

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

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Background

1. My statement refers to my knowledge since 6 February 1995 when I was appointed as a UBHT Chaplain with special responsibility for the BRHSC and St Michael's Hospital. I was ordained as a priest on 2 July 1995. My previous relevant experience is as follows. In 1982 I became a lay reader in the Church of England. From 1982 -1987 I trained for ordination. I obtained the relevant qualification, namely the General Ministerial Examination of the Church of England, and then waited for selection. In 1987 I was selected and in 1988 I was ordained as a Deacon. In 1991 I attended theological college to make the transition from a non paid to a paid position. In 1992 I was appointed assistant Chaplain to the University Hospital of Wales, in Cardiff. During this period I was to some extent involved in the care of children. During my time in Cardiff I obtained a counselling qualification from the Associate Educational Board in theory and skills.
2. Reverend Charmian Mann was my predecessor at the BRHSC. **Annex 1**, attached to my statement, is a diagram illustrating the structure of chaplaincy service and individuals in post over the period of the Inquiry. I confirm its accuracy since I joined in 1995 to date. In addition to my responsibilities at the BRHSC and St. Michael's, I am on the rota for chaplains on call for the whole of UBHT. I did not attend children undergoing cardiac surgery at the BRI.

3. When I took up my post at UBHT I also took responsibility for a voluntary group known as 'Friends for Parents', which was formed roughly 11-12 years ago. This group was responsible for the parents' practical needs, for example providing them with soap, toiletries and food. This service was for all parents, but especially for parents who had to travel some distance. Mrs Dorothy Willis, a volunteer herself, is the present co-ordinator of this group. We also had the help of one volunteer, Angela Bebbington, who visited patients in the wards and who subsequently left in about 1996, approximately a year after I joined.

4. I have been asked to comment on Issues B10, E15, G12, H and I and do so below.

Issue B: The BRI and its Paediatric Cardiac Surgery Unit

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

5. I cannot provide any information in relation 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. In respect of liaison of staff with parents, I refer to my comments under Issue I.
7. In relation to the participation of parents with their children's care I was not present in clinical meetings and cannot comment on the extent to which parents were included in their child's assessments. However, it was my understanding that parents were provided with accommodation and understood where they could buy food or obtain any other relevant information to ensure that they could spend as much time as they wanted with their children. Parents were always encouraged to help with basic care of their children e.g. bathing and feeding.

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

8. I refer to my comments above at E15.

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 and the BRI and the paediatric ICU of the Children's Hospital; and transfer of children between the two sites

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

9. I did not sense during this time (early 1995, when I joined the BRHSC) that the split site caused any difficulties.

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 or after surgery**

10. My comments are based on my own experience at BRHSC. I have not worked at the BRI, except when called out at night on the rota mentioned in paragraph 2 above. I cannot comment specifically on the services there. In respect of the services provided by the Chaplains at the BRHSC, I can provide the following information.
11. Our first involvement with parents was normally when we were contacted either by telephone, or bleeped by nursing staff or Helen Vegoda (who was the Paediatric Cardiology Counsellor based at BRHSC), or occasionally by social services, following a request by the parents for a Chaplain to attend. This commonly took place when a child was either very ill or dying. We would either baptise or bless the child before death. Parents sometimes requested baptism.
12. After death we would always talk with the parents, with any relatives and/or staff. I would then, if parents wished it, pray and anoint the child. I always kept everything informal, but dignified, to ensure that parents were as comfortable as possible. It was very important to remain sensitive to the situation and to assess what exactly the parents wanted. I always tried to ask them as few questions as possible, so as not to add to their distress, but also tried to take the most appropriate course of action. I tried to provide everything the parents wanted. I made it quite clear that it is their goodbyes, and not anyone else's, and it must be carried out in the way they wish. After the anointing I would gauge whether the parents wanted me to stay or whether they preferred to be left alone. If parents wished to be left, I would leave them alone.

