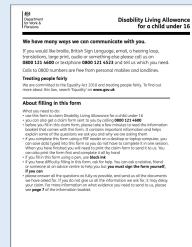
# **CARERS TRUST**

### St Helens Carers Centre

## Self Help Guide



### **CHILD** DISABILITY LIVING **ALLOWANCE** (CHILD DLA)

This guide has been produced by St Helens Carers Centre to help you in completing your Child **Disability Living** Allowance claim form

If you are a Carer and care for someone in St. Helens and feel you still require support with completing your form, then please call us on

01744 675615

St Helens Carers Centre, 31-35 Baldwin Street, St Helens, WA10 2RS Tel: 01744 675 615

Email: info@sthelenscarers.org.uk

Web www.sthelenscarers.info



WA10 2RS.





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#### Introduction and welcome

Welcome to our self help guide. This will guide you through your Child Disability Living Allowance claim form (Child DLA) giving you advice on how to complete it.

We hope you find this guide useful but note that if you need any further help or advice around filling out this form, and you are registered with St Helens Carers Centre, you can contact us on 01744 675615, or you can pop online to chat to us by logging on to our website at www.sthelenscarers.info Monday to Friday 10 a.m. till 3 p.m.

If you are not registered with us and are a Carer, caring for someone residing in St Helens, contact us and we can help you.

If the above does not apply and you still need help, contact your local Citizens Advice Bureau <a href="https://www.citizensadvice.org.uk/">https://www.citizensadvice.org.uk/</a>

#### Let's get started

At this point, you should have received your Child DLA form. It will be date stamped in the top right-hand corner. There will be two dates. One of those dates (the bottom one) is a return date and if you return the form by that date, the date of claim will be the date you ordered the form. This does not always mean an award of Child DLA will commence on this date – please check with a benefits adviser for further information if you are unsure about this (you can call us on 01744 675615 or pop on to our website for live chat at <a href="https://www.sthelenscarers.info">www.sthelenscarers.info</a>).

If you haven't received this form, you may need advice on eligibility around Child DLA so give us a call on 01744 675615 and ask to speak to one of our Welfare Benefits advisers, or pop online at www.sthelenscarers.info

If you haven't received a Child DLA form yet, and you have spoken to one of our Welfare Benefits advisers, it may be worth ringing them again to order a form. You can call them on the following number to request a Child DLA form:



0800 121 4600

If you have got the Child Disability Living Allowance form, it should look something like this:



#### Disability Living Allowance for a child under 16

#### We have many ways we can communicate with you.

If you would like braille, British Sign Language, email, a hearing loop, translations, large print, audio or something else please call us on **0800 121 4600** or textphone **0800 121 4523** and tell us which you need.

Calls to 0800 numbers are free from personal mobiles and landlines.

#### Treating people fairly

We are committed to the Equality Act 2010 and treating people fairly. To find out more about this law, search 'Equality' on **www.gov.uk** 

#### About filling in this form

What you need to do:

- · use this form to claim Disability Living Allowance for a child under 16
- you can also get a claim form sent to you by calling 0800 121 4600
- before you fill in this claim form, please take a few minutes to read the information booklet that comes with this form. It contains important information and helps explain some of the questions we ask you and why we are asking them
- if you complete this form using a PDF reader on a desktop or laptop computer, you
  can save data typed into this form so you do not have to complete it in one session.
   When you have finished you will need to print the claim form to send it to us. You
  can also print the form first and complete it all by hand
- if you fill in this form using a pen, use black ink
- if you have difficulty filling in this form, ask for help. You can ask a relative, friend or someone at an advice centre to help you but you must sign the form yourself, if you can
- please answer all the questions as fully as possible, and send us all the documents
  we have asked for. If you do not give us all the information we ask for, it may delay
  your claim. For more information on what evidence you need to send to us, please
  see page 7 of the information booklet.

If you have a form, you should have the actual claim form, and then notes on how to complete the form separately. The notes and guidance are there to provide you with some information

around Child DLA and how to fill in the form – which hopefully we can add to with this guide, so let's get going!

Q 1
Special Rules

There are special rules for children who are terminally ill. For the purposes of benefit claims, this means children who have a progressive disease and are not expected to live longer than another 6 months. From April 2023, this will be increased to 12 months.

These claims are fast tracked and usually dealt with within 7-10 days. To ensure it is dealt with as quickly as possible, it is important to send a DS1500 report (see below for an explanation of this report) along with the claim.

If it cannot be sent with the claim, send the claim form, and follow it up with the DS1500 as soon as possible.

#### DS1500 report:

This is a report about a person's medical condition. They are issued by a doctor (i.e., GP or hospital doctor). There will be no charge to the patient for a DS1500. An appointment with GP is not needed and a request can be made to the receptionist to check with GP if one can be issued. A DS1500 is not a claim form and sending a DS1500 alone will not form a completed claim for a benefit.

A DS1500 can be issued on request to a representative which includes employees of St Helens Carers Centre. The DS1500 will be white. There is a pink copy which is for the doctor to claim a fee direct from DWP for completion of a DS1500. Ask for the report to be in a sealed envelope if you are concerned of the contents being seen.

If you are claiming for a child under the special rules, you do not need to complete questions 54 to 72 but complete everything else, including the mobility questions (questions 43 to 53) if your child is aged 3 or over and has any difficulties with their mobility or if they need guidance and supervision when outdoors.



#### **Personal Details**

This is asking about the child's name, address, date of birth, sex, and National Insurance number. You are likely to only know their National Insurance number if you have ever made a claim for Child Disability living Allowance before so don't worry about leaving this blank. Pop the child's name in BLOCK CAPITAL LETTERS.

#### Q's 9-18

The next few questions are asking about the child's nationality and any time spent abroad so hopefully these are self-explanatory. If you require advice around whether your child will be eligible for Child Disability Living Allowance, as they may have spent time living outside of the UK, our team will be able to advise you so just pop online at <a href="https://www.sthelenscarers.info">www.sthelenscarers.info</a> between 10 and 3 weekdays (excluding bank holidays)

#### Q's 19-20

These two questions are hopefully self-explanatory and are asking about the child's parent/guardian and whether they receive pensions or benefits from an EEA state or Switzerland, as well as if they are working or paying insurance to them.

#### Q's 21-22

These two questions are asking if the child is currently in hospital, or they have had any overnight stays in a hospice, residential college, or similar accommodation in the last 12 months.

