

The BRI inquiry into paediatric cardiac surgery in Bristol (1984 – 1995)Issue J – post-mortems and inquests

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1. The Inquiry has asked for my comments on this issue in my role as Patient Affairs Officer at the BRI. I have been in this post for 16 years (since 1983). During that time the principle underlying the work I do has remained the same. My role is to see relatives through a very difficult time, immediately following the death of a patient in hospital. At that time there are requirements of registration of death, arrangements for the funeral and obtaining the signature on the consent form for a hospital post-mortem at the BRI. I provide a point of information and practical help for relatives of those who have died following treatment in the Division of Medicine or Surgery at the BRI. I have undertaken internal training courses on handling aggression, understanding the grieving process and 3 short counselling courses on bereavement to help me in this work.
2. The way in which I provide information to the bereaved is both orally and in the form of helpful leaflets. This has always been the case, since I started the work in 1983. It is fair to say that the way in which information is given by me has improved over the years in that there has been an increased awareness of the importance of giving full and clear information on a number of issues. For example I attach as **Annex 1** a booklet prepared in 1998 by Mr James Brennan, Consultant Clinical Psychologist. This was prepared in consultation with me and the Bereavement Counselling Service

and hospital Chaplaincy. It explains aspects of grief. This would not have been a matter dealt with in information leaflets provided when I started my job.

3. Following a death in hospital the family are given by the Nursing Staff the booklet 'When Someone Dies' (**Annex 2**). This leaflet tells them to ring me the next working day after 10 a.m. so that I can make an appointment for them to come in to collect the death certificate and property of the deceased.
4. When the family arrive I give them the completed death certificate and property and talk over any issue they might need help with. I then give them the booklet 'A guide to the Days Ahead' (at **Annex 1**). This booklet includes telephone numbers for CRUSE and other helpful organisations.
5. In this statement I set out the steps I take at the BRI in providing that support to bereaved relatives. I have described this by reference to whether (i) there is to be no post-mortem; (ii) there is to be a Coroner's post-mortem or (iii) there is to be a hospital post-mortem. I comment later on the specific questions raised by Issue J.

No post-mortem

6. I explain to the bereaved relatives that it will be necessary for them to register the death and that after registration they should make contact with a funeral director. I give information to the relatives, as appropriate, to allow them to contact CRUSE and/or the Compassionate Friends (a national charitable organisation helping relatives of children who have died). I also telephone the GP of the patient and follow that with a letter and inform the relatives that I have done or will do this.
7. If the family live a long distance away or are infirm I can register the death for them. I explain this to the family who are usually greatly relieved that we are able to provide this service, although it is thought to be an important part of the grieving process and should be done by the family if at all possible. I register a death in the capacity of the 'occupier' of the building in which the person died and as the representative of the

Hospital. If the family are unable to pay for the funeral I provide information so that they can obtain help with that cost. I can usually deal with all the necessary information giving and the resolving of practical problems in one visit from the family. Occasionally relatives come back to see me for a chat and I regard this as a type of counselling; this happens particularly when the bereaved relative has no family.

8. Unfortunately there has not been an increase in the number of external organisations available to support the bereaved since 1984. As a result the referral points have remained the same since 1983 when I took up this post. CRUSE is under serious threat as identified in their recent Annual General Meeting. It has been my experience that most who take up the offer of external referral go to CRUSE.

Coroner's post-mortems

9. In cases where a Coroner's post-mortem is to take place; for example a death following a road traffic accident, or death within 24 hours, the clinician responsible for the patient would speak to the Coroner's officer as soon as the patient died. It was my responsibility to speak to the family, who I would usually see the day following death. At the time of the death the family would have been advised to telephone me in order that I would either explain about coming to see me to obtain the death certificate (if there was no need for a Coroner's post-mortem), or so that I could tell them about the contact they would need to have with the Coroner's staff. It would usually be the case that the clinician and the nurses would have explained that it was necessary to inform the Coroner of the death. I would reinforce this information by repeating it when the family telephoned me, explaining that they would need to speak to the Coroner and/or his staff. I would try to reassure the bereaved relative, who would usually be worried and sometimes assume that a Coroner's post-mortem meant that an Inquest would be held.
10. Sometimes relatives would be very distressed at the thought of a Coroner's post-mortem, particularly if they were very opposed to any post-mortem taking place. I

would explain that this was purely to establish the cause of death and that it was a legal requirement. I would explain that the Coroner would speak to them, asking them a couple of questions, their name and address, and then usually be able to tell them when they could go to register the death. At this stage I would also give information about speaking to the funeral director; that they should inform him that it was a Coroner's case. It would also be my function to inform the mortuary staff that this was a Coroner's post-mortem, although they would usually already have received a fax from the Coroner to confirm that the Coroner's post-mortem should go ahead.

