RememberMe

FREE-WRITING IN PALLIATIVE CARE AND BEREAVEMENT

ANDREW GOODHEAD







Freewriting in Palliative Care and Bereavement

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About the Author

Rev Dr Andrew Goodhead, Chaplain St Christopher's Hospice. Andrew Goodhead joined St Christopher's as Chaplain in January 2005, completing his doctoral research in 2007. He is a Methodist Minister with 14 years Church based experience gained in several localities throughout the UK, both urban and rural. In his role at St Christopher's Andrew is concerned to ensure that all End of Life Care professionals have the skills and confidence to offer spiritual assessment and ongoing support to all patients and their families. He has a particular interest in the concept of spiritual pain as a way of understanding spiritual need. For patients with faith needs Andrew is developing the pastoral and religious role of the Spiritual Care Lead. Andrew graduated in 2014 with the King's College, London, MSc in Palliative Care. His dissertation explored the experiences and attitudes of community clergy in caring for dying people.

Andrew has published his thesis with Wipf & Stock (USA) under the title A Crown and a Cross; the Origins, Development and Decline of the Methodist Class Meeting in Eighteenth Century England. In November 2010, Mortality published the results of Andrew's research into memorialisation: A textual analysis of memorials written by bereaved individuals and families in a hospice context. In July 2011, The European Journal of Palliative Care published Physiotherapy in Palliative care: the interface between function and meaning, this is a philosophical examination of how physical ability affects the way in which meaning can be made. His most recent paper, (accepted by Palliative Medicine) based on his MSc dissertation study is 'I think you just learnt as you went along' — Community clergy's experiences of and attitudes towards caring for dying people: a pilot study [in process of publication]. Andrew is a co facilitator for the Spirituality Education Group on the European Association of Palliative Care and a member of the Spirituality Taskforce of the EAPC.



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1 Deceased 28.8.2017



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Research Highlights

- Meaning making is a significant purpose for those who free-write and for attendees to Memorial Services.
- The grief theory of continuing bonds is apparent in the free-writing entries in Memorial Books. These are expressed by describing personal attributes and sharing news. Free writing indicates that the dead are clearly involved in the continuing life of the bereaved. Hospice memorial books provide an environment where these relationships can be expressed and maintained.
- There is an interface between public and private grief rituals. Free-writers share their thoughts and emotions with others who will read an entry at a later date. During a Memorial Service act of remembrance, attendees recognised the common experience of bereavement when names were read or a shared action was engaged with.
- > Symbols in the form of cards, drawings or photographs in Memorial Books, or stones, candles or flowers at Memorial Services are imbued with meaning by the bereaved and reconnect the bereaved to the deceased.
- Acts of Remembrance at memorial Services provide attendees with an opportunity to actively participate in an event at which they are otherwise mainly passive observers.
- There is clear evidence that free writing memorialisation themes are common across the UK.
- There appears to be confusion among the organisers of Memorial Services about their purpose and content. Clarity is required by the organisers in what these events aim to do.
- Hospices have a pivotal role in creating helpful opportunities for the bereaved to remember the deceased.



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Executive Summary

Purpose and Scope

The Hospice memorialisation research study into the content of hospice memorial services/ events and free writing in Memorial Books was undertaken as part of the *Remember Me: The Changing Face of Memorialisation* research project, funded by the Arts and Humanities Research Council. (See www.hull.ac.uk/rememberme)

The study considered two distinct memorialising opportunities:

- The content and themes of memorial services or events offered by hospices to bereaved service users some months after the death of a patient
- The content and themes of hand written (free writing) entries in in Memorial Books held on hospice premises

The study sought to understand and describe how hospices enable bereaved men and women to remember those who have died, in a communal event or through the availability of a book in a quasi-public space. Memorialising the dead appears to be a practice which is needed by some bereaved people to help with the bereavement process and to continue to maintain the deceased in the present.

Method

11 hospices were invited to participate in the study. 10 agreed to take part; 1 in Scotland, 1 in Northern Ireland and 8 in England.

Memorial Services: the researcher was an observer participant, maintaining notes through an observation schedule to ensure that the same questions and observations were made at each event. The researcher ensured that his presence was discreet and that no attendees were spoken to or disturbed prior to, during or after the event.

Memorial Books: it was intended to collect data from memorial Books covering the same time periods in each hospice, the month of July and the periods around Christmas and St Valentine's Day. Many hospice books held insufficient data to cover these periods. A decision was made to either capture all the entries in a Memorial Book or an amount of entries equivalent to the period originally chosen. One hospice did not maintain a Memories Book and agreement was made with the internal research committee that 'leaves' submitted for previous memorial services could be treated a free writing.

All observations entries were entered into Nvivo 8 and free nodes (codes) created for the themes which arose as data was analysed. Where appropriate, nodes were collapsed into nodes with similar themes.

Findings: Memorial Services

The purpose and function of each Memorial Service was decided by the leaders of these events. Across the study, the purpose and function of services differed depending on content choices made by the service organisers.



A number of approaches to death, loss and bereavement were seen through these Memorial Services, ranging from expressions of continuing bonds, letting go and holding on and the denial of death. Contents included poetry, prose, hymns, addresses and talks by bereaved relatives. Imagery and metaphor was present in the description of death, loss and bereavement. Christian content was explained by service leaders to attendees. Secular and non-Christian poetry, prose, readings or music was not explained. This suggested a lack of confidence that religious themes would be understood by attendees.

The services were primarily led by hospice Chaplains or Spiritual Care Leads assisted by volunteers or other hospice staff. Leadership was predominantly white. Attendees to the services were drawn from white, Black Minority and at one service an Asian ethnic background.

At nine services an Act of Remembrance was included. Attendees responded in unison to recall their deceased relative or friend. Attendees displayed emotion, comforted each other and actively participated in the remembrance. Even if attendees were disengaged from the service prior to and post the Act of Remembrance, this moment enabled them to be active participants at an event where they were primarily passive observers.

Findings: Free Writing in Memorial Books

Free-writers attend hospices to write in memorial Books at significant times of the year or for significant events. Writers describe their response to be eavement and write about ongoing events in their lives and share news with the deceased.

There may be a substantial period between a death and a person attending at a hospice to write in a Memory Book. Some attendees return year on year. Others write of multiple bereavements and address a number of deceased people in a single entry.

The bereaved describe the attributes of the deceased which are found within a family unit, or the attributes which will be 'passed on' to other generations within the family.

Belief is expressed by free-writers but this is mainly within a Judaeo-Christian framework. There were only a few entries from non-Christian traditions, with two hospice Memorial Books holding entries from the Sikh and Hindu traditions.

Memory Book free-writing enables the bereaved to undertake a ritual act. The presence of the writer is essential to the creation of a ritual and these acts are suffused with personal and familial meaning.

Findings: Cross-Cutting Themes

Meaning-Making: Free-writers and service attendees sought to make and take meaning from writing and engaging in Acts of Remembrance. This was seen in free-writing through the recognition of death, its significance and the expression of relational bonds. During Acts of Remembrance the use of symbols (candles, flowers or stones) became meaningful for individuals and families by taking and/or placing these purposefully at the direction of the service leader.



Continuing bonds: The passing of news and reminding the dead they are missed and loved illustrates how free-writers maintain relationships with the deceased. In Memorial Services, this theme was described in poetry, prose, readings and addresses. Bonds are also held when a process of letting go takes place. The bereaved continue in relationship with the deceased (holding on), but are also able to let go. This is best seen in the placing of the deceased in an afterlife where they can be recalled, but where they are out of reach.

Public and private memorialising: although open to the public, hospices are not wholly public spaces. They offer semi-public spaces to facilitate memorialisation. Free-writing demands the attendance of the writer at the hospice and attendees at a Memorial Service must deliberately travel to the hospice. The personal and private entries of writers can be read by others intending to write. There is a mimetic quality to many entries as themes and language are found across many entries in each book. Those attending a Memorial Service come as individuals and families but enter into a shared act by their presence and participation in any Acts of Remembrance.



1. Introduction

Goodhead's 2010 paper discussing memorialising in one hospice identified the ways in which individuals and families take the opportunity to free-write, both on 'paper leaves' in a hospice chapel and on 'green slips' written for memorial services (Goodhead 2010). The analysis of data identified that recent grief theories were present in the content of free-written entries. Writers expressed continuing bonds (Klass, Silverman et al. 1996) with the deceased and also recognised that in writing they were holding on and letting go of the deceased (Walter 1997). Many themes were identified during data analysis including loving and missing, a hope for reunion, placing the deceased and marking anniversaries and events.

A study on modern funerals by Holloway *et al* identified a need to seek, create and take meaning as part of the process of planning and preparing a funeral (Holloway, Adamson et al. 2013). The work in planning funerals is done in collaboration, or with the assistance of clergy or funeral celebrants who guide the bereaved through the planning process and into the funeral. Walter described people who do this work as 'death-work mediators' (Walter 2006). Holloway *et al* described the process of making meaning as a way to 'manage the transition to a new relationship with the deceased' (Holloway, Adamson et al. 2013, p.44). In Goodhead's study, the post-death relationship is established, yet the bereaved continue to seek to make meaning with the deceased in their continuing life, 'loss is ongoing and is expressed in the present and gives meaning to the present narrative. A task of bereavement is the renewal of the narrative of living' (Goodhead 2010, p.355).

