

WHEN A PATIENT DIES

Advice on Developing Bereavement Services in the NHS

CONSULTATION DOCUMENT

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Contact Details	Marjorie Thorburn Bereavement Policy, Human Tissue Branch Room 652C, Skipton House 80 London Road, London SE1 6LH 0207 972 5302 http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCare/B
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WHEN A PATIENT DIES : PART I

Advice on Developing Bereavement Services in the NHS

Introduction

1. It has been recognised for some time that dealing sensitively and carefully with patients who die in hospital and with the relatives and carers of dying (or deceased) patients, is crucially important. The information set out in Part I of this document describes the basic elements required to provide an appropriate bereavement service to this group of people. Part II of the document describes examples of the experiences of bereaved people and practical solutions already in place in hospitals around the country to deal with these various experiences. These may provide helpful models. NHS Trusts may wish to consider the advice contained in this document when developing their own policies and services relating to bereavement.

Background

2. Bereaved people depend on bereavement services and on the professionals who provide them, at a particularly stressful, difficult time. Memories of the death and of the person who has died can be affected by the quality of these services; and the experience around the time of death and afterwards can influence the grieving process and the longer term health of bereaved people.
3. The quality of services available is also important for the wide range of staff who are involved in caring for bereaved people. All staff need to feel confident that what is offered and what is done, is appropriate, soundly based, and respectful.
4. The need to review services relating to death and bereavement was made clear in the reports of the inquiries at Bristol Royal Infirmary and Royal Liverpool Children's Hospital in 2001¹. Although these inquiries focused on specific events at the Trusts concerned, the inquiry reports set out recommendations that are fundamentally important and generally applicable.
5. In his initial response to these inquiries, the Chief Medical Officer recommended that **all NHS Trusts should provide support and advice to families at the time of bereavement**². Since then work has been undertaken by the Department of Health and across the NHS to improve services. The Chief Executive reminded Trusts of

¹ *The Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984–1995: Learning from Bristol*. 2001. *The Royal Liverpool Children's Inquiry Report*. Department of Health, January 2001, <http://www.dh.gov.uk>.

² *The Removal, Retention and Use of Human Organs and Tissue from Postmortem Examination. Advice from the Chief Medical Officer*. Department of Health, Department for Education and Employment, Home Office, January 2001, <http://www.dh.gov.uk>.

this important area of work during 2004³. The Chief Medical Officer has stated that providing sensitive, responsive information and support for bereaved families is not an optional extra but something that should be a passion for us all⁴.

Standards for Better Health

6. *Standards for Better Health*⁵ (July 2004) sets out the level of quality that healthcare organisations (including NHS Foundation Trusts) and private and voluntary providers of NHS care will be expected to meet in the domains of safety, clinical and cost effectiveness, governance, patient focus, access and responsive care, care environment and amenities, and public health. These seven domains are designed to cover the full spectrum of healthcare as defined in the Health and Social Care (Community Health & Standards) Act 2003. The desired outcome of the Patient Focus domain is that :

Health care is provided in partnership with patients, their carers and relatives, respecting their diverse needs, preferences and choices, and in partnership with other organisations (especially social care organisations) whose services impact on patient well being.

7. Within this, Core Standard C13 (a) states that healthcare organisations should have systems in place to ensure that :

Staff treat patients, their relatives and carers with dignity and respect;

and Core Standard C13(b) states that healthcare organisations should have systems in place to ensure that:

Appropriate consent is obtained when required, for all contacts with patients and for the use of any confidential patient information.

8. The way in which a healthcare organisation delivers bereavement services clearly relates to these standards.

Assessment for Improvement

9. The Healthcare Commission is the body responsible for promoting improvements in the quality of healthcare and public health in England. Following a wide ranging consultation, it has developed a new approach to assessing and reporting on the

³ Chief Executive's Bulletin 1st April 2004; <http://www.dh.gov.uk>

⁴ CMO Update, May 2005;

<http://www.dh.gov.uk/AboutUs/MinistersandDepartmentLeaders/ChiefMedicalOfficer/CMOPublications/CMOUupdate>

⁵ *Standards for Better Health*, Department of Health July 2004, <http://www.dh.gov.uk>.

performance of healthcare organisations. “Assessment for Improvement The annual health check *Measuring what matters*”⁶ describes how performance will be measured by reference to the Government’s standards⁵. The Healthcare Commission has also published criteria for assessing core standards⁷. Criteria in respect of Core Standard C13(a) include for all organisations that:

The healthcare organisation has taken steps to ensure that all staff treat patients, carers and relatives with dignity and respect at every stage of their care and treatment; and

The healthcare organisation has systems in place to identify areas where dignity and respect may have been compromised and takes action in response.

10. Additionally, criteria in respect of Core Standard C13(b) include for all organisations that:

The healthcare organisation has processes in place to ensure that valid consent, including from those who have communication or language support needs, is obtained by suitable qualified staff for all treatments, procedures (including post-mortem)

.....

11. NHS Trusts may wish, therefore, to consider these criteria in relation to the provision of bereavement services (including issues relating to post mortem consent) across their organisation. The information set out below may help NHS Trusts in this respect.

12. Described below are the various elements considered necessary to set up and provide adequate bereavement services; or to further develop existing bereavement services if appropriate.

13. Real examples of bereaved persons’ experiences are included as part of this advice (see Part II) along with some examples of the ways in which NHS Trusts are developing services in response to these experiences. These are intended to demonstrate the practical application of many of the points outlined in Part I. Trusts may wish to use these to inform their own services depending on local circumstances.

14. The Department of Health has also funded the development of a training resource which will be issued separately during 2005 to help provide in-house training for staff in the understanding and skills they need. This specialist training resource supports this advice; will help Trusts meet the principles outlined in this document; and support Trusts in recognising that staff need appropriate training and development – all of which are required for the effective delivery of a bereavement service.

⁶ Assessment for Improvement The annual health check *Measuring what matters*; Healthcare Commission March 2005; www.healthcarecommission.org.uk

⁷ Assessment for Improvement The annual health check *Criteria for assessing core standards*; Healthcare Commission April 2005; www.healthcarecommission.org.uk

Independent Providers of Care

15. Independent providers of care face the same issues in the provision of bereavement services as does the NHS. For example, the National Minimum Standards (NMS) for Care Homes for Older People⁸ set out the regulations on all aspects of care that must be met for individual care homes to legally operate. The NMS contain standards on death and dying with the stated outcome as:

“Service users are assured that at the time of their death, staff will treat them and their family with care, sensitivity and respect.”

16. Standard 11 states that the following need to be met:

11.2 that “policies and procedures for handling dying and death are in place and observed by staff.”

11.8 that “Palliative care, practical assistance and advice and bereavement counselling are provided by trained professionals/specialist agencies if the service user wishes.”

17. Similarly, the National Minimum Standards Care Home Regulations for Younger Adults and Adult Placements (Independent Health Care)⁹ have a relevant core standard on “*patient-centred care*”. The outcome is that “*the treatment and care provided are patient-centred*”. This covers consent issues, diversity issues, access issues and that “patients’ privacy, dignity and confidentiality are respected at all times.”

Delivering Bereavement Services

PRINCIPLES

18. The following principles underpin the development of services and professional practice around the time of a patient's death and afterwards. They apply equally to the care and support of the patient before death and the subsequent support of the partner, family, relatives and/or others who are bereaved.
19. They are of especial significance for particular groups such as those suddenly bereaved from unexpected traumatic death, those who lose a child or children who themselves who have been bereaved.

⁸ *Care Homes for Older People National Minimum Standards*, Department of Health, 2002.

