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My name is Helen Stratton.

Training

1. I qualified as a registered nurse in 1982. I worked in England for a year and then went to Australia from 1983-5 where I worked in intensive care. When I returned, I worked at Frenchay Hospital in Bristol in a neurological intensive care, and then in the accident and emergency department at Frenchay. I studied for the ENB course in intensive care at the Bristol Royal Infirmary (the BRI) in 1986-7. When I finished this course I began work at the BRI in the accident and emergency department.

2. In October or November 1988, I was appointed as the first regional transplant co-ordinator for the South West based at the renal unit at Southmead Hospital in Bristol. This was a new post and I had to co-ordinate the provision of transplant services across the region. I stayed in this post for two years, and then reached a point where I wanted to move on. I had worked with distressed and bereaved relatives, and I wanted to develop my career in another area. I wanted to work for a charity and use my nursing skills, and I could see that one option open to me could be a co-ordinating or fundraising role for a health related charity. I was planning to undertake a direct marketing diploma in order to help in my development. When I saw the advert for the new cardiac liaison post at the BRI, I thought this was a good opportunity to use my clinical background and to gain an insight into working for a charity.

Cardiac liaison appointment

3. In October 1990 I was appointed as the first cardiac liaison nurse at the BRI. I was not employed by the BRI. The post was funded by the Bristol and South West Heart Circle. This was a charity set up by Jean Pratten some time in the 1960's after her daughter had undergone cardiac surgery at the BRI, and she had been aware that there was no support for the families. My understanding was that Jean had spoken to Julia Thomas the senior cardiac sister at that time with a view

to the Trust taking on the funding of the post after 3 years. I began work in November 1990 on a three-year contract.

4. There was no requirement for the post holder to be a Registered sick children's nurse. The advert did not require that the postholder had to be a nurse, although a nursing background would be advantageous. I believe that some of the applicants for the post were not nurses. There was no requirement that the person have a counselling or a bereavement qualification. I think the fact that I had worked with bereaved families as a transplant co-ordinator was seen as a positive attribute.

5. At the time of my appointment there was only one other cardiac liaison nurse in the country and she worked at Great Ormond Street (GOS).

6. I have not kept a copy of my job description but my job description was, as with any new role rather broad and included working with the Heart Circle in fundraising activities and attending meetings in the regions which covered the south west. The role required flexible hours.

7. My understanding of the role was to bring together the BCH paediatric/cardiac activities with those of the BRI. The aim was to ensure the smooth transition for parents and children from the BCH to the BRI. This would include corresponding with the child's health visitor and/or GP. I also had to ensure that parents had accommodation and had practical information on the child's admission to the BRI and their forthcoming stay. This would include advice on transport and the envisaged length of stay. This was important where for example the parents had other children. I would work in a very practical way with the parents, some of whom were coming from Cornwall and who had lots of arrangements to make. My understanding was that I was there to support the parents so that when the child was in surgery or in intensive care the liaison nurse could spend time explaining for example why the child was on a ventilator and what the lines were for, and the reason for sedation. The nurses caring for the child often did not have the time to spend with the parents and explain at length what was happening.

8. Before I had been appointed I think Jean Pratten would pick up on most of these activities through the regional co-ordinator for the Heart Circle and it was becoming more complex, particularly as Jean was not based at the BRI. I think the Heart Circle had seen the importance of having someone based at the BRI who could carry out this work.

Year 1

9. At the time of my appointment, I was aware that there was a paediatric counsellor called Helen Vagoda who was employed at the BCH. I believed she had relevant counselling qualifications to counsel people, and in particular parents. She was not a nurse. At my interview I was informed about her position at the BCH but there was no discussion about how our respective roles were linked. Jean Pratten was very supportive to me when I began but as it was a new role, I decided to meet Mary Goodwin who was doing a similar role at GOS. Through her I met Adelaide Tunstill who was the senior paediatric/cardiac manager. I also met a lot of the staff at GOS and got an idea of Mary's job and its relation to the Cardiac Unit. Mary was employed by GOS. I was very struck by the multi disciplinary approach to care. She worked closely with the social work dept, the cardiologists, the nurses and surgeons. It was very much a team approach. Following these meetings, I think the key thing that came across for me was that I should meet the parents at the earliest possible stage, either when they were meeting the cardiologist at the BCH, or when they saw the surgeon at the BCH.

