

A follow-up bereavement service: 'completing the patient pathway'



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Abstract: The article describes an initiative, The Bereavement Care Follow up Service (BCFS) in Cambridge University Hospitals (CUH) NHS Trust which offers brief intervention and support for relatives following the death of a loved one in hospital. The service includes sending a letter of condolence, and offering an opportunity to talk to a member of the team involved in the care of their relative. It presents its historical context, its pertinence to grief theory and practice and gives a description and evaluation of the service. The service provides an alternative, less problem-centred pathway to the standard route for those with problems relating to the hospital and gives relatives the opportunity to voice concerns, and to seek information and answers from those best equipped to meet them (experts in clinical and bereavement care). Reported satisfaction with the service is high, both among relatives and staff.

Keywords: bereavement care pathway, brief intervention, hospital complaints, complex grief

Historical context

Following *The Alderhey Report* (Crown Copyright, 2001) there has been increasing interest in and guidance on the provision of Bereavement Services within the NHS in England and Wales. It is recommended that Hospital Trusts have clear written policies which include Bereavement Care Pathways (Department of Health, 2011), encompassing both the period leading up to a patient's death and the support that may be needed for relatives following it (Department of Health, 2005). Worden (1991) suggests that

how a person has died as well as the subsequent support available for those left bereaved are key factors in whether their grieving processes will be normal, or become more complicated.

Yet surveys have shown that although bereavement care is gradually becoming more integrated into hospital care, there is still a lack of assessment of patients' and relatives' needs and of any systematised follow up or support of relatives following the hospital death of a loved one (Department of Health 2005; NHS 2010). There is also concern about the gap between hospital

The BCFS Process

1. The BCFS is informed of all the deaths that have taken place within the hospital.
2. Within 2-3 days of a death: the Senior Sister/Charge Nurse from the relevant ward sends a condolence card to the next of kin (NOK).

The card is provided & pre-addressed by the BCFS (see Appendix 1).

(Letters are not sent where a relative is already in the process of making a complaint, where there is no NOK recorded or where the NOK has requested no further contact. Letters to NOK of patients under 16 years are administered through the Paediatric Counselling Department.)

3. 4-5 weeks later: A follow-up letter is sent (either by BCFS or the Senior Sister/Charge Nurse), inviting the NOK to a follow up meeting if they would like the opportunity to talk to a member of the team involved in the care of their relative (this is usually the Medical Consultant or Ward Manager, depending on issues/questions raised by NOK – see below). See Appendix 2 for sample letter.
4. The BCFS Lead contacts any relatives who request follow up to discuss/discern key areas of concern – whether a further meeting is required and (if so) with whom that might be helpful and most appropriate. The BCFS Lead liaises with those concerned to arrange a meeting and writes a letter to the relevant consultant/member of staff highlighting key areas of a relative's concern. This clinician then reviews the patient's history and notes in preparation for the meeting.
5. The BCFS Lead facilitates the meeting, based on relatives' particular questions/concerns. Following the meeting involving the clinician, he/she offers a short 'debrief' with the relative(s) to offer further care/support and to ensure that their hopes/expectations of the meeting have been met – or to see if any further action/follow up is necessary.

and community in the provision of good bereavement care. The Bereavement Pathways Timeline (Bereavement Care Association 2013) charts the different dimensions needed to deliver a continuous and comprehensive bereavement care service for both patients and relatives before and after a death. It particularly highlights the links necessary to bridge the existing gap between the support and advice given immediately following a death (which is often practical and hospital-based, culminating in the funeral) and the ongoing care and support that is needed in the longer term (which is more focussed on bereavement, back in the community after the funeral).

Added to this is growing evidence that a substantial number of complaints within hospitals may be related to grief and grieving processes. In Cambridge University Hospitals (CUH), a significant proportion of relatives who have been given standard death certification papers following the death of a relative send letters of complaint to the hospital 10-12 weeks later.¹ These complaints detail a variety of issues relating to matters of diagnosis care and/or treatment in the last few days or weeks of care (Healthcare Commission, 2008).

