

Scottish Government Health Directorate

SHAPING BEREAVEMENT CARE

**Consultation on A Framework for
Action for Bereavement Care
in NHSScotland**

September 2010

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in NHSScotland**

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The Scottish Government
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Health Directorates**

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Dear Colleague

CONSULTATION ON "SHAPING BEREAVEMENT CARE"

I invite you to consider and comment on the draft guidance on developing bereavement care in the NHS in Scotland, "Shaping Bereavement Care - a framework for action for Bereavement Care in NHS Scotland"

The purpose of the guidance is to develop a recognition of the need for support of those who have been bereaved by the death of someone close, and to encourage health boards to clarify planning in this area.

The guidance will provide a framework for health boards to reassess their local policy and procedures around the time of, and following, the death of a patient and to do so in the context of the impact of such policies and procedures on the grief of those who have been bereaved. The guidance also provides an opportunity to examine the training and support available to all NHS staff whose work involves contact with the dying and the bereaved.

The consultation period ends on 2 December 2010. You can access the consultation document, questionnaire and respondent information forms on the Scottish Government website at:

<http://www.scotland.gov.uk/Consultations/Current> and we would be very grateful for your views and feedback.

Responses should be sent using the consultation questionnaire provided, by email to Bereavementcare@scotland.gsi.gov.uk or by mail to the undersigned

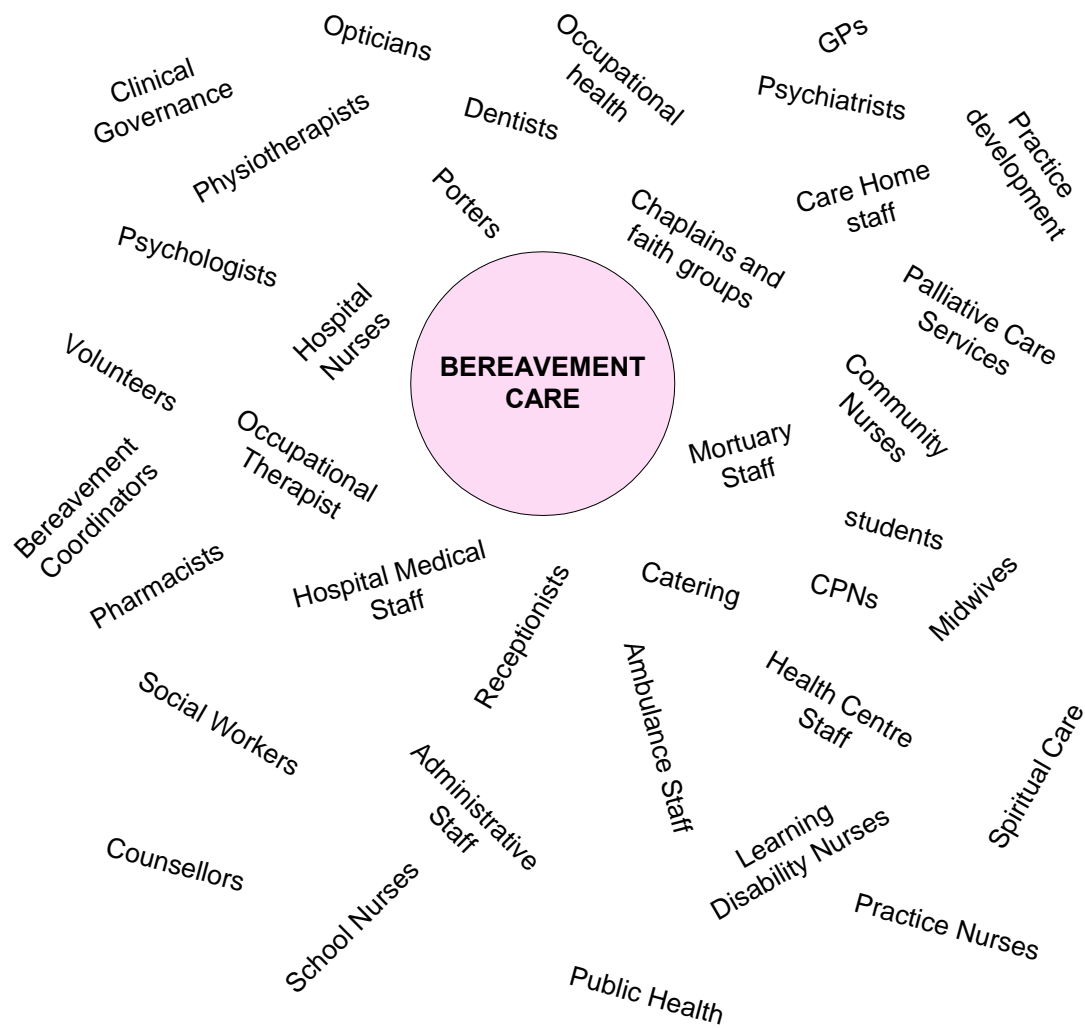
Yours faithfully

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Bereavement Care

Within health and social care settings the range of staff who deal with people who have been bereaved or have some involvement with bereavement care is considerable, from those who give directions or information at front desks to those who deal with the immediate distress and those who may need to provide care for the bereaved at a later date. For some staff the involvement may be acute and short lived, for others long lasting and for most staff there will also be a personal component. The diagram below seeks to begin this report by highlighting broadly the range of staff involved and the present perceived lack of a systematic approach to developing bereavement care in Scotland.



The Recommendations

Shaping Bereavement Care presents a framework for action to develop quality bereavement care within the NHS in Scotland.

Recommendations addressed to all Health Boards with patient contact

1. Each board should nominate an Executive Lead at board Level to be responsible for the development and delivery of quality bereavement care within the service. (Chapter 5)
2. Each board should identify a Bereavement Services Co-ordinator to lead the development of quality bereavement care and to promote partnership working (Chapter 5)
3. Each board should undertake a review of all current policies and procedures relating to care of the dying patient, and care of the deceased, to ensure that they reflect good quality care and to assess and reduce any real or potential negative impact of these processes on those who have been bereaved. (Chapter 2)
4. Each board should develop a policy on care of those who have been bereaved. (Chapter 3) The policy should reflect the principles of this framework and should seek to:
 - ensure that bereavement care is provided on an equitable basis to relatives and carers following a death, in ways that are responsive to their needs and which reflect spiritual, religious and cultural requirements;
 - ensure that the board's bereavement care services are adequately staffed and funded;

- recognise the frequent need for the newly bereaved to raise questions following a death and offer opportunities for them to do so
- promote a co-ordinated approach to bereavement care, both within the health care services and in partnership with other service providers, relevant external agencies and third sector bodies;
- emphasise the importance of staff education, training and support;
- where the NHS Board contributes funds to external bereavement services, try to ensure that bereavement care provided by such services reflects the spirit of ***Shaping Bereavement Care***

5. Each board should review the quality of printed information given to those who have been newly bereaved, and the consistency with which it is given to them. (Chapter 3)

6. Each board should develop a planned and consistent approach to bereavement awareness, training and education, which should be available, at appropriate levels, for all staff. (Chapter 4)

7. Each board should review its staff support structures to ensure that support is available for staff who are distressed by experience of death or trauma, and those who experience personal bereavement. Arrangements for debriefing should be reviewed in critical care areas such as Intensive Care and Accident and Emergency. (Chapter 4)

8. Recognising the exposure of staff to matters relating to death and dying, each health board should consider the terms on which staff return to work following personal bereavements. (Chapter 4)

9. Each board should establish lines of communication with other stakeholders including the Crown Office, Local Authorities, Funeral Directors, Registrars, relevant third sector agencies and independent burial and cremation authorities. (Chapter 5)

Recommendations addressed to specific Special Health Boards

10. NHS Education for Scotland should explore the development of training and education resources to support health boards in the task of training staff across the workforce in bereavement awareness and bereavement care. (Chapter 4)

11. NHS Quality Improvement Scotland should recognise the key messages of ***Shaping Bereavement Care***, as appropriate, in their current work, and explore areas where they can support health boards in the implementation of the recommendations.

Implementation and support:

12. Each health board with patient contact should produce a one year Action Plan for the fulfilment of the recommendations 1 - 9.

13. The Bereavement Project Manager appointed by SGHD should provide support to health boards during the initial implementation phase of the recommendations.

14. SGHD should support the establishment and maintenance of a national network forum to facilitate a link and sharing of good practice between bereavement co-ordinators and other partners in planning and delivering bereavement care. (Chapter 5)

CHAPTER 1

INTRODUCTION:

In this world nothing can be said to be certain, except death and taxes.

Benjamin Franklin 1706 - 1790

There is a range of evidence (Stephen et al 2006) that the way those who have been bereaved experience the events around the time of death will influence the trajectory of their grief journey. Where health services get it right, showing empathy and providing good quality care, bereaved people are supported to accept the death, and to move into the grieving process as a natural progression. Conversely if the health services get it wrong, then bereaved people may experience additional distress, and that distress will interfere with their successful transition through the grieving process, with implications for them, those around them and for the social economy of the nation.

