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

Name	Canon Charmion Mann
Address	C/o Beachcroft Wansbroughs
	10-22 Victoria Street
	Bristol
	BS99 7UD
Occupation	Vicar of Lacock Parish, Wiltshire

In this statement I comment on issues I, and on aspects of issues B, E, G, H, J and L, relating to bereavement counselling at the Bristol Royal Hospital for Sick Children during 1988 - 1994, when I was Chaplain to the hospital and 1985-1988 when I was Assistant Chaplain.

Background

1. From 1967 to 1977 I taught in secondary schools, and later worked for the Pre-school Playgroups Association and as a Nursery School Teacher. In 1980 I began my training at theological college and this concluded in 1982. In 1982 I became a Deaconess in the Church of England, and worked in the parish of St. Matthew's, Kingsdown in Bristol for a period of 3 years. In 1985 I left to become the Assistant to the Chaplain at what was known then as the Central Bristol Hospitals. I worked with Reverend Michael Jarvie, who was responsible for the Chaplaincy service for all the hospitals, but with particular responsibility for the BRI, until 1988. My post was newly created. Until 1998 it was 50% funded by the Special Trustees of the United Bristol Hospitals and 50% funded by the Diocese (so that I continued to be, technically, an employee of the Church Commissioners). In 1987 I was ordained Deacon in the Church of England. In the following year, 1988, I was appointed by the Central Bristol Hospitals as Chaplain to the BCH, St Michael's and the Bristol General Hospital. Michael Jarvie remained in overall charge but was specifically responsible for the BRI while I was responsible for providing chaplaincy services to the BCH, St Michael's and the BGH. In 1994 I was ordained as a Priest and later offered a parish appointment, in charge of the

parish of Lacock, Wiltshire. In February 1994 I was made an Honorary Canon of Bristol Cathedral in recognition of my pastoral work as a Chaplain within the Trust.

2. To assist in identifying the personnel involved I attach as **Annex 1** a diagram of the Chaplaincy service from 1984 to date. This is also attached to Rob Yeoman's statement and I believe was prepared from information provided by him. It identifies the structure of the Chaplaincy services for BCH, St Michael's and BRI. I confirm the diagram is representative of personnel who were in post during my employment, namely 1985 to 1994. Michael Jarvie, who was responsible for the BRI between 1984 to 1992, was replaced by Rob Yeomans. Between 1988 and 1994 I worked with, amongst others, Father Claudio Rossi, then Father Bernard Charles, the Roman Catholic Chaplains, and Rev. A Howell, followed by Rev. Jonathan Pye and then Rev. Mike Pullan, the Free Church Chaplains, all of whom were part-time. I was succeeded by Reverend Helena Cermakova. I worked closely with M Jarvie/R Yeomans and we met frequently. Ministers, Rabbis etc of other faiths came in to see patients of their own faith and worked independently, although I sometimes referred patients to them.

3. I covered for Michael Jarvie on an on-call basis. I therefore dealt with emergency referrals only. We also shared out the evenings and nights on call. I also covered his leave four weeks a year. I was on call for the BRI and the BCH for 24 hours at these times. I recall that whilst covering Michael Jarvie I provided communion, provided baptisms and sometimes support. However a very small proportion of my time was spent on Ward 5 and most of my time was spent on oncology and casualty. I cannot remember any details about my time on Ward 5. My comments are therefore based on my own experiences at the BCH, BGH and St Michael's only. I do not therefore comment at all on the services at the BRI unless specifically identified.

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

4. I was never formally involved in any complaints regarding the BRI. The only involvement I had was when Ian Barrington, Manager of the Children's Hospital, received a complaint and he asked me for my views because the complaint was in the form of a letter from a patient whom I would have known. I cannot recall details of that complaint now. I cannot provide any further comments in respect of this issue.

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

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

5. I cannot remember patients or parents complaining about medical work at the BRI and again I have to stress that I was not formally involved in handling complaints at all during my time with UBHT. I can add no further information to this issue.

