

OVERCOMING THE OBSTACLES

...leading the way for **Heart Families**



children's heart
FEDERATION

**A Guide to Meeting the Non-Medical Needs
of Children and Young People with Heart
Conditions**

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Introduction

This document gives a summary of the main services that parents of heart children may need at different stages of their child's life. The guide concentrates on the non medical needs of heart children from early years to adulthood.

The health difficulties of children with heart conditions are not always obvious. It is not clear from their appearance that they have a medical problem. As a result, any learning, physical, and emotional difficulties may be easily overlooked or misunderstood. This can make it even more difficult for parents to get the help and support that their child needs.

This is one of the reasons why it often helps to get schools and other community services to recognise your child as having special needs or a disability. Although parents may be reluctant to 'label' their child in this way, they may find it helps to open door to specialised support and that it will be easier to get appropriate health, education and social provision.

What does SEN mean?

The term 'special educational needs' has a legal definition. According to the Department of Education and Skills (DfES), *"Children with special educational needs all have learning difficulties or disabilities that make it harder for them to learn or access education than most children of the same age. These children may need extra or different help from that given to other children of the same age."*

What is a disability?

The Disability Discrimination Act (DDA) defines a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.

Pre-School

Early Years

Children with heart conditions may also have other disabilities or health problems such as developmental delays in walking, feeding or communicating. If this is the case, it is important that your child's special needs are addressed right from the start.

- ♥ **Portage** is a home visiting educational service for pre-school children who need additional support. It takes place in the child's own home and aims to equip parents with the skills and confidence they will need to help their child, no matter what the child's difficulties may be. Portage offers practical help and ideas to encourage a child's interests and make learning fun for all the family.

General Enquiries - info@portage.org.uk; www.portage.org.uk

Nurseries

All nurseries must support children with special educational needs. The nursery will have a Special Educational Needs Coordinator (**SENCO**). They can start an **Early Years Action Programme** which will outline extra or different activities that will be undertaken with your child. The SENCO should put together an **Individual Education Plan (IEP)** which shows what the needs are, how they will be addressed and describe the targets.

Your child may need support from other specialists as well, e.g. speech therapist or educational psychologist. In this case, a new **IEP** should be drawn up so your child can benefit from outside help.

If your child needs a lot of support, you may want an assessment of his or her special educational needs by the **Local Education Authority**, which may result in a **Statement of Special Educational Needs**. The statement will outline what your child's needs are and what actions need to be taken to deal with them.



Sometimes you may feel your child needs extra support but it is not offered, if that is the case you may consider asking the Education Authority to undertake an assessment of

your child's needs. Getting the early years action, individual action plan or statement may not be a simple process. For further sources of support, please refer to the '**List of organizations and professionals that you may need to liaise with**' at the end of this guide.

Parent's experiences

"We struggled to find a nursery capable of meeting her needs and then we were only able to arrange 2 days a week because of the cost"

"My son has complex issues, and we got a statement when he was aged 2 $\frac{1}{2}$ at our request. The preschool try to follow the statement but the statement itself is too vague as professionals try their hardest not to commit to concrete hours or provisions"

"I felt that I was the one supporting the teachers because of the lack of understanding that there are different kinds of heart defects"

"I think that support is very patchy, and a lot depends on how staff are themselves supported/ offered further training"

"My own experience of Maisie going to nursery was a good one - she was looked after well and staff were certainly aware of her lack of stamina and her need to rest"

"We were able to talk to the nursery teacher before Mia started nursery and discuss everything. We felt they were very good about treating Mia the same as the other kids and letting her set her own physical limits"

"The IEP is generally very good - I am fully included and they have already asked me to involve my son (aged 4) to find out his thoughts"

"The nursery has undertaken extra training to deal with each problem as it arises. They have also had 'practice runs' to prepare for any situation"

"In my experience the staff are keen to support all children as individuals, including those with special educational needs"



Finding a nursery school

If you are having difficulty choosing a nursery below are some contacts that may be able to help:

- ♥ Your **local education authority**
- ♥ Your **health visitor** or **GP surgery**
- ♥ **ChildcareLink**
A Government service that provides information and advice on childcare.
Tel: 0800 096 0296
Website: www.childcarelink.gov.uk
- ♥ **The Independent Schools Council information service (ISCis)**
Can provide a list of independent schools in your area.
Tel: 020 7798 1500
Website: www.iscis.uk.net

Child care

As a parent and main carer of your heart child, you may find that you need childcare to work, study, or take a break from your caring responsibilities or you may want your child to spend more time with other children. If so, you may find you need child care facilities. All formal childcare provision in England is registered with and regulated by OFSTED (Office for Standards in Education).

- ♥ **Contact a Family**
Has detailed information and advice on different types of childcare and how to access it.
Helpline: 0808 808 3555 www.cafamily.org.uk
- ♥ Visit www.direct.gov.uk/CaringForSomeone/CaringForADisabledChild/ for more information on childcare.
- ♥ **ChildcareLink**
A national service providing childcare and early years information. The website helps you find useful information about the different types of childcare and early education in your local area.
See contact details above.
- ♥ **Daycare Trust** is the national childcare charity providing information and advice on childcare, including childcare for disabled children.
Tel: 020 7840 3350 www.daycaretrust.org.uk

School Issues

Starting School

The majority of children with heart conditions will be like anyone else of their age and achieve according to their individual abilities and talents. However, some children with heart conditions may need extra help at school. It may be that a difficult start to life means that they find it hard to keep up with children of the same age. Some children may have learning disabilities, others may have intermittent disability – e.g. after surgery they may be very well for a while, and then gradually develop more problems as a shunt narrows or a valve starts to leak, or they just outgrow previous surgeries.



If you have concerns about your child you can express them and ask for the school to take action. The school will have a policy on dealing with Special Educational Needs (SEN) children.

The levels of action the school can take are as follows:

- Your child's head teacher or SENCO will put together an **Individual Education Plan (IEP)** outlining what your child's needs are, what actions will be taken to help them, how often, what should be achieved (targets) and when progress is checked.
- If it is felt that your child would benefit from other specialists as well, the school can request help from **outside services or specialists** to help meet a child's needs. This should be done after a meeting with parents, SENCO and other colleagues involved with the child.
- **Request for a statutory assessment** – If you believe your child still has extra needs which cannot be met by the actions of previous levels, you may need to get **statement of educational needs**. You will need to ask the education department at your Local Education (LA) for a **statutory assessment**.