1. This Framework is addressed to health boards in Scotland to guide them in the development of good quality bereavement care in their area. The Framework may also inform the development of similar quality bereavement care in other areas of practice such as social work and education.
2. While the situation in each Board area will differ with respect to the numbers of deaths, and the contexts in which people die, and while there are significant geographical and cultural differences across Scotland in the approach to death and dying, the Framework seeks to introduce certain basic requirements for all Boards and to outline parameters within which the development of bereavement care should be planned and implemented.
3. The term "Bereavement" is frequently used in the health and social care to refer to any matter relating to the death of a patient or client. For the purposes of this document, the following terms are used with the specific meanings noted (Stroebe et al 2008)

- Bereavement: the objective situation of having lost someone significant through death
- Grief: the primarily emotional (affective) reactions to the loss of a loved one through death
- Mourning: the public display of grief, the social expressions or acts that are shaped by the (often religious) beliefs and practices of a given society or cultural group (p5)

4. Within this document the term “those who have been bereaved” has been used to denote those people who were close to the deceased and are significantly affected by the death. While this may normally be family members or other carers, it is recognised that this is not always the case. It is also recognised that staff who cared for the deceased may be among those who experience bereavement following a death.

5. The aim of bereavement care has been defined in general terms (Schut et al 2001) as;

“... to benefit the bereaved individual, to help him or her deal with the emotional and practical problems following the loss of a loved one” (p705)

Shaping Bereavement Care adopts the assumption used by Stephen et al (2006) that the term “bereavement care”,

“may cover a spectrum of services from informal and formal befriending approaches, to care provided by health and social care practitioners before, at the point of death and beyond, to that provided by mental health practitioners for those who develop complicated grief” (p4)

6. One of the few certainties we face is that life is finite and that every person will one day die. That being so, grief and bereavement are the experience of all of us as we face the death of colleagues, friends and family. The very routine of birth-life-death, however, stands in contrast

to the way most people appear to avoid speaking of death and the way that bereavement has, all too frequently, been ignored in the health and social care professions.

7. Despite the publication by the Scottish Health Service Advisory Council (1991) of "Everybody's death should matter to somebody", offering guidance on care of the dying and those who have been bereaved in Scotland, little evidence exists to suggest that care of those who have been bereaved developed to any great extent within healthcare, other than in the specific areas of specialist palliative care and in a number of localised services, particularly around baby and child death.

8. In 2005, in response to a range of significant developments in health care, such as increasing public involvement, extensions of palliative care into non-cancer services, tissue and organ retention and increasing emphasis on meeting spiritual care needs, the then Scottish Executive Health Department, along with NHS Education for Scotland and NHS Quality Improvement Scotland commissioned studies on bereavement care in Scotland. That work carried out by a team from the Joanna Briggs Institute Collaborating Centre based at the Robert Gordon University in Aberdeen, consisted of a systematic literature review on bereavement and bereavement care (Wimpenny et al 2006), followed by a mapping exercise which explored the practice of bereavement care being delivered in Scotland (Stephen et al 2006). The literature review identified 13 key messages. The mapping exercise sought to combine the key messages into recommendations for action. It is these recommendations, which implied a need to re-shape bereavement care, which underpin the present document.

9. One of the recommendations in the mapping exercise (Stephen et al 2006) was the development of a national framework which would bring together the significant level of identified expertise, knowledge and experience and harness this with the

"genuine groundswell of support for the opinion that change was necessary across all sectors to improve bereavement care provision."

10. In a statement in September 2008, the Minister for Public Health and Sport¹ said: "The introduction of bereavement guidance is long overdue in Scotland." The Minister undertook that the guidance, whilst setting out key principles and advice for health professionals, would not in any way intrude on the individual's right to deal with bereavement in a manner they believed to be most appropriate to meet their particular cultural needs or circumstances, be they physical, mental, spiritual or a combination of all three.

11. It is in fulfilment of that undertaking that ***Shaping Bereavement Care*** is now presented to the NHS in Scotland. This Framework is a first step in putting bereavement care firmly where it belongs – on the agenda of NHS Boards in Scotland who, while accepting responsibility for the care of the living, and of the dying, must also accept a responsibility to address the needs of those who have been bereaved.

12. ***Shaping Bereavement Care*** is the outcome of debate over the past year among a wide-ranging multi-disciplinary project group and a series of specialist topic groups; much more it is the outcome of discussions with a wide range of people, both within, and outwith, the health service, and the experience of the many people to whom members of the project group have spoken, and with whom they have worked clinically and therapeutically, over several years. The document has been the subject of extensive consultation with a wide variety of stakeholders including health professionals, the voluntary sector, and groups representing bereaved people.

13. ***Shaping Bereavement Care*** makes reference to, and integrates with other Scottish Government policy initiatives including the call for a mutual NHS which underlies *Better Health, Better Care* (Scottish Government Health Directorates [SGHD] 2007), the development of spiritual care in *Guidance on Spiritual Care* (Scottish Executive Health Dept [SEHD] 2002, SGHD 2009 and

¹ Speaking at Pathways Through Grief, the first National Conference on Bereavement in a Healthcare Setting, Dundee 2008

NHS Education for Scotland [NES] 2009a) and the promotion of palliative and end of life care in *Living and Dying Well* (SGHD 2008).

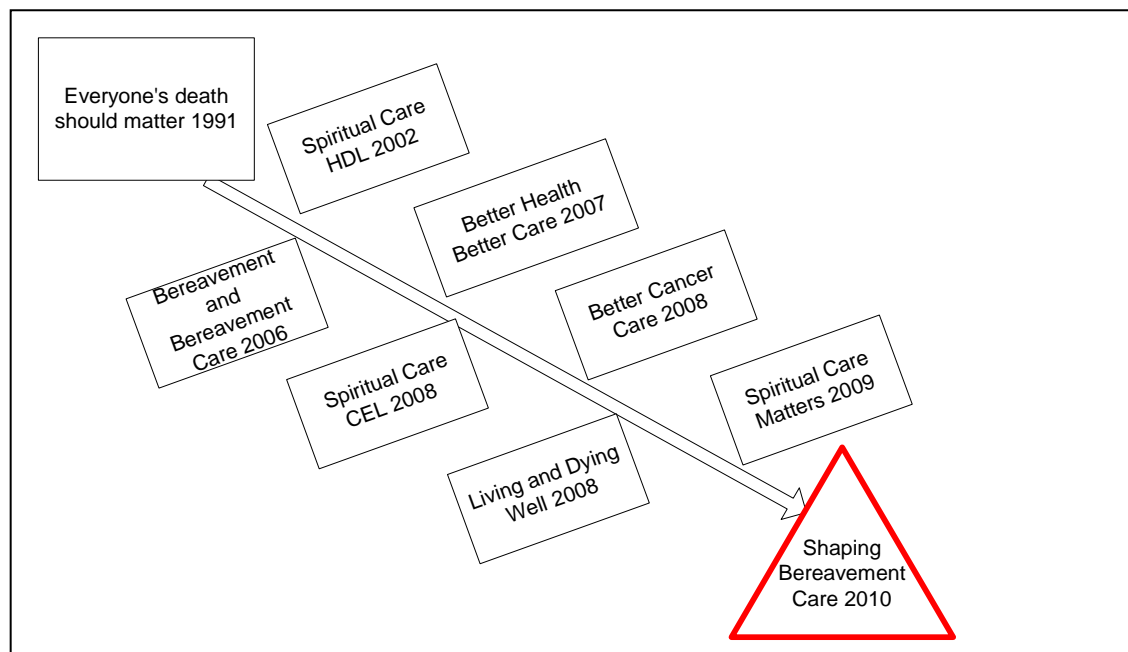


Figure 1.1 An idea whose time has come

14. ***Shaping Bereavement Care*** also fits the expectations of the The Healthcare Quality Strategy for NHS Scotland (2010) and meets the key drivers of that strategy:

- Person centredness – recognising and meeting the needs of bereaved people as individuals
- Patient safety – addressing areas of risk in the physical, mental, emotional and spiritual health of bereaved people
- Clinical effectiveness – drawing on the most recent research into effective support and care for those who have been bereaved

15. While ***Shaping Bereavement Care*** was commissioned for, and is directed to, the health services in Scotland, there is much within this framework for action which will be of interest to, and relevance, for other areas of public life in Scotland (including, for example, social care, criminal justice, and education) and those working in the third sector.

16. Whilst death, grief and bereavement are inherent features of all cultures it is clear from the literature that understandings of grief and

bereavement have changed over time. We now know more about bereavement in terms of its processes and impact (Stroebe et al 2001, 2008) and in such circumstances it seems appropriate to consider how care for those who have been bereaved can be enhanced. However, from the outset it is important that we caution ourselves not to become too prescriptive about grief reactions and their effect on bereavement and to remember that bereavement as a process, is affected by religious and cultural beliefs and by a range of mediators¹. The meaning of the loss to the person, the combination of risk and protective factors and the level of internal resilience and coping skills are important aspects. Moreover, grief is also mediated by social factors such as the age of the bereaved person, the circumstances of the death, the social background of those who have been bereaved and the extent to which mourning, as the public face of grief, takes place.

