent statement on page 32 and the Declaration on page 38.

Then send the completed form back to us.

If you are not sure where to send this form, phone the Benefit Enquiry Line on **0800 88 22 00**.

Part 42 - How we collect and use information

The Department for Work and Pensions collects information for the purposes of dealing with social security, child support, vaccine-damage issues, employment and training, private pensions policy, retirement planning and the Financial Assistance Scheme. The information we collect about you depends on the reason for your business with us, but we may use the information for any of these purposes.

We may check information about you with other information we have. We may get information about you from other people and certain other organisations. We may give information to certain other organisations, as the law allows, to:

- check the accuracy of information
- prevent or detect crime
- protect public funds in other ways, and
- use in research or statistics

These other organisations include other government departments, local authorities, and private-sector bodies such as banks and organisations that may lend you money. We will not give information about you to anyone outside our department unless the law allows us to.

The Department for Work and Pensions is the Data Controller for the purposes of the Data Protection Act.

If you want to know more about what information we have about you, or the way we use your information, please contact us. You can contact any of our offices and ask for the leaflet called Data Protection Act 1998. Or you can find a copy of the leaflet on our website. The address is **www.dwp.gov.uk**