A survey of 16,000 complaints made about NHS organisations over a two year period (DOH 2008), showed that approximately 50% of them related to the provision and delivery of care in acute hospitals: 'Of these, no less than 54% related in some way to end of life care' (p24). When half of these cases were examined in more detail, the primary complaint was found to be about end of life care, specifically: poor communication;

lack of basic comfort, privacy and psychological care; and late (or no) referral for specialist palliative care.

Figures also show (NHS 2010) that there are fewer subsequent complaints from relatives of patients who have been of an End of Life Care Programme, before they died in hospital. When relatives do complain, their complaint is usually related to the breakdown of communication between staff/relatives/patient.

The pilot project

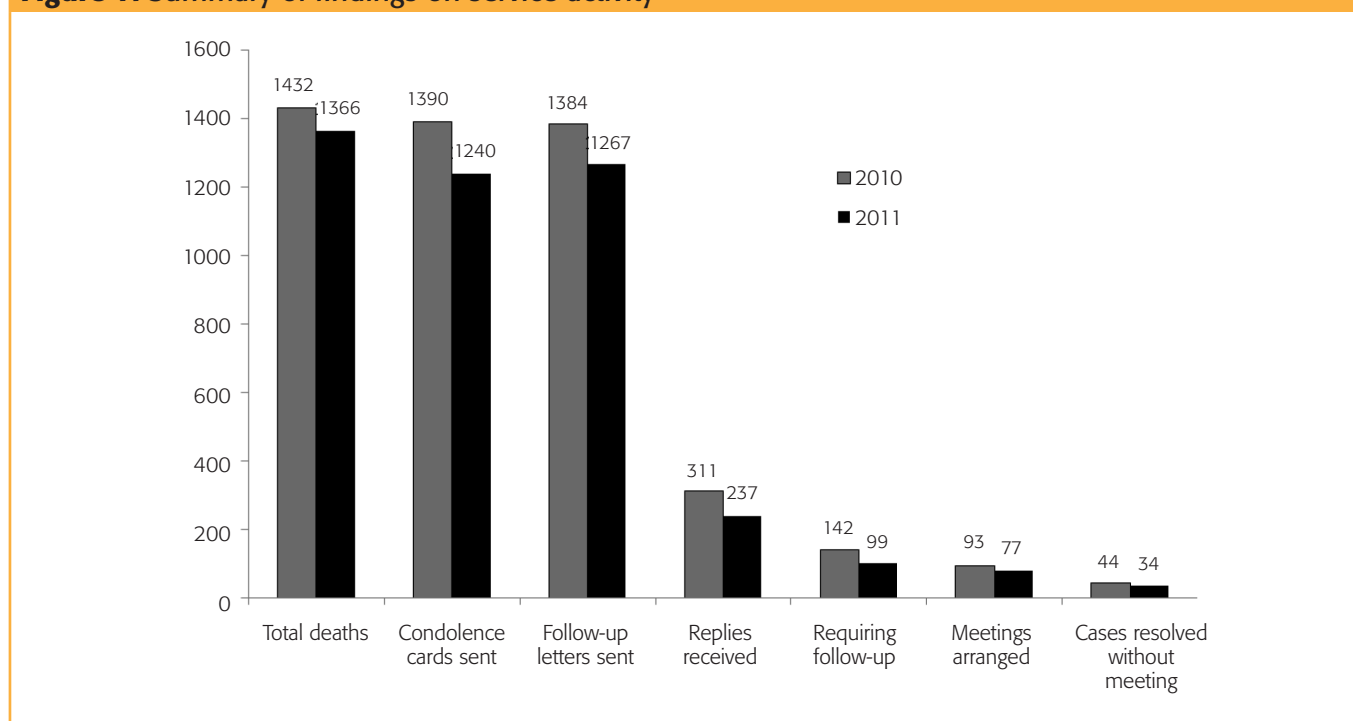
In response to these phenomena, a 'Bereavement Care Follow up Service' (BCFS – see Box) was first piloted on a couple of wards and then implemented systematically throughout Addenbrookes Hospital, Cambridge. This article aims to examine and reflect on the experiences of the BCFS over the first two years of its running, with a particular view to potential benefits and implications, both for the NHS and for the understanding and practice of bereavement care.