⁹ *Care Homes for Younger Adults and Adult Placements*, Department of Health, 2002

20. The principles are:

- **Respect for the individual;** when a patient dies a bereavement service should be available which respects confidentiality, and individual preferences, values, culture and beliefs at all times in respect of both the person who has died and the bereaved family, partners or others.
- **Equality of provision;** all bereaved people are entitled to a service that responds to and respects their basic needs. Trust policies should describe a core service which is inclusive and can accommodate the range and variety of users' needs equally.
- **Choice;** professionals involved in caring for and supporting people who are dying or bereaved should offer choice – and the information, time and support people may need to make their choices.
- **Communication;** communication with people around the time of a death and afterwards should be clear, sensitive and honest. This is particularly important when addressing issues such as post mortem or donation of organs.
- **Information;** people who are dying, and those who are bereaved, need accurate information, appropriate to their needs, communicated clearly, sensitively and at the appropriate time (the role of the voluntary sector can be of particular importance here).
- **Partnership;** when a patient dies services should be responsive to the experiences of the patient and people who are bereaved; these experiences should inform both service development and provision. In one-to-one contact, patients and families should be enabled to express their needs and preferences, through sharing expertise and responsibility, and facilitating informed choice.
- **Recognising and acknowledging loss;** people who are bereaved need others to recognise and acknowledge their loss. Recognition by professionals, appropriately expressed, may be especially valued. Professionals should be aware of the importance of time and timing and should try to work at the pace dictated by people's feelings and needs.
- **Environment and facilities;** every effort should be made to conduct discussions and/or counseling in a private, sympathetic environment away from interruptions.
- **Staff training and development;** it is essential that staff involved in caring for people who are dying and for people who are bereaved are well informed so they feel confident about the care and support they give. They should have adequate opportunities to develop their knowledge, understanding, self-awareness and skills.

- **Staff support;** staff need to be supported by the knowledge that they are working within a carefully designed, well managed, high quality service. In addition, it is essential that all those who care for and support dying and bereaved people, regardless of their role, should be provided with support for themselves.
- **Health & Safety;** consideration should be given to the health and safety of both the bereaved and to staff working with the bereaved to ensure that the health and safety of an individual is not compromised by issues relating to the cause of death (eg infectious disease or similar).
- **Review and audit;** systems need to be in place to enable appropriate reviews and audits of bereavement services to be carried out, and the results of these evaluations to be disseminated and acted upon.

Delivering Bereavement Services

CORE ELEMENTS

21. The following information identifies the core elements of the services NHS Trusts are advised to have in place around the time of a patient's death and afterwards. Trusts may wish to consider having agreed policies and procedures in place which encompass this advice. **This advice highlights the critical elements considered necessary in a good quality bereavement service and Trusts may wish to build their own services on this advice.**

POLICY

22. It is recommended that NHS Trusts consider putting in place a written policy, ratified by the Trust Board, covering all services relating to death and bereavement.
23. Such policies should identify bereavement care pathways for both expected and unexpected deaths. Such pathways should encompass the time before or around death to the time when the body is released including the support that may be needed by relatives after the release of the body. In developing pathways, Trusts may wish to take account of the *Gold Standards Framework*¹⁰ which aims to improve the supportive/ palliative care of patients nearing the end of their life. It is used primarily by people who receive care at home or who attend the GP surgery but can be adapted for other care settings.

¹⁰ The Gold Standards Framework;
http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LongTermConditions/BestPractice/PalliativeCare/PalliativeCareExample/fs/en?CONTENT_ID=4105215&chk=Y5hdrc

24. The care of the deceased, the practical management of procedures and documentation; awareness of consent and post-mortem issues as well as the needs of the bereavement professionals should be included in the pathway. It would also be helpful for policies to identify other pathways which recognise particular needs and variations (for example, for the death of a baby, child or young person or for sudden and traumatic death).

25. To inform local policy, NHS Trust policies should take account of relevant key documents relating to death, bereavement and the health service such as the code of practice on consent for post mortem examination¹¹. Existing codes of practice and other information available at the time of publishing this advice can be accessed on the Department of Health website at:

<http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Tissue/TissueGeneralInformation>

26. Trusts will wish to ensure that the work of the new Human Tissue Authority (the Authority) is taken into account where relevant. Section 26 of the Human Tissue Act (2004) makes provision for the Authority to prepare codes for the purpose of (amongst other things):

- Giving practical guidance to persons carrying on activities within its remit, and
- Laying down the standards expected in relation to the carrying-on of such activities.

27. It should be noted that the Authority is expected to develop, consult on and issue codes of practice on a number of areas - including communicating with families about post mortem consent - during 2005.

28. In devising their policies and developing services, it is recommended that Trusts should consider consulting and working with:

- Coroners and coroners' officers;
- service users and others in the community;
- outside stakeholders, contractors, agencies and voluntary organisations providing services to bereaved people;
- local Primary Care Trusts;
- staff across directorates who are involved with death and with the support of bereaved people (such as Specialist Palliative Care Teams)

to ensure appropriate co-ordination of, and consistency between, all services which relate in any way to the needs of dying and bereaved people. NHS Trusts may wish to consider developing local protocols with other organisations as appropriate.

¹¹ *Families and post mortems A code of practice*, Department of Health 2003

STAFF

29. It is desirable that the responsibility for death and bereavement services is clearly defined within NHS Trusts' management structures. It is desirable to have:
- a nominated executive lead whose portfolio includes executive responsibility for the corporate delivery of services relating to death and bereavement; and
 - a senior manager, trained in relation to death and bereavement, with primary responsibility for the day-to-day management of services.
30. Bereavement and related services are likely to be delivered through different parts of the organisation. The role of a senior manager should therefore include:
- the development of formal mechanisms for close, co-operative working between all those involved (including specialist services), to ensure that management and delivery of services is effectively co-ordinated throughout the Trust; and
 - the development and review of policy and services, and the development and implementation of a Trust-wide strategy, in consultation with stakeholders both within and outwith the NHS. The manager should work directly with the executive lead to ensure that the necessary resources are identified to develop the service.

STAFF DEVELOPMENT AND TRAINING

31. All staff involved in caring for dying patients, and in supporting partners, relatives and others at the time of a death and afterwards, should participate in education and training of a kind, and to a level, that is appropriate for their role.
32. All staff who have significant contact with dying patients and/or bereaved people, should have available to them training and learning opportunities to enable them to develop:
- accurate, practical knowledge of hospital policy and procedures;
 - an appropriate level of knowledge and understanding about death, bereavement and grief;
 - self-awareness;
 - appropriate interpersonal and communication skills.
33. All staff should also have opportunities to develop their understanding and practice through mechanisms such as clinical supervision, case review, critical incident analysis and risk management meetings. Learning about death and loss should be an integral part of these procedures.

34. All staff involved in caring for and supporting patients who are dying and people who are bereaved in whatever role should have access to a range of formal and informal support. This is particularly important for staff who have provided care for patients over a long period of time (such as in renal care). Such staff may themselves need access to bereavement care and time should be allocated to ensure that staff are able to access the support they need.

BEFORE DEATH

35. When it is known in advance that a patient will die staff should, if possible and appropriate, talk to the patient to discover if they have particular wishes about what happens when they die. This should encompass resuscitation decisions which are amongst the most sensitive decisions that patients, parents and clinicians have to make. Patients have as much right to be involved in those decisions as they do other decisions relating to their care and treatment. Further information on developing resuscitation policy can be found on the Department of Health website¹².
36. If possible, and within the bounds of confidentiality, staff should also talk with the patient's family or others close to the patient, remembering, however, that the patient's wishes are paramount. The difficulty and sensitivity of such situations reinforces the need for staff to be appropriately trained – especially so where children are involved.
37. The manner in which a prognosis is given to a dying patient (and where appropriate the relatives or carers) and the palliative care services available will impact on the bereavement process. Whilst giving an honest prognosis may be difficult it may help those dying (especially from long term conditions) to prepare for death and ensure their wishes are taken into account. This is already recognized in the development of care pathways for dying patients such as *The Liverpool Care Pathway for the Dying Patient*.¹³
38. There will be close links in many Trusts between those providing palliative care and those involved in bereavement care. The National Institute for Clinical Excellence has issued guidelines¹⁴ on improving supportive and palliative care for those with cancer. These guidelines recognise that patients have different needs at different phases of their illness and that services should be responsive to patients' needs. It also recognises that family and carers need support during the patients' life and in bereavement. The National Service Framework for Older People¹⁵ also recognises that the needs of family, friends and carers need to be provided for including relieving distress, meeting spiritual needs and offering bereavement counselling.

