

Palliative and End of Life Care Priority Setting Partnership (PeolcPSP)

Bereavement: experiences, needs and supportive interventions

Dr Emily Harrop, Jordan Van Godwin, Dr Stephanie Sivell, Dr Jessica Baillie, Dr
Anthony Byrne and Dr Annmarie Nelson

Marie Curie Palliative Care Research Centre,
Cardiff University School of Medicine

June 2015

Contents

Acknowledgements	ii
Palliative and End of Life Care Priority Setting Partnership	Error! Bookmark not defined.
Managing and Coding the Data	v
Coding framework	vi
Bereavement.....	1
Death experiences and impacts on bereavement	2
Bad deaths and good deaths	2
Improving communication during the dying stages and post death	4
Filling the void: The need for bereavement support	6
What support is currently available?	8
What bereavement support is optimal?	10
What kinds of support should be provided?	10
When and for how long should support be provided?	13
Meeting the needs of different groups.....	16
Summary	21
Appendix: Further extracts	23
Improving communication during the dying stages and post death	24
What kinds of support should be provided?	29

Acknowledgements

These reports were created with the support of the PeolcPSP Steering and Data Management groups. The authors would also like to thank the patients, carers, family members, friends, professionals, volunteers and members for taking part in the survey.

Introduction

This report presents data arising from 1403 completed responses from the first PeolcPSP survey, which was open from December 2013 to May 2014.

The report focuses on analysing survey data that are outside the scope of the James Lind Alliance protocol, which focuses on clinical interventional research questions in relation to evidence uncertainties.

http://www.palliativecarepsp.org.uk/wp-content/uploads/2013/09/PeolcPSP-PROTOCOL_2013-FINAL.pdf

Most respondents gave detailed narrative accounts in response to the survey questions. Questions related to interventions within palliative and end of life care were extracted for prioritisation by the PeolcPSP using the standard James Lind Alliance methodology, as described in the JLA guidebook (<http://www.jlaguidebook.org/>). The final report of this project with the top 10 research priorities identified and prioritised by patients, carers and health and social care professionals is now publicly available (<http://www.palliativecarepsp.org.uk/finalreport/>).

However, there remained much data which did not fall within the PeolcPSP's scope, including non-specific questions or observations relating to overarching issues within palliative care.

The Steering Group of the PeolcPSP was keen for these 'out of scope' data to be further analysed in line with the aims of the PeolcPSP *'to identify the unanswered questions about palliative and end of life care from patient, carer and clinical perspectives and then prioritise those that patients, current and bereaved carers and clinicians agree are the most important'*. Using a supplementary methodology applied to the entire data set, this provides a valuable opportunity to thematically explore the uncertainties, questions and experiences of a wide variety of people and provide further research areas to supplement the interventional questions taken forward by the standard analysis carried out by the PeolcPSP.

Palliative and End of Life Care Priority Setting Partnership

The Marie Curie Palliative Care Research Centre (MCPCRC) was commissioned to analyse the data from the James Lind Alliance Priority Setting Partnership to identify research questions for palliative and end of life care¹. A public survey was generated using Survey Monkey and members of the public, patients, current and bereaved carers/friends/relatives, professionals and others were given the opportunity to anonymously ask questions about palliative and end of life care, as depicted in the figure below.

PAGE 2: Consent

Q1: I have read the consent section and I am happy to take part Yes

PAGE 3: Section 1 - Your questions about palliative and end of life care

Q2: What question(s) do you have about care, support and treatment for people who are in the last few years of their lives that could help them to live as well as possible? This could also include question(s) about care and support for current carers or families.

How can families be better supported at home to manage the symptoms of people in their last few weeks of life?

Why is the psychological support of people and their families not available to all that may need it?

Q3: What question(s) do you have about care, support and treatment for those rapidly approaching the end of their lives? This could also include question(s) about care and support for current or bereaved carers or families looking after someone at the end of their life.

Why is it that not all patients have access to hospice care and if they do, they don't always understand what care they can expect to receive? Many patients are admitted to hospices frightened, would contact earlier in the journey be more beneficial?

PAGE 4: Section 1 continued

Q4: Which of the following categories best describes you? (please tick all that apply) We need your answer so we can fully process your questions. Your name or organisation will not be published in association with the question.

I am a professional working with people in the last few years of life

PAGE 5

Q5: Where do you live? England

PAGE 6

Q6: Which is your primary profession? (Please tick one box only) Specialist palliative care nurse

¹ <http://www.palliativecarepsp.org.uk/>

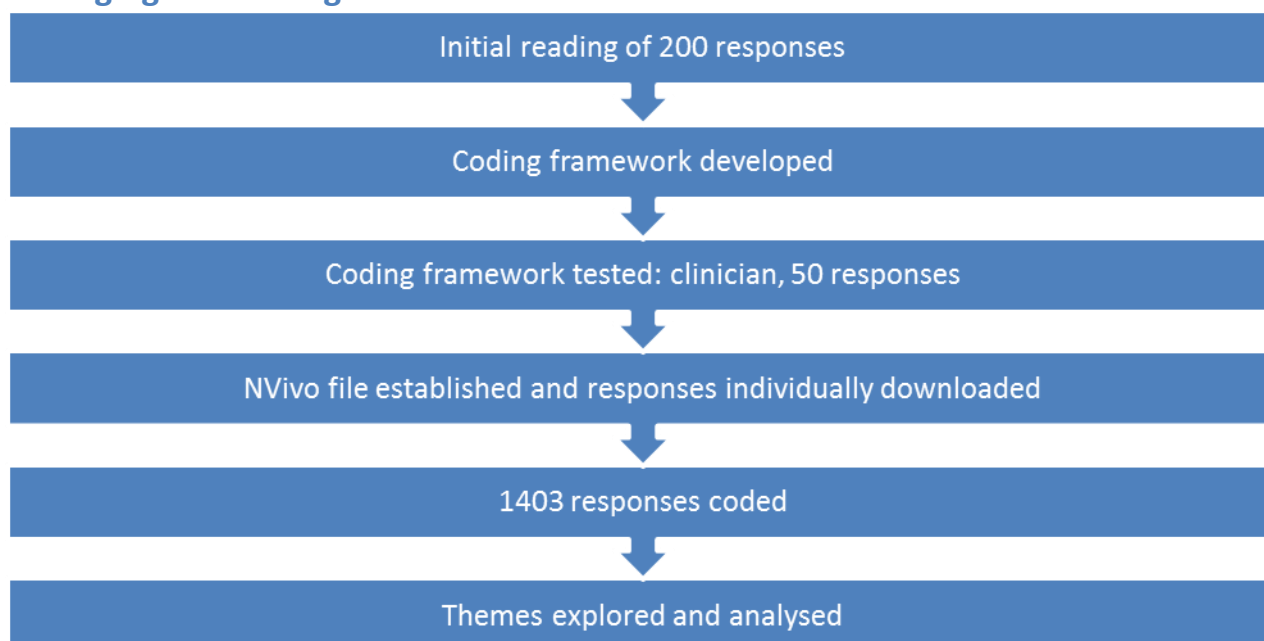
SUMMARY OF DATA MANAGEMENT PROCESS

An initial reading of 200 responses to the survey on Survey Monkey was undertaken and a coding framework developed and tested. In total, 1403 responses have been exported from Survey Monkey. Further details on the data management process and the coding are detailed below. In terms of responses, multiple conditions are represented by participants in the survey:

- Cancer;
- Dementia;
- Motor Neurone Disease (MND);
- Chronic Obstructive Pulmonary Disease (COPD);
- Multiple Sclerosis (MS);
- Parkinson's Disease;
- Frailty;
- Learning disability.

