

The BRI inquiry into paediatric cardiac surgery in Bristol (1984-1995)

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Introduction

1. I have been asked to comment on Issue I, and on aspects of Issues B, E, G, H, J and L.
2. I took up the post as Chaplain to the Bristol Central Hospitals in 1981 and remained in post to 1983. Reverend Michael Jarvie took on the post after me. I understand he remained in post until his death in 1992. I describe the service and my role during 1981-1983, as best I can now recall it.

Background

3. I was ordained in 1968 and served my first Curacy at Holy Trinity, Wordsley in the Diocese of Lichfield. An important component of my job was to be Chaplain of Wordsley Hospital. The hospital had a regional plastics unit. This was where I first became involved with children and their families. In 1970 I moved to a Curacy at All Souls, South Ascot, where I was also Chaplain to Heatherwood Hospital, Ascot, a District General Hospital. From 1972-1976 I was Priest in Charge of St Barnabas, Emmer Green, Reading where I was also assistant Chaplain, Battle Hospital, Reading, which is another District General Hospital. From 1986-1981 I was full time Chaplain to Selly Oak and Birmingham Accident Hospitals, which meant I was dealing with many children. As well as general paediatrics at Selly Oak, the job covered the Regional Burns and Major Injuries Units at Birmingham

Accident Hospitals. I was responsible for an annual 6 weeks residential training course for student ministers, as well as regular involvement with the training of nurses, doctors and Theological students in Birmingham.

4. I moved to Bristol in 1981 and left in 1983. Since leaving Bristol I spent some months in Dar es Salaam with Missions to Seamen. I spent 5 years as Rector of Peopleton, near Pershore. During that time I assisted part time at Dudley Road and St. Chad Hospitals, Birmingham. From 1988-1998 I was Vicar of Bengeworth, Evesham and also Chaplain to St. Richard's Hospice, Worcester. I retired in 1997 due to heart problems. Thankfully these have been resolved and I now work as Chaplain to the Princess of Wales Community Hospital and Brookhaven Psychiatric Unit, Bromsgrove.
5. As stated above, I took up post as Chaplain to the Bristol Central Hospitals in 1981 and remained in post until 1983. At that time, Father Bacon was the part time Catholic Priest who worked 5 afternoons a week. Bill Cobley, based at Broadmead, was the part time Free Church Chaplain. When I joined I was responsible for all the Bristol Central Hospitals, which included 6 hospitals, namely, the BRI, the BRHSC, Maternity and Radiotherapy, the Bristol Eye Hospital, the Homeopathic Hospital, and the Bristol General Hospital. I was also the Vicar of St Michaels on the Mount.
6. When identifying below the service that was passed to Michael Jarvie, I also provide a general outline of my role. In essence, my role was to provide appropriate spiritual and pastoral care for both staff and patients in the hospitals for which I was responsible. This involved services in the Chapel, taking Holy Communion to the wards, and spending considerable time listening to staff, patients and relatives. As people came from a wide area, an important aspect was to liaise with people's home ministers, where appropriate and consent had been obtained.

Issue I: Treatment of Families, including the Bereaved**Issue I1: The nature, extent and adequacy of the services that were established to inform, support and counsel families with children receiving surgical cardiac care at the BRI, whether before, during and after surgery**

