BEREAVEMENT SUPPORTER PROJECT

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EVALUATION (INTERIM REPORT)

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The Project in Brief
The Bereavement Supporter Project is a five-year partnership between Cruse Bereavement Care and the ExtraCare Charitable Trust (referred to hereafter as ExtraCare), funded by the National Lottery Community Fund. The project aims to address the bereavement needs of ExtraCare residents, including people with dementia. Figure 5 depicts the three-tiered approach employed within the Bereavement Supporter Project. First, the project aims to increase awareness of: bereavement (both pre- and post-death bereavement); the impact that grief can have on physical and mental health; strategies that residents and staff can use to support themselves, and each other; and signposting to wider support services that are available (including, but not limited to, Cruse Bereavement Care). Additionally, the project will recruit, train, and employ ExtraCare residents to be Bereavement Supporters who will act as first-contact listening support to their bereaved peers (see Appendix 1 for the Bereavement Supporter volunteer role description). Finally, the project will provide clearer signposting so residents and staff whose need require more specialist support can access this service easier, and faster.
Figure 5. Depicts the three-tiered approach to improvement bereavement support within ExtraCare villages and schemes.

A Public Health Approach to Bereavement Support

In its national framework for local action (2015), the National Palliative and End of Life Care Partnership notes that any end of life care strategy should include support in preparing for, and during, bereavement. Drawing on earlier NICE guidelines on Supportive and Palliative Care for Adults with Cancer (NICE, 2004), the national local action framework identifies the need to accelerate public health approaches to bereavement support (Rumbold & Auoun, 2014; Kellehear, 2005), in which raising public awareness of bereavement needs and building compassionate and resilient
communities are key elements. This growing recognition of the need to develop the capacities of communities to support friends, neighbours and family members through ‘normal’ processes of grief has led to thinking in terms of a 3 component model of bereavement care (see Figure 6), in which most support can be accessed and delivered in supportive communities, thereby reducing the need for more professionalised grief counselling in cases where grief becomes more entrenched, complicated and may give rise to mental health problems.

Figure 6. Demonstrates the public health approach and NICE guidelines adapted from National Bereavement Alliance, 2017.

This community approach, it is argued, is more in line with the kind of support that people say they would like, but often cannot access (Penny & Relf, 2017; Independent Age, 2018) and meets the requirements of the Gold Standards Framework (GSF) in which meeting the needs of those experiencing or anticipating bereavement is a key component of end of life care planning (Gold Standards Framework, 2018). As such, the intention is that the Bereavement Supporter Project will eventually be rolled out to all retirement villages and housing schemes run by

<table>
<thead>
<tr>
<th>Component 1 (Universal)</th>
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<tbody>
<tr>
<td>• Information about bereavement &amp; relevant supports</td>
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<tr>
<td>• Support provided by family &amp; friends</td>
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</table>

<table>
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<tr>
<th>Component 2 (Selective/Targeted)</th>
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<tbody>
<tr>
<td>• Non-specialist support</td>
</tr>
<tr>
<td>• Support provided by trained volunteers, mutual-help groups, community supports</td>
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</tbody>
</table>

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<th>Component 3 (Indicated)</th>
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<tr>
<td>• Professional specialist interventions</td>
</tr>
<tr>
<td>• Support provided by mental health services, bereavement services, or psychotherapy</td>
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</table>
ExtraCare within the framework of its universal health and wellbeing programme and GSF-accredited end of life care planning.

The Bereavement Support Project (as depicted in Figure 5) is most obviously located within component 1 of the public health model, but also contains elements of component 2 in so far as support will be given by trained volunteers.

**Peer Support and Volunteering**

A key principle of the public health approach to bereavement support outlined above is that bereavement and grief are a part of everyday life and that the everyday experience of it that inheres in communities can be harnessed in support of others. Volunteers in the Bereavement Supporter Project commit to sharing their own bereavement and grief experiences and capacity for neighbourly support as well as, in some cases, relevant professional experience. As such the project is an example of the kind of asset-based, peer support approach advocated in healthcare by NESTA (Graham & Rutherford, 2016) and National Voices (Nesta and National Voices, 2013). As other research on volunteering among older people has indicated, the provision of support for volunteers and volunteer activities is crucial not only to the success of programmes, but also to the volunteer experience (Hornung, 2018).

Each of the ExtraCare villages has, or will have, a Volunteer Organiser, whose task it is to support the recruitment, training, and retention of resident volunteers. Many functions within ExtraCare villages are delivered by volunteers (reception, shops, the gymnasium, library etc.) and for many volunteering is a valued aspect of ExtraCare life (West et al, 2017). More challenging functions like befriending and buddying new residents are also delivered by volunteers, but it is probably fair to say that the function of volunteer Bereavement Supporter is the most challenging volunteer role.
to date. As such it requires a particularly robust framework of support. Part of the Bereavement Supporter Project framework is the wider programme of health, wellbeing and end of life support across the villages within ExtraCare. In addition to the Volunteer Organiser, the Bereavement Supporter volunteers can draw on the Wellbeing Advisors and Locksmiths (senior staff members who support vulnerable individuals, often people living with dementia, to ensure that residents reach their potential for well-being).

Cultures of Death and Dying
The public health approach to bereavement and grief support works from the premise that people can seek support from within supportive communities who are willing to talk about death and dying; to engage in the kind of memorialising ‘activities that reconnect bereaved people with the ongoing life of their community’ (Rumbold and Auoun, 2014, p 133); and which ‘recognise the solace that sorrow can bring’ (ibid). This broader cultural aspect, although hugely important (Kearl, 2012; Kastenbaum, 1998), is harder to capture in a formal evaluation. In previous research with ExtraCare, which was based on extensive and longitudinal engagement with residents, we have noted that ExtraCare's health and wellbeing programmes have tended towards the physical more than the emotional dimensions of health and wellbeing (see West et al, 2017 and Shaw et al, 2017). An early interview with one of the main coordinators of the Bereavement Supporter Project indicated that a certain resistance to talking about death and dying among some residents was hampering efforts to promote awareness of the project. As he also explained, the project represents an opportunity to broaden understandings of wellbeing in ExtraCare beyond physical and cognitive health and to apply the Gold Standards Framework to end of life care and support planning. Although our previous research
does not constitute baseline data as such, it is a reference point for us in thinking about the Bereavement Supporter Project as a cultural change programme.

**Key Achievements (To Date)**

Since it started in January 2017, the Bereavement Supporter Project has been launched in nine ExtraCare villages and schemes. Some key achievements to date include:

- Recruited 41 Bereavement Supporters who provide preventative, first-contact listening support and sign-posting to their bereaved peers;
- Designed, developed, and delivered bespoke bereavement and loss information session and one-day training;
- 256 residents, 77 staff, and 17 people from the wider community have attended the ‘bereavement and loss information and awareness sessions’;
- 171 ExtraCare staff, and 1 external volunteer have attended the one-day training with Cruse;
- There have been 156 reported individuals (125 residents; 17 family members; 14 friends of the village) who have accessed support from a Bereavement Supporter, many on multiple occasions;
- 7 residents and 1 family member have also been supported by Cruse Bereavement Volunteers following a formal referral to Cruse;
- 60 Dementia Friends have been created within Cruse;
- Three arts-based bereavement and loss sessions for residents have been delivered; and
A carer’s guide, exploring how carers of people with dementia experience grief and loss, has been developed in collaboration with carers who care for someone with dementia.

Project Evaluation
The Bereavement Supporter Project is being delivered by Cruse Bereavement Care and ExtraCare, and evaluated by an independent evaluation team based at Aston University, Birmingham and the University of Bristol. This report is a summary of our main findings at the half-way point of the project.

In broad terms there are three key areas of focus:

1. The effectiveness of the public health approach in meeting residents’ needs for bereavement support;
2. The experience of volunteers engaged in the project; and
3. The impact of the project on cultures of death and dying in ExtraCare villages.

To do this, the Bereavement Supporter Project will be evaluated in terms of: the organisation of the service; the quality of information delivered; outcomes for individuals (Bereavement Supporters, residents who have received support, and staff); wider impacts. Furthermore, we will draw on the various literatures outlined above (peer support, volunteering, public health approaches to bereavement as a component of end of life planning and support) in data collection and in drawing out conclusions and recommendations.
ExtraCare Locations

We have employed a largely qualitative approach to evaluating the Bereavement Supporter Project in order to generate detailed and nuanced data which captures the experiences of a range of key stakeholders. In doing so, we will therefore be in a position to comment holistically on the impact of the Bereavement Supporter Project. To permit such an approach the management group (which includes representatives from the research team, Cruse Bereavement Care, and ExtraCare) discussed and agreed, to focus the evaluation on four ExtraCare locations. The agreed locations are: Longbridge Village; Pannel Croft Village; New Oscott Village; Hagley Road Village. At the time of writing, across ExtraCare the average number of apartments within a village is 260, and the average number of residents is 350 although there is variation between villages.

We have concentrated our evaluation on ExtraCare locations within the Birmingham area of the UK, and endeavoured to include sites which had different profiles (for example in terms of: resident demographics; time that the location has been open; and geographical location within the city). The first author has spent time in each of the four locations conducting observations, having informal conversations with staff and residents, and introducing the evaluation (in terms of aims, strategies for data collection etc.) to residents in order to better understand how each location operates.

It is noted that in our original evaluation plan we had included a scheme, which typically house a greater proportion of older residents and/or older adults who have greater care needs, and are much smaller in size. However, as the project was rolled out it was apparent that a different approach would be required to deliver the project meaningfully and appropriately in schemes. For example, the schemes do not have the Bereavement Supporter role and instead more attention is given to
better supporting and training ExtraCare staff. Given that one of the outcome measures relates to the impact of the Bereavement Supporter Project on volunteers we substituted the scheme for another village. A final substitution was made in September 2018, this was due to delays in recruitment and training which would have had cascading effects to the evaluation timeline.

Data Collection
Data has been collected from multiple sources, including:

- Delegate feedback of the ‘loss and bereavement information and awareness session’ (staff and residents);
- Delegate feedback of the bereavement and loss one-day training (staff and residents);
- Focus groups and case study interviews with Bereavement Supporters;
- Case study interviews with residents who have received bereavement support from a Bereavement Supporter;
- Focus groups with ExtraCare staff; and
- Focus group with ExtraCare residents.

With the exception of the feedback forms from the information and loss session and the one-day training (which were collected by Cruse Bereavement Care), all data has been collected by the first author.

Data Analysis
Open-ended questions from the information session and the one-day training were analysed using inductive qualitative content analysis (Elo & Kyngäs, 2007) which allowed us to organise, code, categorise, and summarise the most salient aspects of delegates’ written responses. We followed this procedure with each respective question first in isolation, and then together to produce over-arching themes.
Data from focus groups and interviews were audio-recorded, transcribed, and analysed using thematic analysis (Braun & Clarke, 2006), following the six-phase process. This consisted of: (1) familiarisation with the data through transcription and multiple readings of the data; (2) systematically coding pertinent features of the data; (3) collating codes into potential themes; (4) reviewing themes; (5) refining themes to establish clear definitions and names for each; and (6) reporting the themes. Finally, pseudonyms have been used to preserve participants’ anonymity.

**Structure of this Report**
To do justice to the rich data that we have collected, and to better inform both Cruse Bereavement Care and ExtraCare of opportunities that may improve the service, we have produced this very detailed report. Chapters are organised by the stream of data collection (e.g. focus groups with staff, Bereavement Supporter case studies etc.) and present core findings of our analysis and recommendations. Links are also made to the National Lottery Community Fund outcomes measures (see Table 1). We conclude by bringing together our learning and recommendations, and provide a brief outline of what’s next in terms of the evaluation.
Table 1. National Lottery Community Fund outcome measures mapped against chapters within the evaluation.

<table>
<thead>
<tr>
<th>National Lottery Community Fund Outcome Measures</th>
<th>Chapter(s) Addressing Outcome Measure</th>
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<tbody>
<tr>
<td>1. Older people are more active, more engaged, more independent, less isolated and better supported after bereavement.</td>
<td>2, 8, and 9</td>
</tr>
<tr>
<td>2. Older people are able to live fuller, healthier lives with increased opportunities to volunteer and support each other.</td>
<td>4, 7, and 8</td>
</tr>
<tr>
<td>3. Older bereaved people with dementia and their carers have increased access to appropriate bereavement support.</td>
<td>6</td>
</tr>
<tr>
<td>4. Increased awareness of impact of bereavement on older people’s mental and physical health.</td>
<td>1-5</td>
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Chapter 1: Bereavement and Loss Information Session
The bereavement and loss information session was designed to open up a dialogue with staff and residents about death, dying, and bereavement. The session was promoted internally and attendance was entirely voluntary. The session provided introductory information on aspects of loss, grief, and bereavement pertinent to the population. At the end of the session delegates were provided with a feedback form to complete. This section draws together the primary findings from the feedback data.

Questions were designed to provide a snapshot of delegates’ experiences of attending the bereavement and loss information session. As such, the majority were closed questions with respondents indicating their level of agreement to a statement (e.g. ‘I understand the impact of grief on emotions, body, and mind’ with five response options ranging from ‘strongly agree’ to ‘strongly disagree’), or providing an
overall evaluation to a directed question (e.g. ‘what was your overall impression of the training materials?’ with five response options ranging from ‘excellent’ to ‘very poor’).

The bereavement and loss information session has been delivered to staff and residents from 17 ExtraCare locations; Pannel Croft Village, New Oscott Village, Terryspring Court1*, Camoys Court*, St Dominic’s Court*, James Beattie House*, Berryhill Village*, Longbridge Village, Brunel Court*, School Court*, Hagley Road Village, Earlsdon Park Village, Bournville Gardens, St Crispins Village*, Hughenden Gardens Village, Verona Court, and Humber Court. In total, 63 staff members and 105 residents from our four evaluation sites have attended the information session.

Across all sites we have received 169 completed (or partially completed) feedback forms. We will attend to each of the questions in turn, first we provide overall responses (combining staff and resident responses across all sites), followed by breakdowns by site and attendee (i.e. staff or resident).

The event met my expectations
Overall, 48% of respondents reported ‘strongly agree’, 48% reported ‘agree’, and 2% reported ‘don’t know’ indicative that the event met delegate’s expectations. Similar response patterns (roughly 50/50 split between ‘strongly agree’ and ‘agree’) are revealed among Pannel Croft staff, Hagley Road staff, and Hagley Road residents (Figures 7 & 8.). Residents at Pannel Croft village had the highest percentage of ‘strongly agree’ responses (64%) compared to residents at New Oscott (33%) and Longbridge village (36%). 9% of Pannel Croft residents and 7% of Longbridge residents reported ‘don’t know’ in response to whether the event met their

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1 Locations marked with an * are no longer part of the ExtraCare Charitable Trust.
expectations. Finally, staff at New Oscott and Longbridge provided very similar responses with approximately two thirds responding ‘strongly agree’ and one third ‘agree’. These findings indicate that the information session met both staff and resident’s expectations.

I am aware of the services available for bereaved people
As demonstrated in Figures 9 and 10. overall 45% of respondents reported ‘strongly agree’ to this statement, with 48%, 6%, and 1% reporting ‘agree’, ‘don’t know’ and ‘strongly disagree’ respectively. Findings reveal that a higher proportion of staff reported ‘strongly agree’ compared to residents at each of the four locations, with the biggest difference observed at Longbridge village where 63% of staff reported ‘strongly agree’ compared with 20% of residents. Indicative that bereavement services need to be promoted and signposted more to residents within all of the ExtraCare locations.
Figure 7 (above). Demonstrates staff responses and Figure 8 (below) resident responses to the item ‘the event met my expectations’
(depicts overall response across sites and breakdown for staff/residents for the four evaluation sites).
Figure 9 (above). Demonstrates staff responses and Figure 10 (below) demonstrates resident responses to the item ‘I am aware of the services available for bereaved people’ (depicts overall response across sites and breakdown for staff/residents for the four evaluation sites).
The content was useful and easy to follow
Overall, the majority of respondents either ‘strongly agreed’ (60%) or ‘agreed’ (38%) with the statement that the content was useful and easy to follow. There was again a higher proportion of staff reporting ‘strongly agree’ compared with residents across all four of the evaluation sites, with the biggest difference observed at Longbridge (Figures 11 & 12.). It is also noted that a single resident at Pannel Croft village responded ‘strongly disagree’ indicative that, for them, the session was not useful and/or easy to follow.

I understand the impact of grief on emotions, body and mind
Figures 13 and 14 demonstrate that overall, 54% of respondents ‘strongly agree’ with this statement and a further 42% ‘agree’. Reviewing the findings further reveals that a higher proportion of staff in all four locations report ‘strongly agree’ than residents. Longbridge staff report the highest percentage (75%) compared with New Oscott (69%), Pannel Croft (64%), and Hagley Road (60%). In contrast, residents at Pannel Croft report the highest percentage of ‘strongly agree’ (58%), compared with Hagley Road (50%), Longbridge (50%), and New Oscott (22%). While the majority of remaining respondents reported ‘agree’, it is noted that among Pannel Croft residents there were single responses for ‘don’t know’ and ‘strongly disagree’ respectively. And at New Oscott there was a single resident response of ‘disagree’.