A LA may consider the request but then decide not to proceed with the statutory assessment. If so, you have a right to **appeal** to **SENDIST** (Special Educational Needs and Disability Tribunal) but should also continue to negotiate with the LA.

Please refer to the '**List of organizations and professionals that you may need to liaise with**' at the end of this guide. Getting a statement may not be a simple process. Be prepared for a challenge. You may need to liaise with many of the professionals and organisations mentioned in order to ensure that your child gets the provisions he/she requires. You can also ask your child's Cardiac Liaison Nurse (CLN) to speak to the school. CLN's are trained to advise teachers on meeting a heart child's needs and are also normally able to reassure them about any concerns they have.

For further information on your child and special educational needs:

- ♥ **Department for Children, Schools & Families website** - visit the section on SEN at www.teachernet.gov.uk/wholeschool/sen, which provides a wide range of special education needs and disability advice and materials for teachers, parents and others working with children with SEN.
- ♥ **Contact a Family** has detailed information and advice on education for children with special needs. See contact details on page 34.
- ♥ **IPSEA (The Independent Panel for Special Education Advice)** is a national charity. They aim to help ensure that children receive the special educational provision appropriate to their needs and to which they are entitled in law. Freephone: 0800 0184016; www.ipsea.org.uk
- ♥ **ACE (Advisory Centre for Education)** offers free guidance and advice on all aspects of state education as well as leaflets on other education topics. Freephone Advice Line: 0808 800 5793 (Mon-Fri, 2-5pm)
Exclusion Line: 0808 8000 327 (Mon-Fri, 2-5pm) ; <http://www.ace-ed.org.uk>
- ♥ **CSIE (Centre for Studies on Inclusive Education)** gives information and advice about educating children with special needs within ordinary schools. Tel: (0117) 328 4007; <http://www.csie.org.uk>
- ♥ **Disability Rights Commission (DRC)** is an independent body established to stop discrimination and promote equality of opportunity for disabled people. Tel: 08457 622633
<http://www.drc-gb.org>
- ♥ **Rathbone Training** gives general advice about all aspects of SEN to parents and professionals. Special Education Advice Line: 0800 917 6790; <http://www.rathboneuk.co.uk>.
- ♥ **National Parent Partnership network** Offer information, advice and support for parents of children and young people with special educational needs (SEN)
<http://www.parentpartnership.org.uk>



♥ **Parents for Inclusion**

Parents helping parents so their disabled children can learn, make friends and have a voice in ordinary schools and throughout life.

Tel: 0845 652 3145 www.parentsforinclusion.org

Parent's experiences

General

"How much support a child receives comes down to how vocal their parents are."

"I think there is a problem that because a major heart defect is not as visual as other disabilities, teachers don't see heart children's difficulties."

"I chose my child's school by the one that had the best attitude towards my son."

"Sometimes I wonder if Mia could do with extra help as I think she can lose concentration easily. The teachers haven't mentioned anything and I don't want to make a fuss. We don't want Mia to feel different, so it's quite difficult to get a balance."

"Staff are keen to work with parents in identifying special needs (e.g. behavioural/ linguistic development) although they are limited by time, specific training needs and financial resources."

"The school was excellent and offered all the support we required. In particular, they were very creative in finding solutions to problems that did not embarrass our daughter. We could have not wished for more help and genuine support."

School action and statementing

"All children with special educational needs are assigned a special needs assistant to look after them during school hours. There has been a huge improvement in recent years to address this issue."

"The biggest issue is getting the statement the child needs, and in this our LEA offered no support or help. Another parent mentioned the SEN Toolkit, and it is enormously helpful - I tell every other parent I know about it if their child has special needs."

"IEP (Individual Education Plan) papers were a joke. I was never asked my opinion about what went on the IEP and was only given the IEP when I finally took my daughter out this primary school and placed her in another one."



"A child with special needs only gets a well written, clearly worded statement if their parents fight very hard. Parents sometimes lack the voice or determination to see this through and the LEA often intimidate and put parents off also. Add to this that some parents themselves have special needs, e.g. visual impairment or speak a different language and the problem intensifies even further."

"We have just completed the statementing process and am pleased to say the authority we have dealt with were excellent. I did initiate the process earlier than advised as I had been warned it can be a battle to get your child what they require."

"I involved the help of the Parent Partnership and paediatric consultant and gathered information this way." (On gathering evidence to support a request for a statement)

Good communication

"I visited the school in advance and told them of Oliver's condition. Then, the CLN at Southampton, the school and school nurse had a meeting at the end of the term before Oliver started school to discuss his condition and any particular needs he might have. They then had plenty of time to consider what special arrangements they needed to put in place. The hospital have also been asked to copy the school nurse in on any hospital letters so she is always up to date on his condition."

"My daughter was awarded full support when she starts school in Sept 07 which is obviously a great relief to me. The school are also very supportive and I have had regular meetings already with the Head to ensure the transition to school goes smoothly."

"A key to getting good help is to engage with the head(s) of the schools and to involve them in all the details. I copied them in on almost all the correspondence from the medical teams which was a great help for both sides. Communication was the key."

"In our case the school has worked closely with us and takes time to understand Emma's needs. Emma's outreach nurse was also available to provide the school with input and advice."

"In event of an emergency, the class teacher has both our mobile numbers and the school instructions on what action to take."

"The teachers are excellent at keeping us advised of anything that might be a concern, keep an eye on his eating and let us know if he doesn't eat his school dinners and even make a special effort to let us know that there was a chickenpox outbreak in case it affected Oliver!"

Management of students with medical needs within schools

The Department for Children, Schools & Families advises that:

“It is for schools and their employers to develop their policies on the management and administration of pupils' medicines and putting in place systems for supporting individual pupils with medical needs.”