#### Q 23-25



#### **Health professionals**

The next few questions are asking about tests, and there is also a question asking if you are sending any reports along with the form (Q24). Diagnostic reports can be very helpful when applying for Child Disability Living Allowance. They focus on the difficulties a child has and so we often recommend these are sent along with the claim form if you have one. You may have lots of reports but look at the ones that detail the help the child needs. Read them though — often reports can only be because of a snapshot situation within a controlled setting, so read the reports and look to see which one is best in terms of identifying the difficulties faced and the help needed — if you are not sure, our advisers at St Helens Carers Centre can help with this. It may not always be beneficial to pay for reports as they can be costly and might not supply any evidence in terms of assessing eligibility for Child DLA so if you do not have any reports to send just send the form without.

Question 25 is asking about health professionals involved in the child's care, other than the GP. This can include neurodevelopmental team, psychiatrists, counsellors, G.P., specialist nurses, consultants, physiotherapists, and so on.

We would advise to put the person (health professional) that is most appropriate first so pop their information/details on question 25. There may be numerous healthcare professionals involved in the child's care/treatment but put the one that knows them best first. If they have multiple health conditions, then put the healthcare professional associated with the health condition that affects them the most first. It goes on to ask about their GP on the next questions (Q26-29) so you don't need to put their GP details here. This question only allows space for one health professional on this page so add on further health professionals (where appropriate) at question 89.

Have a think about who you would prefer to be contacted in the first instance and put them at the top of your list.

Don't worry if you don't know names, or the exact date your child last saw them — put as much information as possible such as the team/department, and an approximate date when last seen. If you have the hospital number (you can find this on any hospital letters you might have) — great! If not, do not worry — it is ok to leave it blank.

Q26 - 29



**GP** 

Put down child's GP here — if you don't know the GP 's name just put the surgery and again do not worry about what date last seen — if you are not sure just put 'about...months ago', or the month last seen if you know it.

Q30 - 37



School

The next few questions are asking about school, and special educational needs.

**Q38** 



Statement from someone who knows the child

This does not have to be filled in. If there is someone who knows the child well, and the difficulties they face then you can ask them to complete this. It can be someone involved in their care, or it may be a family friend. If it is from someone involved in their care (social worker, doctor, portage worker, teacher/SENCO) then it can act as supporting evidence. If it is a family member or friend, then this can add further useful information and acts as a first impression about the child in terms of their difficulties and the care and support they need.

#### **Q39**

This section is asking for you as the parent/guardian to tick a consent box (yes or no) and sign and date it here. It allows sharing of information between the DWP and any relevant health professionals. There are two signatures required on this form and this is the first.

#### **Q40**



#### Child's illnesses or disabilities

This question is asking you to list all health conditions of the child. Again, start with the one that affects them the most first, and work your way down. It doesn't have to be in any specific order so don't worry if you miss one out — just add it on to the end. They may not have a diagnosis for their health condition for whatever reason. If they are being investigated for a condition and don't yet have a diagnosis, still add it on and if there is something that is suspected then pop this on as 'suspected....and under investigation'. You can pop on if they are on the neurodevelopmental pathway here too if a diagnosis has not yet been made. It might be you have no idea what it may be, just write the symptoms as a summary, e.g. bad back, pain in left leg causing limp, etc. In terms of the start date, if you are not sure just pop on the year — don't worry!

It's also asking you to detail any therapy or medication here – if you have a prescription list then you can send this (make sure the child's name and address and date of birth are on there) and write 'see attached'. Make sure you include therapy even if you carry this out yourself at home – this could be massage therapy for children with cerebral palsy or play therapy.

#### Q41

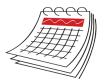


#### Aids and adaptations

Here list any aids or adaptations that help the child, whether at school, home, or both. This may be visual aids to help them if they have learning difficulties, or it may be physical aids such as a wheelchair. Anything that helps your child to manage daily activities and that is

needed due to their health condition then list it here. Make sure you list any difficulties they face using it – they may have a wheelchair but might not be able to self-propel. They may have picture exchange cards but need prompts from you or someone else to use them.

**Q42** 



#### When the child needs help

This question is asking if the condition of the child varies from day to day or most of the time. For example, a child with arthritis may have flare ups so their condition may affect them for periods of time throughout the year. This is where you should detail this. It can be difficult to quantify if you haven't recorded it but try to think of examples such as you may be aware they had a flare up around Christmas time and it lasted at least a couple of weeks or complete a diary for a few weeks to see if this helps you.

Some parents tell us their child's condition can vary yet when we discuss this with them it is clear they are affected every day. Think about the consequences of carrying out daily activities. For example, a child with autism may struggle to cope with loud noises. You may be thinking to tick 'it varies' as when you don't take them out or you limit noise and avoid consequence/they won't have a meltdown on this day. This is not their condition varying—it is you limiting or restricting the exposure to certain triggers so in this situation you would not tick 'it changes from day to day' but would tick 'majority of days' and you will have the opportunity to explain how they are affected by certain triggers later in the form.



We are now ready to tackle the main bulk of the form. It is split up into two parts: Mobility and Care but before we start....



#### Be Honest!

The upcoming questions are asking about how the child's health condition affects their ability to manage some daily activities. It is important to be honest! Many people will think it is ok to talk as if it is the worst day. Whilst this is important, it is important to show how someone's condition varies (even if it affects them every day). If you only talk about a bad day and bad days are not every day, then this won't be an accurate picture. If the child's condition affects them every single day, but the help they need varies then start off with how it can be on a bad day, and then follow this up with the help needed/difficulties when it is a good (or better) day. For example, someone may have depression. On a bad day they may not be able to get out of bed or get dressed. On a better day they may still need help in the form of prompting and motivation from another person to get out of bed and to get dressed. Remember you have a specific question (Q24) about how the child's condition varies so this is your chance to pop this there as a summary and you can go into detail on each specific question.

#### Help needed!

Another reason to be honest is that often parents and guardians of children may find that what they do for the child can be sub-conscious. You might find you do things for them without even thinking about it or you may be so used to what you do, it is just your daily life in terms of looking after a child and being their mum/dad/guardian. With Child DLA it is important you distinguish the EXTRA help you give because the child has a disability or health condition. It might take you a lot longer to carry out an activity such as dressing because of reasons connected to the child's health condition/disability. An example might be they may have a meltdown when trying to dress them due to frustration. This might be because they have ADHD and they don't like the feel of certain clothes, or they might not understand why they must wear a particular item of clothing such as a coat even though it is freezing cold outside.