¹² See HSC 2000/028

¹³ Care of the Dying A pathway to excellence; <http://www.lcp-mariecurie.org.uk/publications>

¹⁴ National Institute for Clinical Excellence; Improving Supportive and palliative Care for Adults with Cancer ; March 2004; <http://www.nice.org.uk>

¹⁵ National Service Framework for Older People; Department of Health 2001; Standard Two, Person-Centred Care; Pg 26 <http://www.dh.gov.uk/assetRoot/04/07/12/83/04071283.pdf>

39. In discussing care options with people who are dying, staff need to be aware that people may reach a stage where they are not able to make decisions for themselves. These people may also have made an advance statement setting out their views on how they would like to be treated when they are dying. People have the right to refuse treatment and for this refusal to apply if they lose capacity in the future.¹⁶ The Mental Capacity Act will introduce a statutory framework for advance decisions which will come into force in 2007 (information will be available from both the Department of Health and the Department for Constitutional Affairs websites).
40. Information about whom to contact when a death occurs, and how to contact them, should be kept up to date and easily accessible. When it is thought that a patient may die, the person or people closest to the patient should be informed, and kept informed, within the bounds of confidentiality, about the possibility, probability, and the imminence of death. They should be given a number to phone, and arrangements should be made for keeping in touch.
41. When a death is known to be imminent, family and/or others close to the patient should be informed and if at all possible, given the opportunity to be with their relative, child, partner or friend when he or she dies, if that is what they and the patient wish. Provision of overnight accommodation should be considered.

Organ and tissue donation (see also post mortem consent)

42. When it is certain that a patient will die, staff will wish to consider, where appropriate, issues relating to the donation of organs or tissue for use in transplantation, therapy, education or research. Patients and/or families will need access to a range of information before making a decision and close liaison across a number of disciplines may be necessary eg with organ transplant coordinators. Good communication will be essential and special training for staff may be required in order to manage these situations well.
43. Formal, informed consent is needed for the donation of organs or tissue. Where donation is for transplantation, formal consent could come either from the potential donor (eg from a living will or through being on the Organ Donor Register) or from a person in a 'qualifying relationship' as stated in Section 27 of the Human Tissue Act 2004. NHS Trusts will wish to ensure that the work of the Human Tissue Authority (the Authority) is taken into account where relevant. As mentioned previously (see paragraphs 25 & 26) the Authority is expected to develop and issue codes of practice in 2005 covering areas such as donation, communication and consent which will be relevant here.

INFORMATION : GENERAL

¹⁶ Reference guide to consent for examination or treatment; Department of Health; <http://www.dh.gov.uk/assetRoot/04/01/90/79/04019079.pdf>

44. The provision of written information (listing and describing sources of support, helplines and web-based information for example) is recommended, to help people who are bereaved manage the practical arrangements necessary after a death. Written material should be sensitive to the cultural values and religious beliefs known to be held by the local community and to the special needs of those who have lost a child or have been bereaved through sudden or traumatic death. Where necessary, it should be produced in other languages, and information should be produced in other formats, such as large print and on audio or video tape. Children's information needs should also be considered in an effort to ensure equal access to bereavement support information for all bereaved people.
45. Consideration should be given to advising the bereaved on any aspects of safety relevant to their interaction with the deceased either at the time of bereavement or later. For instance, depending on the cause of death (eg from a highly infectious disease), handling of the body may not be appropriate but the reasons for this should be openly communicated.
46. Whilst written information is important, it should be used to support, and not replace, information given verbally. It will be of great help to bereaved people to have opportunities to meet and talk with knowledgeable staff, including members of staff who have been involved in the patient's care. These opportunities may be needed around the time of the death or at some point in the future.

IMMEDIATE NEEDS

47. When a patient dies, staff should ensure that all those who need to know about the death are quickly and sensitively informed. People who need information will include:
 - family and/or others close to the patient
 - staff who have been or may be involved with the patient
 - and, if the death has taken place on a ward, other patients. If it is necessary for the body to remain on the ward, this should be explained to other patients, with reasons given. Staff should do all they can to maintain the dignity and privacy of the person who has died.
48. Ideally, people who are bereaved should be provided with a comfortable, private room where, if they wish, they can spend time alone, or with the body of the person who has died, immediately after the death.
49. If the death is to be referred to the coroner, it is important to check in each case whether drips, tubes, lines or other equipment should be left in place.
50. If the death is not to be referred to the coroner, an offer should be made to remove any drips, tubes, lines or other equipment, to close the eyes and mouth, and to arrange (or help to arrange) the body if that is what is wanted. The patient's partner or family

may wish to clean the body of the person who has died, brush their hair, or change their clothes. These and similar wishes should be met wherever possible, and help given if wanted.

51. Depending on their faith, families and/or others close to the person who has died may benefit from the support of the hospital chaplaincy service which may also provide a link with representatives of a variety of faiths or other organisations in the community. It may be helpful to explain the kind of support these groups of people can offer.
52. Relevant professionals in the community (especially the GP), including any social care professionals known to be in contact with the patient, should be informed about the death as soon as possible and certainly by the end of the next working day. There should be an agreed protocol to ensure that information is passed on quickly and confidentially. Families, or those close to the person who has died, need to know who has been informed and why.
53. In all of the above, the ability to listen and communicate sensitively and be aware of religious, cultural or other needs will be paramount.

CARE AND STORAGE OF THE BODY

54. All those whose role involves care of, or contact with a body, at whatever stage and in whatever way, should respect the dignity and confidentiality of the person who has died and ensure that the body is secure at all times.
55. Nothing should happen or be done to the body of a person who has died without the knowledge of those closest to that person. Those responsible for the care and storage of the body should bear in mind that relatives or others may wish to be consulted or involved. They may, for example, wish to be involved in laying out the body.
56. At an appropriate time after the death, the body should be moved to the hospital mortuary. The timing of the move will depend in part on hospital facilities but relatives' wishes should be taken into account as far as possible. Bodies should be moved discreetly.
57. It is recommended that NHS Trusts have in place:
 - secure systems for the identification of bodies, in order to ensure that the correct body is prepared for viewing and/or released for cremation or burial;
 - adequate facilities for the storage of bodies. Guidance is available on what to take account of when improving or rebuilding mortuary facilities.¹⁷
58. Ideally, relatives and others should be able to see and spend time with the body of the person who has died when they wish to do so, with as few restrictions as possible.

¹⁷ *Facilities for Mortuary and Post Mortem Room Services, NHS Estates 2001 HBN 2; <http://www.nhsestates.gov.uk>*

For this purpose, mortuary facilities would need to include at least one private, comfortable room where a body can be seen by relatives and others. Good practice guidance on mortuary services is currently being developed by the Department of Health.

59. If a death has been referred to the coroner, opportunities for the family to see and care for the body may be restricted. Consideration should be given as to how best arrangements can be made for the family to discuss (or receive) information from the Coroner or Coroner's Officer and close liaison with those agencies is therefore important in this respect.

CERTIFICATION AND REGISTRATION

60. Relatives should receive information (both orally and in writing) on the certification and registration of a death. It is important that Trusts work closely with their local registry office to ensure that arrangements are as convenient and easy as possible for bereaved families.
61. When a death is certified, relatives (or another appropriate person) should be given the death certificate within 24 hours of the death, or, if the death occurs at a weekend or during a public holiday, by the end of the next working day. When it is not possible to provide a death certificate (for example, because the death has been referred to the coroner), this should be explained to relatives.

