

HeartLine

Issue 59

Summer 2003



Jack's our lad

FROM THE EDITOR

Summer 2003

This edition of the magazine has an article written by Chantalle's father – he was her main carer through a nightmare time of illness, hospitalisation, deterioration, and uncertainty. In the Autumn magazine you can read how Emma's father gave support, worked out timetables, and dealt with the sharp end of the feeding processes while his daughter refused to cooperate. Having a baby with a heart condition increases the chances of relationship

problems considerably. It is one of the things that is most difficult to share with a partner – all the practical, exhausting aspects of caring while fear and grief struggle for the upper hand. Here are two families where fathers have taken over feeding and other cotside duties. Once families accept that these are men's roles, maybe employers will be persuaded that fathers are much too valuable at home to be at work during days of crisis.

Hazel Greig-Midlane



HeartLine

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Please send your pictures and stories for Issue 60 Autumn 2003 – as this should be out in November, I particularly would like to see Christmas pictures (it's the hottest it has ever been in London as I write!)

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Front cover:

Jack Sage

A FATHER'S STORY - Part 1

Michael Spencer writes

Seiko was booked in to have Chantalle on November 14th. As with our other two, Seiko was to have a c-section - it was considered the safest way since her cervix is small. I was with Seiko, as I had been with the other two, during the operation. The atmosphere in the operating room was as light humoured as usual - we had the same anaesthetist and gynaecologist as with all three. The only slight difference to before was the amount of amniotic fluid - a little more than was expected.

Shocked

Chantalle was born at 3.15pm. She was a bluish/purple colour and, as with our other two, had a fair amount of hair. She barely cried at all. At first I did not think too much was wrong. Seiko was fine to let me go straight over to see how our latest new addition was getting on, and I remember commenting that the vitamin D injection would be sure to get her crying. Chantalle only grunted, and remained her bluish/purple colour. Despite ten minutes of oxygen there was no improvement. By this time the nurses had called for the paediatrician. I think I held Chantalle for about a minute before she was examined again. The paediatrician informed us that Chantalle would have to go to intensive care for 24 to 48 hours - her lungs were wet, and she required observation. We were shocked - 24-48 hours! Seiko hadn't even held her!! I was allowed to show her to Seiko before I accompanied Chantalle up to intensive care in her incubator.

Intensive care

Chantalle was put on a monitor - and put on CPAP. I remember Intensive care was quite full - it seemed it was quite normal for c-section babies to have wet lungs since the fluid would not have been squeezed out as with normal childbirth. Despite the CPAP, SAT levels remained in the low 80s. SAT was my first introduction to the many abbreviations. She was put on a ventilator - her nasal tubes were so small it was put through her mouth. Despite ever increasing concentrations of oxygen, her SAT levels did not improve. Even on 100% Oxygen, they deteriorated.

By this time it was 10 pm. I had been switching between Seiko and Chantalle, but Seiko recalled afterwards that my face grew more and more worried. And the time I spent in NICU got longer and

longer. Early in the evening, I called some of my family, as did Seiko. It's all right, I said. She would be out of NICU in the next day or so.

Transfer

The consultant Paediatrician was called. He took blood samples from her cord - her veins were so small, they could not find one to take a sample. It showed CO₂ at low levels, so it was not ventilation. The chest X ray showed her lungs to be clear. Dr Douek took me into an office, explaining that it could be that the arteries from the heart that were the wrong way round. For this reason, as well as the fact that the Portland did not have nitric oxide, the decision was taken to transfer Chantalle. Dr Douek accompanied me to break the news to Seiko, who was still fairly immobile after the c-section. The only bed available was in GOSH. In consultation with the doctors at GOSH, Chantalle was started on prostine. She was also given several doses of surfactant to open up the airways in her lungs. At this stage she stabilised with her sats in the low 80s and blood pressure at reasonable levels. Her heart rate was 190 bpm.

We now had to wait for the team to come and meet Chantalle. GOSH was too busy to let another doctor go, and the team was on its way from Bedford. By 1 am, Seiko, who had been worried to death, gathered the strength to go and see Chantalle. The nurses gave her extra pain relief and a wheel chair to make the journey up to NICU. At 6.15 am the next morning the team arrived to take her to GOSH. A chest X ray and a cardiogram were performed. I had a meeting with the cardiologist. She explained that Chantalle had a very large VSD as well as problems with her pulmonary valve - it was stenotic and dysplastic. I was presented with three options, all of which involved surgery within twenty four hours.

No surgery needed ...

Chantalle was now on nitric oxide, prostine, dopamine, morphine and a drip. A few hours later, another cardiogram revealed that the pulmonary valve was working better - the arteries had opened up (in her body and lungs) so flow was better. On the afternoon of the 15th November, she was taken off prostine, and it was decided that surgery would not be required. It all looked very

positive - I even called Seiko telling her we would be back at the Portland soon, maybe before her week was up. The nitric oxide was reduced, and oxygen concentrations reduced - she was virtually breathing air!! The surfactant had to be suctioned out quite regularly. She was well enough for me to return to the Portland to spend a few hours with Seiko. However, I had been a little too optimistic, and she deteriorated - but still better than when we had arrived.

First feed

The two weeks that Chantalle spent at GOSH I spent between GOSH, where a room was provided for me to sleep, the Portland and home. My mother-in-law came over from Japan to help out with the other children, and with luck, we had found a nanny two weeks before Chantalle was born. Chantalle had her first feed on the 16 November - 4 mls of expressed milk.

Syndrome?

Chantalle's problems were primarily with her heart, so she was transferred to DJW - the semi-intensive ward of the cardiac unit. Meanwhile, the geneticists came to see her - and chromosomes taken to be tested. Her neck was fat, she had one crease on her hand, widely spaced nipples, odd shaped feet and downward sloping eyes suggesting some form of syndrome. At the time, Seiko and I were in denial. Seiko is Japanese and I am English, so Chantalle's eyes are likely to be different, and our son had a fat neck when he was born too. Looking back on it though, Chantalle did look different to other babies.

A few small kicks

She remained on a ventilator, but the support slowly decreased. Fluid continued to appear in her lungs so the frequency of suctioning had to be increased. Her feeds were cut down in preparation for extubation - in any case, her fluid input was minimal to stop straining her heart. Yet, she was not successfully extubated after several attempts. By the 17 November she was more alert, did a few small kicks, and on the 18th I took Seiko to see her. They tried to extubate Chantalle for about the fourth time on that day, yet were unsuccessful again. The 19th, we had a meeting with the registrar to discuss the tests that Chantalle would go through. In addition to her heart problem, it

appeared that Chantalle was 'floppy'. Wednesday 21 November, Seiko was discharged. and we went straight to GOSH. Seiko and I held Chantalle - it was the first time for Seiko. It was rather complicated, with Chantalle still on her ventilator.