These findings suggest that while there is overall a high level of understanding among both staff and residents, some further attention may be required to increase residents understanding of the impact of grief on emotions, body and mind.
Figure 11 (above). Demonstrates staff responses and Figure 12 (below). Demonstrates resident responses to the item ‘the content was useful and easy to follow’ (depicts overall response across sites and breakdown for staff/residents for the four evaluation sites).
Figure 13 (above). Demonstrates staff responses and Figure 14 (below) shows resident responses to the item ‘I understand the impact of grief on emotions, body and mind’ (depicts overall response across sites and breakdown for staff/residents for the four evaluation sites).
Plenty of time was provided for questions and discussion
With the exception of one resident at Pannel Croft who reported ‘strongly disagree’ and two residents at New Oscott who reported ‘disagree’ all respondents agreed (or strongly agreed) that plenty of time was provided for questions and discussion during the information session (Figures 15 & 16.). Furthermore, staff in each location had a greater proportion of ‘strongly agree’ than the residents within the respective location.

I know how to help myself cope after a bereavement
In response to this statement overall, 33% responded ‘strongly agree’, 52% responded ‘agree’, and 11% responded ‘don’t know’ (Figures 17 & 18.). Further examination of the data indicates that there is more variability in responses to this item among both staff and residents, within all subgroups (with the exception of staff at Longbridge) there are respondents who report disagreement (or don’t know). While these numbers are relatively small it nevertheless suggests that additional attention is required to help residents and staff feel better able to cope after a bereavement.
Figure 15 (above). Demonstrates staff responses and Figure 16 (below) demonstrates resident responses to the item ‘plenty of time was provided for questions and discussion’ (depicts overall response across sites and breakdown for staff/residents for the four evaluation sites).
Figure 17 (above). Demonstrates staff responses and Figure 18 (below) resident responses to the item ‘I know how to help myself cope after a bereavement’ (depicts overall response across sites and breakdown for staff/residents for the four evaluation sites).
I know how to support someone else who has had a bereavement
Overall, 35% of respondents reported ‘strongly agree’ to this statement, with a
further 54%, 10% and 1% reporting ‘agree’, ‘don’t know’ and ‘disagree’ respectively.
Residents across all four evaluation sites demonstrated a greater proportion of
‘strongly agree’ responses than staff. With the most marked difference observed at
New Oscott where 88% of residents reported ‘strongly agree’ in comparison to only
46% of staff. Across the four sites there were nine ‘don’t know’ responses and one
‘disagree’ response. While this is a minority it is suggestive that both staff and
residents require more attention could be given to increase confidence in supporting
someone else who has experienced a bereavement.

How do you rate the session overall?
Overall, 54% of respondents rated the session ‘excellent’, with a further 43%, 2%
and 1% rating it ‘good’, ‘average’, and ‘very poor’ respectively (Figures 21 & 22.).
Across all four evaluation sites a higher proportion of staff delegates reported the
session to be ‘excellent’ overall compared with residents, with staff from New Oscott
showing the greatest percentage (76%). It is noted that one resident from Pannel
Croft and one resident from Longbridge rated the session ‘average’, and a single
resident from Pannel Croft rated it as ‘very poor’. Nevertheless, across the four
evaluation sites the majority of both staff and residents rated the session as either
‘excellent’ or ‘good’.
Figure 19 (above). Demonstrates staff responses and Figure 20 (below) demonstrates resident responses to the item 'I know how to support someone else who has had a bereavement' (depicts overall response across sites and breakdown for staff/residents for the four evaluation sites).
Figure 21 (above). Demonstrates staff responses and Figure 22 (below) demonstrates resident responses to the item ‘How do you rate the session overall?’ (Depicts overall response across sites and breakdown for staff/residents for the four evaluation sites).
Open-ended questions
The feedback form also gave respondents several opportunities to provide written comments to expand on their experiences and/or provide suggestions for improvement or clarity. Taken together, there were 44 written comments and were varied in terms of length and/or detail. Three themes were identified using content analysis (Elo & Kyngäs, 2007): ‘positive learning’; ‘future learning’; and ‘logistics’. Each will be examined in further detail below.

‘Positive learning’
The most frequently occurring code (20 unique comments) identified through our analysis has been captured through the theme of positive learning. Respondents, both staff and residents, reported that the information session had been informative and important:

“Very good enlightenment on bereavement” [ExtraCare Staff]

“Very good informative, particularly dealing with bereavement care and dementia”

[ExtraCare Resident]

Staff in particular mentioned that they intended to apply their learning to better support bereaved residents within their village, indicative that there is potential for the material covered within the training to be translated into ‘real world’ application(s).

“Received lots of valuable information which I will pass on to our residents” [ExtraCare Staff]

“Very helpful because everyone will go through this pain and now know how to deal with it” [ExtraCare Staff]
‘Future learning’
This theme reflects respondents’ suggestions for how the session may be improved in terms of content and structure, as well as some suggestions for further training. It is important to note that these comments were endorsed by a single respondent only, and so must be viewed and evaluated through that lens.

Suggestions to improve the content and/or delivery of the session included;

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<th>Quote</th>
<th>Source</th>
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<tr>
<td>“How to look after yourself if you are the main support for others in your family”</td>
<td>Extracare Staff</td>
</tr>
<tr>
<td>“Information given on theoretical models of bereavement in the form of a printout”</td>
<td>ExtraCare Staff</td>
</tr>
<tr>
<td>“More interaction with group/discussion”</td>
<td>ExtraCare Resident</td>
</tr>
<tr>
<td>“Not enough time”</td>
<td>ExtraCare Resident</td>
</tr>
</tbody>
</table>

Staff in particular were keen to receive further bereavement training;

<table>
<thead>
<tr>
<th>Quote</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Welcome further bereavement training”</td>
<td>ExtraCare Staff</td>
</tr>
<tr>
<td>“Would like more training regarding this issue. I have used the service found it helpful”</td>
<td>ExtraCare Staff</td>
</tr>
</tbody>
</table>

Whereas residents requested future training sessions that were more specialised or focused in scope;
Finally, there were two comments that related to the promotion of the session. With a staff member suggesting that more people (presumably ExtraCare staff, although this is not made explicit) should be made aware that the bereavement information session is available. Indicative that perhaps improvements can be made in terms of how the information sessions are promoted to ExtraCare staff. Secondly, one resident requested that more information is required in advance to ensure that attendees are fully informed about the content and purpose of the session.

“Logistics’
This theme captures the five comments that pertained to the logistics of the information session, and specifically how this might be improved in the future. It is noted that all of these comments came from residents. The majority of the comments (n=4) related to the venue selected, and consequently the acoustic challenges experienced.

“Not an easy room to meet in. Microphone would be helpful” [ExtraCare Resident]

“Venue not helpful. People scattered and couldn’t hear” [ExtraCare Resident]

“Wrong venue” [ExtraCare Resident]

“Residents’ comments should be repeated by counsellor as I could not hear sufficiently (and I’m not deaf)” [ExtraCare Resident]
On tracing back these comments back it is apparent they came from two different sessions, at two different villages. However, these were among the first information sessions to be conducted (both late 2017), so given that no further comments have been made regarding the locations (or acoustics) it is suggested that learning from these comments have already been taken forward.

Learning and Recommendations

- Our evaluation has demonstrated that overall the bereavement and loss information session has been well received; meeting the expectations of both ExraCare staff and residents, and facilitating a positive learning experience.
- While the majority of respondents indicated that they were aware of bereavement services (93%), understand the impact of grief on emotions, body, and mind (96%), and know how to support a bereaved person (88%) it is noted that there was variability when comparing staff and residents – with residents agreeing less strongly, or not at all to these statements. It is therefore recommended that more attention is given to these aspects going forward.
- Consideration may also be given to respondents’ suggestions for improving the bereavement and loss information session which included: (1) providing print-outs of bereavement theories and/or models; (2) more time for discussion; (3) more attention on how carers can look after themselves; (4) dementia specific training; (5) more visible promotion of the session.
Conclusion
Taken together, the feedback data revealed that the loss and bereavement information session was well received by both staff and residents within ExtraCare. Overall, delegates agreed that: the session contained useful and/or informative content; they understand the effect that grief has on emotions, the body, and the mind; they know how to support themselves and others following a bereavement; and that the session was structured in a way that encouraged discussion and participation. There is also evidence that ExtraCare staff in particular would welcome further training so that the themes of loss and bereavement within the context of older adults can be explored in more detail.

Chapter 2: Arts-based bereavement and loss sessions
In addition to the information sessions, the Bereavement Supporter Project has also delivered three arts-based sessions designed to explore loss, grief, and bereavement in covert as well as overt ways. These sessions were delivered by the Project Manager and a Cruse Bereavement Volunteer from the local Cruse branch which allowed for one-to-one attention to be provided as required. During one session residents were encouraged to make a collage using magazine cuttings and coloured pens to express feelings of grief and loss following a bereavement and/or to
remember a loved one. In another, residents were given Christmas baubles to
decorate and keep. We have received 19 feedback forms from the three sites who
have, to date, received an arts-based bereavement session to include in the
evaluation.

Overall, respondents indicated that the session had been either ‘excellent’ (50%) or
‘good’ (50%) indicative of a very well received session (Figure 23.). Large
proportions of the respondents ‘strongly agreed’ that participation and interaction
was encouraged (74%) and plenty of time was provided for questions and discussion
(59%). With the remaining residents responding ‘agree’ to both items. Likewise,
residents ‘strongly agreed’ (59%) or ‘agreed’ (41%) that the session was useful and
easy to follow. There were more variable responses to the item ‘I understand how
art can be used to cope following a bereavement’, with 53% reporting ‘strongly
agree’, 20% ‘agree’, and 27% ‘don’t know’. Nevertheless, 94% of respondents
‘agreed’ (or ‘strongly agreed’) that they would recommend the session to someone
else (Figure 24.).

In addition, we received 12 written comments which were unanimously positive.
Residents indicated that they had enjoyed the activity itself but also the opportunity it
provided to socialise and reflect on their experiences.

“So fun, staff were kind and inclusive. Great activity, lots of things to use on baubles.

Had lovely time. Thank you and merry xmas [sic]”

“I had no expectations. I enjoyed the session tremendously. Well balanced between work
and ‘chat’”

“It’s been a great help”
Learning and Recommendations

- The three arts-based bereavement and loss sessions have been well received, with delegates unanimously reporting the session to be either excellent (50%) or good (50%).
- Respondent feedback suggests that it is valued as an opportunity for socialising as well as exploring loss and grief in a different way.
- All respondents would recommend the session to someone else.
- We recommend that more arts-based bereavement and loss sessions are provided where appropriate.

National Lottery Community Fund Outcome Measures

This chapter has demonstrated attending an arts-based bereavement and loss session has had a positive impact on bereaved residents. Specifically, it enabled them to explore their grief in a different way, and provided an opportunity to socialise and be engaged with others.
Figure 23 (right). Demonstrates delegate responses to the item ‘how do you rate the session overall?’

Figure 24 (below). Demonstrates delegate responses to all other items on the feedback form for the arts-based bereavement session.
Chapter 3: Bereavement and loss awareness one-day training (Staff)

The bereavement and loss awareness one-day training is a self-selected training day where loss and bereavement are explored in more depth. The training has been adapted to ensure that it pertinent to older people and the loss and bereavements they may experience (i.e. loss associated with moving into ExtraCare, loss of friendships or social groups, as well as bereavement experienced in response to the death of a loved one). Furthermore, while models and theories of grief are introduced and examined the training has been designed to include working examples, discussion, and visual aids to support learning and practical application of the material covered.

Staff from eight locations have attended the bereavement and loss training session; Pannel Croft, New Oscott, Hughenden Gardens, Longbridge, Hagley Road, Verona Court, Earlsdon Park, Bournville Gardens, and Humber Court. Of these, 71 staff members and 26 Bereavement Supporters from the four evaluation sites have attended the training.

In total, we have received 132 feedback forms from staff across these sites which will be explored in more detail in the sections below.

What was your overall impression of the workshop?
As demonstrated in Figure 25, overall the sizeable majority of delegates (79%) reported that the training was ‘excellent’, with a further 21% who reported ‘good’.
Similar findings were revealed across the four evaluation sites, with the majority of respondents reporting ‘excellent’ (Pannel Croft = 79%; New Oscott = 100%; Longbridge = 75%; Hagley Road = 86%), with the remaining respondents reported ‘good’.
Figure 25. Demonstrates respondent’s overall impression with the workshop (across all sites and for each of the four evaluation sites).

What was your overall impression of the trainer?

Overall, 81% of respondents reported the trainer to be ‘excellent’ with the remaining 19% reporting ‘good’ (see Figure 26 for full breakdown). Again, few differences are reported between the four evaluation sites with the majority of respondents from Pannel Croft (86%), New Oscott (100%), Longbridge (63%), and Hagley Road (86%) reporting their overall impression of the trainer to be ‘excellent’.
What was your overall impression of the training materials?
As demonstrated in Figure 27, overall 65% of respondents reported the training materials to be ‘excellent’, with the remaining 34% and 1% reporting ‘good’ and ‘average’ respectively.

I understand the impact of grief on emotions, body and mind
Overall, 72% of respondents reported that ‘strongly agree’ with the statement ‘I understand the impact of grief on emotions, body and mind’, with a further 27% and 1% reporting ‘agree’ and ‘don’t know’ respectively. Similar patterns were observed when reviewing each of the four evaluation sites with the majority of respondents at Pannel Croft (77%), New Oscott (77%), Longbridge (75%), and Hagley Road (86%) reporting ‘strongly agree’ (Figure 28.).
Figure 27. Demonstrates respondent’s overall impression with the training materials (across all sites and for each of the four evaluation sites).

Figure 28. Demonstrates respondent’s agreement to the statement ‘I understand the impact of grief on emotions, body and mind’ (across all sites and for each of the four evaluation sites).
I know how to support someone else who has had a bereavement
45% of respondents reported ‘strongly agree’ to this statement and 50% reported ‘agree’, a minority reported ‘don’t know’ (4%) and ‘strongly disagree’ (1%) respectively. A similar distribution of responses is revealed when examining each of the four evaluation sites (Figure 29.).

Figure 29. Demonstrates respondent’s agreement to the statement ‘I know how to support someone else who has had a bereavement’ (across all sites and for each of the four evaluation sites).

I am aware of the services available for bereaved people
Overall, 63% of respondents reported that they ‘strongly agree’ with the statement ‘I am aware of the services available for bereaved people’, with the remaining 37% reporting ‘agree’. Comparisons with the four evaluation sites (Figure 30.) reveal similar findings, although Hagley Road have a greater response of ‘highly agree’ (86%) than Pannel Croft (62%), New Oscott (62%), and Longbridge (69%).
Chapter 4: Bereavement and loss awareness one-day training (Residents)

Completion of the bereavement and loss awareness training is a pre-requisite for ExtraCare residents who intend to be a Bereavement Supporter. While the training for staff and residents is identical, it was decided, based on learning from Beyond Words, another Cruse Bereavement Care Project with parallels to the Bereavement Supporter Project, that training would be delivered separately. The rationale was to provide a space where delegates could, if they choose to, speak freely about their experiences with grief and loss. Given that staff may wish to discuss their thoughts and feelings pertaining to the death of a resident it was decided having combined training may not be professional or appropriate.

To date, the training has been delivered to residents from seven ExtraCare locations; New Oscott, Pannel Croft, Longbridge, Hagley Road, Earlsdon Park, Bournville.
Gardens, and Hughenden Gardens. In total, we have received 41 feedback forms across all ExtraCare sites. With the exception of two items, respondents across sites all responded to items as either ‘excellent’ or ‘good’ (i.e. there was little to no between site differences). Therefore, only the overall responses will be reported.

As depicted in Figure 31, residents reported ‘excellent’ \([e]\) or ‘good’ \([g]\) to the item related to their overall impression of; the workshop \([e]: 61\%; [g]: 39\%\); the trainer \([e]: 78\%; [g]: 22\%\); and the training materials \([e]: 48\%; [g]: 52\%\). Furthermore, 54% reported ‘strongly agree’ and 44% ‘agree’ in response to the item pertaining to their understanding of the impact grief has on emotions, body and mind (Figure 32.). A single resident (2%) reported ‘don’t know’ in response to the item ‘I feel comfortable supporting someone who has had a bereavement’, while 44% reported ‘strongly agree’ and 54% ‘agree’. Finally, in response to the item ‘I am aware of the services available for bereaved people’; 32% ‘strongly agreed’, 54% ‘agreed’. 12% ‘don’t know’, and 2% ‘disagree’.
Figure 31. Demonstrates residents’ overall impression of the workshop, trainer, and training materials.

- What was your overall impression of the workshop?
  - Excellent: 61
  - Good: 39

- What was your overall impression of the trainer?
  - Excellent: 78
  - Good: 22

- What was your overall impression of the training materials?
  - Excellent: 48
  - Good: 52

Figure 32. Demonstrates residents’ level of agreement to statements about the physical and mental impact of grief, their comfort supporting a bereaved person, and their awareness of bereavement support services.