10. I came back to BRI and I discussed the idea of being present at the first meeting with the parents with Jean. She thought that was a good idea. I think I then asked the outpatient sister if it would be all right for me to attend. She said she did not see that it would be a problem. I also discussed this with Helen Vagoda and she did express some concern as she felt that this was quite a large part of her role. I was quite surprised at this, as I thought there were some clinical aspects which could arise from the meeting that she would not be in a position to explain. For example, if the cardiologist or surgeon had used language or referred to procedures that the parents did not understand, then I felt I would be in a better position to explain this to them. I then went up to the BCH one afternoon and

Helen Vagoda asked me what I was doing there. I had discovered that she was not happy about my appointment as she felt that care of the parents on both sites had been part of her role. It was a rather tense atmosphere and rather than stay and discuss this with her in outpatients, I decided to discuss this again with Jean. She suggested that I speak with Julia Thomas and Mr Wisheart. I talked this over with Julia who said that she would speak to Mr Wisheart. A few weeks went past and I went back to Julia who said that Dr Joffey the cardiologist at BCH had spoken to Mr Wisheart about Helen Vagoda's concerns. It was suggested that we have a meeting at the BCH to discuss the way forward.

11. I went to the meeting with Julia and Mr Wisheart and Helen Vagoda came with Dr Joffey. The meeting lasted about 45 minutes and was held in one of front meeting rooms on the ground floor which overlooked St Michael's Hill. Mr Wisheart chaired the meeting. I put forward my understanding of my role and the outcome of my visit to GOS and how I thought it would be beneficial for both of us to work on this as my perception was that my role was very different from her role. I do not recall that there was any support from either Julia or Mr W and I think that they felt that if Helen Vagoda was unhappy with me going to the outpatients then I should not go there. Otherwise they did not feel that any change was needed. She had been going to some of the outpatient meetings but this was not on a regular basis. They agreed that things should stay as they were and that I should meet on a weekly basis with Helen Vagoda to discuss the parents and children who were coming to BRI for heart surgery in the future. As a result of this, I was not involved with the discussions between parents and surgeons regarding the risks associated with the surgery. I tended to learn of the children's admission when the operating list for the month was published.

12. It was at that stage that I was extremely disappointed in the lack of support that I appeared to be getting and the contrast that this had with GOS. The team work approach which existed at GOS didn't exist within cardiac services in Bristol. This was in contrast to the team approach I had experienced in accident and emergency at the BRI. There also seemed to be a team approach in the intensive care unit at the BCH. When I had been a transplant co-ordinator it was a new role and it was not a nursing role so it was in some ways similar to this role. There

was a strong multi disciplinary approach to the care of the renal patient from the nurses to the transplant surgeons and nephrologists. It would not be unusual for all the disciplines involved (junior doctors, nurses, physios and dieticians) to meet weekly to discuss patients. I assumed this was normal practice.

13. My concerns also at this stage were that Helen Vagoda felt threatened by my role and I am unclear as to whether this new role had been discussed with her prior to my appointment. At my interview I was told that there was a paediatric counsellor at the BCH and I did not know that she was specifically a cardiac children's counsellor until after I was appointed and went to the BCH to meet the cardiac nursing staff. I met Helen Vagoda and had thought that she covered the whole of the BCH. It was only then that I discovered that she only covered the cardiac children and parents. She seemed quite defensive and questioned me about what exactly I would be doing. In retrospect she may have felt threatened by my appointment, and both she and I were somewhat confused by our respective roles and where the boundaries of these lay.

14. After the disappointing meeting with Mr Wisheart, Dr Joffey, Helen Vagoda and Julia Thomas, I thought about other ways that I could create strong links between the Heart Circle and the BRI. I set up a strong link with the social work department at the BRI which was mirroring the set up at GOS. I met with Sarah Appleton the social worker who was assigned to the cardiac unit and discussed my role. We worked well together. She told me that she was assigned a couple of hours a week to look after social issues on the unit but as she also covered the whole of the geriatric and medical unit there were enormous demands on her time. We decided to meet once a week to discuss parents/children who were either on the unit or who were likely to come in. I would provide information from the Heart Circle representative or the health visitor who had raised issues over benefits or where for example, the child had been fostered. There were often children who, for a variety of social reasons I needed to contact her about. She had a Samaritan fund and she would give some money to the parents and we co-ordinated this with money from the Heart Circle. This link worked extremely well and she developed a rapport with the social worker at the BCH which enhanced

the service we could deliver. I had an excellent working relationship with Sarah and I believe that this was highly beneficial to parents and adult patients alike.

