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Introduction

There can be many extra expenses involved when you are looking after a child with a single ventricle heart condition, for example with feeding, warm clothes for winter and frequent hospital trips.

We hope that this information will help to point you in the right direction of some of the sources of funding which may be available to help families with disabled children. **We can't guarantee that you'll be eligible for everything listed here, so please contact the relevant organisation directly to explain your circumstances and make sure that it is worth your while to apply, and to make sure the information we have given is still correct as many of these things change regularly.**

The majority of the information in this pack refers to England, Wales, Scotland and Northern Ireland. In the instances where we are aware of a different situation, we have tried to make this clear in the table.

When your child reaches the age of 16, they are entitled to claim certain benefits in their own name. However, it is very important that you seek proper advice about whether they should get benefits in their own right, or whether you will be better off as a family if you continue to claim on their behalf if they are still in full-time education.

To Discuss Benefits in General

If you would like to discuss benefits and entitlements in general, you can contact Little Hearts Matter, your Cardiac Liaison Nurse or hospital Social Worker. Other general sources of information are your local Citizens Advice Bureau, Social Services, your child's community nurse, a specialist health visitor or the nurses and health care assistants on hospital wards. It can be worth chatting to these people to find out whether they have any ideas or experience.

Two useful websites for general searching are the government website www.direct.gov.uk and the Citizens Advice Bureau (CAB) website www.adviceguide.org.uk (the CAB site has separate sections for England, Wales, Scotland and Northern Ireland).

Another general information point is Contact A Family, a charity supporting families with disabled children. They have a freephone helpline with advisers who can help with benefits or tax credit issues. The helpline can be contacted Monday to Friday 10am - 4pm, and Monday evenings 5.30 - 7.30pm. Tel: **0808 808 3555** (freephone) or email helpline@cafamily.org.uk. To find out more, visit www.cafamily.org.uk/families.

General Living

Benefit or Item	Main Criteria	Means Tested?	From What Age	To Find Out More...
Disability Living Allowance (DLA) Personal Care Component	If baby or child needs more care than a non-disabled child of their age. The LHM office has information available specific to claiming DLA	No	3 months	www.direct.gov.uk/disability - DLA is found under the Financial Support menu. Benefits Enquiry Line: 0800 88 22 00
<ul style="list-style-type: none"> DLA consists of two components - personal care and mobility. See overleaf for information regarding the DLA mobility component. Extremely long application form to demonstrate that baby or child needs care over and above a child of that age without the condition. Always keep a copy of your application. Awarded at different levels depending on care needed during day and night. Timings - phone to request form even if you then subsequently complete an electronic version, as your request date is the earliest the claim could be backdated to. Paid every four weeks. Use a computer if you can, as it will save time on future applications. 				
Carer's Allowance	DLA personal care component at middle or highest rate. Earnings below £95 per week after certain deductions have been made (rate correct in 2009).	Yes	As DLA	www.direct.gov.uk/carers - then go to ' Money Matters '. Tel: 01253 85 61 23
<ul style="list-style-type: none"> A person who is looking after a disabled person may be able to get Carer's Allowance and claim income related benefits. Visit www.nidirect.gov.uk if you live in Northern Ireland or call 0800 22 06 74 				
Extra Child Tax Credit	DLA personal care at any rate.	Yes	As DLA	Helpline phone number: 0845 300 3900 ; 08.00 - 20.00 for England, Scotland & Wales.
<ul style="list-style-type: none"> An extra amount is added to your CTC calculation for each child who is on DLA. If your child gets the highest rate of DLA care component, a further amount is added. You need to tell HM Revenue and Customs that you receive DLA for your child, and the level of the DLA - they do not automatically know. Based on your joint annual taxable income. Contact a Family employ welfare rights specialists who can advise on claiming tax credits. Helpline tel 0808 808 3555 				
Income Support	Low income and savings below £16,000.	Yes		
<ul style="list-style-type: none"> Income support - means tested benefit for families. There is an initial personal allowance followed by a series of premiums which may apply e.g. Carer Premium if you get Carer's Allowance. 				