Chantalle's genetic tests came back all clear, but the CT scanner was broken. Meanwhile, on the 22nd, Chantalle was extubated, and successfully breathing without the ventilator - though she was on the CPAP. Her weight was fairly stable at 2.68kg.

Back to the Portland

On leaving Great Ormond Street, they pronounced her heart to be stable and stopped her diuretics. They said it was only a matter of re-establishing her feeds and she could go home. However, with the trauma of the journey back to the Portland her liver swelled to 3 cm and she had difficulty breathing. The Paediatrician who was there on her admittance re-prescribed her diuretics. She still required oxygen (CPAP) and she remained in the NICU. She was weaned off the CPAP at the age of 1 month. Her heart rate seemed fairly stable at a high rate and as time progressed, she was taken off the monitors, and with more babies being admitted, she was moved to the less intensive care ward. Her feeding appeared to be progressing quite well - she was 'demanding' more and more. She was feeding on expressed breast milk from the bottle, as well as via her nasogastric tube. She was still too weak to take that much via the bottle.

Heart failure

After about one week in the less intensive ward Seiko thought that she did not look well - she was sleeping an awful lot, and looked rather pale. The next day she was rushed back into the NICU, taken off her feeds and put on a drip. She was in heart failure. They increased her diuretics and she lost all the weight she had put on since her return from GOSH. Apparently, this weight gain had merely been fluid. Whilst remaining in NICU, her feeding resumed but the volumes were restricted. To try and increase the calorie intake Duocal was introduced into her feeds. Since it did not mix well with breast milk, she had to be fed on Neocate. Not long after this was started blood was found in her stools - it just so happened that a gastro-

specialist was in the ward, having been asked to take a look at another baby on the ward. He took one look at the X-ray of her intestine and pronounced necrotising enterocolitis. This required a course of antibiotics and nil-by-mouth for a period of ten days.

Hickman line

She had a Hickman line inserted and was fed on TPN. The next ten days were the best in terms of weight gain for Chantalle. The TPN is fed directly into the blood stream via the Hickman line, which is a line fed through the chest, into a major artery and sits just next to the heart. After ten days, her feeds were slowly increased - starting at 1 ml an hour. In consultation with GOSH, it was decided to leave the Hickman line in. It was very useful 'access'.

Hypotonia

The team at GOSH had decided that her heart was 'stable' and that it would only be a matter of time at our local before we would go home. They thought that it was important that the reasons for her hypotonia were discovered before any surgery took place. The muscle specialists had carried out a few tests during her first few weeks at GOSH but had found nothing. The paediatrician at the Portland also worked at Queen Mary's - he knew a very good team, to whom he would refer Chantalle.

Syndrome

The geneticists at GOSH had suggested that she may have Noonans Syndrome. Noonans is associated with pulmonary valve disorders - but it was difficult to see any off the other symptoms at that stage. As the geneticists explained to us, with Chantalle there were some mild dysmorphic features which included a simian crease, small left ear posteriorly rotated, up slanting palpebral fissures, short fingers and wide nipples. The investigations for chromosomal abnormalities did not show anything up. The genetic team at GOSH regularly stopped by but since she was ventilated, as well as being half Japanese made it quite difficult for them to conclude anything from observing her features.

Heart first

The paediatrician at The Portland, on her arrival, told us that he would refer her to Professor Muntoni's team at the Hammersmith, and that we may be



transferred there within days. It was his team that would investigate her hypotonia. It was with some luck that a registrar in Professor Muntoni's team was working at The Portland at that time. She examined Chantalle and also 'interviewed' us - a lot of questions about our families as well as the pregnancy. Seiko and I had been in somewhat denial of Chantalle's hypotonia - we argued that what baby wouldn't be weak having gone through what she had gone through? Maria, this registrar, explained - in a sympathetic way - that Chantalle was clearly 'floppy'. She and the paediatrician reported to Professor Muntoni. He said that contrary to GOSH's assertion, the heart should be 'fixed' first, and the muscles seen to later.

So we were essentially waiting for the operation. Chantalle had to overcome her necrotising enterocolitis, as well as try to gain some weight. The chances of survival of open heart surgery are increased with weight and age. Once over the NEC, Chantalle remained in NICU. I can not recall the exact number of times, but either Seiko or I (or both of us) would be in NICU till late in the night as a registrar desperately tried to get a cannula in to administer antibiotics as she got a fever and her heart rate headed towards 200.

We spent Christmas on NICU. They discovered that Chantalle had a hole at the bottom off the spine. Babies with spina bifida have this characteristic, so an ultrasound was carried out - but thankfully nothing was discovered. Chantalle was finally scheduled to have her heart surgery. She had made slow weight gain during January, and despite a mild fever, she was transferred to GOSH on the 27th January, weighing 3 kg, for her operation on the 28th January.

GOSH

Victor Tsang, the surgeon, came to visit

on the morning of the operation. We were really worried that the operation would be cancelled, due to her slight temperature. The surgery would be to close the VSD, and also to carry out a limited valvotomy to the dysplastic pulmonary valve. Despite our worries, the surgery would proceed as planned, and we took Chantalle down at 1.30pm. We returned about two hours later, expecting her to be in CICU. As we were waiting, Victor walked past - and told us that owing to an emergency, Chantalle's operation had been delayed. Her operation would take place around 4pm.

Post op problems

The surgery was carried out with no problems. Chantalle was initially stable but within an hour her blood pressure decreased fairly dramatically, she had episodes of desaturation and her CVP measures increased. We were asked to leave as they tried to stabilise her. To treat Chantalle's pulmonary hypertension, she was started on nitric oxide. The decided to keep her paralysed and hyperventilated, as well as increasing her drugs to help her heart beat. Her kidneys failed too leading to oliguria so she had a PD catheter inserted. Her Hickman line became 'infected' so antibiotics were started. On the fourth day she developed a pleural infusion, for which a chest drain was inserted - she in

fact had developed a chylothorax. As a result of that she was started on Monogen feed. Eleven days after surgery she was described as fairly stable, and was successfully extubated. Her chylothorax also suddenly stopped. In no time she was out of CICU into DJW.

Chantalle's face became red and blotchy. I pointed this out on the ward round one morning, and in fact discussed it with her cardiologist. Did he not think she was looking worse? He just hummed and agreed she did look rather red....and we transferred to Ladybird that afternoon. The same evening she spiked her temperature to 38.5 degrees, and also developed serious difficulty breathing. She had developed a 'large' right pleural effusion - the chylothorax had returned.