- I understand the impact of grief on emotions, body and mind
  - Strongly Agree: 54
  - Agree: 46

- I feel comfortable supporting someone else who has had a bereavement
  - Strongly Agree: 44
  - Agree: 54

- I am aware of the services available for bereaved people
  - Strongly Agree: 32
  - Agree: 54
Open-ended questions
The feedback forms also included open-ended questions to allow delegates the opportunity to provide more detailed feedback about their experiences. The questions fit into three broad areas: ‘training in relation to role and/or self’; ‘training content and delivery’; and ‘learning’. Each of these will be expanded upon in turn.

‘Training in relation to role’: Staff
Staff were predominantly motivated (86 comments in total) to attend the bereavement and loss one-day training to gain more understanding of loss and bereavement so that they then might better perform their roles and support residents.

> “Better understanding on how to deal with somebody who has suffered a loss or bereavement”

> “This will enhance my knowledge in my role as Locksmith”

> “As a resales for EC I see several families that have lost parent/s and have to surrender apartments and wanted to learn”

Staff members across job roles within ExtraCare have attended the training; from reception to housing, from care to sales. These comments suggest that there is learning to be gained irrespective of position. Indicative that the training has been developed to be suitably tailored to allow attendees to reflect upon their own experiences and roles and if/how this material may be applied to their particular context.

It is noted that there were 16 staff comments which suggested that prior to attending the training they were preoccupied with how to talk about death, dying, and
bereavement with residents. We propose that there was a fear, or concern, about ‘knowing the right thing to say’ and that staff perceived that the training may be able to alleviate some of these concerns and/or provide guidelines on what to say, or what not to say.

“The need to know what to say to people”

“To gain confidence in saying the right thing”

“As I often have to talk to residents when there has been a death. What to say!”

Finally, for some staff delegates the training also acted as a vehicle through which they could traverse their own past, current, or anticipated losses which demonstrates that the training effectively enriched delegate’s personal, as well as professional lives.

“[To better] understand my own experiences” [ExtraCare Staff]

“To be able to help myself and others more effectively” [ExtraCare Staff]

“I needed to reflect, knowledge and what to expect when my dad dies of cancer”

In total, there were 125 comments in response to the item ‘how will the training help you in your role?’ Of these, 55 related in some way to communication, and the vast majority asserted that the training had provided them with understanding and confidence of “the right things to say” to a bereaved person.
Given that so many staff comments related to their concerns about “saying the wrong thing” we suggest that talking about a resident’s bereavement and grief can be personally challenging for some staff members. They fear making the residents, and we suspect themselves, uncomfortable, as well as a fear that they will make things worse by “saying the wrong thing”. Receiving some guidance in these domains appears to have alleviated some of this tension, reflected in comments claiming that they now feel more confident in initiating conversations about death, dying, and bereavement indicative that the training has, to some extent, elicited a shift in culture. There are also more subtle examples of how one might effectively communicate with bereaved people, for example the recognition that sitting with silence can be equally meaningful and supportive.

Finally, respondents emphasised that the training had provided them with greater insight and understanding of loss and bereavement, which they automatically viewed
through the framework of their role within ExtraCare and how their learning may be applied to better support residents and colleagues.

“I feel I have a better understanding and will hopefully be better equipped [sic]”

“What I learn I will put into practice in my work role”

“Gave me a better understanding of how to support staff members”

In summary, this theme has demonstrated that staff were primarily motivated to attend the bereavement and loss training session to learn more about bereavement and loss with the aim of applying their learning to better support residents and colleagues. Finally, communication - what to say, what not to say, when and how to say it - was a particularly salient sub-theme within staff responses.

‘Training in relation to role’: Residents
This theme encapsulates delegate’s motivation(s) for attending the one-day bereavement and loss training session, as well as exploring how the training might help within their respective roles (i.e. Bereavement Supporter or ExtraCare staff member). Within this theme we present the findings for staff and residents separately to ensure we do justice to the thematic divergence as well as convergence evident in the responses.

Among resident responses there was recognition that death and bereavement were inherent to the context of ExtraCare, that death is frequently a visible presence within the village, and that this can be an incredibly painful and difficult time that for some may require additional support.
It is inferred that the Bereavement Supporter Project is valued because it recognises the salience, and inevitability of grief and loss within this context, and provides a channel through which previously unmet needs may be redressed.

Perhaps unsurprisingly, many respondents (n=16), were motivated to attend the training because they wanted to help others.

“To walk with and support where possible with someone who has been bereaved”

Some argued that their own experience of significant bereavement (and in one case accessing bereavement support from Cruse) placed them in an empathic position whereby they could better relate to, understand, and support bereaved people within their communities because of their shared lived experience.

“To be available to help in an ExtraCare village context, because there are so many deaths per year in this particular context”

“Because there is a need for it in our village”

“Because bereavement is all around us”

“Having been through bereavement myself I have some knowledge of what people are going through”

“I had a Cruse counsellor when my husband died. It was so helpful to me. Like to do the same for someone else.”
In addition to ‘giving back’ on an individual level, residents were also motivated to ‘give back’ to ExtraCare, or more specifically to other members of their village community.

“First and foremost to make a significant contribution to my village and residents”

“[I’m] passionate about improving awareness/support here”

“[I] want to contribute to life in the village”

Furthermore, residents also viewed the skills developed in previous employment and/or volunteer roles as a significant motivating factor for training to be a Bereavement Supporter. Residents were keen to demonstrate that they were ‘right for the job’.

“Working experience in social services and think this is an area where I can contribute”

“Because it is something I have done before I moved here”

It is evident through these excerpts that there was a strong motivation to (continue to) cultivate a supportive community, and for residents to feel like they are making a “contribution” or “difference”. It is suggested that by bringing their wealth of experience and expertise, cultivated through years of paid and unpaid work, residents within ExtraCare have positioned themselves as assets to their communities, as well as willing ‘givers’ to enrich said communities. The Bereavement Supporter role could therefore be viewed as a means of empowering residents to support each other, to strengthen community bonds, and to recognise the rich histories of ExtraCare residents.
Taken together, there were 41 comments outlining the ways in which the training was perceived by residents to help them in their role as a Bereavement Supporter. These can be broadly divided into three distinct, but related categories: learning and information; development of skills (particularly listening skills); and promoting confidence and self-reflection.

Residents argued that the training provided them with new information, or refreshed their previous understanding about bereavement and grief, and in particular the uniqueness of how an individual may present their grief. They suggested that having this information will better equip them to provide appropriate and meaningful bereavement support.

“I feel I have gained a much greater insight into bereavement and how it can affect people in different ways”

“Good update on bereavement support and will help my future practice”

“Reinforcing things that I possibly was already aware and other things which I was not aware of”

Residents also identified skills, and in particular listening skills, to be an important point of learning gained from the training which likewise has ‘real world’ application.
We suggest here that residents have reflected on the nuances of ‘listening’; that there is recognition that a shift may be required in how one might listen within the context of being a Bereavement Supporter compared with a ‘regular conversation’. And that this has been acknowledged by residents as significant, and perhaps, unexpected. We are of course used to listening, we do it in every exchange we have ever had, but often we do so while waiting for our turn to speak; to share our own thoughts, beliefs, or experiences. The excerpts above imply that residents have, on some level, reflected on their conversational style and identified aspects that may require refinement in order to enhance their communication skills to ensure it is appropriate and sensitive to the context of their role as a Bereavement Supporter. Finally, residents asserted that the training gave them greater confidence in their ability to provide bereavement support to bereaved persons within their community.

“Opens the mind to various questions what to look for how to listen to people”

*It will help me not to make unwarranted assumptions, and will help guide my approach to listening and speaking*”

“Has made me think about listening more, rather than try to advise”

“Made me more aware of my weaknesses as a listener and my strengths. Gave me confidence”
Through this theme we have presented residents’ key motivations for attending the training, and entering the first stage in becoming a Bereavement Supporter, and the ways in which the training has prepared and supported them to undertake this role.

‘Training content and delivery’
This theme brings together feedback pertaining to the ‘active’ elements of the training: the trainer; the training materials; and the most (and least) valued aspects of the training. Responses for this theme have been collated as there were few noticeable differences between staff and resident responses.

There was unanimous praise (over 100 comments) for the trainer who delivered this session. Commendation was centred on four main competencies: knowledge; communication; teaching methods; and management. While these categories are intended to be self-explanatory, we will briefly attend to each by using examples from the data collected.

Firstly, participants recognised the trainer’s knowledge and expertise in the subject material;

“Given me a lot more confidence”

“I feel I can be more confident in my role and also have some resources to refer to”

“The reassurance that I don’t have to be ‘clever’”

“Very clear obviously knows his subject” [Resident]

“Trainer showed great knowledge and experience” [Staff]
Secondly, the trainer was able to communicate the material in a way that was relatable and easy to understand;

“Very easy to follow and made the training extremely interesting” [Resident]

“The trainer has very good knowledge of the course covered and has expressed himself in a way that can be understood fully.” [Staff]

Next, the respondents appreciated the variety of teaching methods used within the session;

“He paced the course with good mixture of practice and materials” [Resident]

“Really good – no boring bits – all very useful” [Resident]

“Made learning more interesting instead of just off a PowerPoint” [Staff]

Finally, respondents commented on the ways in which the session was managed;

“Listened and incorporated ideas along the way” [Resident]

“Encouraged participation. Good at gently controlling the contributions and keeping focus” [Resident]

“Fun and interesting even with a potentially dark subject matter” [Staff]

“Liked his style – he made the sessions fun and easy to take in and remember” [Staff]

In terms of the training materials, both staff and residents were grateful to have been given handouts that they could take away with them to read and reflect on at their leisure to build on the knowledge generated through the session.
Furthermore, 66 respondents reported that they valued all aspects of the training material;

“Difficult to answer all points I felt valid really” [Resident]

“All of course was valuable to my learning and personal development” [Staff]

Of the respondents who identified specific features of the training that they valued there were: 31 comments commended the use of visual aid and activities; 18 comments related to improved communication and in particular listening skills; and 10 comments identified the group discussion.

“The handouts will be very useful as there was so much to take in” [Resident]

“Good slides and handouts to refer to at a later date [Staff]

“There were a couple of comments that mentioned specifically their appreciation that the training did not fall back on PowerPoint presentation. It is apparent that by using visual aids and metaphors to explain grief theories, and encouraging active participation through directed activities and discussion delegate’s attention was
maintained. Critically, this dialogic and visual approach was also effective at ‘bringing the material to life’ and encouraged delegates to connect the material to their own working and/or personal lives.

‘Learning’
While comments overall were positive it was important to ensure that delegates had the opportunity to make suggestions for how the training might be improved. In total, 18 resident responses were received and 35 staff responses were received. Staff overwhelmingly (31 comments) reported that there was nothing that would improve the training, and six residents likewise reported that there were no improvements that they could identify. A further six residents explained that suggestions for how the session might be improved would come later, after they had had the opportunity to put into practice what they had learned.

As a consequence of the openness of this question, there are a number of suggestions that have been endorsed by a single delegate only. Nevertheless, we include eight recommendations for the future provided by the delegates in the box below.

“Would like a follow up once I have undertaken the Supporter role” [Resident]

“Will know better if and when I have had some experience” [Resident]
<table>
<thead>
<tr>
<th>Comment</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>“As a personal thing some pointers to theories re grief counselling”</td>
<td>Resident</td>
</tr>
<tr>
<td>“Learning outcomes could have been given at the start of the day”</td>
<td>Resident</td>
</tr>
<tr>
<td>“Has there been any ‘filtering’ of volunteers who may not be suitable either ‘style’ or personal bereavement issues”</td>
<td>Resident</td>
</tr>
<tr>
<td>“More advice on how to deal with someone who has inconsolable guilt or lack of desire to be motivated to be active or ‘self-care’”</td>
<td>Staff</td>
</tr>
<tr>
<td>“Depending on location include more cultural information on what individuals do i.e. West Indian, Irish etc.,”</td>
<td>Staff</td>
</tr>
<tr>
<td>“More opportunities to practice connecting with people in grief. Deal with uncomfortable feelings. More embodied work (Paul Linden). More practical. Enjoyed the chatting but wanted more”</td>
<td>Staff</td>
</tr>
<tr>
<td>“More picture images of situations if possible”</td>
<td>Staff</td>
</tr>
<tr>
<td>“Box – need more items”</td>
<td>Staff</td>
</tr>
</tbody>
</table>
Learning and Recommendations

- Our evaluation has demonstrated that the bereavement and loss awareness one-day training session: (1) was well-received by ExtraCare staff and Bereavement Supporters; (2) communicated complex grief theory and concepts in an engaging and memorable way; (3) encouraged staff to reflect upon their own grief and/or their relationship(s) with bereaved residents and colleagues; (4) challenged and refined communicative practices; (5) increased confidence in supporting a bereaved person; and (6) furthered conceptualisations of grief, and how grief manifests idiosyncratically and dynamically.

- However, there were notable differences between staff and resident awareness of the services available to bereaved people – with residents demonstrating less awareness overall. More attention could therefore be given to improving the visibility of bereavement services available to residents within the respective villages.

- Staff were motivated to attend the training so that they could better support bereaved residents (and in some cases their colleagues).

- Residents were motivated to attend the training (and more broadly to become a Bereavement Supporter) for more varied reasons which included: wanting to ‘give back’ to their communities, wanting to use their own loss to help others, to develop skills, and to meet the (perhaps previously unmet) needs of bereaved residents.

- Developing communication skills was identified as the most valued aspect of the training for both residents and volunteers. However, for staff this was largely framed in terms of “what is the right thing to say” whereas for residents listening, and sitting in silence, were the central learning points taken from the training.

- Recommendations from delegates included: more emphasis and exploration of how different cultures grieve/make sense of death; more guidance on how to respond to a person exhibiting complicated grief; more theories relating to grief counselling.
Conclusion
Findings from the evaluation forms have revealed that both staff and residents considered the loss and bereavement one-day training to be an informative, valuable, and useful training session. The closed questions have provided an instructive snapshot into how delegates perceived the training, and the open questions provided an opportunity for delegates to provide more detailed responses about their experiences.

Chapter 5: Focus Groups with ExtraCare Staff
All staff members who had attended the one-day loss and bereavement awareness training were invited to participate in a focus group conducted within their village. The number of participants, and the length of the focus group varied between locations; ranging from two-six participants and 35-45 minutes. In order to understand the impact of bereavement awareness training in all aspects of the ExtraCare environment, we sought to include all job roles. Professions included the village manager, the wellbeing advisor, the Locksmith, a personal support assistant,
the care manager, the volunteer organiser, and representatives from housing, sales, and reception. Broadly, the purpose of the focus group was to explore:

- Staff experiences of attending the training (e.g. what they liked about the training, ways it could be improved etc.);
- If, and how, the material from the training had been applied within their professional and/or personal lives;
- Staff perception of how grief and loss are experienced by older people, and the residents in their village in particular;
- Staff perception of how the Bereavement Supporter Project is being delivered and accessed within their village; and
- Other aspects relating to the topics of death, dying, and bereavement that were important to them and/or that they thought the evaluation team should know about.

Through our thematic analysis we have identified four themes to discuss here: ‘culture’; ‘family dynamics’; ‘communication’; and ‘boundaries and limits’. Each will be examined in turn.

Culture
Staff members in all four locations recognised the salience of death and bereavement within the context of their village, and the unique ways in which ‘village life’ contributed to resident’s experience of grief and loss. Many commented on the inevitability of death and loss when working in an environment where older adults are concentrated:
Differences in the number of resident deaths experienced emerged between villages, with newly established villages experiencing fewer deaths than more established villages which tend to have an older age profile of residents. A staff member from a newly established village commented:

“I think especially this year because we’ve lost like 12 residents you know, probably more than we’ve lost before” [Elizabeth]

“When you think we have 260 apartments so that’s more than there are houses in a street and if you filled a street with this age then you’d expect a lot more” [Marcus]

The relatively low incidence of deaths within this village (staff members could not agree on an exact figure but placed the number at around seven since opening two years ago) was said to be the product of being newly established and so housed relatively young residents who will “age together” [Dan]. Relatedly, staff asserted that the ‘age’ of the village contributed to how the death of residents were experienced by the village collectively, including themselves. In other words, as staff and residents cultivate relationships (and equally residents cultivate relationships with each other), resident deaths are consequently felt more strongly and this grief can ripple throughout the village.

“we’ve been here like six years, we’ve known these people for six years (…) some of them have been end-of-life, some of them had a lot of input from staff” [Elizabeth]
The impact of resident death, and bereavement, on staff is going to be considered in more detail in a subsequent theme (‘boundaries and limits’), for now it is sufficient to note that ‘ageing together’ can elicit intimacy that results in greater loss that permeates through a village which can be challenging for both residents and staff to manage.

In one village, staff explained that the training had come at a particularly appropriate time;

“It gave us some space to talk about bereavement, death, and how we respond to it and I say it was timely because we was experiencing that and it’s a bit like “that didn’t feel right” and we could talk about why it didn’t feel right and what we might do slightly differently next time” [Dan]

Through this excerpt Dan explicitly positions the training as being an important opportunity for staff members to reflect upon their current experience and practice and draw out aspects that “didn’t feel right” to improve or refine going forward. We argue that an openness to reflect upon, and talk about bereavement and death, is an important step towards shifting the culture around death, dying, and bereavement within the village(s).