Issue E: Pre-Operative Management of Cases

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

6. I can only make comments in relation to the hospitals for which I was responsible. I thought that liaison of staff with parents in those hospitals was particularly good. Parents were encouraged to do as much as they could to help with their child's pre and post operative care. I cannot comment on the participation of parents in the assessment of those children.

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

7. I can add no further information apart from that set out in E15 above.

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

8. Some of the children who were at the BCH obviously had to go to the BRI for open heart surgery. I felt it was probably disconcerting for parents to have two groups of carers looking after their child. There was necessarily a break in the continuity of care. We, (the staff) within the BCH were aware that the BRI was not staffed as a Children's Hospital and felt that it was a shame that the site was split. At that stage however there seemed no alternative to this arrangement.

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

In the following paragraphs I describe:-

9-15 - my work directly with parents and patients.

16 – the support I gave to staff.

17 – the voluntary support group established to befriend parents.

18 – information provided in the form of printed material.

19 – my involvement with support groups.

20-21 – Support and information shared with managers and superiors.

9. My work as a Chaplain was principally at St Michael's and the BCH and involved two main areas. First: working with parents, family and staff where a pregnancy did not go well, in ante natal care for example where there was a termination for an abnormality; or a still birth (inter-uterine death), or following a cot death. When I began working at the BCH there were as many as 50 cot deaths a year in Avon. All these babies were brought into the BCH. I also conducted the funerals of stillborn babies/babies delivered before 24 weeks gestation. The numbers were such that this was at least a weekly occurrence. The second area was supporting patients and their families whose children had life threatening conditions such as leukaemia, cancer, cystic-fibrosis or cardiac problems. The key areas of my work were in St Michael's Special Care Baby Unit and Delivery Suite, and in BCH in ITU, the Oncology Unit and Casualty Department. Given the broad context of my area of pastoral care (including support of staff) it will be appreciated that, numerically the children with severe cardiac conditions, and their families, represented a minor, but NOT an insignificant proportion. As mentioned above I did occasionally attend the BRI when

Michael Jarvie was on holiday and attended on an emergency basis while I was on call once a week. I now have no recollection of these visits.

10. When I did see the parents of children with severe cardiac problems, who came into the BCH, they usually were referred on to the BRI for surgery. It would then be the BRI Chaplain who was responsible for them. However, I would, on occasion, follow up those I had met at the BCH. I would call in at the BRI particularly if I were covering for Reverend Jarvie to see how the parents were, how things were developing, and to see generally how the parents and child were getting on. I would also have maintained contact if specifically asked to by a parent. Reverend Jarvie and I met together at least weekly. We also bleeped and phoned one another to refer BCH to BRI and BRI to BCH transfers of patients.

11. Religious services in the hospitals for which I was responsible were as follows:- I held regular services at St Michael's, which consisted of a Sunday Service with Holy Communion and one at lunch time mid-week for staff. I would also, if requested by parents, hold the Thanksgiving Service for the Birth of a Child. This service was offered via notices in place through the BCH and St Michael's. I also took Holy Communion to adult patients on the wards at their request (sometimes referred by their home church).

12. There was a Chapel on both the sites. However, when I began working there, the BCH Chapel was not in general use, as it was the Mortuary Chapel. One of the first things I did was ask for it to be opened as long as it was not being used for the viewing of the deceased. It was then used freely by parents of children at the BCH. Many commented to me that they found it a place of peace. There were facilities for prayer requests to be made.

13. I also offered the Church's rite of Emergency Baptism. This mostly took place at the BCH, on ITU, and on the Special Care Baby Unit at St Michael's. In the BCH this often took place before surgery. Baptism was available at the request of parents, often suggested by nursing staff.