Shifted the cardboard boxes ,,,

The registrar had to insert a chest drain that night - after signing consent, we went into the treatment room near the Ladybird ward. We shifted a few cardboard boxes off the couch, they administered a local anaesthetic and I left the room while they inserted the chest drain. Chantalle was in a lot of pain, and I held her all night. She would wake up crying every half an hour or so. She lost about 100 ml of fluid per day through the chest drain.



Full pain relief

On the 20th February they removed the chest drain and her hickman line. The next day her chylothorax returned, so she had to have the chest drain inserted yet again. This time, it was done in an operating theatre and the nurse insisted on full pain relief. Chantalle was started on Octreotide on the 25th February, and thoracic duct ligation was planned for 28th February. It was cancelled for some reason - but luckily, following that, the loss of fluid through the chest drain decreased, and the chest drain was clamped on the 6th March. We asked that it was not removed for a week - we did not want to go through the same situation where the pleural effusion came back. After seven days it did not reappear, and we were allowed to go home on the 14th March.

Part 2 of A Father's Story will appear in Autumn 2003 magazine

Terms used:

CPAP: constant positive airway pressure

Sat levels: the amount (saturation) of oxygen in the blood

NICU: neonatal intensive care unit

CO2: carbon dioxide

Prostine: a drug given to keep the fetal circulation passages open in the heart.

Surfactant: coating that protects the lungs

VSD: ventricular septal defect, a hole between the ventricles

Stenotic: narrow

Dysplastic: didn't work properly

CT: cerebral topography - mapping the brain

Heart failure: heart failing to keep up with the demands on it

Diuretics: medicines used to reduce fluid by increasing urine output

Necrotising Enterocolitis: serious inflammation of the bowel

Hickman line: a hollow tube sewn into a vein in the chest

TPN: Total Parenteral Nutrition: all the nutrients needed are put directly into a vein.

Hypotonia: floppiness due to lack of muscle tone

Dysmorphic features: unusual features sometimes associated with a

syndrome.

Simian crease: a single crease as compared to two creases in a normal palm.

Posteriorly rotated: turned towards the back

Up slanting palpebral fissures: eye slants from nose upwards (normal in Asian people)

Valvotomy: cutting the valve, sometimes removing it altogether

Oliguria: lack of urine

Chylothorax: fatty fluid leaks into the chest

Thoracic duct ligation: tying off the leaking duct in the chest

Gastrostomy: making an opening into the stomach so that food can be passed directly into it.

MY STORY – Isolda Kate

I'd like to introduce you to Isolda, who is a very happy, strong-willed three-year old. She is a little miracle and we are forever grateful that she is here with us today.

Scan

We found out that Isolda had two congenital heart defects, a coarctation and a VSD around the time of our 20-week anomaly scan. We had been referred to Guy's hospital for further scanning after a possible VSD was suspected at the 20-week scan. We were told that our baby "might" have a VSD and were subsequently left waiting an entire weekend, only knowing half a story! So by the time we arrived to see the cardiologist at Guy's you can imagine the sort of thoughts going through our heads! After a very thorough and nerve wracking scanning session, we were told the news we'd hoped that we would never hear.

Unknown territory

The diagnosis was that Isolda had in fact two very serious heart defects. The VSD was confirmed but he had also found the coarctation. In my naivety I began asking all sorts of questions and so our cardiologist began to draw diagrams of how the heart worked and what was wrong in Isolda's case. I feel as if I know everything there is to know about Isolda's heart defects now but at the time I was completely naïve. It's very hard to take in all the facts and figures when trying to digest such an emotive subject. I was in complete shock but at the same time had to try and put on a brave face in front of (who was then) a complete stranger and try and follow what we were being told about Isolda's future. All I wanted to do was to retreat on my own with my husband and be able to fully express how I really felt about this. The cardiologist, who I cannot fault in any way, was obviously used to talking to parents about this sort of thing but for us it was unknown territory.

Absolutely necessary

We were told that Isolda would need to undergo surgery to repair the coarctation and probably the VSD as

well, within a few days of birth. This was absolutely necessary for her survival due to the coarctation. We were then told that the hospital had a good success rate from such an operation with a small mortality rate, which in retrospect was extremely positive under the circumstances. However, just to make matters worse for myself I chose to focus on the fact that there were evidently some babies who didn't make it, which I know was incredibly negative.

As if things couldn't have got any worse, we were then told that there was a strong link between Down's Syndrome and congenital heart disease and were offered the amniocentesis test. However, this was not as straightforward as it sounded. The test carried a 1% risk of miscarriage. I was 24 weeks into the pregnancy by now so if something went wrong, the chances of Isolda surviving were small, especially with her heart problems. We were referred to another doctor specialising in Fetal Medicine to help counsel us in our decision, but by now our heads were spinning and so we were advised not to make any decisions regarding the test that day, which was probably just as well for our sanity!

Nearly the worst day

However, it was suggested that we have the nuchal scan before leaving, which focuses on looking for the physical signs of Down's, but this didn't pick up anything significant. I think I can safely say that this has to be the worst day of my life apart from the day of Isolda's actual operation. Firstly we had discovered that our baby had serious heart problems and now we were faced with such an agonising decision regarding her future. I have never in my wildest dreams ever imagined having to make such a difficult decision regarding my own child's future. Isolda's heart defects



were beyond our control but if we made the decision to go ahead with the test, we would be doing so knowing what a fundamental influence it could have on her future.

We eventually had to weigh up the quality of life for a Down's baby with two serious heart defects and this helped us decide that we really needed to know the full reality of what we were dealing with, both for our baby's sake and for our own lives too.

Clearer idea

So we went ahead with the test, which went to plan. We had to wait three days for the results but when we finally got them, our baby did not have Down's. At least we now had a clearer idea of what lay ahead of us, which helped us get through the rest of the pregnancy. It had been agreed that Isolda would be born at Guy's Hospital so that they could provide the appropriate care for her immediately.

Hard to let her go

Isolda was two weeks late so I was induced. The labour went fairly smoothly. After 16 hours there was slight concern that the labour had gone on for too long. I was taken to theatre and prepared for a Caesarean but fortunately this wasn't necessary and Isolda was eventually born via ventouse at 12.40am on the 18 May 2000. She was absolutely beautiful and with a full head of hair she looked about a month old! She weighed

81bs 2oz. We have since recalled that there were approximately fourteen people in the delivery room at this point! There were three cardiologists present as a precaution. I literally had time for a quick cuddle before she was taken to Intensive Care. I knew this would happen but it was still very hard to let her go so soon. I don't think you can prepare yourself for how you are going to feel on the birth of your child. Certainly for me emotion far outweighed logic. We had planned beforehand that my husband would go with her, as we didn't want her to be alone.

Smitten

The euphoria I felt was amazing. I knew that I would do absolutely anything for this little person, it was total unconditional love and I could not believe that she was ours. I was totally smitten!