17. According to the General Register Office for Scotland, there were 55,700 deaths recorded in Scotland 2008 (GROS 2008). If we conservatively estimate the number of people who are significantly affected by each death as four it can be seen that a large number of people experience bereavement each year. While bereavement is frequently a very painful experience, and can be disruptive to daily living, most people experience bereavement as a normal life process. In general, “normal” bereavement involves a number of adaptationsⁱ until a point is reached where those who have been bereaved may be said to have adjusted to the death. In practice the intensity of their emotions diminishes over time to a point where the observer cannot discern an obvious cause for concern and where their functioning is no longer impaired.

18. To become overly prescriptive about grief reactions can influence our thinking and cause us to label or *pathologise* bereavement as an illness, which is not the intention of this document. At the same time, while the majority of those affected by these deaths will experience

¹ For example Worden (2003) outlines seven mediators of grief.

“normal” bereavement, there will be a significant number of people who are at risk of a more complicated grief reaction and for whom formal intervention may be required.¹

19. There is a spectrum of bereavement responses from “normal” grief to prolonged or complicated grief, any point on which has the potential to impact on people’s lives in ways which will diminish their health and well being for a period of time which may last from months to several years. In earlier research on grief, the end point of the bereavement journey was thought to be to relinquish the attachment to the deceased. More recent literature stresses the existence of “continuing bonds” between bereaved and deceased and that the preservation of these bonds is integral to successful adaptation (Field 2008).

The ability to detect and ameliorate acute distress and disability associated with bereavement should become ... recognised as a public health concern.

Prigerson et al (2008)

20. It is clear that enhancing understanding and care for those who have been bereaved will contribute to the health and well being of the people of Scotland. Evidence also exists to suggest that bereavement impacts not just on individuals who are bereaved, but also on those around them, for example family and colleagues, and on the various services of government and local authorities and on the productivity of the nation (Corden et al 2008, Abdelnoor and Hollins 2004). That being so, the detection and amelioration of the varied and complex symptoms of grief must be a matter of concern for government and for the economy as well as for the individuals concerned.

21. Historically bereavement care has largely been associated with palliative care. *Living and Dying Well*, the National Action Plan for Palliative and End of

¹ For example Prigerson et al have published a number of articles on the prevalence and nature of what they have called Prolonged Grief Disorder (PGD). Prigerson et al (2008) suggest that 11% of bereaved people will experience PGD

Life Care (SGHD 2008), drew attention to the need for the development of bereavement services:

"NHS Boards will require to carry out assessments of their current services and of patient/carer needs in order to develop appropriate delivery plans. This will include consideration of areas such as provision of respite care and bereavement services." [Paragraph 44]

22. In contrasting two concepts of palliative care, the old and the new, the authors of *Living and Dying Well* offered the diagram below, which, as well as illustrating the change in thinking about supportive and palliative care, represents the emergence of bereavement care as a feature of care, with a relevance both before and following the death of the patient. It is from this triangular block of bereavement care (outlined in red in Figure 1.2 below) that the present document draws its title, *Shaping Bereavement Care*.

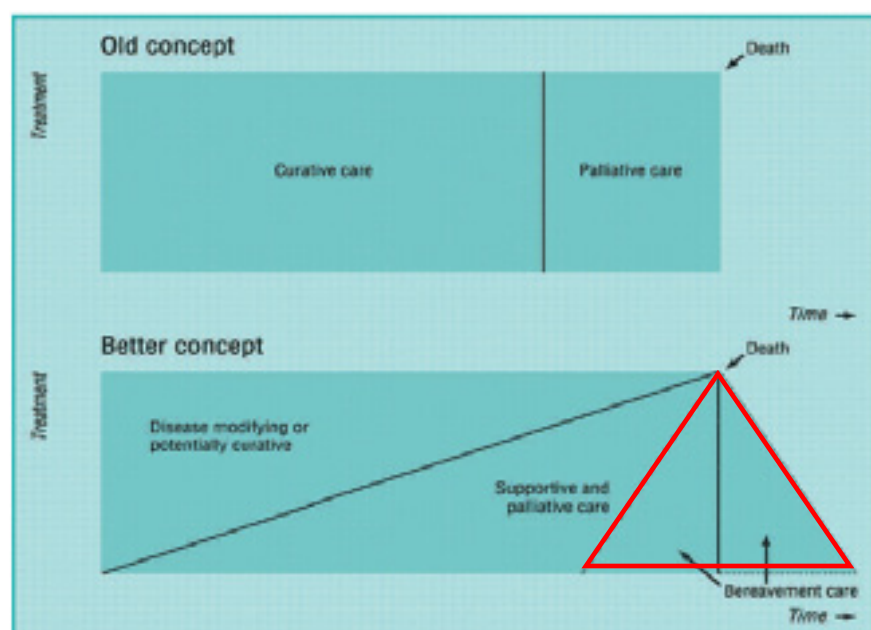


Figure 1.2 from *Living and Dying Well* (2008)

23. Given the inevitability of death, the numbers of people who die in Scotland each year, and the number of people who experience grief, it is perhaps surprising that death appears to retain a shadow around it which discourages conversation or debate: there appears to be an increasing taboo where, although people will avidly read in the press accounts of the

deaths of people here and across the world, there is a reluctance to think or talk about our own death or the deaths of those who are significant to us.

24. In its 2003 report *Public awareness of palliative care*, the Scottish Partnership for Palliative Care found that 70% of respondents thought that Scottish society does not discuss death and dying enough, and in 2009 a survey across the UK conducted by the National Centre for Social Research for Dying Matters (2009) found that while 68% of respondents indicated that they are comfortable talking about death, only 29% had discussed their wishes around dying and only 4% had written advance care plans. These, and similar figures, lie behind work being undertaken as part of the *Living and Dying Well* programme to explore,

"ideas and issues for addressing palliative and end of life care from a public health and health promotion perspective".

The working group is grateful to those pursuing this remit in *Living and Dying Well* for the opportunity to share in their work, and would support the work being undertaken to encourage conversations about death, dying and bereavement at national and personal levels.

25. Audit Scotland, in its 2008 review of Palliative Care gathered the views of almost 1000 bereaved families and friends. Among their findings they noted:

"Patients' families and informal carers often need support around, and after, the death of a family member or friend. Bereavement support is most readily available where the patient has been cared for by specialist palliative care services, but provision is inconsistent."

26. Audit Scotland (2008) also reported that while six NHS boards were reported to have specialist bereavement support provision in their hospitals or hospices,

"specialist psychological and bereavement support is largely hospice-based, so those who live a long way from a hospice are disadvantaged"

leading them to a recommendation to the Health Department that they should

"review the provision of psychological, social, spiritual and bereavement care to ensure it is available and appropriate to meet current and future needs".

27. The patchy nature of bereavement support in the NHS was also apparent in the preparation of *Shaping Bereavement Care*. Both in a survey of boards and in visits to boards across Scotland, it was clear that few Boards had designated senior managers with responsibility for bereavement care, and while there was evidence of policy and documents relating to, for example, the care of the deceased, mortuary procedures, security of property of patients who had died, these had seldom been drawn up from the viewpoint of, or measured against the needs of, those who have been bereaved. There was limited evidence of specific guidance or policies in place related to the support of those who have been bereaved. Against this, many examples of good practice can be found - evidence of a desire to provide support to those who have been bereaved - however, these tended to be limited to particular patient groups (often in palliative care), or specific units in individual hospitals.

28. Within Scotland, with its rich diversity of cultures and faiths, the development of spiritual care within healthcare has allowed for the needs of different groups to be recognised and prioritised. A number of recent publications (NHS Education for Scotland 2006a, NHS Education for Scotland 2009a, Scottish Interfaith Council 2007) have helped advance the development and understanding of spiritual care in the Scottish health context and *Spiritual Care Matters* (NHS Education for Scotland 2009a), contains a useful chapter on Bereavement Care as part of holistic spiritual care.

29. Scotland is also fortunate in its wealth of third sector groups who contribute to support and care for those who have been bereaved (Bondi et al 2003), and there are examples of good partnership working between statutory and third sector groups.

The Perth and Kinross Schools Bereavement Project is a collaboration between NHS Tayside, Perth and Kinross Council and Cruse Bereavement Care Scotland.

30. In order to promote best care for those who have been bereaved, the working group considered four major areas of concern. These are dealt with in detail in Chapters 2 – 5. Each of these chapter starts with an explanation of why the area is important in bereavement care, and then outlines guidance for improving care in that area. The chapters end with a summary of principles for action.

31. It is not possible to include, in this published report, all of the work undertaken by the project group. Along with ***Shaping Bereavement Care***, SGHD will publish on its website a toolkit of articles, references and good practice examples to support health boards in fulfilling the requirements of this report.

CHAPTER 2

Bereavement care around the time of death

How people die remains in the memory of those who live on.