They have produced guidance together with the Department of Health on *‘Managing Medicines in Schools and Early Years Settings’*. The guidance is aimed at helping schools to develop effective management systems to support individual children with medical needs who require access to their medicines while in school. The publication also provides information for schools on drawing up a **health care plan** for children with medical needs in order to identify the level of support needed. Parents

can request that an **individual health care plan** be drawn up for their heart child through the **school nurse** or **head teacher**. This may not be as straight forward as you would like so be prepared to be persistent. This guidance can be downloaded from the **TeacherNet** website at: www.teachernet.gov.uk/wholeschool/healthandsafety/medical/.

The Department of Education and Skills in collaboration with the Department of Health have also published guidance for schools setting out the minimum national standard for the education of children and young people who are unable to attend school because of medical needs. Copies or summary of the report are available via the **DfES Sick children** website www.dfes.gov.uk/sickchildren or via DfES publications 0845-6022260 quoting reference number DfES/0732/2001 or DfES/0025/2002. Again, you may find you have to be persistent if the school is not cooperative in recognising this guidance and/or acting on it.

Parent’s experiences

“We did not have a health care plan drawn up as my son is well, and medication is only taken twice a day, but I did have to meet with the nurse and discuss any needs he may have and with the PE teacher to let them know what his limitations are.”

“The school were happy to administer drugs if written instructions were supplied”

"I was asked to write my own health plan for Maisie because I think the school were frightened of doing so."

"I ended up going over to the school everyday at lunchtime to give Lucy her medicine as her class came out to the playground to walk to the canteen for lunch. Luckily I wasn't working at the time."

Behavioural & Emotional Issues

Educational psychology services

Educational psychologists tackle the problems encountered by young people in education, which may involve learning difficulties and social or emotional problems. They carry out a wide range of tasks with the aim of enhancing children's learning and enabling teachers to become more aware of the social factors affecting teaching and learning.

Educational psychologists visit schools and early years settings regularly to offer support, advice and consultation. Educational psychologists should work directly with individual children and with groups of children. Assessment takes place within the context of the school and may involve, for example, observing (in the classroom and playground), discussion with parents, teachers and others who know the child well, and the use of standardised psychometric tests and measures. The educational psychology service is responsible for contributing psychological advice on individual children and young people with special educational needs who are being assessed in accordance with the Education Act 1996.



In most cases, requests for help for individual children are made by schools. Parents concerned about a child are normally encouraged to discuss their worries first with the school. However, referrals may sometimes be accepted from parents, social workers and GPs, for example. The exact procedures will be determined locally.

Parent's experiences

"My son had a behavioural and developmental delay that we think is a result of having surgery before the age of two. A lot of his behaviour was put down to being 'just a boy'."

"He was assessed and we were happy to go with the label mild Asperger's to get him the help he needed. He then got access to social skills groups and speech therapy but I did have to be a bit of a squeaky wheel. We put a lot of work in when he was younger and he's now matured into a lovely 14 year old! Which makes me pretty certain that the developmental delays were caused by earlier surgery rather than the Asperger's. Although as I said, without the label we wouldn't have got the help we needed."

"My son has input on his statement from an educational psychologist, but she has only met with him once a long time ago. So I fail to see why her input is relevant. She also has little experience of children with the same issues as my son, and rather than admit that she doesn't know everything, she tends to generalise, which I think is unfair at best and dangerous at worst"

"We have only had the involvement of an educational psychologist during the statementing process, but I do know she has strong links with the school my daughter is attending. She (the educational psychologist) is very approachable and I know I can contact her if I need to"

Bullying

Many children and young people are bullied, usually at school. All schools should have an anti-bullying policy so if your child is being bullied, tell the school what is happening and make sure they address the issue.

The following organisations can help support and advise you and your child:

♥ Changing Faces

Changing Faces supports young people who have a visible difference who are being bullied. www.changingfaces.co.uk
0845 4500 275 (Mon-Fri 9am -5pm) or
email info@changingfaces.org.uk

♥ Kidscape

Kidscape specialises in preventing bullying. www.kidscape.org.uk or
telephone their helpline on 08451 205
204.



- ♥ **Bullying Online**
Bullying Online helps people deal with school bullying.
www.bullying.co.uk
- ♥ **Need2Know**
Website for young people being bullied and where to go for help
www.need2know.co.uk
- ♥ **Beat Bullying**
This organisation aims to reduce and prevent bullying by putting together action plans written by young people. You can read these on their website:
www.bbcllc.com
- ♥ **ChildLine**
For help with anything, anytime, call Childline free on 0800 1111 (0800 44 1111 in Scotland) or text phone 0800 400 222. You can also write to them by sending a letter to Freepost 1111, London N1 0BR (no stamp needed).
www.childline.org.uk
- ♥ **Bullywatch**
Info on what do if you are being bullied at school, as well as other links
www.bullywatch.org

Physical Activity & School Trips

Some children with heart conditions may not be able to do as much physical activity as a child without a heart condition. They may tire and become breathless more quickly than other children or become breathless more quickly in cold weather. Some children may be on anticoagulant medication and will need to take care not to get bruised. This means that they will not be able to take part in robust playground activity and contact sports (e.g. football, judo, hockey, etc.).



It is important to note that because there is a wide range of congenital heart conditions, the degree and complexity means that each child's needs are individual and different to others and so the way each child will be treated will be different. It is important to get advice from your child's **cardiologist** and/or **cardiac liaison nurse** on what they are able to do physically and what they should avoid.

As a general guideline, unless the doctor specifically advises that your child avoid all sports, your child will be able to participate in some regular physical activity. It is imperative of course that the school be informed of your child's specific restrictions as advised by the cardiologist so that suitable activities can be planned.

The Disability Discrimination Act, 1996, specifies that all school facilities must be equipped to support pupils with additional support needs. Schools should consider whether additional equipment or alternative activities are required to ensure that all pupils can take part in PE and extra-curricular activities. Yet we are aware that some parents find that their child's school does not make the necessary adaptations to enable a heart child to be fully included in activities. It is important that, if possible, you form a strong partnership with the school and work together to plan appropriate alternative activities to enable participation in both curricular and extra-curricular activities. Inclusive physical activity should ensure opportunity and choice, with programs tailored to individual needs.

Parent's experiences

"I've heard of some horror stories about children being told they cannot go on school trips unless they have a parent with them. Can't really understand this or why parents would stand for it"

"We are lucky as there is a wide range of physical activities in the school so he has a chance to take part in sports that do not require a high level of stamina."

