

The Bristol  
Royal Infirmary  
Inquiry

Chairman: Professor Ian Kennedy  
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Valerie Mandelson




8/11/99

Dear Valerie

I hope you will not mind my writing with a further request for written expert advice to the Inquiry. We have not been in touch in the last few weeks so I apologise if this comes at a busy time. When you have had an opportunity to consider the request below, perhaps we could speak on the telephone to discuss whether it is feasible and what might be a reasonable timescale.

The Chairman and Panel recently heard evidence from parents about the experience of their child dying in hospital, and the subsequent discussions with hospital clinicians about arrangement for a post mortem. This evidence raises questions about the practices of communicating and managing the consequences of bad news when a child dies in hospital.

We would be very grateful if you could comment as follows:

- (a) In relation to three parents (Mr Paul Bradley, Mrs Sharon Tarantino and ) any comment you wish to make on their experience, as they describe it, of learning of the death of their child, and subsequently, of dealing with hospital staff in relation to the child's post mortem, and organ retention.
- (b) Arising from the specifics of that evidence, your opinion as to the apparent practices and procedures of the United Bristol Hospitals (Trust) highlighted by the evidence, and your opinion as to how that compared with practice elsewhere at the time.

(c) For the future, the lessons, as they strike you, for the future on how to improve practice within NHS hospitals for communicating and managing the consequences of bad news when a child dies in hospital.

Copies of the relevant statements are enclosed along with the transcripts of the days when Mr Bradley, Mrs Tarantino and [REDACTED] gave evidence. We would like your advice to be made available to the Chairman and Panel, and thus it will be made public. Remuneration will be at the standard rate agreed for members of the Expert Group.

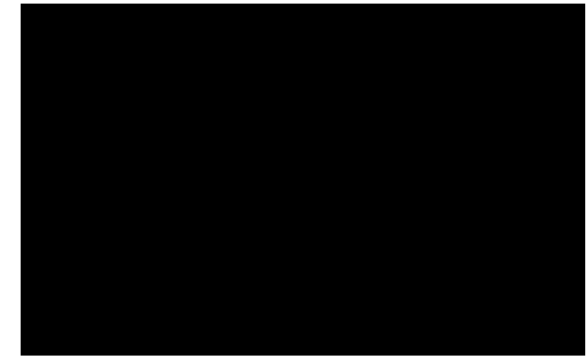
I do hope you will be able to help; your assistance thus far has been very valuable to the Inquiry.

Yours sincerely



Una O'Brien  
Secretary to the Inquiry

RECEIVED  
28 MAR 2000



Una O'Brien  
Secretary  
The Bristol Royal Infirmary Inquiry  
2-10 Temple Way  
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24.3.2000

Dear Una O'Brien

As requested I am making comment on the written statements and testimony of three parents involved with the Bristol Inquiry. I hope my comments will be useful.

The process of breaking bad news is a difficult challenge for professionals. Imparting bad news to a patient and family is, without question, a painful and unenviable task for health professionals, this duty involves giving information which is probably some of the most painful ever likely to be received. Many health professionals can feel helpless in such difficult situations. There is a strong case to be made that not only should breaking bad news become a part of pre registration medical education but that such education is available for all the caring professions.

I am aware of initiatives for example a Project Proposal: Learning Together: a collaborative educational programme to prepare and support health professionals involved in breaking bad news which has been formulated by a colleague at Alder Hey and submitted to the Foundation of Nursing Studies. No doubt there are many similar projects nationwide.

Any information, such as diagnosis or new clinical information should be given in a planned way. Mrs Tarentino in her evidence talks of seeing letters written on her daughter's notes and on asking what they meant being told by a nurse that her daughter had a hole in her heart.

No matter how familiar health professionals become with interventions and procedures when giving bad news it is important to recognise and demonstrate the uniqueness of the experience for the family. Frequently during the course of an interview there is a need to clarify the family's understanding and to give them time to assimilate information and order their thoughts. I note that this is something that [redacted] felt happened during the course of his meetings with medical staff.