Dame Cicely Saunders 1918 - 2005

...to reduce morbidity among the bereaved and to promote their continuing health, good care of the dying is categorically demanded

*Everybody's death should matter to somebody
(Scottish Health Service Advisory Council 1991)*

1. This chapter addresses the importance of commencing bereavement care prior to the death, where the death is expected, or at the earliest possible point in the event of sudden or unexpected death. This is in accordance with the new shape of bereavement care illustrated in Living and Dying Well (see Figure 1.2) This approach may therefore involve interaction with the dying patient as well as with those who will be bereaved by the death.

2. Lasting memories of what happened around the time of death can stay with those who have been bereaved for many years and can support or hinder them in their adjustment to the death. This is true of the way things are said as well as of what was said; the way things are done as well as what is done.

3. Particular types of death, such as death by suicide, the death of a child or young person, still-birth or the loss of a non-viable foetus carry additional emotional complications and the importance of the quality of care of the deceased and of the attitude of staff to, is heightened in these circumstances.

4. On occasions deaths must be referred to the Procurator Fiscal (Crown Office and Procurator Fiscal Service 2008). This chapter should be read with the understanding that in such circumstances restrictions may apply to areas such as choice over post-mortem examination or contact with the deceased. Sensitive communication with people who have been

bereaved, who frequently feel confused in such circumstances, will be of great importance in such cases.

5. The reluctance of people to talk about death contributes to the difficulty of preparing them for the impending death of somebody close. Evidence shows that where bereaved people have been prepared for the death, and for the events which follow death, the bereavement experience is usually easier. The Department of Health's End of Life Care Strategy (Department of Health [DoH] 2008) states:

"there is some evidence to suggest that assessing and addressing these issues early and providing appropriate support, is preventative healthcare, helping carers to prepare for their loss".

The Marie Curie Palliative Care Institute publish a leaflet as part of the Liverpool Care Pathway entitled *Coping with Dying* which helps people understand, and therefore be better prepared for, the dying process.

6. Where decision making has been shared with the patient and those who will be bereaved, and areas such as place of death, and funeral arrangements have been discussed openly, both the death and the grieving can be easier. The current developments in advanced care planning provides an excellent opportunity to promote such discussions, which may include issues such as post mortem, organ donation and Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) instructions.

7. Explanations of an impending death, and of the dying process need to be given in a way which is sensitive to the cognitive ability of those being addressed. It is important that children and those with learning difficulties, for example, be included in the discussions at an appropriate level, and that information is presented in a way and at a level which they can understand. The involvement of guardians or those holding a power of attorney can be helpful here. Collusion around the likelihood of death is particularly common with children and young adults who are often shielded from death, with the consequence that they do not develop coping strategies around bereavement.

8. Spiritual, cultural and religious needs vary from patient to patient. Person-centred care requires that each individual's needs are met as far as is possible, and the knowledge that dignity and respect for a patient's individual needs are continued through the dying process and in the aftercare of the deceased is important to people who have been bereaved.

9. All health boards will have in place policies and protocols governing what must be done before, at and following the death of a patient. These will include guidance on care of the deceased, last offices, certification, transportation of the deceased, and support for those who have been bereaved along with information on referral to the Procurator Fiscal and on issues such as infection control. On occasion these policies may owe more to clinical efficiency than to the care of people who have been bereaved. It is important that in all matters relating to the care of the deceased health boards should review all such policies and procedures to assess their impact on people who have been bereaved and to ensure they are consistent with this guidance.

10. For each health board, in the development of all new policies and procedures, it will be important that issues around death of the patient, care for the deceased and support for those who have been bereaved should be considered.

Prior to death:

11. Clear information should be offered to the patient and / or the close relatives as to what may be expected. Patients should be given the opportunity to speak to clinical and/or spiritual care staff if they wish and also be encouraged to discuss what they wish to happen both before and after death. Emotive issues such as post mortem examinations and tissue donation may need to be discussed and often the patient may have specific wishes which they should be encouraged to discuss with their families.

12. Where death is expected, the patient's wishes should be paramount and they should be allowed to choose where they wish to die if this is possible. Where a patient is dying in hospital, the patient should, if possible, be offered a single room with natural light away from the busy ward to give both family and patient peace. Any decision to transfer a patient who is dying to another area of care should be made in conjunction with the patient and / or the relatives.

13. In preparation for an impending death, staff should take care to check whether there are spiritual, religious or cultural requirements which need to be met either before or following the death, and if so should ensure that appropriate steps are taken. Copies of *A Multi-Faith Resource for Healthcare Staff* (NES 2006a) should be available in all areas.

14. Although it is generally accepted that patients should not die alone, some will express a preference for this. Where relatives or carers are present during the final stages, staff should offer support in a non-intrusive way, but should recognise that relatives in this situation may feel lonely and uncertain and should be able to spend time with the relatives if appropriate. Where relatives and carers are not present, and unless the patient has indicated a wish to die alone, staff should try to remain with the patient.

At the time of death

15. At the time of the death, relatives or carers may be present. Staff should offer support for those present with the patient, but also respect requests for privacy. In the absence of family or friends, staff should offer the same time and respect for the deceased as they would if relatives were present.

16. It is important to check that staff are aware of any spiritual, religious or cultural requirements relating to the time of death or to the care of the deceased. (See section 13 above)

17. Verification of the death should be carried out sensitively, and confirmation should be given to those present in a straightforward and empathic manner. Language used to inform relatives and carers about a death should be clear, as should information about what will happen next. People who have been bereaved should always be given the opportunity to ask questions and should receive clear unambiguous answers.

18. Where death is sudden or traumatic the impact on relatives and carers is likely to be heightened, and additional time will be required for initial adjustment. A designated member of staff should remain with, or be available to, those who have been bereaved throughout this period.

19. Where death takes place in a shared setting such as a hospital ward it should be recognised that seeing or hearing someone die can be frightening for other patients. Staff should address such a situation by being open and honest about what has happened. The attitude of staff to the deceased and to people who have been bereaved will do more to reassure other patients than the traditional dimming of lights and closing of doors and curtains as the body is removed, which was aimed at hiding the fact of death.

Care of the deceased:

Nursing care should not stop when the patient dies. "Last Offices" is the term for the nursing care given to a deceased patient which demonstrates continued respect for patients as an individual

Royal Marsden Hospital Manual of Clinical Nursing Procedures

(Dougherty and Lister 2008)

20. Last Offices, and any other required care whether at the place of death or in the mortuary, should always be carried out with respect and sensitivity.

21. Close relatives and carers should be invited to share in the care of the deceased, for example by participating in Last Offices or by sharing in any religious or cultural rituals.

In NHS Greater and Clyde mortuary staff prepare a box which contains everything that is required for care of the deceased and also contains guidance on last offices and spiritual/religious care along with copies of the printed bereavement information. These boxes are held on each ward and replaced following each death by the porters who collect the body.

22. Transportation of the deceased to any mortuary or funeral home should be carried out with dignity, and any arrangements to delegate responsibility for transportation should include this as a requirement.

23. Any discussions relating to post mortem examinations, referral to the Procurator Fiscal or organ / tissue donation should be facilitated by healthcare staff who have the relevant knowledge and who have received training in facilitating such discussions.

Care of people who have been bereaved:

24. Care for those who have been bereaved immediately following the death should, where possible, be provided by a designated member of staff, ideally one already known to the patient and relatives. It is important to ensure that people who have been bereaved have sufficient time with the deceased, either alone or in the company of the member of staff.

25. Where viewing the deceased is not possible at the place of death, arrangement should be made for viewing in the appropriate mortuary, where facilities should be designed to provide a calm, comfortable space for those who have been bereaved to see and spend time with the deceased.

The viewing room was nice, but the corridor to get there was a disgrace, the nurse apologised for the state of it.

Bereaved wife

26. Where viewing takes place in a hospital mortuary, people who have been bereaved should be accompanied to the viewing area by a staff

member experienced in such tasks and preferably one who is already known to the relatives or who knew the deceased. As mortuaries are frequently in less accessible parts of hospitals, health boards should ensure that the route to the mortuary is clearly known by staff, and that it is clean and well maintained.

Since employing a Bereavement Coordinator, NHS Lothian has undertaken a programme of auditing and improving bereavement facilities using an inclusive, arts-based approach to create calm, caring and dignified environments for bereaved families. Facilities standards are now in place which will inform ongoing maintenance and development, as well as future building projects.

27. The completed Medical Certificate of Cause of Death (MCCD) should be given to the bereaved relatives or carers along with a clear explanation of the certified cause of death and with clear information concerning on where, when and how to register the death. The MCCD may be handed over immediately following the death, or arrangements made for it to be given at a later date. Clinical staff should ensure any associated paperwork such as cremation forms are completed in a timely manner to prevent any delays to funeral arrangements.

"A nurse simply handed me an envelope and a holdall with my father's clothes and said to call if I had any questions."
A bereaved son

28. Clear written and oral information should be given to those who have been bereaved concerning what will happen to the deceased, and also concerning immediate tasks which they require to undertake [See Chapter 3].

NHS Tayside's policy on the care of the deceased explains how belongings should be dealt with and the board provides robust dark coloured carrier bags for property to be packed into.

29. The deceased's property should be sensitively packed and returned to the relatives or carers in accordance with board policy. Any expressed wishes for items to remain with the body should be met.