"Sometimes I think with heart kids people can forget there's a health problem; there's nothing that you can really see on the outside"

"We don't wrap Nicky in cotton wool so we don't want the school to either!"

"On a recent school trip, Mia was conscious that she would be the only one with the buggy - she'd be 'different'. The teacher was really good - she suggested that Mia talk to the class about her heart and the operations she'd had, and why she needs to use a buggy. I thought it was very thoughtful of the teacher. Mia was really excited and looked forward to telling the class all about her experiences!"



"We have not had a good experience of trips or physical activities. My son has some challenges but these can be helped and overcome if people think 'outside the box' which sadly they don't seem to"

"The trips have upset us as parents because of their lack of inclusion. Whilst the school have a medical protocol, they seem to want a parent to accompany my son on trips. This is not appropriate and makes our son seem 'different' and encourages his peers to treat him differently."

"She can walk and does get quicker with time and patience, but she isn't given the opportunity to do this as the school prefer her to take a buggy. They don't take the initiative to notice that she is getting bigger and stronger, and consider alternatives to support on trips without needing us there."

"Experience to date has been good with Anya able to attend school trips and take part in PE subject to her ability. Our concern is for future trips which may require overnight stays where responsibility for drugs and physiotherapy will have to be managed by others."

"Communication with the school and teachers involvement prior to the trip meant that our child took part in almost everything that was on offer. Her class was well briefed as to her limitations and they supported our daughter. When she came last by more than an hour on a hike, they all stood up and cheered and made her feel that her achievement was as great as the winner."

"Oliver is generally OK to do PE. He has been a little "dizzy" on one or two occasions but his teacher is well aware of his limitations and she just gets him to sit down until he feels ready for more."

"I was going to put Peter in a vest on P.E. days in case the other children stared at his scars. His teacher assured me that at that early age children don't really make much of things like scars so I went with her advice and didn't put him in his vest on PE days. He hasn't come home upset so I'm glad I took her advice as now hopefully his scar won't cause a problem in the future with his classmates."

Medic Alert bracelet

Many parents have found a **Medic Alert** bracelet to be a useful extra reminder to teachers that their child should not be asked to participate in physical activity that is inappropriate. The medic alert bracelet is also beneficial in emergencies to alert clinicians and others of the child's heart condition. Contact Medic Alert on freephone **0800 581420** or visit www.medicalert.org.uk.

Time away from school



Children with heart conditions may need considerable amount of time off from school due to ill health, visits to or stays in hospital. This will be one of the reasons why a **statement** is required and a suitable plan ought to be in place. As mentioned before, parents should work closely with the schools' SENCO, school nurse and other appropriate staff to ensure that the heart child receives the required support in order to compensate for the time off from school.

The Department of Education and Skills

in collaboration with the Department of Health have published guidance for schools setting out the minimum national standard for the education of children and young

people who are unable to attend school because of medical needs. Copies of the report or summary of the report are available via the **DfES Sick children** website www.dfes.gov.uk/sickchildren or via DfES publications 0845-6022260 quoting reference number DfES/0732/2001 or DfES/0025/2002.

Parent's Experiences

"As a result of frequent hospitalisation, we found that on joining reception Anya was significantly behind her peers and despite additional support still remains in that position"

"It is important for them (heart children) to have some kind of home teaching when recovering from an operation. I think some kind of liaising with the school, the head teacher and parents is important as is the feeling of not being forgotten by classmates"

Making friends

Making friends is easier for some children than for others. Some parents find that their heart children don't like to draw attention to themselves and struggle to be seen as 'normal'.

Some websites offering advice on making friends:

- ♥ **BBC Onion Street, School Advice** – www.bbc.co.uk/schools/communities/onionstreet/advice/makingfriends
- ♥ **Kidscape** - www.kidscape.org.uk

Further guidance for teachers

Schools and their employers are advised by the Department of Education and Skills to develop appropriate policies and systems for supporting individual pupils with medical needs.

Children's Heart Federation have a fact sheet aimed at teachers, ***Information for Teachers***. It explains what congenital heart defects are and the general needs of a heart child that schools should be aware of. You can download a copy from www.childrens-heart-fed.org.uk/resources/ or a hard copy can be ordered by calling our helpline on 0808 808 5000.

Remember that it is a statutory requirement for schools to make the required provisions for any child with special educational needs both with and without statements. It is important that the school fully involve parents and students every step of the way in any plans and decisions regarding the heart child. A strong partnership with the heart child's **GP** and/or **cardiac liaison nurse** is also important to ensure that appropriate provisions are made and in the case of physical activity, alternative activities are considered to enable participation in both curricular and extra-curricular activities to take place.

Relevant Government publications:

- ♥ *Managing Medicines in Schools and Early Years Setting* – See details on page 8.
- ♥ *Access to Education for Children and Young People with Medical Needs* – See details on page 8.

Respite Care

Finding suitable respite care



Respite care for families with disabled children is an essential service. It offers families a short break from caring and a chance to recharge their batteries. At the same time it can offer opportunities for children to become more independent, have new experiences and form real friendships outside their family.

Respite care can be provided in a variety of ways, within the family home, through accessing community facilities or by the child staying overnight with another family or in a residential setting. Talk to your local social services department to find out what is available in your area.

Organisations that can help:

- ♥ **Shared Care Network** – This is a national organisation which promotes family-based short breaks for disabled children in England, Wales and Northern Ireland. They represent over 300 local schemes linking families of disabled children with people in the community providing regular short-term care. Tel: 0117 941 5363; shared-care@bristol.ac.uk; www.sharedcarenetwork.org.uk
- ♥ **Carers UK** – Provides information on how to access short break services. Carers Line: 0808 808 7777 (Wed & Thurs 10am-12pm, 2pm-4pm) info@carersuk.org; www.carersuk.org
- ♥ **Family Holiday Association** - Provides grants to families towards the cost of their holiday. Tel: 020 7436 3304; info@fhaonline.org.uk; www.fhaonline.org.uk
- ♥ **Make a Wish Foundation UK** - Generating wishes to children aged between 3 and 17 living with a life threatening illness. Tel: 01276 24127; info@make-a-wish.org.uk; www.make-a-wish.org.uk.
- ♥ **Starlight Children's Foundation** - Offers children aged between 4 and 18 who have a life threatening illness, a special wish. Tel: 020 7262 2881; prw1@starlight.org.uk; www.starlight.org.uk
- ♥ **Tourism for All UK** - Provides information to people with disabilities and older people in relation to accessible accommodation. Tel: 0845 124 9971; info@tourismforall.org.uk; www.tourismforall.org.uk

Parent's experiences

"We are very lucky and get hospice care for Rachel. This was awarded to us when Rachel was deemed unsuitable for further surgical treatment and was assessed for transplant. As Rachel becomes more stable our concern is that we will lose the facility. We live 300 miles from our families and have no immediate support. It would be devastating for us to lose the hospice care but know that at some point this will happen. We have spoken to our local authority social services. They say that to get any help we need to have her fully assessed which we don't think is necessary."