14. My objective was to be available for parents or patients whenever they or staff requested. I was always keen to ensure that people knew I was available. I was contactable by bleeper. My normal hours at the hospital were 9.00am to 5.30pm. The BRI Chaplain and I shared out the on call duties for nights. So I would be on call 4 nights one week and 3 nights the next week. A night equalled 5.30pm to 9.00am. The wards contacted the switchboards who had the on call rota. I ensured people knew I was available by frequently visiting the wards, particularly ITU and by placing notices around the hospital. I worked beside the sisters, the ward staff, social workers and the BCH cardiac counsellor to promote my services and offer support wherever I could. I believe that all these staff offered my services to parents or patients when they felt it was appropriate. In addition I would also check the admissions list daily to identify the religion of patients, and to see if people I expected to have come back in had been re-admitted, for example. In addition there would often be referrals from the patient's own Clergy outside the hospital which I would follow up. I met with the BRI Chaplain twice a week to pray and during the course of this meeting we would refer those patients/parents who had been transferred from the BRI to the BCH. I also tried to attend the BRI Chapel mid-week communion service. In these ways I maintained my knowledge of patients and families.

15. The Cardiac Counsellor for BCH and I set up a Bereavement Support Group for parents from 1992-93. This was found to meet a deep need for those parents who attended. I think that about 6 sessions were held for the first group, and 6 planned for the second. The second group had some difficulties in travelling to Bristol for evening meetings and consequently it was less effective and it was decided to discontinue the sessions.

16. I also provided support to staff who, naturally, also became upset when a child was ill or died. I would often see staff informally in the staff dining room, as this was a good opportunity to meet them away from the wards when they had time to speak freely about their feelings. This staff dining room was used by both hospitals. We

also set up a support group (I think this began in 1988) for staff working in Casualty and ITU at the BCH, and in St. Michael's. This support group was available to the sisters, staff, social workers or any member of staff who wanted to attended. We found it helpful to meet regularly on a monthly basis. Marion Stoneham, the General Manager at St Michael's and the BCH, was very supportive and agreed to fund outside speakers to speak at seminars on bereavement. The group continued from about 1989 to 1994. (It continues, co-ordinated by Mrs Ann Dent.) In addition I checked when I went onto the wards how staff were coping, and considered it part of my role to provide support for them when needed.

17. In 1987 I set up the body known as "Friends for Parents". I was finding that I had less and less time to give those parents whose children were sick, but not seriously ill, the day-to-day support they required. I felt there was a need for these parents to be befriended and so supported. Sister Dominic, who was the Roman Catholic Assistant Chaplain, and I gave a joint talk in 1987 to the Church of England Mothers' Union and the Roman Catholic Union of Mothers groups at Clifton Cathedral about our work. A lot of them in the past had accommodated parents staying in Bristol with a child referred to the regional hospital, but as the hospitals had since provided this facility they were keen to find out what else they could do. The "Friends for Parents" group was formed in 1987 as a result of this meeting. A rota was drawn up under which volunteers visited people or helped parents e.g. with their children, or by taking them food. (For example, if the mother was vegetarian and she could not get any great variety of food within the hospital). Essentially they gave practical help wherever possible. In addition the staff often rang up and asked for their help for example, in providing support for an anxious parent; providing some care for a sibling; sitting with the patient when the parent left the hospital e.g. to go shopping. It was a good scheme, and provided great support to staff and families. The hospital management provided a yearly party as a thank you to the volunteers as well as inviting any current parents who were being supported by the group. Attached, as **Annex 2** to my statement is a leaflet which I first produced in 1987 (with updated graphics in 1989) which was provided to parents on the child's

admission to the ward explaining the "Friends for Parents" group so as to identify the help it could give.

18. Where appropriate we provided parents with details of other support groups who could assist if the "Friends of Parents" could not.

19. I also became involved with the Heart Circle and attend functions whenever possible to maintain links with them so that I could be readily available to families and colleagues.

20. There were also monthly Heads of Department meetings within St Michael's and within the BCH and I always would attend these. They were of mutual help to the staff, keeping us informed of one another's role and work. I felt that they enabled me to support staff more effectively.

21. While in post I had regular meetings with Marion Stoneham, General Manager of the BCH, and later Ian Barrington, to find out what was going on within the hospital, so that I felt up to date.