A range of participants took part in the survey, including patients, bereaved and current carers, family members and friends and health and social care professionals working with people in the last few years of life. The survey was also open to volunteers working with people at the end of life and interested members of the public. Respondents had the option of choosing multiple categories which they feel best described them. As such, respondents may have multiple identifiers, e.g., state that they are a bereaved carer/family member/ friend *and* a professional working with people in the last few years of life.

Managing and Coding the Data



Coding framework

The initial coding framework was developed after reviewing 200 printed copies of the survey responses. The coding framework was applied to 50 survey responses to confirm that it reflected the data. Researchers at the MCP CRC then entered the coding framework into NVivo 10 qualitative software and systematically coded the survey responses.

The coding framework was reviewed and refined until the final version (displayed below) was agreed upon:

Communication	Communication & Decision-Making / Offering Help / Asking for Help / Media Portrayal; Goals and wishes / Spiritual / Counselling / Psychological Support; Place of Care / Death / Advance Care Planning.
Managing symptoms and medications	Managing Medication; Symptom Management.
Perceptions of palliative care	(Mis)understanding of Palliative Care; Assisted Dying / Suicide / Euthanasia; Care vs. Cure / Hope vs. Acceptance.
Service use	Access to Service / Equitable Service Delivery; Care pathways / Individual Care / Legislation/ Policy; Community; Emergency Care; Out of Hours Care; Palliative Care Team/Roles.
Support	Bereavement; Carer / Family Support; Financial / Benefits; Staff Support / Education.
Understanding dying	Prognostication / Staging death: Trajectories and transitions; Being aware / Unaware of prognosis / Talking about dying / Non-cancer.

This report explores the theme: bereavement. There is little engagement with the literature at this stage; the report is descriptive only in order to isolate questions from the data for further interrogation.

BEREAVEMENT

Experiences of bereavement and the improvement of bereavement support for families were a strong theme throughout these data². One theme was established to cover these data – Bereavement. Further sub themes offered a more in depth view of the data (below):

1. Death experiences and impacts on bereavement

- a. Bad deaths and good deaths
- b. Improving communication during the dying stages and post death

2. Filling the void: the need for bereavement support

3. What support is currently available?

4. What support is optimal?

- a. What kinds of support should be provided?
- b. When and for how long should support be provided?

5. Meeting the needs of different groups

- a. Age and familial relationships
 - b. Complicated bereavement needs
-

Due to the high number of responses a proportion of the supporting responses under each subtheme have been placed into the appendices.

This report covers all survey responses from #1 to #1403.

The quotations here have been copied directly from the data set and therefore are complete with grammatical and spelling errors as written by the respondents.

DEATH EXPERIENCES AND IMPACTS ON BEREAVEMENT

Respondents provided accounts in which they connected 'bad' and 'good' experiences of the deaths of loved ones with their coping and general wellbeing in the months and years that followed. Following such experiences practical suggestions were also made for improving communication during the dying stages and post death.

Bad deaths and good deaths

Many participants described how troubled death experiences, where the patient appeared to be physically suffering, sometimes as a perceived result of being put on the Liverpool Care Pathway (LCP), left unanswered questions and enduring feelings of guilt and regret which clearly impacted on their bereavement experience and general wellbeing:

"My mother died of breast cancer in the hospice in Ipswich. My questions would have been about the Liverpool pathway - it still haunts me whether we did the right thing, and now that it has been stopped, I live with a terrible feeling of guilt that my suspicions were right. It felt wrong to stop fluids but the doctor told me she would effectively drown if they were continued. My mother kept trying to speak to me but was too weak, and I couldn't make out what she was saying. I am so afraid that she was asking for water. Would it be possible to guarantee a nurse to be with a carer in those final hours at home, to manage the pain, so that a last wish to die at home could be granted? Maybe this is not financially possible. But it's what my mother wanted and I would love to have been able to fulfill that wish. I live with that regret."

(R398 - I am a carer or family member or partner or friend of someone in the last few years of their life; I am a bereaved carer or family member or friend)

"I have experienced the loss of two members of my family one person died at home with the support of our GP, District Nurses, carers and Marie Curie nurses. I recovered emotionally from this experience quicker as I felt my mother had the best of care and support and I was not as physically exhausted as when my sister-in-law died. My sister-in-law died in hospital, she was put on the Liverpool Care Plan - this was not explained fully to my brother-in-law and the whole experience has left him emotionally fragile and requiring our support."

(R458 - I am a bereaved carer or family member or friend)

"My mum died of secondary lung cancer and died a horrific death as palliative care was forgotten about and in the end it all happened very quickly. The guilt and grief is so hard to deal with so how can the government make sure this never happens to another family again..?"

(R50 - bereaved carer or family member or friend)

"I had concerns about how my relative was feeling in the last few days of their life. Did we do enough? Were they comfortable? Were they scared? This question haunts me to this day."

(R780 - bereaved carer or family member or friend)

By contrast one lengthy example was given by a widowed husband detailing 'what went right' in the death experience of his wife, which he felt to have also helped him in his grieving process (see appendix for full extract):

"My wife (aged 79 then) died rather suddenly of a very aggressive cancer of the uterus in GEVADE (sp?) 2012. In the final weeks we both fear that the care that one received could not have been better. I am thus prompted to reply to you saying 'what went right' rather than pose questions to say 'what went wrong'.....

**Since (name...) death the hospice has sent me repeated message offering bereavement counselling - which I did not feel I needed. On the day following her death a small team met me for *1 1/2 hours to give me death certificate and also the various things I had to do. (name) and I both realise and are grateful for the very start period of the illness - and of me being a carer (I was for the time) So many of our peers have very different experiences!!...."*

(R1009 - I am in the last few years of my life; I am a bereaved carer or family member or friend; I am a member of the public who has an interest in the subject)

Responses also demonstrated interest in finding out more about the health and health care consequences of negative and more positive death and bereavement experiences for bereaved family members. It was suggested that such evidence could provide an economic rationale for increasing the support provided to bereaved family members:

"my mother in law died after a long cancer illness my father in law suffered with her loss &subsequently had a stroke and therefore i ask what is the like hood of a partner suffering a life changing illness in the 1st year after a partners death? How many extra doctor/hospital visits does a bereaved relative make in the 1st year post death? what support mechanisms/asessments should people have after a bereavement?"

(R36 - carer or family member or partner or friend of someone in the last few years of their life; bereaved carer or family member or friend)

"does debt caused by paying for a funeral increase negative bereavement outcome?' 'does increased participation in organising a funeral, a more personalised funeral increase bereavement outcomes ?'"

(R1346 - 'charity')

"I also think continued support for carers after bereavement is essential as this could possibly prevent depression and illness and increased burden on the health care system at a later stage."

(R1349 - professional working with people in the last few years of life)

"Good bereavement care and support offered to those looking after someone at the end of their life is associated with better outcomes in relation to the grief effect. I am witnessing this at first hand since the bereavement support I received when my mother was dying was absent."

(R994 - carer or family member or partner or friend of someone in the last few years of their life; bereaved carer or family member or friend)

QUESTIONS

1. How do death experiences impact upon the grieving process and health and wellbeing of bereaved family members?
2. What constitutes 'good' and 'bad death' and what role do health professionals play in facilitating 'good' and avoiding 'bad' deaths'?
3. How can bereavement services address 'troubled death' issues amongst bereaved loved ones?