"Occasionally our biggest want is a baby sitter for an evening - someone with a rough medical knowledge who could allow us to go to the cinema and turn our phones off for a few hours."

Benefit entitlements

Disability Living Allowance

Many families will be eligible to claim for Disability Living Allowance (DLA) for their heart child.

Children`s Heart Federation have a fact sheet which provides guidance on how to apply for DLA, including advice on filling the form in.

This can be downloaded from www.chfed.org.uk or a hard copy can be ordered by calling our helpline 0808 808 5000.



Other sources of help:

- ♥ **Contact a Family** can provide advice on claiming DLA. They also have a range of fact sheets explaining the range of benefits, tax credits & financial support that families may be entitled to. See contact details on page 34.
- ♥ **Citizens Advice Bureau (CAB)** - You can contact your local CAB *welfare rights adviser* (usually based in the local social services department) who will have detailed information about benefits and other financial help which may be available. They will also be able to help you with any claims.
- ♥ **CarersLine** 0808 808 7777 (Wednesday & Thursday, 10am-12pm & 2pm-4pm)
- ♥ **The Benefits Enquiry Line** 0800 88 22 00 (Tel: 0800 22 06 74 in Northern Ireland) can help with filling out forms and can then fax them to your local benefits office. The Benefit Enquiry Line also provides a service to people whose first language is not English.

Parent`s experiences

"Whilst we do currently receive DLA, the way the forms are set out make it difficult to explain the impact of congenital heart disease on the child and the family. The forms for DLA are very much biased towards 'visible' disabilities."

"It is very hard to claim DLA. The forms are repetitive, they ask how many minutes do you do this and that - very confusing. It is hard because you have to ask cardiologists and other really busy people to fill in forms and you feel like you are detracting from their important job. It is also very distressing writing down how ill your child is - it leaves you depressed and dejected."

"In our experience almost everybody gets turned down at first and has to appeal."

The forms are incredibly time consuming to fill out, and they are depressing to do as you end up having to note every difficulty your child has. We have received no help whatsoever in filling out the forms and were only told we should apply by another parent."

"We didn't have a problem. The cardiac liaison nurses helped me to apply when my daughter was first diagnosed and we were successful with our first application."

"It is very difficult and experience has taught me how to apply successfully, but the forms intimidate many families. Or they apply and get turned down and lack determination to try again. It can be very hard to articulate your child's problems and describe how they affect their quality of life."

"DLA has made a huge difference for us, but filling out the form is just so emotionally draining and difficult. It makes you think about all the things your child can't do, and all the negative aspects."

"I imagine a person in the DLA office, with no medical experience, reading the form to get a picture of Mia's condition, so I always give lots of detail so they get as clear a picture as possible."

"Not sure that the guidelines are clear for who is eligible for this."

Post-School Options

College & University



After school, young people nowadays have a wide range of options to choose from, including pursuing further education, apprenticeships, doing short courses and finding a job. Most people with heart conditions will be able to go on to do what they want after school. However, it might be useful to discuss individual needs and how

these may affect future life choices with your **cardiologist**, especially if you are planning to do studies with large amounts of physical exercise, such as Physical Education, some modern apprenticeships etc.

Below are some of the organisations that offer information and advice on life after school:

- ♥ **GUCH Patients Association** – An organisation supporting young people and adults with congenital heart disease. Offer a helpline for issues facing young people and adults with CHD. Also have fact sheets, publications and a message board to share experiences, advice and information.
Helpline: 0800 854759; www.guch.org.uk
- ♥ **Contact a Family** - Transition Factsheet containing information on education, training and work options. See contact details on page 34.
- ♥ **TheSite.org** – Run by YouthNet UK, this website provides support and advice for young adults on various lifestyle issues, including information and advice on post - GCSE options.
Tel: 020 7226 8008; www.thesite.org
- ♥ **Aim Higher** - A national programme run by the Higher Education Funding Council for England (HEFCE) with support from the Department for Education and Skills (DfES). Information and guidance for young people and parents on planning careers and the options available.
www.aimhigher.ac.uk
- ♥ **Directgov** – provides information from across UK government departments on various topics. Has a general section on going to university or college - www.direct.gov.uk/en/YoungPeople and a section for disabled people and further education - www.direct.gov.uk/en/DisabledPeople
- ♥ **Connexions Direct** – National organisation with local services for young people (aged 13-19) offering information and advice.
Tel: 0808 001 3219; www.connexions-direct.com

- ♥ **After 16** – This is a website which provides young people with information on opportunities and services after they leave school. Aimed at young people with a wide range of abilities and disabilities.
www.after16.org.uk

Personal experiences

"Whilst I was doing my PGCE (teaching qualification), one of my lecturer's said that teaching would be too stressful"

"One teacher told me not to bother with my GCSE's as it was likely I'd never get to use them (they thought I would die before getting a job). So I took great delight in sending them a copy of my degree and post grad certificates."

"I was in mainstream education and never considered my heart condition to hold me back in any way."

"There were doubts raised by my family as to whether I would have the emotional and physical ability to become a children's nurse. But I still went ahead, endured 3 hard long years of training and am more than able to do my job under very harsh conditions: constantly on my feet, very few breaks to get drinks/meals, and highly stressful work environment."

Careers

Most adults with congenital heart disease will be able to do the jobs, and follow the careers, that they want to. However, for some adults with complex heart conditions it might be useful to discuss their career choices if they want to have a career with a lot of physical activity, such as being a joiner, police officer etc. In these cases they should discuss whether there are any physical restrictions, and other questions, and concerns with their **cardiologist**.