It might be that you are doing something for the child at an age where you would expect they could do it independently, but due to their health condition/disability they are unable to. For example, you would expect a baby could sit unsupported between the age of 6-8 months, or that a child aged 3 would be dry through the day in terms of toileting. To help with this check out milestones online – one great website to look at is <a href="http://www.earlyyearsmatters.co.uk/ourservices/school-and-nursery-support/early-years-adviser/child-development-2/">http://www.earlyyearsmatters.co.uk/ourservices/school-and-nursery-support/early-years-adviser/child-development-2/</a> and this will give you an idea of where children are expected to be in terms of their development. Or we have included a basic development chart (Appendix A) which should give you an idea of developmental milestones up to the age of 6. We know every child is different and can all be at different stages, but if the child is delayed and not reaching their milestones because of their health condition/disability then this should be included in the form.

#### **Explain why!**

Always explain the difficulties in detail and explain why the child has the difficulties. An example a child who cannot cross a road without supervision – you need to explain why - it is not enough to just say 'they cannot cross a road without help/support' – tell the DWP why they can't. It might be because the child has ADHD and has no sense of danger and will just run out into roads. They may have learning difficulties and are unable to retain information so will not follow the green cross code. They may have poor spatial awareness and be unable to judge the distances of oncoming vehicles. Paint the true picture and be as descriptive as possible in terms of the help they need and why they need it. It is difficult when talking about children as children will often need help with the activities because they are a child so tell them why extra help is needed because of their health condition/disability. Remember think of the EXTRA attention and support you give because of their health problems and describe the difficulties. You might be inclined to not add any additional information as a lot of the questions are tick box answers. If there is no space to explain why the child needs help, you need to detail the additional information on question 72 and this will allow you to detail why the child has difficulties with the activity in question.

Why, why?? Why can't they do it, why do you do it for them, why does it take them so long, why do you avoid that? Ask yourself why and answer your own questions and this will help you to be as descriptive as possible.

#### **Examples**

Give examples where you can and where relevant. For instance, the child may not be safe around roads. You may have had encounters where there have been cars having to stop to avoid the child or where you have pulled them back out of a car's way so put this on the form.

#### **Timings**

On some of the questions, you will see it might ask about how long something might take – think about the timings carefully. People often underestimate the length of time it takes for them to do something so if you are not sure put an approximate time. If it can vary put this so for example '1-2 hours' and you can go on to explain in the text box. If you really are not sure, time some of the activities over a few days.

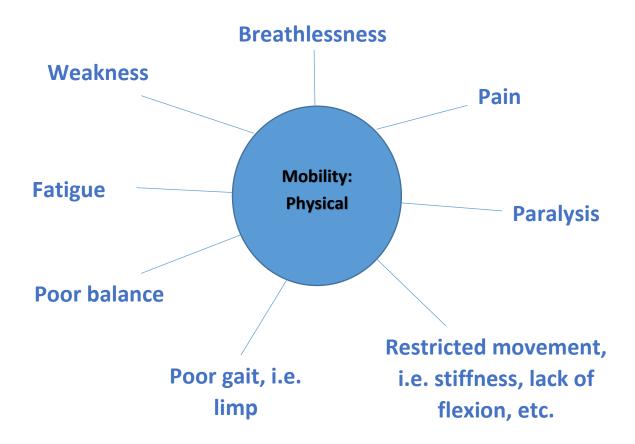
We are about to give you some examples\* around the difficulties that children may face with each activity and where appropriate, we will try to cover an example for both physical and mental health/cognitive impairment.

\*Please note these are examples only and are to act as a guide only – it is important you detail YOUR child's health conditions and how they affect you.

#### **Mobility questions**



Questions 43 to 48 are centred around physical difficulties with mobility. You will only need to complete these questions if the child is aged 3 (if the child is due to reach 3 in the next three months, you may want to complete them as an advance claim can be made) The reasons you may complete these questions might be one or more of the following:



If the child doesn't have physical difficulties jump straight to question 49. If they do let's move to helping you describe their physical mobility. The first few questions (43 to 48) should hopefully be self-explanatory. On question 53 you will need to describe their difficulties with walking so let's give some examples:



#### **Mobility**

Think about going out with the child and walking outdoors at any time. There may be times when they are unable to walk outdoors so start here and explain why this might be the case. Then go on to think about a day when they can go out and start at the very point of how they might experience symptoms so upon standing, and then with every step they take. Look at their gait. Why might they stop walking? What are they saying? Look at some of the symptoms in the spider diagram on page 11 and describe them. If it is painful – where is the pain and how severe is it— does it stop them in their tracks? Where possible say the reasons for the pain or the difficulties they face

#### **Example:**

Kitty has cerebral palsy and often struggles to walk at all. She has more bad days than good and majority of the time she is unable to walk outdoors so we use a wheelchair. However, due to her having cerebral palsy she is unable to self-propel in the wheelchair, so we have to push her in a wheelchair when outdoors at all times. This is again because she has cerebral palsy. Her limbs are severely restricted due to muscle tightness, and she experiences frequent involuntary muscle spasms. She has muscle weakness so lacks the physical strength to push herself in the wheelchair. If she is on a better day (which are getting less frequent as time goes by) and she did walk outdoors, she would still need significant support. She would need help from another person as her legs can give way on her causing her to fall without any warning, so she requires physical support to stop her from falling. She tires extremely easily so can only manage a very short distance. She walks extremely slowly and has a very poor gait as she has severe restricted movement in her legs due to having cerebral palsy. Her muscles are very tight, so this causes her to walk with a significant limp and she experiences pain in her legs.



### Guidance and supervision outdoors

These questions are asking if the child needs guidance and supervision when outdoors. It also asks about falls so this might be related to poor coordination so might be applicable for children with certain conditions such as dyspraxia. With guidance and supervision outdoors, it can be difficult, particularly if the child is very young as you may be thinking you wouldn't let them be alone outdoors anyway. However, it is important to think about the extra help you give them because of their health problems/disability. Think about what would be reasonable for a child of the same age without their health problems. Factors you need to think about when outdoors are:



#### **Example:**

Kitty has ADHD and has no sense of danger. She cannot ever go out unsupervised. She is not safe around roads due to her having ADHD. She is unable to stay on task and cannot focus so will not stop and wait and check for traffic. She is easily distracted, and this means she is not safe around roads. She will step out into roads without even thinking or will run across to see something she is distracted by. She has done this on numerous occasions, and I have had to pull her back out of the road. I have to hold onto her at all times even though she is 8 years old. I have to prompt her to stop at the roadside and will tell her to check both ways but even if she did look, she would not process the oncoming traffic and even when she has checked she will still walk out into roads when cars are coming. She takes things literally and will believe anything that is said to her so she is very vulnerable and as she has no awareness of danger she would be at risk around strangers or even people who she knows who may take advantage of her, so she needs constant supervision. She will wander off and has no sense of direction. She does not know her left from her right and if she got lost, she would not be able to speak to a stranger. She would not know what to ask or how to find her way around. She could not tell someone her address.