Utilities/Household Bills

Benefit or Item	Main Criteria	Means Tested?	From What Age	To Find Out More...
Council tax benefit	Room in your house specifically required by a disabled person.	Yes		www.direct.gov.uk/disability - then go to ' More about financial support ', then the ' Tax relief and reductions ' section. Contact your local authority or local council to find out if you are eligible.
<ul style="list-style-type: none"> The disabled band reduction scheme aims to ensure that disabled people do not pay more Council Tax because they live in a larger property than they would have needed if they were not disabled e.g. a second bathroom or kitchen needed by that person. Having a disability does not automatically entitle you to a reduction, and the rules are quite strict. 				

Utilities/Household Bills (Continued)

Benefit or Item	Main Criteria	Means Tested?	From What Age	To Find Out More...
Warm Front	Warm Front grants - qualify through DLA entitlement. In England, the householder or householder's partner must be receiving DLA to qualify.	No	As DLA	www.direct.gov.uk/money - then go to 'More about benefits, tax credits and other support', then the 'On a low income' section. Freephone: 0800 316 2805 JobCentre Plus www.direct.gov.uk/over50s - then choose 'Concessions and other help' under Benefits .
Cold weather payments	Cold weather payments - Income support with a disabled child premium or, Income Support Plus or Child Tax Credit with disabled child element.	Yes		
<ul style="list-style-type: none"> • Warm Front is the Government's main grant-funded programme for tackling fuel poverty. If you need help paying for heating and insulation improvements in your privately owned or rented home, you may be able to get money from the government's Warm Front grants scheme if you're receiving income or disability-related benefits. • If you're on a low income, you may be eligible for a Cold Weather Payment to help you with extra heating costs during very cold weather in your area. • Each country has its own scheme with slightly different levels of grants - Energy Assistance Package (Scotland) tel 0800 512 012, www.energyassistancepackage.com; Home Energy Efficiency Scheme (Wales) tel 0800 316 2815, www.heeswales.co.uk and Warm Homes Grant (Northern Ireland) tel 0800 181 667, www.eaga.com. The qualifying criteria are also different with Wales and Scotland considering a child in receipt of DLA (not just the householder). 				
Specific bills	Extra needs or problems paying due to a disability.	Yes		Contact your utility provider. EDF Energy Trust www.edfenergytrust.org.uk Tel: 01733 421060 Thames Water Trust Fund www.twtf.org.uk Tel: 0845 456 6863
<ul style="list-style-type: none"> • The Water Sure Scheme offers help with water bills if customers are high water users due to a disability within the family which requires the use of extra water e.g. having to wash large quantities of clothes and bedding regularly such as due to diuretics and you receive certain benefits e.g. Income Support, Working Tax Credit. • It might be worth contacting other utility providers to see if they can offer any discounts if there is a specific need for additional spending on your part due to your child's disability. • EDF Energy Trust offers grants to help pay debts on gas, electricity and other essential domestic bills for families in "need, poverty, hardship or other distress". They need detailed financial information from the family. • The Thames Water Trust Fund provides grants to people facing hardship to help with water charges. 				

Out and About

Benefit or Item	Main Criteria	Means Tested?	From What Age	To Find Out More...
Disability Living Allowance (DLA) Mobility Component	If child unable or virtually unable to walk at age three. If your child needs guidance or supervision when walking out of doors at age five. <div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 0 auto;">The LHM office has information available specific to claiming DLA</div>	No	If your child is 3 you can only get Mobility allowance if he or she is entitled to the higher rate. From age 5, two rates are available.	www.direct.gov.uk/disability - DLA is found under the Financial Support menu. Benefits Enquiry Line: 0800 88 22 00
<ul style="list-style-type: none"> • There are two different levels of financial support available, depending on your child's mobility needs. The higher rate is the only possibility from age 3 to 5. • As with the DLA personal care component, the application form is long and time consuming. 				