About an hour after Isolda had arrived on the Intensive Care unit and I was trying my first attempt at breastfeeding(!), completely exhausted after the labour and extremely emotional, the on-call cardiologist came to scan her and we had a last feeling of hope. We had been told that the extent of the coarctation could not be accurately diagnosed until she was born. Sadly both defects were confirmed. So the next step was to start giving her a drug which keeps the duct open, resembling the circulation in the womb. She would have problems if this duct began to close, so it had to be kept open until a date could be set for surgery. I then tried to get a well-earned rest!

Isolda not alone

The next couple of days were exhausting, both physically and mentally. I was trying to recover from the labour but the maternity ward was full of new mothers with their babies which was soul destroying. I knew I should be resting but I also wanted to be getting to know my baby and vice versa. I was her mother; I wanted to be the one caring for her. The nursing staff were very caring and attentive but rushed off their feet and I didn't want there to be any occasion when Isolda was alone and possibly crying for something she

needed, and she needed love. As a new mother, I also had so much to learn.

Shaved hair

On one occasion when we took a break, we came back to find they'd shaved Isolda's hair and I admit it was unusual for her to have so much hair but she looked drastically different. The doctors had needed to move her drip and since all her other veins were too small they had decided to use one in the side of her head. It obviously looked a lot worse than it was but up until now she had looked like a normal healthy baby. This was now a constant reminder that she was very ill. Having a drip in the side of her head looked very dramatic and was very upsetting for everyone; especially family who didn't know what to expect when they came to visit Isolda for the first time.

Abandoned breast-feeding

I had to abandon my hopes of breastfeeding. Isolda didn't get to grips with it very easily and just became very agitated each time we tried. I felt as if it was causing more harm than good. She had enough going on in her life without this added stress. Nevertheless, it was very disappointing for me as a mother. She eventually had to have a naso-gastric tube inserted anyway because she wasn't taking the bottle very well. She became very tired and breathless

Proud of her

Waiting for the day of the operation was a difficult time, especially since my husband and I were separated to some extent. I could remain a patient as long as I wanted but he had to go home alone each night, which was difficult. We just wanted to be together at a time like this but I also couldn't bear the thought of leaving Isolda at the hospital alone and so this wasn't an option. We were also dealing with the situation in different ways. My husband was trying to look after and worry about both of us, whilst I was also trying to deal with various hormonal changes. My feelings fluctuated between being very down and tearful and actually feeling very positive. As far as I was concerned, I had the most beautiful baby in the world and I was

extremely proud of her! I just kept looking at our beautiful little girl, so tiny and innocent, oblivious to what was ahead of her and so wishing that this wasn't happening to her.

Tests and tests

Watching Isolda suffer the various blood tests they insisted on doing was also very difficult. I felt that some of the doctors did not always approach this in the most sensitive way! There was an occasion when they needed a urine sample and past attempts had been unsuccessful so they decided to insert a syringe into her bladder to take out the urine. This seemed very dramatic to me, I know the tests were obviously necessary but there were times when I felt that enough was enough.

Down to theatre

Isolda was five days old when she eventually had her operation and it's a day I will never forget for the rest of my life. The surgeon had been to visit us the day before and had warned us of some of things that could happen resulting from the surgery such as brain damage and worst case the chance that she may not make it. We went down to theatre with her; she was wearing a tiny surgical gown, which seemed very ironic. We had to wait when we got there and I sat holding her for what seemed like eternity and then eventually the anaesthetist came and took her from my arms. I kissed her and we were allowed to stay whilst they put her to sleep. She drifted off immediately, which I think is the only time in her life I have seen this happen! We were reassured that they would call us as soon as she was back in Intensive Care.

Pain

We just hugged each other and cried. The pain I felt then was just indescribable. I didn't know whether I would see her again. We agreed we had to leave the hospital otherwise we would climb the walls for the next six hours or so. This was the estimated time we had been given for her operation.

We went to the Tate Gallery but there seemed to be babies everywhere,

normal, healthy babies and I just craved to see Isolda like this one day soon. We then went back to the hospital and waited for someone to call us.

Tricky

Eventually at about 7.30pm we received the call. Isolda had been in theatre since around 2.30pm. We were well briefed by the nursing staff and been shown photographs of what to expect but when it's your own little girl lying there with so many tubes in place, it's very hard to absorb everything. I wanted to be brave for my husband and for Isolda but I just completely lost it. However, we were so relieved that she had got through the operation. It had proved a tricky one, apparently her heart had not responded initially after being taken off the heart and lung bypass machine and they were extremely worried about her. My biggest concern now, apart from her getting through the next couple of days, was whether she was feeling any pain. I was reassured that she was being kept well dosed with morphine.

Liberating bath

Appearances aside, Isolda had made it this far and we were immensely proud of her. We spent the next couple of days at her bedside, willing her to recover. She is certainly a real fighter. She regained consciousness the following morning and was making good progress - she was even taken off the ventilator. However she then had a setback with her breathing, and we were told at one point that she had a collapsed lung! In Isolda's case, we now know that this sounded far more dramatic than it really was. Thankfully one of the nurse's translated what the doctor had really meant and basically Isolda had not been ready to come off the ventilator as early as she did. The nursing staff encouraged us to be involved in her care and not to be afraid of all the equipment. Isolda was eventually back up on the ward three days post-op with no machines or tubes! I even got to give her her first bath before she went! Believe me this small task was extremely liberating!

Finally a mother

This was wonderful news for us, Isolda was now on the road to recovery and we could finally begin going forward. We

could now care for her in the way we wanted to. Prior to this we had been too nervous to do too much for fear of interfering with the tubes and machinery! So we had been at the mercy of the nursing staff, who were great but now I felt like I could finally be a mother to my daughter. We even got to take her for a walk around the hospital, which was a real treat! Just little things like this which new parents may take for granted, felt like a huge revelation for us! The main thing of course was that she had got through the operation and subsequent recovery.

About a week later we were finally able to take her home! It was only this long because Isolda then contracted an infection in her belly button, of all things! This was very frustrating as by now we were desperate to get home.

Addicted to machines and monitors

I think the reality of what we had been through finally hit me when we were at home and everything was back to normal. I still felt tearful too often and was a very anxious mother. I didn't realise how addicted I had become to the machines and monitors. It was pretty scary without them at home to see what was going on and no nursing staff on hand 24 hours a day!

We are forever grateful to her surgeon and all the nursing staff for their skills and kindness. They were all fantastic. My heart goes out to all those children and parents who have been through what we've been through and are still going through it, I know that we are one of the lucky ones.