7. I went to Ward 5 and the general ITU at the BRI, ITU at the BRHSC, and the Special Care Baby Unit nearly every day. I also tried to ensure I went to Casualty twice a day. These were the areas of acute anxiety for patients and families, where I felt it was most appropriate for me to spend most of my time. Father Bacon attended Ward 5 with me every afternoon. We would chat with the nursing staff to obtain any referrals. We would visit all the patients and their families so they knew who we were and that we were available, whether or not a referral had been made.
8. There were 3 or 4 lay visitors who I involved in the less acute wards, so that I was free to spend time in the acute wards mentioned above. I felt it was important that someone experienced in giving spiritual support should always be available on those acute wards.
9. Having been Hospital Chaplain to the Burns Unit in Birmingham Accident Hospital and having dealt with children, my previous experience was helpful when talking to parents. I felt I was a neutral figure as I was not part of the clinical team. Parents were far more comfortable talking to me about their concerns and worries. I would listen and help them to form their own conclusions. Sometimes I was asked clinical questions, which I would pass on to the Nurse or Consultant.
10. I saw my main role to be there as a listener. I also, of course, provided spiritual and pastoral care for both patients and their families, and for staff. This involved bedside communion, Sunday and weekly services and the conducting of baptisms and funerals. Baptisms for paediatric cardiac patients would normally take place in the BRHSC before children went to the BRI for their operation. We tried making it

as normal, and as special, as possible, to make an occasion of it and, if possible, to have the whole family there. I recall that the nurses would make a cake. As people came from a wide area, an important role was to liaise with people's home ministers where appropriate and consent had been obtained.

11. As well as working closely with the clinical staff I also worked closely with the social workers who I recall at the time were Sue McMullen and Edna Culverhouse. They also made referrals to me.
12. When I joined, I felt that covering 6 hospitals and being the presiding Vicar at St Michael's on the Mount, was far too much work for one person. I arranged to give up my role as the presiding Vicar at St Michael's on the Mount and then concentrated only on the hospital work.
13. There were no voluntary groups, such as the Heart Circle or Friends for Parents, at that time. There were voluntary groups for other illnesses such as CLIC, which supported the families of children with leukaemia and cancer. There was a hostel provided for parents whose children were suffering from such conditions. I recall that sometimes heart patients' families stayed there. I think I may have possibly passed on as a suggestion to Michael Jarvie that such a voluntary group needed to be set up for cardiac children. I also recall indicating that we needed more volunteers to assist the Chaplaincy service.
14. I knew Reverend Jarvie well, having met him regularly at various Hospital Chaplain conferences. When I left, we met on a couple of occasions to discuss the services and so that I could provide him with a formal handover.

Issue I2: The nature, extent and adequacy of the services that were established to inform, support and counsel families with children who died or suffered permanent disability after receiving cardiac care at the BRI, including liaison with community and social services

15. If a child died I was always called, even during the night. I attended if the parents wished me to be there, and they usually did. I often performed baptisms, before or after death, and sometimes conducted the funeral. I recall taking some funerals for cardiac children, but I cannot remember the precise details. It was sometimes the case that parents hadn't got as close to a Vicar as they had to me in the hospital, or that they had not gone to a church before and felt more comfortable with me conducting the funeral. We always tried to do exactly what the parents wanted.
16. Once patients were discharged, or after I had conducted a funeral, the families then usually left the area. The Cardiac Unit was a regional service and patients came from many miles away. After this I had very little contact with them. On occasions I remember calling up parents to see how they were, but this was only in a few cases. I would always ask if they wanted me to ring their Parish Priest or Vicar, and if they wanted me to I would do so.
17. I did not liaise with the Community
18. Services and Social Services outside the hospital, as there were hospital Social Workers to fulfil this professional link, and discharge letters were routinely sent out to general practitioners.

Issue I3: The financing of the support and counselling services

19. There was not a budget for Chaplaincy services at this time, to my knowledge. If I needed items I would put a request in and they would be ordered. If it was for something more substantial like a piece of equipment, then the request would go through the hospital administration.

Issue I4: The priority afforded to support and counselling work by hospital management and clinical staff

20. I felt that there was strong recognition amongst the nursing staff, the clinicians and management, that there was an important role for the Social Workers and Hospital Chaplains. There were, of course, no Bereavement Officers or Counsellors at that time, and I believe this was the case nationally.
21. In my previous post in Birmingham, I had given lectures on counselling to medical students. This was a very new idea at that time. After I came to Bristol, it was not something that I managed to get off the ground in the short period I was there.