Others commented that the training had challenged, and shifted their conceptualisation of bereavement to include losses which could be termed pre-death bereavement (e.g. loss of mobility or independence, loss of previous home and furniture, loss of social opportunities etc.). Staff reflected that this broader conceptualisation resonated with their various professional roles, and had encouraged them to view residents more holistically.
In these excerpts (above), Lydia (who works in sales) explained that while she had always been empathic and understanding of the stress that residents may experience whilst moving, she had not fully considered the parallels between these losses (e.g. downsizing, leaving a house they had lived in for many years, etc.) and grief. She reflected that while she does not regularly have contact with residents after they have moved into a village, and so would be unlikely to offer them direct bereavement support, the training nevertheless resonated with her experiences and encouraged her to attend to the individual experiences of residents. Lydia’s experiences are a good illustration of how having increased knowledge and awareness of loss and bereavement can pay dividends for every role within ExtraCare. A point succinctly, and effectively, made by Marnie (above).

However, discussion with staff also surfaced some challenges to, or tensions around, talking openly about death, dying, and bereavement. For example, Francis explained that a number of talks and stalls were arranged as part of Dying Matters week which “was about raising the awareness of and trying to get rid of taboos and bring it [death] out into the open”. Francis said that she didn’t know if “it was pitched quite right” as “the feedback seemed to be divided 50/50” between those who thought it was “great” and those who found it “upsetting”. Dan countered this by saying he thought:

“[there are] many different ways of losing things and grievin’ for things without people”

[Lydia]

“So we’re all dealin’ with different sort of bereavements really, she’s in care, you’re in houses, and I’m in reception so we’re dealin’ with it in different ways” [Marnie]
Dan’s comments suggest that he views death and bereavement awareness and support as being another feature of the ‘ExtraCare package’ that residents can access and engage with (or not) as they wish. There was a sense of determination that he would not allow what he perceived to be a small but vocal number of residents to stifle the opportunity for these conversations and services to be available. Many participants also made connection to the introduction of the Gold Standards Framework accreditation, asserting that “it’s all linked, it all works well together” [Dan].

“With the GSF we are not promoting death, that’s the wrong way, but we’re promoting the fact that you can plan and have advance planning in place (...) so we’re looking more at the individual” [Karen]

Another example pertaining to the tensions around talking about death came from Samantha whose first contribution to the discussion was to express her relief that you “didn’t have to speak [in the training] if you didn’t want to”. We were struck by Samantha’s palpable anxiety about having conversations about bereavement despite her voluntarily attending a bereavement and loss training session. Samantha goes on to say that within her training session there were people who were:
Here, Samantha voiced concern that some staff members shared their lived experience believing that they “could deal with it” but it was evident that the experience remained “raw”. There is also an acknowledgement that staff delegates have a choice about whether or not they share their experiences, and for Samantha this was a relief.

Through this theme we have examined some of the ways in which the bereavement and loss one-day training specifically, and the Bereavement Supporter Project more broadly, have made important first steps in shifting the culture around death, dying, and bereavement within ExtraCare villages. We have also touched upon some of the current challenges and tensions among ExtraCare staff (and residents) pertaining to this agenda.

Family dynamics
This theme attends to the ‘family dynamics’ activity which was frequently cited as being the most surprising, valuable, and memorable aspect of the training among staff members. We will first briefly describe the activity, before moving on to how staff members have interpreted and applied learning to support residents, each other, and themselves.

Within this activity each delegate is provided with a character from a fictional family who have recently experienced a bereavement. Each character has a ‘backstory’ which provides contextual information about their position in the family and how they

“open to talk about it whereas others think they can deal with it but then as they talk about it realise they actually can’t, even though it was decades ago it was still quite raw”
might be experiencing the bereavement (for example, a granddaughter whose primary concern is her inheritance). Participants are then asked to stand up and move into an open space where they are asked to use proximal space to the deceased person to represent their relationship and experience of grief.

This interactive and dynamic activity was appealing to staff as it “provided the tools but without providing a 600 word theory” [Marcus] which made it “easier to grasp and retain”. Having to connect to a character and extrapolate what their thoughts, feelings, and behaviour might be placed delegates into ‘unfamiliar shoes’; they were encouraged to think about the multitude of grief reactions that may be produced from a singular bereavement. As Daisy evocatively expresses;


“the training itself I think opened my eyes to be fair. I think I looked at it blinkered from my point of view (...) it was mind blowing”

Irrespective of whether this activity was mentioned explicitly, staff in all four focus groups mentioned that the training had resulted in them considering the idiosyncratic and oscillating manifestations of grief. Martha explained that the training “brings it home that people grieve in very different ways” and drew upon an example from her personal experience which resulted in a “blow out with one of my siblings purely because I thought he wasn’t acting in a way that I thought he should be”. She then reflected that “he was actually really upset but he dealt with it in a way I didn’t see because I was more concentrating on how I was dealing with it”. Francis also recalled a personal experience whereby her father’s second wife acted aggressively towards her while she was visiting her father in hospital;
These examples demonstrate that we all have ideas of what ‘good grief’ looks like, and that we may judge and/or respond to others negatively if their grief has not manifested in a way that we think is appropriate. This training is to be commended in challenging delegate’s conception of ‘good grief’ and encouraging them to respect individuality and oscillation in theirs, and others’, experience. In this way, the training has provided staff with an opportunity to connect with, understand, and support residents better.

Moreover, Marcus commented that the activity also served as “an icebreaker” which was an important factor for him because while the staff in his village “sort of knew each other at the time”, as a relatively new village this activity in particular, and the training more broadly, were effective at building team dynamics. Demonstrating that the training can have perhaps unintended positive outcomes for team rapport and cohesion.
This theme draws upon a single activity from the bereavement and loss awareness session that particularly resonated with staff. We recognise that ExtraCare staff already possessed deep empathic skills and a motivation to provide exceptional care, however we argue that the training was effective at challenging delegate’s conception of ‘good grief’. And consequently, staff understanding of grief and what may be an ‘appropriate’ response has shifted, enabling them to provide superior care.

Communication
This theme will explore the significance of communication within the context of loss and bereavement, as well as touch upon some areas of tension.

Shifts in language use and communicative style were frequently cited by ExtraCare staff as being a valuable feature of the training that had been applied in their interactions with residents.

“I’ve learned to listen a lot more, you don’t have to fill the gaps” [Elle]

“Keep it shut, just let them do the talking” [Daisy]

“Without the trainin’ I don’t think that I’d be able to deal with it the way that I do (...) I learn to listen more and not give advice” [Marnie]

“Sometimes it’s ok not to say anything” [Melissa]
It was striking that staff members in all four focus groups reflected on their new appreciation for ‘sitting with silence’. The training had encouraged them to prioritise the needs of their residents which they argued empowered residents to take ownership of instigating and guiding conversations about death and bereavement.

“I feel now I am going to be thinking a bit more of, is this the conversation that person wants to have?” [Shireen]

“They just want you to listen so I think I gained from the training, is how to listen” [Elle]

A number of participants acknowledged that in the past they had reverted to platitudes, intended to comfort residents, but which they now try to avoid as the training confronted whether this was appropriate, and indeed whether it was comforting.

“Before I think I was trying to say ‘there-there, it’s okay’ and reassure constantly’ [Elle]

“I would say things like ‘they’re in a better place now’ or ‘just give it time, you’ll come to terms with it’ things like that, but now I don’t say things like that” [Daisy]

Threaded throughout the discussions were concerns about saying or doing the ‘right thing’.

“It could be that somebody’s opened up to a care erm staff member because they’ve actually said the right words” [Samantha]

“That’s a sad thing for me, is not being able to help them or say the right things [Daisy]

“People who were hoping that they’d come out of the training with like the perfect thing to say in that situation and there just isn’t anything” [Elizabeth]
It was evident that ExtraCare staff are ambivalent about whether or not there is a ‘right way’ to talk about and respond to resident’s grief. Some, like Samantha, assert that shifts in language (for example, ‘how are you?’ as opposed to ‘are you ok?’) provide residents with the space to “open up”. While not necessarily a product of the training, Samantha recognised that the training reaffirmed this approach to eliciting conversation from residents. In contrast, Daisy felt frustrated, and sad, that there are no words she can say to alleviate resident’s pain; it is argued that this might be particularly poignant for carers. In another discussion, Elle (also a PSA) explained:

“Normally with care, you know, you’ve got somebody you have to action it, whereas if somebody is just talking, it doesn’t necessarily need an action”

Elle framed this positively, but equally it provided an interesting insight into why other carers, such as Daisy, may be saddened or frustrated in not being able to “action it”, and instead are encouraged to ‘sit with the silence’ when communicating with, and caring for, residents who are bereaved. There were also instances whereby staff members are perhaps now being too cautious; seconding guessing, and inhibiting themselves because they are afraid of ‘doing the wrong thing’ or overstepping the mark with residents.

“It was the funeral last week and I just felt I wanted to go and check if that person was okay again, but then I thought, is it my place, I might upset them, I don’t know” [Shireen]
Within this theme we have examined the ways in which the training has challenged and changed the ways in which ExtraCare staff communicate with residents. Staff for example reported using stock phrases or platitudes a lot less, and silence (or listening) a lot more. We also reported on staff ambivalence and tension around the ‘right’ things to say or do when communicating with bereaved people which in some cases remain unresolved.

Boundaries and limits
In this final theme we examine the recurring interconnected sub-themes of “professional boundaries”, blurred lines and limits. With the exception of the newest village, staff either explicitly or implicitly registered ambivalence about maintaining “professional boundaries” with residents.

“But, you can’t help the way you feel yourself inside, can you, for people? (…) you do get attached to residents and the families even though we’re not supposed to” [Daisy]

“I think you get given the professional boundaries and I think we’ve got to understand that they get crossed because we care” [Karen]

These excerpts (above), are a dialogue between Daisy (a PSA) and her manager Karen. Daisy explained that she finds it difficult sometimes to maintain an ‘appropriate’ emotional distance from residents despite being directed to do so. Interestingly, Karen then asserted that crossing the boundary is an inevitable, and indeed a desirable, feature of care. There seems to be an implicit understanding among staff that there is ‘a boundary’ between themselves and the residents, but that this is not clearly defined and so difficult to navigate, and consequently the impact on staff remains unrecognised and unsupported.
Furthermore, in one focus group in particular, staff members explored their experiences of traumatic incidents and the ramifications that this can/has had on their wellbeing.

“He and Elizabeth had to attend to somebody who had passed away and we had to do CPR and their family member was telling us that they did not want it and we just had to do it anyway because that is our policy (...) I had to deal with that family member quite a few times after” [Shireen]

Shireen explained the training was helpful when there was a distance between herself and the death and therefore the bereavement, but that she did “struggle when I’ve been there and that person’s passed away, and then maintaining a relationship with their family members” and questioned how useful the training had been in managing and coping with this “traumatic situation”.

Others reciprocated with their own traumatic and fraught experiences;

“Some of it you are walking into situations that are all up in the air and it’s fine while you’re there and then it’s like, as you walk away, you then have to carry on and do your shift and then no one is like ‘are you ok’” [Elizabeth]

“And before now we have had PSAs where a resident has passed away and they’ve actually been so close, that for months afterwards it affecting them” [Shireen]

“It’s no disrespect but it’s almost as though, ‘okay you haven’t got your nine o’clock call any more so we’ll put you somewhere else,’ but you’re thinking about the nine o’clock call you’ve been doing for the last however long, you know” [Elle]
Similar experiences were reported in other focus groups, however this group (who work in an established village who had experienced 12 resident deaths in 2019), spent a considerable amount of time sharing and examining each other’s experiences. Unanimously, participants advocated for a support group or debriefing session(s) designed first of all to recognise the emotional labour involved in working within ExtraCare, but critically, to better support those who are supporting others.

“I would like to see in the training, a procedure for doing a staff debrief after incidences like that because that’s something ExtraCare don’t do very well” [Elizabeth]

While all participants agreed that additional support for staff would be beneficial, what this would look like in practice was considerably less well defined. Some argued “it [debrief] does need to be a bit formal sometimes to make sure that it done with every, like every time” [Shireen], while others suggested having a structure or procedure that gave them the autonomy to take 10 minutes if they felt like they needed it without having to explain where they’d been which invariably made them feel worse. Elle provided a parallel to her time volunteering for a children’s charity that managed incoming calls from children in distress;

“You had a brief before you went in, so to get rid of what you’ve had for the day, you focus on your calls and you literally have a 15 minute debrief when you finish your shift”

These conversations reflections culminated in the participants asserting that “literally just to sit and have a chat like we have today” [Elle] was helpful. Elizabeth then proposed that they should put together a support group which met “once a month or once every two months (...) and chat about anything” which they all agreed was a
good idea. However, Elizabeth’s colleagues noted that she was their touchstone when experiencing difficulty or conflict:

“I know I would go to Elizabeth [if I needed someone to talk to]” [Elle]

“We all do” [unknown]

“It shouldn’t be that everyone goes to Elizabeth because that’s what happens at the minute (...) we just literally pile on our troubles on top of Elizabeth, but then who does Elizabeth go to?” [Shireen]

Elizabeth did not respond directly about how she feels about, or manages the weight of her colleague’s outpourings. It is safe to say, first and foremost, that the responsibility of sitting with her colleague’s grief and tension blurs ‘professional boundaries’. We are not privy to Elizabeth’s biography so make no claims regarding whether or not she has the sufficient skills and expertise to act in this capacity, however it seems to us that Elizabeth is a lynchpin for her colleague’s wellbeing at work which is a heavy burden to carry. Where staff are reliant on a single member of staff, support would be absent if the member of staff left, was signed-off from work for an extended period, or decided they could no longer support their colleagues in this way.

We recognise that ExtraCare staff members are incredibly motivated to provide the best possible care and support to residents, evidenced by them engaging with the loss and bereavement one-day training session. However, this theme demonstrates that staff are concerned about ‘professional boundaries’ when it comes to grief work (and possibly beyond). They also identified limits to the effectiveness of the training
in helping them to manage family and/or resident bereavement when they witnessed the death. And finally, there was evidence that staff members may require further support to acknowledge and manage their own grief. These are aspects of the broader culture around death and dying that also need to be considered.
Learning and Recommendations

• Our findings suggest that ExtraCare staff welcome the opportunity to open up a dialogue about death, dying, and bereavement both personally and professionally. Specifically, staff appreciated being able to reflect on their current practice and consider ways in which they might better support residents, and each other, after a bereavement.

• The broader conceptualisation of loss (i.e. pre-death bereavements) and the family dynamics exercise were identified as being particularly valued and encouraged staff to reconsider how they respond to, and support bereaved people. Staff reported that this shift in their conceptualisation of bereavement has encouraged them to view residents more holistically.

• However, we have also revealed some challenges experienced by ExtraCare staff, namely around professional boundaries, blurred lines, and limits.

• We recommend that more attention is given to supporting ExtraCare staff manage the emotional labour inherent in grief work. Our evidence suggests that there is some unmet need here which requires further examination, and collaboration between ExtraCare, Cruse Bereavement Care, and ExtraCare staff members.

• Relatedly, while mentioned by relatively few participants we were struck by the unique challenges of performing CPR that is ultimately unsuccessful; being witness to a death; and ‘breaking the news’ to relatives that surfaced in our discussions with staff. These were demanding and traumatic experiences and there was a sense that staff members remained deeply affected by these incidences, and feared reoccurrence. We suggest that exploring if, and how, ExtraCare staff can be better supported following these incidences would be valuable for staff going forward.

• Communication was identified as important by staff members in all four locations. We commend the Bereavement Supporter Project for challenging the status quo regarding what and how language is used to communicate to bereaved persons, and we argue that important and valuable changes have been demonstrated. However, staff are preoccupied with the ‘right’ language, and the ‘right’ way to respond to bereaved people that in some cases may stifle their genuine compassion, and desire to connect with residents. Spending more time examining language and communication within the training may offer an avenue to alleviate some of this tension. Alternatively, ExtraCare staff may value additional resources and/or training that specifically explicates these issues.
This chapter has demonstrated that the bereavement and loss one-day training has equipped staff with skills and knowledge to better support bereaved older people. The emphasis on communication was identified as being particularly important to staff. Many shared examples of how they have altered the ways in which they communicate with residents (e.g. listening more, avoiding platitudes etc.) after the training, allowing them to have more open and resident-led conversations about bereavement.

Conclusion
This chapter has explored staff experiences of attending the bereavement and loss one-day training session in more detail, and in particular has considered the ways in which learning from the training has been applied outside of the ‘classroom’. In addition, this chapter has examined how ExtraCare staff experience loss, grief, and bereavement within the workplace; their strategies for managing this grief work; and an insight into how staff bereavement may be better supported.

Chapter 6: Focus Group with ExtraCare Locksmiths
In addition to conducting four location-specific focus groups with ExtraCare staff from a variety of job roles (see preceding chapter), we conducted an exploratory focus group to examine loss and bereavement within the context of dementia. The management group agreed that it was important to explore dementia-related grief within the context of ExtraCare. We were concerned that if we relied upon dementia-related grief being discussed spontaneously we would run the risk of this important and complex experience being side-lined. Equally, we did not want dementia to overtake the whole conversation; as demonstrated in the previous chapter ExtraCare staff shared invaluable experiences and insights. This additional focus group was
then designed to provide a platform to examine the bereavement within the context of dementia.