Improving communication during the dying stages and post death

Suggestions were made by carers and health professionals for improved communication and support for carers in the final days, in particular around the dying process and decisions to withdraw hydration:

"I would have liked more guidance in the final moments of my loved one's life. Perhaps someone with me at the bedside from time to time to let me know what was happening and what I could do. I think this is most important for a carer or family who has not experienced the death of a loved one before."

(R283 - bereaved carer or family member or friend)

"How can we improve communication with families whose loved ones are dying? How can we effectively give information to families about what to expect when their loved one is dying and what to do after death?"

(R817 - Professional working with people in the last few years of life)

"When end of life/place of care and similar issues are being discussed, with the GP or specialist nurse perhaps, should there be some very gently handled introduction of the idea of the patient being free to discontinue their treatment if they have 'had enough' and when he or she can no longer speak out for him or herself - ie the introduction of the idea that PEG feeding or NIPPY could be discontinued? The spouse/carers would need great support if the plwMND decided to have the treatment which was keeping them alive withdrawn."

(R136 - Bereaved carer or family member or friend; volunteer working with people in the last few years of life)

"Are families happy with TLC interventions and removal of medical intervention and monitoring? Everyone is different but what is the best way to broach this with relatives at this emotive time? How can we get families to express their wishes, concerns so they can be dealt with effectively? Unexpressed niggling concerns could affect the grief process that could have been very easily dealt with at the time (I understand some will not be present at the time)."

(R369 - Carer or family member or partner or friend of someone in the last few years of their life; professional working with people in the last few years of life)

There were also calls for post death consultations so that families' questions about the death can be answered at the time by the health professionals who were directly involved at the end of life:

"After a death could it be possible to talk to a doctor about what happened at the end and explain what was happening as the bodies functioning breaks down?"

(R380 - Bereaved carer or family member or friend)

"Existing policy regarding whether consultants have to offer an interview to bereaved families about how and why their loved one died?"

(R1101 - Professional working with people in the last few years of life)

"Value should be given to the possibility of nurses who were involved in the care of the dead patient to make one or two visits to allow the bereaved to talk over any confusions/issues in how it all went."

(R1239 - Bereaved carer or family member or friend; I am a professional working with people in the last few years of life)

"Why did the hospital department responsible for her treatment (cardiology, RIE) never contact me after her death to ask if there was anything they could have done differently or better in order to learn from what went wrong and improve care for others in the future?"

(R498 - Bereaved carer or family member or friend)

This was raised specifically in relation to child death and the need for parents to be assisted in interpreting medical notes which are made available to them under current policy:

"Provision of bereavement support: Does unlimited access enable bereaved parents to manage demands of grief/create dependency? Current policy re obtaining medical notes: parents who request their child's notes are not assisted in interpreting notes, often raising more queries rather than providing clarification."

(R1093 - Professional working with people in the last few years of life)

QUESTIONS

- 4. How should communication around the dying process and medical interventions be improved so that carers' have a better understanding of what will happen when their loved one dies?**
- 5. Should psycho-emotional support be offered to carers at the time of death and what form should this take?**
- 6. Should carers be offered a post death consultation and what form should this take?**

FILLING THE VOID: THE NEED FOR BEREAVEMENT SUPPORT

A number of carer participants described how they would have appreciated some or more professional support after the death of their loved ones. Many respondents reflected on feeling “cut off” and the “void” that is left following the withdrawal of services that had been available during the end of life stages:

“We had plenty of help during palliative care but had nothing afterwards would have been nice to have had some support after husband died”

(R188 - Carer or family member or partner or friend of someone in the last few years of their life)

“Sadly when someone dies, not only is there a huge hole where their loved one was, but also an immediate void from all the HSCP's involved, understandably, but maybe there needs to be mechanism whereby they are not left to their own devices (unless they want to of course) sometimes creating mental health issues, which is not helpful to anyone.”

(R381 - bereaved carer or family member or friend; volunteer working with people in the last few years of life)

“Is their support for bereaved people if they need it? It can feel like being “cut off” once the caring stops.”

(R847 - bereaved carer or family member or friend)

“Following on from my last comment.....it was a huge shock after caring for my husband for 24 hours a day for 20 years to lose him. Not only did I lose my husband but also my whole purpose to live myself. He was also my “full time job”. I felt totally lost when I lost him. We had regular contact with various professionals when he was alive ie DNs, the hospice, dietitians, stoma nurse, speech therapist, GPs (very regularly). Suddenly, when my husband died, all this stopped. My income also stopped the day he died as he was in receipt of disability benefits. I felt totally lost and abandoned.”

(R396 - bereaved carer or family member or friend)

A number of health professionals also felt that they should be providing more support to family members post death, again also reflecting on the ‘void’ caused by the withdrawal of services and the need to have continued support available for those that need it:

“I often think that as a Health Care Professional that we do not follow up post the death of our patients ‘re their families, and loved ones more so if we have been present in the final hours. How do we not ??”

(R1242 - professional working with people in the last few years of life)

“Is it possible to have more support after bereavement for families?”

(R1283 - bereaved carer or family member or friend; professional working with people in the last few years of life)

“How can we support bereaved families better? They go from everyone 'interferring' in their lives to virtually no-one. This can be very strange and disquieting, and sometimes exactly what is needed as life stages change.”

(R1326 - professional working with people in the last few years of life)

A bereaved carer who was also a health professional commented on the need for services that provide “someone to talk to” and suggested that the absence of this results in carers unnecessarily being prescribed anti-depressants:

“Little support generally for carers during bereavement. Not enough organisations offering this. Carers often end up on antidepressants when they are not clinically depressed, but just need someone to talk to.”

(R1286 - bereaved carer or family member or friend; professional working with people in the last few years of life)

A person in the last few years of life and a bereaved carer questioned the role of support agencies in helping people through the grieving process, noting how support from multiple agencies could be intrusive and suffocating for some families:

“Death and dying has always been with us. Grieving is a natural process which everyone goes through in one form or another. I question the over emphasis of "support" which is becoming quite suffocating for some families. There are so many bodies now involved in this process that it can be overwhelming in the extreme for families. People mean well but they also have to know when to draw the line between care and unwarranted intrusion.”

(R1295 - person in the last few years of my life; carer or family member or partner or friend of someone in the last few years of their life; professional working with people in the last few years of life)

“Why is bereavement and my grief a problem for other people?”

(R1180 - bereaved carer or family member or friend; professional working with people in the last few years of life)

QUESTIONS

- 7. What effect does the withdrawal of services have on carers following the death of their loved ones?**
- 8. How should ‘continuity of care’ post death be operationalized and what difference would this make to families?**

WHAT SUPPORT IS CURRENTLY AVAILABLE?

A large number of respondents asked questions about the availability of bereavement support and how to access it. Many patient/carer participants asked what bereavement support was available locally for their families and why they weren't being provided with information on such services, suggesting a lack of information and/or absence of available services:

"Once my parent has died is there any support for those who are left behind?? If so, who do we ask??"

(R42 - Carer or family member or partner or friend of someone in the last few years of their life; bereaved carer or family member or friend)

"Why aren't families asked to attend support groups or given information about help with their bereavement?"

(R73 - bereaved carer or family member or friend)

"How to access bereavement support?"

(R1221 - I am a bereaved carer or family member or friend; 'also work in hospice')

"What care and support is available for those left after the person has died??"