15. During my first year I continued to go to GOS to establish links with Mary Goodwin and to look at what improvements I could bring to BRI. During my visits to GOS I met with a number of paediatric cardiac nurses of all levels and we decided that it would be beneficial to set up a forum for paediatric cardiac nurses to come together to share ideas and information. It was envisaged that nurses from all over the UK in this speciality would want to join. We had nurses from Birmingham, Liverpool, Ireland, the Brompton, Newcastle, etc. I saw this as an ideal opportunity for the nurses at both the BCH and the BRI to exchange experiences and ideas. The group was called the Paediatric Cardiac Nurses Association. I became the secretary and wrote the monthly newsletter. We also managed to get a nursing session tagged onto the paediatric/cardiology conference held annually at the Brompton. I took part in getting an agenda together and got Freda Gardner to speak about her research. Martin Elliot a consultant paediatric cardiac surgeon came along to talk. I encouraged nurses at both the BRI and the BCH to join so that they could make a contribution and learn from other centres. One sister from the BRI joined and I think that 3-4 of the staff nurses joined from BRI. The nurses at the BCH thought this was a brilliant idea but most of them already belonged to paediatric associations and as they were not solely cardiac paediatric nurses they did not feel it was a priority.

16. Another initiative that I brought back from GOS was the idea of parents going to theatre with the child if they wanted. Before I arrived I think they could go down as far as the door of the theatre but it was quite rare that this happened. I wanted the parents to have the choice of coming into the anaesthetic room with their child. I wanted to do this with the co-operation of the anaesthetists and the theatre nurses and I discussed it with them. There was some concern that there was the potential risk that some parents may be so distressed that it would be disruptive and dangerous. The decision we came to was that if we felt that it would be inappropriate for the parents to come to the anaesthetic room I would discuss this with the parents after talking to the anaesthetists and the theatre nurse. From then

on I always offered this as a choice to the parents who could carry their baby down if they wished.

17. Another idea I implemented was that the older children could paint their theatre gown prior to the operation and get the surgeon, anaesthetist and nurses to sign this for them to take it home. The concerns were that these were hospital gowns that could not be re-used and who would pay for them. The nursery nurses were in favour of this initiative, particularly a nurse called Helen who had been funded by the Heart Circle to go on a play specialist course. On her return she was employed by the Heart Circle as a play specialist at the BRI. The BRI employed another nursery nurse in her place. This idea of the children painting their gowns was taken up and proved very successful. The children thought it was great, and Helen used this as a form of art therapy to encourage the children to express their feelings and thoughts about their operation. For example she would ask them to draw what they thought their heart would look like after surgery and use this to discuss anxieties about the surgery.

18. I had come across a book at GOS called "Heart Children" which was A5 size and which had concise and easy to understand explanations of the commonest cardiac conditions with diagrams. It was written for parents and was very good. I asked Jean if the Heart Circle would buy a batch. They were not cheap so I had a master copy to show to the parents and if they wanted to buy a copy I would sell them one and give the money back to the Heart Circle.

19. I sent all the regional representatives of the Heart Circle and health visitors that I had come into contact with a copy of the book at no charge. The master copy was always available to parents in my room.

20. I discussed with Jean and some of the senior nurses the idea of taking a hand or footprint of the baby or a lock of hair from a baby that had died. The parents could take this away or I would send this to them when they were ready to receive it. Sometimes they would ask for this six months later. The Heart Circle bought a Polaroid camera and I would take a photo of the baby in a Moses basket which

again the parents could take away or ask for later. Appropriate cards were purchased by the Heart Circle to place the hair or photo or print in.