Things need to be routine led for Kitty. She needs to know where she is going and if something is unexpected or she encounters certain things such as loud noises (even a bus pulling up) she cannot cope and has frequent meltdowns. She will scream and shout and hold her ears and if I try to comfort her or encourage her to stop, she will lash out. If I try to stop this, she will either hit out at me or drop to the floor wherever she is. She needs restraint as she will try to pull her own hair out.

#### **Q51**

Make sure you pop a date in here. It doesn't need to be exact – it might be 'from birth', or a specific age or 'about x months/years ago'.

#### Q52

This question is only asking if you would like more information about Motability and nothing to worry about. This can apply if your child were to receive higher rate of mobility. See the website for more details.

https://www.motability.co.uk/

#### Q53

This is your space to explain why and to give examples so as much information as possible.

#### **Care questions**



**Q54** 



### Getting in and out of bed and settling

Think about the child's bedtime routine here. What extra do you have to do to help your child to settle? Do they need a strict routine – what happens if this routine is broken? Will they have a meltdown? How long does it take for them to settle? Do they struggle to switch off? What happens when it is time to get up in a morning? Have they been up most of the night so struggle to wake? To follow a routine would you need to give them extra prompts and encouragement to wake due to their health condition. Would this cause them to have a meltdown? Also consider are they at an appropriate age where they would be able to tell the time and know when it is a reasonable time to go to bed and when to wake. It is also asking about physical difficulties regarding getting in and out of the bed. They may have restricted movement or pain and struggle to get in and out. Do you have to physically help them? Have they fallen out of bed due to their health problems? There may be a number of reasons they need help so think about what you do every night and every morning. Think about what you do and if it is reasonable? Does it take a long time? It might be the norm for you to help to settle the child and this might take a good hour. You might be used to doing so much so that you do it without thinking but if what you do is EXTRA attention due to their health condition/disability then it is important to include this. Remember, your opportunity to explain this will be on question 72. You may find you will need more room so use additional sheets of paper and make sure you head up the paper with your child's name, address, and date of birth (national insurance number if you have it).

#### **Examples:**

1. I have to physically help Kitty to get out of bed and this is every morning. She has Spina Bifida which causes her to have severe weakness in both legs. The muscles in her legs

are very weak and this causes her to be very unsteady and she has experienced falls when trying to weight bear. She has broken bones as it affected the development of the bones in her legs.

2. Kitty has autism and needs a strict routine. Every night it takes us an hour to settle her, and we have to follow a strict routine. She is 8 years old and is unable to go to sleep without this extra attention. This is because she has autism. She does not realise why things cannot be on her terms so if we were to break her routine this would result in a meltdown. A meltdown for Kitty often leads to her requiring physical restraint as she will become destructive and will throw things around her room, break things, and will bang her head against the wall. When we try to restrain her, she will lash out at us. It can take a while to calm her down. The routine we follow is very lengthy and we have to carry out certain actions such as read, stroke her hair, sing the same song, arrange certain toys in the correct way and we have to stay with her until she falls asleep. If we did not do this, this would be very distressing for Kitty. She has autism and must follow a very strict routine as she feels unable to cope unless in such a routine.



Here you need to consider difficulties children face with all aspects of toileting. They might need to be prompted when to go else they will have an accident. They might need help to manage their clothing to be able to toilet. They may need prompting and encouragement to wash their hands. Some children cannot cope with certain aspects of toileting and may find is distressing for them so you may need to accompany them to reassure them and offer them support. You might need to supervise them as they may try to touch faeces. They may not be able to physically get on or off the toilet (remember the reason must be due to their health condition). It might be they are not toilet trained and this has been delayed due to their health condition. You would expect a child to be dry through the day at age 3. Remember, your opportunity to explain this will be on question 72. You may find you will need more room so use additional sheets of paper and make sure you head up the paper with your child's name, address, and date of birth (national insurance number if you have it).

#### **Examples:**

1. I have to physically help Kitty to toilet. She has poor motor skills and cannot manage fastenings on her clothing to get them on or off. She struggles to wipe herself due to her poor motor skills and poor coordination due to having dyspraxia. She cannot

manage to even get the toilet paper to tear off let alone coordinate her movements to wipe herself. I have to help her at every toilet visit.

2. Kitty has ADHD and will hyper focus on certain things as she has obsessive behavioural traits. She will become so engrossed in certain situations that she will not even think to go to the toilet when she needs to. I have to prompt her as it will be obvious, she needs to go. I prompt her frequently throughout the day as she has had numerous accidents where she has wet herself as she will just not go and struggles to take her attention away. When she does go to the toilet, I have to supervise her as she does not like faeces and will refuse to wipe herself when she has done a bowel movement. She will cry when she has to pass one, so I have to comfort and reassure her. She will have meltdowns when I have to wipe her, and she will cry and scream and will try to pull my hair as I am wiping her.

**Q56** 



#### Moving around indoors

With this question you need to think about different places indoors, and not limit it to your own home so think about school or a family members house. Many people relate this question to children who have physical difficulties, but it is about moving around safely so you also need to have a think about this question if your children have no awareness of danger.

When thinking about this question there are a number of different things to think about: Think about sitting down in a chair – are they comfortable? Do they experience pain? Do they struggle to keep still? Do they need help or have difficulty getting in and out of a chair (or wheelchair)? Remember don't just think about your chairs at home. You might have a specially adapted chair for them at home so mention this if this is the case but also detail the difficulties they would face if this chair wasn't available and any difficulties they still have with any aids or adaptations.

Next think about walking from room to room. Do they have mobility problems? Do they experience pain, or breathlessness, or do they lack the ability to get around certain parts of the home or school? Think about the danger aspect — will they run and climb due to having no awareness of danger. Have they hurt their self? Do they have a high pain threshold and so this will limit your ability to know if they have caused damage or need to seek medical attention? Will they try to climb out of windows or run out of the door so need constant supervision? Give examples where you can.