Out and About (Continued)

Benefit or Item	Main Criteria	Means Tested?	From What Age	To Find Out More...
Motability	DLA mobility component at higher rate.	No	3	www.motability.co.uk Tel: 0845 456 4566
<ul style="list-style-type: none"> If your child receives higher rate mobility allowance, you can get a car through a purchase scheme to help disabled people to hire or buy a car - you need to have at least 12 months DLA mobility award remaining. 				
Road Tax Exemption	DLA mobility component at higher rate. Need exemption certificate from benefits agency.	No	3	www.direct.gov.uk/disability - then choose 'More about motoring and transport', then 'Vehicle tax for disabled people'. Ask for form DLA 404 from DLA Unit. Tel: 0845 712 3456
<ul style="list-style-type: none"> Road Tax Exemption - if your child receives higher rate DLA mobility allowance, you can apply to not pay for road tax, provided that the car is used only for the benefit of the child concerned. 				
Blue Badge	DLA mobility component at higher rate.	No	You can apply from age 2, but it is easiest to apply from age 3 with DLA Higher Rate Mobility or a mobility aid.	www.direct.gov.uk/disability - then choose 'The Blue Badge parking scheme' under 'Motoring and transport'. Contact your local authority or council.
<ul style="list-style-type: none"> Blue Badge - parking concessions (places and sometimes prices) - easy to apply for with higher rate mobility component of DLA. Please see individual websites (links available from main direct.gov site) for information about how the scheme applies in Wales, Scotland and Northern Ireland. 				
Disabled Person's Railcard	DLA mobility either lower or higher rate Or DLA personal care middle or highest rate.	No	Children only pay for train travel from age 5.	www.disabledpersons-railcard.co.uk Tel: 08456 050 525
<ul style="list-style-type: none"> Disabled person's railcard costs £18 per year and gives 1/3 off most fares for the person plus accompanying adult. Also local schemes to provide cheap transport for people with mobility problems. 				
Pushchair	Individual assessment if child has difficulty walking.	No	3 (possibly 2 and $\frac{1}{2}$)	Referral from your GP or physiotherapist. Phone NHS direct on 0845 4647 or in Scotland, NHS 24 on 0845 4242424.
<ul style="list-style-type: none"> NHS Wheelchair Service will provide Maclaren Major Buggy or may provide vouchers to that value towards a different pushchair. Accessories are not included, but you may find charities which will fund them. 				
Driving Lessons	Young people aged between 16 and 24 and in receipt of the Higher Rate Mobility Component of DLA may be eligible for help towards the cost of driving lessons.		16 - 24	www.motability.co.uk/carscheme - then choose 'Financial Help'. Tel: 0845 456 4566
<ul style="list-style-type: none"> There are a number of different scenarios regarding the level of funding available, depending on whether you have a Motability car, whether you are in full-time education, etc, so it is best to phone to discuss your individual circumstances. The Family Fund may fund parents learning to drive if they need to drive their disabled child around. Further information is available from www.familyfund.org.uk or by telephone 0845 130 45 42. 				

Holidays/Days Out

Benefit or Item	Main Criteria	Means Tested?	From What Age	To Find Out More...
Family Fund	Includes income related criteria (gross income less than £23,000 and savings of £18,000 or less for England, please see website for other countries).	Yes	Any time	www.familyfund.org.uk Tel: 0845 130 45 42
<ul style="list-style-type: none"> The Family Fund gives grants to low-income families to meet the additional needs of caring for a severely disabled child. The value of the grant depends on the items requested, family circumstances and the funding available. There is no entitlement to a grant from the Family Fund. All grants are discretionary. Holidays or family breaks have been successfully applied for. Can apply to Fund more than once. 				
Free Swimming	Swimming forms a part of a child's therapy.			Contact your local leisure centre or pool.
<ul style="list-style-type: none"> Some pools will offer free entry to disabled people. 				
Free/Reduced Entry Fees	DLA award letter or letter from your GP giving proof of disability.			Contact the attraction you plan to visit, or look on their website.
<ul style="list-style-type: none"> Free or reduced price entry to certain attractions for either your child or yourself as their carer. Some examples are Twycross Zoo - reduced price for child and free carer, Space Centre - free carer, Warwick Castle - 50% for child and carer, Cadbury World - free carer, Legoland - free carer. Most National Trust properties will admit a companion for a disabled visitor free of charge. Obviously LHM cannot guarantee any of these prices - they are based on genuine personal experience but should be checked by yourself. The Plus One card is a system to automatically give free entry to a carer - it appears to only exist in some parts of the UK. 				
Cinema Exhibitors' Association Card	DLA.	No		www.ceacard.co.uk Tel: 0845 123 1292
<ul style="list-style-type: none"> This is a national card that verifies that the holder is entitled to one free ticket for a person accompanying them to the cinema. A processing fee of £5.50 is charged per card, the card is valid for three years. 				