It was so important that Jean's teddy bear which had been with her through her final illness went with her when she died. It meant she wasn't on her own.

Bereaved mother

30. Arrangements for the care of deceased children and babies, including still-births and non-viable fetuses require particular attention.

31. **Principles for care around the time of death**

- Staff should be accepting of the fact that death happens and should refrain from being part of the collusion to avoid talk of death and use of words like dying and dead
- When a patient dies the care does not end and that continuing duty of care should be recognised
- Bereavement care should begin as soon as death is expected
- Sensitive communication with the dying patient and with close relatives from an early stage can ease the transition into grief
- Spiritual, religious and cultural needs should be identified and met both before death and after death
- Close liaison between departments of Spiritual Care and staff involved with the dying and deceased is important
- Those who sit with dying patients should be offered information about what to expect
- Dignity and respect should be shown at all times to the deceased, and those who have been bereaved
- Clear guidance on last offices and protocols around death need to be provided by each Board, but must be flexible enough to meet the needs of the deceased and those who have been bereaved.
- Accurate information should be given at all times, and should include all choices which are open to the dying patient or those who have been bereaved
- All staff who may have contact with the dying or should have received training at the appropriate level

- All staff involved in discussions around issues such as post mortem examinations, organ and tissue donation, certification of death should be fully trained for the purpose and regularly updated on changes to protocols and legislation
- Relatives and friends of the deceased should be given a clear point of contact should they wish to speak to someone before or after a death

CHAPTER 3

BEREAVEMENT CARE FOLLOWING THE DEATH

No one ever told me that grief felt so like fear

C S Lewis 1898 - 1963

We remember so clearly those last things... it makes a huge impact, those last impressions, they feature in your dreams..."

Bereavement Suite user¹

1. This chapter addresses the steps that healthcare staff should take to support people who have been bereaved following a death. The aim of such support is to facilitate an acceptance of the fact of the death and, through that, to lay a foundation which will enable good outcomes for those who are bereaved.

2. A wide variety of healthcare staff may be in contact with people who have been bereaved [See Frontispiece Page 3]. Staff should offer support to those who have been bereaved, within their competence, and be prepared to refer to others where necessary.

3. Bereavement is best viewed as a process that occurs over time. The journey of grief may begin at the time of death or at the point that the possibility or the imminence of death becomes apparent. For some the sense of disbelief at the fact of death may result in grief being delayed and grieving may only begin some days, or in exceptional circumstances months or even years following the death.

4. Each person is different, and will experience grief in an individual way. There are, however, recognised components and stages in grief of

¹ Quoted in Waller S, Dewar S, Masterson A, Finn H, *Improving Environments for Care at End of Life*, Kings Fund, 2008.

which healthcare staff should be aware and on which planning of care should be based¹.

5. As bereaved people experience their grief following a death, they frequently report in some detail their memory and perception of the words and actions of the staff who were present at that time. Staff will be able to facilitate the initial acceptance of the death through their attitude both to the deceased and to those who have been bereaved.

6. Bereavement can raise a wide range of practical, social, emotional and spiritual needs. Some people will have clinical questions about the circumstances leading up to the death. Some people will need information about practical matters, and the process of grief. Some will demonstrate emotional or spiritual distress and will require empathic care from staff. A number of healthcare providers have introduced follow up processes in which the opportunity for such discussions with clinicians is pro-actively offered and this is reported to lead to a marked drop in the number of complaints received around end of life issues.

7. In the longer term, a variety of needs may become apparent: some will benefit from peer-support, especially those who are particularly isolated or lacking in social support; some may require the opportunity to explore the emotional or practical implications of their loss: and a smaller number will need more specialist therapeutic intervention.

Guidance:

8. Every health board should adopt basic principles for the ongoing care of people who have been bereaved. These should recognise the need for dignity, sensitivity and discretion in the handling of the death and the recognition of the vulnerability of bereaved people. Respect for the spiritual, religious or cultural needs of the deceased and of those who have been bereaved is essential. Such basic principles should be incorporated in a Bereavement Care Policy.

¹ In particular see: Kubler-Ross (1969), Five stages of grief; Worden (2003), Four tasks of mourning; Stroebe and Schut (1999), The dual process model.

9. A designated member of staff should remain with, or be available to, those who have been bereaved in the period following a death until they leave the hospital.

10. Staff designated to support people who have been bereaved following a death should have received training for that role. Areas of responsibility for staff in that role might include giving explanations and information regarding what requires to be done following a death, ensuring that necessary paperwork is complete, accompanying those who have been bereaved in viewing the deceased, and packing and returning property. Where people who have been bereaved are asked to return at a later date for any of these items, the designated staff member should make the appointment, or ensure that people know where and when to go.

11. Clear and accurate information, both verbally and in written form, should always be given to people who have been bereaved. This will help them both with practical tasks, such as registration of the death and the funeral arrangements, and with the emotional tasks of starting to adjust to the death. Literature produced by the Scottish Government, and by the third sector could be integrated into bereavement packs along with local information. A balance needs to be struck – too much information will swamp the people it is intended to support while too little can leave them at a loss as to how to proceed. The content of such information should be carefully considered and staff should be aware of the content of information provided. Written information should always be shown to people who have been bereaved and a verbal explanation given of what it contains rather than just be handed over.

"I've been told by the sister not to speak to bereaved families as we don't do bereavement counselling."

Nurse in an acute hospital

12. In the immediate aftermath of a death, people who have been bereaved may experience a range of emotions. Staff members supporting bereaved people at this time should be aware that they may be numb, confused or in denial. They may experience anger and express it against staff, relatives or the deceased. Retaining information and remembering explanations may be difficult. Staff need to be clear and patient in these circumstances and ready to repeat information if necessary.

13. Following deaths in hospital, the walk to the exit can be lonely. It is good practice for a member of staff to accompany those who have been bereaved to the exit of the hospital – or to the chapel, quiet room or canteen if they prefer.

14. Prior to leaving the hospital, or shortly thereafter, people who have been bereaved should be given information as to whom they should contact if they have any questions regarding the patient's death.

15. Informal support for bereaved people includes the provision of good information about the grieving process, the provision of time and space for people who have been bereaved to tell their story, and reassurance concerning the nature of "normal" grief. Such informal support is the role of any staff member who may have contact with those who have been bereaved.

The Ayrshire Hospice has developed draft principles and standards for a bereavement service which will operate in an evidence based way to support those who have been bereaved by a death in the hospice.

16. With respect to more formal interventions with bereaved people, evidence does not support the provision of routine specialised therapeutic interventions to all bereaved people. Clinical interventions in grief should be of a high quality, should be delivered only by those specially trained in that area of work and should be targeted at those who, after a period of months, manifest a more complicated grief reaction and who request such help [See Chapter 1, para. 18]. It will not normally be within the remit of

health services to offer such interventions as part of routine follow up care, but rather as a distinct service to be accessed as required. Staff should be able to signpost such services where need is indicated.

17. It should be noted that children are also vulnerable to complicated grief and for them evidence does support early intervention. A number of specialist interventions have been developed to support bereaved children and details of services available locally should be held and maintained.

Staff in NHS Borders have developed a child bereavement service, undertaking training from a leading children's bereavement charity and then recruiting volunteers and cascading the training

18. Health boards should ensure that in major centres such as acute hospitals, resources are readily available to support bereaved people, and that a range of materials is made available to other localities.

19. Where health boards are unable to deliver specialised bereavement services they should initiate and develop partnerships with agencies which can demonstrate that they work to recognised and evidence based standards. Referral pathways to such specialist services should be agreed and health boards should accept responsibility for supporting such agencies.

20. Evidence suggests that while some bereaved relatives and carers may be reluctant to revisit the place where the person died, others may find comfort in doing so. An invitation to return for some kind of memorial event may sometimes be appreciated, and the provision of such events should be considered. Such events may include input on the process of grief as well as a time for remembering and sharing. Memorial events should reflect the diverse needs, experiences and beliefs of those who will attend and take part, and may therefore include both sacred and secular elements. Other types of follow-up such as phone calls and cards should be considered where this appears appropriate and where the service can be sustained.

21. Principles for Bereavement Care

- Dignity, sensitivity and discretion are essential in supporting bereaved following a death
- Spiritual, religious and cultural needs of the deceased and people who have been bereaved must be respected
- Staff supporting people who have been bereaved should be trained for the task and should work within their competencies
- Written and verbal information should be carefully prepared and sensitively presented
- Systems should be developed which facilitate the ongoing support of people who have been bereaved where required, including the opportunity for bereaved relatives or carers to return to meet with a named member of the healthcare team to obtain clarification of any points which cause anxiety.
- Follow up of people who have been bereaved should include awareness of risk of suicide, post-traumatic stress and prolonged grief
- Where necessary health boards should work in partnership with external quality assured agencies to provide on-going support
- A list of resources for bereavement support should be prepared locally and be available to all staff
- In areas where it is felt appropriate, memorial events, bereavement awareness sessions or other such measures should be considered

CHAPTER 4

BEREAVEMENT EDUCATION, TRAINING AND STAFF SUPPORT

Well has it been said that there is no grief like the grief that does not speak.
Henry Wadsworth Longfellow 1807 - 1882

Work in healthcare focuses on diagnosis, treatment and recovery, but our work also takes us into areas of pain and suffering, of death of the patient and the grief of the relatives or carers. And because we are human, we ourselves can feel grief when a patient dies,...