POST MORTEM EXAMINATION

62. As noted in paragraph 25, the Human Tissue Act (2004) (the Act) makes provision for the Human Tissue Authority (the Authority) to prepare codes of practice. The Act specifies amongst the codes to be dealt with by the Authority one on "communication with the family of the deceased in relation to a post-mortem examination". The Act also says that in relation to this code, the Authority "shall, in particular, lay down the standards expected in relation to the obtaining of consent". It is expected that the Authority will issue a code of practice on post mortem examination in 2005.
63. Pending the above, the Department of Health issued interim guidance on the post mortem procedure and NHS Trusts are advised to take account of *Families and Post Mortems. A Code of Practice*¹⁸ until new guidance from the Authority is available. The code provides detailed guidance for all those involved in communicating about post mortems with families and others close to a patient who has died, and makes recommendations about who should communicate with families and in what way.
64. In particular, the code seeks to ensure:

¹⁸ *Families and post mortems A Code of Practice*, Department of Health, April 2003

- that those close to the person who has died are given the opportunity to understand the reasons for hospital and coroners' post mortems, the processes involved, and their rights in the decision-making process;
 - that the wishes of the person who has died and those close to him or her are ascertained and respected;
 - that organs and tissues are not retained following post mortem without consent or other lawful authorisation (such as that of the coroner);
 - that the disposal of retained tissue and organs, stillborn or miscarried babies, fetal remains, and where possible all products of conception, is in accordance with the expressed wishes of the individual (where applicable) or those close to him or her, subject to meeting legal and health and safety requirements;
 - that general information about post mortem examinations is readily accessible.
65. Post mortem examinations must be carried out in accordance with the latest professional guidelines from the Royal College of Pathologists¹⁹.

BURIAL, CREMATION AND FUNERALS

66. Many bereaved people need specific information about how to arrange burial or cremation and how to organise a funeral. Written information on these topics should be made available (see above). Information on dealing with bereavement is also available from the Directgov website at <http://www.direct.gov.uk/Audiences>.
67. Impartial information about local funeral directors and their services should be provided. The National Association of Funeral Directors²⁰ provides guidance on the kind of support and range of services that can be expected from a funeral director. The National Funerals College²¹ provides a list of questions that can be used to survey local funeral directors' services.
68. Staff involved in talking with bereaved families and others about burial and cremation should consider visiting local cemeteries and crematoria regularly so that they are clear about what they are describing to bereaved families.
69. Care needs to be taken to identify implanted devices where appropriate as these will present a hazard at cremation. Further guidance on the safe management and disposal of healthcare waste will be available by the end of 2005.

¹⁹ Currently these are *Guidelines in Autopsy Practice*. Report of a working group of the Royal College of Pathologists, September 2002. Available at www.rcpath.org

²⁰ National Association of Funeral Directors available at <http://www.nafd.org.uk>

²¹ National Funerals College; 3 Priory Road, Bristol, BS8 ITX, Tel : 0117 954 5558

Procedure for funerals where the NHS Trust takes responsibility

70. Information previously issued by the Department of Health²² deals with patients who die in hospital and with patients' relatives before and after the death. It provides information on how hospital staff might deal sensitively with bereaved families and with related issues such as death-bed marriages, and handling the estates of deceased patients.
71. That information notes that providers have a duty at common law to dispose of the bodies of patients who die in their hospitals where no arrangements are made by relatives. Therefore arrangements (including paying for) need to be made for a funeral where:
- relatives cannot be traced; or
 - relatives cannot afford to pay for the funeral and do not qualify for Social Fund Funeral Payments.
72. This may be a burial or cremation unless there is reason to believe that the patient would have preferred a particular option or the relatives do so. If the relatives are unwilling to arrange and pay for the funeral but there is reason to think that they can afford to do so, the local authority in whose area the body lies should be asked to arrange for burial or cremation under Section 46(1) of the Public Health (Control of Disease) Act 1984. NHS Trusts will wish to make all reasonable enquiries consistent with the sensitivity of the situation before deciding that the relatives are unable to pay for the cost of the funeral.
73. In order to secure the best competitive rates for the services of funeral directors, NHS Trusts and/or Health Authorities may wish to collaborate in placing a contract within their area. Some NHS Trusts have access to endowment funds to fund the cost of the funerals. However, contracts should not be awarded on the grounds of price alone.
74. NHS Trusts may wish to consider the following recommendations²³:
- It is important to be sensitive to the wishes of the family and friends of the deceased, and to take account of any known cultural or religious beliefs of the deceased. The choice between burial or cremation should be made only after taking into account any known views of the deceased, including

²² HSG(92)8, Department of Health; <http://www.dh.gov.uk>

²³ HSG (97)43; Patients who die in hospital – supplementary. HSG(92)8 dated 23 January 1992 provides information for the NHS on dealing with patients who die in hospital. This is supplementary to the original and sets out the procedure for funeral and burial or cremation arrangements where NHS Trusts take responsibility for these arrangements; see www.dh.gov.uk

religious preferences; the views of relatives closest to the deceased; and in the case of long-stay patients with no relatives, the views of any friends in the hospital, including both patients and staff. Where there is no known preference, and the faith of the deceased does not indicate any preference, the NHS Trust should consider cremation as the preferred choice.

- The funeral arrangements should be made by a funeral director, who will be responsible for the service, the burial or cremation, and a memorial or plaque to record the deceased.
- A minister of religion or appropriate religious representative of the faith of the deceased should be present to conduct the service in accordance with that faith. Depending upon the faith of the deceased, the appropriate hospital chaplain, religious representative or adviser should be consulted at an early stage to advise about any special faith observances.
- The arrangements by the hospital should respect and meet the needs of families and carers from differing religious and cultural groups. For example, the needs of prayer and facilities appropriate to the faith of the deceased should be observed, which might include washing of the body by a designated person, dressing of the body and the length of time the body lies in state. Some faiths require the burial to be within a time limit, and NHS Trusts should be sensitive to such requirements.
- The location of the service and burial place should be appropriate to the faith of the deceased.
- The deceased may have been known to many people. However, even when there are no known relatives, other patients and staff members may regard themselves as family. They may wish to attend the funeral and should be given the opportunity to attend the funeral service. If the funeral is by burial, consideration needs to be given to whether a permanent mark of remembrance is possible. Where the burial site is not owned by a Trust, liaison will be necessary with whoever does – most often the Local Authority. If the funeral is by cremation, the ashes should be scattered or interred in a suitable place and a memorial plaque with the name of the deceased provided. In the rare cases where the full name of the deceased is unknown, the memorial can record the name by which the patient was known by the hospital.

DISPOSAL OF RETAINED TISSUE AND ORGANS

75. As noted in paragraph 25, the Human Tissue Act (2004) (the Act) makes provision for the Human Tissue Authority (the Authority) to prepare codes of practice. The Act specifies amongst the codes to be dealt with by the Authority one on “the removal from a human body, for use for a scheduled purpose, of any relevant material of which the body consists or which it

contains;” and one on “the storage, for the use for a scheduled purpose, and the use for such a purpose, of (i) the body of a deceased person, or (ii) relevant material which has come from a human body;”. It is expected that the Authority will issue such codes of practice in 2005. Trusts will wish to refer to any new guidance from the Authority when considering policies on disposal (including where existing holdings are unidentifiable or identifiable but unclaimed or where the wishes of the person who has died (or their next of kin) are not known).

76. In the meantime, Trusts will wish to ensure that the disposal of tissue and organs retained after a post mortem examination is in accordance with the expressed wishes of the person who has died (where applicable) or those close to him or her, subject to meeting legal and health and safety requirements. However, many bereaved people are not clear about what options are available to them in respect of burial or cremation or legal requirements and will need information before proper decisions can be taken.