Household Costs

Benefit or Item	Main Criteria	Means Tested?	From What Age	To Find Out More...
Washing machine or extra bedding	Varies according to potential source of funding.	Family Fund and Social Fund are means tested.		See fund details below.
<ol style="list-style-type: none"> The Family Fund gives grants to low-income families to meet the additional needs of caring for a severely disabled child. The value of the grant depends on the items requested, family circumstances and the funding available. There is no entitlement to a grant from the Family Fund. All grants are discretionary. Eligibility includes income related points (gross income less than £23,000 and savings of £18,000 or less for England, please see website for other countries). Further information is available from www.familyfund.org.uk or by telephone 0845 130 45 42. The Social Fund gives various types of payments designed to help people on a low income with specific costs. The purpose of the fund is "to ease exceptional pressures on families". Community Care Grants may be applicable for families with disabled children e.g. for extra bedding or household items. Further information is available at www.direct.gov.uk/carers, then choose 'Guide to financial support for carers' found under 'Money Matters'. 				

Household Costs (continued)

Benefit or Item	Main Criteria	Means Tested?	From What Age	To Find Out More...
Disabled Facilities Grant	Adaptations must be considered essential, within a fairly rigid set of rules.	Not means tested if for child.		www.direct.gov.uk/disability - then choose 'Adapting your home' under 'Home and housing options'. Social Services Occupational Therapist.
<ul style="list-style-type: none"> A Disabled Facilities Grant is a local council grant to help towards the cost of essential adaptations to your home to enable you to continue to live there. Available in England, Wales and Northern Ireland. Can be a very long process, so get in touch with Social Services as soon as you know that you might need to adapt your home. 				
Free Nappies	If child still needs nappies due to their disability.	No	Age 3 or 4 depending on the local policy.	Your health visitor or school nurse should be able to put you in touch with the Continence Service.
<ul style="list-style-type: none"> NHS Continence Service can fund and deliver nappies if your child needs them due to their disability. 				

Hospital Costs

Benefit or Item	Main Criteria	Means Tested?	From What Age	To Find Out More...
Visiting costs such as travel	Varies according to potential source of funding.	Family Fund and Social Fund are means tested.		See fund details below.
<ol style="list-style-type: none"> The Family Fund gives grants to low-income families to meet the additional needs of caring for a severely disabled child. The value of the grant depends on the items requested, family circumstances and the funding available. There is no entitlement to a grant from the Family Fund. All grants are discretionary. Hospital visiting costs have been funded. Eligibility includes income related points (gross income less than £23,000 and savings of £18,000 or less for England, please see website for other countries). Further information is available from www.familyfund.org.uk or by telephone 0845 130 45 42. Local charities to the hospital may have emergency funds. Ask your Cardiac Liaison Nurse or hospital social worker. These funds may vary from time to time. The Social Fund gives various types of payments designed to help people on a low income with specific costs. The purposes of the fund is "to ease exceptional pressures on families". Community Care Grants may be applicable for families with disabled children e.g. costs of hospital visiting. Further information is available at www.direct.gov.uk/carers, then choose 'Guide to financial support for carers' found under 'Money Matters' or you can contact your local Jobcentre Plus. If you are on an income related benefit, please contact the hospital benefit office to find out about help with travel costs to and from hospital appointments. 				
Medic Alert Bracelet				www.heartline.org.uk Tel: 01276 707 636 www.medicalert.org.uk Tel: 0800 581 420
<ul style="list-style-type: none"> Heartline may fund this, especially if child is on anti-coagulants. Medic Alert may provide subsidised or free membership to people on a low income or benefits. 				

Other Sources

There are a number of other sources of funding which can be used for different purposes.

BDF Newlife

This is a child health and research charity which offers Child and Family Grants for specific items (equipment or other support) needed by a family to help care for a child with an inborn condition (ie a condition or disability they are born with).