The process of the BCFS was developed by thinking through what might provide a timely and effective intervention in response to the difficulties described above (see *Historical context*). The information in the box above describes each step of the process: from the initial contact made by the hospital with bereaved relatives (a condolence card) following a death; followed by another letter four-five weeks later – offering the opportunity for them to return to the hospital for a 'follow up meeting' with a clinician who has been involved in the care of their loved one, so they can talk through any particular questions or concerns they have in relation to the death/loss. If the offer is taken up, the BCFS communicates their questions to the clinician

1 An emerging pattern observed by the Complaints Manager: hard evidence still needs to be gathered and analysed.

Table 1: Summary of findings on service activity

Item:	2010		2011	
Total deaths	1432		1366	
Cards Sent	1390	98% of deaths	1240	91% of deaths
Follow-up letters sent	1384	97% of deaths	1267	93% of deaths
Replies	311	22.5% of letters	237	19% of letters
Requiring follow-up	142	46% of replies	99	42% of replies
Meetings arranged	93	65.5% of followed-up cases	77	78% of followed-up cases
Cases resolved without meeting	44	31% of followed-up cases	34	34% of followed-up cases
Cases resolved through meeting	93	100% of meetings arranged	77	100% of meetings arranged

Figure 1: Summary of findings on service activity

in preparation for the face-to-face meeting. After the meeting, any further follow up is arranged, or the case closed.

The primary aims of this article are to:

- Describe the activities of a BCFS initiative.
- Review routine service data to explore people's experience of the BCFS and how this relates to grieving and grief support.
- Consider intended and unintended impacts of the service.

Data collection and analysis

Routine data was gathered directly from the BCFS database, where a range of information had been recorded at each stage during the process. This included details of: those to whom condolence cards and follow up letters had been sent; responses

(together with the means of response – whether telephone, letter or email), highlighting anything considered to be of relevance.

Information was also gathered by other means: handwritten notes (which are always taken during phone calls); then typed/transferred onto the database. The information gained from any such conversation was obviously deeper and richer than the simple 'facts', and the contact made in these (and subsequent) calls was often the beginning of establishing rapport and an alliance that was then built on in preparation for any later meeting. (Indeed the needs of many relatives who initially requested a full follow up meeting, were met and satisfied through a single phone call – see Table 1.)

Relatives' individual questions and concerns were then used as the basis for a letter, sent to the relevant consultant/clinician, requesting a meeting with the relatives concerned. These, together with any subsequent exchanges (eg. dates for

meeting, further questions/ideas) are also always recorded and relationships were established and developed (both between relatives and the BCFS Lead, but also the clinicians with the BCFS Lead) before the actual meetings.

The BCFS Lead arranged to meet relatives 10-15 minutes before the arrival of the Consultant at a follow up meeting in order to clarify and confirm their questions and the purpose of the meeting. The BCFS Lead would then introduce the Consultant and facilitate a conversation between those present based on their particular questions and concerns (there are no 'standardised' questions or topics).

Notes are always written immediately following each follow up meeting, transferred onto the data base, where the case is either recorded as 'closed' on the system or put in an 'Issues Outstanding' folder and followed up as appropriate. These were reviewed and sorted into categories for the purposes of this study.

Written correspondence received from relatives and/or staff has been filed and kept with the hopes that further analysis (not afforded within the confines of the present study) might become possible at some point.

Findings

Observations and comments

Our findings show that approximately one fifth of bereaved relatives replied to the letter and between 7-10% of those who died in the hospital required follow up. The response rate to the letter, and the proportion who request a meeting, are strikingly similar between the years.