Occasionally, adults with heart conditions may experience workplace discrimination as employers may not know about their condition and make assumptions about how it affects individuals. If you feel that you are being treated unfairly by your employer because of your CHD, and discussing the issues with them does not seem to address the issue, you may have protection under the Disability Discrimination Act 1995:
www.direct.gov.uk/en/DisabledPeople.

Other organisations that can offer advice:

- ♥ **GUCH Patients Association** – An organisation supporting young people and adults with congenital heart disease. Offer a helpline for issues facing young people and adults with CHD. Also have fact sheets, publications and a message board to share experiences, advice and information. See contact details on page 33.
- ♥ **Contact a Family** - Transition Factsheet containing information on education, training and work options. See contact details on page 34.
- ♥ **TheSite.org** – Run by YouthNet UK, this website provides support and advice for young adults on various lifestyle issues, including information and advice on post - GCSE options. See contact details on page 23.
- ♥ **Connexions Direct** – National organisation with local services for young people (aged 13-19) offering information and advice. See contact details on page 23.
- ♥ **Breakthrough UK** - This is a company for disabled people, employers and anyone with an interest in disability, employment and independent living. Tel: 0161 273 5412, www.breakthrough-uk.com.
- ♥ **Directgov** – Provides information from across UK government departments on various topics including careers advice: www.direct.gov.uk/en/Employment/Jobseekers/JobsAndCareers

Personal experiences

"I went on to higher education, did A levels and then a 2 year course at a polytechnic, during which time I lived in Halls. The only concession I asked for was a ground floor room."

"I applied to do a degree which included a placement year but the uni didn't seem keen to take me as they thought employers wouldn't want me."

"I have a heart defect myself and have never had any adverse reaction. I do not divulge the fact to employers or colleagues and have not had to detail it as a medical. I suspect that there could be ramifications if I had to do so, despite it having no impact on my day to day living or working."

"My abilities and talents are mental not physical so my heart condition was and is irrelevant to my career choice."

"Some GUCH's do say that they have problems if they need further invasive treatment requiring greater than 6 weeks off work."

"I had to have a medical as a result of telling my employer about my heart condition."

"When I had to go into hospital for catheters my employers were very sympathetic."

Growing Up

Sexual Activity

A lot of young people worry about sex; whether they'll get any, whether it will hurt, if they'll get pregnant or catch something.

Some young people with heart conditions worry about the impact that sex will have on their hearts, and although studies show that sex can be the equivalent to walking up 2 flights of stairs it is important to remember that you and your partner can vary positions or intensity to ensure that it is enjoyable for both of you.

If you do have concerns then talk to either your cardiologist or cardiac liaison nurse.

Some of the drugs people with heart conditions, both males and females, are given can effect both their desire and ability to have sex, these are well known side effects. If you think you are being affected by your drugs in this way you need to discuss possible alternatives with your cardiologist.



Contraception

Most women with heart conditions can use various methods of contraception: a barrier method (male or female condom, diaphragm or cap); an intrauterine device (IUD); injections; implants; or the oral contraceptive pill.

The 'combined' pill contains both oestrogen and progesterone and is the most effective. However, if you have cyanosis (which means your skin appears 'blue' because there is not enough oxygen in your blood), the 'mini' pill or progesterone only pill may be safer for you. The reason for this is that your blood may be thicker which means there may be a higher risk of thrombosis (blood clots).

If you use an interuterine device it is useful to check with your cardiologist if you should have antibiotics before it is inserted as there may be a slight risk of infection.

Talk to your **cardiologist** to decide which is the best method for you.

For more information and advice on contraception:

- ♥ **GUCH Patients' Association** produces information sheets on contraception and pregnancy that you may find useful. See contact details on page 33.
- ♥ **Contact a Family** – series of booklets on issues around sex and relationships for young people. See contact details on page 34.
- ♥ **Brook Advisory Centres** – offer free and confidential sexual health and contraception advice for young people.
Helpline - 0800 0185 023
www.brook.org.uk
- ♥ **www.likeitis.org** – website for young people with information and advice on sex, contraception and teenage life.
- ♥ **Moving on Up** – a website for young people on changes that happen when you are moving on to being an adult. Web: www.movingonup.info

Pregnancy



Most women who have heart condition and are symptom-free should be able to manage a pregnancy. However there are some types of heart conditions where pregnancy can pose certain risks or may not be advised at all. It is very important that you speak to your **cardiologist** before you consider having a baby to discuss the risks to mother and baby, and the risk of congenital heart disease in the baby.

For more information:

- ♥ The **GUCH Patients' Association** produces information sheets on contraception and pregnancy that you may find useful. See contact details on page 33.
- ♥ **Contact a Family** - the national charity for families with disabled teenagers has produced three comprehensive guides entitled 'Growing up, sex and relationships'. Areas covered include self-esteem, making and keeping friends, personal relationships, body image, puberty, sex education, and sex and relationships.

In the booklet for children and young people, disabled teenagers pass on their tips about dealing with some of the toughest aspects of growing up. Free copies of the booklets can be obtained from Contact a Family. See contact details on page 34.

Personal experiences

"I was advised not to get pregnant. Especially whilst I was still on warfarin."

"I have been given very good information regarding pregnancy and the facilities available to me."

"I have had a discussion about the genetic component of CHD and whether there would be a risk to any children I had."

Alcohol & Drugs

Going out and having a drink is part of most peoples lives, and everyone whether they have a heart condition or not has to be careful about the amount they drink and whether they "binge" drink. Alcohol can have serious health and personal safety implications for all of us.

Some people with heart defects may be advised not to drink any alcohol especially if they are prone to heart rhythm problems (arrhythmias) which can be triggered by alcohol or if their condition has affected their liver.

Alcohol can also interact with the cardiac medications reducing their effectiveness or causing an adverse reaction.

The risks of drinking alcohol will depend on the particular heart condition and on the amount and/or frequency of alcohol consumption. It is best to consult your cardiologist how alcohol will affect your heart condition. To find out more about the effects of alcohol and how to cut down visit www.howsyourdrink.org.uk.