13. I would then check how the staff were, as they were often saddened, although always professional, in the handling of parents after a baby's death, especially if they had cared for the child for some length of time.
14. I was also, on occasions, bleeped when a child was not in imminent danger of dying. Sometimes parents in an extreme situation want to discuss a possible course of action. When I was invited into a discussion about treatment being stopped, parents sometimes felt that I might be able to add to the ethical/faith discussion.
15. Whether I saw the parents again later was completely up to the parents. If they had not specifically requested it, I would pop in just to see if they were alright, or ask Helen Vegoda how they were and what the position was with the child.
16. I have always tried to ensure that all members of staff know who I am via notice boards and leaflets, in order that they know who to call if the parents request it, or if they want to suggest to parents that a Chaplain is available. I spend a lot of my time in the more acute areas of both the hospitals, for example, ITU, special care, and oncology, to ensure that everyone knows I am available and there to assist. The volunteer visitors in the department tend to spend time on the other wards where illnesses are not so acute. In this way Chaplaincy cover is provided for the whole of each hospital.
17. These volunteers are members of the public who are recruited by the Chaplaincy service and then appropriately trained in listening skills. They attend the hospital one day a week for 2 hours. At present 2 volunteers cover St Michael's Hospital, while 2 others cover the BRHSC. I refer to paragraph 26 where I comment in more detail on this. The co-ordinator of Chaplaincy Volunteers provides in-service training on a regular basis.
18. On taking up my appointment in February 1995, I felt that there was a confusion of roles in the bereavement services offered at St. Michael's. I attempted to re-define who was responsible for what, and the procedures that needed to be followed after a

neonatal death. I duly informed all the on-call Chaplains for UBHT so they were aware of the process when called in to a death at St Michael's. Attached at **Annex 2** are copies of the document dated 3 April 1995 and subsequently updated on 24 March 1996 which arose from this.

19. Following a complaint, Babs Williams called together the relevant people involved in dealing with bereavement; for example, myself and two bereavement officers. We decided to meet on a regular basis, monthly, then every other month, to discuss and improve the bereavement services at St. Michael's. This has been a very successful discussion group and has led to the reorganisation of bereavement services at St Michael's. The services have been evaluated from the parents' perspective.
20. The BRHSC has also had a similar bereavement group, of which I am a member, which is currently reviewing provision of bereavement services when Graham Milkins retires in September 1999. I am aware that bereavement services are the subject of a Trust-wide review by Lindsey Scott, Director of Nursing.
21. I hold a counselling certificate and always offer counselling where appropriate. The counselling I give may be secular in nature, or religious, depending on what is appropriate. In essence, I act as a sounding board. In addition, I also make the funeral arrangements where requested, and carry out the funeral service. I discuss with the parents to ascertain exactly what they want from the service, and together we agree on the contents of the service.
22. Helen Vegoda was also a paediatric cardiology counsellor and we worked very closely together, to keep each other updated and informed. My understanding was that she would indicate to parents that a Chaplain was available where this seemed to be appropriate.

23. If the parents were of another faith or denomination I would use the All Faiths document compiled by the chaplaincy at UBHT, and call the appropriate person to attend.

24. Once a year there was a remembrance service arranged by Helen Vegoda specifically for children who had died following cardiac surgery. I believe this had started in 1994. I first helped to organise the remembrance services when I joined in 1995. From 1997 the service became one for all children who had died in the previous year. This was at the suggestion of William Booth, the Ward Manager for PICU, and I was very much in agreement with this.

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

25. I am not able to comment about services at the BRI. My comments are limited to my own experience, and work at the BRHSC since February 1995.
26. When I joined the BRHSC we had one volunteer visitor. I felt we needed to increase the number so that the Chaplaincy service could cover all wards. We began this process when the Reverend Peter Browne was appointed in 1996 as the Chaplain with responsibility for developing and training Chaplain volunteers. He looked at the need for volunteers throughout the whole of UBHT. I asked specifically for volunteer help with my two hospitals. With his assistance, we appointed a number of volunteers. They received training for a period of, I believe, 8 weeks at the BRI. Reverend Peter Browne left the Trust in 1998 and a lay co-ordinator, Mrs Joanna Abecassis, was appointed in his place.
27. Another voluntary organisation, the 'Friends for Parents', provided for the practical needs of the parents and also visited patients on the wards. Responsibility for this group formed part of my job description when I was appointed. I arranged to upgrade their training and recruitment arrangements so that they could carry on the service in the future.