The disparity in the percentage of cards and letters sent between the two years (2010 and 2011) is likely to be partly because cards and letters are sent at particular points in time (2-3 days following a death and five weeks later respectively) and may therefore have been sent and recorded in the year following an actual death. Another possible explanation for this may be the increase in collaboration between PALS (Patient Advisory Liaison Service) and BCFS as BCFS became more established and in some cases PALS advised that it was not appropriate to send a card or follow-up letter to relatives already involved in a complaints process.

Experiences of relatives

Relatives who requested a follow-up meeting all reported (without exception) how helpful they found the meetings. They gave the following reasons:

*A meeting has given the chance for them to reflect on what happened in the light of new/further information. For example: 'Thank you for arranging the meeting. I found it useful if extremely hard to do, but I feel I have now had several questions answered which will eventually help me to come to terms with the death of my beloved John.'*²

Many have then been able to 'lay to rest' some of the many issues and fears (which have often been 'imagined' and/or 'fuelled' through lack of information) that have been preoccupying/overwhelming them. For example: 'Thank you for the offer to speak to a member of the team involved in my mother's care. After a long gap I took this up and talked over a number of matters that had continued to trouble me through a meeting. This was helpful and has enabled me to move forward with the various tasks around bereavement. It has helped me to "put some of the missing jigsaw pieces together"'

The process has helped to give some sense of meaning and reason to what they have gone/are going through. For example: 'Thank you very much for our meeting yesterday. It made me realise how vulnerable we all are in the grand scheme of things and that ultimately the timing of our death, like our birth, is beyond our control. The meeting was very helpful: more than anything I appreciated Dr X's honesty and openness.'

Their questions and feelings are validated ('given permission') and heard. For example: 'I am very grateful to you for your support and the time you spent listening to me – helping me to understand Dad's illness and my feelings at this time. I found the discussion with me and my husband afterwards made a great difference in helping me to feel more at peace during the sad time we are experiencing and my range of emotions.'

Returning to the hospital functions as a sort of 'pilgrimage' and/or 'milestone' in their grief journey (c.f. Worden, 2009). For example: 'I must admit that I felt very apprehensive about the prospect of returning, however it was something I felt I had to do in order to clear my mind and help towards achieving some sort of closure. I knew that I needed to talk to Dr Y to clarify the details of Michael's illness although I knew from the long days that I sat at his bedside that he could never have had better care, attention or expertise anywhere.'

Several families reported (usually through telephone calls) that they had fully intended to make a complaint against the hospital, but had changed their minds as a result of receiving either the card of condolence and/or follow up letter from the hospital.

A significant number of relatives did not end up having a follow up meeting, but nevertheless expressed appreciation of each stage of the process: receiving a card, the follow up letter and the opportunity to have a follow up meeting. Even if they did not want to take up the offer of a meeting, many replied to the offer with a card or letter of thanks (both for the offer and to the staff for the care of their loved one). For example: 'I would like to thank you for your letter. It is a great comfort to know that people really do care and take the time to contact the deceased relatives [SIC]. I would also like to thank Y, the Senior Sister at the Emergency Department for the hand written card she sent me after the death of my mother. As you will see, I have decided not to speak to anybody at this time and I don't feel there are any unanswered questions for me or my family.'

² All names have been changed.

Experiences of staff members

Many clinical staff (doctors and nurses) involved either directly or indirectly in the BCFS expressed their appreciation and support for the service. This feedback was nearly always given verbally. Two particular reasons were mentioned: firstly, that it gave them an opportunity to meet with families again when they would otherwise have had no further contact with them following a patient's death. Secondly, that as well as enabling them to provide support and bereavement care for relatives, the BCFS helped them in their own grieving processes, by giving them the chance to revisit and resolve some of their own grief in relation to particular patients.

A number of staff members whose relatives had died in the hospital said that the BCFS had helped them overcome difficulties in returning to work in a place which held so many memories and associations with personal loss, equipping them to provide the patient care required of them.