21. Where a child died, I would notify the Health Visitor and would tell them how the parents had reacted and their plans for returning home. This then allowed the Health Visitor to go and see them. I would tell the Health Visitor as much as I was able to so that the Health Visitor could meet the parents and already have an idea of what had happened while the parents and the baby were at the BRI. I could say for example that Mr Wisheart had told the parents that the baby's heart had been unable to beat independently after they had taken the baby off the bypass machine. Mr Wisheart and Mr Dhasmana used to offer parents the opportunity to come back at a later date to discuss the child's death with them. This was information that I passed on to the Health Visitor so she could use this as a discussion point with the parents. Parents often chose to see Mr Wisheart or Mr Dhasmana at the BCH rather than the BRI, so I was not involved with these discussions. There may have been two occasions where the parents saw Mr Wisheart at * the BRI and I sat in on those. I cannot remember who the parents were or any details about * the meeting.

22. At the beginning of every month I would get a theatre list with all the adult and children's names on it along with the referring GP. I would write to the parents and introduce myself and say that they may have met Helen Vagoda at the BCH and that my role was to provide support and care while they were at the BRI, in conjunction with Helen Vagoda. I would tell them that I was employed by the Heart Circle. I also rang the Health Visitor to notify her of the admission and to let her have my number. Sometimes the Health Visitor would inform me of any social aspects of the family that I would relay to Sarah Appleton the social worker. Along with these activities based at the BRI, I was working with Jean Pratten on organising various fundraising activities for the Heart Circle. I visited Heart Circle groups in the south west which included visiting Health Visitors in Cornwall and Shepton Mallet.

Year 2

23. At the start of the second year I was still very enthusiastic about my work as a cardiac liaison nurse, and I felt I was making a difference. I wrote and published an information pack for parents which outlined the process for admission to the BRI for surgery. Details included how may days before the surgery the child would be admitted and what would take place during the pre surgery preparation. The parents were offered the chance to look in the intensive care unit prior to the child going to theatre. The information also gave details of accommodation facilities and useful telephone numbers which included mine, Helen Vagoda's and others at the BCH and the Heart Circle that they could contact if they were concerned. Information about Sarah the social worker was also provided. At the same time, I produced a leaflet for adult patients who were going to undergo cardiac surgery which outlined admission details and addressed a number of common concerns. The idea was that we would make a library of these documents regarding cardiac services, all funded by the Heart Circle.

24. At the same time I felt that parents whose child had died were often overloaded with information at the time of the child's death. There was no information that they could take away for reference. I produced a small leaflet which gave the parents the name of Diane, the patient affairs officer at the BRI. She dealt with the coroner and the mortuary and helped parents and their relatives organise the death certificate. The leaflet also had my number and Helen Vagoda's number together with other relevant and useful information that they may need following the death of their child. I worked closely with Diane to develop a number of initiatives to make the situation more paediatric orientated at this difficult time. One initiative was the funding by the Heart Circle of a Moses basket and a small mortuary box for carrying the baby. Diane was always extremely kind and sensitive to parents and adult relatives often going out of her way to help parents who often lived some distance away.

25. The Heart Circle also brought equipment. They brought most of the toys for the nursery and furnished all the accommodation for the parents (beds, duvets, curtains etc). The Heart Circle rented unused hospital houses and furnished them with Heart Circle money. Medical equipment funded by the Heart Circle included

syringe pumps, or specific pieces of equipment requested by the nursing or medical staff.

26. I did not have an office when I started my job, and the BRI gave me a linen cupboard which the Heart Circle painted and furnished with a desk and some comfortable chairs for parents to use. The Heart Circle also furnished two small rooms near the unit with bed settees for parents whose child was immediately post operative. The parents could stay there for a couple of days before vacating them for other parents. Sometimes this could be stressful, as the parents did not want to move outside the hospital to the other heart circle accommodation. The Heart Circle also furnished a small room near the intensive care unit for parents and relatives to sit in. A small kitchen area was developed and financed by the Heart Circle in the adult dining room for parents to make coffee or prepare snack meals.

27. I had also started to arrange support meetings for the theatre and intensive care nurses at the BRI giving them an opportunity to talk about how difficult and upsetting it was for them to look after a child that had died. Sarah the social worker came to facilitate the meetings and the chaplain sometimes came along as well. The theatre nurses could not always come along that easily during a shift. The main group of nurses who came were the more junior nurses from intensive care. We held these support meetings once a week. The feedback that I had was that the meetings were very helpful and allowed them to offload before going home.