Issue I3: The financing of the support and counselling services

28. There was (and is) a Chaplaincy budget which covers items such as wages, books, items needed in the Chapel, travelling expenses and training. The BRHSC shared its budget with St Michael's. Ian Barrington, General Manager of Children's Services, is responsible for that budget with me.

29. In respect of the 'Friends for Family' group, this was partly funded by the Mothers' Union and by UBHT.

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

30. I am unable to comment on the above issue, save to say that I always ensured all staff, including clinicians, knew exactly who I was in order that they could advocate my work. There were also various leaflets promoting the work of the Chaplains. I felt that the staff all did this particularly well, and that they put forward my services where appropriate.

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

31. From my experience, staff at BRSHC and St Michael's were very sensitive when a child died. They made themselves available to parents whenever needed. They got involved at every stage. They themselves were very upset when a child died. Staff were available to the parents whenever needed, and helped to comfort the parents. I felt that there was a "general togetherness" between all staff when a child died; that they supported each other well. Staff did try, if possible, to come to funerals, to pay their respects.
32. I always made sure that after the death of a child I met with staff afterwards on the ward in order that, if necessary, a de-briefing meeting could take place. I felt that this was very important to support the staff.

Issue J: Post-Mortems and Inquests**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

33. I cannot comment in any detail on this matter. The only information I can provide is as follows. In about January or February 1999 I supplied information to Ian Barrington, General Manager, at BRHSC who was setting up a help-line to answer parents' enquiries regarding retention of hearts. I gave Ian Barrington information, e.g. types of burials, multi-faith documents and a rota of the chaplains who were on call and at the same time briefed the chaplains on this matter.

Issue L: Informed Consent

Issue L5: How the paediatric cardiac surgeons at the BRI, or other advisors, treated to 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

34. I cannot comment on this as it did not form part of my responsibility.

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

35. I cannot comment on this as it did not form part of my responsibility.

Issue N: The Expression of Concerns

36. Since I joined BRHSC in February 1995, I have taken the funeral of a child who died following cardiac surgery in May 1995. Since that time I have provided pastoral support to the family, which has expressed concerns about the cardiac surgery. That family is participating in this Public Inquiry, and my involvement has been solely with providing pastoral support. I cannot provide any information or make any informed judgement as to the adequacy or otherwise of the paediatric cardiac surgical service in Bristol.