A number of consultants said that it was helpful to be reminded of the depth of impact that the death of an individual patient had/has on those around them (relatives as well as staff/team members) and that they have found it fulfilling and rewarding to be able to contribute to the healing and well being of the wider family through a relatively simple and early intervention: particularly when they had been able to do nothing more for that particular patient.

Barriers to service delivery

Although there have been remarkably few difficulties during the implementation and running of the service, they would include:

- The availability of adequate systems for data collection and analysis (this has improved with the adoption of Safeguard's Bereavement Module Computer Programme).
- Occasional hesitation/reticence from individual consultants due to the pressure on their time (although this has nearly always been overcome with patience and persistence on the part of the BCFS).
- High levels of mortality and pressure on the BCFS at certain times of year (although increasing staffing levels on a temporary basis would alleviate this).
- Inadequate resources, time and expertise to record and analyse data sufficiently (funding for research and further training and specialist input would enable more comprehensive and sophisticated study and research).

Discussion

Of the many theories of grief and loss contributing to our current understanding and practice of bereavement and bereavement care, several suggest that there are certain emotions, dynamics and tasks that contribute to whether a grieving process is likely to be normal, or is at risk of becoming complicated (Boelen *et al*, 2006). These include: denial, anger, bargaining, sadness/depression and acceptance (Kubler-Ross & Kessler, 2005); and: accepting the

reality of a loss, working through the pain of grief, adjusting to the environment where the deceased is missing; and finally relocating the deceased (Bollas, 1987) and moving on with life (Worden, 1991). Each one plays its part in someone coming to terms with their loss – even if progression through the stages is less than smooth and involves an oscillation between contrasting feelings and orientations (see Stroebe and Schut, 1999).

By contrast, the process is likely to become complicated if someone feels that their feelings of grief are unacceptable and/or if they have been bereaved through a premature, sudden, violent, or unexpected death. Other factors are influential too (insecure attachment patterns, fragile sense of self, previous difficulties with grieving, previous history of depression and so on), but particularly pertinent to this study is the part that quality of communication surrounding a death plays in whether and how someone will cope with the death of a loved one. (Zhang *et al*, 2006)

Findings from the BCFS relate to two of these phenomena in particular: anger and communication.

Within the range of emotions associated with bereavement, anger can be one of the most challenging to work through: it is often confusing and difficult to acknowledge because of the feelings of guilt, ambivalence and fear which compound it: 'How can I be angry at X? He didn't choose to die.' (Worden, 1991) Primitive anxieties are often evoked and feelings of panic can make it difficult for the bereaved to absorb information or make decisions, and until these feelings can be thought about and processed, they are at risk of being acted out through demanding, irrational, aggressive or abusive behaviour, and/or passivity and withdrawal – and/or longer term physical illness (Bion, 1967; Lindemann, 1998; Kiehl-Glaser & Glaser, 1998). Those who suffer traumatic or sudden bereavements are more likely to bear a grudge or grievance (Garland, 1998) and in a society which currently cultivates complaint and litigation, this is particularly problematic for organisations like the NHS.

Through careful timing of its follow up letters and meetings, the BCFS offers an early intervention which pre-empts difficulties which might otherwise arise later in the bereavement pathway: both complaints (CUH receives most of its death-related complaints 10-12 weeks following a death) and longer term morbidity and mortality (Lindemann 1998).

At this stage (4-5 weeks following the death), relatives are often beginning to experience and express a fuller range of grief emotions than the initial ones of shock and denial: particularly guilt, anger and protest ('I didn't realise how ill they were.' 'I'd never have left their bedside if I'd known'. 'Why didn't anyone tell us that she was going to die so quickly?' 'Why didn't they do more to help his pain?' etc). If these feelings of guilt and anger are not addressed, complications are likely to arise and there is a higher risk of them either being acted out and directed at others (through blame) or turned inwards, leading to longer term depression (Worden, 1991).