Think about stairs and any physical difficulties they face, or any help needed. Do they need to stop and rest? Do they need to hold on to something? Do they run and jump on the stairs due to the lack of awareness around the consequences of their actions? If you are answering yes and it is due to their health condition, then these are things you need to be detailed on

question 72. You may find you will need more room so use additional sheets of paper and make sure you head up the paper with your child's name, address, and date of birth (national insurance number if you have it).

#### **Examples:**

- 1. Kitty has juvenile arthritis. She experiences constant joint pain and fatigue. She encounters flare ups where her condition will worsen and when she experiences a flare up, she will not move around the home at all. She will be in too much pain and be too weak and tired. She requires physical support to help her to move around and this is only when necessary, such as to go to the toilet. These flare ups can occur at any time and can last any length. In the last 6 months she has experienced two flare ups, and this was the case for 2 weeks each time. Even when she is not having a flare up, she experiences difficulties. Her joints ache and she walks with a limp. She tires easily and so often will ask others to fetch and carry for her. Her right knee can give way and she is generally unsteady on her feet. Her brothers who are younger will be running around and playing and she is unable to do this due to pain, weakness, and tiredness. She needs physical help on the stairs due to her unsteadiness and the risk of falls with her knee giving way it is not safe for her to use stairs without such support as she would not have the physical strength to support herself and stop her from falling.
- 2. Kitty has ADHD and has no awareness of danger or consequence. She has a high pain threshold, so it is very difficult to know when she has caused any damage. For example, on one occasion she had an accident and fell hurting her finger. She did not complain and yet when we had this checked out, she had broken it. Kitty will want to mimic certain things she sees and does not understand that she is not able to do them. For example, she will see someone fly on the television and will try to 'fly' herself. No matter how many times I speak to her about how dangerous it could be to jump down the stairs she keeps trying to jump. We have had to have locks put on the windows to stop her from climbing out she needs constant supervision to ensure her own safety.

**Q57** 



**Washing and Bathing** 

Firstly, think about the child having a bath. You may not have a bath at home as you have a walk-in shower or a wet room. Still explain the help they would need with a bath and what difficulties they would face and then go on to explain any difficulties with a shower and a

wash to ensure you cover everything. If your child can have a bath or a shower think about what support, they would need because of their health condition. Again, we know this is difficult as many children will need help with a bath/shower because of their age — it is important to distinguish the help needed because of their health condition/disability. Think about running the bath, turning on the shower, testing the temperature of the water – would they get in and stay in even if too hot or too cold? Do they require supervision due to the lack of awareness of danger as they might start jumping or running the hot water, risking burning themselves? Do they require prompting to wash and if so, is it continual? Would you need to prompt them to wash each part of their body? Do you physically have to help them to wash? Think about washing their hair and drying themselves. Think about other aspects of maintaining their hygiene such as brushing their teeth, cutting their nails, brushing their hair, shaving (where applicable). Would they wash if not prompted? Do they have any awareness of personal hygiene? Have you noticed any smells? Would they go without washing without prompting and encouragement? Would they check their appearance? Remember, your opportunity to explain this will be on question 72. You may find you will need more room so use additional sheets of paper and make sure you head up the paper with your child's name, address, and date of birth (national insurance number if you have it).

#### **Examples:**

- 1. Kitty is unable to use a bath without physical assistance from another person. I have to physically hold on to her as she lifts her legs over the side of the bath. She has restricted movement due to muscular dystrophy. She struggles due to weakness and is not steady, especially when standing on one foot so I have to hold her. She is unable to get out of the bath without physical assistance as she lacks the strength to get up out of the bath due to muscular dystrophy. She has weakness in her shoulders and cannot raise her arms above her head so is unable to wash, dry and style her hair so I have to do this for her.
- 2. Kitty needs help with all aspects of washing, bathing, showering, and looking after her appearance. Kitty has learning difficulties and does not understand the importance of washing or taking care of herself. Kitty would not know to wash and so needs to be told to do this daily. She would not know to check her appearance and even if food were around her mouth, she would not know to wash it off, so I have to check her appearance throughout the day. Kitty would not understand how to turn on the bath or the shower and would not know how to regulate the temperature. She would just get in no matter how hot or cold. She requires constant supervision as she has no awareness of danger and does not understand the consequences to her actions. She is never safe to be left alone. She would just sit in a bath and not wash even if I told her to wash, she would not put the shower gel on the sponge and would not rub so I have to wash her whole body for her. I have to take care of every aspect of her personal appearance.



#### **Dressing and undressing**

Think about the process from the start so think about what clothes will they wear today and any difficulties with this. Will they refuse to wear certain clothes due to sensory issues, or clothes with labels in? Will they wear clothes that are appropriate for the occasion/situation? For instance, will they wear a coat if it is cold, or shorts if it is hot? Will they wear a uniform to school? Will they want to wear clothes at all? How long does it take you to get them dressed if you have to help them? Do you need to guide them or physically manoeuvre their limbs through arm, head, and leg holes? Would they put on clothes the right way? Can they manage buttons, zips, tie laces etc.? Will they have a meltdown if they have to get dressed or if you try to help them? Remember, your opportunity to explain this will be on question 72. You may find you will need more room so use additional sheets of paper and make sure you head up the paper with your child's name, address, and date of birth (national insurance number if you have it).

#### **Examples:**

- 1. Kitty needs help to get dressed as she has Cerebral palsy. Her arms and legs are stiff, and she struggles to flex them, so I have to help her to dress and undress. She is unable to coordinate her movements due to the stiffness and weakness to do this herself. Her limbs are too stiff. Even when I help her it can take me a while as her limbs are stiff. She is unable to manage fastenings due to poor motor skills. Kitty has poor gross and poor fine motor skills. She cannot fasten or unfasten buttons, zips, laces so needs physical help to dress and undress daily.
- 2. Kitty has autism. She needs help with dressing and undressing daily. Kitty needs to have her clothes picked out for her as she would not know what would be suitable. She always wants to wear a coat with her hood up even when it is 100 degrees outside. She also wants to wear the same clothes repeatedly and these are usually a pair of jogging pants and a loose-fitting Minnie mouse top. She needs a great deal of encouragement to wear certain clothes, such as shorts in warm weather. Kitty does not understand why she cannot wear them, and this can cause her to become very frustrated. It can take a long time trying to get her dressed as if she wants to wear something (i.e., something that is dirty) and I encourage her to wear something else, she will have a meltdown. She will become aggressive towards me and will try to hit me. Kitty does not like the feeling of many items of clothing. She will not wear jeans and certain kinds of materials. I might go through 10 outfits a day trying to encourage her to wear something. She cannot cope with labels in clothes and does not ever want to wear socks as she does not like the feel of the seam. It takes me a long time to encourage her to wear socks and she has frequent meltdowns She tends to be in her bare feet most of the time. If I do manage to get

her to wear socks this can be very distressing for her, and I have to try to get the seam in a very particular position to limit the discomfort.