(R1223 - member of the public who has an interest in the subject)

Many health professionals were also concerned with the availability of support services at local and national levels and expressed a need to ensure equitable access to routine, standardised bereavement support:

"How can bereaved relatives gain rapid access to good standardised bereavement care?"

(R1080 - professional working with people in the last few years of life)

"AFTER THE PATIENT DIES, WHOM CAN THE BEREAVED RELATIVES GO, IF THEY NEED COUNSELLING?"

(R722 - professional working with people in the last few years of life)

"Do family members routinely have access to support/bereavement services?"

(R38 - professional working with people in the last few years of life)

"I am unsure of exactly what support is offered with respect to bereavement services for families i.e. is it individual counselling, group therapy sessions etc."

(R1163 - professional working with people in the last few years of life)

Questions were also asked about the care available for families who have not been involved with hospices, for example of patients who die in hospitals or long term facilities:

What support is available for families who chose not to use a hospice - around the time of death and afterwards?

(R499 - professional working with people in the last few years of life)

"What can be offered to bereaved relatives of patients who die in hospital"

(R541- professional working with people in the last few years of life)

"What do bereaved families of those who have cared for someone with end stage copd feel the support is like from those involved in their care after they have died ie - gps do follow up visits to families - to my knowledge nurses or ahps don't"

(R998 - professional working with people in the last few years of life)

"In long term facilities, do they have outreach programmes to make sure that, families and relatives are coping with the death of their loved ones?"

(R510 - professional working with people in the last few years of life)

QUESTIONS

9. What bereavement care is routinely available in the UK; what are the different kinds of bereavement care provided in the UK; and how does this vary by place and type of institution?
10. How could families be kept better informed of local bereavement services available to them?

WHAT BEREAVEMENT SUPPORT IS OPTIMAL?

A number of different questions were raised with regards to service design and delivery and how to optimise bereavement support. These included questions over what support should be offered and when and how often it should be given.

What kinds of support should be provided?

A number of respondents asked questions about what kind of bereavement support should be offered to families, and how this could be provided in a cost effective and equitable fashion:

“Is there any support or training that can realistically prepare someone for the loss of a relative or the grieving process?”

(R299 - professional working with people in the last few years of life)

“How can we help carers to be better prepared and support them during the early bereavement period?”

(R963 - member of the public with an interest in the subject)

“What is good practice in terms of supporting carers and recently bereaved carers? Why is this not available as standard?”

(R354 - bereaved carer or family member or friend)

“How long... What happens What support is available for those left Palliative care counselling for carer and patient”

(R200 - bereaved carer or family member or friend)

“Lack of bereavement services for families who have cared for loved ones. How do we help care for carers after bereavement?”

(R486 - professional working with people in the last few years of life)

More specifically, respondents asked questions about the effectiveness or role of different approaches such as counselling, group support and social activities:

“What are the different kinds of bereavement, can they be categorised into different levels and can this be linked to appropriate support or treatment regimes? For how many people are simple social activities (such as cookery groups or art groups or cinema clubs) enough to support a successfully management of bereavement?”

(R603 - professional working with people in the last few years of life)

“Evidence for the effectiveness of different types of bereavement support approaches”

(R1106 - member of the public with an interest in the subject)

“Bereaved families often ask for follow up in the form of groups or events not in the setting where their relative died. Could this be a need that could be met.?”

(R1257 - Carer or family member or partner or friend of someone in the last few years of their life; professional working with people in the last few years of life)

“Recognising the natural symptoms following the death of the individual such as the persistent yearning/longing for the deceased. Recognising the importance of storytelling for all those involved to help clarification.”

(R1007 - bereaved carer or family member or friend; Volunteer; member of the public with an interest in the subject)

A couple of GP respondents asked what type of support their profession should be offering to the bereaved and if they could be resourced to be able to offer the kind of support that they had previously been able to provide:

“Care for the bereaved: - what support do the bereaved want from their GP? - how can GPs best identify those needing additional support”

(R1046 - professional working with people in the last few years of life)

“A few years ago as a GP I would carry out bereavement visits - this has gone now with conflicting time pressures and QOF - how can the resource be made available to improve bereavement care again? What does good bereavement care look like? Are outcomes better for relatives with advance care planning for patients?”

(R47 - professional working with people in the last few years of life)

The importance of targeting resources towards those who would benefit from support and to avoid undermining the normal coping processes of those who may not need support was also raised:

“What evidence is there for bereavement counselling? can it be harmful for some people, which people benefit most?”

(R542 - volunteer)

“How do we design and fund services to bereaved people that are properly targeted to those that need them? How do we ensure that service provision to bereaved people does not subvert the normal grieving process or their usual coping strategies?”

(R243 - carer or family member or partner or friend of someone in the last few years of their life, bereaved carer or family member or friend, professional working with people in the last few years of life)

A couple of respondents also described the need for a more supportive and understanding workplace for bereaved employees to return to in the aftermath of the death and funeral of a loved one:

“Bereavement at work is a very important issue. When a loved one has died it can be a shock so profound, even if it had been expected, that the lives of those affected are changed forever. The earth changes on its axis particularly if a very close relative or significant other dies. It cannot be assumed that a person can just carry on as normal a couple of weeks after the funeral.”

(R588 - bereaved carer or family member or friend)

“How will you tap into and break out of the current Western view of grief?- Can you challenge employers, and key mental health advocates, that grief, though not a mental illness, is a very pivotal part of someone's life?”

(R943 - bereaved carer or family member or friend)

The issues raised above concerned the provision of emotional/psycho-social support. Many respondents also described a need for more practical information and advice on arranging funerals and financial issues that arise following the death of a family member:

“When I lost my father, my main questions were about the practicalities of what to do when someone dies. Who to inform, where to send documents, just what to do in general. I also would've liked to know where I could get support as a family member. My doctor referred me for bereavement counselling, but I didn't have the money to pay for it, it would have been useful to know if there was support available elsewhere.”

(R1118 - bereaved carer or family member or friend)

“Helping someone arrange funeral, finances and personal items.”

(R1121 - bereaved carer or family member or friend; work in hospice)

“More proactive help with the future planning for those who are left behind”

(R121 - bereaved carer or family member or friend).

“‘does debt caused by paying for a funeral increase negative bereavement outcome?’ ‘does increased participation in organising a funeral, a more personalised funeral increase bereavement outcomes?’ ‘do people know how much a funeral costs and the choices available?’ ‘can pall care professionals answer basic consumer questions about funeral choices and costs to enable them to help patients & families?’ ‘do pall care courses include a session on funeral choices?’”

(R1346 - Other: charity)

“What advice is available to help people to prepare for the future? Arranging funerals and such like?”

(R563 - person in their last few years of life)

A carer respondent also raised the issue of medication disposal following death, and explained the sense of risk and vulnerability that her family experienced due to the large volume of drugs which remained in the house for the family to dispose of:

“When my husband died we were left with a huge amount of medication in the house which I was told to dispose of via the chemist. The nurses only took away iv drugs. I was left with two distraught daughters and enough pain killers of all sorts to kill us all. I thought this was very unsafe and should be addressed for future carers. You feel so vulnerable”

(R1157 - bereaved carer or family member or friend).

QUESTIONS

11. What evidence is there on the effectiveness of different kinds of bereavement support?
12. What information and advice on the practicalities that follow the death of a loved one should be given to families eg financial affairs, arranging funerals, and how should this be delivered?

When and for how long should support be provided?