Seeking permission for post mortem examination presents another difficult challenge. It can be all the more difficult where post mortem is required to comply with legal requirements rather than for reasons of widening medical understanding. It remains anomalous that permission is sought for a procedure for which, in fact, the family cannot refuse their consent. When a post mortem is requested parent's fears and

concerns about the procedure will emerge. The child continues to be a part of the parents and so the decision to submit their child to a post mortem is a painful one. The views of parents in Bristol and certainly the view that has been most forcibly expressed in other parts of the country is the need for informed consent before organs are removed or retained.

It has been suggested in available literature that health professionals require more specific preparation, including breaking bad news skills, to effectively prepare them for their role in supporting family members contemplating organ donation or allowing the retention of organs for medical research and training.

I note differing opinions within parents statements and testimony as to the perceived helpfulness of discussing the issues of post mortem and organ retention before a child's death as a means of preparation. When we are dealing with a life threatening illness we need to look at how we achieve a balance between maintaining a realistic degree of hope when the family might be faced with a hopeless situation. This sense of hope is less about being unrealistically optimistic and more about supporting families to construct and adapt a sense of hope which is reality based. As well as information we need to give families permission to talk about their feelings and their fears of their child not surviving and it needs to be done with great sensitivity. To introduce practical issues around post mortem or organ retention well in advance of any planned surgery would, for some families, do much to destroy any hope they had and may well affect their relationship with the medical team.

With regard to the support available to families during their child's illness and after their child's death, it does appear that each family's experience is different and this may well be because there were no protocols or procedures in place to alert staff to the needs of families. Of the three statements and transcripts that I have read there is mention of support during the time of the child's illness but little in way of support following a child's death. Families do mention that they were allowed time to be with their child immediately death had occurred. It is practice in many hospitals to give families time to be with their deceased child and, if parents want to, for staff to involve them in washing and dressing their child. It is also usual, again if it what the parents wish, to take hand and foot prints or photographs. Mrs Tarentino says that this is what happened following her daughters Corinna's death and that she was told she could stay with Corinna as long as she wanted to.

Beyond any immediate help families talk of feeling left to cope with it by themselves, feeling abandoned, unsure of what to do. Mr Bradley, who spoke highly of the support they received from Helen Vegoda during their daughter Bethan's illness felt so strongly about the lack of information and support following Bethan's death that the family sponsored a booklet for parents. Mr Bradley says that some time after Bethan's death he contacted Helen Vegoda who told him she was not been aware that Bethan had died. Reaching out to families is important because in their state of grief they are less likely to ask for help. Supporters need to ask what kind of help is needed as a family's statement of need may differ from those identified by a support worker. In the immediate period after a child's death there is the need for a person who is knowledgeable about procedures and is able to offer practical advice and support. Families also need to be made aware of the availability of on-going counselling and

support either at the hospital, in their local community or through parent support groups and how it can be accessed.

In 1989 when the Alder Centre opened in Liverpool, it was the first Centre of its kind with a remit to offer support to anyone affected by the death of a child, of whatever age and from whatever cause. It was an innovative project and attracted attention from many other hospitals that, at that time, were looking to improve bereavement care for families. The project was well supported by Alder Hey Hospital and therefore had the resources to offer comprehensive care and support to anyone affected by the death of a child. I think it is fair to say that at that time there were many individuals around the country providing excellent bereavement care but that this was the first time that the needs of bereaved families had been acknowledged in this way. Whilst other hospitals and agencies looked on it as a model of good practice, for a number of reasons, they adopted only certain aspects of the service and so during the period of time being considered by this Inquiry the Bristol Hospitals would not be alone in offering a limited service.

In conclusion I would state my personal view that ideally what should be in place is a programme of care that starts when a child is admitted to hospital and, if we are to offer a truly holistic service, it should extend into bereavement care for those families that sadly need it.

Not every family wants or needs to use the support services provided but what should be in place are procedures and protocols that ensure equity of access to information and appropriate interventions for those families that do. That support should be offered by staff who have received adequate training and have the appropriate resources to be able to help families.

Yours sincerely



Valerie Mandelson