

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

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Introduction

I have been asked for my comments on Issues I and J in my role as Hotel Services Manager. I have also commented on aspects of Issues B, F, G, H and L, as requested by the Inquiry.

Background

1. In 1983 I joined the RAF as an aerospace systems operator. I remained with the RAF for 7 years. When I left, I took a degree in hotel catering and institutional management. In 1993 I worked for Trust House Forte in their Welcome Break chain as a Manager. After that I worked for P&O as a senior purser for a period of 3 years, at the end of which I was made redundant when the line closed. In January 1996 I took up my role as Hotel Services Manager at UBHT. I am responsible for St Michael's and the Children's Hospital (BRHSC).
2. As Hotel Services Manager I am responsible for approximately 140 staff in the BRHSC and St Michael's Hospital. The role covers all portering services, catering, domestic cleaning, security, reception and the bereavement services. When I joined in January 1996 I became responsible for overseeing the bereavement services. I took over from Dillis Waterman who had had similar responsibilities.

3. My comments on bereavement services are based on my own direct experience since I joined UBHT in January 1996, and limited to my role at BRHSC and St Michael's. I have had little contact with families who have been bereaved after paediatric cardiac surgery. This is partly because the percentage of cardiac patients is small in relation to the overall number of patients treated at the BRHSC and St Michael's. Also, the bereavement service at the BRHSC is provided by Graham Milkins, the Head Porter there. Paediatric cardiac surgery is now carried out at the BRHSC. My own role in bereavement is at St Michael's Hospital, with supervisory/managerial responsibility for the service at both hospitals.

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

4. The bereavement services cover practical matters following the death of a patient such as registering the death; liaising with the Coroner (if necessary), the pathologist and undertaker. At St Michael's Hospital, we do not deal with the consent forms for post-mortem, as these are dealt with by the medical staff. Our role is practical and supportive, to take parents through what has to be done and help them carry it out if necessary. This aspect of my job takes up a good deal of my time, with seeing parents, and continuing to liaise with them, and with the Chaplaincy. Graham Milkins at the BRHSC and Joan Sidwick at St. Michael's Hospital, both now graded as Health Service Assistants co-ordinators, also deal with bereavement to a large extent.
5. My other responsibilities include staff recruitment in all the areas in my remit, for example reception, security. I am responsible for budget and planning allocation of resources in those areas. I attend meetings at each hospital on infection control and on security. I also attend food and nutrition groups in respect of catering. I attend any meetings relating to individual projects which affect the services for which I am responsible, for example the new Children's Hospital. My responsibility for the departments under my remit is to take an overview on what needs to be put in place to resource their services. This includes staffing and recruiting.
6. When I took on the role as Hotel Services Manager in 1996, I was not aware that the post involved responsibility for bereavement services. As mentioned in paragraph 4, I was responsible for the two people, Graham Milkins and Joan Sidwick, who were already involved in the administration of bereavement services

and they were the only two people who knew what to do and essentially they got on with it.

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

7. All my comments are limited to BRHSC/St Michael's and to the period since I joined UBHT in 1996. When a child dies the parents will sit with that child on the ward for as long as they wish. When the child's body is removed to the mortuary, the parents can view their child there. The protocol in respect of viewing allows access between 9.00am and 8.00pm. We are producing a new protocol where access will be given 24 hours a day, but in some instances it may not be practical as we do not have enough staff to provide this kind of access at night.
8. I do not normally arrange funerals as I understand that it is recognised as something the parents usually prefer to do. However, I do verbally give all the information I have available on how to make such arrangements. We will register the child's death if the parents ask us to, but it is seen as part of the grieving process for a family to do it, if they can cope with it.
9. I now attend the new SHO's training and tell them how to fill in the death certificate. We also usually ask them to sign both a burial and a cremation form at the time a death certificate is completed so that we can use the appropriate form when the family makes a final decision, and destroy the other one. Often families change their minds. This way it is easier to accommodate any changes without taking time to re-do forms, with the inevitable delay incurred in finding the relevant doctor to complete the new one. We always tell parents that we are doing it that way so that they know they can change their minds at the last minute and it will not hold anything up. It helps them to keep their options open until they feel ready to finally decide.

10. Each month I list all the deaths at the BRHSC for Dr David Hughes, the Clinical Director of Children's Services, from the mortuary book. I give details of the name, the department in which that person died, and the cause of death if it is recorded. This enables him to have an overview of events and of any trends there may be.
11. I did not as part of my role liaise with Social Services, but in 1997 I did have a meeting with CRUSE. This was a multi-disciplinary meeting with a couple of GP's, a vicar from Southmead, Reverend Rob Yeomans (the Trust's Chaplain to the BRI), psychiatrists, and representatives of CRUSE, to review bereavement services as a whole in Avon. The aim was to help CRUSE to obtain funding from Avon Health Authority and to make Avon Health Authority aware of the shortfall in bereavement services. There was a study day for the region with Avon Health Authority which was set up by CRUSE in 1998. They looked at different models of care, for example those used in Oxford and Portsmouth. It was attended by a multidisciplinary audience involved in the provision of bereavement care. A representative of SANDS (Stillbirth and Neo-natal Death Society) came to see our work at St Michael's in 1997. Her comments were very positive and she indicated our procedures were very much improved and in line with best practice nationally.