Questions were also raised concerning when bereavement support should be offered, and how long it should be sustained for. A number of people suggested that support should be offered prior to the death of a loved one:

“How can bereavement support be offered to everyone at a suitable stage.? My guess is that had I had early intervention I might have recovered much quicker and needed much less time for support. I am lucky I can pay for the support I needed and my colleagues recognised the need and suggested a useful contact to help.”

(R129 - bereaved carer or family member or friend, professional working with people in the last few years of life)

“When is the best time to offer bereavement care?”

(R252 - professional working with people in the last few years of life)

“Is there counselling available for people before their loved ones die, in order to help them come to terms with this?”

(R1043 - professional working with people in the last few years of life)

“Marie Curie needs to follow patients and families into the community to centre to provide pre + post bereavement support and provide continuity of care”

(R1146 - professional working with people in the last few years of life)

There were also calls for immediate reactive support for the bereaved, for example a 24 hour helpline and round the clock support available at hospitals:

“As the degree of reaction to loss and its timeline is so unpredictable it is effectively unmanageable on an individual basis. Provide an 24 hour phone helpline.”

(R164 - person in the last few years of life, bereaved carer or family member or friend, member of the public with an interest in the subject)

“People in hospital often die at night and loved ones are left to go home on their own, should there be some sort of 24 hour support for those just bereaved?”

(R12 - professional working with people in the last few years of life)

"I would have also appreciated some care myself after my partner's death. He died in the middle of the night in hospital and I was conscious that staff wanted to move his body before morning. A friend was able to come to the hospital but there was no one "official" there to help. Twenty two months after his death I am having six sessions of counselling provided by my GP's surgery but that has been the extent of the help I have received and it's as a result of my asking. I have no complaints about my GP but the whole palliative care system seems to have bypassed us."

(R213 - bereaved carer or family member or friend)

"Should a family be left alone, when they have sought staff support in the final moments of life, with no staff contact for over 30 minutes after their Wife / Mum had died?"

(R1049 - I am a bereaved carer or family member or friend; I am a member of the public who has an interest in the subject)

Others requests were for supportive interventions at three months and six months post death, and that support should be available on a continual basis for families to use as they need it, with no prescribed cut off:

"I needed to know that our whole family would be cared for - Is bereavement counselling available about 3 months down the line - I wanted the Hospice to phone me, not the other way around"

(R663 - bereaved carer or family member or friend, professional working with people in the last few years of life)

"Can support be offered to the bereaved about 6 months or so after the death?"

(R814 - bereaved carer or family member or friend, members of the Public with an interest in the subject)

"Is there any counselling automatically available long term? i.e. - if you don't take it up at the time your loved one dies, can you get in touch and ask for it at a later date?"

(R986 - bereaved carer or family member or friend)

"(g) bereaved families and carers will need support for quite sometime after losing the patient, it should not be calculated in weeks, there must be unexpected visits made, not previously arranged, as often you can see the real needs when a doctor or nurse just drops in"

(R1170 - bereaved carer or family member or friend)

"3. CAN BEREAVED CARERS BE SUPPORTED IN THEIR HOMES? 4. HOW LONG CAN THIS SUPPORT OCCUR FOR?"

(R932 - bereaved carer or family member or friend, Member of the Public with an interest in the subject)

QUESTIONS

- 13. At what point should bereavement support be offered to loved ones and how long should support be sustained for?**

MEETING THE NEEDS OF DIFFERENT GROUPS

Responses highlighted concerns over meeting the different needs of different groups of people in terms of the age and relationship of carer/patient within families and the enhanced needs of more complicated groups such as those with dementia and other forms of cognitive impairment.

Age and familial relationships

A number of respondents questioned how bereavement needs might vary by different groups of people. One difference discussed related to the age of the bereaved person and/or their relationship with the dying person, for example children who have lost parents or vice versa:

“WHAT IS THE BEST FORM OF SUPPORT FOR THE OLDER BEREAVED PERSON, ARE THEY DIFFERENT FROM THE YOUNG”

(R289 - bereaved carer or family member or friend, professional working with people in the last few years of life)

“Provision of bereavement support: Does unlimited access enable bereaved parents to manage demands of grief/create dependency? Current policy re obtaining medical notes: parents who request their child's notes are not assisted in interpreting notes, often raising more queries rather than providing clarification”

(R1093 - professional working with people in the last few years of life)

“What are the key supports for parents in the immediate time around a child's death?”

(R558 - professional working with people in the last few years of life)

“What facilities and support are available for families that have lost their child?”

(R964 - carer or family member or partner or friend of someone in the last few years of their life)

There was particular concern with finding out how parents can be supported to prepare and help children and young people grieve for the loss of the other parent or close friends:

“How do you best support children when a child they are close to is terminally ill. Should you protect them as much as possible or prepare them? And how?”

(R369 - bereaved carer or family member or friend, professional working with people in the last few years of life)

“What provision is there for bereaved children later on? Example: my daughter was a baby when her dad died. And alas I was 4 when my own mother died. Grief hit me in my teens, as it is starting to with my daughter who is now 15. What facilities are available such as dictaphones and camcording? This can be a precious memory.”

(R46 - bereaved carer or family member or friend, professional working with people in the last few years of life)

“Do you feel you were given enough support on preparing your children? What would you change in relation to the children experience of the death? Feel there was adequate family support during illness and after death?”

(R1086 - professional working with people in the last few years of life)

“How best support a bereaved parent to care for their child? What resources can workers use to assist them with their grief, whilst the parent struggles to support their children through their own grief. Would like more recent research insight into what works”

(R1089 - professional working with people in the last few years of life)

The role of other professionals and organisations, such as counsellors, schools and universities, in preparing and supporting bereaved children and young people was also discussed:

“Why can children who have lost a parent only receive 5 sessions with a bereavement councillor?”

(R467 - carer or family member or partner or friend of someone in the last few years of their life, bereaved carer or family member or friend, member of the public with an interest in the subject)

“How will you reach out to young people who have lost someone and do not want to be told they are experiencing 5 key stages/be left out of decision making etc”

(R943 - bereaved carer or family member or friend)

“Would educating CYP in schools about death and stages of bereavement help to equip them to cope with the death of a loved one when the situation arises?”

(R1097 - professional working with people in the last few years of life)

“Bereavement at university, particularly soon after leaving home, is very tough and pastoral care is very varied. What national guidance should be in place?”

(R1062 - professional working with people in the last few years of life).

A professional respondent also questioned the differences in take up of bereavement support between men and women:

Why don't men take up bereavement support at the same rate as women?

(R252 - professional working with people in the last few years of life)

Several respondents also asked whether bereavement support could be offered to those outside of the immediate family:

“Why is it just the NOK who is invited for bereavement support”

(R385 - professional working with people in the last few years of life)

“Bereaved carers/ families - could we offer other options for Bereavement Support e.g. groups/ informal/ teens etc. -Could we offer support to people other than families of patients of SFH”

(R1392 - professional working with people in the last few years of life)

"Could the information sent out after a loved one dies go to every family member affected, rather than just the primary carer? I think I missed out on a lot of information as all letters, invitations to memorial days went to a house I don't live in."

(R986 - bereaved carer or family member or friend)

"Why children of life limited adults not immediately considered in overall care plans? How do we move beyond competitive care of the bereaved?"