Robert Neimeyer has described human beings as 'inveterate meaning-makers' (Neimeyer 2005, P.28). By this he meant that throughout life people need to interpret and understand events that happen around, or to them. He described grief as a process of 'meaning reconstruction' and argued that this is primary task of mourning. (Neimeyer 2005, P.28). This contrasts with Holloway *et* al's argument of a three 'stage' process of meaning making during the funerary period (Holloway, Adamson et al. 2013). Using a constructivist framework, Neimeyer also contended that Bereavement is a challenging experience, demanding much of the bereaved. Constructivist understandings of the person argue that an individual's identity is a 'narrative achievement ... established through the stories that we construct about ourselves and share with others' (Neimeyer, Burke et al. 2009). The challenge of bereavement is also highlighted by Fortuin *et al* 'as the occurrence of death can, and will often, cause bafflement, suffering and moral paradox, it will generally induce a search for meaning' (Fortuin, Schilderman et al. 2017).

Parkes described bereavement as a 'complex interweaving of psychological and social processes, whose implications are far from clear to the person who undergoes them' (Parkes 2000). This suggests that a process for those who survive bereavement is to set the deceased into their ongoing life, personally and socially, even though they are no longer present. Parkes, Niemeyer's and Fortuin *et al's* descriptions of meaning make clear that the psychosocial transition of bereavement, including emerging as a 'different' person after bereavement does not mean that bonds to the deceased are severed; rather, the dead are maintained in the life of the living, although not physically present. Holloway *et al's* meaning seeking, making and taking process offers a compelling addition to the processes of bereavement by including meaning making into a broader psycho-social-spiritual



transition. After bereavement alongside reshaping the person's life and creating continuing bonds, a meaning making occurs that 'transforms and transcends the ordinariness of life and the challenge of death' (Holloway, Adamson et al. 2013). Bereavement is an experience which threatens existential models of being and in the processes of meaning making during bereavement each individual must transition their spiritual meaning just as their psychosocial meaning must be transitioned (Holloway 2007, p.73).

Goodhead's study supported Neimeyer's assertion relating to the re-creation of personal, familial and social meaning after a bereavement (Goodhead 2010). Holloway *et al's* research into modern funerals also resonates with this work. Through free-writing more than mere declarations of love and loss were explored by the bereaved. Free-writing, on 'leaves' placed on a Remembrance Tree in a hospice chapel or presented as 'green slips' written for a Memorial Service explored continuing bonds and social ties as well as letting go of the deceased. Writers made meaning through writing. Free-writing of 'leaves' took place in a quasi-public setting where they were left. Others could easily read the work of another and had access to intimate expressions of ongoing relationships following bereavement. Strangers accessed the meaning that the life of the dead still held for the living.

Jonsson and Walter noted the importance of 'place' for bereaved people as a means to enable continuing bonds to be maintained. Not every patient under a hospice's care will die in that hospice, but the physical space has significance; 'the meaning of a place, in a continuing bond context, is shaped by imagination, sometimes by memory' (Jonsson and Walter 2017, p.413). Winter described the way in which Commonwealth War Grave sites offer visitors an opportunity to 'rehearse and perpetuate the social memory' (Winter 2011, p.463). The importance of place for bereaved people visiting hospices, as for visitors to a large Commonwealth grave site should not be underestimated. Winter, quoting Andriotis suggests that visitor's books at Commonwealth grave sites allow attendees 'opportunity to publicly articulate and express their experiences in a creative way' (Winter 2011, p.467). This process is found in the entries in Memorial Books within hospices, but in a much more personal manner.

The use of symbols to make meaning was described by Adamson *et al* and drew on data from the large study of contemporary funerals (Adamson and Holloway 2013). The symbols used at funerals are highly personalised and included football scarves, photographs and flowers. Of particular interest is the finding that participation in the funeral was a symbolic event (Adamson and Holloway 2013, p.147). Symbols are a silent means to make meaning. In Goodhead's study writing on a 'paper leaf' to be placed on a papier maché 'Tree of Life' or a green slip, which is then presented to the service leader during a memorial service are ways of making significant symbols that help the process of meaning making and taking. These symbols were publicly (or quasi-publicly) created for others to read and note, 'during each Thanksgiving and Memorial Service, returned slips are brought to the front ... and placed on a table. All who return slips are aware that their writings will be available for scrutiny ... allowing others to see personal writing is a public act' (Goodhead 2010, p.335). The public nature of death rituals which include the symbolism used in funerals and beyond is noted by Donald Heinz, 'death rituals function to get the truth and the human condition told. And such truths get told only in community. Each of us must have others to throw a little earth over him or her' (Goodhead 2010, p.335).



The modern hospice movement began in 1967 when Dame Cicely Saunders opened St Christopher's Hospice in South East London (Monroe, Hansford et al. 2007). Her endeavours were a protest against the medicalisation of death. Dr Saunders emphasis on holistic care for patients and their families during the course of illness and into bereavement for those who remained created a new way of caring for bereaved people, albeit a minority. Parkes reflected that those who have experienced the support of a hospice and preparation for the death of a relative are 'less at risk than others who have had no such opportunity' (Parkes 2007). Those same men and women are also the minority who have the opportunity to free-write or attend an organised Memorial Service.

Memorial Services and Memorial Books are two opportunities available to those bereaved of a relative or friend under the care of a hospice to remember the deceased. Fortuin *et al* offer an insight into a possible reason for this development, suggesting that the demise of an authoritative religious narrative has led to people seeking meaning as 'an individual project' (Fortuin, Schilderman et al. 2017). When a single religious meaning is held collectively, there is little need for the individual search. Memorial Services and Books provide a means to explore this individual project.

The ten hospice study of Memorial Services is the first time that Memorial Services have been researched on a larger scale. A 2004 evaluation of memorial services at a Newcastle-upon-Tyne hospice invited attendees to feedback views on the event. Respondents reported that the Christian/secular balance of the event was acceptable and that the symbolic act of remembrance was helpful (Duncan, Findlayson et al. 2004). They suggested that for some, the service represented a social gathering. A few attendees sought to meet with the staff that had cared for their deceased relative. Attending a Memorial Service is to recognise that bereavement is a common experience. Memorial Services demand that attendees are willing to be present with others and with others to express their grief.

2. Method

Background and Rationale

Background, Design and Setting and Data Collection

This research formed one strand in the AHRC funded interdisciplinary project, 'Remember Me. The Changing Face of Memorialisation.' The study was approved by The University of Hull's Faculty of Arts and Social Sciences Ethics Committee.

To build on the author's previous limited study of free-writing in one hospice, this research project allowed a larger study of memorialising opportunities available in UK hospices. Ten hospices participated (see Appendix 2). Two means of memorialising were studied concurrently; free-writing in Memorial Books and hospice Memorial Services. Data collection usually took place on the same day. Data from hospice Memorial Books material was to cover the same time periods on each site; July and the periods around Christmas and St Valentine's Day. However, many books held insufficient data to cover these periods. It was decided that all Memorial Book entries or an equivalent amount of entries to the period chosen should be recorded. Two hospices did not maintain a Memories Book. Agreement



was reached with their internal research committee that 'leaves' submitted for previous memorial services could be treated as free writing.

Entries were redacted to remove any identifiers. Entries were typed into a word document. Pictures and other symbols were noted. The hospices without a Memorial Book concerned the author. The purpose of invited writing for a Memorial Service is different to that of self-directed free-writing. However, as will be seen from the analysis and discussion, the themes addressed by writers was the same as those at the hospices which do maintain Memorial Books.

The researcher was a participant observer at ten Memorial Services and used an observation schedule to ensure parity at each event (Appendix 1). Hospices provided attendees with a printed order of service.

Analysis

The entries from individual hospices were entered into Nvivo 8 consecutively and free nodes (codes) created for the themes which arose as data was analysed. The author created a coding frame using a grounded theory approach, referring to themes which arose from his previous study as analysis progressed. Where appropriate, nodes were collapsed into nodes with similar themes.

3. Free-Writing in memorial books

The size, shape and location of hospice Memorial Books varied from site to site (Appendix 1). In most settings the book(s) were placed into a chapel or quiet room. Those which were labelled for use as a book for prayer requests were requisitioned as Memorial Books and contained few prayer requests. The following factors and themes emerged as significant.

a. Timing of writing

Significant points in the year

Free-writing has significance at particular times of the year or when specific events/dates are commemorated; this allows the bereaved to choose significant personal points across the calendar. Within the Christian Church, formal commemoration of the dead happens only on the 2nd November at All Soul's. This is restrictive and irrelevant to those who have no connection with organised religion.

A death anniversary was one of the most frequent reasons to attend a hospice, '24/12/16 Merry Christmas Mum. 1st Christmas without you. [female name] x' [Hospice ten] or, 'it's been 29 years. Wow, how long? Life can be cruel to deny you so much.' [Hospice two] Time does not dull the experience of loss. Some recalled multiple bereavements:

15.03.15

Came back for the first time today since the terrible events of (date 14) and (date 14) when my Mom and husband passed away ... Miss you both more than you will ever know. Love you (female name) xxxx [Hospice six]



Familial memorialising was common at Christmas when the opportunity to gather as a family allows shared memories to surface. Four different familial entries reflect this:

19 Dec 2015 (entry 2)

Merry Christmas Dad! Can't believe this will be the 4th Christmas without you but will be thinking about all the good times ... Will raise a glass to you. Loads of love [Male name] (Decoration of Christmas stocking) [Hospice two]

Every entry from this family included comments about the deceased's enjoyment of Christmas and previous gatherings while the deceased lived.