As part of the Enriched Opportunities Programme (Brooker, Argyle, Clancy & Scally, 2009) each ExtraCare location has a senior member of staff -the Locksmith- who is employed to work with vulnerable individuals (often people living with dementia) to ensure that residents reach their potential for well-being. We therefore scheduled a focus group to coincide with a Locksmith peer group meeting to enable a dementia-specific discussion. All attending Locksmiths were invited to participate, irrespective of location; whether or not the Bereavement Supporter Project was live in their village/scheme; or whether they had attended any bereavement training. We had modest attendance, with three Locksmiths agreeing to take part. The focus group lasted a little over an hour. There was some thematic overlap between the focus group with Locksmiths and those conducted with the wider staff team (e.g. the training broadening the conceptualisation of loss). So as not to duplicate these findings, we will focus here on the unique, and the dementia-specific themes and discussions that were identified through our analysis of this data.

**Diagnosis**

Immediately, Locksmiths identified with the broad conceptualisation of loss (i.e. pre-death bereavement(s)), and suggested “losing their memories can be a form of bereavement as well” [Lisa]. Debbie argued that for both the person with dementia and their families “it’s bereavement on diagnosis really”, and as the disease progresses many experience “constant losses all the time” [Mary]. All Locksmiths agreed that this can be an incredibly challenging time for residents and their families which is compounded by the stigma and fear surrounding dementia.
In a subsequent theme we will explore the techniques and skills that Locksmiths employ to support people with dementia, and their families, to better understand the condition, and to make sense of and manage their loss(es). Here, we attend to Locksmiths’ appreciation and empathy for how residents affected by dementia may think, feel, and behave after receiving a diagnosis. As Debbie powerfully summarises;

“There’s an awful lot of stigma around dementia and that doesn’t make it easier for the families or the person with dementia because they haven’t got a true knowledge of it and they just look at the person like they’re mad.” [Mary]

They explained that a dementia diagnosis can elicit a multitude of responses and reactions, from denial to despair; stemming in large part from uncertainty and fear.

“They just blank it, it’s not happenin’ to me, it’s not real, because they are scared of it”

[Lisa]

“The amount of people that come to me and still don’t really know what they’ve been diagnosed with” [Debbie]

In summary, within this theme Locksmiths argued that a dementia diagnosis can be experienced as a bereavement by both the person with dementia and their families, and that they may continue to experience loss as the disease progresses. A similar ‘journey of loss’ was identified and explored within our evaluation of the Bereaved by
Dementia Project\textsuperscript{2}. The next theme will draw upon more explicit examples of how memory loss and bereavement may interact and manifest.

**Post-death bereavement(s)**

Throughout the focus group Locksmiths peppered the conversation with a variety of examples illustrating the myriad of interplays between dementia and bereavement. We have selected four to present here.

Firstly, Debbie described a resident whose husband had recently died. This lady was visibly distressed as she “sobbed her heart out”. When Debbie sat down with a cup of tea to talk to her the resident said, “why am I so sad? Why do I feel like this?”

Paraphrasing the resident, Debbie says:

“I am sad, I am devastated, I have loss, I feel it, I feel the pain but the brain has tripped out and it can’t remember why.”

Through this evocative and moving exchange Debbie placed herself (and by extension us) in the position of the resident experiencing grief and loss but not being able to make sense of this pain because the connection to the tangible, recent event (the death of her husband) had been disrupted. Debbie continued, “that’s sad because it robs you of the opportunity to grieve for the loss that you’ve experienced”.

Relatedly, Lisa described a case whereby a lady with dementia found her husband dead in bed, she called on the intercom system repeating “he just won’t talk”. Lisa was called to sit with the resident, Lisa explained;

\footnote{The Bereaved by Dementia Project was a three-year (2016-2019) collaborative project between Cruse Cymru and Alzheimer’s Society Cymru (funded by the Welsh Government) to address the bereavement needs of people with dementia whose loved one/carer has died, and people bereaved by someone with dementia. The project received a one-year extension to its funding.}
The resident in this example is in an incredibly painful situation. She is aware at some level that there are actions and rituals we perform after the death of a loved one, but she does not recognise what these are, and cannot perform them. As in Debbie’s example, there is the suggestion that she has been “robbed of the opportunity to grieve”.

Lisa, another Locksmith, shared the case of a woman with dementia who “had lost a baby that she was desperate for (...) but as her Alzheimer’s kicked in she progressed and that became a closer memory, so it was like she was re-living all the bereavement”. Lisa explained that it was not until this lady’s disease had progressed further that she experienced relief, that is, she no longer remembered that she had had a baby that had died. All of the Locksmiths shared examples where residents had “reverted back” to younger versions of themselves which posed significant challenges to their wellbeing.

“We had a gentleman who suffered with Parkinson’s and Lewy Bodies and his, his memories were of the war not just because they were deeper seated and older memories but because they were very emotive and if he heard a bang, he might’ve been eighty something, but he’d be off that chair and under the table before you could say ‘where’s Albert gone?’” [Debbie]

“This gentleman was about 84 and he’d be talking about his mother in the sense that she’s still, still there” [Mary]
These are examples of some of the unique ways in which bereavement may manifest within the context of dementia. Next, we will explore the strategies, techniques, and challenges employed by Locksmiths to better support people with dementia and their families.

“Welcome to the world of Locksmithing”
While there was the claim that “there’s something that just can’t be trained, it’s intuitive” [Debbie], all of the Locksmiths nevertheless recalled specific skills and techniques that they had applied, and in some cases taught, to better support residents affected by dementia. It was evident that their work was underpinned by a motivation to respect and honour the individuality of anyone who they came into contact with. As Mary succinctly expressed, “you have to pick up on what’s right for the individual”.

In the previous theme we presented the case of a woman with dementia who was deeply distressed but could not remember why (her husband had recently died). Debbie went on to explain that initially she and her colleagues would tell the resident that her husband had died which flooded the resident with pain and anguish as she re-lived her grief.

“I don’t think tellin’ somebody over, and over, and over, and over again and lettin’ them experience that (. that moment that you find out for the first time that is the rawest that is the most intense feelin’”

Debbie acknowledged that “there’s a lot of moral and ethical” challenges and considerations when navigating “truth and lies” and that “lies, deceit of any kind is used at a minimum and with the upmost consideration of possible repercussions”
within a dementia-context. Debbie and Mary revealed a similar approach in this regard, first “you’re validating [their experience] and then you try to steer them to a different activity” [Mary]. Both women provided an example to illustrate a time that this strategy had been effective, however Debbie noted;

“It doesn’t always work (…) I think it’s how you interact as an individual because I could give you a list [of things to do] (…) but if the wrong person is trying then it doesn’t matter, it ain’t gonna happen”.

There is the suggestion in this excerpt that you can all the right tools and tricks but you will ultimately ineffectual because you are the wrong person for the job. Lisa extends this argument by saying;

“Even within Locksmiths it doesn’t always work, you can’t make a connection with every single person (…) sometimes you don’t gel”

This led on to a really interesting discussion of how Locksmiths “support them [other staff members and/or family] to do the job rather than do it directly”. The Locksmiths displayed impressive personal insight and shared instances where they had recognised “I can’t do anything good for this person [so] I need to stand back” [Debbie] and “give them [staff/family] the knowledge and the tools to [support the resident]” [Mary]

Moreover, when asked ‘what does knowledge about bereavement and/or having the Bereavement Supporter service add to the Locksmith role?’ Debbie immediately asserted:
There is the suggestion here that there is an overreliance within ExtraCare villages that Locksmiths will carry the weight of ‘grief work’ within their villages, and for Debbie at least the Bereavement Supporter Project was welcomed as an initiative that would lighten her load. In practice however, a number of the locations within our evaluation are reliant on Locksmiths to manage and support the Bereavement Supporters within their village. This is a further drain on the Locksmith’s personal resource (in terms of time, effort, and emotion labour), as well as being a source of contention for some Bereavement Supporters (which will be discussed in more depth in the subsequent chapter). It is acknowledged that all ExtraCare locations have/will introduce a new appointment -Volunteer Organiser- who will take ownership of the recruitment, training, and retention of volunteers (including Bereavement Supporters) within the village. We will explore the implications of this appointment on how the Bereavement Supporter Project is experienced going forward.

This theme examined skills and strategies used by Locksmiths to support residents who have dementia and who are bereaved. Prioritising, and responding to an individual resident’s needs was of paramount importance in the Locksmiths’ delivery of care and support.
Learning and Recommendations

- The Locksmiths included in this sample connected with the broader conceptualisation of loss (one that includes pre-death bereavement) that is being communicated to ExtraCare staff and residents through the Bereavement Supporter Project. They also recognised that losses are experienced by both the person with dementia and their loved ones/carers.

- Locksmiths recounted their experiences supporting people with dementia with bereavement, and emphasised the importance of responding to an individual’s needs.

- At the time of the focus group the Bereavement Supporter Project was not live in all of the villages or schemes the Locksmiths worked in. However, all welcomed and/or expressed the benefit in opening up the conversation about death, dying, and bereavement, and critically, better supporting bereaved residents within their villages.

National Lottery Community Fund Outcome Measures

This chapter has demonstrated that there are many residents within ExtraCare who are or have been bereaved by dementia.

While ExtraCare Locksmiths demonstrate empathy and are motivated to provide support that meets individual needs there is recognition that their resources are limited. All Locksmiths welcomed or communicated the benefits of having the Bereavement Supporter Project within their village or scheme.

Finally, it is recognised that the Bereavement Supporter Project has undertaken several pieces of work (see below) that aim to address the bereavement needs of people living with dementia within ExtraCare villages and schemes.
Conclusion
Conducting a focus group with Locksmiths provided incredible insight into the complex and nuanced ways in which dementia and bereavement meet. We have explored some strategies and techniques that are currently employed by Locksmiths to alleviate the grief experienced by people with dementia and their families.

While not a focus within this evaluation, it is noted that the Bereavement Supporter Project has undertaken several pieces of work to better support residents living with dementia, and carers of people with dementia. In consultation with resident carers, the Bereavement Supporter Project has developed, designed, and will soon launch, a carers’ guide for residents caring for a partner with dementia. This resource has been designed using resident’s own words and imagery, in collaboration with a local artist and designer. Furthermore, the Bereavement Supporter Project has developed a factsheet ("Responding to distress and behaviours that challenge: Short-term intervention and long-term planning") that outlines two frameworks, VERA (Blackwell, Hawkes, Hingley, & Wood, 2011), and Truth and Lies (Kirtley & Williamson, 2006), designed to support staff respond to residents living with dementia who may experience confusion and distress following bereavement, leading to behaviour described as ‘challenging’ (see Appendix 2).

Chapter 7: Bereavement Supporter Focus Groups
To investigate further Bereavement Supporter’s experience of attending the bereavement and loss one-day training, and more specifically, if and how they had applied any learning from their training to the support they provided, we conducted two focus groups. Additionally, we were motivated to cultivate a dialogue between Bereavement Supporters residing in different locations to identify patterns of convergence and divergence. We also thought that providing the opportunity for
Bereavement Supporters to visit other villages and share their experiences would be enjoyable for them.

The four sites were divided into two groups; a decision informed by, and in collaboration with, members of the management group. The final grouping consisted of Pannel Croft and Longbridge, and New Oscott and Hagley Road. As we were motivated to elicit description of concrete experiences of support provision, only Bereavement Supporters who had been active in their role for at least six months were invited to participate in the focus group. The focus group with Pannel Croft and Longbridge was conducted in May 2018 and consisted of 3 Bereavement Supporters from Pannel Croft and 3 Bereavement Supporters from Longbridge. The focus group with New Oscott and Hagley Road was conducted in November 2018 and consisted of 2 Bereavement Supporters from New Oscott and 4 from Hagley Road.

The themes we report in the subsequent sections were identified by first analysing each focus group transcript individually, and then combining analyses to formulate an over-arching narrative of themes.

“The fabric of my [working] life”
This theme examines the experience of being a Bereavement Supporter in terms of personal, and collective identity. It is informed by Bereavement Supporter discussion about their motivation to become Bereavement Supporter, how support is currently being provided in their village, and for some, how this threatens their sense of self.

The level of experience and expertise among both groups was striking. A number of Bereavement Supporters held professional and/or voluntary roles that either explicitly (e.g. vicar, palliative nurse, or bereavement counsellor) or implicitly (e.g. physiotherapist or family support for those with alcohol or drug addiction) involved
loss, bereavement, and grief. Others were motivated by their own personal experiences of loss.

“Though my working life I listened to people a lot, I worked as a physiotherapist and so I was accustomed to working with people who were bereaved in all sorts of ways” [Lil]

“This [volunteering as Bereavement Supporter] is a continuation of what I used to do volunteering before” [Richard]

“I decided to take part because again my working life as a nurse and a nurse tutor (…) I taught care of the dying and bereavement to a whole variety of people (…) so I felt I’d like to perhaps use some of that knowledge in the village” [Elizabeth]

“I just think I done it so that I know how I felt when I lost my parents that I hadn’t got no one, even though I had a big family. I wanted someone to talk to” [Dawn]

“When my husband died I went to Cruse (…) so for the organisation I knew how it had helped me” [Steph]

The title of this theme came from Meredith who had worked extensively in bereavement and loss in both charity sector and primary care, and she jokingly said “when they told us about it [Bereavement Supporter Project] my heart sank, in a sense of can I truthfully walk away from this”. There was a sense that the Bereavement Supporters were compelled to participate in this project, and confident (quite rightly) that they had “something to contribute”. Furthermore, some suggested
that the project had empowered them to better support their community and utilise skills cultivated through years of lived experience.

“We ourselves are supporting ourselves right and we are using the skill that we’ve got (...) to support one another. We don’t have to depend on the establishment.” [Nancy]

It is clear then that the Bereavement Supporters are highly motivated and skilled to provide bereavement support to their communities. However, as we move forward through this theme, we will argue that Bereavement Supporters’ professional background(s) has (in some cases) established rigid expectations and judgements about what ‘good’, or ‘proper’ bereavement support looks like. Consequently, there is a gap between what they expected bereavement support, and being a Bereavement Supporter, would be like, and what it is actually like.

First, let’s examine a situation, discussed in the focus group with Pannel Croft and Longbridge, as an example of the type of support that is typical for the project as a whole. Prior to this exchange Richard had been explaining that a challenge for him was untangling what is counselling, or bereavement support, and what is general ‘chit chat’ with a neighbour. To illustrate his dilemma he provides an example which we will briefly summarise. Richard and his wife had gone down to their car where they met two other couples who were talking. They said hello and initiated further conversation, and were still there an hour later! One of the woman drew close to Richard and spoke at length, and in detail, about the death of her father which had been quite fraught. He recognised “now she would never be referred because she doesn’t feel like she needs to be referred but she does need support”. He appealed to the group, “is this the sort of thing I should document?”
Overwhelmingly, the answer was yes. Cynthia for example asserted, “the thing is though, through your training etc. you were quite happy to listen to what was probably quite harrowing (Richard agreed) situation whereas other people, I guarantee would ‘ave shut her down in some way”. Here, Cynthia suggested that the training cultivated an openness to talk about the ‘dark stuff’; a strength and confidence to listen and empathise with someone’s pain on a deep level without judgement, and without flinching. This, she argues, is a unique and valuable attribute that permits subtle bereavement work to flourish. Dawn progresses Cynthia’s argument by proposing that the exchange that Richard described could be understood as “testing the waters”; the lady in the carpark had initiated this conversation in a neutral space to gauge Richard’s receptivity, as a result, she may return to him for further support. Richard agreed that if “she sought me out to talk again, then yes, I think that would be an obvious supporting role but the majority of them are as I say, casual [conversations]”. Then, we get to the crux of the problem for Richard, “from my previous role where I had referrals this is totally different and it’s the mist around the boundaries”.

To establish a parallel to the discussions held within the focus groups we opened this theme by illustrating the salience of professional and volunteering expertise and skill as drivers motivating Bereavement Supporters to engage in this project. There is evidently a misalignment between what their professional lives have prepared them to expect, and the reality of their current lived experience. Making sense of, and reconciling to this appears to be easier for some that others. Charles for example argued, “well that isn’t formal counselling but it’s equally important for her development”, similarly Nancy noted, “the fact is, she needed help and that’s the only way she could do it”. There was a sense in this focus group that Richard was,
to some degree, convinced by his peers’ arguments and would continue to reflect upon his experiences. However, a noticeably different atmosphere and discussion was held in the New Oscott and Hagley Road focus group.

During introductions, four of the Bereavement Supporters spontaneously commented about how “not much has developed here” [Marcus], or, “the project hasn’t really taken off very well here” [Steph] which prefaced and shaped the direction that the discussions took. The majority of Bereavement Supporters in this group were incredibly discontent with the paucity of formal referrals, and did not identify informal conversations as bereavement support.

