

Chapter 12. Bereavement Adviser

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1. Background

- 1.1 In the late 1980s and early 1990s cardiac social workers provided a 24-hour on call service in the Alder Hey Cardiac Department and would sit with bereaved parents and talk to them. Clinicians would often take their lead from the cardiac social workers in terms of when the parents were able to cope with being given the necessary information following their child's death. The system worked very well and in the mid-1990s the cardiac social workers were replaced by cardiac liaison nurses. The service now is equally as good as the system it replaced.
- 1.2 There is always a cardiac liaison nurse available for consultation at Alder Hey. There is also a community-based cardiac liaison nurse supported by the British Heart Foundation who is available to speak to parents at any time.
- 1.3 In evidence the parents identified the need for this type of service. It should not be restricted to the cardiac department, but should be generally available. In his Interim Guidance on Post Mortem Examination issued on 1 March 2000 the Chief Medical Officer indicated that all NHS Hospital Trusts should designate a named individual in a Trust who will be available to provide support and information to families of the deceased where post mortem examination may be required, whether this is requested by a hospital doctor or the Coroner. This person should be trained in the management of bereavement. We feel that a bereavement adviser would be the person to discharge this role.
- 1.4 Parents must be involved in decision-making as well as in requesting and accepting support. The aim is to assist them in the difficult period following death. Their individual feelings and needs must be identified and respected. Their paramount need is for accurate, consistent, co-ordinated information. Choices available to parents should be fully explained, with all the necessary information provided. They must be given time together and time with their child. Time must also be available to make practical arrangements. They must be treated with respect and dignity at all times.

- 1.5 The bereavement adviser should not be judgmental in dealing with parents. Parents must be supplied with clear, factual, unbiased information. Confusion must be avoided. Parents may need help with thinking what they want to ask and even asking their clinician questions. No subject should be avoided and they must be treated with honesty even if the truth is painful. Their confidentiality must be respected at all times. The bereavement adviser should try and ensure that parents are dealt with on equal terms by the clinician and other professionals and time must be made available to meet the parents' needs.
- 1.6 It should be understood that grief can be expressed differently in different cultures. The nature of grief is personal and private. In a hospital, which often appears impersonal and public, there should be a private place where the bereavement adviser and parents can meet and have time together or alone. Parents must have time, space and support to relive, think and talk about what has happened to them.
- 1.7 The training of a bereavement adviser should include the appropriate use of language, the need to provide individual attention and to anticipate the requirements of bereaved relatives.
- 1.8 They must have a full understanding of post mortem procedures and the issue of consent. This will include identifying and distinguishing between a Coroner's and hospital post mortem examinations. They should be able to obtain information from clinicians and pathologists about the identification of organs to be retained and whether or not they will be retained beyond the funeral. Training must include why certain organs have to be 'fixed' before examination and the length of time necessary to 'fix' and examine a particular organ.
- 1.9 The bereavement adviser must be able to advise on all aspects of the funeral including return of organs to the body following post mortem examination, or identification of organs, tissue, blocks, slides, X-rays and photographs retained beyond the funeral. An awareness of all funeral procedures, religious requirements and the purpose of memorial services is necessary.
- 1.10 There will be a psychological component in bereavement advisers' training, relating to sensitive and respectful communication as well as gentle treatment of stressful topics such as consent to post mortem procedure. They will require liaison skills in order to discuss matters with clinicians, Coroners and other professionals.
- 1.11 The bereavement adviser should try to involve the pathologist more openly with clinicians and parents. The pathologist will be of particular assistance with regard to explaining why organs are retained and what purposes, including therapeutic, medical education and research, are served by retention of organs or tissue.

- 1.12 Parents should be given every opportunity to express their wishes about the eventual disposal of organs. A bereavement adviser can facilitate this. Parents' wishes must be respected. The need for respect cannot be overstated.
- 1.13 Every hospital should have a bereavement adviser. A dedicated office should be provided and include a private sitting area for parents or surviving relatives.

2. Recommendations

- 2.1 We have considered the evidence and recommend that the functions of a bereavement adviser include:
 - Explaining the circumstances of death, identifying when, where and who was present.
 - Arranging and attending a meeting for relatives with anyone who was present at the death if requested.
 - Encouraging a meeting between relatives and the treating clinician to explain the clinical circumstances of death and if requested arranging and attending the meeting.
 - Ensuring that relatives have a full explanation of the reasons for post mortem examination including therapeutic, medical education and research.
 - Explaining the need for consent to carry out a hospital post mortem examination (HPM) and the retention of organs.
 - Explaining that consent is necessary for the retention of organs following a Coroner's post mortem examination (CPM) and that the consent must be obtained before the CPM is undertaken.
 - Ensuring relatives have sufficient time, privacy and support to reflect upon the request for consent to an HPM or the retention of organs following a CPM or an HPM.
 - Ascertaining whether the clinician will attend post mortem examination.
 - Facilitating meetings between parents, clinician and pathologist as appropriate.
 - Noting discussions between relatives, clinicians and pathologists and providing a copy to each party involved.
 - Developing and using information packs for relatives on all aspects of death in hospital.

- Assisting relatives in the following practical matters:
 - collecting the deceased’s personal belongings and arranging return to relatives;
 - ensuring provision of certificate of death and the formal notice;
 - explaining the procedure to register the death;
 - providing support in attending the registry office if requested;
 - arranging contact with funeral director;
 - arranging contact with hospital chaplain and/or local priest as required;
 - contacting the Coroner’s office as appropriate;
 - offering to attend if contact with police necessary;
 - ensuring that the General Practitioner is informed;
 - ensuring that schools are informed as appropriate (including the schools of siblings);
 - assisting the relatives in informing other persons, including other relatives, friends and employers, of the death and its consequences;
 - assisting the relatives in dealing with the Benefits Agency, insurance company, housing matters;
 - assisting the relatives to place announcements in newspapers if wished.
- Discussing counselling or long-term support needs with relatives, including the needs of wider family members and making contact with appropriate counselling/support agencies if requested.
- Ensuring that relatives are aware of the full range of counselling/support resources available including those external to the hospital and bringing these matters to the attention of the relatives.
- Accessing translation/interpreting services including services for people with hearing or visual impairment and providing appropriate written/taped information.
- Assisting with any other individual problem presented by relatives in consequence of death.
- Undertaking general liaison duties.

- 2.2 We intend this list to be illustrative rather than prescriptive. There must be recognised training courses for bereavement advisers. Qualification should be certificated, perhaps at a National Vocational Qualification level. Annual assessment and appraisal should be routine and the role should be performance managed. Continuing education and training is essential. The bereavement adviser should work closely with the hospital management, clinicians, the Coroner and the full range of non-medical services including counsellors and other non-medical professionals. There will of course be relatives who do not wish to avail themselves of the services of a bereavement adviser. Nevertheless the service should be offered to everyone as should the facility to return to the bereavement adviser in the event of their services having been declined in the first instance.
- 2.3 The distinction between a cardiac liaison nurse and the bereavement adviser is that the nurse has the advantage of contact with the parents in the period prior to death. We suggest that some aspect of the bereavement adviser's multi-factorial function will bring them into contact with the parents before the death of their child.
- 2.4 We have been heartened at the support for the concept of bereavement adviser from parents and clinicians. We commend the concept for development and implementation.