Issue I3: The financing of the support and counselling services

12. The bereavement services are funded out of my department's budget. I am the budget holder for the BRHSC and St Michael's. My budget provides for practical things such as duvet covers for the mortuary, mortuary cleaning etc. The Chaplaincy budget is also relevant, but separately held and managed.

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

13. When I first joined, it was my impression that bereavement services were not high profile and perhaps not seen as particularly important, but that has changed over the years. This is in line with national developments and recognition of the value of bereavement services. We are always making developments to improve services. We are now looking at trying to get Helen Vegoda to see parents earlier, to give support at the very first stage when first referred to BRHSC, and also to give support to parents and patients in A&E.

Issue 15: 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

14. I believe staff are generally supportive, sensitive and generous with their time. Staff often become quite upset, as do other families nearby, when dealing with bereavements. A list of trained Counsellors for staff based at St Michael's hospital and a Trust wide counselling network were available from 1997 to support staff.

Improvements after 1996 onwards

15. During my first week in the job a complaint was received at St Michael's concerning the burial of a stillborn baby. I cannot recall the details of that complaint, but I do recall that the mother came to discuss the bereavement services with Reverend Helena Cermakova (the hospital Chaplain), myself and the Assistant Manager of St Michael's, Babs Williams.
16. As a result of that meeting a number of matters were identified by us that should be improved, for example that leaflets were not produced about bereavement services, that there were no written protocols regarding death certificates and funerals, nor any flow-charts and that our post-mortem consent forms could be set out more clearly. As a result, the whole of the bereavement service at St Michael's was reviewed.

17. We set up a bereavement group at St Michael's. This was a multi-disciplinary group representing the pathologists, the chaplains, representatives from the wards, and others. We met monthly from Spring 1996 for about 18 months. We looked at the service being provided and what we understood to be the best practice. At these meetings we looked through the paperwork, the procedures and the training which staff were receiving as well as the information and support given to the bereaved.
18. The first aspect we looked at was the consent to hospital post-mortem forms used in St Michael's. There was no reference to the retention of organs for training and research so we had the form re-typed following recommendations from the Pathology Department. This form was also used at the BRHSC. We also changed it to record that consent was to be counter-signed by a senior doctor, i.e. of Registrar grade or above. This was to ensure that the family had a meeting with the doctor so that he could explain the post-mortem procedures. I think the new form was introduced in about May 1996. A copy of the new form is at **Annex 1**.
19. The second issue we looked at was that of the written information provided to parents and patients. There was no written information then provided formally by the hospital to families about bereavement services. I wrote a leaflet spelling out the legal requirements for the registration of births and deaths. It set out what the hospital could offer, for example funerals for a foetus pre 24 weeks and stillbirths. The leaflet explained practical things such as what the coffins were like and that there were no ashes for cremations of very young babies under a certain weight. It set out the points of contact and telephone numbers for the Chaplains, undertakers, Registrar of Births & Deaths, and my contact details. I attach a copy of the current leaflet at **Annex 2**.
20. The third issue the group considered was bereavement training for staff. Essentially no training had been given to staff and it was felt there was a real gap. We introduced formalised training. Staff were given initial training over 4 weeks which involved 2 to 3 hours per week. These courses aimed to identify the basic issues

that arise following a bereavement. Ann Dent, who works in the University and is now the National Co-ordinator for Bereavement Services, provided this training. The course covered cultural issues and we were assisted by a representative of the Asian Community Groups. I gave a talk on the practical procedures necessary for the transfer of bodies and how to arrange viewings. We also had a talk from one of the technical officers from the mortuary about what happens at a post-mortem.

21. These training sessions were for any member of staff who was interested, from the cleaners to the nurses and the porters. The courses were started in 1997 and took place every 6 months, for 12 members of staff at a time.
22. All of the above was discussed and implemented at St Michael's. The changes were brought to the attention of Julie Vass, who was the Assistant General Manager at St Michael's in 1997, who agreed that the same type of development should be implemented at BRHSC. A discussion group was set up, comprising of Helen Vegoda, Graham Milkins, Reverend Helena Cermakova, Julie Vass and myself, with the aim of producing a document to assist staff in dealing with the practical aspects surrounding bereavement.
23. The bereavement service at the BRHSC was completely different. Their procedures were different, as were viewing arrangements, and the support which was needed for staff, who had often been nursing the child for a long period. At BRHSC there are a number of highly specialised acute services, for example, bone marrow transplant and oncology.
24. A protocol was created setting out our approach to bereavement care of parents and families. It was entitled "When a child dies". It was modelled on the protocol in place in Great Ormond Street, following my contact with Great Ormond Street to try to identify best practice. The protocol looked at what happens when a child dies, death certificates, whether the Coroner will be involved, which staff to involve, and what paperwork needs to be done. This was to assist staff who had not been trained on the practicalities following a death in hospital.