ARRANGEMENTS FOLLOWING PREGNANCY LOSS BEFORE 24 WEEKS GESTATION AND FOLLOWING STILLBIRTH or NEONATAL DEATH

77. NHS Trusts will wish to consider putting in place arrangements for the respectful disposal of foetal tissue resulting from a number of different pregnancy losses including: ectopic pregnancies, miscarriages, early intrauterine foetal deaths and abortions. Arrangements for the respectful burial or cremation of the bodies of babies following stillbirth or neonatal death need also to be considered. A woman (or couple) may seek information on a Trust’s policy on disposal of foetal tissue. Staff will need to be informed about policy and practice in the Trust and be prepared to discuss arrangements with the woman (or couple), enabling her to express her own wishes about what happens to her baby’s body, remains or products of conception.
78. The Department of Health has issued information on the above in the form of “Question and Answer” briefing and this is available on the Department’s website²⁴. Guidance is also available in “*Pregnancy Loss and the Death of a Baby. Guidelines for Professionals*” published by the Stillbirth and Neonatal Death Society (1995 – currently under revision) and “*Sensitive Disposal of All Fetal Remains*” published by the Royal College of Nursing (2001).

REVIEW AND AUDIT

79. It is recommended that the management and delivery of services relating to death and bereavement are reviewed and audited annually (see also Healthcare Commission

²⁴ Q and A on disposal following pregnancy loss before 24 weeks;
<http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Tissue/TissueGeneralInformation/fs/en>

audit procedures, paragraphs 9-10 above). Procedures to help ensure this takes place might include:

- Collecting relevant quantitative and qualitative data;
- Obtaining feedback from staff;
- Obtaining feedback from a wide range of users of the service through for example, PALS and complaints monitoring, questionnaire surveys and one-to-one or group consultation;
- Involving users in discussions and decisions about service development;
- The use of agreed standards to audit the service.

80. The results of evaluating services should be disseminated (including to relevant stakeholders and agencies outside the Trust), properly discussed, and, as far as possible, acted upon.

WHEN A PATIENT DIES : PART II

Practical Solutions in Developing Bereavement Services

“The little things make all the difference”

Introduction

1. The experiences of those who have been bereaved following a death in a hospital suggest that often it is the little things that make all the difference, be it the language used by the hospital staff, the care taken when washing the deceased or the flowers in the waiting room.
2. Part II of this advice therefore describes some of the experiences of users of hospital bereavement services in order to highlight some questions and issues that could be considered when reviewing and developing these services. It also identifies the approaches used in some hospitals to address users’ concerns. Within Part II the following notation has been used:

❖ Issues and concerns raised by Bereavement Service users (the experience)

 Examples of how some hospitals have addressed these issues (solutions)

3. Obviously, this document does not contain an exhaustive set of issues and concerns. Those included have been selected to demonstrate the variety of issues that exist and to inspire changes that position service users at the centre of decision-making.

Approach to Death & Bereavement

4. The approach a NHS Trust adopts to death and bereavement can be underpinned by five key elements:
 - ❖ Continuing respect for the deceased regardless of their age
 - ❖ Acknowledgment that “bereavement” has taken place.
 - ❖ Equality of provision through a responsive and inclusive service
 - ❖ Admission, acceptance and openness about the deaths that happen within Trusts.
 - ❖ Death is a normal part of hospital work and not something to be hidden away.

5. There are a number of ways of achieving open, equal and respectful culture:

- Openly using the term “bereavement” around the Trust
- Talking about death as a natural event rather than in terms of the failure of medical treatment
- The development and implementation of care pathways for death and bereavement
- The inclusion of death and bereavement issues in all care pathways implemented within the Trust
- Hospital and Trust wide death and bereavement policies
- Inclusion of bereavement issues and practice within all tendering documents and contracts with external services
- Regular meetings of a cross Trust bereavement forum
- Bereavement coordinating groups between hospitals within the same Trust to liaise, coordinate and maintain consistency of Bereavement Services

6. Key to this is the acknowledgement of death and bereavement within all levels of hospital management and active consideration of how death and bereavement issues can be addressed as part of every decision made. Trusts may also wish to ensure that services are:

- ❖ Organised according to the needs of users rather than a routine made to fit around the organisation and other functions of the Trust.
- ❖ Implemented by skilful specialist staff with sufficient time, resources, organisational structures and support processes to enable them to fulfil their roles.

- Named individuals with responsibility for death and bereavement issues at executive level and within each management tier
- Employing Bereavement Coordinator(s) to act as champions for the service across the hospital.
- Identifying needs through a service user group
- Supply of sufficient and regular initial and in service training for ALL staff and volunteers on communication with people who have been bereaved

What is a Hospital Bereavement Service For?

7. The vast majority of people who have been bereaved neither seek nor need focused professional help or counselling in connection with their bereavement. Their families and social networks within the community often offer all the informal help they need, in circumstances commonly accepted as the “best place to grieve”. The Bereavement Services within a hospital are most likely to be involved in the immediate period following a death. At this time practical help and informal support can be of most value.

8. Hospitals are usually not the only providers of bereavement support in their area. Local statutory or voluntary agencies and specialist counselling services within the community may be better placed to carry out long-term support for those who have been bereaved. In each area the availability, accessibility, quality and type of services will differ according to local circumstances. Trusts or individual hospitals may wish to contribute to filling any gaps in local service provision. However, Trusts may wish to carefully consider how appropriate it is for them to offer formal long-term support or counselling services themselves and their capacity to do so by :

- Audit of bereavement support and counselling services supplied by statutory, voluntary and community groups available locally
- Assessment of local service provision, quality and accessibility and the identification of gaps in services within the local community
- Provision of bereavement support services not available elsewhere locally
- Joint funding of additional local community services either directly or through the supply of resources “in kind” such as accommodation.

9. In some circumstances, continuing emotional support from valued and trusted professionals who were involved in the care or treatment of the deceased in the period immediately prior to the death, can be beneficial for people who have been bereaved. This tends to be in circumstances where the manner of death is known to significantly affect the extent and nature of the bereavement process experienced, for example:

- the speed of death e.g. sudden and unexpected as in A&E
- the predictability of death e.g. long term illness such as cancer
- the role of others in a death e.g. accident, violence, clinical treatment
- age at death and lost years of potential life e.g. death of a baby

10. In these circumstances continued involvement by hospital staff is often appropriate and many hospitals have specialist staff to offer bereavement services for these special circumstances. Specialist staff could be :

- Specialist Bereavement Nurses in A&E and named bereavement lead nurses in each A&E team
- Specialist Bereavement Midwives and Bereavement Co-ordinators within Midwifery, Obstetrics and Gynaecology
- Specialist Bereavement Nurses within Pathology
- Preparation for death specialists within Oncology and other tertiary care areas
- Bereavement Co-ordinators within Children’s wards and Paediatric & Intensive Care Units
- Preparation for death and bereavement lead nurses within Intensive Care Units

11. People die in hospitals at any time of day or night and on any day of the year. Often bereavement offices/officers have limited availability and Trusts may wish to consider flexible working practices to ensure an equitable service for all their users. In doing this particular attention should be paid to the wishes of user groups, the temporal pattern of deaths within their hospital, the presence of cultural and religious groups within the area served and the accessibility of next of kin by phone during the working day.

- ❖ I had to wait all weekend as they did not open again until Monday morning
- ❖ I found out she had died that morning when I got back from work. There was a message on my answer phone. But I couldn't find out what I should do - the office was closed by then

Being there when someone dies in hospital

12. For those patients whose death is anticipated, due to their age or medical condition, being able to get things in order and make preparations for their passing can help. If relatives and friends are aware of these discussions and if the patient agrees, any decisions made, before death they will have time to develop a greater understanding and acceptance of the wishes of the deceased. This is possibly most important in relation to "do not resuscitate" decisions.

- Development of a "Preparation to die" policy for the terminally ill
- Policy and procedures in relation to "do not resuscitate" decisions

13. Being present at the death of a loved one and being able to stay and say goodbye can be a significant help for many people in coming to terms with their loss.