Discovering HeartLine

I hope that sharing our experience helps just one parent somewhere feel that they are not alone. I found great comfort in reading about other people's stories through HeartLine. How people cope is incredible and there are some truly amazing people out there. When you find out about something like this, it's very easy to feel that you are the only one living through it. Discovering HeartLine through our hospital reassured me that congenital heart disease is much more common than I

had first realised.

It is possible that Isolda may need further surgery one day if the coarctation should re-occur. However, for my sanity I just cannot let myself dwell on this. Right now we are concentrating on enjoying Isolda in the present time and are busy worrying about all the usual childhood complaints and concerns, like chicken pox, falling over in the playground and choosing a suitable school. Of course this in the back of our minds all the time but there is so much else going in her life and we have days when we have personality struggles like any other parent with a wilful three-year old!

Isolda is such a happy, loving little girl with a great personality and we are just so grateful to have her with us; the only reminder of her surgery is the little scar on her chest, which is healing well as time goes by. One day soon we shall need to explain her "special" heart to her. We can only emphasise what a unique person she is; after all she has had to fight harder than most to get this far. She will be celebrating her third birthday on Sunday and we are extremely proud of you Isolda Kate!

Terms used:

VSD: Ventricular Septal Defect – a hole between the two ventricles, the heart's two pumps.

Coarctation: a narrowing of the aorta, the main blood vessel taking oxygenated blood from the heart to the body.

Amniocentesis: withdrawing amniotic fluid from the uterus to test for abnormalities. Some abnormalities of the chromosomes and genes can be checked for this way.

Duct: the Ductus Arteriosus which in the baby, before birth, links the pulmonary artery and the aorta.

MEMBERSHIP FORM

We welcome all friends and families with children with heart disorders, and professionals with an interest, into HeartLine Association. You need to return this form to the Office Address to become a member, or update your or your child's details – such as changes of address or your child undergoing treatment.

Your details will be kept on a database used by the Office.

Your details will not be given to anyone without your permission.

Please describe your relationship to the child, e.g. parent, grandparent, etc.

Name..... Partner's Name

Address

.....

Telephone Number Email Address

Heart Child's Name Date of Birth

Name of Heart Condition

If the child has other health problems, please give broad details

If the child has been treated for the Heart Condition, please give the name of the hospital and details

.....

Other children in your family

..... Date of Birth

..... Date of Birth

How did you hear about HeartLine?

- Please pass my details to my local HeartLine Area Contact yes / no
- I would like contact with local families yes / no
- I would like contact with families and children with a similar condition yes / no
- I am willing to support other families yes / no
- Please delete as appropriate

HeartLine does not charge a membership fee but relies heavily on voluntary donations for services to families. We are grateful for any support you can give us.

"I would like to help HeartLine. Please find enclosed donation of"

If you are a tax payer and agree to HeartLine reclaiming the tax please complete and sign the following:

I want HeartLine Association to reclaim tax on:

- The enclosed donation of £.....
- The donation of £..... which I made on (date)
- All donations I make from the date of this declaration until I notify you otherwise.
- (Delete as applicable)

I understand that I must pay an amount of income tax or capital gains at least equal to the tax HeartLine reclaims on my donation in the relevant year.

Signed Dated

*Please return completed form to: HeartLine Association,
Community Link, Surrey Heath House, Knoll Road, Camberley, Surrey GU15 3HH*

HEARTLINE OFFICE SERVICES

The Camberley office is open Monday through Friday, between 10am and 4pm. Messages can be left outside of office hours, and will be dealt with as soon as possible on the following working day.

Tel: 01276 707636 Fax: 01276 707642

E-mail: heartline@easynet.co.uk

Web Site: <http://www.heartline.org.uk>

HeartLine Association, Community Link, Surrey Heath House, Knoll Road, Camberley, Surrey GU15 3HH

Administrator: Pamela Lawrence

Fundraising Officer: Neville Terry

LEAFLETS AVAILABLE

Dental Care for Children with Heart Problems

Feeding for Children with Heart Problems

Respite Care

FOR SALE

Pin Badges	£1.00
HeartLine 20th Birthday T-shirts Age 3-4, Age 7-8	£5.00
Dental Pack	£2.50 per pack (p&p)
New Updated 'Heart Children' Book	£5.00 plus £1.00 (p&p)

BOOKS TO BORROW

Pregnancy Loss • Choosing for Children • Parent's Consent • When a Baby Dies
Operation Fix-It • Rosie Goes Red, Violet Goes Blue

VIDEOS TO BORROW

Children and Heart Disease • Children and Catheterisation
Children in Surgery & Intensive Care • First Sight
Compilation from Children's Hospital, Ablation, Pacemaker, Closing ASD with Device
Living with Warfarin • When Our Baby Died

The Office also has a large number of leaflets about children in hospital, their rights, medicines, pain, feeding, education and information about a number of different kinds of heart defects.

ORDER FORM - please send to HeartLine Association, Community Link, Surrey Heath House, Knoll Road, Camberley, Surrey GU15 3HH

Name

Address

Postcode.....Daytime Tel. No.

Item or descriptionQuantity.....Price.....

I enclose a total payment of £.....plus a donation of £

A contribution towards postage would be much appreciated, and would help us to help more families.

Thank you.

UPDATE

An update on Jack, our cover star, from his mother Karen

Jack Sage

We have been in the HeartLine magazine twice now, but for those who don't know Jack's problems, I'll give a brief description.

Jack was born seven weeks early weighing 2lb 14oz. He spent four months on the scbu at Harrogate, N Yorks. I knew about Jack's heart condition – pulmonary atresia, tricuspid atresia, hypoplastic right ventricle – before he was born. He had a BT shunt at four months old. Jack is 6½ now and continues to make steady progress in most areas.

Colour very poor

In July 2001 he went to see his consultant at Leeds General Infirmary for his check up. Dr Dickinson thought his colour was very poor and we agreed that it was. He wasn't thriving as much as he had been. He was more breathless than normal too.

Dr Dickinson arranged for Jack to have a balloon catheter. He had it done on 2.November 01. At this point it was agreed his pulmonary arteries were big enough for him to have the full Fontan operation.

The good and the bad

We went to see Jack's surgeon in January 02. As usual they have to tell you the good and the bad about the operation. Mr Watterson was telling us more bad points than good, but he said Jack needed this operation to survive, otherwise he would slowly go down hill. Our heads were all over the place.

Waiting

We agreed he should have the operation. The waiting list was 12 months. I couldn't believe how long it was going to be. That 12 months was like a death sentence hanging over us.

A date came through: early February 03 for Jack to go in on 11 February, to have his Fontan done on 12 February. We rang the hospital on the morning he was due to go in to check there was a bed available. Sadly there were no beds free in picu as they had four emergencies over the weekend.