Contact the BDF Newlife Nurses on **0800 902 0095** or visit the website **www.newlifecharity.co.uk** for further information including examples of successful grant applications.

Family Welfare Association

This is a charity with a remit to help children and families in need or disadvantaged. Applications for grants must be made by a social worker on your behalf. Small welfare grants are available for medical treatment (particularly special treatment), services, facilities or equipment for those who are sick or physically disabled.

For further information, contact **020 7254 6251** or visit the website **www.fwa.org.uk**.

Community Care Grants

The Social Fund gives various types of payments designed to help people on a low income with specific costs. The purpose of the fund is "to ease exceptional pressures on families". Community Care Grants may be applicable for families with disabled children.

Further information is available at **www.direct.gov.uk/carers** then choose 'Guide to financial support for carers' found under 'Money Matters' or you can contact your local Jobcentre Plus.

The Family Fund

This fund gives grants to low-income families to meet the additional needs of caring for a severely disabled child. The value of the grant depends on the items requested, family circumstances and the funding available. There is no entitlement to a grant from the Family Fund. All grants are discretionary. Eligibility includes income related points (e.g. gross income less than £23,000 and savings of £18,000 or less for England, consult the website for other countries).

Further information is available from **www.familyfund.org.uk** or by telephone **0845 130 45 42**.

Chest, Heart and Stroke Scotland

This charity offers Personal Support Grants e.g. for holidays, hospital visiting, equipment, white goods. Need to live in Scotland and have a sponsor (e.g. health visitor) apply on your behalf.

Further information is available from **www.chss.org.uk** or telephone **0131 225 6963**.

One-Off Special Holidays

These charities offer special treats or holidays for children who are very ill or are living with severe disabilities. They cover the whole of the UK but have different eligibility criteria so you will need to check with them directly for further information.

Make a Wish Foundation UK

329-331 London Road
Camberley, GU15 3HQ

Tel: **01276 405 060**
Web: **www.make-a-wish.org.uk**

Granting wishes of children aged 3-17 living with a life-threatening illness.

Starlight Children's Foundation

Room PRW1, PO Box 4267
Goring, Reading, RG8 0WY

Tel: **020 7262 2881**
Web: **www.starlight.org.uk**

Grants the wishes of children aged 4-18 suffering from a potentially life-shortening or life-threatening illness.

Dreams Come True Charity

Knockhundred House, Knockhundred Row
Midhurst, GU29 9DQ

Tel: **0800 018 6013**
Web: **www.dctc.org.uk**

Fulfills 'dreams' for children and young adults, 2-21 years of age who are living with a serious or terminal condition.

Happy Days Children's Charity Clody House

90-100 Collingdon Street
Luton, LU1 1RX

Tel: **01582 755 999**
Web: **www.happydayscharity.org**

They fund and organise holidays, days out and theatre trips throughout the UK for disadvantaged young people (aged 3-17) with learning difficulties, physical or mental disabilities and with acute, chronic or life limiting illnesses.

When You Wish Upon a Star

Futurist House, Valley Road
Nottingham, NG5 1JE

Tel: **0115 979 1720**
Web: **www.whenyouwishuponastar.org.uk**

Aims to fulfil wishes for any child (aged 2-16 years) who has a life threatening or terminal illness.

Family Holiday Association

16 Mortimer Street
London, W1T 3JL

Tel: **020 7436 3304**
Web: **www.fhaonline.org.uk**

Helps disadvantaged children and their families with much needed breaks. The family must be referred to the Association by social services, a health professional or local voluntary organisation. At least one of the children must be over the age of three.

Pearson's Holiday Fund

PO Box 3017, South Croydon
Surrey, CR2 9PN

Web: **www.pearsonsholidayfund.org**

Makes grants that financially assist disadvantaged children and young people living in certain areas of the UK to have holidays or take part in respite activities in the UK away from their normal environment which would otherwise not be possible without some external financial support. Grants of up to £75 per child for families who are on benefit-level income. Applications can't come directly from families, but the process is apparently very simple.



Little Hearts Matter
*Half a heart
... not half a life*



Benefits

A guide for parents

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