**Q59** 



#### **Eating and drinking**

Here let's think about you having made a meal and giving it to the child. Remember the help needed must be because of their health problems/disability and not just their age. Would they refuse to eat it? If so, why might this be? Can they cut up the food on their plate or manage to use cutlery at all? Can they manage cups to drink? Do they need prompting and encouragement to eat? Remember, your opportunity to explain this will be on question 72. You may find you will need more room so use additional sheets of paper and make sure you head up the paper with your child's name, address, and date of birth (national insurance number if you have it).

#### **Examples:**

- 1. Kitty has Anorexia nervosa. She limits the amount she eats daily so needs a great deal of encouragement to eat throughout the day. She needs a great deal of support around her eating due to this eating disorder. She has lost a considerable amount of weight in the last few months because she is self-starving. She will often refuse to eat at all or will try to take her meals to her room, where we suspect she may be disposing of it rather than eating. We have to try to monitor her food intake to ensure she is eating. Kitty requires a great deal of emotional support around eating. It takes her a long time to eat a meal.
- 2. Kitty has poor fine motor skills due to her having autism. She is unable to coordinate her hands to cut up food and struggles to even bring food to her mouth, often dropping it off her spoon. Because of this she tries to pick up food off her plate with her hands, even soft foods such as mashed potato. I often have to feed her as she will get it all over her and the floor.

#### **Q60**



#### **Medicines and therapy**

Do you have to prompt and encourage the child to take their medicines? Will it result in a meltdown if you try to encourage them? Will they flat out refuse? Do they know what they take, why they take it and when they should take it? Do you have to prompt and encourage them with therapy? This might include children with diabetes. Are they able to monitor their own health condition? Will they take the necessary steps such as testing blood sugars? Remember, your opportunity to explain this will be on question 72. You may find you will need more room so use additional sheets of paper and make sure you head up the paper with your child's name, address, and date of birth (national insurance number if you have it).

#### **Example:**

1. Kitty has type 1 diabetes. She is aged 8 and is not able to monitor her own health condition as she does not understand the importance of this due to her age. I have to monitor her health condition at all times. I have to inject her daily with insulin. Kitty would simply not be able to manage this herself as she is not responsible enough. I have to check her blood sugar levels several times a day to monitor her condition.

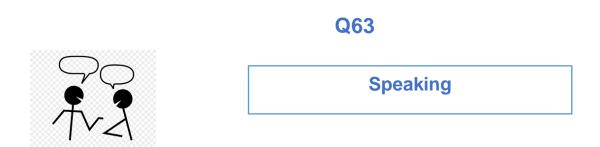


When answering this question, if your child wears glasses/contact lenses, then you need to consider the questions as if they were wearing them, and not without. Think about any environmental factors which may affect their sight. You might also want to tell them if they should wear glasses or contact lenses but don't due to reasons associated with their health condition/disability. For instance, a child with learning difficulties may not understand the importance or significance of wearing them and may continually take them off or break them, leaving them not able to see. Remember, your opportunity to explain this will be on question

72. You may find you will need more room so use additional sheets of paper and make sure you head up the paper with your child's name, address, and date of birth (national insurance number if you have it).



When answering this question, if your child wears hearing aids, then you need to consider the questions as if they were wearing them, and not without. Think about any environmental factors which may affect their hearing. You might also want to tell them if they should wear hearing aids but don't due to reasons associated with their health condition/disability. For instance, a child with learning difficulties may not understand the importance or significance of wearing them and may continually take them out or not let you put them in at all. Remember, your opportunity to explain this will be on question 72. You may find you will need more room so use additional sheets of paper and make sure you head up the paper with your child's name, address, and date of birth (national insurance number if you have it).



With this question think about the child's talking out loud. Can they speak at all? Can they pronounce all letters? Do they mumble or have a speech impediment? Would a stranger be able to understand what they were saying? Can they form sentences which are understandable? Can they use the correct words in context and form sentences, so they make sense? Remember, your opportunity to explain this will be on question 72. You may find you will need more room so use additional sheets of paper and make sure you head up the paper with your child's name, address, and date of birth (national insurance number if you have it).

#### **Example:**

1. Kitty has global developmental delay. She is unable to pronounce certain sounds and letters such as 'sh'. She will miss parts of letters off words, so the word is not

recognisable. For example, for the word 'school' she will say 'coo'. She struggles to form sentences and strangers are unable to understand what she is saying. I am her mum and yet still find it very difficult to understand her and what she wants. She will often just say words in isolation rather than form a sentence. She will use incorrect words and if she does ever say a few words together it will not form a sentence – there will be no conjunction or order to it. I often have to translate wherever I go, and this can take time as although I know her extremely well as her mum it is not always recognisable to me, and this can cause Kitty to become frustrated.

#### **Q64**



#### Communicating

Think about having a full conversation here. It follows on and may include information you have presented in the previous question but don't worry about this. Say it again if you need to.

Can the child have a conversation? Will they turn take? Will they engage with other people? Think about the topic of conversation and asking questions? Will they become withdrawn or ignore people? Can they communicate how they feel? How are they with facial expressions, intonation, and body language? Can they 'read' people? Do they show emotion? Do they take things literally? Can they understand humour or metaphors? Remember, your opportunity to explain this will be on question 72. You may find you will need more room so use additional sheets of paper and make sure you head up the paper with your child's name, address, and date of birth (national insurance number if you have it).

#### **Example:**

1. Kitty has ADHD and has communication difficulties. She needs a great deal of support from me and her dad to communicate to others. She struggles to have a conversation. She does not understand turn taking and will just talk when she has something to say, even if this means speaking over someone. If she is not interested in what someone is saying, she will just ignore them and walk away. If she is talking about something that interests her, she will talk and talk about it, even if this is completely out of context of what has been said. She would not recognise when it is time to stop or let someone else speak. She struggles to interpret meaning and this makes her vulnerable. She cannot 'read' people as doesn't understand body language, facial expressions, and tone of voice. She takes things literally causing her to not understand humour. If someone was sarcastic or talked metaphorically this can cause her to become upset and frustrated as she does not understand that this might not be what someone means. I have to support her a great deal by interpreting and explaining what people say to her and have to break it down on very basic terms.

