

# The Bereavement Supporter Project

## Evaluation report

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# 1. Introduction and Background

Older people are the most likely group in society to experience bereavement, yet are the least likely to seek support or to be referred for bereavement support.<sup>i</sup> The Cruse-ExtraCare Bereavement Supporter Project was developed to tackle this gap in support for older adults.

Funded by The National Lottery Community Fund and commenced in 2017, the Bereavement Supporter Project is a five-year partnership between **Cruse Bereavement Support** (henceforth, Cruse) and **The ExtraCare Charitable Trust** (henceforth, ExtraCare) to develop the capacities of volunteer Bereavement Supporters to support bereaved residents in retirement villages.

Cruse worked in collaboration with ExtraCare to develop a Bereavement Supporter service. Cruse is the national leading charity for bereaved people. Their position is that grief can be overwhelming and devastating and that they are there to support people after the death of someone close.<sup>i</sup> ExtraCare's vision is to provide better lives for older people by providing sustainable communities of homes older people want, lifestyles they can enjoy, and care if it is needed.<sup>ii</sup>

Communities of any kind experience death and bereavement, and the literature suggest that fear of death actually declines with age, but in communities with older adults, the presence of death and bereavement is more keenly felt. Nevertheless, supporting people in death and bereavement has not featured strongly in ExtraCare's vision, perhaps not surprisingly. Death is often perceived as something to be avoided or postponed, even in later life. Working with Cruse offered ExtraCare an opportunity to be proactive about the support provided to residents affected by bereavement. Furthermore, the Project's ethos acknowledges other kinds of loss, e.g. the loss of the family home, furniture or artefacts of sentimental value, neighbourhoods, as well as experiences of loss related to physical health or cognitive function as the kinds of losses that might lead to experiences of grief. This wider understanding of loss and grief helps bring into focus the vulnerabilities that coexist with the opportunities for social engagement, support and care afforded in ExtraCare retirement villages.



i <https://www.cruse.org.uk/>

ii <https://www.ExtraCare.org.uk/about-the-charity/the-trust-overview/>

## 2. The Evaluation Final Report

This document reports the final results of the evaluation carried out by independent researchers from the University of Bristol and Aston University. The Evaluation aimed to determine whether the Bereavement Supporter Project achieved its objectives. The objectives were to:

- Provide information and increase awareness about how grief may be experienced and support services that are available.
- Recruit, train, and deploy ExtraCare residents to be Bereavement Supporter Volunteers (RBSVs) who will act as first contact listening support to bereaved people in their communities.
- Improve signposting and access to specialist bereavement and mental health support services.

The project objectives were set in order to achieve the outcomes agreed with the funding body, The National Lottery Community Fund. The outcome indicators were:

1. Older people are more active, more engaged, more independent, less isolated and better supported after bereavement.
2. Older people are able to live fuller, healthier lives with increased opportunities to volunteer and support each other.
3. Older bereaved people with dementia and their carers have increased access to appropriate bereavement support.
4. Increased awareness of impact of bereavement on older people's mental and physical health.

Throughout the Final Evaluation Report, we will use the data gathered to determine as far as possible whether those outcome indicators have been met and to consider the future sustainability of the project.

A rich and varied dataset was established involving stakeholders including Project Managers from Cruse and ExtraCare, Bereavement Supporter volunteers, residents, ExtraCare staff, and residents who had received support. We are enormously grateful to all who participated and gave generously of their time. Throughout we have tried to illustrate key messages through direct quotations from our participants. Although you will hear their voices, we have taken care not to reveal their identities, which means that sometimes we have had to subtly change some of the details.



## 3. Setting

### 3.1 The ExtraCare Charitable Trust (ExtraCare)

The Bereavement Supporter project complements ExtraCare's end of life strategy, underpinned by the Gold Standards Framework for End of Life Care<sup>iii</sup>, which seeks to provide better supportive care, in all settings, enabling older people to live well until they die. Part of this is about enabling people to die in their place of choice (often their own homes) and to encourage advanced care planning so that decisions are made ahead of time to make things easier when death becomes imminent. The Bereavement Supporter project was developed in this context not only as an important aspect of end of life care, but also an avenue for opening up conversations between residents, staff and family members about residents' end of life wishes and preparations.