25. A bereavement services forum was also set up. We invited all those hospital staff we thought could assist. This included the ward representatives, Chaplains, Ann Dent, Helen Vegoda, Michelle Twist (the nurse trainer), and myself. This was chaired by Julie Vass. We discussed what we were doing at the time, what we wanted to improve, and how to make these improvements.
26. In respect of staff training at BRHSC, we set up a similar course to that at St Michael's, but with a paediatric slant. We grouped staff for training into senior nurses, junior nurses and multi-disciplinary. This division was made because each group needed to know slightly different things. The first course was started at the end of 1997 and ran for a full day. The courses were run by much the same people as those at St Michael's. There were two courses every 6 months for the different groups. The BRHSC course covered similar topics to the St Michael's course.
27. Julie Vass went on maternity leave at the end of 1997 and I took over the bereavement forum during this period. Professor Fleming, Professor of Infant Health and Development, joined the bereavement group a couple of months ago. My manager, Sarah Garrett (Ian Barrington's assistant), is now taking the group forward.
28. Graham Milkins retires in September 1999. He and I are currently the 2 main members of staff who know all about the bereavement services, at BRHSC and St. Michael's respectively. The bereavement group is now addressing the gap that will result when Graham Milkins retires. We are also discussing the nurses' request for a Bereavement Care Nurse who would deal fully with bereaved families. There is currently no budget for this role, unlike the arrangements at other hospitals, such as Liverpool, Birmingham and Great Ormond Street, which have bereavement care nurses.
29. Before 1996, when porters were recruited they were not asked how they would feel about dealing with the transportation of bodies, and cleaners were not asked the

same question in respect of meeting bereaved parents and seeing patients dying. The job description for porters now sets out that they will be responsible for the transportation of bodies and we ask them at interview how they would feel about dealing with that. We also explain to cleaners that they will come across bereaved parents, and often parents will talk to them as someone independent of the treatment. We are aware that some staff may be frightened by this. I explain it to them on the basis that if it was their child, they would not like the thought of other people being frightened of their child. This seems to help staff to be sympathetic to the needs of parents.

30. Mrs B Baldwin has recently produced a questionnaire on the bereavement services provided. This was passed through the Ethics Committee and was then sent out. We are now awaiting the results, which are imminent. This will give us some indication of how we are doing. In my view, this illustrates that the Trust takes bereavement services seriously. In 1998 the group reported to the Patient Care Standards Committee, a Board level committee, about what we had done so far at St Michael's.

Issue B: The BRI and its Paediatric Cardiac Surgery Unit

Issue B10:Complaints procedures available to referring clinicians, and to members of the public, on the standards of treatment and care attained at the BRI

31. I have not been involved in complaints and can add no information on this issue.

Issue E: Pre-Operative Management of Cases

Issue E12: The protocols or clinical guidelines, machinery, equipment or technical services (eg radiological interpretation) available to the cardiologists to assist them in this task

32. I have no information to provide on this issue.

Issue G: Post-Operative Care

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

33. I have no information to provide on this issue.

Issue H: The Split Site

Issue H1: The extent to which (if at all) the quality of care offered was adversely affected by the fact that paediatric cardiac surgery and immediate post-operative care were carried out within a cardiac theatre and ICU catering for both adults and children

Issue H2: Communication and collaboration between the ICU of the BRI and the paediatric ICU of the Children's Hospital; and transfer of children between two sites

Issue H3: The response of the clinicians and the management of the BRI to any problems created by the split site

34. I can make no comments in relation to the quality of paediatric cardiac surgical care.

Issue J: Post-Mortems and Inquests

J1: The nature and extent of the responsibilities of (a) hospital staff; (b) hospital pathologist; and (c) HM Coroner to report and investigate deaths.

J2: The functions of post-mortems and inquests in helping to establish the cause of death of a child or the adequacy of the surgical or other services provided.

J3: The extent to which post-mortems and any inquests held upon children who died following complex cardiac surgery at the BRI performed such a function.

35. I have no information in respect of issues J1 to J3 inclusive.

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

36. Please refer to paragraph 18 above. At BRHSC and St Michael's, consents to post-mortem were dealt with by medical staff who also completed the relevant forms. My own involvement was practical, liaising with the Coroner's office and the family if there was to be a post-mortem. I was not involved at all in the obtaining of consent to post-mortem, and neither were my staff at BRHSC or St Michael's Hospital.

Issue L: Informed Consent


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

37. I can add no information on this issue.

Issue L6: What parents and guardians attending at the BRI were told, and how they informed, as to the risks associated with surgery, including 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 or surgery, and/or alternative treatment methods or the merits of non-intervention**

38. I can add no information on this issue.

SIGNED : 

TONY SULLIVAN

DATED : 3-9-99