Mother's Day and Father's Day were also significant, 'our first father's day without you dad. [Female name] xxxxx.' [Hospice five] The experience of writing on Mother's Day appeared to reignite grief and a search for the deceased, but also locate the deceased into a safe, but uncertain place:

2016 Mother's Day

My baby girl why are you here! We should be having our Sunday roast and opening my mother's day gift. It hurts so bad inside ... I am forever grateful for the time we have had and forever sad and angry for not having any more time with my baby girl. To the moon and back [female name]Mom xxx [Hospice six]

Only six books referenced birthdays. These entries were warm in tone and recalled the deceased in a familiar way, 'happy birthday ... miss you every day! Will have a cold one for you.' [Hospice two] Birthday remembrance also allowed time to reflect and make an effort to have a memorable day without the deceased:

'24.2.15 [Male name] thinking about you always and how life was, with all the happy memories you have left behind from the past. This would have been your special day as [female name] the family and I are still going to make this a day to remember. Lots of love [female name]' [Hospice three]

One family of Asian heritage [hospice 5] each wrote an entry. Common to this group was the expressing of a person being missed, a wish the deceased was still alive and a placing of the deceased in an anthropomorphic next life:

Happy 62nd birthday day! Hope you have a great day and some cake! ...love and miss you forever.

[Male name]Your birthday today ... still miss you. God bless you wherever your soul is. Loving wife [female name]

Happy 62^{nd} birthday dad. Hope youre (sic) doing well up there, wish you was here with all of us right now ... I know your (sic) looking down on us everyday.



Time since the death

Bereavement is a permanent state. The ongoing nature of bereavement and the longevity of continuing bonds are described through one individual's return to write at Christmas 13 years after bereavement:

25th Dec. Merry Christmas [male name] and happy birthday for tomorrow. Yesterday was still very hard – even though it's been 13 years. I still miss you so very much ... I never stop thinking about you. My love and friendship always love [female name] xxxxxx [Hospice ten]

The memory of the deceased among the living does not diminish, 'on the anniversary of your passing today 16th May 1993 your loving son [male name] is here to remember as always and to let you know that you always burn brightly in my heart. Loving Son.' [Hospice two]

Alongside temporal time is the concept of perceived time. This is expressed simply; 'still seems like yesterday' [Hospice four] indicating that the death event is a 'fresh experience', although tempered by time. Four years after a death one writer reflected on the impact of bereavement, '4 years; strange how it feels like a lifetime and a blink of an eye rolled into one.' [Hospice four] Similarly, 'you left me 4 years ago. Time passes yet stands still!' [Hospice eight]

b. Content of Entries

Free-writers impart more than their emotions towards the deceased onto paper. Perhaps to simply remember or to attend for a specific purpose; to remind the living of promises made before the person died or, to offer in a quasi-public place a commitment to the future. Free-writers make these books rich with their thoughts and emotions. Analysing these entries shows that the bereaved intend to enable to dead to live on in through themselves or others.

Loving and Missing

These two emotions were present in almost every written entry. Severed attachments create a sense of loss. Those who take time to attend a hospice to free-write, hold positive emotion towards the deceased. References to loving or missing are made in the present tense, regardless of the time lapse between bereavement and the present. Loving and missing the deceased are related in short and long entries. At the conclusion of an entry, they are valedictory; a final chance to say how much the dead person means to the living, 'I've lit a candle for you ... I still miss you lots and will love forever.' [Hospice one] Recognition of the absence of the person, elicits the same emotion, 'I know you now have no pain and in a wonderful place. Miss you, love you.' [Hospice five] Time does not appear to diminish this:

My father ... It's been 25 years today just to say keep him safe and all our love from his wife & small lads and will always been in loved and missed by everyone. Sons ... Daughters ... [Hospice ten]

Some free-writers added other family or friends into an entry; they too are loved and missed as much as the person who was the primary reason for travelling to the hospice, 'mum, dad [4 female and 4



male names] whom we have lost over the years. They are loved and missed very much indeed.' [Hospice ten]

Attributes: Shared and Lost

Seven entries described attributes that were shared with the deceased. More frequently writers described elements of the personality, morals and ethics of the deceased to be passed to future generations; again, keeping the deceased alive. One writer suggested that the living shared attributes of the dead by ensuring the deceased was 'always in my deeds' [Hospice one]. Another spoke of being good because of the deceased's influence [Hospice two]. Another expressed the passing of attributes to future generations 'you taught me lots and lots of things that will carry me on in my life and will continue to show your grandchildren.' [Hospice six] One writer, having written about personal memories of their relationship concluded, 'my roots and yours will be forever entwined' [Hospice seven].

Others expressed attributes that would be passed on because of the deceased's display of them in life, 'your influence on me to always be kind and loving to my children is the most important one in my life' [Hospice eight] 'you were the strongest woman I've ever met' [Hospice six] another was 'an inspiration' [Hospice six, Hospice seven] 'strong and brave' [Hospice two] 'a wise head, teacher' [Hospice five]. Some attributes were not always easily lived with but family bonds maintained relationships positively:

Thursday 29th December 2011 [female name]

Mum, you made me what I am today. You taught me love respect and honesty. You are strong determined character and someone I've always looked up to! We didn't always, don't always agree, but we've learned to compromise! You've been there through all my troubles and held me together and because of all your care and devotion I have (and you have) two beautiful sons, grandsons, that I am so proud of, they has done us all proud, and will continue because of your guidance! Love you [female name] xxx [Hospice seven]

A child described the attributes of a grandparent in simple terms:

GRANDMA

Grandma as funny as mummy, As smart as an Author,
As cuddly as a bunny, Reliable like God,
As nice as my best friend, Truthful like Jesus,
As magic as a magician, As colourful as the rainbow,
As strong as a wrestler, The most encouraging person in the world,
My Grandma, [Hospice nine]



Watching over the living

The leitmotif of the deceased watching the living portrays a continuing existence, in another place, for the deceased. The deceased were not always placed in an afterlife, as a continued spiritual existence may not be required to enable a concept of continuous watching to be expressed, 'I know you're watching over us' [Hospice one] or 'I know you're watching down upon me' [Hospice ten]. Some request the watching to have purpose, 'I hope you are still with me and looking over me and guiding me through losing you.' [Hospice five] Or, 'I guess now you'll be watching from where you are! Please keep your family safe and strong to get them through this difficult time! You'll never be far from my thoughts!' [Hospice seven]

Christmas drew people to remember the deceased's participation in festivities, 'Christmas is a special time of year I know you enjoyed putting up the decorations and lights and we are carrying on the tradition. Wherever you are I know you will be looking down on us.' [Hospice two] Family events also feature, 'my new house is nearly ready ... I'm sure you're there having a look from above.' [Hospice ten]

Expressing Belief

There were a number of entries from the Christian tradition with a small number of entries from two hospices expressing Hindu and Sikh perspectives. A Hindu writer stated '(Hindu symbol OM) [male name] may you always be happy in the garden of love. [Female name] xxx' [Hospice five] another entry from an Asian writer drew on secular and Christian themes rather than those associated with Asian religious perspectives;

To dad. Happy 62nd birthday. Wishing you were still here to celebrate with us. We miss you every day and not a day goes by that we don't think about you. Love ... my angel. Happy birthday. I know you're looking down on me keeping me safe. Love [child's name] [Hospice five]

A bereaved Sikh relative described a wish to see the deceased at their place of worship:

[Sikh greeting] I have to say it every time I meet with you so you don't get upset. I hope you are OK and at peace with granny. I'm glad you two are together now ... Please give us your blessings every day ... we will meet again — probably at the Gurdwara. [female name] xxx [Hospice six]

Christian themes were more common. Some used Biblical quotations to frame their entry, 'I've been praying ... for you over the years am reassured you are with Jesus. "In a little while you will see me no more, and then after a little while, you will see me." John 16:16' [Hospice eight] Christian entries thanked God that the deceased was in heaven, 'death is not the end – it is the beginning, to be present with you Lord and with all the angels praising you. It is a privilege.' [Hospice 7] And, 'thank you Lord for answering my prayers by taking my mum home quickly to be with you ...absent in the body, present with her Lord. To live is Christ, to die is gain.' [Hospice seven], One writer drew upon a phrase used in prayers for the dead, 'May you rest in peace and rise in glory. [Hospice ten] Another entry described death as an end to suffering and a gateway into heaven A passage from John's Gospel frequently read at funerals illuminated this;



The suffering is no more, your time on earth has been great, your time now begins in heaven with God and all his angels ... 'do not let your hearts be troubled ... you know the way to the place I am going'. John 14 v 1-6 [Hospice seven]