The Bereavement Supporter Project draws on a three-tiered model of bereavement support (see Figure 1), which aims to develop awareness of the needs of bereaved people and to provide information about bereavement and avenues for support across 21 ExtraCare's villages and schemes, and the 4330 residents who live there. It aimed to create a volunteer resident Bereavement Supporter role which would facilitate peer-led bereavement support for its residents. Finally, if required, it would refer to specialist support. The Bereavement Supporter project in partnership with Cruse was developed to deliver this model of bereavement support.

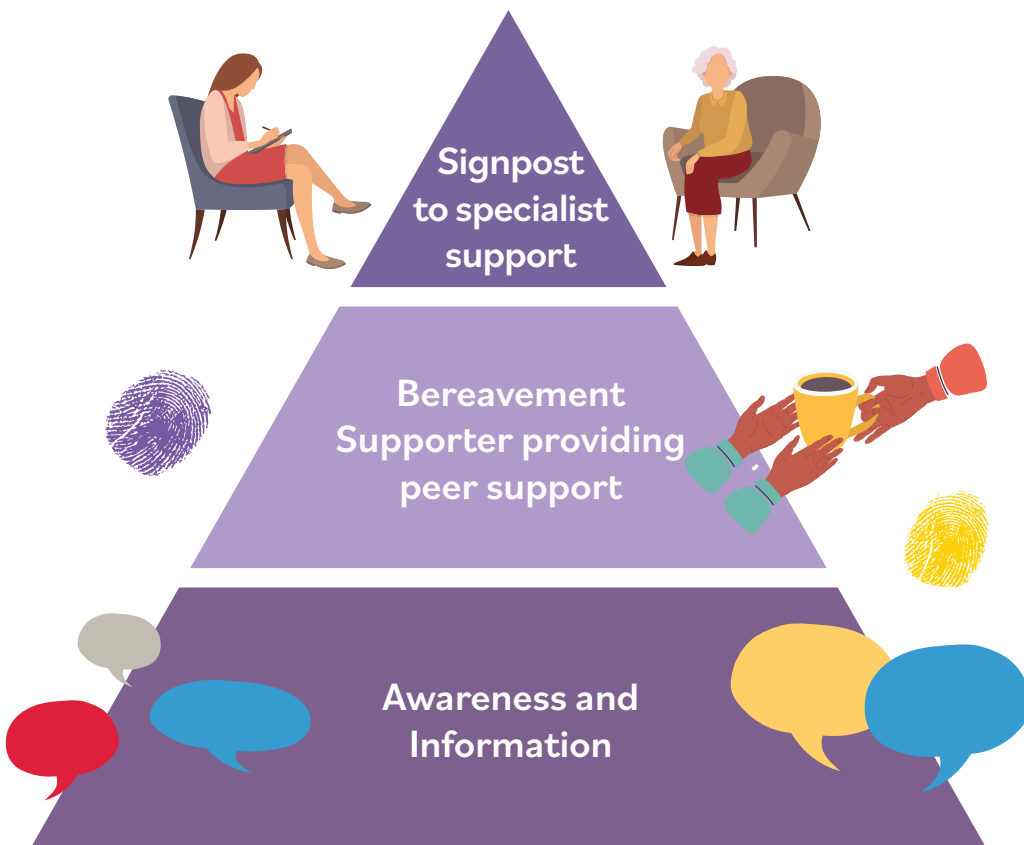


Figure 1. The three-tiered approach to improving bereavement support within ExtraCare villages.

iii <https://www.goldstandardsframework.org.uk/>

### 3.2 Volunteering

Volunteering is an integral feature of ExtraCare village life. Resident volunteers occupy a variety of different roles, e.g. staffing reception, working in the shop, restaurant, gymnasium and gardens, buddying and befriending other residents. The Bereavement Supporter role was added to this variety of volunteer roles and, arguably, is the most challenging to date. The role was specified as part of the Cruse-ExtraCare Bereavement Supporter project and training was provided. The original intention was that Bereavement Supporter Volunteers (henceforth referred to as RBSVs) would be supported by the Volunteer Organiser in each village, and that the RBSVs could draw on the Wellbeing Advisors and Dementia and Mental Wellbeing Enablers (staff members who support vulnerable individuals, often people living with dementia, to ensure that residents reach their potential for well-being). In practice, the Project was organised somewhat differently, as we will discuss.