SIGNED : *Helena H. A. Cermakova*
Reverend Helena Cermakova

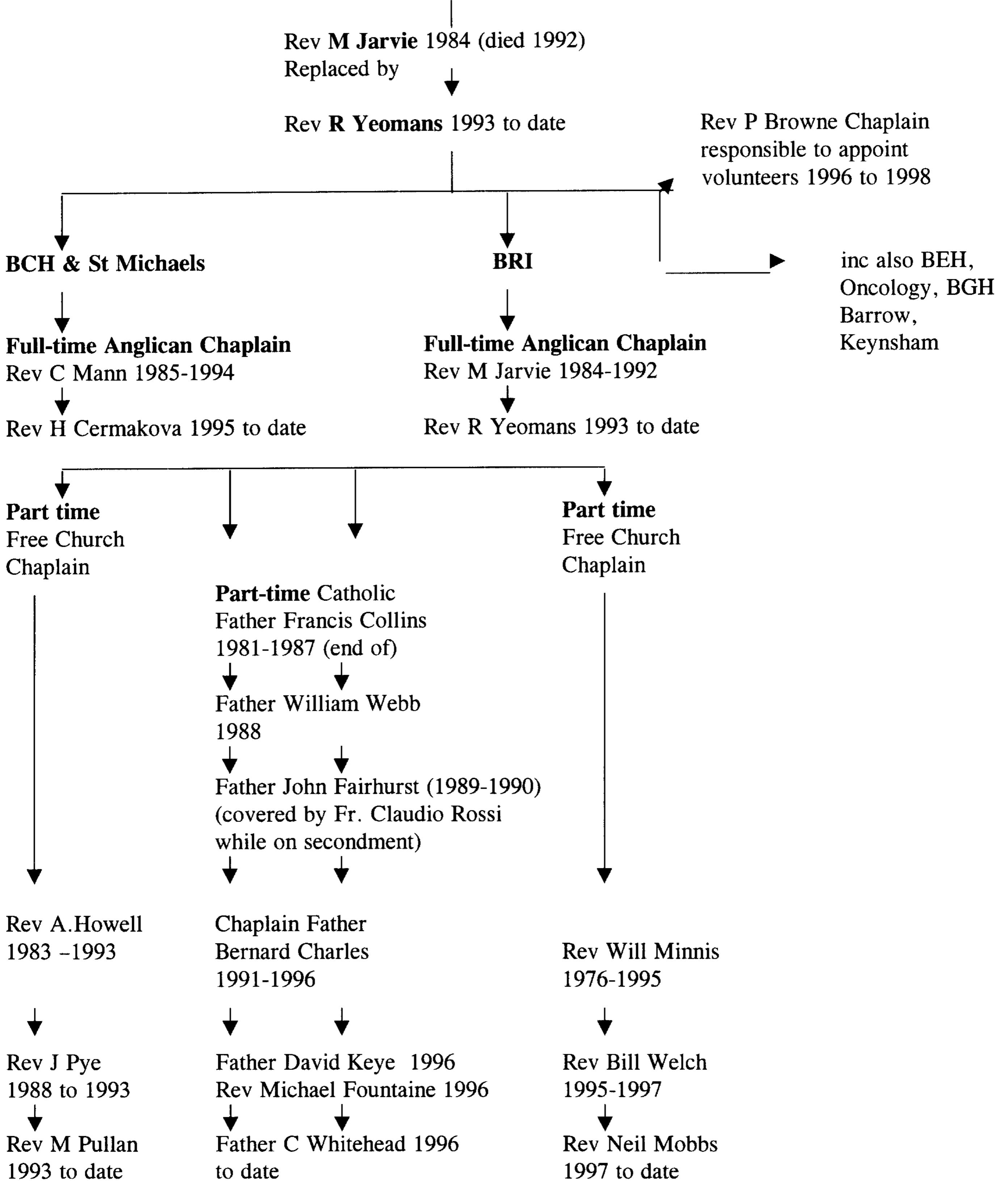
DATED : *27th August 1999*

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ANNEX 1

**Issue I – Structure of Chaplaincy Services 1984
in relation to the BCH, the BRI & St Michael’s**

Advisor to the Hospital in spiritual and religious matters
oversaw chaplaincy services (all denominations/religions)



ANNEX 2

Procedure for Funeral arrangements
BCH/St Michael's

Initial contact.....Ward with Dilys Waterman
Joan Sedwick
Gillian Gill

Initial contact with Chaplains, re funeral arrangements, should be made through The Rev Helena Williams, Bleep 2558, who will either take the funeral or ask the appropriate Chaplain. In her absence the Chaplain on call for BCH/St Michael'S should be contacted through the switchboard,

The Rev Rob Yoemans BRI, Bleep 2649 is normally on call.

The Rev Mike Pullan BCH/St Michael's, Bleep 2965 to be contacted if both full-time Chaplains are not available.

Practical procedures

1. Initial contact with wards/CDS/SCBU etc, through Dilys Waterman, Joan Selnick and Gillian Gill or appropriate social worker/s.

It has been suggested that some of the paperwork could be done by staff on the wards.

Bereaved families should be asked if they would like to see a Chaplain

2. Feotal remains to be transported between Pathology and Mortuary and prepared in time for Co-op funeral services to transport to Undertakers and subsequently to funeral service

2. All practical details regarding funerals to be handled by the Co-op funeral services whatever the gestation i.e. pre and post 24 weeks.