Envisaging the afterlife

Those who mentioned an afterlife suggested that this is similar to a lived existence, 'hope you're OK up there partying away with your Valencia wine!' [Hospice four] or 'it's been strange without you over Christmas, but I hope you've had a ball up there!' [Hospice ten] or 'please have a good time up there' [Hospice two] or even, 'hope you have a new boat up in heaven.' [Hospice four]

The concept of the deceased becoming and angel or being watched by angels was present in this study. Writers wished the deceased would be 'resting up there ...angel in the sky' or 'sleep tight my little angel' [Hospice one] or 'sleeping with the angels now forever.' [Hospice two] The angelic motif was developed with the deceased becoming an angelic being 'heaven's gained an angel.' [Hospice one] Angels may collect the dead, 'your angel saw you lying there and whispered come with me.' [Hospice nine] or, 'may the angels carry her to heaven.' [Hospice two] Angels appear to be dualistic; the deceased become angels, or angels take the dead to heaven. Only two entries offered a traditional Biblical understanding of angelic activity, the worship of God, 'be present with you Lord and all the angels praising you' [Hospice seven] or 'your time now begins with God in heaven and all his angels.' [Hospice three]

The bereaved desire the dead to be reunited with predeceased family members, 'we know you are both in heaven' [Hospice seven] or '1 ... know you are in a beautiful and peaceful place with God and your brother and sister.' [Hospice two] For another writer the remembrance of the deceased is enlarged as other deceased family members are mentioned:

Well here I am on this sad day remembering how you left us peacefully here 6 years ago ... say hello to Dad ... grandma and grandad for me. [Hospice one]

Any desire to be reunited with the dead is tempered with a hope that such an event does not happen quickly, 'see you soon but not too soon with the help of God' [Hospice one] and 'we'll be with you again forever daddy, but not too soon with lots of adventuring to do first.' [Hospice eight]

c. Purpose and Function of Memory Books

The purpose and function of Memory Books is best understood in the exploration of themes relating to letting go and holding on, the maintenance of bonds and rituals.

Continuing Bonds

Continuing bonds are maintained by passing on news. Some news will be widely shared and the bereaved include the dead in this. Marriage is one newsworthy event, 'getting married again, met a wonderful man, you would have loved him, same sense of humour, and loves to be near the bar for a drink' [Hospice three] or 'our wedding day was so beautiful mum it was all that I imagined and hoped



it would be, you would of absolutely loved it.' [Hospice five] Free-writers shared other familial news, 'I'm having twin boys you would be so proud' [Hospice ten] and 'wanted to tell you the news that I'm pregnant on an important day, was too ill to come on your 6 years but I'm here now. Great Grandad to my little one.' [Hospice five] This entry gives insight into the motivation for writing; to ensure news is delivered, attendance at a significant place for the deceased and the bereaved brings the dead into the realm of the living and a record of that contact is left behind. One hospice based in the area of a successful football team prompted several footballing entries; 'hope you are having a cold John Smiths up in heaven and celebrated when Leicester won the Premier League.' [Hospice five] Another wrote 'you would be proud of Leicester City football club!' [Hospice five]

The living do not let go of the deceased in their cognitive, emotional or familial worlds, but integrate them into their ongoing life. To write 'forever in our minds' [Hospice one] or 'we feel you always' [Hospice ten] or 'you are still part of everything I do' [Hospice four] suggests that dead people have an internalised continuing existence with those who live. The remembrance of the dead at specific times of year or at significant dates or events demonstrates the depth of familial ties. Writing about weddings, pregnancies, births and other events keeps the absent dead present:

23/12/15 [male name]

Another Christmas without you grandad ... You are loved and missed by everyone every day ... Have a lovely Christmas. Love the gang!! [Hospice four]

The dead can also be invoked to assist the living, giving purpose to ongoing bonds, 'To my dearest mum ... and dad ... I miss you so very much. Now that I too have cancer ... wish I could talk to you both. [Name] xxx' [Hospice five]

Letting Go and Holding On

To let go of another is to recognise that they are not physically present, to hold on means maintaining the deceased in daily life. The nuance to this theme is that of 'watching' in that the dead have an externalised presence to the bereaved. Thus a school age writer stated, 'I wished you were here to see me go into high school, but I know your (sic) watching down upon me.' [Hospice ten] A new home owner sought approval from a deceased relative, 'my new house is nearly ready it would be lovely if you could be here to help us but I'm sure your (sic) there having a look from above.' [Hospice ten] Family events also trigger the need to hold on, yet realise that the deceased is not a presence, 'I hope your (sic) looking down and watching over us all. I know you adore [baby's name] as we all do and so wish you could meet our little princess.' [Hospice four]

Ritual Acts

Free-writing is a deliberate record creating act. Writing requires the presence of the writer at the hospice – to make a journey from home or work – and this enables ritual. Ritual acts are consciously undertaken and suffused with meaning. Whether the entry is short or long, an act which is ritualistic is undertaken. This is particularly clear on anniversaries, 'Merry Christmas … happy birthday for tomorrow. Yesterday was still very hard – even though its (sic) been 13 years.' [Hospice ten] Other rituals may also be noted, 'I sat on your bench and shared our morning cup of coffee with you today.' [Hospice six] It is simplistic to consider that free-writing is just a way of keeping the memories alive.



Many entries mentioned that the deceased is never forgotten. Living people recall the dead away from the hospice, but attending and writing creates the space where ritual where can be enabled.

A form of obituary

Hospice free-writing is a means to create a continuing obituary of the deceased. As the bereaved write, they leave behind information which offers an insight into a life to others. This may be in the form of recollecting memories 'Missing you so so very much. Words can't say how I feel. I miss you felling me its (sic) my turn to wash-up. Our wonderful rides in the country. Miss you calling me a spoilt brat, which of course I am. [Hospice two] Or 'It's Grandad (male name) Day. A day when we celebrate your life and your time amongst us. ... To me you were my Dad and I was proud to call you Dad. We spent many special hours together bowling (I never won), talking football having a quiet pint and a game of pool, memories. I will cherish for the rest of my life these memories. [Hospice ten] It may also by recalling how the deceased influenced the bereaved, 'you taught me lots and lots of things that will carry me on in my life' [Hospice 6] or are remembered with others, 'she asks about her nana, who's (sic) picture is on our wall smiling down at us every day.' [Hospice One]

Every entry is in some way an obituary for it indicates that the deceased person is not forgotten and that others are reminded that a life was lived when they read a Memorial Book entry.

4. Hospice Memorial Services

Each participating hospice held a Memorial Service. Appendix 2 describes the location of the event, the setting and focal point.

a. Purpose, Function and Contents

Service leaders were responsible for stating the purpose and function of each event to the attendees. This was usually clear, but on the leaders' terms rather than an open invitation to use the opportunity to remember as they wished. One leader stated the event was 'not to reconnect with grief' [hospice five] and offered an invitation to engage as people wished, but added that if attendees were not religious then the leader 'prayed' that the service would have meaning [hospice eight]. The welcome included general 'housekeeping' information. Printed orders of service included a running order (see Appendix 4).

The choices of Poetry and prose suggested to attendees a number of approaches to death, loss and bereavement within one event. Living with loss, the absence of the deceased, the transitory nature of bereavement and continuing bonds were related through the services. Poetry and prose relies on metaphors to describe and define death and/or a response to it. Similarly, those services which included Judaeo-Christian Bible readings or writings from Sufi Muslim, and Hindu traditions drew heavily on imagery. In using poetry or prose, the service leaders were inviting attendees to imagine for themselves the themes expressed by authors. In using religious readings a different narrative was invoked, offering a perspective in which life and death were understood through a lens in which an afterlife was available to the faithful. The Old Testament reading suggested an encompassing, repeating cycle of events, again, in the control of a Deity.



The musical content of each service was varied (Appendix 4). Unlike verbal contributions it was more difficult to understand the purpose of a piece of music. Musical interludes were described as opportunities for reflection and the choices suggested attendees interpret each song in their own way, through the prism of grief and bereavement. Two hospices selected hymns. One was sung to a DVD 'Songs of Praise' recording. In an informal conversation with the service leader, the author was informed that attendees would struggle to sing without this. *Praise, my soul the King of Heaven* was sung at hospice two to a piano accompaniment.

An address was given at six of the services (see Appendix 4). The author observed that the addresses which drew upon personal experience or used a metaphorical story appeared to have greater impact on the attendees than a distinctly religious address which drew on unfamiliar existential themes. This was partly due to language and the need to explain religious concepts, absent from non-religious addresses (see Appendix 4).

b. Leadership, Participants and Attendees

Appendix 3 details the leaders of each memorial service. Service leaders were predominantly white with only one Black and Minority Ethnic staff nurse participating. In areas of diverse cultural, ethnic and religious background it would be expected that Memorial Services reflected this in content, participants and attendees. This was not the case (see Appendix 2). Attendees at all the services in this study were from White, Black Minority or in one case Asian Ethnic groups. Across all the sites, attendee's ages ranged from parents with babies to the elderly. There was a preponderance of older, retired adults with many family groups. The number of attendees ranged from 20 to over 100, with babies and children in the minority.