(R1092 - bereaved carer or family member or friend)

Complicated bereavement needs

A number of respondents described concerns that they have over the support needs of more complicated groups. These included the families of patients with illnesses like Dementia and MND where diminished capacity means that experiences of loss begin well in advance of death:

"Care and support for bereaved people who are suffering from dementia is a chronically under-researched area. Proper care and support for a person with dementia in dealing with the approaching death of a loved on, particularly if that loved one is their primary carer, is very important. This needs to be handled sensitively by specially trained counsellors. What research there has been shows that people with dementia can feel bereavement but will have difficulty in expressing it in ways that might be recognised. It can't be assumed that a person with dementia won't have a clue what's going on. My mother knew that my father had died even though she had had dementia for 8 years at that point - we had to keep gently reminding her every so often that he was no longer with us when she asked when he was coming to see her and it caused some very upsetting times. support from a specialist would have been so welcome for her and for family members."

(R588 - bereaved carer or family member or friend)

"With dementia not everybody is aware that you can access the services of their local hospice or the Macmillan services. With dementia you are already grieving for the person with dementia because of the changes which take place due to the illness, you then grieve again when the person dies. why can't it be publicised just what support services people can access in local areas to include bereavement support and End of Life Care?"

(R905 - bereaved carer or family member or friend, member of the public with an interest in the subject)

"The psychological loss of someone to dementia illness begins early in the illness which may be many years before their death. When will care and support for carers and their families be offered in the same way as those dealing with, for example cancer illness?"

(R994 - carer or family member or partner or friend of someone in the last few years of their life, bereaved carer or family member or friend)

"I know now that there is support for the bereaved, should this not be given soon after death occurs? Professionals seem to know how long before the end - this information would help prepare family if some indication was given to them. I think every nursing home/hospice should have a member of staff able to dedicate themselves to emotional support of close family and friends - a little company, the opportunity to talk, while visiting a loved one. 'Bereavement' can start long before the actual death especially in patients with Alzheimer's .."

(R1360 - professional working with people in the last few years of life)

"I would like to know what support is available/provided for carers of people with MND to help prepare them for bereavement. Some bereaved carers will need extra support to help them cope with their loss, but how can these carers be identified before bereavement so that appropriate support can be provided before they are bereaved?"

(R389 - Other: researcher)

A couple of professionals also raised the issue of finding ways to support bereaved people who have learning disabilities:

"What bereavement support is there for people from hard to reach groups and those who have a learning disability. how can you offer such support if there is a barrier to accessing these services due to age, language, cultural barriers or staff members qualified and experienced in working with people with a learning difficulty"

(R104 - professional working with people in the last few years of life)

"I have a learning disability and my dad has just died. Can you offer me appropriate bereavement support?"

(R331 - professional working with people in the last few years of life)

A need to find ways of identifying and providing additional support to those at risk of complicated bereavement was also described in a couple of responses:

"How can we identify people who may be at risk of complicated bereavement?"

(R869 - professional working with people in the last few years of life)

"For someone with complicated bereavement - (multiple deaths over a few years) is there extra support there for them or are they left to find their own way?"

(R1394 - professional working with people in the last few years of life)

QUESTIONS

14. What are the different bereavement needs of different groups of people? How can these needs be addressed with professional support and services?

SUMMARY

Multiple respondents representing different perspectives (carers, patients, professionals and members of the public) have offered their thoughts on and experiences of losing loved ones, including factors which they felt worsened their experiences and suggestions for what would improve such experiences. Respondents highlighted needs for better information on and availability of routine bereavement care, and for evidence on what kinds of bereavement support are optimal and for which groups of people.

This supplementary methodology has enabled a thematic approach to PeolcPSP respondents' concerns which are out of the scope of a standard JLA priority setting process, focusing on the topic of bereavement.

Identification of Questions

Based on the responses within this report 14 questions related to bereavement in palliative and end of life care have been identified:

QUESTIONS

1. How do death experiences impact upon the grieving process and health and wellbeing of bereaved family members?
2. What constitutes 'good' and 'bad death' and what role do health professionals play in facilitating 'good' and avoiding 'bad' deaths?
3. How can bereavement services address 'troubled death' issues amongst bereaved loved ones?
4. How should communication around the dying process and medical interventions be improved so that carers' have a better understanding of what will happen when their loved one dies?
5. Should psycho-emotional support be offered to carers at the time of death and what form should this take?
6. Should carers be offered a post death consultation and what form should this take?
7. What effect does the withdrawal of services have on carers following the death of their loved ones?
8. How should 'continuity of care' post death be operationalized and what difference would this make to families?
9. What bereavement care is routinely available in the UK; what are the different kinds of bereavement care provided in the UK; and how does this vary by place and type of institution?

QUESTIONS

10. How could families be kept better informed of local bereavement services available to them?
11. What evidence is there on the effectiveness of different kinds of bereavement support?
12. What information and advice on the practicalities which follow the death of a loved one be given to families e.g. financial affairs, arranging funerals, and how should this be delivered?
13. At what point should bereavement support be offered to loved ones and how long should support be sustained for?
14. What are the different bereavement needs of different groups of people? How can these needs be addressed with professional support and services?

The responses and questions within this report highlight issues over the bereavement experiences, needs and availability of supportive services for bereaved loved ones.

The holistic nature of the questions generated in the PeolcPSP priority setting process encompasses a number of the questions generated within this report. However, by including all the data it has been possible to identify additional questions that primarily relate to service delivery, implementation and evaluation.

Many of the questions generated by this thematic approach will best be answered by non-interventional research designs as earlier stage work into knowledge, attitudes and perceptions is needed before addressing these overarching topics.

The respondents of the PeolcPSP were asked to answer big questions. In return, they gave big answers often with highly personal narrative accounts in illustration of their concerns. The dual approach of the PeolcPSP protocol and a thematic approach can appropriately explore the entire dataset in recognition of the time and personal effort given by the survey respondents.

Finally, it is hoped that the publication of these responses and questions can promote further research and have positive practical implications for the future of palliative and end of life care in the UK and Ireland.

APPENDIX: FURTHER EXTRACTS

Good deaths and bad deaths

“during the process of my mum passing on she fought continually against the driver that was in and came awake frightened and in fear of what was happening and found it hard to calm her when she did and I quite often felt guilty about it .”

(R240 - I am in the last few years of my life; I am a carer or family member or partner or friend of someone in the last few years of their life; I am a bereaved carer or family member or friend)

“The individuals actually providing the support were very welcome but as her husband I was totally unable to actually comprehend why was happening and felt left out of things.”

(R1131 - Bereaved carer or family member or friend)

“We as a family have not been able to grieve for our mother who was taken away from us she was put to death on the LCP and nothing was explained ,we were told this is whats going to happen now !! There was no dignity watching my mother gasp for breath over 4 days ,she was denied food and water why was this .”

(R502 - I am a carer or family member or partner or friend of someone in the last few years of their life; bereaved carer or family member or friend)

“My wife (aged 79 then) died rather suddenly of a very aggressive cancer of the uterus in GEVADE (sp?) 2012. In the final weeks we both fear that the care that one received could not have been better. I am thus prompted to reply to you saying 'what went right' rather than pose questions to say 'what went wrong'. I decided to give a narrative 'blow by blow' account rather than complete section 1 but to transpose anything relevant. I have completed Section 2.

(.....) experienced very slight bleeding and (resolved with a piece of toilet tissue) in May 2012. It was not possible to tell whether this came from the uterus/vagina or bladder. The GP arranged 304 hospital tests of which pointed negative or incohesive. But the bleeding continued.