11. The only reason the bereaved relative would see me following a death which required a Coroner's post-mortem would be to pick up property. Otherwise, all other matters would be dealt with by me on the telephone.

Death followed by request for hospital post-mortem

The following paragraphs set out what has usually happened (since 1983) in paragraph 12; the exceptions to this, at paragraphs 13 and 14, then the change in about 1994 set out in paragraphs 15, 16 and 23 – 27.

12. Since 1983, my role has been to identify that a hospital post-mortem has been requested and consented to, on receipt of the medical notes, immediately following the patient's death and, if so, to obtain the signature to the consent form. If consent has been given, this should have been documented in the patient's medical notes. The next of kin is usually asked to sign this entry on the ward. I believe this has always been the case both before and since 1983. (I am not sure if this practice is a hard and fast rule since in any event the post-mortem will not take place without the official signed consent form which I am responsible for. The junior doctor will advise me that a hospital post-mortem has been agreed to, when he/she comes to my room to complete the death certificate. I then know what the position is when the family come to me to obtain the death certificate. I will later confirm with the family that they still agree. I remind them that the doctor has already spoken to them about the

hospital post-mortem. If they confirm that they remain willing for the post-mortem to be carried out, I go through the form with them.

13. On several occasions since 1983 I have been asked if I would raise the question of hospital post-mortems with relatives if the Doctor was too busy. I cannot be more precise as to the number of times. I would say this happens about once a month and this has continued to date with the rate broadly unchanged. Mostly this occurred in the Division of Medicine cases but sometimes in Surgical cases too. I found this easy to deal with and as far as I am aware it never presented any problems at all. I have found on occasions that a consent form has already been signed by relatives. I would still ask them if they were willing for the hospital post-mortem to go ahead. Sometimes consent has then been withdrawn.

ITU

14. ITU procedure for obtaining consent is different to the above. ITU would not have covered paediatric cardiac surgery, who had their own ITU Unit and any consents obtained by clinicians to hospital post-mortems from the paediatric cardiac surgery unit would have come to me. To complete the picture, deaths arising in ITU at the BRI would usually be Coroner's cases because they would usually follow trauma. The ITU have their own death certificate book. They deal with all consents for hospital post-mortems, in the event one is sought, where a Coroner's post-mortem is not considered necessary. I believe they hold their own consent forms.
15. The BRI is a teaching hospital. Hospital post-mortems are therefore encouraged. Between 1983 and July 1994 I had no responsibility for obtaining initial consent from bereaved relatives for those post-mortems or for donation of organs, only responsible for the relative signing the consent form afterwards. From July 1994 or later (I am uncertain exactly when this started) I have been that person mainly responsible for obtaining consent to a hospital post-mortem for a limited number of Consultants and their clinical staff in the Division of Medicine. (I say mainly responsible since sometimes clinicians have asked for consent to a hospital post-mortem even though I

have been instructed to do so on their behalf). I have also been responsible for the relative signing the Consent form afterwards in such cases.

16. This request to extend my responsibilities stemmed first from Dr C Roberts having identified that there seemed a problem in junior clinician's willingness to seek consent from relatives, so resulting in a reduced number of hospital post-mortems and then from Dr R. Mountford asking me if I would be the person responsible for first asking the relatives for their consent to a hospital post-mortem. My additional role from about 1994 until about 18 months ago was limited to those patients' whose Consultants had previously asked (through Dr Mountford) that I should perform this function of being the first to raise the request for a hospital post-mortem
17. In summary in all other hospital deaths within the Division of Medicine and in Surgery, save for those identified at paragraphs 13 - 16 above, it has been, since 1983 (and it remains), my responsibility to obtain the relative's signature to the consent form and not to obtain their initial consent to hospital post-mortem, which is always dealt with by a clinician.