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

22. There were different forms of funerals for babies who had died according to their different stages of development. I conducted funerals at a local crematorium for those babies who had died pre 24 weeks gestation, or were still born. There was a protocol for the burying of babies who were pre 24 weeks. I attach, as **Annex 3** a copy of the protocol together with a copy of the service for babies miscarried or still born. There was a book of remembrance kept in each hospital and this was readily accessible in the Chapels. This was especially important for this group as there were few places outside the hospital with which to associate the memory of their

baby. I cannot recall conducting any funerals for cardiac child patients as these would have been held in their home area.

23. The Chaplaincy initiated annual Remembrance Services for those parents whose babies who had suffered cot deaths or who were still born. Other bereaved parents then requested a similar service and therefore a service was held to include children who had died from cardiac problems. Staff attended when they could. The cardiac counsellor for the BCH and I planned the first one in, I think, 1994. The service continues to be held annually, and, I understand, has been extended to include all BCH ITU deaths.

24. I liaised with the community and with social services to try and ensure that support provided in the hospital was continued within the community. If the parents or family wanted me to, I would liaise with their Vicar or other religious leader or Funeral Director in the area and discuss the funeral arrangements. I always offered to do this and it was often taken up. I cannot comment on the adequacy of services.

Issue I3: The financing of the support and counselling services

25. There was a Chaplaincy budget which I managed from 1988. (The coffins made by the works department fell within this budget). We also bought the materials for religious services, for example, Baptism Certificates and cards, supportive reading and prayer material for parents or families, wine and wafers for Holy Communion. Prior to 1988 the finances of the Chaplaincy at the BCH were included in the BRI budget, I think.

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

26. I felt that the support offered to both patients and families was particularly good for its time. Of course we could only undertake it whilst the families were in contact with the hospital. We therefore made efforts to put families and patients in touch

with groups, for example the "Compassionate Friends", in order to provide the aftercare and support that would be needed. In respect of staff I felt that they wanted recognition from management of the stresses that they were under. There was a UBHT counsellor available to staff and I recall a staff member telling me they had met this person. However, I never actually met this person myself although I tried to make contact by phone. I felt that there was always more that the Chaplaincy service could have done, but we were constrained by both time and resources. There was considerable pressure, especially on full time Chaplains. It helped when my part-time colleagues' hours were increased (Reverend J Pye) and when a separate part-time Chaplain, Reverend Sue Ruston, was appointed for BGH in 1994.

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

27. I felt that staff in the BCH were very sensitive in dealing with parents. They usually felt very involved with the patients and families and often attended the Services of Remembrance and sometimes a patient's funeral. It was clear when I began in 1985 that the nursing staff were not always aware of the particular religious requirements of other faiths in the treatment of patients and of a deceased person. For example, that only specified people shall wash the body after death, which is a requirement of the Moslem and the Jewish faiths. Therefore a Jewish social worker Mrs Mavis Hyams from St Michael's Hospital and the liaison person for Asian families, whose name I cannot now recall, and I undertook the preparation and presentation of a training session for BCH nursing staff to explain the impact of different customs and religious beliefs on the care of patients and treatment of the families. This training session took place with every intake of nurses , about every 6 months I think.

Issue J: Post-Mortems and Inquests

28. My involvement with post-mortems was only on the pastoral side. I remember sometimes parents telling me what they had been told about post-mortems and that they were deciding whether they should agree to one taking place. They sometimes came to me for advice. I would always stress to them that hospital post-mortems were done carefully, and that when they saw their child later, the effect of the post-mortem would not be apparent. (I was very often present with them on these occasions). Essentially I was trying to re-assure them. I would also add that it would benefit others, and particularly other parents, and help to establish the cause of death, which would be healing for them to know. If I had any indication that parents were reluctant, or needed advice of a clinician, I referred them to the clinician responsible for their child. I have no knowledge as to whether parents were told that organs would be retained. I can add no further information to this issue.

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

29. I can provide no information in relation to 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

30. I can provide no information in relation to this issue.

SIGNED : ....

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