Taking drugs can have serious consequences for anyone. People with heart defects can be particularly at risk because drugs cause reactions such as enlarged blood vessels, increased heart rate and blood pressure. To find out more about the health risks and the effects of different drugs visit www.talktofrank.com or call their free confidential helpline 0800 77 66 00.



Personal Experiences

"I understood the risks with drugs and cigarettes myself. I have never been given any formal advice and enjoy a drink or two with no problem."

"I made sure my son had all the information about why too much alcohol was dangerous for him - but he's an adult now so it's up to him."

"I have always drunk alcohol but I was always open about my social drinking habits at appointments. "

"I was advised not to smoke, but have never been advised not to drink."

Smoking

The harmful effects of smoking are already well known. It is an avoidable health hazard, and even more so in the case of those with congenital or acquired heart conditions as it will have a more pronounced effect on the heart and lungs. Smoking produces damage to the smooth lining of the arteries. Clots form in this now roughened area and it is the blockage of arteries as a result of these clots that cause heart attacks and strokes.

Some useful organisations that can help people to quit smoking:

- ♥ **QUIT** is the independent charity whose aim is to save lives by helping smokers to stop.
0800 00 22 00 www.quit.org.uk
- ♥ **NHS Smoking Helpline: 0800 169 0 169**
- ♥ www.gosmokefree.co.uk - An NHS site which lists all the various types of services available through the NHS to help stop smoking.

Piercings

Piercing and tattooing involve 'breaking' the skin and can result in bacterial infections. If these bacteria enter the blood stream, they could cause endocarditis. Therefore, many doctors advise people with heart defects against having piercings or tattoos or to have preventative antibiotic cover beforehand. Using a properly qualified practitioner who uses sterile equipment and techniques to carry out these procedures is also vital. The risks of having a piercing or tattoo will depend on the particular heart condition and on the part of your body you wish to pierce or tattoo. It is best to consult your **cardiologist** or **cardiac liaison** nurse. For more information on piercings and tattoos visit www.thesite.org/healthandwellbeing. The **GUCH Patients' Association** also produces information sheets on lifestyle issues that you may find useful.

Personal Experiences

"I received information on endocarditis when I was 20 - bit late as I'd already had piercings without antibiotic cover and wasn't aware of the caution required when visiting the dentist."

"Antibiotics at the dentist have been the order of the day since I first needed dental treatment. A doctor did once explain what endocarditis is as well and why I'm at a higher risk of it."

"I know there's information in the GUCH leaflet about piercings but I don't remember a cardiologist mentioning it."

"Our daughter is asking about piercings but we are persuading her against this. We are looking forward to the new teenage unit at Brompton, where we hope these issues will be more widely discussed and advised."

Travel

Rail

Anyone who receives Disability Living Allowance may be entitled to a Disabled Persons Railcard. This costs £18 for 12 months and entitles you to a third off normal rail prices. Visit www.disabledpersons-railcard.co.uk for more information.

Car

Driving licences

Adults with congenital or acquired heart conditions may need a medical certificate saying they are OK to drive before applying for a driving licence. If a licence is refused or seems to be unfairly restricted, you can complain to the Driver Vehicle Licensing Agency telephone 0870 240 0009 or your local magistrate. If the refusal is on medical grounds ask for the Drivers Medical Group or phone them direct on 0870 600 0301.

Free road tax

In order to be eligible for a free road tax (Vehicle Excise Duty) disc, the car owner must have DLA mobility at the higher rate and a car which is mostly used by you or for you (it could be owned either by you or your parent or carer).

Contact Disability and Carer Benefits on 0345 123456 for an application form.



Air travel

Air Travel is safe for the majority of people who have a congenital heart problem. However it is a good idea to discuss your plans beforehand with your **cardiologist** who can advise you about any risks specific to your particular condition.

Travel insurance

Getting travel insurance can sometimes be difficult if you have a pre existing medical condition. Children`s Heart Federation has a list of insurance companies that offer cover for pre-existing medical conditions - contact our helpline on 0808 808 5000.



Parent's experiences

"We had terrible problems trying to obtain travel insurance for my daughter. Her condition is obviously not on their database so she was refused cover."

"My son has numerous difficulties so we have had huge problems trying to get travel insurance. We also cannot travel far from hospitals or where English is not spoken, and we ascertain where the nearest hospital is when we are travelling. Time on a plane or a boat could be dangerous as my son sometimes needs immediate medical intervention. I am concerned for his future and imagine that he will experience the same problems himself as he gets older."

Physical Activity

Most young people with a heart condition will not have many or any restrictions when it comes to physical activity. However, everyone is different so it is important that you get *individual* advice from your **cardiologist** about what you can and can't do.



As you grow older, your heart problem may change over time, and so it is important that the information you have is up to date. Again, check with your cardiologist if you aren't sure.

There are very few people who will be advised not to do any exercise at all. For most people with heart conditions, it is usually better and safer to participate in activities that do not put too much of a strain on your heart and that you can control (i.e. take part in at your own pace and your own level) such as: cycling, walking, swimming, badminton. It is usually best to avoid activities such as: weight lifting, athletics throwing events, boxing, martial

arts. This is because these activities may put more of a strain on your heart and blood vessels. For those that are on anticoagulants such as warfarin, or have a pacemaker, it is advisable to avoid sports with a high risk of collision, e.g. boxing, rugby, football. It is best to ask your cardiologist if you are unsure if a particular activity is suitable for you.

For more information:

- ♥ The **GUCH Patients' Association** produces information sheets on lifestyle issues that you may find useful. See contact details on page 15.

Personal experiences

"My parents were told that I would not be able to participate in sporting events or do strenuous activities. Hence I was wrapped in cotton wool and not encouraged to lead a 'normal' life."