The Consent Form

18. A copy of the form I currently use is attached at **Annex 3**. I believe the consent for the post-mortem has been used in its present form since I took over the post in 1983. To the best of my knowledge it has not changed in any way. I sit down with the relatives to go through the form with them. I have always taken care to read the form out to them and explain to them what each paragraph means. I explain that they can delete paragraphs 2 and 3 (so that tissue cannot be removed for therapeutic purposes and so that an eye for corneal grafting or corneal graft research cannot be removed from the body). I explain to the relatives, if they should ask, what paragraph 1 means ("the removal of such tissues that are considered necessary for the purposes of diagnoses, investigation of abnormal conditions, medical education and research") that it is to complete tests or research on the tissue. In relation to organ donation a separate consent form is signed, **Annex 4**. I would explain that heart valves may be

removed or that skin and bone may be taken from the body in order to help someone else.

19. After the consent form has been signed by the relative I tell them that the result of the post-mortem will go to the patient's GP who will be happy to talk about the report with them. I also tell them that if they wish to speak to the clinician who had looked after their relative, or the pathologist, they should do so. Quite a number take this up, I believe in addition to speaking to the GP. If I was asked to put a figure on this I would say about 10%, but it is very difficult to tell. I have always been very aware that if I am asked questions by relatives which I am not happy to answer I should contact the houseman or clinician concerned with the care of the patient, to come down to see the relatives immediately. I can recall being asked questions about the consent form, in as much as the family often wish to know exactly what can be gained by a hospital post-mortem in certain cases. I would then need to contact the Clinician so that he or she can go into more detail with the families regarding the clinical history of their particular patient and the subsequent benefits of further investigation through post-mortem.
20. I recently had one experience where consent was given to the clinician, but by the time the family had come to me, probably on the day after the death, the relatives had decided that they wished to withdraw consent. As far as I can recall this has only happened about 3 or 4 times since 1983.
21. I feel very strongly that the subject of hospital post-mortems is best raised the day after the death, as well as immediately after it. My views have in part been formed by the 3 or 4 occasions (as mentioned above) when I have had a family withdraw their consent to a post-mortem after having had time to consider, when the initial shock of being informed of the death has subsided and also after discussion with the rest of the family (all whom should be in agreement before a post-mortem takes place). Therefore I feel the question of consent to a post-mortem should definitely not be limited to the occasion when obtained by the clinician.

22. The main purpose of that meeting between myself and the relatives is the giving and receiving of information, so that questions can be asked by the relatives on all matters arising from the death. I have found it helpful for relatives to have that time between the death and seeing me to compose their thoughts.

My changed role after 1994

23. The change in my role after about 1994 arose following Dr Clive Roberts, Consultant in Medicine expressing his concerns to me that the BRI was not getting enough hospital post-mortems. He had raised this concern in a meeting of the Division of Medicine in May 1994 noting also that I had been reported by some of his clinical staff as hindering the obtaining of consents to hospital post-mortems. As a result, this was raised with me by my manager Mrs Penny Brown. She reported my response to this claim to Dr Roberts and so to the next meeting of the Division of Medicine in July 1994. I had explained to Mrs Brown that I had had problems with some junior doctors in the Division of Medicine who had sometimes sought consent to a hospital post-mortem and sometimes not. My suspicion was that they had been reluctant to raise the issue of consent to a post-mortem with patient's relatives and I had been unfairly blamed for their unwillingness to do so. (I have been unable to locate these Minutes).
24. It was my understanding that Dr Roberts believed that the BRI needed more hospital post-mortems as a teaching hospital for the purposes of teaching and research – the only reason I believe a hospital post-mortem is carried out. As a result of what I felt to be unfair criticism I carried out a short survey in November 1994. This survey covered the 34 deaths in the Division of Medicine that occurred in the 4 week period 1st November 1994 to 2nd December 1994 at the BRI. As a result I identified to Dr Roberts that of the 34 deaths that had occurred over that period post-mortems had not been requested in 12, there had been 10 refusals, consent to 5 hospital post-mortems, and 7 were Coroner's cases. Junior housemen and senior house officers would often tell me, as I also reported to Dr Roberts following that survey, that a post-mortem would be "inappropriate" in those cases or that "nothing would be gained". This

survey was not relevant at all to paediatric or adult cardiac surgery, which are surgical specialities. The survey was limited to deaths occurring in the Division of Medicine. The correspondence I have been able to find is at **Annex 5**.