After the latest test she had an appointment in early August to see a cancer consultant in the Royal Sussex County Hospital. I think (....) suspected that an operation might be necessary - but nothing worse.

** In the event the consultant gravely pronounced a terminal diagnosis – (....) had metastatic small cell endometrial cancer (of uterus) and he gave her 3-6 months to live.*

**He set out 3 options: - radiotherapy - impractical as the cancer had spread too far - chemotherapy (to begin in following week) - this used to be a very aggressive treatment and he estimated 1-2 extra months - let nature take its cause. (....) after a day of thought took this option - a wise act as it turned out*

**From the start of this interview the consultant had with a Macmillan nurse and a community nurse. They then outlined what they used to do*

**(....) asked if a second opinion was possible; the Macmillan nurse arranged one (with an ever more expert at this type of cancer) within an hour (in fact just before he started his afternoon clinic). His prognosis was identical.*

**The next day, the Macmillan + community nurse visited us at home to explain the services in great detail, leave etc. *The Macmillan nurse completed the Attendance Allowance application (+ payment care a week letter).*

The next six weeks passed with (....) remaining relatively active - feeling a little more tired, but nothing more. The nurse visited a couple of times to check out.

**The last 3 days of this period were active: a trip to Chester, to the theatre, lunch out with son and daughter-in-law; a visit to GP and hospital xray to check for DVT in a slightly swollen leg*

**Then suddenly (....) woke early on Tuesday in great pain. The 2 nurses came almost immediately and in the following days worked very closely with our GP to change the morphine prescription - to reduce pain, make it easier to take etc. They + GP came once almost every day*

**The nurses managed to get a bed for Barbara at the Hove Matter hospice on Friday: she felt she wasn't in enough (though she had not left the bed) so refused to go. She accepted a bed on the following Tuesday ie 7 days after pain started.*

**The care provided at the hospice was excellent 1 / 2*

Do you have questions about palliative and end of life care, support and treatment?

*If you do *The staff served to manage the pain well; also excellent personal care.*

**I especially valued the time that doctors and nurses gave me in describing (....) decline (There are things they cannot predict was the exact number of days left!)*

**The doctors also gave two longish telephone calls, out of hours, to my son (a consultant gastroenterologist in Winchester) to give him a doctor-to-doctor update.*

**Since (...) death the hospice has sent me repeated message offering bereavement counselling - which I did not feel I needed. On the day following her death a small team met me for *1 1/2 hours to give me death certificate and also the various things I had to do.*

(....) and I both realise and are grateful for the very start period of the illness - and of me being a carer (I was for the time) So many of our peers have very different experiences!!

*So, as I said at the beginning, I cannot think of many things that went wrong; I have however put an * in the margin to indicate the most important things that seem to have contributed to a successful outcome. I can only hope that I am as lucky as (...) was.*

PS Please excuse handwritten letter. I do not use IT/computer/e-mail

PPS I realise that I've said nothing about emotional issues during the terminal period. I'd be more than happy to discuss them - tho they are more difficult to itemise"

(R1009 - I am in the last few years of my life; I am a bereaved carer or family member or friend; I am a member of the public who has an interest in the subject)

Improving communication during the dying stages and post death

"The palliative care services we experienced were first rate on the whole, however I think families of dying patients would benefit from research on ways to support them

in coming to terms with the withdrawal of IV drips and hydration in the last days of life. I'm convinced this is the source of much dissatisfaction with end of life care."

(R275 - Bereaved carer or family member or friend)

"With hindsight I don't feel we were told how close to death my parents were. Staff are overworked and it was very difficult to get anyone to talk to with any confidence. Since they died I have read that signs they were displaying meant that death was probably very close but no-one told me at the time and I didn't make it back in time to see my mam before she died."

(R1103 - Bereaved carer or family member or friend)

"My husband had MS for over 30 years. For the final 13 he was quadriplegic and unable to speak. A year before he died he lost the ability to swallow. He died quite suddenly after 8 days of altered breathing. I did not realise he was actually dying until the day previous to his death. He died at home with me being his sole carer throughout. He was receiving day care support from our local hospice and we were visited by hospice at home nurses on a couple of occasions in the final week. I wish now that somebody had sat down and talked to me about what was happening. It wouldn't have changed the outcome but I was totally unprepared for his death. I had been caring for so long but had never talked to anybody about the end of his life despite his deteriorating condition."

(R396 - Bereaved carer or family member or friend)

"Exactly what the Liverpool Care Plan was should have been explained to him fully. He has only just been able to talk about his wife's death after 2 years. All treatments should be fully explained to closest relatives. There didn't seem to be anywhere we could go for support to help him when he wasn't sleeping (sometimes he didn't go upstairs to bed) for the first year after her death. Is there anywhere to get help?"

(R458 - Bereaved carer or family member or friend)

"How carers can cope with decisions by their loved one to hasten end of life by refusing food, drink or medications that would almost certainly prolong life."

(R254 - Bereaved carer or family member or friend; work for a charity supporting people with a life limiting condition)

Filling the void: the need for bereavement support

"My mother who had dementia for around 18 years, 12 of those in institutional care died in an EMI care home in 2009. Now 5 years later I find myself suffering from delayed grief following two more recent family bereavements."

(R994 - carer or family member or partner or friend of someone in the last few years of their life)

"How do you talk about it: as a carer three times at end of life I remain hugely affected by the early loss of one's future. On two occasions I cared for my wife - both in their forties. On the third occasion I was with my dad. My dad's experience was a happy one at age 90: he said: I have no concerns..I have had a wonderful life..I have

had a wonderful wife..I have wonderful children... I have been all over the world...I want to be with Peggy again (his wife,my mum)...and its fine.....”

(R1140 - I am a carer or family member or partner or friend of someone in the last few years of their life; I am a bereaved carer or family member or friend)

“I feel that when a patient passes away it means such a lot to the families to have a last contact telephone call of condolence from staff members who have been supporting them regularly and for a long period of time, it is Marie Curies policy not to have this contact, can it be considered for change?”

(R476 - carer or family member or partner or friend of someone in the last few years of their life; bereaved carer or family member or friend; professional working with people in the last few years of life)

“When will we have a system in place that can guarantee that all patients can fulfill their wish of dying at home and ensuring a better support system for relatives when the worst happens as at this time they are left with the emptiness that prevails following a stream of differing care professionals having been in their home occasionally for many months at a time just stopping overnight, this can be very depressing for many people young and old. Can we have a system in place where carers are allowed to call following a bereavement of a relatives loved at least once following death?”

(R1206 - professional working with people in the last few years of life)

“As a palliative care SHCA we often leave after a patient has passed away in our care, it would be extremely helpful to friends relatives to be able to pass on to other agencies when we feel that there may be a further need for continued support. We do pass on our concerns to our Clinical Nurse Manager, but do not get feedback on any further care given once we leave.”

(R768 - professional working with people in the last few years of life)

“Continuity of care for families after bereavement”

(R683 - Member of the Public with an interest in the subject)

“Should the support extend to family? and after they die? when my husband died from cancer I was left with a toddler and desperate for support (outside the grieving close family) I could have done with continued support, even just to talk it all through.”

(R216 - bereaved carer or family member or friend)

“Whilst there were services put in place as soon as my husband was told he was dying there was no consideration of support or counselling after his death. Having saved the NHS considerable sums personally nursing him at home in the last six months of his life, my own health would have benefited at least from referral to counselling and a GP review.”