We were a bit frustrated as it takes a while to arrange every thing. On the other hand I was grateful it wasn't Jack who had been rushed in! I felt so sorry for the parents of the children who were urgently admitted. I couldn't imagine what they were feeling.

Be there today

We were told it would probably be at least two weeks before he went in. So I'm on tenterhooks waiting for the phone to ring when we got a phone call from Mr Watterson's secretary on 24 February saying

they had a cancellation and could fit Jack in. We had to be there after lunch that day and he would have his operation the following day.

All systems go. I was slowly starting to panic as I had like a thousand phone calls to make. We got there and they did all the usual things. Jack was prodded by lots of different doctors. He gets very scared, especially when doctors come up to him in scrubs.

8.30 – 4.30

Jack was the only patient on the list that day as it was a long operation. We took him down about 8.30am. We went into the anaesthetic room with him and they put him to sleep. This is always an upsetting time especially when he is always fighting it.

Jack came out of theatre at 4.10pm, and we went to see him about an hour later. We had to wait that long because it took a while to get him settled on picu.

Went fairly well

The surgeon, Mr Watterson came to see us. He said the operation went fairly well. He couldn't do the full Fontan because they had to do a lot of work on his pulmonary arteries and that it wasn't in Jack's interests to be on bypass any longer. Jack had a bi-directional Glenn shunt done.

Jack made good progress and came home after a week in hospital. I didn't notice that big a change in Jack. His lips were not as blue but still had a tinge of blue. His fingers and toes were a bit pinker too.

Head start

Jack had six weeks off school to recover. He was glad to get back to school and see his friends. I've noticed recently that Jack seems to have a bit more energy. He proved that when he did his sports day. He won two out three races. He was given a head start to stand any chance. Last year he couldn't do sports day because he had no energy.

Jack has a Major Buggy to get him around. He is OK plodding around home or his classroom as he can sit down when tired. He can't walk the distance to school or into town.

Eating? No

Jack still has his gastrostomy and is fed all the time through it. He won't eat anything at home. He might nibble a quaver or have an odd spoon of yoghurt. At school they try him with cooked dinners and he will put bits in his mouth. Everyone keeps telling me that he will eat one day, school, dietician and speech therapist. I know that he won't. I know Jack better than any



health professional. They don't agree with me and I sometimes feel that they are not listening to what I'm telling them. Jack has been tube fed from the day he was born.

Jack is a very happy, sociable little boy. He has a bit of support to help him with PE, and some of his work and is doing very well at school.

Terms used:

Scbu: Special Care Baby Unit

Pulmonary Atresia: the main pulmonary artery is blocked or missing
Tricuspid Atresia: the tricuspid valve is blocked or missing

Hypoplastic right ventricle: the ventricle is small and doesn't pump properly

BT shunt: taking blood from an arm artery into the pulmonary artery to increase blood to the lungs

balloon catheter: a fine tube with a collapsed small balloon on the end is threaded into a vein and into a part of the heart which is narrow. The balloon is inflated and withdrawn to widen a narrow artery or narrow valve.

Fontan: change the circulation in the heart so that the left side takes on the pumping work of the right side, and blood moves back to the heart without going through the right ventricle.

Picu: Paediatric Intensive Care Unit

Pulmonary arteries: the arteries that take deoxygenated blood from the heart to the lungs

Bi-directional Glenn shunt: some of the blood returning to the heart is linked directly into the pulmonary arteries leading to the left and right lungs.

Gastrostomy: Jack is fed directly into his stomach.

Tube fed: as a baby Jack was fed through a nasogastric tube which was threaded through his nose and into his stomach.

Heart Children Translation

In our increasingly multi-cultural society, there is an urgent need for our handbook *Heart Children* to be translated into thirteen languages spoken in the UK. This is a new and ground-breaking project. The transcripts will be hosted on a new HeartLine website. The website address will be www.heartlinetranslations.co.uk. The first language to be published onto the internet will be Arabic. This is planned for October. The Royal Embassy of Saudi Arabia has generously donated the money to pay for the website and the Arabic translation. We are extremely grateful for their tremendous financial support.

Heart Children is an acknowledged guide for parents who need to understand their child's heart disorder. The handbook covers a comprehensive range of topics. This includes education, and social service provision in the UK. It is written and illustrated to make this complex subject a little less daunting.

The handbook was first published in 1989, and updated in 2002. It has helped to inform thousands of parents in the UK and overseas. However, it is only available in English. We have been asked by clinicians if we would consider a translation project. To evaluate the need for such an undertaking, we sent a questionnaire to 17 children's cardiac centres. 75% of the centres responded. The information they provided enabled us to formulate a list of priority languages: Arabic, Hindi, Urdu, Bengali, Gujarati, Punjabi, Somali, Cantonese, Italian, Spanish, Portuguese, Turkish and Albanian. This will include the full text and diagram notation.

The translations will be a valuable asset to cardiologists and cardiac nurses, and to general practitioners and community nurses, who are responsible for communicating this complex subject to parents from minority groups. This will be of tremendous benefit to parents who do not speak English, and to parents who speak English as a second language.



HeartLine Trustees: From left to right: Chair Anya, Treasurer Sharon, Clinical Liaison Adelaide, Vice-Chair Clare, Director of Operations Anita



Christmas Draw 2002

Thanks to your combined efforts, the draw has raised £4,042.50. The money will help us to maintain and develop our main core activities in 2003. Therefore, we sincerely hope you will all benefit in some way. The prizes have been donated by many leading companies who have chosen to support HeartLine's valuable work. Without their patronage, we would have been unable to hold the draw. Therefore, we would like to extend our sincere thanks to all of them. The names of the winners and sponsors are detailed in the table below.

20893 Nicola Goldthorpe	Combi DVD/VCR Unit	Toshiba (UK) Ltd.
20822 Ann Gold	Playstation 2 Games Console	SEEBOARD Energy
26351 Richella Stowell	Digimax Digital Camera	Samsung Electronics Research Inst.
29370 Tom Ayerst	Hand-held Colour TV	Casio Electronics Company Ltd.
28873 Stacie Hopley	Inkjet Colour Printer	Lexmark International Ltd.
19484 Tracey George	Champagne & Chocolates	Fortnum & Mason Plc.
23644 Aaron Sisson	Calculator	Canon (UK) Ltd.
2444 Sharon Brooks	Calculator	Canon (UK) Ltd.
24547 Sue Rose	Calculator	Canon (UK) Ltd.
26024 Toni Vince	Sandwich Toaster	Sanyo Europe Ltd.

Gentle Adventures Sailing Days

Have you ever thought about sailing a yacht on the Solent?

HeartLine has received sponsorship to send heart children and their families sailing for the day! The sailing is to take place during this summer with Gentle Adventures, with whom HeartLine members have sailed before, on numerous occasions. You may even have read about some of these sailing days in previous issues of this magazine.