Spiritual Care Matters – NES, 2009

1. This section addresses the need to develop and provide education, training and staff support in bereavement care, with the aim of enhancing patient care through a well supported workforce. Providing quality education, training and support around bereavement results in staff having a more positive attitude towards bereavement care (Chan et al 2004). The information contained here may be used to inform pre- and post-registration courses for all healthcare professionals

2. According to the 2009 figures from the Information Services Division of NHS Services Scotland¹, within the NHS in Scotland there are over 168,000 staff employed with 40.4% in nursing and midwifery posts and 84% in frontline positions. A significantly high number of staff will encounter death and dying in the workplace on a regular, if not a daily, basis. As employers, health boards have a duty of care to their staff. The provision of quality education and training at appropriate levels will empower and enable staff to operate in this highly sensitive area and ensure quality care for those who are bereaved. The provision of support for staff who may be adversely effected by their exposure to traumatic deaths and to grief which may be emotionally draining, will be essential to enable them to continue to function effectively. Such education, training and support will also increase staff morale and subsequent retention, with all staff being able to offer support, not just those in specialist areas

¹ http://www.isdscotland.org/isd/CCC_FirstPage.jsp

(Charles-Edwards 2009) Increased support and education and training may also reduce the incidence of complaints.

3. The range of staff within the healthcare system who are involved in bereavement care is much wider than might be imagined (see Frontispiece Page 3). Traditionally education, training and support have been directed at staff working in oncology and palliative care, as well as some accident and emergency and intensive care settings. However, experience shows that staff working in diverse areas and at all levels will be engaged in bereavement care. This in itself poses a major challenge when planning education and support.

4. Responses to death and bereavement are highly personal. As human beings, staff members will carry their own grief and bereavements, as well as other emotional experiences, which will influence how they react to any particular circumstance. It is therefore essential that any education, training or support takes into account the past experience of the individual and recognises the need for self-awareness and reflection on their history and on their own mortality. What must also be taken into consideration is the complexity of family relationships in today's diverse society.

5. Overall, with regard to education and training in bereavement care, it is essential to offer the opportunity for ongoing development and support, as well as clinical supervision, in order to maintain good practice (Mackenzie and MacCallam, 2009). A range of courses and modules exists, however the quality of the available education and training is variable and there is an absence of guidance for managers as to what is required for healthcare staff at each level of involvement.

GUIDANCE - STAFF EDUCATION AND TRAINING

6. The need for appropriate staff education and training should be recognised by all health boards and a commitment to provide this should be included in the Board's Bereavement Care Policy.

NHS Forth Valley has appointed a bereavement facilitator to support staff on the wards to deliver good bereavement care by providing appropriate education in the working environment. The facilitator will also develop and implement policies around bereavement care, working with the staff across the organisation to ensure best practice.

7. ***WHO should be educated and who should deliver it?***

All healthcare workers regardless of role should have access to education and training in bereavement with the level being dependent on the nature of their role and their exposure to death and dying. It should be delivered by appropriately qualified and experienced staff.

8. ***WHAT should be delivered?***

Education and training should be quality assured and delivered at a level appropriate to the needs of staff attending, should be in accordance with the Scottish Qualifications Authority framework and contribute to meeting the core dimensions of the Knowledge and Skills Framework and should be considered in a range of dimensions focusing on the **practical**, the **psychological** and the **socio-cultural** aspects of care.

9. Education and training will give staff the knowledge, the skills and the confidence needed for a consistent approach to the giving of information about bereavement or at the time of a death. Staff need to know what information and literature is available and is used locally and also how to communicate such information.

10. ***WHAT core elements should be included?***

- Emphasis on the *normality of grief*
- Considering bereavement care in three stages, before the death, around the time of death and following the death
- Communication skills – including the management of distress
- Recognition of risk factors in grief and awareness of applicability, accessibility and limitations of assessment tools
- Theories and models of grief and the nature of grief
- Self awareness and reflection
- Practical aspects of local policies following a death

11. ***WHERE and WHEN should it be delivered?***

Education and training can be made available to staff in a variety of settings, for example:

- Planned education programmes as well as specific training according to assessment of need e.g. sudden death in A and E
- In any setting, dependent upon model of teaching and resources e.g. shadowing
- Significant event analysis could be used as an opportunity to enhance learning around bereavement care, by reflection on “good” and “bad” deaths
- Courses offered by Further and Higher education institutions, such as Colleges and Universities, Professional Organisations, Hospices and specialist organisations within the voluntary sector such as Cruse Bereavement Care Scotland (CBCS)
- Inclusion in undergraduate level education for all healthcare and social care professionals
- Inclusion in Post graduate level education and training
- Induction courses and local orientation courses
- Incorporated into updates on communication skills programmes
- Informal settings such as participation in a Bereavement Forum

12. ***HOW should it be delivered?***

A **tiered approach** (Figures 1 and 2) is recommended, based on the National Institute for Health and Clinical Effectiveness (2004) guidance that suggests three components to providing bereavement support:

- component 1: practical support and advice for all bereaved that would include an explanation of the normality of grief
- component 2: more formal opportunity to reflect on the loss
- component 3: specialist support required by those at risk of prolonged grief

13. The structure of education and training might therefore follow this model with core principles common to all (see Fig.1). Education could be developed based on this model as described below:



Figure 1: Levels of support required

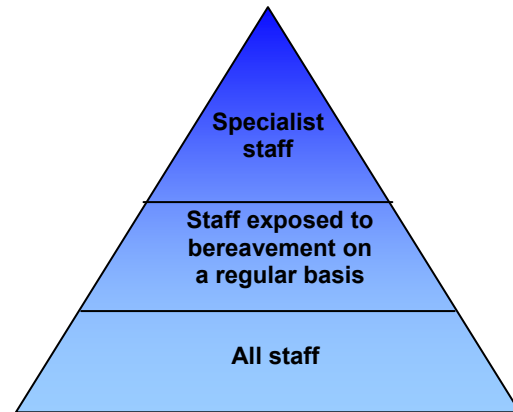


Figure 2: Levels of staff involvement

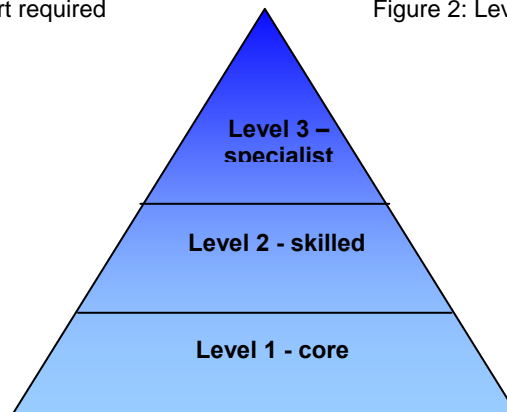


Figure 3: Levels of training

14. This would suggest (figure 3) a training and education plan as follows:

level 1 – Core education and training for all staff: core principles – e.g. grief is normal, theories of grief, communication skills – self awareness and how to respond to extreme distress

Reflects Knowledge and Skills Framework levels 1 – 2

level 2 – Skills training for staff exposed to bereavement on a regular or deeper basis: e.g. initiating end of life conversations; informing family/carer of death; providing practical and psychological support

Reflects Knowledge and Skills Framework levels 2-3

level 3 – Specialist education and training for specialist staff: e.g. Core Dimension 1 Communication - management of complex grief; specialised training for staff's particular requirements

Reflects Knowledge and Skills Framework level 4

15. Principles for Education and Training

- All education and training should be quality assured.
- All education and training should link to KSF
- All education and training should be quality assured, be in accordance with the Scottish Qualifications Authority framework and contribute to meeting the core dimensions of the Knowledge and Skills Framework.
- A range of teaching methods should be employed
- A resource list of where bereavement education can be accessed should be available to managers and staff
- A robust evaluation process should be developed for all education and training
- Those undertaking the delivery of bereavement education should be suitably qualified and have undergone training in communication skills, self awareness and reflection
- Due to the sensitivity of the subject matter, all educators and trainers should be sensitive to the need for, and issues around, self-awareness of participants relating to personal loss and grief
- Where appropriate, education and training should include raising staff awareness of the advance/anticipatory care planning philosophy
- Those working with patients with cancer should comply with the capability frameworks developed by NES (2006b, 2009b)

GUIDANCE - STAFF SUPPORT

16. A range of support should be made available to all staff working in the area of death, dying and bereavement, and a commitment to staff support should be included in the Board's Bereavement Care Policy.

17. *WHO by?*

While peer support should become the norm for all staff, creating a supportive culture, managers should take overall responsibility for ensuring that staff are supported. Medland et al (2004) recognised the need for peer support within an oncology team and the value of creating a supportive workplace where coping skills can be developed. Others who should provide support to staff will include spiritual care, occupational health, psychology services, palliative care teams as well as human resource departments.