“I feel like I’m wasting my time because I’m not actually doing anything and they say well if you have a casual chat with somebody who has been bereaved but I don’t but I would’ve done that anyway” [Steph]

“I don’t feel I’ve had the opportunity yet to give any help I’ve never had any referrals” [Marcus]

While Meredith offered a counter argument, “I’m wondering actually if the informal is actually more important (…) they’re almost taking the top off the pain and the upset and they get rid of that by chatting to us and then they can go about their daily lives” this was entirely sidestepped by the other Bereavement Supporters who then channelled the discussion into strategies for promoting the visibility of the project in their respective villages (a point we will return to in a subsequent theme). The Bereavement Supporters in these two villages were at an impasse; they could not be persuaded to think differently about the value of informal support, and formal referrals were not forthcoming. This culminated in Marcus stating sadly, “I think, and
to be honest with you, I think that the future is for me from my point of view could be that I withdraw from the project”. This sentiment was echoed by both Lil and Steph, Marcus continued, “I want this thing [being a Bereavement Supporter] to help me and encourage me and give me more opportunities but they’re not coming”. It was saddening to hear that two Bereavement Supporters “felt like a failure” indicative of disappointment not only in the lack of opportunities in formal referrals but also disappointment in themselves, that they have not been able to fulfil their role.

We have observed that informal bereavement support predominates across all ExtraCare locations, which has been unexpected, and in some ways, challenging for all stakeholders involved in this project. This theme has explored what motivated Bereavement Supporters to participate in the role, and the ways in which their professional acumen intersected with how they have made sense of, and in some cases shifted, their understanding of what it means to be a Bereavement Supporter.

“We’ve got to get the logistics right” Within this theme we examine the various ways in which Bereavement Supporters indicated that ‘ExtraCare’, as a setting for this project, was significant to their experience. Speaking about ExtraCare as a backdrop to the project Nancy asserted, “in the environment that we are in, where we are at an old age and we are dropping off like flies sometimes, it’s a fact! (…) it’s good to have support (…) and it’s a privilege if we have the opportunity to actually help and support”. While spoken with humour, Nancy’s comments are incisive. She states explicitly that residents within ExtraCare live, and die, in place; that this can be a challenge; that bereavement support is wanted and valued.
It was evident from both focus groups that negotiating available, and appropriate space to support bereaved people was challenging within the village environment.

“It’s so busy in our [village] it’s difficult to find somewhere where other people aren’t talking or passing by all the time” [Charles]

“I’ve had that happen, they’ve started to talk to me and someone else has come up and talked about something else and then you’ve lost it” [Steph]

Some, like Richard, mitigated this issue by meeting people in their apartments (if this was their preference); “my belief is if someone wants to open up and talk to me and get support from me, I’ll talk to them anywhere, I’ll go anywhere”. Others however did not feel comfortable entering another person’s apartment (as a Bereavement Supporter) for fear of negative repercussions, “I can’t be sure that I can always trust them though and false accusations can easily be made [Charles]. While Charles recognised that within each village there are a number of communal spaces that are sometimes empty “anyone can go in at any time (…) there’s nothing dedicated”.

Given what we know about the informality of the support provision – it is often ad hoc, shrouded as ‘chit chat’, and can be fleeting – it is difficult to justify a dedicated space. Equally it would be challenging to book a room during certain periods given the episodic nature of the support provision.
Additionally, Bereavement Supporters in the Hagley Road and New Oscott focus group made parallels between the perceived the project’s lack of success (i.e. formal referrals) and ExtraCare.

“I’ve said this before so I’ll put my neck out, I don’t know that ExtraCare have embraced the project in the way that you’d hoped they would. They kicked off with a fanfare of trumpets but I think they just let it run now” [Marcus]

“We haven’t had anybody from any of the meetings have we, I’ve met members all sorts of other staff from other villages at meetings but I’ve never seen one of ours” [Steph]

“I think that ExtraCare could clarify the roles of people and I doubt if any of them has got the role of getting behind this project and making it run” [Marcus]

For many of the Bereavement Supporters formal referrals were understood to be ExtraCare staff, and Locksmiths specifically, identifying residents who may benefit from bereavement support and, with permission, refer them to an appropriate/matched Bereavement Supporter. Lack of staff engagement with the project was therefore suggested to be a barrier to stimulating referrals. To our knowledge, relatively few staff referrals have been made across the sites, rather formal referrals (when they do occur) are initiated by the resident themselves (i.e. self-referral). Exploring these avenues for formal referrals with Bereavement Supporters would begin to mend relationships between Bereavement Supporters and staff because there is an implication here that staff are unjustifiably being blamed for the paucity of formal referrals. It is also noted that in both of the villages the ownership of the project lies with the Locksmith, who the Bereavement
Supporters acknowledged “have to do too much”. We note that a new Volunteer Organiser is being appointed with a view to addressing some of these challenges.

Finally, Data Protection and GDPR sparked a lively debate in both focus groups:

“The other thing that I’d like to mention that is limiting sometimes is the emphasis that there is within ExtraCare on Data Protection because you are not told if someone is in need, if someone is grieving for example” [Charles]

“Well that’s the thing, it’s the excuse for doing nothing in lots of cases Data Protection” [Steph]

Echoing previous discussions on this topic, Bereavement Supporters were frustrated that ExtraCare were not able to advise them when a resident was in hospital or had died, and argued passionately that this denied residents with the opportunity to receive support.

“Nobody had communicated with her at all, she hadn’t had a get well card, she hadn’t had a phone call, because nobody knew where she was, nobody was told by the management because of data protection” [Charles]

The Bereavement Supporters advocated for an ‘opt in’ scheme whereby residents could elect to bypass data protection under these circumstances (e.g. hospitalisation) and allow staff to divulge information about their whereabouts. Implementing such a scheme would evidently require high level discussion and sign-off within ExtraCare, and indeed, it may not be feasible. Regardless of the decision we are of the understanding that further conversations about Data Protection and
GDPR will be had during the next peer group meeting which will hopefully ameliorate some of these issues.

In this theme we have attended to the significance of ExtraCare as the site of the Bereavement Supporter Project. We have examined why this project is valuable within ExtraCare, as well as some of the unique structural and logistic challenges identified by Bereavement Supporters.

“I bet they don’t even know it exists”
This theme captures Bereavement Supporters (Hagley Road and New Oscott) discontent about the perceived lack of visibility of the project, and themselves, within their respective villages. Again, this was linked to the dearth of formal referrals.

Steph was particularly incensed about this issue;

“Ours [photos] are as well except they’re in a place where no one will see them!”

“It needs to be more prominent because most people don’t know, if you don’t go to a street meeting because half the people don’t go to a street meeting, I bet they don’t even know it exists”

“I think it was mentioned in the street meeting in the beginning but nothing since, nothing since”
The Bereavement Supporters devised a number of strategies to improve the visibility of the project, and themselves, within their villages which, given their espoused discontent, was surprising as it inferred continued motivation to ‘make things work’. Suggestions included: moving the referral box to a more prominent position; advertising the project, and perhaps introducing themselves, in the Grapevine (resident-run newsletter) or the ‘What’s On’ newsletter; standing up in street meetings (monthly meeting where staff and residents can voice current issues within the village) to introduce themselves.

“We have one [a newsletter] every two months, a publication called the Grapevine, and they have all sorts of things in it (…) so we could actually put an article in there”

[Elizabeth]

“the only other thing there is for one of us to stand up at a street meeting (…) I think when it’s one of us standing up speaking they will listen and take it on board a bit more than if it’s the village manager” [Elizabeth]

We concur that these suggestions are feasible for Bereavement Supporters to implement, and would be effective in both increasing the visibility within the village, and empowering Bereavement Supporters to instigate and drive change. We encourage the staff member in-village responsible for the project, and where appropriate the project manager, to support Bereavement Supporters to act upon some of their own recommendations.
Learning and Recommendations

- The level of experience and expertise of Bereavement Supporters included in this evaluation was striking.
- Bereavement Supporters across all four sites expressed challenges, and in some cases unmet expectations regarding how bereavement support was being delivered in their village.
- While some Bereavement Supporters valued the informal support that they had provided, others found it difficult to reconcile their unmet expectations and/or to untangle what is being a “Bereavement Supporter” and what is being “neighbourly”.
- We support Bereavement Supporters’ request for the ExtraCare staff member(s) who have taken ownership of the project within their village to regularly engage with, and support the Bereavement Supporters. We encourage staff to facilitate, where possible, Bereavement Supporters’ ideas to improve the visibility of the project within their community.
- We also encourage the continued open discussion with Bereavement Supporters about Data Protection and GDPR as our findings suggest this remains a point of contention for some Bereavement Supporters.
Conclusion

As we have seen elsewhere Bereavement Supporters described being highly motivated to help their communities; to use and extend skills, knowledge, and empathy developed during previous (un)paid work; to feel valued and useful; to breakdown some of the stigma around conversations about death. However, this chapter has also comprised of some challenging themes. Primarily, we have seen the cascading effect that a scarcity of formal referrals has had on how some Bereavement Supporters view and value the project, and their role within it. We are somewhat concerned that this discontent could lead to disengagement, and potentially dissolution. Nevertheless, it is promising that newly appointment Volunteer Organisers will have the capacity to take ownership of the project within their respective villages, and we hope that they can facilitate improved cohesion and satisfaction among the group.

Chapter 8: Bereavement Supporter Case Studies

In order to gain an in-depth understanding of what it is like to be a Bereavement Supporter in our four ExtraCare locations we invited all Bereavement Supporters to...
participant in a one-to-one interview. We intended for this interview to explore Bereavement Supporters motivations, experiences of providing support, challenges, and concerns. To date, we have conducted three interviews with Bereavement Supporters from two of our four locations. It is noted that we have received no contact from Bereavement Supporters at the other two locations. However, it remains a priority going forward to capture the experiences of Bereavement Supporters in all four sites.

To do justice to the richness of the data collected during our interviews we will present each of them in turn in the form of a case study. Our approach to these interviews was informed by narrative and biographical approaches, where participants are encouraged to ‘tell their story’.

Lois
In her late eighties, Lois is the oldest Bereavement Supporter we have spoken to as part of the evaluation. She lives in a relatively new ExtraCare village with her husband Bernard. Over the last few years she has experienced a number of significant illnesses, and was hospitalised for several months. Nevertheless she is active and social within her village, including, but not limited to, volunteering as a Bereavement Supporter. Like many of the Bereavement Supporters we have spoken to Lois has lived a rich life of volunteering which she recalled fondly. When asked what motivated her to help others she replied, “it’s the story of my life (...) you know I haven’t got many attributes but people find it easy to talk to me, that’s what I’ve found in life” which, we feel, captures the essence of her character. Unlike the other two Bereavement Supporters we spoke to, Lois spent the majority of her interview narrating the cases of support she had provided as a Bereavement Supporter. To honour this, we present these cases as brief vignettes.
Bertha
Lois has a gift for storytelling, she explained “those who have come [for support] have come in their own way rather than going through a request. I’ve only had five people, would you like to hear about them?” Having effectively drawn us in, Lois proceeded to build up the scene, “the one lady just knocked on the door. Rang my bell one night. It was about seven, can you believe”. Despite her surprise of being interrupted unexpectedly at seven in the evening, Lois empathised with the bewildered woman (Bertha) standing in the hallway and invited her in for a cup of tea. Bertha spent two hours with Lois, relaying her losses and the devastation that she felt. Lois was very respectful of the privacy of the recipients of her support and so fine-detail of their conversation is unavailable. At the end of their conversation Lois accompanied Bertha to her floor asking, “will you be alright now?” Bertha nodded and went into her apartment. This was the only time that Bertha approached Lois for support, however Lois continued, “but I have seen her about and she always comes and gives me a hug and says [thank you]”. Lois initially seemed hesitate to comment on what this late-night conversation might have meant to Bertha, after a slight pause she reflected, “I do believe I really did her good. Oh yeah, I’m sure about it”.

Eleanor
Lois explained her path crossed with Eleanor’s in the reception area of the village, when Eleanor walked passed her soaking wet. They got talking about where she had been, her interests, and social plans for the week. Eleanor had plans to go to the orchestra that coming weekend, and so Lois agreed to join her. The following day Eleanor knocked on Lois’ door, “I’ve just come to thank you for taking us out last, it did me a world of good. Because, I had been wondering what I’m doing here and why my life has turned out the way it has”. Lois then invited her in and explored why
Eleanor felt this way. Eleanor described a multitude of losses: the death of her parents which caused overwhelming anguish; divorce; moving to ExtraCare alone, and from another city; limited opportunities for socialising. Lois encouraged her to “make the most out of life” and said, “if you need a friend, I’ll be your friend if you want to be”. Eleanor has taken Lois up on this offer and the two have met a number of times over the last three months. Lois reflected, “I don’t think I can say [anything] that will make her feel better. The only thing that does make her better is that she can come round. And I do think that makes her feel better so”. Lois asserted that her relationship with Eleanor was likely to be “an ongoing thing” and that she was “glad that she’d found somebody she can talk to”.

Bertie
Lois described a man, Bertie, who would “sit in that main reception, every day, for hours” so one day she approached him and asked “do you go to the library?” He claimed not to know where the library was – which shocked her as it was “only over there”. Bertie accompanied Lois to the library, she asked “do you like reading”, and he said “I used to read all the while but I can’t concentrate now since I lost my wife”. She exclaimed, “he only needed one little thing to get him to come out and say it!” They shared a cup of tea, and Lois felt he was “really utterly depressed” over the death of his wife and estrangement from his son. She explained that living within ExtraCare can compound loneliness, “the trouble is, you’ve got so many ladies and then we’ve got so many couples, so if you fall outside of that and you know, it’s quite difficult if you’re quiet”. Lois tried to encourage Bertie to spend time in the library - a space that is naturally quiet but nevertheless receives a lot of ‘foot traffic’ throughout the day – although it was not clear whether or not he acted upon this.

Demonstrating deep empathy Lois also explained that whenever she came
‘downstairs’ she would look for him and offer to have a cup of tea with him, which she did follow-up on several occasions. Lois automatically recognised both the value and the limits of the support she provides as a Bereavement Supporter, concluding, “I think I probably did get as far it could be with him because he really did tell me all about his wife that day and how he’d lost her and how he missed her and I’m sure he felt better after and I certainly felt that I’d been able to do a little bit for him although I couldn’t do a lot”.

Final words
Lois did not spend a considerable amount of time considering the Bereavement Supporter Project in its wider sense, for example the challenges she has experienced or the implications of the ExtraCare context. She was firm that she “was glad she did it [being a Bereavement Supporter]” despite wishing she “could have done more”. She concluded, “I don’t know how many of us, 20-30 of us in our 80s so there’s going to be people die here and then I think we’ll be glad we’ve got counsellors. I think that time will come”.

Richard
Richard is a white British man in his mid-sixties and has been a Bereavement Supporter in a relatively new village for over a year. Richard lives with his wife, and is not currently receiving care. Richard is active within the village community, and playfully described “being’ here [ExtraCare] as a third working’, a third on holiday, and a third my home life”.

When asked to narrate his experience, Richard immediately drew parallels to previous (volunteer) support work he had done prior to moving to ExtraCare, he explained “it wasn’t a big step into coming into bereavement counselling (…) it seemed natural for me to become, or want to become, a supporter”. Like many of
the Bereavement Supporters across all four locations Richard has a wealth of experience that he wanted to share and cultivate so that he can support others and better understand grief.

“It was an interest to me how the process, how the grieving process however illogical and emotional it carries through.”

However, it quickly became apparent that the delivery (including the way(s) in which it was accessed, the frequency, and duration), and form (including what was ‘delivered’) of the support provided in each of these contexts was markedly different. In his previous support role Richard would meet with clients who had scheduled an appointment, or ‘walked-in’ to a centralised office. Richard would take “everything they were telling me, let them talk to me and again listening and looking to see where I could help to point them towards perhaps a different direction (…) encourage them to look at it in a different way, encourage them to think what they wanted”. This support then could be characterised as: structured; overt help-seeking; a combination of listening and counselling skills and signposting; having clear avenues for ‘recovery’; hopeful. It was clear from the examples of support Richard recounted that he was deeply fulfilled and rewarded personally.

Richard then contrasted his previous support work to his current role as a Bereavement Supporter, which he characterised as being largely informal; conversations, often brief and/or sporadic, that were usually initiated through ‘chit chat’ and then develop to have a bereavement focus. Richard found this challenging, in part, because “it was a little bit fuzzy” and so “you don’t know whether you’ve actually supported that person in a way that you consider am I supporting this
person through Cruse or am I just being’ a neighbour?”. This refrain is incredibly salient, and is repeated numerous times, to Richard’s experience and his sense-making journey as this interview progressed. Given the prominence to his experience, we will examine Richard’s exploration of what the informality of bereavement support means to him in more detail separately. For now, we will keep focus on the differences between Richard’s previous support work and his experience as a Bereavement Supporter.

Early on in the interview Richard asserted his belief that bereavement support was not a “big step” from his previous experience volunteering. It was therefore unexpected (for both Richard and ourselves) when he described “the support basis is subtly different, no, it’s majorly different and I found it difficult at first”. He explained that against the background of his previous volunteering, supporting someone’s grief “it is extremely difficult to say there’s a light at the end of the tunnel because for some people, there isn’t (…) for these people [residents in ExtraCare] the loss part of it, whether it’s a bereavement through a partner, a pet, or even coming from their family to a village it’s almost like final (…) there is no way back”.