25. Sometime later, I am uncertain exactly when, Dr Richard Mountford, Consultant in General Medicine (also in the Division of Medicine) asked me if I would be willing to ask the relatives of some of the patients who had died in the Division of Medicine to give their consent to a hospital post-mortem and for organ donation. He made it clear to me that was this only for those Consultants who had expressly said they wished me to take on this new role. I understood that about half the Consultants within the Division of Medicine were in favour of my being the person to first raise the issue of consent and half were against it, preferring the clinician to deal with it.
26. He thought that I would be an appropriate person, I believe, because of my contact with the patient's relatives. This was for a trial period of 6 months and was restricted to the Consultants in Medicine who were in agreement to my involvement in this. This continued until about 18 months ago when I found I did not have sufficient time to carry on with this aspect of my work, having been asked to undertake other additional duties.
27. I was willing to assist as it was my view that junior housemen, who were not experienced in speaking to bereaved relatives, found it very difficult to approach the question of a hospital post-mortem. **Annex 6** consists of the only relevant documents I have been able to locate. Although they are dated 1996 I believe the change in practice as described from paragraph 23 took effect in 1994 although I cannot be certain.

Minutes of Patient Care Standards Committee

28. I have been asked to comment on my role in the obtaining of consent and in particular on the minutes of the Patients Care Standards Committee meeting on Tuesday 3 June 1997 which I attended (at **Annex 7**). I had not suggested, until that meeting in 1997,

to any Consultant or other clinician that I could take on the role of being the first person to raise the question of a hospital post-mortem with the patient's relatives (a role I had undertaken for Dr Mountford in some deaths arising in the Division of Medicine since about 1994).

29. The explanation I gave of my role as Patient Affairs Officer does not accurately reflect exactly what I would believe I have said. I may have said that I had done this job for 12 years, but in 1997 I had actually carried it out for 14 years, having started it in 1983.
30. The average number of deaths I referred to, 20 – 25 per week, referred only to deaths in the BRI and covered deaths arising in both Surgery and in the Division of Medicine.
31. The statement I made that post-mortems were carried out on 10 – 15% of adult deaths would have referred to hospital post-mortems. In fact 60% of post-mortems were carried out and not 10-15% as I stated. These 60% refer to hospital and Coroner's together. The reference to post-mortems carried out on 90% of baby deaths referred only to Coroner's cases.
32. The statement I made, that more hospital post-mortems were needed for teaching and research purposes, would have been information I had received from Dr Roberts in 1994 and, of course, with my own understanding of the needs of a teaching hospital.
33. My statements that, "half of the Consultants were happy [for me] to deal with post-mortems and retrieval consent" referred only to those Consultants in Medicine. I have already described in this statement how, from I believe about 1994, at the request of Dr Mountford, (for some Consultants and their clinicians, but not all) I was the first person to raise the question of a hospital post-mortem with the relatives of some patients who had died in the Division of Medicine. As earlier stated, this was since there had been reluctance on the part of some junior housemen to approach families about this subject. As a result some Consultants in the Division of Medicine, but not

all, asked me through Dr Mountford to raise the question of consent instead of the clinicians.

34. My statement in the minutes that it was hospital policy to request a post-mortem in all cases, but that doctors were not doing so, again referred to the Division of Medicine only. My statement that in my experience I found that I was able to bring up the subject of consent following time spent talking with and counselling families, also referred to my experience of being the first person to raise the subject of consent with the bereaved families following some deaths arising in the Division of Medicine. This statement did not apply to deaths arising in Surgery or to those deaths in the Division of Medicine (where certain Consultants had identified that I was not to be the first person to request the relatives' consent to post-mortem). In such cases (with the exception of those identified in paragraphs 13 and 14 above) consents to hospital post-mortems continued to be obtained by the clinicians and noted in the medical notes and in such cases my responsibility would be limited to obtaining the signature of the relative to the consent form I held.
35. The sentence in the minutes referring to "a counselling service and self-help groups co-ordinated across the Trust could be set up," was not my suggestion. However, I would have taken part in the discussion that followed. Similarly I would have had some input to the minute which noted that "improvements and better handling in the initial stages of bereavement could prevent complaints at a later stage; an example was the viewing room that needed improving and had no wheel chair access..." I would have raised the question of the viewing room and lack of wheelchair access. I do not recall providing the information concerning the initiative noted between CRUSE and Avon Health to take bereavement counselling nearer to GP's and the community instead of hospitals.
36. With reference to the particular questions set out under Issue J I have the following comments.

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

37. It was not part of my job to report deaths to the Coroner. I am aware that prior to 1983 when I took on the role of Patient Affairs Adviser, my predecessor reported deaths to the Coroner, but that this was thought to be not appropriate. This was not part of my responsibility, but that of the clinician.

J2: The functions of post-mortems and Inquests in helping to establish the cause of the 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.