## 4. The Bereavement Supporter Project

The Project ran over a five-year period (2017-2021) with the evaluation embedded within the Project from the outset. This meant the project management could respond to preliminary findings, and especially findings presented in the interim report while the Project was in progress. This meant that iterations of the project design were made during the course of the first four years of the project, with the result that a new community model of peer support has been developed and is now under trial.

### 4.1 Project design

The ethos of the Project is that anyone who has been bereaved or who has experienced bereavement can volunteer to be a RBSV. RBSVs are described as good neighbours but with additional insight from formal training that gives them the confidence to talk about death, dying and bereavement and have the capacity to listen and to 'sit with it'. Informing staff and residents about death, dying and bereavement and giving people the skills to listen and talk about it comfortably and confidently was a core element of the project. These listening and talking skills we will refer to as 'grief literacy'.<sup>3</sup>

### 4.2 Loss and Bereavement Awareness Training

A 1-day training course was delivered by Cruse to ExtraCare staff across a range of roles (e.g. care staff, sales, reception, and housing) and to residents who volunteered to become a RBSV. At the time of writing this report, 392 members of staff across ExtraCare villages, schemes and head office, and 49 RBSVs across 8 villages had attended the training (See Appendix 4). The objectives of the training were:

- To outline the impact of grief on emotions, body and mind.
- To develop skills to support someone who has had a bereavement.
- To improve awareness of bereavement support services and information and advice available.

The training was adapted to fit the needs of older people and the range of losses 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). The training introduces theories of grief and worked examples, discussion, visual aids and role-play to support learning and practical application of the material covered.

### 4.3 Informal Loss and Bereavement Information Sessions

Informal opportunities to raise awareness of loss and bereavement were also held across the villages and schemes involved. These included bereavement and loss open dialogue sessions for residents and staff to encourage talk about death, dying and bereavement. Sessions provided introductory information on aspects of loss, grief, and bereavement pertinent to the ageing population. Arts-based sessions offered opportunities to explore loss, grief, and bereavement creatively in covert as well as overt ways. Informal sessions were delivered by the Project Leads from Cruse and ExtraCare, which allowed for one-to-one attention to be provided as required. At the time of writing this report, across ExtraCare villages and schemes 218 ExtraCare staff members, 351 residents and 19 people from the wider village community had attended bereavement and loss information sessions (See Appendix 4).



Feedback on those sessions indicate a high level of satisfaction with the sessions and that, among staff in particular, these had enhanced knowledge of the services available to people who are bereaved and a greater understanding of the impact of grief on emotions, body and mind.

#### **4.4 Bereavement Supporter Volunteers (RBSVs)**

Volunteers were recruited through participating ExtraCare villages and received the Cruse 1-day training course. A week after the training, Eve Wilson, the Cruse Project Manager in ExtraCare, met with volunteers and the village Volunteer Organiser to complete the volunteer briefing and to outline expectations around delivering support to residents and logging this support. The model is that Volunteer Organisers will then monitor the volunteer logs and meet with volunteers monthly. There is a volunteer role description and recruitment process for the role. Also, the Cruse Project Manager and Volunteer Organisers assessed volunteers' suitability to the role and followed safeguarding procedures where necessary.