18. Staff should also be made aware of agencies that they can contact for support after experiencing a personal bereavement, while acknowledging the fact that most bereaved relatives will receive effective support from friends and family.

19. *WHAT types of staff support?*

The type of support will be dependent on the situation and level of need and will fall into two main categories of **Informal:** such as *peer support, debriefings* and **Formal:** such as *significant event analysis, clinical supervision and formal counselling e.g. employee counselling*

20. Creating a culture that talks openly about death and dying will in itself provide support and this has been highlighted in *Living and Dying Well* (Scottish Government Health Directorates 2008). Consideration should be given to more formal clinical supervision (such as that provided for psychologists and for people in counselling positions) for those who, as the focus of their job, are providing bereavement care at a more intensive level, such as chaplains and bereavement service staff.

In NHS Greater Glasgow and Clyde the Bereavement Service based in the Women and Child Health Directorate offers a debriefing service to staff following the death of a child. This enables staff to explore their feelings in a safe, secure and supportive environment.

21. ***WHERE and WHEN should the support be provided?***

Where the support will be provided is again dependent upon the level of support required but it should always begin in the workplace and at the time or immediately following the death. In some areas, when a death is expected, support for staff should be provided by creating a culture of "checking out" that staff are coping.

22. Recognition should be given to the fact that events in staff members' own lives may make them more or less able to cope with stressful deaths or traumatic grief at work. Where possible sensitivity should be shown to staff by not exposing them to very stressful deaths within work too soon following a personal bereavement.

23. Local provision of support is more cost effective, but staff should also have the opportunity to access employee counselling services outwith the organisation if they prefer.

24. Senior staff should support the development of more junior staff in providing bereavement support by allowing exposure to difficult situations in bereavement within a supportive environment. Attempting to protect them from such circumstances inhibits their learning resulting in them feeling inadequate when qualified (Begley and Quayle 2003).

25. ***HOW is staff support provided?***

Informal peer support will be achieved by ensuring adequate and appropriate training of staff in the principles of bereavement care. Formal support should be provided by staff who are trained in communication and/or counselling skills. By creating a supportive culture, staff should

feel more able to deal with the areas of work where they are exposed more frequently to death and dying.

NHS Ayrshire and Arran has adopted a model of staff care which includes Critical Incident Stress Management (CISM). It provides a comprehensive staff support structure and represents an integrated “system” of interventions designed to prevent potentially harmful psychological reactions often associated with traumatic incidents. An example of how it works is to facilitate a debrief at the end of particularly traumatic deaths in casualty.

26. High risk areas should be identified and prioritised for regular support and update training, adopting a staged approach to educating staff where it is impossible to educate all staff at once.

27. In areas where there are ongoing relationships between patients, their families and a specialist team, it can be helpful to staff to sign and send sympathy cards, develop a memory board and increase chaplaincy and educational support (Medland et al 2004)

28. By building up a network of support, with a structured model and with a recognised lead for Bereavement Care in each organisation, staff support should be increased.

“My boss was very supportive. I was told that nothing can’t wait and I was allowed to withdraw from patient care until I was ready.”

Bereaved nurse

29. Managers need to be aware of the needs of staff who have experienced a personal bereavement and should adopt a more flexible approach to the work environment

32. **Principles for Staff Support**

- Management should recognise an obligation to support staff both through their involvement in the death of a patient and support of people who have been bereaved or when experiencing a personal loss
- A supportive culture needs to be created within each organisation to facilitate staff coping with bereavement especially in traumatic situations
- Time allowed for debriefing should become the norm
- Links with Spiritual Care departments should be increased
- A resource list of where to access support should be available for managers and staff alike
- Particular consideration should be given for staff in areas where they are exposed to death and dying on a regular basis or following particularly traumatic deaths

CHAPTER 5

COORDINATION OF BEREAVEMENT CARE

Bereavement is a darkness impenetrable to the unbereaved.

Iris Murdoch 1919 - 1999

Introduction

1. This chapter seeks to outline existing work on co-ordination of bereavement and bereavement care in the UK, consider the findings from a recent survey of health boards examining provision and outline the steps which should be taken to develop coordination both at Board level and nationally.

2. Co-ordination was already a key feature of the work undertaken by Stephen et al (2006) when they explored the provision of practice for bereavement care in Scotland. The box below shows a number of quotes from a range of practitioners and others which are notable in that they highlight a perceived need for co-ordination of services, from a variety of perspectives.

There is no co-ordinated approach to bereavement nationally

Practice Educator

There is a need for co-ordination of activity around bereavement care: the range and type of information; the range and type of access

Researcher

There are odd pockets but there is no co-ordination

Independent Bereavement Organisation

There is poor co-ordination between service providers... more collaboration between agencies is needed

Funeral Director

A co-ordinated approach to bereavement and bereavement care across statutory and voluntary agencies is definitely needed; different groups doing things but no-one knows exactly what is on offer

Support Worker for Children and Young People, Cancer support centre

Stephen et al. 2006

3. What these quotes all indicate is the need to develop some form of co-ordinated approach which will bring together a range of different groups both within and outwith the Health Service who are all engaged in bereavement care activity but as yet often work in isolation from each other. Providing a central point of contact would perhaps enable the gaps between different providers at differing points along the bereavement journey to be reduced. It may be possible to consider three distinct phases which need to be linked through co-ordination: prior to death or pre-bereavement, at the immediate time of the death and in the period following the death.

4. The extent to which co-ordination can be achieved and what it may consist of is not straightforward. Each locality will have differing needs and, within the terms of this framework, will need to address bereavement care in different ways to ensure provision of care across the three phases and for all groups is consistent.

Background

5. One of the first approaches to co-ordination of bereavement care in the UK was *When a Patient Dies*, undertaken by the Department of Health (DoH) for England and Wales in 2005. Whilst this was developed in response to the organ and tissue retention problems it sought to identify bereavement care as a wider responsibility and one which required greater understanding and acceptance by health service organisations. The principles and core elements on which bereavement care should be based were highlighted and clear indication of the need for leadership and coordination of day to day services was outlined:

"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."*

6. Each Trust was to be expected to develop local policy and practice related to all aspects of bereavement care and to

"ensure appropriate coordination of, and consistency between, all services that relate in any way to the needs of dying and bereaved people."

7. A more recent document from Northern Ireland (Dept of Health, Social Services and Public Safety [DHSSPS] 2009) identified standards of care for a range of aspects related to bereavement and bereavement care: raising awareness, promoting safe and effective care, communication, information and resources, creating a supportive experience, knowledge and skills, and working together. In addition an already existing group of area bereavement co-ordinators for each of the five regions in Northern Ireland contributed to these developments. It was clear from the audit undertaken as part of the information gathering work for these standards, that there was variation in practices within areas and within specialities. Creating a national set of standards was considered highly appropriate to develop and enhance services.

8. The above responses by other main health services within the UK highlight the need for someone within health and social care organisations to ensure that care at such a crucial time is appropriate and available. In addition, implementing standards and guidance would be a necessary component of this role.

9. To assess views within Scotland a questionnaire was sent to all health boards and other organisations, such as emergency services, to assess what is already being done in relation to training, support, resources, co-ordination and also what is already done well. Responses were received from eleven of the territorial health boards. The majority of territorial health boards were also visited. Overall, health boards identified

a variety of training, support, resources and co-ordination. Within this there was a particular emphasis on provision in specialist palliative care settings, which might seem obvious, but often negates death and bereavement in other settings where the majority of people will die. However, significant expertise exists in palliative care and this can be valuable to the development of services across all settings. Types and approaches to training also appeared to vary across Boards and there was a view that some coordination here would also be of benefit – possibly a national approach to bereavement training.

NHS Fife has developed a Bereavement Forum which draws together representatives from a wide spectrum of statutory and voluntary agencies working in a range of ways within the field of bereavement care. The forum meets once a year and provides an opportunity to explore ways which facilitate increased interagency sharing of information and good practice in bereavement care and enables wider discussion and consideration around potential future developments.

10. The manner in which the NHS collaborates or links with voluntary groups also seems, from the information provided, to be patchy. This may be because local groups aren't active or they do not feature in NHS perspectives on bereavement care. This is reflected in the variation in levels of funding of local branches of voluntary groups by different territorial health boards which may make it difficult for the voluntary groups operating nationally to maintain consistent standards across the country. There was evidence of some good developments being planned by some health boards but the range of responses appears to be a reflection of a lack of knowledge of what is available within a locality or of how it is provided from a particular perspective. There were a greater number of links for cancer and palliative care with fewer that reflected other areas of care. However, one health board which already has a co-ordinator in place provided a far more comprehensive picture of bereavement care in its area. This suggests that the appointment of a co-ordinator in each health board area could provide a greater consistency across Scotland, and in care for all settings, through provision of appropriate training, support and resources.