Although two services included personal bereavement narratives, the reliance on staff and volunteers to lead them and speak, delivered a professional or organisational perspective of bereavement, advocating to attendees how dying, death and bereavement should be navigated.

c. The Acts of Remembrance

The inclusion of symbols gave a clear direction to the Act of Remembrance (Appendix 4). Where symbols were used, attendees gave them a memorialising significance and, noticeably 'owned' this act. The writer, as a participant observer perceived that emotions were heightened during the Act of Remembrance. Individuals cried and families' huddled together, hugging each other and talking quietly. This was done with enormous respect for others present and recognised the shared experience of bereavement and the purpose of attending. The composure of attendees was noticeably restrained; quiet speech or silence with interest being taken in symbols available for the Act of Remembrance. Parents with young children sought to keep them quiet. During the service, some attendees appeared disinterested in the leader's words, readings or music and talked among themselves. Disinterest evaporated when the Act of Remembrance began. Even if verbally boundaried by the service leader's instructions, it was obvious that those who chose to participate did so on their own terms; expressing sadness, lingering at the place where memorial stones or flowers were placed, hugging relatives and guiding younger children in the act.



The omission of an Act of Remembrance led the observer to reflect that there was no sense of shared experience or purpose. Attendees to one service, despite being told that the event was not an opportunity to reconnect with grief, engaged with sadness. Bereavement as a shared experience was only lightly drawn on by the service leaders. In some instances it was left to the service contents to describe this as there was no reference to it by the leaders.

5. Cross-cutting themes

a. Meaning -making

Expressions of religion and spirituality

Some Memorial Book entries and some Memorial Service content were clearly religious. Other entries used religious terms but did not intend these to be interpreted as explorations of faith, for example the use of 'God bless' in a valedictory comment alongside a list of family names. This usage appeared to be colloquial rather than expressing belief.

Central to the expression of religious themes is the spirituality which is integral to a particular tradition, articulated through Scripture readings, hymns and in the case of two Memorial Services the addresses. Memorial Book free-writers brought their personal religious and spiritual understanding and conveyed this by invoking God's care for the deceased, or a belief that the dead have a place in heaven with God. That writers used religious terminology (heaven, angels, blessing etc.) does not mean that all authors were religious. Those who have a belief used Bible excerpts or hymn verses to reinforce their entry, while those who may lack a secular vocabulary to describe and underpin their thinking related familiar if, for them, incongruent terms. The author's earlier study highlighted this,

The traditional language of religious belief may offer some comfort or reassurance that life, in some form, continues after death. Deceased people were often mentioned as being in heaven, reunited with other family memes and waiting for survivors to join them. Only texts that were explicitly religious invited God to take care of the dead (Goodhead 2010). (p.336)

When Christian Bible verses were quoted these were used to reinforce a system of faith in which the bereaved took meaning and a sense of comfort and purpose for the deceased that death is not the end of all things and that the complexities of life are at an end. Undoubtedly the comfort for the bereaved was not that they will be spared grieving, but that the dead are safe and that God cares for the living in their sadness. This sentiment was reflected by one of the participant's in Holloway *et al's* study, 'I think it (the funeral) was a confirmation of my, my faith really ... as the sort of positive aspect of death' (Holloway, Adamson et al. 2013). (P. 46)

For free-writers of identifiably non-Christian traditions, it was not straightforward to understand how their religious beliefs help with bereavement. As has been noted above, writers from Sikh and Hindu traditions adopted broader spiritual perspectives when writing and only one person specifically referred to a place of worship; the Gurdwara.

Some Memorial Services avoided all content with a religious theme, but when these were introduced, there seemed to be a need for the service leader to explain them; as if the metaphors contained within



a Bible reading or hymn or piece of poetry required explanation to a group of people who may not otherwise understand what they were describing or addressing. The addresses based on a Christian Bible reading were delivered as an apologia for faith and its place in grief and bereavement.

Non-religious narratives

Some free-writers expressed their spirituality in the ways in which they sought to make sense of a death and its ongoing impact in the life of the bereaved. Here, meaning-creating and meaning-taking were clearly seen as writers recognised that a death had occurred, related its significance and expressed bonds of affection and relationship. The giving of news to the deceased through free-writing is a clear way in which this took place. Sharing personal and familial or communal news enables meaning to be made in its giving, and taken through the knowledge that a record of the presence of the writer remains and, that news has been passed on. The theme of reunion, present in this research as in the author's previous work, continues to suggest that the religious theme of immortality - the soul being in the presence of a deity - has been supplanted by the soul's reunion with those who died previously and, ultimately, with those who write (Goodhead 2010, p.336).

In the memorial services, poetry and prose and the addresses which described non-religious themes were not explained at all. Attendees were left to consider for themselves their meaning and how a theme might apply to their own experience. Here the assertion by Fortuin *et al* of the decline of the Grand Narrative comes into clearer focus (Fortuin, Schilderman et al. 2017). If one perspective no longer has the authoritative voice in making meaning of dying, death and grief, individuals may pick and choose from a range of perspectives to make their personal bereavement journey. Hence, in spiritual terms, there is no dissonance in hearing readings in a Memorial Service which express continuing bonds, or holding on and letting go or even the denial of death, for all possibilities are open to each attendee. Howarth recognised that individuals are seeking to 'rekindle the relationship between life and death. This is often defined as an individual search for meaning that rejects the collectivist and prescriptive structures of established religions' (Howarth 2007, p.100). The making and taking of meaning from Memorial Services and in free-writing sits neatly within Howarth's description.

Symbols

Frequent use was made of symbols in the form of pictures, cards and drawings in Memorial Books and objects in Memorial Services. Drawing a heart, pasting a birthday card or, ending an entry with kisses in a Memorial Book facilitates 'emotional expression' (Adamson and Holloway 2013, p.145). and each image or item left by free-writers 'incorporate popular culture and the idiom of everyday life' (Bell, Bailey et al. 2015, p.376). The objects chosen as symbols of the writer's presence are familiar and show affection towards the deceased. The symbolic items used within the Act of Remembrance at Memorial Services were not chosen by the bereaved, but by the service organisers. Candles, flowers, leaves and stones were provided to attendees for use in a prescribed manner; the service leaders informed attendees what was to be done with these symbols. During the Act of Remembrance however, each individual and/or family attending clearly gave the object a personal significance that related to the deceased person they were remembering. As an observer at ten services, it was as if placing a flower or a stone became a way for the bereaved to remember the deceased afresh, and



make and take meaning from an event in which they were otherwise passive observers. These symbols enabled the bereaved to:

Express the inexpressible; to capture mysterious essence; to inspire and strengthen; to signify and embody continuing connections; to grapple with the unfathomable; and to claim control over the unimaginable and fearful (Adamson and Holloway 2013, p.151).

Simple inanimate objects were given meaning and a purpose by attendees. Jalland, writing about funerary developments in Australia highlighted how important a symbol can become at any moment in time. Quoting a funeral celebrant, Dally Messenger, Jalland wrote, 'there is a deep human need to surround important occasions in life with ritual, symbolism, expressions of belief and feeling' (Jalland 2006, p.299).

b. Continuing bonds

Continuing bonds are explored in free-writing by passing on news and reminding the dead that they are missed and loved. In the services this theme is presented through 'liturgical' content. The theory surrounding continuing bonds argued that the bereaved do not let go of the deceased as the dead person continues to live in the memory of those who live. (Klass, Silverman et al. 1996) Walter's descriptive phenomenon of letting go and holding on to the deceased is seen in personal writing and also in some of the poetry and prose within the services. His development of Klass *et al's* work indicated that the bereaved do 'let go' of the deceased, yet continue to maintain a bond (Walter 1997). The author's earlier work on free-writing considered this was a common theme throughout free-writing (Goodhead 2010). An example of how individuals let go and keep hold is seen in the use of personal attributes. Writers who described the deceased's attributes and promise to uphold or pass them on are holding on to something 'tangible' from the deceased despite their death.

Through the living sharing news with the dead, the dead, although no longer present are deliberately included in the existence of the living. Although the dead becoming an angel is a recent development in Europe, moving across the America in the 2000's (Walter, 2015, p. 22) Walter also describes the 'angelic dead' who are memorialised as perfect beings. Becoming an angel enables a continuation of relationship. This is very different to the religious concept of the soul which represents 'the deceased's continuing identity' (Walter, 2015, pp. 14-15). Access to the soul is lost to the living when the deceased's soul goes to heaven; access to an angelic being is not.

c. The interface between public and private

The author concluded from his earlier research that free-writing is not a private matter, but a 'public and social act' (Goodhead 2010, p.338). Writing requires the writer attend at a hospice to write. It demands attention to what is to be written and to what others have already written. However, it is discreet. Anyone reading memorial book entries must be in the hospice. Hospices offer a semi-public space to the bereaved to facilitate memorialisation. Free-writers undertake a personal, private act in writing in Memorial Books but they will be aware of the writings of others and may recognise their own entry will be read by those they do not know. This explains why a mimetic quality to entries can be seen in the language and terminology chosen (Goodhead 2010). There is a sense of shared experience in free-writing when authors recognise the common themes which others describe. There



is also a shared experience during the Act of Remembrance at Memorial Services. The 2001 study by Duncan *et al* recognised that an important element of returning for a memorial event was this Act, 'Some said "knowing others are in the same situation is helpful" and found it "helpful to have opportunity to reflect and remember". It would seem that this act of remembrance and thanksgiving is valid and beneficial' (Duncan, Findlayson et al. 2004).