28. About half way through the second year I began feeling concerned about the time the children spent in theatre and also the time that they spent in the intensive care unit. These concerns arose following discussions with the nurses at GOS and to other nurses in the PCNA. They began to express some surprise when I told them that some children had been in intensive care for two weeks. I also found I was spending an increasing amount of time dealing with bereaved parents and I asked Mary Goodwin how she coped with dealing with bereaved parents on such a regular basis and in particular working late into the evening. I told Mary that I would start a shift at 7.30am going down to the theatre with the parents and often be there until as late at 11pm waiting for the child to come back from theatre. She

was surprised at this length of time for the surgery and she also questioned me as to whether I should be working those sorts of hours.

29. About the same time, Susie Hutchinson began as the cardiac liaison nurse at Birmingham Children's Hospital and she made contact with me. She visited the unit about 6-8 months into her job and I discussed my typical day and week to her and took her round the intensive care unit. Neither she nor Mary went with the parents to surgery on a regular basis and did not consider it their role to be there when the child returned. Both of them told me that children with similar operations in their units would be back at lunchtime or early afternoon in their hospitals. Susie also expressed surprise at the length of time that a child was in intensive care when I explained that some of the children were there for a number of weeks. Both Susie and Mary could call on a strong multi disciplinary team for support. This included a dedicated accommodation officer, social worker and psychiatric support if necessary.

30. Following on from these meetings I had already become friends with Steven Bolsin who lived near me in Bristol and I had met Steve on the unit. I talked to Steve about my concerns to see if he had a view on it. It was then that I discovered that he had quite serious concerns about the surgery and that he had taken steps to meet with people to discuss this with them. He told me that he had expressed his concerns to John Roylance and to Mr Wisheart and to Dr Chris Monk who was the head of his department. He told me that he was continuing to try to raise the issue through the appropriate channels.

31. For my part I expressed my concerns to Fiona Thomas (Julia Thomas had gone on maternity leave) and to Leslie Salmon who was the cardiac business manager. As they shared an office I went to see Fiona and it was fortunate that Leslie was in the office. I explained that I had been talking with colleagues at other hospitals and that they were concerned at the length of time children spent not only in theatre but also in the intensive care unit. I now also shared that concern and wanted to know what they thought about this. They both listened and didn't dismiss what I was saying. They said that they would bring my concerns up at the next cardiac

directorate meeting which would have been attended by all the cardiac surgeons. I don't know if they brought it up or the outcome.

32. I also raised these concerns with Jean Pratten but I realised that this was a clinical issue and not really a Heart Circle issue. I knew that it would be difficult raising the subject with Jean as she had known both Mr Wisheart and Mr Dhasmana for a long time and had a high regard for their clinical abilities. Mr Wisheart was very supportive of the Heart Circle and its fundraising and they were good friends. Jean listened to me but gave me the distinct impression that it wasn't part of my job to raise this type of concern. In her view she said that if there were more bereaved parents at the BRI that only served to make my job more important.

33. The switch programme started in early 1992. I cannot be precise about the date. It was a combination of the deaths from this programme together with the other concerns that led me to ask Jean if Dr Freda Gardner could supervise my work, help me cope with the extreme exposure to distressed parents, and also help me manage my time better. I think I was beginning to feel out of my depth in my ability to deal on such a regular basis with distressed parents and other demands on the unit. Freda said that I couldn't spend my time seeing distressed parents all day every day because that made me less effective. She pointed out to me that my role was not that of a psychologist or of a bereavement counsellor but that's what I seemed to be spending the majority of my time doing.

Year 3

34. I continued to give support and help to parents and the nurses but was much more aware that I could not invest large amounts of emotional energy into all aspects of the job. During this year I organised a cardiac study day sponsored by the heart circle for all nurses involved with cardiac patients and I organised speakers from the BRI and other hospitals. Delegates had to pay to attend so this raised money for the Heart Circle. It was at this stage that I felt unable to continue going to theatre with the parents and children as I was emotionally drained. I ensured that one of the other nurses in the nursery was able to carry out this task.