There have been some early indications that there have been more requests for follow up meetings from relatives bereaved through traumatic, unexpected and/or premature hospital deaths

and providers of bereavement care (both within hospital and in the community) could target these particular groups in attempting to prevent longer term complications (Hawton, 2007).

There is some suggestion that there may well be additional cost benefits as a result of fewer complaints, as well as increased charitable giving. But perhaps most hopeful of all are the levels of satisfaction reported by those who have received help and support in their bereavement, together with the number of cases satisfactorily 'concluded' as a result of it.

The BCFS creates a facilitating environment (Winnicott, 1965), through continuity of people, place (the task of relocating the deceased) and care so that relatives and staff can together revisit and explore their grief over the death of a patient (Jackson, 1992). Emotions and behaviours can be voiced, talked and thought about before they are at risk of becoming more complicated and entrenched. Questions can be raised and explored (cf bargaining) through examining and re-telling the story (Machin, 2009) of a patient's treatment and care with those whom are best equipped, as the reality of a loss is gradually confirmed and come to terms with.

Both relatives and medical staff involved in follow up meetings reported that being able to make some sense and meaning of the death had been a crucial factor in this process. Neimeyer (2001) suggests that this ability to make or find some sense of meaning and/or purpose out of loss is a key factor in whether a grieving process will be straightforward (or not) and it may well be that being able to form a narrative aids this through transforming the self narrative of the griever (Neimeyer and Anderson, 2002). The chance to retell and/or reframe the story and meaning of a particular loss is certainly central to the BCFS: both through follow up meetings and through conversations via letter and/or telephone (for relatives who want some support, but not a face to face meeting).

Conclusion

As a model, the BCFS is quick and easy to implement. Once established, it is simple and straightforward to administer and maintain. It provides an alternative, less problem-centred pathway to the standard route for those with problems relating to the hospital (Patient Advisory Liaison Service) and gives relatives the opportunity to voice concerns, and to seek information and answers from those best equipped to meet them (experts in clinical and bereavement care).

It is efficient, already showing signs that it is a cost effective way of providing care at a critical stage in the bereavement pathway. It appears that it may well be self-limited in its scope and provision: figures so far concur with Schut and Stroebe's (1999), showing that 79% of relatives who are invited to meet with the consultant and/or other medical professional do not choose to take up the offer. And this appears to be increasingly so: in 2011, substantially more cases were resolved without the need for a full follow up meeting.

Data to date suggest that the place of a service in the early post-death stage of the Bereavement Pathway may well have a

significant role in helping relatives to resolve their grief. It seems to have a particular place in addressing and working through grief-related anger, benefitting both individuals and the wider system and community through possible prevention of grief-related morbidity and mortality.

One relative wrote about returning home after his wife's death in hospital: 'It was all so quick. I still had so many questions, but I was on my own – I didn't have anyone to help. Receiving your card and letter meant so much.' The BCFS helps to 'bridge the gap' between hospital and community and provides a valuable model for providing continuous and comprehensive bereavement care for relatives in the early stages of their bereavement. ■

Bereavement Services Association (2013). A description and timeline of *The Bereavement Pathways Project* [available at: <http://bereavement.bsauk.org/>; <http://www.web11188.vs.speednames.com/BPPpapers/NetworkingEvents.pdf>; <http://www.web19069.vs.speednames.com/BPPintro.html>]

Bion WR (1967). *Second thoughts*. London: William Heinemann.

Boelen, et al (2006). A cognitive behavioural conceptualisation of complicated grief. *Science and Practice* 13 (2) 109-128.

Bollas C (1987). *The shadow of the object: psychoanalysis of the unthought known*. London: Free Association Books.

Cambridge University Hospitals (CUH), unpublished data and material

Department of Health (2011). *When a person dies: advice on developing bereavement services in the NHS*. London: Crown Copyright, 1.3

Department of Health (2005). *Survey of bereavement care and support services*. London: Crown Copyright, Note 16.