6. Discussion

Participation in this large research project exploring the changing face of memorialisation, has enabled a broad study of memorialising opportunities available in hospices in the UK. This has built upon the earlier findings of Goodhead's work published in 2010. Grief theory, meaning making, a folk belief in an afterlife, the public/private nature of writing and the importance of place to the bereaved are discussed in this section. The findings of this study support and develop the earlier findings and add new layers of detail to this.

Direct comparison of the free-writing material against the Memorial Services is not possible. They exist for very different purposes; free-writing for the individual and family remembrances, Memorial Services for a corporate recognition of bereavement and grief. There are however comparisons between the themes that can be made.

Both free-writing and Memorial Services illustrate the most recent bereavement theories in practice – specifically, grief as meaning reconstruction (Neimeyer 2002) the theory of continuing bonds and letting go and holding on. A search for meaning within religious and spiritual frameworks both for free-writers and service attendees is part of the process of grieving and bereavement. Rituals and symbols, poetry and prose, addresses and talks are means for the bereaved to constantly assimilate the dead into the lives of the living. Symbols are metaphorical and their meaning is often understood differently; between individuals and within families (Adamson and Holloway 2013, p.151) but metaphors matter when trying to grasp the inexpressible and make sense of a death through a religious or spiritual prism.

Memorialising through Free-writing is not directed by any other person. Writing about posts made on Facebook after bereavement, Irwin suggests that after a death:

'our friends, family, and countless others create meaning out of our deaths in the ways they choose to celebrate our lives and to mourn our passing. Through memorialization, the living provide the dead with a sense of immortality' (Irwin 2015, p.120).

In free-writing, authors conform to Irwin's description, creating a sense of immortality for the dead through the maintenance of bonds. This is not achieved through the Memorial Services. Even though individual names are read and an Act of Remembrance takes place, this is transitory and lost to all at the conclusion of the event.

Irwin is also helpful in understanding something of the loss of the Grand Narrative postulated by Fortuin *et al.* The demise of this Narrative (A Judaeo- Christian construct) has removed a single framework in which death and bereavement are understood and negotiated. While traditional rituals remain (the funeral, burial, ashes scattering) there is no longer a narrative that suggests the funeral's



purpose is a termination of bonds and a release of the dead into the hands of God to await the resurrection of the dead to eternal life. Now, individuals continue to hold onto the deceased and form continuing bonds (Fortuin, Schilderman et al. 2017). While helpful in understanding the passing of a single narrative, it does not address the many ways in which the bereaved previously maintained bonds with the dead. Mourning jewellery, cards, dress and other rituals existed within the Grand Narrative, prescribed by society and channelled socially (Prior 1993). Without a single narrative, individuals choose what methods will enable continuing bonds meaningfully and personally.

The use of symbols in Memorial Services and drawn or pasted into Memorial Books indicates the power that abstract objects can have. A photograph or card or the drawing of a heart or smiling face in a Memorial Book has meaning to the writer. Stones, flowers and candles used for Acts of Remembrance are imbued with meaning by those who will present or take them away. These symbols can be representative of continuing bonds, recognise a letting go of the deceased or be a familiar object. In their discussion of symbols in funerals, Adamson *et al* noted the power that symbols have within the funeral service. These can be in the choice of readings, songs, flowers, clothes which 'create and convey meanings which are otherwise difficult to articulate' (Adamson and Holloway 2013). In Memorial Books and services, symbols play a part to express the inexpressible although it was not part of this research to enquire into their meaning. Adamson *et al* again help to understand what their purpose might be as the bereaved were 'finding those symbols which created and expressed meaning for them' (Adamson and Holloway 2013). It was clear that symbols given to the bereaved at Memorial Services could be employed and given meaning even though they were not chosen by the bereaved.

That the free-writing and Memorial Services offer a somewhat individual and elegiac interpretation of death and an afterlife is reflected by Holloway *et al* in the 2010 study of spirituality in contemporary funerals. (Holloway, Adamson et al. 2010) In describing the funeral as a celebration and remembrance of life, religious ministers, family members and funeral celebrants all agreed that one purpose of the funeral was to recall the deceased in a positive manner; to celebrate and remember them. People who Free-write and those who lead Memorial Service do these same tasks, but in different ways to each other. Free-writers may repeatedly return to a Memorial Book to make additional entries to their first writing. In doing so, the dead are recalled and their lives given value; celebrated by the living. More formally, the creators of Memorial Services invite groups to a communal event. Not a second funeral, but an event in which many dead are remembered collectively. 'Celebrate' and 'remember' cropped up frequently throughout the services, both in the words used by the service leaders and in texts. Neimeyer's term 'meaning reconstruction' helps in understanding the process which bereaved people undertake after a death. Bereaved people have a need to reconsider the deceased and to reconstruct who the dead person is in their own ongoing life. This process takes place in a number of ways, including free-writing and attending Memorial Services.

Social media has enabled significant opportunities for online bereavement memorialisation; personally and communally. It is easily accessed, literally from the comfort of one's own armchair. Online support can be accessed 'to connect with others who have gone through a similar experience of loss ...and help might be particularly attractive to the survivors who might be bereft of other support' (Krysinska and Andriessen 2015). A content analysis of Facebook memorial pages demonstrated how the living establish and maintain continuing bonds with the deceased over and



above traditional death rituals (Irwin 2015). Irwin suggested that unlike Klass and Goss who proposed that continuing bonds serve a private purpose, Facebook pages provide a public sphere in which these bonds can be described, a conclusion supported by Willis and Ferruci and extended in their description of online posts as 'emotional release' (Irwin, 2015, p. 141) (Willis and Ferruci 2017). Memorial Books and Memorial Services sit within this orbit of modern memorialising even though they are traditional means rather than online ways to remember. Hospices at 50 years old are offering a relatively new environment in which to memorialise, away from cemeteries, grave sites, columbaria or religious, liturgically based events. In the same way that social media enables the bereaved to write as they wish, when they wish, hospice Memorial Books provide bereaved people with a place in which they can write, semi-publicly about the importance of the deceased. These are continuing bonds, expressed to others, as described above. Memorial Books and Memorial Services allow bereaved people to recognise that their experience is a common one; for others will write in books and describe their loss, share their news and express emotion. Many attend services in which a corporate body are reminded of bereavement and invited to participate together in recognising this. These are collective experiences which social media sites also enable.

Holloway *et al's* descriptor of bereavement as a psycho-social-spiritual transition explains more adequately how meaning is sought, found and taken from free-writing and Acts of Remembrance (Holloway 2007) (Holloway, Adamson et al. 2013). Bereaved people use the opportunities which hospices afford to continue to take meaning from the life of the deceased and for a time at least to bring the dead into their world.

Hospice Memorial Services naturally offer a 'one size fits all' approach. Unlike Memorial Books which allow free reign to the writer to say as much, or as little as they wish, the Memorial Service is designed and delivered by hospice staff and volunteers. The contents are not decided upon in collaboration with the attendees and the religious/spiritual/secular focus is chosen by the professional team. This is differs with the findings of Holloway *et al's* article on modern funerals which showed the bereaved expect bespoke funerals in which the contents are negotiated between family and minister or celebrant (Holloway, Adamson et al. 2013).

People attend Memorial Services specifically to remember their relative. The moments of value are those which allow them to make and take their own meaning within and from the event. In the aftermath of bereavement, that process requires the assistance of a 'death-work mediator' (Walter 2006). In longer term bereavement, individuals make and take their own meaning despite what happens in a planned event that takes place around them. Miles and Corr describe this in their Death Café movement study. Death Cafés are not grief support groups, yet the bereaved choose to attend, aware that their needs are not specifically catered for. (Miles and Corr 2017) Bereaved Death Café attendees make and take meaning from a group which allows open discussion about death and dying.

To return to Niemeyer's term 'inveterate meaning-makers' and Parkes' contention that bereavement is a psycho-social transition, this study has shown that that transition occurs through meaning making (Niemeyer, 2010, Parkes, 2000). Bereaved people make and take meaning constantly after bereavement. Through this process they renegotiate who the deceased is with their ongoing life and retain and expand familial relationships with them. Writing in Memorial Books or engaging in an Act of remembrance enables meaning taking to occur; that a life had value and continues to have worth



and importance for those who remain. Writing on the process of creating a funeral, Holloway *et al* noted that meaning is sought, created and taken from preparing a funeral through to its delivery. Those attending hospices after a funeral has taken place continue to seek, create and take meaning about the deceased from their writing or presence at a service (Holloway, Adamson et al. 2013).

7. Conclusion

Memorialising is an important function of bereavement and the opportunity to remember the dead, formally or informally helps the process of remembering. Many hospices offer to the bereaved the opportunity to attend a Memorial Service and / or free-write in Memorial Books. This study indicates that both activities would benefit from investment by hospices. Ensuring that Memorial Books are easily accessible and possibly purpose made would recognise the importance of free-writing. Services must also be clearly outlined for attendees. It could be argued that moving the memorial service towards a secular event defuses issues over culture, ethnicity or belief, but this may not engage with people who grieve in these ways.

No other organisations work so closely with the dying and bereaved. Their role in enabling memorialising may not be as valued as it could be. In making Memorial Books easily accessible and, if possible purpose made, there will be recognition by the bereaved that the hospice is encouraging free writing.