- ❖ They wouldn't let us be there over night – I just wanted to let her know I cared, to hold her hand.
- ❖ Only two people could stay with her – how could we choose which of her children could stay and which had to go?
- ❖ They made me leave the room, I didn't know what was happening

- No restrictions on the time people can visit and the length of time they can stay as death approaches
- Flexibility about the number of visitors as death approaches
- Policy and procedures relating to viewing of resuscitation attempts

14. The best intentions can be lost through inappropriate actions. In this context staff includes anyone who could be present around the time of a death - doctors, nurses, support and clerical staff, porters, cleaners, volunteers etc.

- ❖ It was all so rushed. They just seemed to want to get rid of him as soon as possible so they could get someone else in the bed
- ❖ They took him away but didn't tell me where he was going. They just left me behind.

- Moving the patient to more private areas of the ward or a private room as death approaches
- Moving the deceased to a special room after death to allow friends and relatives privacy whilst they said goodbye
- Flexibility to allow adequate time for people to say goodbye
- Policy and procedures concerning the identification, removal and transportation of the deceased within the hospital
- Training for ALL staff and volunteers working in the hospital on communicating with the dying and those who have been bereaved

15. Dealing sensitively with bereavement relies on people doing and saying the right things at the right time. This is usually easier for staff working in areas where death is a frequent occurrence. However, all staff should know what to do if someone dies. They also need to know how to communicate with people who have been bereaved and have the opportunity to regularly practise these skills. All staff and volunteers should be aware of, and be able to respond to, the variety of different reactions and expectations of those involved, especially those relating to the requirements of different religions and belief systems.

- Written protocols for dealing with a death for every ward and department
- All staff receiving induction and regular follow-up training on death protocols and communicating with people who have been bereaved
- Death and bereavement checklists for staff in each ward and department and any additional resources and materials required to deal with a death
- Death and bereavement issues a key element of all shift hand-over briefings
- Team briefings for all ward staff when a death is anticipated
- A lead person on death and bereavement in every team or shift
- Inclusion of death and bereavement within briefings for new, temporary and agency staff before they start work
- Documentation of how to deal with death and bereavement for different religious and cultural groups drawn up in agreement with local communities

16. All hospitals should have protocols relating to the removal of the deceased from the ward or department. These will include certain actions carried out for medical, legal and health and safety reasons. These protocols should reflect and accommodate the needs and religious beliefs of the deceased and those who have been bereaved, rather than just serve the demands of the mortuary or local Funeral Directors. It is important that those relatives and friends present understand why these actions are taken and wherever possible have the opportunity, if they wish, to help prepare the deceased for removal, for example by washing their face and combing their hair.

- ❖ They wouldn't take all that machinery away. I wanted him back as he was not with all the tubes connected.
- ❖ The nurse washed him – I wanted to do it but didn't like to ask
- ❖ I wanted to take her ring away with me - it was precious. They wouldn't let me take it off.
- ❖ She didn't have her teeth in. She never let anyone see her without her teeth

- Policy and procedures concerning removal of needles and catheters within wards and departments
- Policy on removal of pacemakers (Health Circular HN(83)6, Ownership of Implants and Removal of Cardiac Pacemakers after Death, March 1983)
- Policy on the removal of jewellery and other valuables by those present
- Policy on replacing and transporting the dentures and spectacles of the bereaved during removal of the deceased from a ward or department

Informing the next of kin

17. The person present at the time of death may not be the next of kin. Given the wide variety of relationships and family structures that can exist it can be easy to make incorrect assumptions about the roles people have. It is important that the ward or department decides at the earliest moment possible who is the next of kin, who should be informed in event of a death and who has permission to take any property away, visit, sit with the deceased or make decisions for them.

- ❖ I had just come to visit They seemed to expect me to take over and do everything but I didn't feel it was my place.

18. If the next of kin is not present at the time of death, the hospital will have to inform them that the death has occurred. This is usually done over the phone, although staff in some very small hospitals embedded within their community will go out to personally inform the next of kin. In some cases of sudden death the police will inform the next of kin. Telling someone a relative or friend has died has to be done with care and sensitivity and wherever possible this should be carried out by an experienced individual, with a special set of skills and the time

to be involved in a supportive conversation if required – however long that might take. However, it is recognised that this is not always possible for a number of reasons.

19. Hospitals need to respond to the needs of the next of kin at the time they are informed of the death wherever possible. This can involve spending a long time on the phone, making arrangements for next of kin or others to come to the hospital and even contacting other people on their behalf.
 - ❖ It was also so sudden, I could not believe it, I just wanted to go and see her even though it was gone 10 at night
 - ❖ I was my own – I didn't have anyone to help
 - ❖ It was Friday evening when he died but I had to wait until Monday morning before I could make an appointment to go and see him

20. Sometimes the hospital will not know who the next of kin is. In these circumstances the hospital should make every effort to identify and trace the next of kin in order to inform them of the death. This is not always easy. Hospital staff and volunteers do not have right of entry into the home of the deceased (even if they have the key). Nor do they have the right to go through the deceased's papers in order to identify a friend or relative who could help.
 - ❑ Contacting neighbours who may have been given a key by the deceased or who may know the next of kin
 - ❑ Setting up formal and informal networks with those who do have right of entry under certain circumstances such as the Police (Missing Persons Unit), Coroners Officers, Social Services, Environmental Health, RSPCA
 - ❑ Contracting a private firm which specialises in identifying and tracing next of kin

21. When the next of kin is told about a death, they are also usually informed of the need to go to the hospital to collect the documentation they will require. The details of these arrangements can be lost in the emotion of the phone call but it is these details that make all the difference when they do visit the hospital.
 - ❖ She was ever so nice about it but after she told me he had died I didn't really take in anything else
 - ❖ I knew I had made an appointment for the next day but I could not remember where or when and didn't know who to ask
 - ❖ She said I had to come to the hospital so I went – I didn't realise that she meant the next day

Arriving at the hospital

22. Finding your way around a hospital can be difficult at the best of times, especially if it is large. For someone who has recently been bereaved, trying to find where they have to go can lead to a high level of frustration and emotion. A few small changes within a hospital can make all the difference. For example:

- ❖ The parking at the hospital is difficult and expensive.
- ❖ There is often no space available in the car park.

- Dedicated parking spaces for Bereavement Services
- Free parking spaces outside the Bereavement Services building (where one exists)
- Parking spaces outside the Bereavement Services for older people and people who are disabled
- Reimbursement of parking costs for Bereavement Service users
- Drop off lay-by outside the Bereavement Services building

- ❖ It is difficult to find out where to go. I was told over the phone but I couldn't remember and I didn't write it down.

- All site maps include the location of the Bereavement Services
- All site maps identify all the locations someone who has been bereaved may have to go to.
- A leaflet available at all the main entrances to the hospital showing the route to the Bereavement Services

- ❖ The hospital was so big and the route so complicated I got lost

- Locating Bereavement Services near a main entrance to the hospital or in a separate building
- Labels, arrows or coloured wall and floor lines for the Bereavement Services from every main entrance into the hospital
- Using the word 'bereavement' at all times rather than sending people to 'PALS', 'Patient Services' or asking them to follow labels for other services

- ❖ I asked someone where I should go and they didn't seem to even know there was a Bereavement Service.
- ❖ I found it distressing having to keep saying I was there because had died.

- Acceptance that any member of staff, contractor or volunteer in the hospital could be asked for directions – porters, cleaners, nurses, those in shops
- Ensuring every new worker knows where to go as part of their induction
- Ensuring all information points/desks have the directions available
- Ensuring all agency and temporary staff are told about Bereavement Services as part of their introduction
- Ensuring every office, department and ward has the directions available
- Arrange for someone (often volunteers) to escort people to the Bereavement Services
- Including in training for all staff and volunteers an understanding of bereavement and communicating with those who have been bereaved

Creating an Appropriate Environment

23. It is recognised that asking the next of kin to return to the ward or department where the death occurred can be very distressing. There are exceptions to this such as after a death in a ward or department where the next of kin has built up a good relationship with the medical and nursing staff eg. in Intensive Care Units and Paediatric Intensive Care Units or departments where there are specialist bereavement support or facilities available eg. from midwives for the death of a baby or A&E nurses for a sudden death. However, hospitals might consider maintaining a level of flexibility if they are to respond to individual needs and requests. This would require close liaison between all the locations where Bereavement Services may be offered within a hospital, ensuring optimum communication across the Trust and a greater use of computer based record keeping.