Department of Health (2008). *End of Life Care Strategy* London: Crown Copyright, 24-25.

Garland C (ed) (1998). Trauma and grievance. In: *Understanding trauma: a psychoanalytic approach*. London: Routledge, 81-82; 93 ff.

Hawton K (2007). Complicated grief after bereavement. *British Medical Journal* 34 962-963.

Healthcare Commission (2008) *Spotlight on complaints*. 2, 21-23; 32

Jackson I (1992). Bereavement follow up service in intensive care. *Intensive and Critical Care Nursing* 8 163-168.

Kieholt-Glaser JK, Glaser R (1998). Disclosure of traumas and immune function. *Journal of Consulting and Clinical Psychology* 62 (1) 130-140.

Kubler-Ross E, Kessler D (2005). *On grief and grieving: finding the meaning of grief through the five stages of loss*. New York: Scribner.

Lindemann (1998). *Guidelines for bereavement care in intensive care units*. The Intensive Care Society. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/12859081>

Machin L (2009) *Working with loss and grief: a new model for practitioners*. London: Sage, 113-165

Neimeyer RA (ed) (2001). *Meaning reconstruction and the experience of loss*. Washington: American Psychological Association Convention.

Neimeyer R, Anderson A (2002). Meaning reconstruction theory. In: N Thompson(ed) *Loss and grief*. Basingstoke: Palgrave.

NHS Choices (2010). *End of life care guide*. [available at <http://www.nhs.uk/Planners/end-of-life-care/Pages/End-of-life-care.aspx>]

Prigerson HG, Horowitz MJ, Jacobs SC et al (2010) Prolonged grief

disorder: psychometric validation of criteria proposed for DSM-V and ICD-11. *PLoS Med* 6(8): e1000121.

Schut H, Stroebe M (1999). The dual process model of coping with bereavement: rationale and description. *Death Studies* 23 197-224.

The Alderhey Report (January 2001) London: Crown Copyright.

Winnicott DW (1965). *Maturation processes and the facilitating environment: studies in the theory of emotional development*. London: Hogarth Press.

Worden JW (1991). *Grief counselling and grief therapy: a handbook for the mental health practitioner* (2nd ed). New York: Springer.

Worden JW (2009). *Grief counselling and grief therapy: a handbook for the mental health practitioner* (4th ed). New York: Springer.

Zhang B, El-Jawahri, A, Prigerson HG *et al* (2006). Update on bereavement research: evidence-based guidelines for the diagnosis and treatment of complicated bereavement. *Journal of Palliative Medicine* 9(5) 1188-1203.

Appendix 1: A guide for condolence cards

Suggested wording for cards sent to NOK by wards 2-3 days following a patient's death (card provided for ward by BCFS)

On behalf of the staff on ward XX, we send our thoughts and sympathy to you and your family during this sad time.

Yours sincerely,

YYY

Appendix 2: Sample 'follow up' letter

(Sent to NOK on headed notepaper by BCFS approximately six weeks following a patient's death – 'personalised' anonymously in this instance)

Dear Mr Austen,

Once again we want to offer our condolences on the death of your wife, Jane.

We appreciate that the period following a death can be difficult and we would like to offer you the opportunity to speak to a member of the team involved in your wife's care if that might help you in any way. Sometimes relatives have questions they wish they had asked when their loved one was in hospital or they would just like an opportunity to visit Addenbrookes again in different circumstances.

If you feel that a meeting and a friendly chat would be of help to you, or to any member of the family, then please do not hesitate to contact us using the tear off slip below. A member of Bereavement Care Services will then contact you and an appointment will be made. Alternatively telephone us during office hours on (XX)

We would like to stress that we do not offer a counselling service but could put you in touch with various agencies if required. If this is of no interest to you then please do not feel obliged to reply.

Kind regards,

(Signed personally)

NN
Bereavement Care Services

XX
Senior Sister, Ward X