#### **Q65**



#### Blackouts, fits, seizures

Try to give some indication of how often the child experiences them. You might have a record/diary of seizures particularly if the child is new to the condition or whilst trialling medication so put a copy of this in with the form. If they have seizures, describe them – are they petit mal or grand mal? How long might the episode last? What about afterwards? Do you need to make sure they rest or reassure them or explain? Remember, your opportunity to explain this will be on question 72. You may find you will need more room so use additional sheets of paper and make sure you head up the paper with your child's name, address, and date of birth (national insurance number if you have it).

#### **Example:**

1. Kitty has epilepsy and has grand mal seizures. They are currently uncontrolled whilst trialling medication. When Kitty has a seizure, she loses consciousness and falls to the floor where she starts to 'jerk'. They occur for usually a minute each time or thereabouts. Upon waking Kitty is very confused and disorientated. She is very sleepy. I have to talk to her and offer her reassurance and explanation. She then needs to lie down and have a sleep for a couple of hours each time.

**Q66** 



#### **Supervision**

This is where you might want to think about the reasons you would be concerned if your child was alone. What if their routine was broken? Would this cause a meltdown? Would they be distressed and need reassurance and emotional support? Do they hear voices? Are they a danger to themselves or others? If they are, describe why and give examples where you can. If they have meltdowns describe them here. They may get easily frustrated and become destructive so explain what happens when they are in such situations – again give examples. Do they self-harm? Have they attempted suicide? Do they have no awareness of danger? Would they be vulnerable if left alone? Remember, your opportunity to explain this will be

on question 72. You may find you will need more room so use additional sheets of paper and make sure you head up the paper with your child's name, address, and date of birth (national insurance number if you have it).

#### **Examples:**

- 1. Kitty has depression and self-harms. Kitty does not self-harm in front of others and will only self-harm when alone, so she always requires supervision. She will cut herself with any sharp object to the point where she will draw blood. We have to try to hide all objects in the house to limit the opportunity, but Kitty will find whatever she can and hide items in her bedroom. She requires constant supervision because of the risk of harm to herself. She has depression and is very withdrawn. She needs a lot of motivation and emotional support alongside supervision. She has expressed feelings of wanting to die and so she is never safe to be left alone.
- 2. Kitty has autism and needs a very strict routine. We have the routine on a visual display chart, and this includes daily activities such as brushing teeth, eating times, etc. Kitty is unable to cope with anything that is unfamiliar to her or out of her routine. There are times when her routine is broken due to circumstances beyond our control, and this causes Kitty a great deal of distress. She does not understand why her routine is broken no matter how many times I try to explain. Kitty will not be able to verbalise how she feels and will rock back and forth holding her head and pulling her hair tight. She will look vacant and will not respond when I speak. She is very upset and distressed and if I try to comfort her, she will hit out at me. She will punch, kick, pull my hair, scratch me. I cannot leave her as Kitty will often start banging her head against the wall out of frustration and I have to intervene and restrain her as she will do it with force. Kitty cannot ever be left alone as she has no awareness of danger.

**Q67** 

**Development** 

Here you want to think about the child's understanding. Think about them playing both alone and with other children. Do they play with age-appropriate toys? Can they play with other children? Do they understand and follow the rules? What about general rules in the outside rules, such as etiquette, queuing, being polite, knowing what is appropriate. Remember, your opportunity to explain this will be on question 72. You may find you will need more room so

use additional sheets of paper and make sure you head up the paper with your child's name, address, and date of birth (national insurance number if you have it).

#### **Example:**

1. Kitty has learning difficulties. She is 8 years old yet mirrors the behaviour and actions of a very young toddler. She is very childlike and does not have any friends. She likes to play alone and will play with things that are age inappropriate or not what you would expect. For example, she likes to sit and watch the washing machine spin and will sit there for a long time watching this. She will play with baby toys. She is unable to play games that are age appropriate. She does not understand the rules and would not be able to follow instructions due to lack of understanding. This is because she has severe learning difficulties. She struggles to retain information. She has no friends and is very vulnerable. Kitty does not understand the world around her. She would not know it would be inappropriate to be naked outdoors in public or that it would be inappropriate to show certain parts of her body to others. She will try to hug people and invades people's personal space due to the lack of understanding she has, and I have to explain to others that she has developmental delay. She also is inappropriate with her language. She will randomly say the word 'F\*\*\*' out loud and will start shouting very loudly in public places.



**Q68** 

**School/nursery** 

Here you have a few tick boxes and need to tell DWP what help they have at school or nursery. This might be one-to-one support. It might be they have quiet time and a safe place to go and sit. Some children may have a separate time for play or dinner due to difficulties being around others due to their health condition/disability.

#### Q69



#### **Hobbies/interests**

You only need to put on hobbies or interests here if they need help to do them. For example, to watch the television, they may be unable to turn it on or use the remote control. To go swimming, they may need physical help to get dressed and undressed, help to get in and out the pool, or a one-to-one teacher due to their health problems. They may go to football but require supervision due to their behaviour. The coach/leader of the group may have been made aware of the child's health condition/disability and adapt lessons accordingly for them.

**Q70** 



#### **Night-time**

Think about when it is time for you to go to bed at night. It is time for the whole house to shut down and everyone to go to sleep. You get in bed and then what happens? Do you wake in the morning and the child has slept through? If not, what has happened? Have they woken up and need help to re-settle or supervision whilst they are awake? If so, why? Have they had an accident in bed, and you need to clean them up?

#### **Example:**

1. Kitty does not sleep much at all during the night and will often only go 1-2 hours with sleep and then will wake and be ready to get up and play. She does not understand the difference between night and day and will think if she wants to play, she can. She has ADHD and does not understand why things cannot be on her terms. I have to try to encourage her to go to sleep but she will have a meltdown and often will wake the whole house. She will start crying and shouting and will want to play. I can often be up for hours through the night trying to settle her. I cannot leave her as she would wander around the home, and she has no awareness of danger. She is never safe to be left unsupervised.

**Q71** 

Make sure you put a date here. If you don't know the exact date just approximate.

#### **Q72**

This is where you will have the opportunity to explain why and give examples around help needed.

#### Q73 onwards

Now go on to tell them about you – the person who the letters will be addressed to and who will deal with the child's claim.