- ❖ When it came to it I could not go back to the ward. I found the Bereavement Office but they didn't even know had died.
- ❖ I wanted to go and see where he had died but they didn't seem to want me to.

- The Bereavement Service is informed immediately of all deaths in the hospital even if they will not be directly dealing with the next of kin
- The development of an automatic “across the hospital notification” of deaths system
- Close liaison between staff at all locations offering Bereavement Services with a hospital including regular meetings of hospital bereavement forums or groups

24. Many hospitals now have special accommodation away from the clinical areas of the hospital for Bereavement Services and it is to these locations that most next of kin will be directed. The location, accessibility, size and environment of the rooms used by Bereavement Services can have an impact on the quality of service users experience. For example:

- ❖ I had to go down into the basement. It was dark and smelly and there was hardly anyone there
- ❖ I had to go to some tatty old building round the back of the hospital
- ❖ They had to come out and see me in the corridor because I couldn't get my wheelchair into the office

- Locating Bereavement Services in offices near one of the main entrances to the hospital
- Locating Bereavement Services in their own building on the edge of the hospital site
- Ensuring that the Bereavement Service offices are accessible to everyone

- ❖ Even when I got there I didn't know I had arrived – there were three closed doors but none of them were labelled “Death” or “Bereavement”
- ❖ When I went in someone was arguing with a member of staff – everyone else there seemed to be making complaints
- ❖ I went in and everyone looked up at me – I didn't know what to do

- Having a dedicated Bereavement Services office(s) rather than sharing accommodation with other services
- Labelling the offices using the appropriate words
- Identifying the reception point and procedure clearly for those who have arrived

- ❖ I waited in the corridor until it was my turn
- ❖ I sat waiting for my turn in a very noisy room with lots of people coming in and out and laughing
- ❖ I seemed to wait for a long time and no one came to see me

- Ensuring that someone greets the next of kin as soon as possible and gives some indication of how long they will have to wait
- Provision of a dedicated Bereavement Services waiting room or area away from the bustle of the hospital
- Creating a waiting room environment that is peaceful, warm and looks different to the rest of the hospital

- ❖ We met in a room, it was an ordinary office really, nothing special, people kept coming in and out and the phone kept ringing. It was like she wasn't a person anymore, just a file and bits of paper.

- Providing a separate room to meet people who have been bereaved individually
- Provision of a room to discuss the deceased in private so that the next of kin can show emotion in whatever way they need
- Creating an environment in the meeting room that is comfortable, peaceful and warm and looks different to the rest of the hospital
- Closing the door to the room to create privacy and people knocking and ask permission to enter if they have been invited to attend or in an emergency
- No phone in the meeting room
- The flexibility and facilities to allow people to stay as long as they wish, ask as many questions as they wish and see who ever they wish

- ❖ I got all flustered and I needed to go outside for some fresh air
- ❖ I needed some time to just sit – the garden was so quite and peaceful, full of beautiful flowers

- Provision and maintenance of a garden of remembrance in the hospital grounds
- Provision and maintenance of a secluded outdoor area next to the Bereavement Office

Who will I see?

25. The attitude, knowledge and skill with which staff and volunteers interact with people who have been bereaved is pivotal to achieving a good quality service. This is especially so for those specialist bereavement staff who meet the next of kin in the hospital.
- ❖ She was just brilliant – I hope the hospital appreciate how good she is
 - ❖ I couldn't have got through that day without her help – she just seemed to know exactly what to say
 - ❖ I listened to the doctor talk about why he died but it didn't mean anything until the lady explained it to me
26. Specialist bereavement staff can offer support to each client in a proactive, responsive and empathetic manner even though they will often not have known the deceased nor met the next of kin before. The same level of professionalism should be afforded to all bereaved persons in a manner that is responsive to their personal and emotional needs and their religious and cultural status. During their meeting with the next of kin, specialist bereavement staff may offer information and advice; answer questions; make practical arrangements; arrange access to doctors or translate the words used by specialist clinical staff into everyday language without loss of accuracy or meaning; organise a viewing of the deceased and establish themselves as a key point of access within the hospital and or to other services available in the local community. In some hospitals they may be

involved in initiating discussions of other issues such as benefits, funeral arrangements and consent for hospital post mortems or donations. They may offer information about relevant local agencies such as registrars, bereavement support and counselling services and may even make appointments with those agencies. The emotional intensity of each meeting and the time taken to bring about a satisfactory conclusion will vary and often there may be a “queue” to manage sensitively.

27. Specialist bereavement staff can be advocates for the deceased and the next of kin in the face of often confusing professional jargon and apparent organisational rigidity. Yet, at the same time they are employed by the Trust and have responsibility to support, promote and represent the hospital in a positive way. They need to be able to interact with other staff at all levels from all disciplines in order to ensure that certain tasks are carried out swiftly and do not unnecessarily delay the process for the next of kin. An awareness of medical and legal issues will aid them in supporting and guiding some medical staff in completing necessary paperwork. Some bereavement staff are also involved in the development of resources and materials, drafting policies, procedures and pathways and training other hospital and community staff about death and bereavement communication and procedures.
28. Managing to achieve all this in a professional manner is not an easy job. It requires a specific type of knowledge and a high level of organisational, personal and communication skills and Trusts may wish to take this into account when recruiting staff.

- Grading key posts in bereavement services to reflect skill requirement
- Identification of key skills for Bereavement Officers for recruitment purposes
- Identification and funding of initial and in-service training for specialist bereavement staff to develop, maintain and enhance their knowledge and skills
- Offering specific formal and informal support mechanisms for staff involved in bereavement services

Documentation : What is needed?

29. Most hospitals have a written record of the procedures to be used following the death of a patient in order to complete a Fact of Death form (if used), the Cause of Death Certificate, a Cremation form (if needed), the documentation necessary to permit the release of the deceased from the hospital and to pass on the necessary documentation to the next of kin. Underpinning these procedures there will be a set of principles about what a good service involves including cultural and religious sensitivity and flexibility in order to enable equitable service provision

for every client. These principles should be consistently applied across the hospital. However, their application will need to be adapted to the specific needs and circumstances of each ward, department and service within the hospital.

30. Hospitals usually offer the next of kin written information to take away with them. This acts as a reminder of what was said in the meeting, gives further information and support and offer contact details for local and community services. In some hospitals additional written information is given to some clients about specific causes of death, involvement in a coroner's case, financial support such as funeral benefits and specific advice for clients known to be most at risk such as young widows. This written information is of most use if it is presented succinctly, in an accessible form and contains details of and contact numbers for local rather than national agencies and services. As a result many hospitals produce their own booklets and leaflets.

- Production and regular updating of a hospital bereavement booklet
- Finding additional funding for the production and updating of a hospital bereavement booklet through advertising, voluntary donations and taking a percentage of the "Doctors Payments" collected by the Bereavement Office on behalf of the doctors.
- Carrying out an annual review of the content of the written material offered to ensure its continuing accuracy
- Putting contact details and other information likely to frequently change on supplementary sheets to ensure information accuracy
- Involving a users group to identify and ensure that the content and presentation of written information is appropriate for those who have recently been bereaved

The Deceased's Property

31. Whilst at the hospital the next of kin will also be given any property the deceased had in the hospital. This property will include the deceased's clothing, other items they had with them in the ward/department and any valuables on their body or kept securely by the hospital. The return of property can be a cause of complaint from the next of kin and may require sensitive handling by bereavement services staff. The care with which these possessions are treated by the hospital will be seen as a reflection of the level of respect and dignity with which the deceased is cared for.