By enabling a clear moment in Memorial Services in which bereaved people can remember together, the shared purpose of attending a service can become evident through the Act of Remembrance. The data collected described the value of a shared act to attendees and this should suggest to service leaders that an explicit reference to this as a reason for being present would be appropriate at the start of the event.

There is also a need for clarity in Memorial Services of the material included in these events. The study noted that these services included religious material among secular poetry and prose and secular material had greater prominence. However, there was no attempt to contextualise the use of material; religious or secular as reflecting people's formed belief or inherent spirituality. It would have been valuable to attendees for leaders to open the service with a description of how people choose to remember and to state that elements of the contents of the service will be affective to some more than other.

In this larger study of ten hospices, the findings of the author's earlier research are expanded with the inclusion of bereaved people returning to share familial or community news with the deceased and the explicit references to the dead becoming angels or being taken to the afterlife by angels.

In the aftermath of bereavement, people of all ages undergo a search for renewed life meaning, shaped by the death of a family member or friend. As inveterate meaning makers, those who negotiate a future separated from another, transition through the psychological and social burden of bereavement and maintain bonds with the dead. There are a number of organisations which offer the bereaved ways to memorialise the dead. On All Souls in the Christian calendar, Churches recall the dead; usually in Roman Catholic or Anglo-Catholic (Anglican) rites. Recently funeral directors and



crematoria have begun to offer the opportunity to remember those who have died. Hospices are in an unrivalled position to offer significant opportunities in which this negotiation can take place; both informally in free-writing and formally in Memorial Services. This is because of their involvement with deceased patients during illness and bereavement support for those who remain after death. In providing Memorial Books or a Memorial Service, hospices allow a relationship with the dead to be maintained by an organisation significant to the deceased person while alive. Hospices can be storehouses for remembering and memorialising by effectively managing the opportunities for free-writing and Memorial Services.

As described earlier, places have meaning for bereaved people and the provision of memorialising opportunities in a significant place allows those who wish to remember their relative to do so, alone or with others. Jonsson suggested that places may serve to permit bereaved people to remember and forget the deceased (Jonsson and Walter 2017, p.409). Hospices may be facilitators of such remembering and forgetting by enabling the memories to be held safely in a place which is part of, but away from the everyday life of the bereaved.

For bereaved people memorialising is an important and meaningful activity, both through free-writing and/or by attending a pre-planned hospice event. Hospices have a pivotal role in creating helpful opportunities for individuals and families to remember the deceased. Those who engage in the activity of memorialising make a considerable effort to do so. Hospices are uniquely placed to create opportunities for memorialisation both planned and unplanned. Hospices who invest in memorialising opportunities will help bereaved men and women through the process of grief and maintain an important connection with the communities they serve.



Recommendations

This study has highlighted a number of findings which hospices can benefit from utilising to facilitate memorialisation. These findings relate to the significance of place, the opportunities to memorialise in free-writing and at Memorial Services and a space in which the ongoing nature of grief and seek, create and make meaning can take place. There are three recommendations from this study of memorialising in hospices which would create meaningful opportunities to remember those who have died:

- 1. Ensuring Memorial Books are readily accessible and that the physical book is invested in to make free-writing in each book have value to the hospice and the writer. This requires a place in the hospice building; chapel, quiet room or reception area where the book(s) can be easily accessed by visitors. The book should also be bespoke rather than 'off the shelf' meaning a financial investment, but it will be a clear indication that the hospice encourages memorialisation and considers this to be significant for the bereaved. Books which are filled should be kept in the same physical space so returning writers can access previous entries and recall earlier thoughts and emotions captured on paper.
- 2. Planners and leaders of Memorial Services must make the purpose and contents of events clear, considering carefully what themes individual and elements the service should describe and contain. For example, where should material describing holding on and letting go be placed when there is also material describing continuing bonds? What place should religious material have within the service? What music would be appropriate and what themes should music encompass? If there is an address, who should deliver it and what is it to be about and/or describe? Any poetry or prose which denies death should be carefully considered by service organiser's for its suitability for inclusion. The Act of Remembrance should be recognised as the primary function of the Memorial Service and thoughtfully approached with time allowed for attendees to engage fully in this. The use of symbols within the Act of Remembrance must be simple, and time allowed during the Act for attendees to imbue these with personal and familial significance
- **3.** Memorial Service venues should be considered as important as the content of the service itself. Hospice teaching rooms or meetings rooms may be convenient for staff and volunteers when arranging an event, but those who attend come for a special purpose; to recall their family member or friend who has died Service venues should, wherever possible, be less functional in nature. The use of a hotel function room and a space which led directly onto hospice gardens by two participating hospices are examples where the attendees are offered a gathering space which gives a sense of something 'other' to the service itself.



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Appendix 1

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|---------------|----|----|------|---|-----|-----|---|
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|----|----------|-------------|------|
| 1 | Physica | l surround | ingo |
| т. | riiysica | ı sarı Gana | HIGS |

- 2. The Service leaders
 - a. Type

Minister of Christianity

CofE RC Methodist

Other What other?

Religious leader other faiths

What faith?

Humanist

Other - what other?

- b. Any staff members or volunteers participate?
- c. Language
- 3. The attendees

Approximate numbers

Age range

Gender distribution

Composure, how people carry themselves

Dress

4. Music

Is there music?

Recorded? Live?

Instrumental? Vocal?

Secular? Religious?

In what way is music used? Express spirituality/emotion or just a filler?

Does music fit the event?

What is the music?

Any hymns? If so, what were they?



5. Readings

From religious texts? From other prose?

Poems?

Who reads?

What is read?

6. Prayers

Are there prayers?

Led by whom?

What do they describe/contain?

7. Silent periods

Are there silent periods?

If so, what are the attendees expected to do with it?

Is there a distinct period of remembrance?

8. address

if so, address by whom?

Content? (story & address) (religious basis) (secular) (content for children)

Language?

9. Any symbol /rituals used? (Candles, flowers, cards etc.)

10. Service format

- a. Is there a service sheet/ script?
- b. What happens when?
- c. Is there any form of announcement of purpose of service? e.g. we are here today to...
- d. Who participates and how?

Reading, singing, prayer

- 11. Any reference to care of deceased under the hospice?
- 12. Any reference to ongoing support?
- 13. Any reference to shared experience?



Appendix 2

Table 1: Memorial books analysed in the study.

| Hospi | Location | Population | Main Socio-Demographic | Main | Memorial |
|--------|-----------------|---------------------|------------------------------|---------------------------------|--------------------------------|
| ce | | (hospice catchment | Groups (over 1% of | Religious/non-religious | Book |
| | | 2011 census) | population) | groups present (over 1%) | |
| Hospic | West | 522,452 | White, Asian and black ethic | Christian, Muslim, | A4 hardbound artist's |
| e 1 | Yorkshire | | groups | No religion, Hindu, Sikh | sketchbook |
| Hospic | South East | Across 5 boroughs | White, Asian and black ethic | Christian, No religion, Muslim | Hardbound purpose made |
| e 2 | London | 1,516,607 | groups | Hindu, Sikh, Judaism | large book |
| Hospic | Scotland | 598,830 | White, Asian and black ethic | Christian, No religion, Muslim, | A5 hard backed lined book |
| e 3 | | | groups | Hindu, Sikh | and A4 lined book headed |
| | | | | | 'PPWH Prayer Room Book' |
| Hospic | North East | 148,535 | White, Asian and black ethic | Christian, No religion, Muslim, | Green, hardbound unlined |
| e 4 | England | | groups | Hindu | book |
| Hospic | Leicester-shire | 330,000 | White, Asian and black ethic | Christian, No religion, Muslim, | No memorial book |
| e 5 | | | groups | Hindu, Sikh | |
| Hospic | West | 1,073,045 | White, Asian and black ethic | Christian, Muslim, No religion, | 5 books, all A5, some plain |
| e 6 | Midlands | | groups | Sikh, Hindu, Buddhist | covers others patterned covers |
| Hospic | Northern | 333,001 | White ethnicity | Christian, No religion | Between A5 and A4; |
| e 7 | Ireland | | | | hardbound. Poem 'Footprints' |
| | | | | | on cover, picture of a beach. |
| | | | | | Poem inside front cover |
| Hospic | South East | 138,265 | White ethnicity | Christian, No religion | Black hardbound book |
| e 8 | England | | | | inscribed with hospice name. |
| | | | | | First used in 1994. |



| Hospic | West | 206,700 | White and Asian ethnic | Christian, No religion, Muslim, | No memorial book |
|--------|-----------|---------|------------------------------|---------------------------------|-------------------|
| e 9 | Midlands | | groups | Hindu, Sikh | |
| Hospic | West | 751,500 | White, Asian and black ethic | Christian, No religion, Muslim, | A5 hardbound book |
| e 10 | Yorkshire | | groups | Sikh | |



Table 2: Memorial services observed for the study.