(R222 - bereaved carer or family member or friend)

“All family members need support through and after the process, we as a family have found it extremely hard.”

(R50 - bereaved carer or family member or friend)

What support is currently available?

"What support is there? Having recently been bereaved I have not received any after long term caring for a sick family member."

(R1133 - bereaved carer or family member or friend)

"What would happen during this process? What would happen physically/ mentally and emotionally to my mother in law? What help was available for the family as well as my mother in law? What do we need to do after she died? Who do we need to contact and what help is available to the family to help them cope with the grieving process?"

(R1213 - bereaved carer or family member or friend)

"What support is in place for families going through losing a relative? How do they know where to go for support?"

(R461- bereaved carer or family member or friend)

"I have a stage 4 terminal incurable cancer, kidney cancer clear cell. What care is available to family members and my husband, my main carer? Especially after I die what care is in place for my family then? Will they get any support to help them cope with day to day things that I have always done?"

(R1015 - person in the last few years of life)

"We have never been offered bereavement counselling. His last few weeks of life felt reactive, 9 weeks in hospital and my mum organising his discharge so he didn't die in hospital"

(R103 - bereaved carer or family member or friend)

"Is there aftercare for relatives"

(R1380 - carer or family member or partner or friend of someone in the last few years of their life)

"Bereavement isn't anything to do with the hospital or care homes as far as I can see (apart from the one my mother was in when they cried, they came to the funeral, they reminisced and laughed with us and supported my father over 3 or so years) but they were closed when it was his turn. As far as I am aware there is no bereavement support. A few days off work and back to normal life."

(R1196 - bereaved carer or family member or friend)

"How can the bereaved be made aware of the services that may support them?"

(R1226 - bereavement support volunteer)

"How can my spouse be helped to cope with my illness and death? How is my spouse going to manage without me? Who will help my spouse to come to terms with life after I die?"

(R1222 - professional working with people in the last few years of life)

“How much help and support will be available to my nearest and dearest . How much help would be available for them after my death. What form would it take”.

(R1020 - person in the last few years of life)

“What is available to help partners/families through dealing with the processes that are needed after the death of a loved one.”

(R1043 - carer or family member or partner or friend of someone in the last few years of their life)

“How are the bereaved treated after the death of a loved one?”

(R658 - bereaved carer or family member or friend)

“Do you provide any help to carers and families after the person has died?”

(R898 - bereaved carer or family member or friend)

“There is a real lack of support for bereaved carers”

(R813 - bereaved carer or family member or friend)

“What is done to help the family after the death of a loved one. What sort of follow up is there for families at this time, and is it continued for a length of time. Does anyone really support the families and help them in the turmoil of the financial issues they come across”.

(R199 - bereaved carer or family member or friend)

“What would happen during this process? What would happen physically/ mentally and emotionally to my mother in law? What help was available for the family as well as my mother in law? What do we need to do after she died? Who do we need to contact and what help is available to the family to help them cope with the grieving process?”

(R1213 - bereaved carer or family member or friend)

“Is there follow up bereavement support for families whose love ones die at home, or in hospitals “

(R1227 - professional working with people in the last few years of life)

“Is there a bereavement counsellor in the area for those family members that need additional support after the death?”

(R1323 - professional working with people in the last few years of life)

“Why is bereavement support not available for all?”

(R1199 - carer or family member or partner or friend of someone in the last few years of their life; professional working with people in the last few years of life)

“What support is in place for bereaved families?”

(R1396 - professional working with people in the last few years of life)

“Lack of bereavement services for families who have cared for loved ones. How do we help care for carers after bereavement?”

(R486 - professional working with people in the last few years of life)

“Do all families have access to bereavement care or any source of home visiting/continuing care support?”

(R643 - bereaved carer or family member or friend; professional working with people in the last few years of life)

“Who checks up on the welfare of people once they are bereaved?”

(R998 - professional working with people in the last few years of life)

“Bereavement support is offered at my place of work, but I do wonder how much is available for others outside our area. A lot of pressure seems to be placed on GP's to provide/resource same.”

(R1273 - professional working with people in the last few years of life)

“What structures are in place to address bereaved carers or families concerns following death?”

(R1365 - professional working with people in the last few years of life)

What kinds of support should be provided?

“What provision do you think should be made to support the bereaved carers and families in the later stages of the patients life and early stages post bereavement?”

(R1069 - professional working with people in the last few years of life)

“How can bereavement support be provided in an equitable and cost effective way?”

(R432 - professional working with people in the last few years of life)

“How can services inc. equipment and bereavement support be promoted with easy, and equal access for all?”

(R1010 - I am involved with EoLC workforce development.)

“What percentage of bereaved people: access bereavement support need bereavement support. What level of bereavement support is optimum?”

(R133 - professional working with people in the last few years of life)

“What is done to help the family after the death of a loved one. What sort of follow up is there for families at this time, and is it continued for a length of time. Does anyone really support the families and help them in the turmoil of the financial issues they come across.”

(R199 - bereaved carer or family member or friend)

*“How can we improve communication with families whose loved ones are dying?
How can we effectively give information to families about what to expect when their
loved one is dying and what to do after death?”*

(R817 - professional working with people in the last few years of life)

*“(My mother recently died in a hospice which was located at quite a distance from
our family home. We intended from the outset to have a memorial service for her at
the local church which was attended by many friends, neighbours and relatives. My
mother's wish was to have a cremation rather than a burial. Because we were having
the memorial in a distant location to the hospice, we wanted to have the cremation
as soon as possible near the hospice so that we could have her remains at the
memorial service a few weeks later. It was fine with her, and us, for the body to be
taken from the hospice to the crematorium for cremation directly. But when we came
to arrange it, we were told that it is a legal requirement to have a coffin, and so we
ended up having to spend quite a few hundred pounds on the coffin which was used
for just a few hours. Then because we had the coffin, we had to hire a hearse for
transportation. Subsequently I have seen on this website
(<http://www.naturaldeath.org.uk/index.php?page=coffins-and-urns-2>) that it is in
fact not a legal requirement to have a coffin.) I hope that clearer, better, information
be provided to families so that they can arrange for a memorial in the way they wish
without incurring £1,000+ in unnecessary and unwanted costs. I think that if it is not
a legal requirement that a coffin be purchased, then it should be a legal requirement
for funeral directors to inform families that they have the choice.”*

(R483 - bereaved carer or family member or friend)

*“The after care is disgusting. You get support for the first week or two and even then
you still don't know what the next few steps are. And often have to sit at home
wondering when a member of the team will come and see you next. They take forms
to fill out on your behalf and either lose them or don't fill them out correctly.”*

(R269 - bereaved carer or family member or friend)

When and for how long should support be provided?

*“Having identified the point at which the end of life process begins, the nature of the
support for families and carers begins - instead of allowing for hope, there needs to
be preparation for bereavement.”*

(R906 - bereaved carer or family member or friend, Members of the Public with an interest in the subject)

“Why does bereavement counselling only kick in after death and why so soon?”

(R919 - bereaved carer or family member or friend)

Meeting the needs of different groups

*“How do you bring up the subject of dying to someone who has cancer but still hopes
for a miracle cure? How do you talk to the children about their parent dying?”*

(R1099 - bereaved carer or family member or friend, professional working with people in the last few years of life)

“Can someone support my children (pre and post) bereavement and encourage dialogue between all family members? Help my partner talk about the possibility of death and convince them that the children need to be told what might happen to their mum/dad?”

(R1100 - professional working with people in the last few years of life)