National Organisations

- ♥ **Barth Syndrome Trust**
Part of a worldwide voluntary community helping boys and families affected by Barth syndrome and working towards a cure.
info@barthsyndrome.org.uk **www.barthsyndrome.org.uk**
- ♥ **Cardiomyopathy Association**
Helps sufferers, their families and their medical advisors to best manage the impact of cardiomyopathy.
0800 0181 024 **www.cardiomyopathy.org**
- ♥ **CRY**
Provide support and information on cardiac risk in young people.
01737 363 222 **www.c-r-y.org.uk**
- ♥ **Downs Heart Group**
Provide support and information relating to cardiac conditions associated with Down's syndrome.
0845 166 8061 **www.dhg.org.uk**
- ♥ **Grown Up Congenital Heart Patient's Association (GUCH)**
Provide support to a growing community of adult congenital heart patients.
0800 854759 **www.guch.org.uk**
- ♥ **Heartline Association**
Provide support, information and local contact networks for families of children with heart conditions.
01276 707636 **www.heartline.org.uk**
- ♥ **Heart Transplant Families Together**
Provide support to families whose lives have been affected by heart/heart lung transplantation
0845 094 5810 **www.htft.org.uk**
- ♥ **Little Hearts Matter**
National support for families where a single ventricle condition has been diagnosed.
0121 455 8982 **www.lhm.org.uk**
- ♥ **Max Appeal**
Supporting families affected by DiGeorge syndrome, VCFS and 22q11.2 deletion.
0800 389 1049 **www.maxappeal.org.uk**

Regional Organisations

- ♥ **Children's Heart Association**
Based in North West England
01706 221988 **www.heartchild.info**
- ♥ **Children's Heart Unit Fund**
Based in Newcastle
0191 2131365 **www.chuf.org.uk**
- ♥ **Evelina Children's Heart Organisation**
Based in Evelina Children's Hospital, South East England
www.echo-evelina.org.uk
- ♥ **Heartbeat**
Based in Northern Ireland
02843768786 **www.heartbeatni.org.uk**
- ♥ **Heart Children Ireland**
Based in Our Lady's Hospital in Crumlin, Ireland
(00 353 1) 8740990 **www.heartchildren.ie**
- ♥ **HeartLink**
Based in Glenfield Hospital, Leicester
0500 382152 **www.heartlink-glenfield.org.uk**
- ♥ **Scottish Association of Children with Heart Disorders**
Based in Scotland including six area branches in Aberdeen, Banff & Buchan, Edinburgh, Glasgow, Dumfries and Tayside.
0131 447 2711 **www.sachd.org.uk**
- ♥ **South West Children's Heart Circle**
Based in South West England, also covering Wales
01454 854656 **www.heartcircle.org**
- ♥ **The Brompton Fountain**
Based in Royal Brompton and Harefield Hospital, London.
020 7776 9000 **www.bromptonfountain.co.uk**
- ♥ **Wessex Children's Heart Circle**
Based in Southampton General Hospital
01935 816156 **www.wchc.org.uk**
- ♥ **Young at Heart**
Based in Birmingham Children's Hospital
0121 357 8200 **www.youngatheart.org.uk**

List of Organisations & Professionals you may need to liaise with:

- ♥ **ACE (Advisory Centre for Education)**
Offers free guidance and advice on all aspects of state education as well as leaflets on other education topics.
0808 800 5793 www.ace-ed.org.uk
- ♥ **Cardiologist**
The child's or young person's cardiologist will be able to advise on individual limitations that may affect life in school and the community as well as general advice on medical needs.
- ♥ **Cardiac Liaison Nurse**
Provide long-term emotional support, information and practical advice for children with heart conditions and their families
- ♥ **CSIE (Centre for Studies on Inclusive Education)** gives information and advice about educating children with special needs within ordinary schools.
0117 328 4007 www.csie.org.uk
- ♥ **ChildcareLink**
A government service that provides information and advice on childcare
0800 096 0296 www.childcarelink.gov.uk
- ♥ **Citizen's Advice Bureau (CAB)**
Can help with information on benefits and other financial help.
- ♥ **Contact a Family**
Detailed information and advice for families with disabled children
0808 808 3555 www.cafamily.org.uk
- ♥ **Daycare Trust**
National childcare charity providing information and advice on childcare
020 7840 3350 www.daycaretrust.org.uk
- ♥ **DfES (Department for Education and Skills)**
Web: <http://www.teachernet.gov.uk/wholeschool/sen>
- ♥ **Directgov**
A government site bringing together the widest range of public service information and services online
www.direct.gov.uk
- ♥ **Disability Rights Commission**
The Disability Rights Commission (DRC) is an independent body established in April 2000 by Act of Parliament to stop discrimination and promote equality of opportunity for disabled people.
www.drc.gov.uk
- ♥ **Educational Psychologist**
A person who assesses a child or young person's learning and emotional needs
- ♥ **Education Social Worker** (also known as EWO Education Welfare Officer)
A person employed by an LEA to help parents and LEA's meet their responsibilities on school attendance
- ♥ **Every Disabled Child Matters (EDCM)**
EDCM is a campaign for disabled children and their families to have the right to the services and support they need to live ordinary lives.
www.edcm.org.uk
- ♥ **Health Visitor**
A health visitor is a qualified and registered nurse or midwife whose role is to promote health and the prevention of illness in all age groups
- ♥ **IPSEA (Independent Panel for Special Educational Advice)**
National charity that helps to ensure children receive the special educational provision appropriate to their needs and to which they are entitled in law.
0800 0184016 www.ipsea.org.uk

- ♥ **Learning Support Assistant/Teaching Assistant**
A person providing support for an individual pupil or group of pupils with special educational needs and/or disabilities
- ♥ **LEA (Local Education Authority)**
Local government body with a wide range of responsibilities for children's education, including carrying out statutory assessments, maintaining statements of special educational needs and providing transport
- ♥ **National Association of Special Educational Needs (NASEN)**
Nasen is the leading organisation in the UK which aims to promote the education, training, advancement and development of all those with special and additional support needs.
www.nasen.org.uk
- ♥ **National Parent Partnership network**
Parent partnership services are statutory services that offer information, advice and support for parents of children and young people with special educational needs (SEN)
<http://www.parentpartnership.org.uk>
- ♥ **Parents for Inclusion**
Parents helping parents so their disabled children can learn, make friends and have a voice in ordinary schools and throughout life
0845 652 3145 www.parentsforinclusion.org
- ♥ **SENCO (Special Educational Needs Co-ordinator)**
Member of staff of a school or early years setting who has responsibility for co-ordinating SEN provision within that school.
- ♥ **SENDIST (Special Educational needs and Disability Tribunal)**
Independent tribunal which considers parents' appeals against the decisions of LEAs about children's special educational needs if parents cannot reach agreement with the LEA.