The finality of the ‘changed state’ - whether loss is physical, biological, emotional, abstract (and so on), it is gone - inherent to bereavement was a cause of tension for Richard that he “found the leap to jump over difficult”.

As intimated earlier, the informality of the bereavement support being provided in Richard’s village (and across the ExtraCare sites) dominated much of his narrative. Richard explained that these ‘casual conversations’ “happen quite often, two, three times a week easy, quite easy” indicative that the tension lies not with the quantity, but the ‘quality’ of these cases. Richard found it difficult, and indeed he claimed it was impossible, to untangle what is bereavement support and what is “being
"When you go down the formal route you’re asking a person ‘I want support’ ‘I need support’ (…) I think that prohibits people from coming to support in some respects (…) older people are from a generation with a stiff upper lip, we don’t talk about it, and then it’s swept under the carpet."
He went on to argue that older people may be making parallels between the ‘formal route’ and other examples of ‘officialdom’ that they had experienced in their lifetime.

“When you have anything official there was always someone official in front of you, bank manager, council man whatever you would have this and that lives with you (…) when we put a formal thing in front of an older person all of those images come back (…) and it’s almost like the barriers go up”.

We suggest that considering the support from this angle then prompted Richard to consider (or at least verbalise), the value of the informal, or what he called “the soft part”. One could interpret this language as derogatory or diminishing - being ‘soft’ stirs connotations of ‘acting/being soft’ which is typically framed to emasculate or demean – instead we suggest that the informal “the woolly and soft stuff” offers residents insulation to protect themselves as they broach their pain with a neighbour. He explained that during ‘casual conversations’ residents will often use everyday conversations to segue into talking about their grief and loss, or Richard will gauge that they may need more space to discuss what’s on their mind and invite them for a cuppa tea. This allows both parties to establish rapport and build up to the ‘grief work’.

“Bereavement and loss it’s so different, so when you’ve got a formal route it’s very difficult sometimes for that person to talk about what they’ve come to talk about because you’ve got none of that woolly stuff at the beginning.”

During the last segment of the interview we turned our attention to the ExtraCare context generally, and the future of the Bereavement Supporter Project within his
specific village. Richard explained that by moving into retirement villages residents are at-odds with stereotypes, “there’s this idea that we’re all dying, we’ve all had a loss, and we’re all on our last legs before we meet our maker, and I think being in a unique environment requires unique services”. For Richard, Cruse was a link that would “bring it [death and bereavement] more relevant to people’s lives” and while good progress had been observed (by him), more was required. Visibility and prominence were identified as specific areas to improve, although he acknowledged the inherent challenge of “how do you broach a subject that to some people is a no go area?” Ultimately, Richard struggled to think of tangible ways to improve the relevance to people’s lives, but he was confident that Cruse and ExtraCare have got “people there who can come up some wonderful things”.

His final request was to have “some kind of refresher training”, that he enjoyed and valued “getting together with all of the other people who’ve been doing it”, and that receiving affirmation on the way support is being delivered “can give you confidence as you move forward on you know, as you go into the support”.

Nancy
Nancy is a black, single woman in her mid-sixties living within an ExtraCare village with a greater proportion of British Afro-Caribbean and other minority ethnic groups than is observed at other locations. Many residents within this village lived in the local area and moved into the village together, there is therefore a great sense of community cohesion. Nancy placed great importance on volunteering, and listed a raft of volunteer activities that she engaged in, including being a Bereavement Supporter. And for her, volunteering was fundamental to life within ExtraCare, “it’s [ExtraCare] is charitable it’s also that people will volunteer”.
Similar to Richard, Nancy started her narration by voicing concerns about the informal nature of the bereavement service. She explained that she had supported many families (we will come back to this point), but she questioned whether “she has identified me as a Bereavement Supporter, or if she’s identified me as a friend who always talked to her? And that is what I find very difficult”. What counts, and should be counted, as bereavement support is a recurring theme throughout Bereavement Supporter narratives. When asked directly if this was something she found difficult for herself, or whether she found this difficult because she knew it was important for us to evaluate the project, she laughed, relieved, and said “ok right yeah, to identify it and quantify it. I’ll leave it with you then!” We argue then that Nancy places a lot of value in the support she provides to families in pain within her community, but that tension has arisen in needing to identify, record, and quantify support. As we’ve seen, how and when to complete paperwork has been a challenge to Bereavement Supporters across all locations, that being said, Nancy’s village is notoriously ‘paperwork averse’.

Unlike in other villages where bereavement support is given to ExtraCare residents, Nancy explained that a lady she is currently supporting is “the first person, that were wife and husband [and] one of the partners is gone and one will be left in the village (...) I thought about it the other day and there are no other ones”. Instead, Nancy has been instrumental in supporting the families of residents who have died. While describing the support as informal, Nancy is deeply involved, she explained, “it’s about putting yourself out there for them, so if I put myself out, if I feel that I want to go to that person’s funeral, I will go to that person’s funeral. There is a presence”. Nancy was adamant that for her being a Bereavement Supporter was not a role, or a job, her identification lay squarely as a ‘supporter’; she positioned herself as an ally,
advocate, and an advisor. As the excerpt above attests, Nancy was comfortable attending the funeral of residents that she did not have a personal relationship with as an act of solidarity, something she did not do as often before joining the Bereavement Supporter Project.

“Even if we don’t know that person (...) we do it because we’re a family [and] it does help”

Furthermore, Nancy displays great resourcefulness, assertiveness, and an intimate and practical wisdom about her village and its inhabitants which she interweaves into her bereavement support. She described the case of a bereaved resident, Laticia, who frequently called her “to come see me one-on-one”. Nancy was a sounding board to their plans and advised them on other things that they might need to consider to prepare for the funeral – booking a hair appointment, hiring the hall within the village, catering for instance. A striking example was the selection of a suitable photograph to display on reception, alongside details of the funeral arrangements. The family had selected a picture of their loved one from their ‘heyday’ (i.e. when they were young), which Nancy pointed out would be unrecognisable to residents within the village. The ramifications of which would be that many residents would not attend their funeral or service.

“We’ll go to the service to show our respects but if we don’t know him then nobody will go which is a shame because that person had been part of this village.”
While she recognised and shared examples where staff had acted “very professional, very, very bereavement-wise”, Nancy suggested that staff not picking up on the suitability of the photograph was indicative of her wider frustrations that “ExtraCare do not take on board the bits and pieces where cultural needs are different and they need to take that on board”. It was evident from Nancy's narrative that a rift had emerged between her and ExtraCare which had resulted in her spending more of her time engaged in activities and pursuits outside of ExtraCare. She stated, “I still think ExtraCare and the villages is the best thing for people (…) but I think I do less, I do less association in here than before”. Given that Nancy had abandoned several volunteer projects and activities from within the village we asked her whether the way she thinks about the Bereavement Supporter Project had changed she was adamant that it hadn’t changed. Nancy emphasised that being a Bereavement Supporter was a “learning process” that she was privileged to do, she explained “it’s a learning curve for us as well as supporters in the sense it’s not just about giving support, it’s about us receiving some sort of information in a sense from them”. Relatedly, Nancy enjoyed peer group session where a “professional came in and gave us some pointers”, and suggested that she would value further training focused on pre-death bereavement. We would argue that it is equally, if not more important, that this wider conceptualisation of bereavement that includes pre-death bereavement is disseminated more widely within ExtraCare villages. Given the eagerness of Bereavement Supporters to provide more support, pre-death bereavement, and critically pre-death bereavement support, may be an avenue to consider visibly promoting throughout the villages.
Learning and Recommendations

- This chapter has informed our understanding of what it is like to be a Bereavement Supporter, and what the impact of supporting and/or being supported has been.

- Additionally, this chapter has revealed the various contexts that bereavement support has been delivered (e.g. Lois’ example of ongoing support, Richard’s “casual conversations”, and Nancy’s examples supporting families after a resident bereavement).

- While two of the Bereavement Supporters in this chapter identified the informality of bereavement support to be a challenge it is suggested that both value the support they have provided. Furthermore, perhaps some of the tension untangling being a “Bereavement Supporter” from a “neighbour” comes from having to quantify and/or document support as part of the evaluation.

- Bereavement Supporters valued receiving training and support (from both Cruse and other Bereavement Supporters), and requested for refresher training to be provided in the future.
This chapter has demonstrated the reciprocity experienced by Bereavement Supporters – they recognise that through their role they provide valuable support which provides them with “great satisfaction” and/or develop skills that they find personally meaningful, as well as supporting someone in their community who is struggling with their grief.

The examples of support shared by Bereavement Supporters demonstrates their skill to recognise and respond to individual grief experiences.

This chapter also indirectly contributes to our understanding of the positive impact that receiving bereavement support (from a Bereavement Supporter) has had on bereaved residents.

Conclusion
Through these case studies we have captured some wonderful examples of how bereavement support is being delivered within these villages. The Bereavement Supporters are to be commended on their empathy, receptiveness, and communication which has enabled them to connect with members of their community wherever they are in their journey. Yet, classifying and quantifying what ‘counts’ as bereavement support persists as a point of contention for Bereavement Supporters. Of course, this has significant implications on the evaluation and how efficacy is established, but critically, this is a salient challenge for (some) Bereavement Supporters to make sense of, and reconcile with.

Chapter 9: Client (Support Recipients) Case Studies
To date, we are aware of 16 formal referrals from residents who have completed a request form to access bereavement support from a Bereavement Supporter. It was critical to our evaluation to include the voice of residents who had received bereavement support from a Bereavement Supporter within their village. We were
interested to examine the context of their bereavement (e.g. what was the primary trigger? Did this resurface any historical losses? Had other support services been accessed?), as well as the process through which they accessed support, and of course the impact and value of the support they received.

A number of strategies were employed to maximise client recruitment: (1) invitation to participate sent to all clients who had received formal support (and consented to be contacted by the evaluation team); (2) first author attended street meetings in each village to promote the evaluation and contextualise what bereavement support might ‘look like’; (3) posters were put in all villages along with a sign-up sheet held behind reception; (4) additional questions were added to the resident survey to identify residents who had received support, and the opportunity to be contacted by the research team.

Unfortunately, to date, we have only been able to conduct three client case studies from two different villages. There are a small number of residents who have put their name on the sign-up sheet (indicating consent to participate) that we have yet to make direct contact with. It is a priority going forward to endeavour to make contact with these residents. This chapter will be structured as individual case studies for each of the clients that we have interviewed. It is also noted that the Project Manager has piloted feedback cards in three locations, it was intended that Bereavement Supporters carried the cards and gave them to the person that they had supported in the moment. Two feedback cards have been received and
included in the box below. Finally, the Project Manager is also exploring the use of various technologies to capture feedback from support recipients.

“I see a Bereavement Supporter every few weeks. We talk about how I am feeling since my husband died. I get very tearful sometimes and lonely. My friend understands how I feel because her husband died as well. I feel sad and happy at the same time when I talk about my husband. Thanks for letting this lady look after me.” [ExtraCare Resident]

“I feel that the volunteer who visited me was experienced and she understood how to help me. I felt comfortable in confiding in her in view of her experience and the visits confirmed in her being able to deal with depression (which, to me, was more important).”

[ExtraCare Resident]
Mrs Carter

Mrs Carter is a woman in her early sixties who has lived in ExtraCare since the village opened (approximately a year and a half at the time of interview). She explained that she had experienced a catalogue of losses throughout her life, “I’ve had no luck, everything has gone wrong for me you know”, and consequently had experienced mental health issues including depression and suicidal ideation. Mrs Carter approached a Bereavement Supporter in her village after an altercation within the village. To protect Mrs Carter’s identity we will not provide specifics of the incident. The incident was significant for Mrs Carter and resurfaced her lifetime losses and sparked depressive symptoms.

“It overloads me and I can’t cope. So I end up in tears all the time, I don’t wanna do anything, I’ve stopped goin’ over there, I don’t go in there very much now.”

Mrs Carter “couldn’t face” being within the communal spaces within her village and withdrew from the activities and events she had previously enjoyed, “I’m the loser and I’ve stopped doing’ all the things I normally do, I love painting’ I love doing’ ‘knitting’ and nattering’, I’ve been staying away from everything”.

A friend encouraged Mrs Carter to approach a Bereavement Supporter to talk through her grief. She initially voiced concern about whether there was a Bereavement Supporter that she would relate with and trust, she said, “I’m not comfortable talking to somebody who thinks they’re better than me”. However, Maggie (Bereavement Supporter) was identified as someone with whom she could connect, who she described as being “down to earth, like me”. She explained her
ease talking to Maggie about her experiences, and her relief sharing the pain and trauma she had experienced with someone who was empathic and non-judgmental.

“She [Maggie] is one of those that I could sit and talk with for hours and we just talked about everything that’s happened in my life. I did a lot of crying, I always do, it doesn’t matter how much I talk about it still hurts”

She felt strongly that “being able to talk to people helps because the more you talk the less hurtful it is, it’s still there, it won’t ever go away but [it helps]”, and that this was part of her motivated for participating in the interview. Ultimately, there was the suggestion that Mrs Carter was slowly beginning to build up her confidence and make small steps to reconnect with her community and resume activities that had previously brought her happiness.

“I’m starting’ to go back now. My life is now better than it was before in here because she’s [Maggie] understood everything I’ve talked about and she understands what my feelings were.”

Mrs Law
Mrs Law prefaced our interviewing by explaining that she still felt “very raw” about the death of her husband. Nevertheless, she was adamant that she wanted to participate in the evaluation research which we respected. Like many residents within ExtraCare Mr and Mrs Law planned their move, and their future together, with
a mixture of excitement and trepidation, sadly shortly before their scheduled move-in date Mr Law died.

“It’s nice (,) and I wish Nigel was here to see it and that’s what hurts me, that’s what makes me cry as well. It’s terrible painful.”

Although Mr Law had experienced a number of health complications in the past including a heart attack, hip replacements, and dementia, his final diagnosis -cancer- acted quickly and aggressively; “he was in the bed for four days, he only had four days poorly”. After almost sixty years together, Mrs Law moved into ExtraCare alone and has found coping with her grief incredibly challenging.

Mrs Law explained that she contacted a Bereavement Supporter to visit her, “she was helpful and I cried and she was nice, she listened. And she came back a second time when I wanted her back”. Unfortunately, this second conversation was cut short as Mrs Law’s granddaughter had come for a visit and no further contact had taken place, or been arranged. It was useful for Mrs Law to be able to communicate her experiences with someone else as she felt guilty talking about her grief with her children; “the kids don’t wanna keep hearin’ it, they’ve got their own problems”. Mrs Law’s grief was palpable, and although she had loving and supportive family, friendships within the village, and activities and events she engaged with she remained utterly bereft.

“I really am doin’ my best (…) but there’s somthin’ missin’ [quietly] I don’t know what it is, I don’t know what it is.”
Mrs Laverty
Mrs Laverty and her husband, Keith twenty years her senior, had been together 27 years until he died last year. In his later years, Mr Laverty had a number of chronic and progressive conditions which, among other things, severely limited his mobility; Mrs Laverty acted as his carer and advocate throughout.

“I’m his carer. I’ve been his carer for 12 years and adjusting life to suit him, although we were together so it didn’t matter (…) there was no point having carers because they would have interfered with our life (…) we’ve got a routine and it works.”

As a couple, both before and after moving into ExtraCare, Mr and Mrs Laverty were inseparable. They were sole owners (and employees) of an independent business, and so spent the vast majority of their lives right next to each other. When they moved to ExtraCare, Mr Laverty would join his wife as she volunteered in various roles within the village; chatting with other residents and visitors, and keeping each other company. This intimacy cultivated deep bonds, and in many respects an interwoven history. While Mrs Laverty whole-heartedly cherished their relationship, she explained, “when Keith died my life died with him, because for so many years, everything we did together, was to try and be together”.

Like Mrs Law, Mrs Laverty was utterly devastated when her husband died and threw herself into various activities and excursions in an endeavour to occupy herself.

“Last year, the various things I was doing, I was sort of buffeting myself, almost running away from it.”
Feeling that she couldn’t “keep on, and on, and on with, with your friends because it’s old news” Mrs Laverty agreed to meet with a Bereavement Supporter. She met with Rose on one occasion who encouraged her to reach out if she wanted further support, however Mrs Laverty explained, “I just didn’t feel she was the right person to speak to”. When asked if the support was fulfilling in any way Mrs Laverty replied, “not for myself no. Probably for other people yes I think not many people will have had the sort of trauma that I had (...) it’s not a criticism in any way, shape, or form”.

Nevertheless, Mrs Laverty was beginning to reflect on her priorities and values for the future;

“I suppose the more I actually now start to structure my life [sic], whereas all of last year was sort of about me living without Keith. I mean ever since I was 16, I’ve always had someone to look after (...) I’ve always had a man in my life! That was quite difficult because all of a sudden, I’ve got to build a life on my own.”
Learning and Recommendations

- This chapter demonstrated the different triggers for, and the idiosyncratic ways in which we might respond to, grief and loss. All of the support recipients expressed feeling overwhelmed and isolated by their grief, and so support from a Bereavement Supporter was welcomed. In particular having the opportunity to talk about their loss was valued.