3. Chaplains should be notified in writing, by funeral directors, of the final funeral arrangements.

4. Pre funeral counselling/visits should be offered by all Chaplains, if possible.

Due to the frequency of funerals at St Michael'S this may not always be possible however many families return to the hospital before the funeral therefore an appointment with families could be made.

5. Post funeral contact should be offered where appropriate. Commendation to parish/congregation in which the family lives should be made, but only with the permission of the family.

6. Bereavement counselling services should be offered if needed. Long-term bereavement counselling may be offered by the Chaplains but only if all other support services have failed or there are special on-going pastoral considerations.

7 Chaplains travelling expenses, to and from funerals and bereavement visits should be paid by UBHT.

*Rev Helena Williams 3/4/95.
Chaplain.*

BEREAVEMENT SERVICES ST Mich's/BCH.

Update 24/3/96.

St Michael's Hospital

It has been decided to review bereavement procedures and attendant counselling services at St Michael's Hospital (conducted by Ann Dent beginning May 1996) with a view to provide improved standards in this area of patient care.

As an interim measure and as far as it is possible; the practical arrangements or inquiry concerning funeral details should be the sole responsibility of Mr Tony Sullivan (Hotel Services Manager), Ext 5205 and bleep 2464, and Mrs Joan Sidwick, Ext 5206 and bleep 2728.

Those otherwise concerned in a particular situation can give general guidelines regarding 'what happens next' but not attempt to arrange the details. This is to avoid the sometimes confused procedures (concerning the arrangement of funerals) that has hitherto taken place, and it allows the family to refer to the same person in any discussion to do with legal documentation and communication with the Co-op with whom the Hospital is contracted too.

During the weekend when normally Mr Sullivan and Mrs Sidwick are not available and the task may fall to the Chaplain 'on-call', then to offer guidelines on what is available, as far as the funeral is concerned, is obviously essential, as it would be any other time, but to leave the practical side to Tony or Joan, on their return to work on the following Monday. An appointment is always made for parents for the Monday, if they should leave the hospital during the weekend, as well as on-going contact with the Community Midwife on duty. When a family is closely connected with a worshipping community, then, with their permission, the vicar or minister should be contacted.

Children's Hospital

Mr Graham Milkins, bleep 2742, is the bereavement co-ordinator for the Children's hospital and is normally contacted by the ward concerned, in the event of a death and is responsible for the subsequent funeral arrangements. At the weekend when Graham is normally not available, the same general guidelines are offered and the practical details carried out by him on his return to work on the Monday.

When Graham is absent from the hospital, then Tony Sullivan and or Joan Sidwick will cover for him at the Children's hospital

Again, when a family is closely connected with a worshipping community, then, with their permission, the vicar or minister should be contacted.

I hope this clarifies the initial procedures that need to take place to avoid a confusion of roles which often leads to a break down of communication, and waste of time and energy for all the parties concerned.

It is hoped that the review will enable us to draw up a working protocol, which includes all those working in this highly sensitive area of patient care, providing a consistent, well run service!!

Rev Helena Williams

Chaplain

Meeting 26/3/96

= Practical Issues re-

Guidelines for on-call Chaplains
Flow Chart to be finalised by Babs Williams
and circulated.

= Theological Issues

RC Chaplain

= Support Group

Once a month to be set up by Babs Williams
For all working in this area
Social Workers
Bereavement Officers
Chaplains
Porters
etc.

= Leaflets on Bereavement etc

to be re-assessed by Ann Dent
Nationwide project to co-ordinating^e
Bereavement Leaflets will begin at the
end of the year, i.e. Sands/Sids etc

= Disposal of Fetal Material

Now Includes Social Terminations, three times a year.
Social Terminations are coded rather than named for
confidentially and are held on computer for any future
inquiry from the parents. Other fetal remains are named
during the service at Southmead, and these names are also
held on a computer.

= Resources

Funeral Liturgies
Reading Material

= Blessing/Baptism

The Blessing card is being re-designed.
Baptism can take place after death but only within the
first hour of death?
New Baptism box in SCBU which contains all equip-
ment needed. Candles are now being given but not
lighted!!!!