#### **4.5 Evaluation sites**

The RBSV model was rolled out to eight ExtraCare villages. Although the original model has been adapted to a more general 'Community Model' in which any resident can undertake 2.5-hour training on bereavement and loss awareness, which has been rolled out to an additional four villages to date. The evaluation focused only on four ExtraCare villages in Birmingham. These are:

- Hagley Road Village
- Longbridge Village
- New Oscott Village
- Pannel Croft Village

These villages offered a range of sites and demographics within Birmingham including low-income inner-city areas, middle- and higher-income suburban areas, communities with predominantly White residents, and one community with predominantly Black and Minority Ethnic residents. The villages ranged in age, including a well-established village (Pannel Croft) built a decade ago and one (Longbridge) opened just three years ago. Our insights in this final report are drawn from across all four villages. All villages have elements of good practice, but it is also evident that the project has worked better in some villages than others. However, in order to retain our commitment to the confidentiality of our participants, we will not comment on individual villages.

## 4.6 Conceptual Framework of the Bereavement Supporter Project

The conceptual underpinning of the Project is that bereavement is a universal experience and thus is something a community should be mobilised to deal with itself, and not confined to medical practice. Accordingly, the Bereavement Supporter project was designed to help a community to become more compassionate in how it manages bereavement and end of life care in line with public health and compassionate communities approaches to end of life care and bereavement support.<sup>4</sup>

This conceptual framework draws on the three-tiered approach illustrated in Figure 1 which prompts bereavement support according to need: all will need support in the form of information and awareness about bereavement (level 1); some will require peer support outside of their usual social network (level 2); and others will require specialist and/or therapeutic support (level 3)<sup>iv</sup>. These levels of support transport nicely into the National Bereavement Alliance Guide to Commissioning Bereavement Services in England, depicted in Figure 2.<sup>v</sup> The Bereavement Supporter project targeted components 1: universal information and support; and 2: selected or targeted non-specialist support.

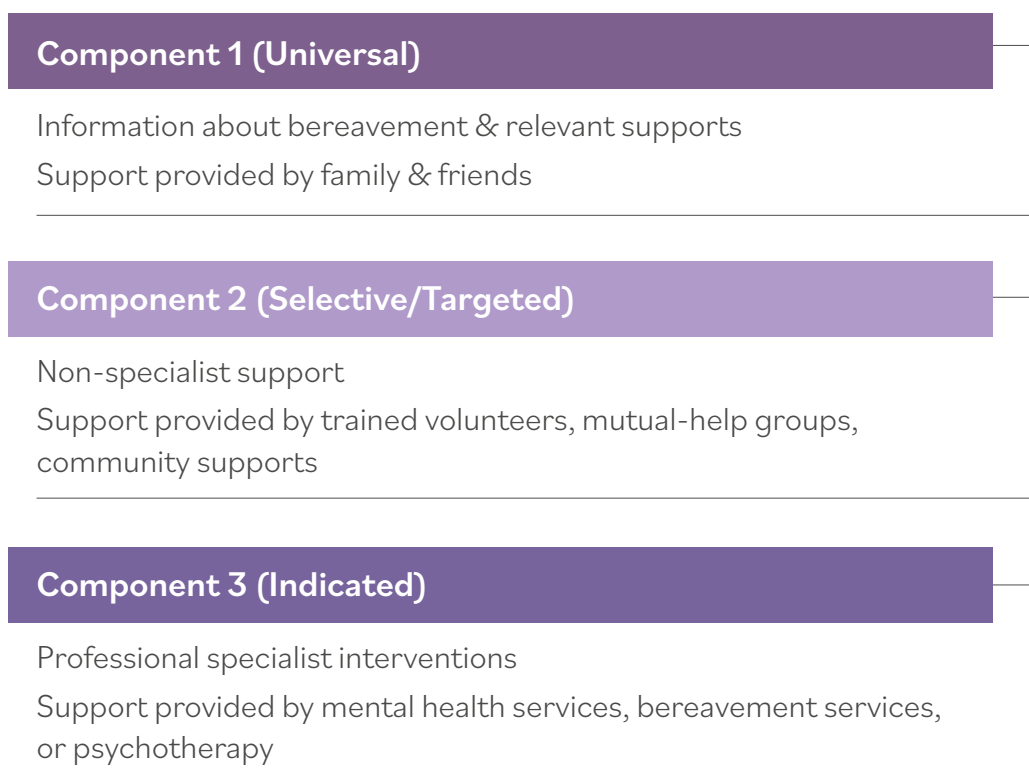


Figure 2. Levels of bereavement Support produced by the National Bereavement Alliance (Penny and Relf, 2017).