#### **Q89**

If there is any important information you feel would be useful, you can also include this here. You may find you will need more room so use additional sheets of paper and make sure you head up the paper with your child's name, address, and date of birth (national insurance number if you have it).

We would always recommend that if you are awarded Child DLA for a child within your household you inform the relevant agency in terms of what benefit you receive. It might mean extra benefit entitlement for you. Another option is to ring St Helens Carers Centre on 01744 675615 or pop online at <a href="www.sthelenscarers.info">www.sthelenscarers.info</a> and chat to us live Monday to Friday 10 till 3 and we will tell you exactly what you need to do, who to ring (if anyone) and how it can affect you. We will also offer to do this for you and can arrange this with you. Child DLA will not reduce any benefits you get but it might increase them.

You then need to choose where you want the monies to be paid if it is awarded, add on extra information if you feel it is relevant.

You then need to read the declaration and if happy with this sign it and send it off in the envelope supplied.



We hope you have found this guide useful and that it has helped you to think about how you support the child, and what extra attention they might need.

Remember, put as much detail in as possible regarding the difficulties they face and the EXTRA attention you give to them. Explain and give examples where you can. If you have any more questions or need further advice, please call us on 01744 675615 or why not pop online and chat to us at <a href="https://www.sthelenscarers.info">www.sthelenscarers.info</a>

Check out our opening times and online chat times on our website.

	Vision and Manipulation	Hearing and Speech	Gross Motor	Social Behaviour	Feeding
Birth	Follow moving objects with eyes	When baby is not crying they will respond to loud noises	New born babies have no head control	New born babies spend most of the day sleeping	
	Range 45 degrees, 8-10 inches away	When baby is crying they will quieten to a noise	Head will flop backwards when laid down		
	Hands remain closed (Involuntary grasp reflex)	4	Head is to one side when laid on its tummy and knees under abdomen		
6 Weeks	Baby can focus and follow an object	May be startled by loud noises	Beginning to gain head control when pulled from lying down to sitting	Will smile at familiar and unfamiliar people	
	Watch their mother intently when she speaks		position  Head no longer flops backwards	May begin to vocalise ie. Respond to speech by making sounds	
3 Months	Will follow a moving toy with their eyes, that is held in front of them, through 180 degrees  Will hold hands in front of face and observe them  Holds a rattle	A baby will babble when spoken to	When laid on tummy the baby is able to lift its head up and bear weight on forearms  The head is help up mostly when the baby is supported in a sitting position	Recognises mother  Squeals with pleasure and becomes excited when given a toy	Feeding, winding and settling at 3 to 4 hourly intervals by day.  Night feed is usually dropped at this age
	momentarily when it is placed in hand		position		
6-8 Months	Can grasp objects and enjoys playing with hands held in front	Can respond to sound from behind Will use their voice to	Able to sit unsupported  When help upright can support own weight to	Responsive to familiar people and apprehensive to unfamiliar people	Can drink from a cup / finger feed / chew and therefore eat solids.
	Will drop an object when another is handed to them	babble, i.e. they will	some extent	Will talk using babble to familiar people	

	Can follow objects with their eyes and can also reach for them	make different tuneful noises such as baba, dada	Can roll over when laid down on the stomach to the back, and vice a versa	In a safe situation can play on their own	
9 to 12 Months	Can reach for and grasp toys and enjoys feeding self with fingers  Can bring fingers and thumb together to pick up objects, i.e. a piece of string  Index finger protrudes as the baby goes for the object  Will respond to simple vision testing e.g. Stycar rolling balls	Beginning to have meaningful babble  May have one or two recognisable words  Will turn on hearing own name	Can crawl and can often walk  Some children will bottom shuffle instead of crawling, often these children are slow to walk compared to the children who crawl	Is wary of unfamiliar adults  Can feed self and drink from cup  Can wave bye, plays pata-a-cake and peek-a-boo, and can play for long periods of time.  Enjoys dropping objects on the floor if there is someone to pick the objects up  Responds to 'NO'	
15 Months	Builds a tower with two bricks	Has a lot of jargon speech	Can get to a standing position without support  Can creep upstairs	Asks for objects by pointing  Displays negative behaviour  Begins to tell parents about wet pants	
2 years	Turns pages singly  Copies a vertical stroke with a pencil with fist as opposed to the tripod grasp of an adult	Obeys four simple commands eg. 'Take it to Mummy'  Able to speak in small sentences and uses the	Walks backwards in imitation  Is able to go up and down stairs using two feet per stair	Becomes more amenable to adult control  Often remains dry at night if lifted late in the evenings	

2 years 6 months	Cooperated with a simple vision test. Eg. Stycar toy test Can build a tower of 6 bricks Holds pen with hand instead of in a fist	words 'I, Me, You.' appropriately  Knows his/her full name  Can name one colour Can name 5 common objects eg. Doggie, car.	Is able to work on tiptoes when asked	Climbs onto the toilet seat  Attends toilet needs without help, except for wiping	
3 years	Cooperates with Stycar vision testing i.e. matches letters on cards which are shown to him by examiner  Develops a tripod grasp of a pencil  Can build a tower of 8 bricks and can build a bridge with 3 bricks	Cooperated with a formal hearing test i.e. will put pegs in a peg board in response to a quiet noise  Has a wide vocabulary of several hundred words	Child is a skilful climber  Can ride a bike with stabilisers  Can run, kick, and attempt to catch a ball  Goes up stairs one foot per step and goes down stairs two steps at a time.  Can jump from the bottom step  Can stand on one foot for a few seconds	Is sociable, friendly and helpful  Joins in with other children to play  Can recite rhymes  Knows own sex  Is toilet trained by day, and in most cases by night	
4 to 5 years	Is able to cooperate with vision testing  Is skilful with a pencil and is able to draw recognisable pictures  Can copy a circle, square and triangle	Can often participate in a formal hearing test  Responds to a noise of a known type and volume played to through headphones (audiometry)  Has a wide vocabulary	Can hop, skip, jump etc. skilfully	Can dress, undress, wash and bathe with supervision	

	Can write own name	Can sing tunefully			
	Read simple words				
	'Handedness' exhibits itself at around 4 years				
6 years	Copies a diamond	Is able to name the days of the week, and name 4	Is able to ride a two wheeled bicycle	Is able to undress, dress, wash and bathe	
	Can draw an accurate picture of a person	coins		independently	
	usually (mummy or	Can count to more than			
	daddy)	10 objects which are not			
		in a row			
	Knows right from left	~			
		Can cooperate fully with			
	Can repeat five digits	audio metrical testing.			