Well now it's your chance to go.

Please note:

- You will need to be able to get yourselves to Lymington, in Hampshire, from where the yacht sails. Sailing is usually from about 10 a.m. to 4 p.m. and lunch will be provided.
- All children who intend to sail should be at least 8 years old.

If you are interested please send your name, heart child's name, address and telephone number, together with note of the number of 'sailors' in your family, to Helen Baker, HeartLine Association, Community Link, Surrey Heath House, Knoll Road, Camberley, Surrey. GU15 3HH. We have only a limited number of sailing days available and so the first members to respond will be allocated these sailings. Please mark the outside of the envelope "Sailing Day".

My Sailing Adventure

"I thought the trip was superb!" writes Nathan Lobo, who sent the following account:

I was invited to go on a sailing adventure along with my mummy and daddy by HeartLine.

It was Saturday 5th July and I woke up to a nice day. We went by car to Lymington, and



then to Yacht Haven where all the boats are in the harbour. The yacht we were going to sail on was called Patricia of Arne. The people who organized this trip were called Gillian and Jon. They gave us a safety talk, we put on our safety life jackets. We then had a drink and a cookie before we left.

We set off for the Beaulieu river. I took the tiller and steered the boat away from the bay. Afterwards I went into the cabin and navigated with the help of Gillian. We went past lots of buoys. Daddy and I put the sails up with the help of Jon when we were going up the river which was great fun. At Bucklers Hard we had our lunch which was prepared by Gillian and we had sandwiches, bagels, some salad, vegetables and strawberries for dessert.

When we were coming back I drew some pictures for Gillian and Jon in appreciation of their kindness to us. When we were back at Yacht Haven Gillian took a photo of us on the deck. We got out of the boat, said thank you and bye-bye. I really enjoyed my sailing adventure. I would like to thank HeartLine for giving me and my family this lovely trip. I hope you will invite me again.

Love from Nathan
Aged 8yrs



There is a new web site available for parents of children with congenital heart disease. It has been developed by DIPEX (an Oxford based charity) in conjunction with the British Heart Foundation. The web site combines parents' video, audio and written accounts about their experiences of their child's heart defect with Resources, Q&A and Information sections.

Parents explain what it was like discovering during pregnancy or after birth that their baby has a heart defect. They talk about their experiences of giving medication and feeding their newborn baby, what support they found useful and where they found information about congenital heart disease. They describe what their child's operation was like and their recovery. They talk about their child's quality of life and development during the first five years of life, including how they got on at nursery and school.

They explain the impact on their daily life, the effect on relationships and siblings, financial issues and employers and work. There is also a section on the death of a child that provides support for bereaved parents.

The web site was funded by the British Heart Foundation and supported by the Children's Heart Federation, Great Ormond Street and Southampton Hospitals.

You can view the web site at www.dipex.org

For further information contact Dr Carol Dumelow, DIPEX Research Group, Department of Primary Health Care, University of Oxford, Old Road Campus, Headington, Oxford, OX3 7LF
Tel: 01865 226670
Email: carol.dumelow@dphpc.ox.ac.uk

Review of Children's Heart Services

(Paediatric and Congenital Cardiac Services Review Project)

Children died as a result of poor services during the 1980s. It has taken a very long time and a lot of hard work to bring about the standards that can safeguard our children now and in the future.

These standards have been agreed by a review which took on board the concerns of surgeons, cardiologists and families from all the paediatric cardiac units.

Now that we have agreed what the standards are, the people responsible for buying the services are looking at how the hospitals in their area are putting them into practice. Because paediatric cardiology is a clinical subspecialty, buying services is called regional specialist commissioning.

Children's Heart Federation have made sure that there is a parent who is a representative on each of the four regional groups, as well as a CHF representative:

North (Alder Hey, Manchester, Leeds, Freeman),

Midlands (Birmingham, Glenfield),

South (Bristol, Southampton, John Radcliff)

London (Brompton, GOSH, Guys)

Some of the standards should make sure that the heart hospital will be responsible for the local clinical network - local hospitals, GPs, Health Visitors etc - which means that children get proper care outside of the heart hospital as well.

If you would like to talk to someone in your area, please get in touch with CHF by calling 0808 808 5000 or emailing chf@dircon.co.uk

Cause of Marfan Syndrome

In the Winter edition of HeartLine Magazine, we listed a number of syndromes, and said that the causes of many of these are not identified. The Marfan Association UK wrote to say that the cause of Marfan Syndrome is known: it is a mutation in the gene fibrillin-1 on chromosome 15. In 75% of cases it is an inherited disorder, in 25% occurring as a result of a spontaneous (new) mutation.

Conference: Life after Operations Saturday 21 September

Once the major treatment is over, what quality of life will heart children have? And what can support groups do for parents?

You will be able to tackle these questions if you are able to attend the Children's Heart Federation Annual Conference to be held in Bristol this year.

The extended lunch period will be an opportunity for an information exchange – a chance to visit the displays and talk to families you haven't met before. Ideas generated for projects outside the health system will be recorded and contribute to the afternoon session.

Late bookings: email – chf@dircon.co.uk, or telephone – 0 808 808 5000.

Terms used:

Standards: these are set out in the Department of Health consultation report.

Heart hospitals: paediatric cardiac units in England

Commissioning: buying services. For example the Primary Care Trusts which are locally based ensure that hospitals provide the services people living in their area need, so they need to make sure that those are good quality. Over 70% of hospital NHS budget comes from the PCT.

Regional groups: the review proposes that the paediatric cardiac units in each region work together, and each should have a defined catchment area.



"Dominic was three when he coloured a picture of himself with blue lips, blue hands, blue feet. Then after heart surgery, his image changed completely, and there was the pink Dominic!"

HeartLine member Fran Davies wrote the story of Rosie and Violet for her three young sons. All children love hearing about children like them, and children with heart disease are no different. But they often have a distinct disadvantage in that they see few positive images of other children who are 'cyanosed' – the medical term for the lack of oxygen in the blood stream that causes blue

lips, fingers, and toes.

With the help of simple illustrations, the story of Rosie and Violet has now been published by the Children's Heart Federation. It is suitable for children from toddlers to six or seven and is within the reach of all families with a child who is blue.

Single copies can be ordered from 0808 808 5000. You can download the story book from www.childrens-heart-fed.org.uk – you will need Acrobat Reader – and copyright is waived for those of you who would like to print it out.



Tom needs an operation on his heart. Among his other worries are who will look after his guinea pig while he is away? Will Mum ever stop asking him how he feels? How long can he stay awake after he starts counting? And what about football?