This approach also aligns with the Adult Bereavement Care Pyramid developed by The Irish Hospice Foundation (2020), with the Bereavement Supporter project delivering in levels 1 and 2, whilst acknowledging factors which impact a person's experience of bereavement, the bereaved person's social network, the circumstances surrounding the loss, and the length of time since the bereavement or how the grief experience has changed over time.

iv This model has been developed in more depth by the national bereavement strategy group in the Irish Hospice Foundation: <https://hospicefoundation.ie/our-supports-services/bereavement-loss-hub/i-work-in-bereavement/adult-bereavement-care-pyramid/>

v <https://nationalbereavementalliance.org.uk/wp-content/uploads/2017/07/A-Guide-to-Commissioning-Bereavement-Services-in-England-WEB.pdf>

## 5. The Evaluation

The Evaluation of the Bereavement Supporter Project was embedded within the larger project from the outset. Aston University responded to a call for tender and won the bid to carry out the evaluation independently, although Karen West (Evaluation Principal Investigator) subsequently moved to the University of Bristol. Although conducted by an independent research team, the Evaluation team worked in close collaboration with the Cruse and ExtraCare project leads, holding regular joint meetings.

### 5.1 Evaluation objectives

The Evaluation was set up to monitor the delivery of the project and to examine whether and how it met its own objectives and the National Lottery outcome indicators (see Appendix 4) and to consider the longer-term sustainability of the project. The remit of the Evaluation therefore was to examine:

- How the service was organised and delivered.
- The quality of training and information delivered.
- Outcomes for individuals (e.g. resident Bereavement Supporter Volunteers, staff, and residents who have received support).
- Wider impacts, particularly in terms of how the project has facilitated conversations about death, dying and bereavement and developed general grief literacy among staff and residents in the villages.

In this final report, we focus on four aspects: 1) service organisation and delivery; 2) training quality and information provision; 3) outcomes for individuals; and 4) wider impacts.

### 5.2 Methods

The Evaluation achieved this by gathering data from stakeholders involved in the Bereavement Supporter Project.