11. All health boards highlighted a willingness to develop services and to seek to do this in conjunction with others so that on-going developments could be fostered through being “*part of national network*”, “*Sharing of examples of good practice and nationally co-ordinated training*” “*.... learn what is happening in other areas.*” However, it was also noted that: *It would be difficult to reply to the question around co-ordination until there is a definitive model*”. Whilst a definitive model may be challenging, it is feasible, based on the views from health boards, a review of bereavement and bereavement care work in Scotland by Wimpenny et al (2006), Stephen et al (2006) and the strategy documents from England and Wales (DoH 2005) and Northern Ireland (DHSSPS 2009) to identify the scope of the co-ordination role and to make some clear recommendations.

The Co-ordinator Role

12. It is possible to identify some of the breadth of co-ordination that may be required in bereavement and bereavement care in Scotland. As this figure shows there is a challenging and considerable role for a co-ordinator as, at present, linkage between groups and services does not occur. This is accentuated when linkage across the bereavement journey is considered from before death, at death and after the death.

13. The role of the co-ordinator, as illustrated in Figure 5.1, is not envisaged to be solely one of providing direct care to people who have been bereaved but ensuring that their bereavement journey can be travelled with some degree of certainty and that consistent and appropriate provision of service is available in all areas or gaps are identified and solutions sought to address these.

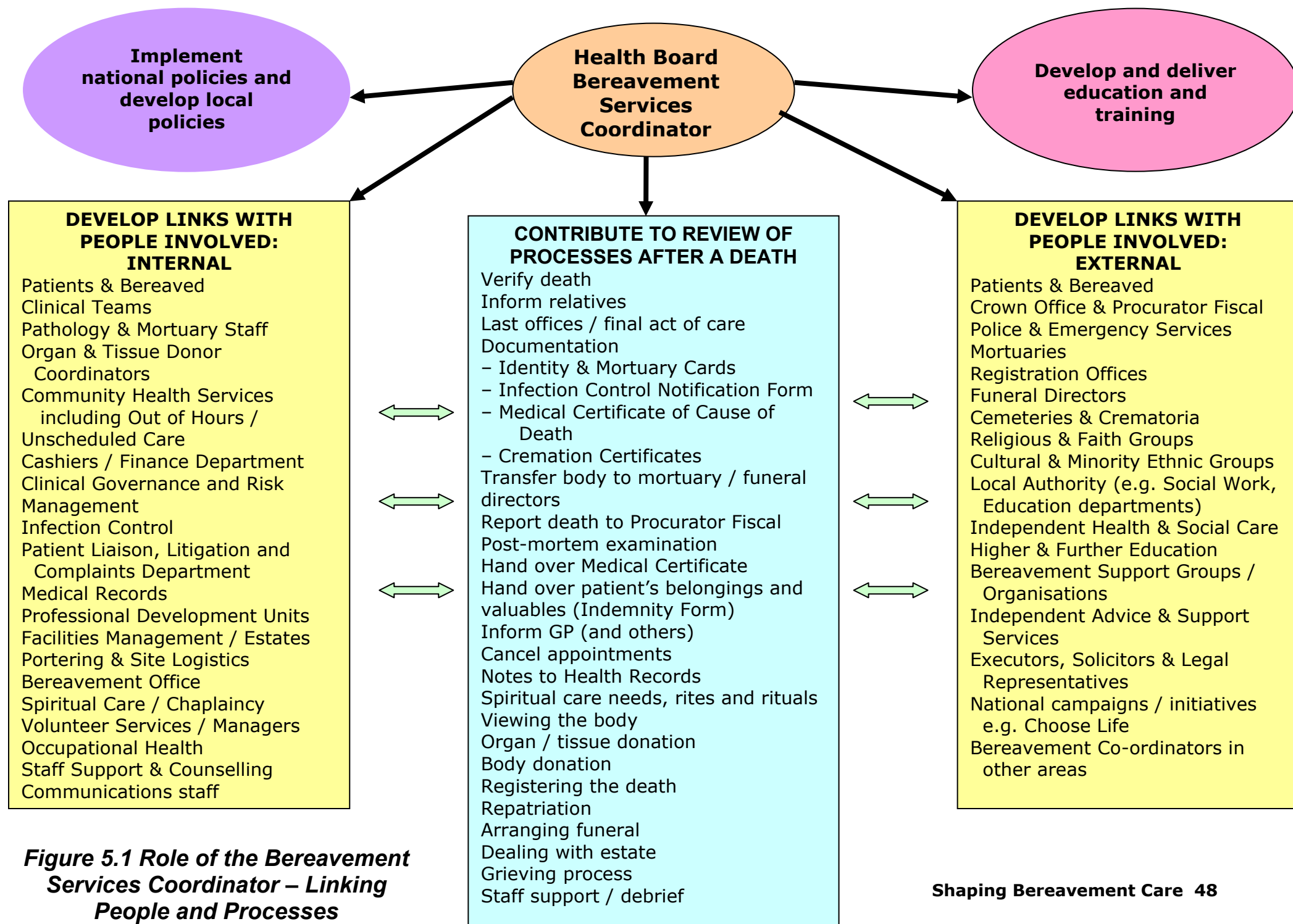


Figure 5.1 Role of the Bereavement Services Coordinator – Linking People and Processes

14. The box below highlights the benefits that have been established in NHS Lothian who appointed a co-ordinator in 2005.

NHS Lothian has raised the standard of bereavement care through establishing the post of Bereavement Coordinator. The coordinated approach has led to wide-ranging improvements, including: development and review of clear, consistent policies and guidelines; design and delivery of training and educational initiatives; new information resources; improvements and renovations to physical environments and facilities for bereavement care and better communication and liaison between NHS Lothian departments and external organisations.

If this could be replicated across all health boards, with the additional opportunity to allow all health board co-ordinators to share information and expertise within a national forum then bereavement care could be enhanced.

15. Principles for Coordination:

- Coordination should take place at two levels – national and local
- At both levels, coordination is required between those working with dying and bereaved within health care
- At both levels, coordination is required between those within healthcare and other services that relate in any way to the needs of dying and bereaved people
- Effective coordination needs to be resourced and supported by senior management
- It is appropriate for the health service to take a lead in coordination both locally and nationally
- At national level, coordination requires clarity about where bereavement services sit, and a named individual facilitating a national network
- At board level, coordination requires both an executive lead and the appointment of a bereavement services coordinator, who might sit alongside other relevant patient experience functions

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APPENDIX A

Members of the Project Group:

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* resigned during the course of the work

** joined during the course of the work

APPENDIX B

Acknowledgements

The members of the Project Group have been deeply engaged in the preparation of ***Shaping Bereavement Care***, both in meetings of the main group, and in the smaller topic groups. Without their diligence, and their knowledge, this work would not have been possible.

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Shaping Bereavement Care



RESPONDENT INFORMATION FORM

Please Note this form **must** be returned with your response to ensure that we handle your response appropriately

1. Name/Organisation

Organisation Name

Title Mr ☐ Ms ☐ Mrs ☐ Miss ☐ Dr ☐ *Please tick as appropriate*

Surname

Forename

2. Postal Address

<input type="text"/>		
<input type="text"/>		
<input type="text"/>		
<input type="text"/>		
Postcode	Phone	Email

3. Permissions - I am responding as...

Individual

☐

/ Group/Organisation

☐

Please tick as appropriate

- (a) Do you agree to your response being made available to the public (in Scottish Government library and/or on the Scottish Government web site)?

Please tick as appropriate ☐ Yes ☐ No

- (b) Where confidentiality is not requested, we will make your responses available to the public on the following basis

Please tick ONE of the following boxes

Yes, make my response, name and address all available ☐

or

Yes, make my response available, but not my name and address ☐

or

Yes, make my response and name available, but not my address ☐

- (c) The name and address of your organisation **will be** made available to the public (in the Scottish Government library and/or on the Scottish Government web site).

Are you content for your **response** to be made available?

Please tick as appropriate ☐ Yes ☐ No

- (d) We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Please tick as appropriate

☐ Yes

☐ No

CONSULTATION QUESTIONS

1. Do you feel the NHS should be involved in supporting those who have been bereaved:

- a) Immediately after the death? Yes ☐ No ☐
- b) Through the early days of grief (say first week?) Yes ☐ No ☐
- c) Until the bereaved person feels ready to move on? Yes ☐ No ☐

2. Do you feel that implementing the Shaping Bereavement Care Framework will help ensure that:

- Boards are more aware of how good planning of the relatives'/ carers' experience around the time of death and can contribute to better outcomes in their grief;
- Staff are better equipped to support bereaved people and will be better supported themselves in their responses to death and grief; and
- Bereaved people will feel more supported at, during and following a death and that their wishes, and the wishes of the person who has died, have been taken into consideration.

Yes ☐ No ☐

Comments

3. Do you agree with the recommendations set out in the Shaping Bereavement Care Framework document (pages 4-6)?

Yes ☐ No ☐

Please provide comments if you disagree with the recommendations or feel that there are some missing.

Comments

4. Do you think that it is important that spiritual, religious and cultural issues are taken into consideration in the delivery of Bereavement Care Services?

Yes ☐ No ☐

5. To what extent do you think this currently happens?

Comments

6. Please provide any additional comments/views you wish to share on the principles and content of the overall document.

Comments



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