35. I did not start the third year intending to give up on my commitment to see out the three years funded by the Heart Circle. I intended to do as much as I was able within the constraints that Freda had advised. Around June/July 1993, I told Jean that at the end of the funding for my post in November I would be looking for other employment. I was beginning to make enquiries about other jobs. Jean was extremely supportive and I think she could see that I couldn't give any more. I think Freda spoke to her as well. Jean was kind enough to say that the Heart Circle would continue the funding of my post if I hadn't found a job in November. In the event, I found a job in February 1994 and the Heart Circle employed me until then.

36. I felt a great loyalty to the Heart Circle and Jean Pratten, and I was determined to see out the 3-year funding. I was acutely aware that my post was funded by charitable means. Although I could have left and done agency work, I did not want to let the Heart Circle down. I knew that they wouldn't be able to appoint another person for the remainder of the funding time and it was still unclear whether the Trust would fund the post when I left.

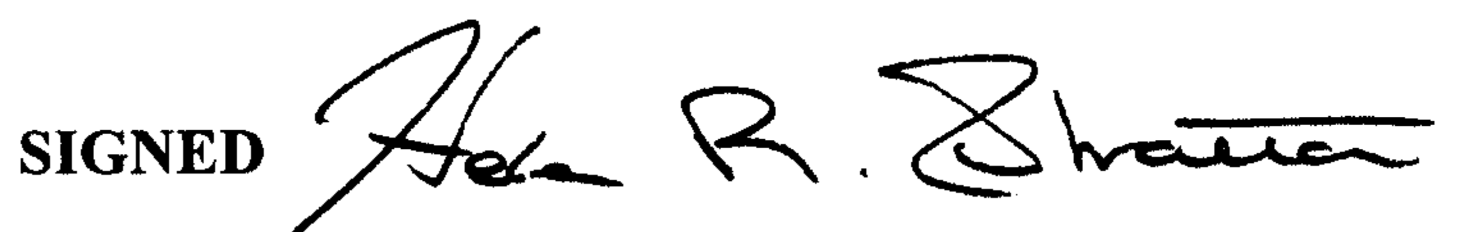
37. Two sisters at BCH, Linda Bailey and Bridget O'Reilly had become tutors for an ENB course in paediatric intensive care. They asked me to speak on the role of supporting parents to nurses who were doing the course. The nurses at BCH were always receptive to my role and ideas throughout my time as a liaison nurse. They were more receptive to change and new ideas than the nurses at the BRI. The senior nurses at the BRI tended to have a perception that a suggestion for change was a personal criticism of what they were already doing. They had done things in a particular way for so many years against a background of a unit that was highly surgically led and controlled and which meant that the surgeons had an input into the nursing decisions but this did not happen the other way round. I realised that at GOS and at Birmingham that the care and decision making for the child following surgery was more balanced and that no one person had overall control, but that each discipline had something to offer. There were other senior staff nurses on the unit who expressed concern about the very strong surgical control in the unit. They were also concerned about the length of surgery and the

length of stay in intensive care. They tended to be nurses who had come to the BRI from other units.

38. It became quite obvious during my third year that I was friends with Steve and that he was asking questions about the care of the children. There was a perception that because of my friendship with Steve that I had sided with him, and broken ranks. I had the impression that some of the sisters on the unit felt that I was being disloyal to the unit. One of the reasons I felt I couldn't be more articulate about my concerns was that I was the Heart Circle representative. I knew from speaking with Jean that I couldn't actively go around saying that I was concerned, as that was not my role and may be seen as the Heart Circle's view. I felt that I had raised the issues through the appropriate channels and was aware that Steve was taking his concerns through official channels. The unit did not have the culture that encouraged or supported the expression of any views. I felt that as a consultant anaesthetist his concerns would carry more weight than mine would as he was collecting hard data and substantive evidence. I only had a gut feeling and my experiences in other units to go on. I did provide Steve and Andy Black with my red book outlining the children's names, the operations and the date that they had died, as they had problems obtaining this data.

39. My role was never compromised as a result of raising concerns. I did not ever witness any member of staff being insensitive or uncooperative when dealing with relatives, parents or patients. In my opinion the standard of paediatric nursing on the unit, under the circumstances, was good. I was not aware of a formal complaints process, and I was not aware of a formal complaint being made while I worked at the BRI.

40. I confirm that this statement is true to the best of my knowledge and belief.

SIGNED 

HELEN STRATTON

DATE 21st July 1999