- One support recipient emphasised that the Bereavement Supporter she had received on-going support from was a caring and non-judgement person which was critical in establishing a trusting relationship. Furthermore, she explained that the Bereavement Supporter had encouraged her to re-engage in community activities, and that she felt she had “got [her] life back now”.

- However, two of the support recipients did not feel that the support provided by a Bereavement Supporter had had any lasting impact on their wellbeing (although they welcomed speaking to someone in the moment).

National Lottery Community Fund Outcome Measures

This chapter has demonstrated that bereaved residents welcome the opportunity to talk about their grief and losses with a Bereavement Supporter.

Additionally, we have evidenced that receiving Bereavement Supporter from a Bereavement Supporter can have a positive impact on bereaved residents (e.g. feeling heard, less isolated, more engaged etc.).
Conclusion
This chapter has provided some, albeit limited, insight into how bereavement and loss are experienced by residents living within ExtraCare. They demonstrate that a significant event (such as the death of a spouse or interpersonal conflict) can often act as a trigger to grief which can in turn reawaken previous losses. Residents welcome the opportunity to speak to someone about their grief as there is the perception that their friends and loved ones, while supportive, do not want to hear about their continued loss. One resident reported that they connected with the Bereavement Supporter who was open and non-judgemental, and that meaningful change had sprung from their conversations. However, for the other two support recipients they found the experience less fulfilling.

Chapter 10: Focus Group with ExtraCare Residents
In a previous chapter we identified that Bereavement Supporters, in some villages in particular, felt that the project was not visible enough within their village. There had also been much discussion, with Bereavement Supporters but also within our management group meetings, about why residents may not access support (either formally or informally) from a Bereavement Supporter. To address these questions, we sent an open invite to all residents within two of the villages included in the evaluation to attend a focus group to discuss bereavement support services, including but not limited to the Bereavement Supporters, within their village. We had to cancel one of the focus groups as only one resident had signed up, the other focus group went ahead. This focus group consisted of five residents, all of whom had experienced a significant bereavement, most of whom since moving to ExtraCare.
Residents immediately asserted that they had received valuable support from inside their community prior to the Bereavement Support Project being initiated. For some, this stemmed from trusted staff members who generously provided both practical (e.g. advice on wills, power of attorney, funeral arrangements etc.) and listening support. Others welcomed the support of other residents who made it known that they were available to talk. While for others, support was given through their religious group.

“Without the support that I had here, I don’t think I would have been able to cope” [Elsie]

“We have church meetings here, religious meetings here and I think it’s nice because it doesn’t matter what religion you are, you can go to them” [Dora]

“I think people do work together very well here when bereavements and crises take place” [Gerald]

“But the thing is that being the manager, she will know where there might be help so she can – I mean she’s busy enough isn’t she?” [Dora]

With the exception of Gerald, all of the residents had lived in the village for many years, some since it opened eight years ago, and it is suggested they had established meaningful relationships with both staff and residents during this time. Nevertheless, they acknowledged that the village can, at times, be hostile,
particularly for residents who have just moved in. Elsie for example, described a
heart-breaking scene;

“A lady came past reception and I was going the other way and I noticed she’d got tears
and I said ‘what’s the matter? Can I help? And she said ‘I’ve just been to the coffee room
and there were some ladies sitting at a table and there was an extra chair so I asked if I
could sit down. And they said no.”

Elsie was saddened by this behaviour and invited the lady to join her in the coffee
bar any time. Others agreed that being personable is an important attribute within
the village, because one incident, like the one described above, could lead to that
person never coming down to the village centre again.

Overall, the group agreed that having the Bereavement Supporter Project was a
good idea, and that some residents, although not themselves, might access it. Elsie
was particularly vocal about not wanting to receive bereavement support from a
Bereavement Supporter;

“I mean we’re residents but there are things that you want to talk about that you wouldn’t
want to talk to a resident about? (…) It’d be in the back of your mind. I wonder what they
think of me and things like that. It isn’t a nice thing I don’t think.”

Elsie’s primary concern, which was echoed by several participants, was that she
would be uncomfortable with another resident knowing so much about them, and
would fear them sharing this information with other people. A level of professional
distance was valued. Dora put it more mildly, “I think it’s useful to have the
bereavement group but it won’t suit everybody”.

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However, Gerald frequently challenged the group narrative, and Elsie in particular. Specifically, he challenged the idea that ExtraCare staff and/or other professionals are de facto the most appropriate and valuable sources of support for residents, and that Bereavement Supporters would not uphold ‘professional values’ (i.e. anonymity). Instead, he argued that Bereavement Supporters are likely to possess a wealth, and diverse, skills and characteristics that would enable them to provide effective and meaningful support to their peers.

“The other residents might have other skills (…) I think if you are bereaved then you need (,) you need to talk. Maybe you’re not thinking much about what you’re talking about but if you are supported by someone that will be on sort of wavelength with you, it does provide immense support and comfort and friendship” [Gerald]

“I’ve heard them say they’ve had had support so hopefully with a dedicated service it will improve beyond that but I think to get the true picture of it, you might have to wait a while to evaluate it” [Gerald]

Finally, we asked residents about their views about talking about death, dying, and bereavement more widely within their village. Again, Dora provided a really interesting anecdote;

“We had somebody coming from the John Taylor hospice to talk to us and some people were offended by it, by the thought of discussing death [and] it wasn’t allowed to go ahead and I thought, but I wanted to hear about that. Why couldn’t the people who didn’t want to hear about just not come to the meeting? So it was all pushed under the carpet and I thought that was a bit.”
Gerald also argued that he would value more discussion about death, dying, and bereavement;

“If you had such a discussion relating to issues around death that could come as part of a series of things there were happening about older people but later life maybe, not end of life but later life and look at different things you can plan for the future”

While perhaps not surprising, given that they had voluntarily agreed to participate in a focus group about bereavement services, these residents demonstrated an openness, and indeed an eagerness, to have more conversations about death, dying, and bereavement. While they recognised that for some this may not be comfortable they argued that they should not be denied opportunities because of a minority. They suggested an approach similar to other activities and events that take place within the village should be applied, “take it or leave it”.
In summary, this chapter has explored what bereavement support services have been accessed and valued by ExtraCare residents. We have demonstrated that bereavement support from ExtraCare staff and other professional persons was the most highly valued overall, along with other residents and religious groups. The majority of residents personally would not request support from Bereavement Supporters driven largely due to concerns about privacy. However, residents welcomed continued, and more open discussions about death, dying, and bereavement within their village.
Overall Learning

- Our evaluation has demonstrated that many ExtraCare staff and residents value the Bereavement Supporter Project in their village.

- The bereavement and loss awareness one-day training has been well attended and well received. In particular, attendees enjoyed: the inclusion of visuals, activities, and discussion to communicate the core messages; developing communication (and listening) skills; learning about the different ways in which people may grieve; applying what they have learned in practice.

- The broader conceptualisation of bereavement (i.e. to include pre-death bereavement experiences) introduced during the bereavement and loss awareness one-day training resonated with both staff and Bereavement Supporters. Many reported that this has allowed them to view bereaved people more holistically in both professional and personal contexts.

- Bereavement Supporters are highly motivated and possess impressive experience and expertise.

- There have been 16 formal referrals (residents self-referring themselves to a Bereavement Supporter). However, Bereavement Supporters provide many examples of informal support (ad hoc conversations; accessing support directly from a Bereavement Supporter). To date, 129 informal contacts have been recorded by Bereavement Supporters across the four evaluation sites.

- Many Bereavement Supporters have argued that the informal support may be more valuable than formal support because it empowers the bereaved person to access support that is meaningful to them, as and when they need it. This very much corresponds to the logic underpinning the public health approach to bereavement support and meets what the literature identifies as an unmet need among older people in particular to talk through their bereavement and grief in a non-professional, supportive, community environment.
• However, the informality of support delivery has been a considerable challenge for some Bereavement Supporters, many of whom have struggled to see the value in support of this kind. Previous research has also found that older adults have a narrow view of volunteering roles (e.g. helping in a charity shop) and so do not recognise what they do as volunteering (National Council for Voluntary Organisations, 2018). It will be interesting to see if Bereavement Supporter’s report any changes in how they perceive and/or value informal support as the project evolves within their respective villages.

• Accurately capturing the number of people who have received bereavement support from a Bereavement Supporter has been a significant challenge for the evaluation (and the project more broadly). We know that Bereavement Supporters do not always record the support they have provided for a number of different reasons (e.g. they do not want to fill in paperwork, concerns of confidentiality, uncertainty of whether a conversation was bereavement support or being neighbourly etc.). Consequently, as one Bereavement Supporter explained; “you’re not seeing, in my opinion, the true value because those conversations are not being recorded and probably never will be recorded”.

• Likewise, capturing the experiences of people who have received bereavement support from a Bereavement Supporter has been challenging. While we have contacted all residents who have received formal support (and consented to be contacted), and employed a number of strategies to recruit residents who may have had informal support we were able to recruit only three case studies. An internal audit within Cruse Bereavement Care revealed that less than 20% of client feedback forms are returned across the organisation indicative of a wider challenge capturing client experience. Having a flexible, and multifaceted approach to data collection is therefore critical.

• Finally, we recommend that more attention is given to supporting ExtraCare staff manage the emotional labour inherent in grief work. Our evidence suggests that there is a significant unmet need here which requires further examination, and collaboration between ExtraCare, Cruse Bereavement Care, and ExtraCare staff members.
Next Steps?
The data collected thus far and reported here represents a promising start, and we look forward to initiating the next steps for data collection. Currently, we are scheduling follow-up focus groups with staff, Bereavement Supporters, and ExtraCare residents. Recruitment for client, and Bereavement Supporter case studies is on-going. The final evaluation report is due by September 2021.
References


Independent Age (2018). *Good Grief. Older People’s Experiences of Partner Bereavement.* Independent Age/ILC.


Appendix 1: Bereavement Supporter Role Description

Volunteer title: Bereavement Supporter

Reporting to:

Hours: Flexible

Location:

The ExtraCare Charitable Trust enables older people to enjoy a healthier, active and more independent lifestyle in a network of inspirational communities that represent a modern alternative to the traditional care or nursing home.

Provide brief information about the scheme/village

Purpose of the role:

To support residents and Friends of the Village with their grief and loss.

Main tasks:

- Listening to and supporting bereaved residents and Friends of the Village on a one to one basis
- Answering queries, providing information and signposting to Cruse services where appropriate
- Supporting individuals who may be experiencing feelings of grief that are not directly linked to the death of someone
- Supporting other events relating to the Bereavement Supporter project
- Completing paperwork to record the support provided

Attributes/Competencies:

- Awareness of the importance of confidentiality
- Trustworthy, honest, reliable and flexible
- A good listener with a friendly and welcoming personality
- Caring approach to bereaved people
• An ability to communicate with a variety of people
• Ability to work as part of a team and under own initiative
• Are empathetic and non-judgmental
• An awareness of own limitations and that of the service and an ability to work within those boundaries
• Interest in bereavement services for residents, including those living with dementia, and their carers

This role does not include the following tasks:

• Personal care tasks
• Administering of medication
• Advice or support in relation to a person’s financial affairs
• No transferring (manual handling) of residents

Requirements:

Completion of a DBS check (including barring list)
2 references may be required

We suggest the role may not be suitable if you have experienced a major bereavement within the preceding two years - although this can be reviewed on an individual basis

Training and benefits:

• Attending Bereavement Supporter one day training
• Acquiring experience supporting people
• Ongoing direction and support provided

Contact:

If you are interested in applying for this opportunity or would like further information please contact:

Name: ???
Address: ???

Contact Number: ???, Email Address: ???
Appendix 2: Responding to Distress and Behaviours That Challenge Factsheet
Responding to distress and behaviours that challenge:

Short-term intervention and long-term planning

This guidance has been produced to support staff respond to residents living with dementia, long-term and short-term mental health conditions, and residents who may experience confusion and distress leading to behaviour described as ‘challenging’.

The term ‘challenging behaviour’ has been replaced in this guidance with the term ‘distress response’. Distress can occur as a result of a person being challenged in some way, often indirectly, resulting in distressed behaviour. A person-centred approach requires us to understand the individuals needs:

A distress response is communication of an unmet need.

Two frameworks are described in this guidance to assist you to support residents.

1. VERA framework (page 1)
   A framework to use ‘in the moment’ when you are supporting a distressed resident with no time to plan.

2. Truth & Lies framework (page 2)
   A framework to use for long-term planning when a resident regularly experiences distress and a consistent approach needs to be agreed on to support them.

Physical Health
In addition to cognitive or psychological issues, distress may be brought on by factors such as pain or infection. If this is a possibility these must be checked as the interventions described in this guidance alone may not alleviate distress.
VERA framework

VERA is a stage by stage process of communication that guides you to providing a compassionate and caring response. VERA was developed by nursing students to improve how they supported someone who was distressed and confused.

The four stages below make up the VERA framework.

<table>
<thead>
<tr>
<th>Validate</th>
<th>Emotion</th>
<th>Reassure</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accept the person’s reality, avoid correcting the person or not listening to their concerns even if you believe them not to be true.</td>
<td>Acknowledge the emotion, what feeling is driving the person’s behaviour? Are they anxious, scared, what do they need?</td>
<td>That you are here to help, by listening to the person and trying to meet their need... if they feel scared help them to feel safe.</td>
<td>Use meaningful distraction, what can be done in the moment to take the person's mind off their concern?</td>
</tr>
</tbody>
</table>

Example: When you visit Lyssa at home in her apartment, Lyssa appears confused and has tried to start making lunch for two people. Lyssa is concerned that someone normally helps her, and says her husband, James, left home this morning and has not come back to help. You know that when Lyssa's son visits he comes in the morning and Lyssa's husband died several weeks ago.

Possible responses:

<table>
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<tr>
<th>Validate</th>
<th>Emotion</th>
<th>Reassure</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>“You sound worried, have you been on your own for long today?”</td>
<td>“I would feel worried too if I thought I was going to lose my job”</td>
<td>“You are safe here Lyssa”</td>
<td>“We have some work to do here Lyssa, can you help me prepare lunch?”</td>
</tr>
</tbody>
</table>

The success or failure of this approach is recorded and discussed with others involved in the planning of Lyssa’s care and support.

Example: When you visit Derek at home in his apartment, he is moving furniture around. When you ask him what is wrong he tells you that he is ‘late again for work’ and fears that he is ‘going to be fired’.

Possible responses:

<table>
<thead>
<tr>
<th>Validate</th>
<th>Emotion</th>
<th>Reassure</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>“You sound really worried Derek, can you tell me about your work?”</td>
<td>“I would feel worried too if I thought I was going to lose my job”</td>
<td>“You are safe here Derek”</td>
<td>“We have some work to do here Derek. Can you help me with this furniture?”</td>
</tr>
</tbody>
</table>

This addresses what Derek is seeing as the problem. Derek’s problem has been accepted and not questioned and he is encouraged to say more. This connects you to an empathic understanding of the worry that Derek has. This simple statement of fact communicates the intention that no harm, real or imagined, will come to Derek. This activity fits with Derek’s preoccupation with work, and incorporates his behaviour rather than invalidates it.
# Truth & Lies framework

This framework was developed as part of a Mental Health Foundation inquiry into the use of truth-telling and untruths in dementia care. The framework can be used to plan a long-term strategy for supporting residents whose understanding of reality fluctuates and creates potential for distress responses.

![Truth & Lies framework diagram]

**Example:**
Lyssa is walking around the village street near her apartment and is distressed and confused. When you ask Lyssa what is wrong she tells you that her husband James is 'not here, he's gone missing' and is worried that when she woke up he was not in their apartment. This is a regular occurrence, James died several weeks ago and Lyssa's understanding of this loss is not always clear.

**Possible responses:**

<table>
<thead>
<tr>
<th>Truth-telling creates happiness or necessary negative emotions</th>
<th>Truth-telling causes unnecessary distress</th>
<th>Untruths create happiness</th>
<th>Untruths cause unnecessary distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Lyssa, a few weeks ago James was very ill, you were with him during a stay in hospital where he died”</td>
<td>“Lyssa, a few weeks ago James was very ill, you were with him during a stay in hospital where he died”</td>
<td>“I can't find James now, I see you're very worried but I'm here. Let's get you home and comfortable, perhaps on the way you can tell me about James”</td>
<td>“Lyssa, James has probably gone out, he's always busy isn't he, I'm sure he is fine”</td>
</tr>
</tbody>
</table>

If Lyssa is able to recall the loss of James, although the news may upset her it allows her to go through a grieving process.

People living with dementia can grieve and have an emotional response to a loss. Even if the person is unable to recall the facts surrounding the loss.

If Lyssa is unable to recall the loss of James, truth-telling will continually cause distress and harm Lyssa's long-term well-being.

**Successes and failures are recorded and discussed with others involved in the planning of Lyssa's care and support. Consistency is key to the use of this framework, ill-being may be caused if Lyssa is given inconsistent responses. An approach must be agreed upon and used by everyone.**

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Cruse Bereavement Care ‘Bereavement, Loss and Dementia’ - [www.cruse.org.uk/bereavement-and-dementia](http://www.cruse.org.uk/bereavement-and-dementia)