38. I have no knowledge of either of these topics and do not wish to make any comment.

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

a. hospital or coronial autopsies;

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

39. Nothing said to me in my subsequent meeting with bereaved relatives ever led me to think that the consent was not properly and sensitively sought by clinicians.

40. As to Coroner's post-mortems since 1983 I have already explained that this was not a matter in which I was at all involved. I only met relatives for the purposes of returning property and it was my usual practice to explain to bereaved relatives that they would need to speak to the Coroner about what a Coroner's post-mortem meant.

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

41. In the time I have worked as Patient Affairs Officers, over the last 16 years, the question of the full implication of retention of tissue has never been raised by any relatives with me. I would not have thought to raise this with the relative, since I would not have thought it appropriate for me to raise it all. Reflecting on this I believe that I assumed that if had someone died from, for example lung cancer, it would be expected that a post-mortem would include the retention of the lungs and associated tissue for further examination. It is not something that I would have thought appropriate to go into detail about with the bereaved relatives.
42. It is fair to say that I have always wondered how much information it is right to give bereaved individuals at the time of a death, when the question of the post-mortem is raised. It seems logical to me, and I assumed that parents did understand, and would have expected, that their child's heart, following heart surgery, would have been retained at post-mortem for the purpose of establishing the cause of death, just as tissue would have been removed for the same purpose following, say, a death from lung cancer. Had any such questions been asked of me on either on Coroner's post-mortems or hospital post-mortems, I would have immediately referred such enquiries to the relevant Consultant, (or to the Pathologist if the enquiry arose after the post-mortem). There have not been any that I can recall, either before signing the consent form or afterwards.
43. I would also say that I have never been given the impression, throughout the 16 years that I have undertaken the role, that consent has been inappropriately sought by the clinicians for hospital post-mortems. I believe that I would have been aware had consent been inappropriately sought, or had there been any concerns as to the way in which this was dealt with. I say this because I am usually perceived as separate from

the nurses or doctors, and relatives seem to be able to speak to me freely. I work in an office on the ground floor away from the wards. The nurses work quite closely over a period of time with the bereaved relatives and get to know them very well, and so I believe that I would be more likely to hear of problems than the nurses would. It is difficult to draw a line between sensitivity and giving proper and adequate information when such information is given at the same time that news of the death of a relative is given.

44. It is now my view, as a result of the recent events surrounding paediatric cardiac surgery and the retention of organs, that more information should be given to families, and made available to families long before a patient comes into hospital. Leaflets could be available at GP's surgeries, for example, to identify the work that occurs as a result of a hospital post-mortem and to distinguish that from a Coroner's post-mortem. In this way there would be a far greater public awareness as to the implications and benefits of post-mortems.
45. I think it is important to state how throughout the period I have worked as Patient Affairs Officer at the BRI from 1983 I am constantly told how wonderfully the relative as well as the patient has been treated by the Hospital staff. It is in fact quite remarkable.

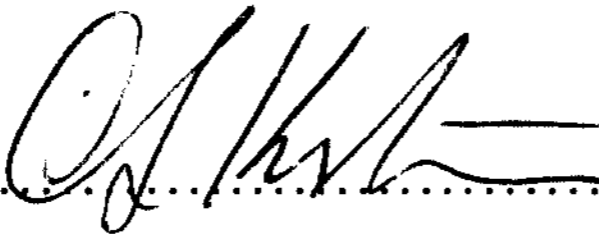
Issue I

46. I have not been specifically asked to comment on Issue I, "Treatment of Families, including the bereaved" but I did have contact with the bereaved parents following the death of a child after cardiac surgery. I was often called to the Ward 5B immediately following a death so that I could give some help regarding the necessary procedure and formalities. I was asked to register the death of a child for parents who very often lived perhaps in Cornwall or Wales and who needed to return home in order to look after other children in the family. Other parents were given my name and telephone number in the usual way so that I could give information regarding the Coroner and again offer any help I could at this time. Helen Stratton was Cardiac Support Nurse

and she passed the care of the parents over to me which provided the continuity which was felt to be important.

47. I would also like to comment on I(4) "the priority afforded to support and counselling work by hospital counselling and clinical staff". Counselling and support has been provided since 1984 as an important part of the Hospital Service. However, there had been an increased awareness over the last 16 years of the importance of the hospital making sure that bereaved relatives have access to this support and the service provided is more proactive in this way than it was years ago. This reflects modern thinking and attitudes.

SIGNED

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MRS DIANE KENNINGTON

DATED

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