This colourful, lively booklet is published by British Heart Foundation. Operation Fix-it follows the actual experience of being in hospital for a heart operation and some of

the emotional issues as seen through the eyes of eight-year-old Tom.

Children from about seven up can be prepared in an interesting and humorous way for their hospital stay – Dean, a 13 year old HeartLine member, says:

"I found this book easy to read, funny and a good story as Tom gets better. Operation Fix-it is a good name for the book as it explains what would happen quite well."

You can order this book from 01604 640016 and ask for M82 Operation Fix-it.



DANIEL'S SYNDROME?

In the Spring magazine Lisa Huddleston wrote

'I was relieved to have finally got a name for the issues that Daniel has, as it has given me the foresight for what the future holds'

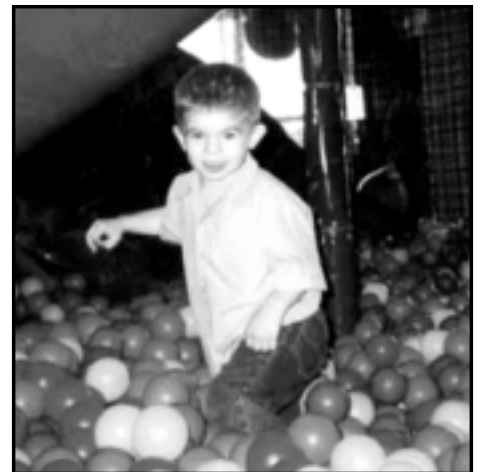
Since writing earlier this year about Daniel's diagnosis of de Lange Syndrome we have been told that the diagnosis was in fact incorrect.

Some doubt was raised into Daniel's diagnosis by the de Lange Foundation's scientific advisor (and geneticist). I called Daniel's geneticist (Dr Yates) at Addenbrookes in Cambridge and we discussed the issues that had been raised. Dr Yates agreed to refer Daniel to the clinical genetics department at Great

Ormond Street to Professor Winter for a second opinion.

In April this year we had our genetics appointment and Professor Winter explained that although Daniel had some of the facial features of de Lange syndrome, like a small jaw, very low hairline, and synophresis (eyebrows that meet over the bridge of his nose), he did not have the characteristic hand, feet, and limb abnormalities. The diagnosis of de Lange was discounted and we are back to square one regards the answer to Daniel's little quirks.

However, Professor Winter said he wanted to test for chromosome abnormalities and to test some blood for telomere (ends of chromosomes) analysis to check for any deletion, translocation, etc. He also said that they would do a micro array analysis (a research tool that can detect extremely



Daniel has a ball!

small deletions and abnormalities).

At the moment we are playing the waiting game to see if any of the tests show anything. It is going to be a good few months before we know the results.

YOUNG PEOPLE AND REHABILITATION

*Part of a research report for young people
by Lynne Kendall of the Yorkshire Heart
Centre*

The researcher wanted to find out what young people thought about 'rehabilitation' services. This was a difficult idea for young people to understand so the researcher used booklets, pictures and verbal description of each of three scenarios used as examples. A fourth scenario, using the Internet/website as a means of communication, was added from interview 8, because young people in earlier interviews had suggested it.

The following rehabilitation scenarios were presented to young people:

Cardiac rehabilitation has been shown to help adults with heart problems.

It has three main parts:

1. Information – learning more about your problem and how to deal with it. Learn how to look after your heart and about medical treatments and pills.
2. Exercise – an exercise plan to get you stronger so that you have less symptoms when you are running or playing. This can help people to live a more normal life. It may protect them from other problems.
3. Other help – to deal with any stress or worries like bullying or problems with friendships. To help the person feel OK about themselves.

They were asked: Do you think that it would be good to have something like this yourself?

The following three ways of doing it were suggested:

- A. **At home:** by working through a plan using workbooks, probably with tapes and videos. Younger children would do it with their parents help. There would be a section to complete each week. Older children would work through it themselves. For both there would be phone support from a worker at the cardiac centre. She would ring you up for a chat now and again for a couple of months to see how you were getting on. The book would have information, a simple exercise plan and advice on

common problems.

- B. **Locally:** a team from the nearest cardiac centre would visit a local hospital or sport centre one day a week. You would come once a week for 2–3 months. You would be there for a couple of hours each time with a group of other people your age and have a talk. Then there would be some exercise and then maybe talk about ways of coping with common problems. Some centres would charge for using their services.
- C. **Through a key worker:** Each family would have a 'key worker' who would try to find out what help you need. They would arrange help locally. For example, they might find out about local exercise facilities you could go to. If you were having problems at school they could try and find a local worker who could help, or they might speak to the school for you if you wanted them to.

The young people were asked:

- What do you think of each of these ideas?
- Can you think of a better way?
- What would you not like to use?

Their views are summarised below.

- A. Home based option. Eleven liked the idea of having 'information' to use at home. A variety of formats appealed, including audiotapes, booklets and videos ideally showing young people with a heart condition explaining their experiences, as well as more 'medical' information. Only three thought they would use written information on its own, most preferred diagrams or pictures combined with videos, tapes or verbal explanation. Two thought a home visit post-operatively, by a health professional, would help the young person regain 'normal' activity levels. One would not want any information for herself, but thought it may be useful for parents; another would not want anything which made him feel different, or that 'there was something wrong', with people 'watching him all the time'.
- B. Group option. Eight thought it might help to meet other young people with a

heart condition, for example to increase confidence to do sports as 'others might need to rest as well'; and to meet other families and talk to people with the same condition. Four would not want to meet as a group, three because they did not like the idea of meeting 'strangers', and one because it would make her feel different. One ten year old suggested that she could talk to others waiting for heart operations as she felt she could offer reassurance, having had two operations herself.

- C. Key worker. Only three of the older respondents would use a 'key worker' or contact person, two of them would prefer to know the person offering them help. One other ten year old, suggested that someone could talk to them on the telephone, but not visit them at home.
- D. Website. Six young people thought using a special website was a good idea. Suggestions included: using the website to find out more about their condition; include information from young people's experiences of congenital heart disease as well as the 'medical' information; have separate sites for parents; brothers, sisters and friends could use the site to help them understand more. A 15 year old summarised her view:

"You do need to ask questions to find things out. Because doctors understand it, they might think automatically that you do as well, so people do need to ask questions so they do understand it, and I think the website would be a very good idea, because then, if there was a lot of information readily available, then they could just check up on it any time they wanted, and they could do it without maybe feeling intimidated by all the doctors and professional people around".

One 14 year old pointed out a possible disadvantage in using personal experiences posted on a website, he thought some young people may think their condition was more severe, if they were unable to do the same things that others described. He also said that it would be important to make sure others did not use a 'chat room', for example "to have a laugh at us".