Issue I5: Whether staff coming into contact with parents who were under stress because of the nature and severity of their child's condition, or who had lost children, showed appropriate sensitivity in their dealings with such parents; and, if not, the importance and effect of any such failures

22. I felt all the staff, the nursing staff and the Consultants and junior medical staff, were both sensitive and caring. They saw their role as not only to inform patients and families as to what was happening, but also to provide support. They all felt upset when a child died, and the nursing staff always made efforts to attend funerals. It was part of my role to support the nursing staff, as well as the family, after the death of a patient.

Issue B10: Complaints procedures available to members of the public, their use and the responses to such complaints by the hospital, Trust or health authority leadership;

23. I cannot comment on this issue in detail, as I was not involved in responding to complaints. I cannot recall anyone being dissatisfied with the service provided. They did sometimes comment on the food or the accommodation, but not on clinical care.

Issue B12: The culture of the BRI, as expressed in such matters as:

(f) the attitudes towards patients who complained of poor service or care;

24. I cannot comment on this issue in detail. My impression was that staff were generally concerned for the welfare and care of patients, and always felt they wanted to be able to do more. I had no direct experience, but would have expected that this attitude was reflected when patients felt they had cause for complaint.

Issue E15: Liaison of staff with parents; and the participation of parents in the assessment and care of their child

25. Parents were actively encouraged by the nursing staff to remain on the ward and to help with the care of their children, such as washing, eating, feeding, etc. The nursing staff always explained clearly what needed to be done and what was happening.

Issue G12: Liaison of staff with parents; and the participation of parents in the assessment and care of their child

26. I cannot provide any more information apart from that stated above at paragraph 24.

Issue H: The Split Site

27. I was not aware that the split site caused a problem. I thought it was inconvenient, but not a problem. There were good communications between both sites and all staff at both sites worked well as a team. I didn't think it was ideal that anxious parents had to move from one hospital to another, but I never saw it as any more than that. As I oversaw all the hospitals, I was able to provide some continuity when parents and children were moved from the BRHSC to Ward 5, and then back again.

J4: Whether consent (if required by law) to:

- (a) hospital or coronial autopsies; and/or**
- (b) the retention of tissue and/or organs of the body**

was properly and sensitively sought; and if consent was not required, whether proper and adequate information about this matter was given to parents, in an appropriate fashion

28. I occasionally got involved peripherally in issues of consent. Occasionally parents would discuss whether they wished their child to undergo a post-mortem. They explained their concerns to me and I would stress to them that some good might come out of it, i.e. that it would help to establish for them the cause of death and also help children in the future. This was my sole involvement, as a sounding-board for parents. I was not directly involved in the process of obtaining consent or signing forms, which were for the medical staff to deal with.

Issue L: Informed Consent

Issue L4: The professional guidance (if any) available to surgeons, or other advisors, upon the subject of informed consent and quoting for risk.

Issue L5: How the paediatric cardiac surgeons at the BRI or other advisors, treated the various factors referred to at (L2) and (L3), when giving estimates of risk. The factors that were used, and how, to arrive at any estimates given, and their adequacy.

29. On a number of occasions parents shared with me the fact that they had been advised that the operation proposed had a less than equal chance of success, but they were happy to consent on the basis that a slim chance of a successful outcome was preferable to the child's certain death if no operation was attempted.

Issue L6: What parents and guardians attended at the BRI were told, and how were they informed, as to the risks associated with surgery, including the risks of:

- a. mortality;
- b. morbidity, especially neurological deficit;
- c. Likelihood of future surgery or protracted drug regimes being needed;
- d. Other side effects or complications of surgery; and/or alternative treatment methods or the merits of non-intervention.

30. I did not attend pre-operative talks between parents and clinicians. However, it appeared to me when discussing matters with the parents that they were well aware that there were risks involved and knew in some detail the procedure that their child was to undergo.

SIGNED : *Leonard L. Burn*
LEONARD BURN

DATED : *6.9.99*

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