- ❖ I was given a plastic sack containing a dirty, screwed up, smelly heap of clothes, books and toiletries – that's not respect
- ❖ I was given a (supermarket) plastic bag full of clothes, all screwed up and damp
- ❖ They had thrown her books and stuff in the same bag as damp, dirty underwear and her wet flannel – it was all ruined
- ❖ They gave me her stuff in a black bin bag as though it was rubbish now she was dead

- ❖ I didn't want her nightdress, its no use to me, but they made me take it away. You would have thought that someone in the hospital could have used it
- ❖ I had to go to three different places all across the hospital to pick up his bits and pieces – it was a nightmare, it took me nearly two hours to sort it out
- ❖ I had to go back into the hospital the next week to get her jewellery because the safe wasn't open
- ❖ When I went in the bereavement office no one was there but I saw all her jewellery just lying on the desk – anyone could have taken it
- ❖ His wallet was just in the drawer. It made me wonder how much money had been in it
- ❖ Some things were missing - they must have given some of her stuff to my brother without asking me but they didn't seem to know who it had gone to
- ❖ I know she was wearing her engagement ring when she went in but it wasn't amongst the stuff they gave back to me

- Washing and folding all clothing before it is returned
- Guidance to all ward staff about the care and presentation of the deceased's possessions
- Acquisition of special bags for the return of property
- The return of damp and dry possessions in different bags
- Policy of automatically disposing of soiled clothing rather than giving it to the next of kin
- Policy of accepting unwanted clothing and possessions from the next of kin, storing them for a period of time in case they change their minds and then passing them on or disposing of them as appropriate
- A safe in the Bereavement Office for the secure storage of valuables due to be returned that day
- Provision of sufficient, secure storage facilities within the Bereavement Office
- Detailed documentation of personal possessions (especially those potentially of financial or emotional value) within the medical records
- The use of terms to describe jewellery and watches that do not make assumptions about what they are made of e.g. white metal, yellow metal rather than silver or gold
- A procedure to enable the timely collection of all possessions into one place so they can all be returned to the next of kin together
- Policy that all rings will be removed by the mortuary staff or Funeral Director in case they have to be cut off
- Documenting in detail the return of possessions, including a description of each item and a note about their condition., to be signed by the person who receives them

What else should happen?

32. The next of kin will have to register the death with the Registrar of Deaths whose offices will be somewhere within the local area.
 - ❖ I thought I would be able to do everything at once in the hospital
 - ❖ The Registrar's Office was miles away
 - ❖ It was three days before I could get an appointment. I lived miles away and I had to take another day off work

33. With so many deaths occurring within hospitals a close link between the Hospital Bereavement Services and the Registrar of Death's office would be beneficial.

- Provision of a jointly organised service to cover evenings and weekends for those whose religious and cultural backgrounds require a quick burial
- Hospital Bereavement Officers making appointments with the Registrar of Deaths on behalf of the next of kin when they meet
- Registrar of Deaths going to the hospital to register a death for certain cases such as stillbirths or where the next of kin also a patient
- Locating a Registrar of Deaths within the hospital for all or part of their working week

34. Although locating a Registrar of Death within the hospital site sounds attractive for the next of kin, hospitals need to consider the practicalities and implications of this arrangement carefully especially if it is only a part time arrangement. For example, their opening hours may not be appropriate for the visits to the hospital made by the next of kin, the next of kin may have to return to the hospital again to go to the Registrar, liaising appointment times may prove difficult and the next of kin may lose access to other support services offered by the Registrars Office or nearby by the local authority.

35. Whilst at the hospital, or at a later time, the next of kin may wish to see the deceased and spend some time sitting with them. This is often organised by Specialist Bereavement staff, who often have a close working relationship with the mortuary staff (if there is a mortuary on site) or local Funeral Directors. Many hospitals have a special location where viewings can take place such as a Chapel of Rest and some hospitals also have special Bereavement Suites within key departments such as maternity and A&E. As with all Bereavement Services the success of this experience will depend upon its timely and seamless organisation, the location and environment of the facilities available, the skilful support of the hospital staff and volunteers and the level of respect and dignity given to the deceased. The organisation of this service should give priority to the needs of the users not the organisational arrangements and convenience of the hospital and its staff. For example limiting viewing opportunities to set times only may be convenient and pragmatic for the mortuary services but is not necessarily pastoral nor supportive of some people who have been bereaved.

- ❖ Being able to visit at weekends and in the evenings shouldn't just depend on the goodwill of staff, it should be a right
- ❖ I wanted to see her but it meant having to come back the next day and I couldn't face going back to the hospital again
- ❖ His ex turned up and they just let her in to see him, even though she had left him ten years ago

- ❖ They just left me there. I didn't want to stay long but I didn't know what to do. I couldn't just leave her there on her own so I just sat and waited for ages for someone to come back
- ❖ I couldn't see her because there was no one available to take her to the Chapel
- ❖ They wouldn't let me touch him or be alone with him. I just wanted to give him a hug and say goodbye
- ❖ I wanted to see him but I had the kids with me. They wouldn't let them in and there was nowhere else for them to go
- ❖ I went to see her as arranged but she had already gone and the lady I talked to didn't know where she had been taken to

- ❖ The lady stayed with me and held my hand – it was a great comfort not to be alone
- ❖ She looked so peaceful as though she was asleep in an ordinary bed

- Procedures and personnel in place during evenings and weekends to allow viewings to take place.
- Policy on who has the right to view the deceased including the criteria used and the legal basis for refusing a viewing.
- The facilities and procedures that take into account the variations in family structures, family disputes, the ages of those who have been bereaved and differing religious and cultural needs
- Ensuring that transportation of the deceased from the mortuary to the viewing area is included within porters job descriptions and contracts with external service suppliers
- Policy on children viewing the deceased and making available Specialist Bereavement Support for Children services and child care facilities
- Accompanying people who have been bereaved to the viewing area and staying with them or nearby for as long as is required in case needed
- Utilising volunteers and/or the Chaplains Service to support those who have been bereaved whilst they view the deceased
- Ensuring the room, facilities, environment and presentation of the deceased are in line with professionally accepted codes of practice
- Ensuring the conditions of viewing for special cases such as those involving the Coroner or infectious diseases are fully understood
- Developing a policy and procedures to identify who can remove the body and when which details under what circumstances the hospital has the right to refuse to let the body be removed such as if the transportation and storage arrangements are thought to be insecure under Health and Safety Regulations

36. In many hospitals it is normal practice to write, often using a standard form, to the deceased's GP to inform the practice that their patient has died. The majority of the public and patients see the health service as a single entity rather than a group of organisational structures such as PCTs and hospital Trusts, each containing a range of vertically hierarchical departments. As a result they are liable to assume that if someone dies in hospital that all the services within the NHS will be told about it.

- ❖ Two days later the District Nurse came to visit. Nobody had told her
- ❖ The hospital kept sending me reminders about appointments even though he had died there

- ❑ Sending a letter to the Practice Manager so that everyone in the surgery is informed
- ❑ Developing IT based links between hospital and family and community services to ensure automatic and quick notification of a death
- ❑ Procedure whereby all relevant hospital services are informed of a death within 24 hours
- ❑ Using hospital computer system to send death notices to all relevant departments when the deceased leaves the ward/department or when the Bereavement Services becomes aware of the death

37. After a short period of time some hospitals make contact again with the next of kin. This demonstrates continued recognition by hospital that bereavement has taken place, respect for the deceased and gives an opportunity to offer further information and/or support. This contact is often made between 4-10 weeks after the death by a letter or card of condolence from the Bereavement Services, the ward/department involved or from a lead clinician involved in the care and treatment of the deceased. In some hospitals, following a child death or a death following a long illness, staff and representatives of the hospital often attend the funeral as mark of respect. Some maternity and children's wards send cards annually on the anniversary of the death and many hospitals have memorial books and special services and events to remember and commemorate child deaths. Although very few clients will contact the hospital again after their initial meeting with Bereavement Services, prompting further interactions should be done with care. To do so, hospitals will have to have in place the resources to respond if people do get back to them.