| Hospice | Memorial | Venue of service | Memorial Service Leaders | Attendees |
|-----------|-----------|---|---|--------------------|
| | Service | | | |
| | Date/Time | | | |
| Hospice 1 | Wednesday | 1 st floor Conference Room | Social Work (lead), | Around 20 people. |
| | 4pm | Chairs in Semi-circle | Nurses, maintenance staff, | All white |
| | | Focal point: Low table with flowers | volunteers | |
| Hospice 2 | Sunday | Ground floor, large Multi-purpose Room looking | Spiritual Care Lead (lead) | Around 120 people. |
| | 4pm | onto the Garden. | Pastoral Assistant, | White and Black |
| | | Chairs in rows. | Humanist celebrant, | Minority Ethic |
| | | Focal point: Table with statue, lit candle, | volunteer | |
| | | Memorial book and two free standing candle stands | | |
| Hospice 3 | Sunday | Ground floor, multi- purpose (day room). | Chaplain (lead), | Around 25 people. |
| | 3pm | Chairs in rows. | trustee, nurse, finance team member, | All white. |
| | | Focal point: table with tags and pens and a | bereavement counsellor | |
| | | remembrance book | | |
| | | One candle stand and a 'tree' of branches. | | |
| Hospice 4 | Sunday | 1 st floor teaching room. | Chaplain (lead), | Around 30 people. |
| | 3pm | Chairs in rows. | social worker, children's counsellor, volunteer, | All white |
| | | Focal point: low table with a lectern and flowers. | | |
| Hospice 5 | Friday | Ground floor multi-function teaching room. | Chaplain (lead), 2nd chaplain, | Around 50 people, |
| | 3pm | Chairs in rows. | two trustees, a nurse, a consultant, a volunteer | all white |
| | | Focal point: Screen with rolling images (landscapes), | | |
| | | lectern. | | |
| Hospice 6 | Saturday | Ground floor multi-function teaching room. | Chaplain (lead), 2 nd chaplain, Social worker, | Around 55 people. |



| | 2pm | Chairs in rows. | a consultant | Mainly white. |
|------------|--------|---|---|--------------------|
| | | Focal point: Table at front with 4 unlit candles, | | One Asian group |
| | | screen showing landscape images. | | one BME group. |
| | | At door a 'tree' for leaves to be attached to. | | |
| Hospice 7 | Monday | Large function room in hotel. | Chaplain (lead), Social workers, Bereaved | Around 90 people. |
| | 7.30pm | Chairs in rows. | relative, volunteers | All white |
| | | Focal point: Screen showing images of hospice and | | |
| | | staff. Table with empty vase and 4 unlit candles. | | |
| Hospice 8 | Friday | Rectangular chapel. Chairs in rows. | Chaplain (lead), volunteers | Around people. |
| | 10am | Focal point: Altar with cross and unlit candle. | | All white |
| Hospice 9 | Sunday | 1 st floor teaching room. Chairs in rows. | Chaplain (lead), volunteer | Around 45 people. |
| | 3pm | Focal point: Table with a large green bowl, 3 battery | | All white |
| | | operated candles, petals strewn on table. | | |
| Hospice 10 | Sunday | Ground floor teaching room. Chairs in rows. | Spiritual Care manager (lead) | Around 100 people. |
| | 3pm | Focal Point: Metal 'tree' for candles, Lit Paschal | volunteers | Mainly white, one |
| | | candle on the top of the tree (cross motif on candle | | BME group. |
| | | visible) | | |



Table 3:Order of memorial services observed for the study.

| Hospice | Address given | Music | Poetry, Prose and Religious | Act of |
|-----------|-----------------------------|---|--------------------------------------|----------------|
| | | | Readings | Remembrance |
| | | | | and symbols |
| Hospice 1 | No | Yes: CD's | The bridge (Joy Cowley) [adapted] | No |
| | | Memories (Elvis Presley) | No timetable (unknown) | |
| | | Bridge over Troubled Waters (Simon & Garfunkel) | When I must leave you (uncredited) | |
| | | Catch the Wind (Donovan) | A letter from heaven (Margi Harrell) | |
| | | Wind Beneath my Wings (Bette Midler) | You can shed tears (unknown) | |
| | | Unchained Melody (The Righteous Brothers) | That's normal (Edith Fraser) | |
| | | I Hope you Dance (Ronan Keating) | [adapted] | |
| | | Forever Autumn (Justin Hayward) | | |
| | | The Promise (Tracey Chapman) | | |
| | | Adagio for Strings (Samuel Barber) | | |
| Hospice 2 | By the Spiritual Care Lead. | Yes: CD's and piano | Perseus in the wind (Freya Stark) | Yes: |
| | Based on a children's story | 'In Paradisum' (Gabriel Faure) [from Requiem] | On death (Kahlil Gibran) | Candles lit as |
| | | 'Praise, my soul' (HF Lyte) | John 14: 1-6 | names read |
| | | When I am laid in earth (Alison Moyet) [from Dido & | Farewell my friends (R Tagore) | and 'green |
| | | Aeneas] | Human Existence (Bertrand Russell) | slips'; with |
| | | | Everyone sang (Siegfried Sassoon) | attendees |
| | | | | memorials |
| | | | | brought to the |
| | | | | front |
| | | | | Excerpt from |
| | | | | the Jewish |
| | | | | Prayer Book |



| Hospice 3 | By the Chaplain. Reflected | Yes: CD's and video recording | The dash (Linda Ellis) | Yes: |
|-----------|-----------------------------|---|--------------------------------------|-----------------|
| | on words of the hymn and | 'Great is thy faithfulness' (T Chisholm) | Lamentations 3: 22-23 (printed) | Candles lit as |
| | Bible reading, | Somewhere over the rainbow (IZ Kamakawiwo'ole) | | names read, |
| | | Footprints in the sand (Leona Lewis) | | stones could |
| | | | | be placed at |
| | | | | the front and |
| | | | | tags written. |
| Hospice 4 | No | Yes: CD's | A litany for All Saints (Jan Berry) | Yes: |
| | | Turn, turn, turn (Pete Seager) | To leave the world a better place (R | Stones could |
| | | Instrumental from 'Celtic Expressions' (Kingsway | Waldo-Emerson) | be placed at |
| | | Music) | The heavy stone (Averil Stetford) | the front or |
| | | Keep me in your heart (Warren Zevon) | Miss me but let me go (unknown) | taken home. |
| | | | Candles for you (unknown) | Names read. |
| | | | A blessing poem (DJ McGill) | |
| Hospice 5 | No but an excerpt from 'The | Yes: CD's | Snow (Tessa Wilkinson) | Yes: |
| | Velveteen Rabbit' was read | Cavatina (S Myers) [Theme from 'The Deer Hunter'] | Memory candles (unknown) | Leaves given |
| | by a trustee | My heart will go on (Horner) | Litany of remembrance (RB | out and |
| | | Spiegel im Spiegel (A Pärt) | Gittelsohn) | invitation |
| | | You raise me up (Josh Groban) | Farewell my friends (Gitanjeli Ghei) | made to write |
| | | | Tomorrow (Derek Dobson) | on them. |
| | | | 1 Corinthians 13: 7 (printed) | Names scrolled |
| | | | | on a screen |
| | | | | before service. |
| | | | | No |
| | | | | introduction |
| | | | | given |



| Hospice 6 | Personal bereavement | Yes: CD's | We remember them (unattributed) | Yes: |
|-----------|---------------------------------|---|-----------------------------------|------------------|
| | experience read by a staff | None mentioned in service booklet | Candles (unattributed) | Candles could |
| | member titled 'The Golden | | Everything you see (Rumi) | be lit, and a |
| | Thread' | | | 'reflection' |
| | | | | listening to |
| | | | | music and |
| | | | | names read. |
| Hospice 7 | Personal bereavement | Yes: live music played by harpist and flautist. | Remember (Christina Rossetti) | Yes |
| | experiences read by relative | Ashokan Farewell (Jay Ungar) | Four candles for you (unknown) | Names were |
| | and bereavement volunteer | Eleanor Plunkett (T O'Carolan) | Kerry Rose (Michael Messenger) | read and |
| | | Ned of the Hill (Unknown) | They have gone (unknown) | attendees |
| | | The lark in the air (unknown) | We come with thanks (Judy Davies) | invited to bring |
| | | Mrs Power (T O'Carolan) | | flowers to the |
| | | Believe me if all (JA Stevenson) | | front. No silent |
| | | | | period |
| Hospice 8 | Difficult to establish if there | Yes: CD's, all recorded. | Matthew 5: 4 | Yes: |
| | was an address or a | None mentioned in service booklet | | Flowers and |
| | discursive introduction | | | cards given to |
| | | | | attendees and |
| | | | | invited to |
| | | | | place these on |
| | | | | a table. |
| Hospice 9 | By chaplain based on a Bible | Yes: CD's | Ecclesiastes 3: 1-8 | Yes: |
| | reading. | None mentioned in service booklet | 1 Corinthians 13: 4-7a, 12-13 | Names read |
| | | | You can shed tears (unattributed) | and an |
| | | | | invitation |



| | | | | given to place a pebble into a bowl on a table at the front. |
|------------|----|--|---|---|
| Hospice 10 | No | Yes: Live music played by a flautist. None mentioned in service booklet | Ecclesiastes 3 Remember me (unattributed) When you lose (J O'Donohue) | Yes: A period of silence after names read. Invitation made to bring unlit candle to the front for lighting and placing on a tree. |









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