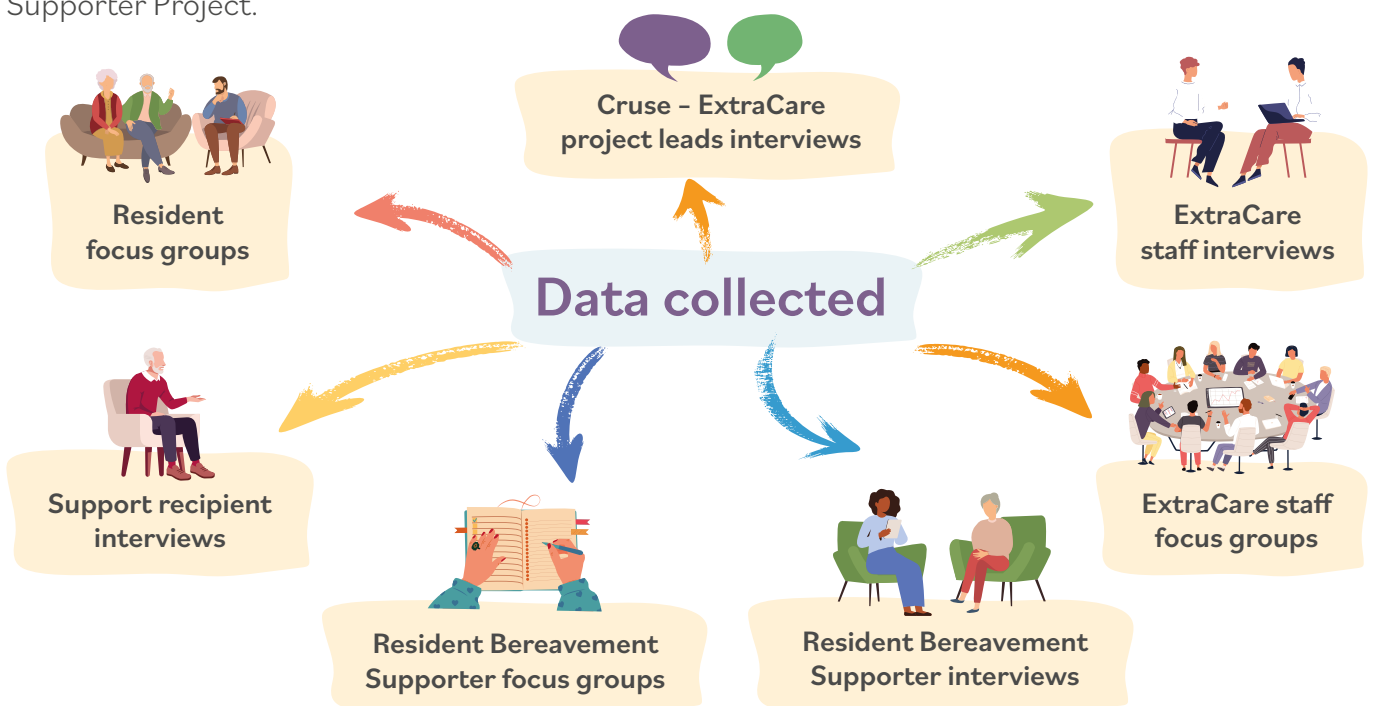


Figure 3: Methods of data collection completed in the Evaluation of the Bereavement Supporter Project

In addition to these formal data collection activities, we attended resident meetings and other events within ExtraCare villages, which provided deep insights into daily life and culture within the evaluation villages. Having carried out previous research in ExtraCare villages, members of the team (Shaw and West) were also able to draw on knowledge of its policies, practices and daily routines. We also held a series of Learn and Share events with residents, the Cruse and ExtraCare Project leads, the Evaluation team, and other stakeholders. These events provided important opportunities to share findings with stakeholders as they emerged and to refine our understanding of them.

The primary data gathered is presented in Table 1. We have described data gathering in two phases: phase 1 data were gathered and analyses presented in detail in the interim report; phase 2 data were gathered toward the end of the project and analyses are presented in this final report. Planned data collection was hampered in the second phase by the social distancing and lockdown measures necessitated by Covid-19. However, this also presented an opportunity to gather further insights into the project through the diary reflections from RBSVs across two of our evaluation sites and two additional sites (Appendix 2). We also drew upon other sources of data such as the National Lottery outcome monitoring data in Appendix 4, feedback from staff training and other ad hoc surveys (Appendix 3).

Group	Location	Method	Number of participants	Phase
Project leads	Cruse ExtraCare	Individual interviews	2	1
Staff	Hagley Road Longbridge New Oscott Pannel Croft	Focus groups	24	1
		Interview with Volunteer Organiser	1	2
Bereavement Supporter Volunteers	Hagley Road Longbridge New Oscott Pannel Croft	Focus groups	21	1 and 2
Bereavement Supporter Volunteers	Hagley Road Longbridge New Oscott Pannel Croft	Individual interviews	8	1 and 2
Support Recipients	Hagley Road Longbridge	Individual interviews	3	1
Residents	New Oscott Pannel Croft	Focus groups	9	2
Bereavement Supporter Volunteers	Across 4 locations (not necessarily evaluation sites)	Diary reflections	4	2

Table 1: Primary data gathered throughout the project

## 6. Summary of Findings from the Interim Report

The interim report was presented to Cruse and ExtraCare project leads in August 2019. The Loss and Bereavement information sessions were well received and 96% of staff and residents who attended agreed they understood the impact of grief on emotions, body, and mind. The most frequently cited motivations provided by ExtraCare residents for becoming RBSVs are presented in Figure 4.

A number of volunteers had professional experience and expertise which they brought to their RBSV role (e.g. clergy, palliative care nurse, bereavement counsellor). Others were motivated by their own experience of bereavement and a desire to support others.

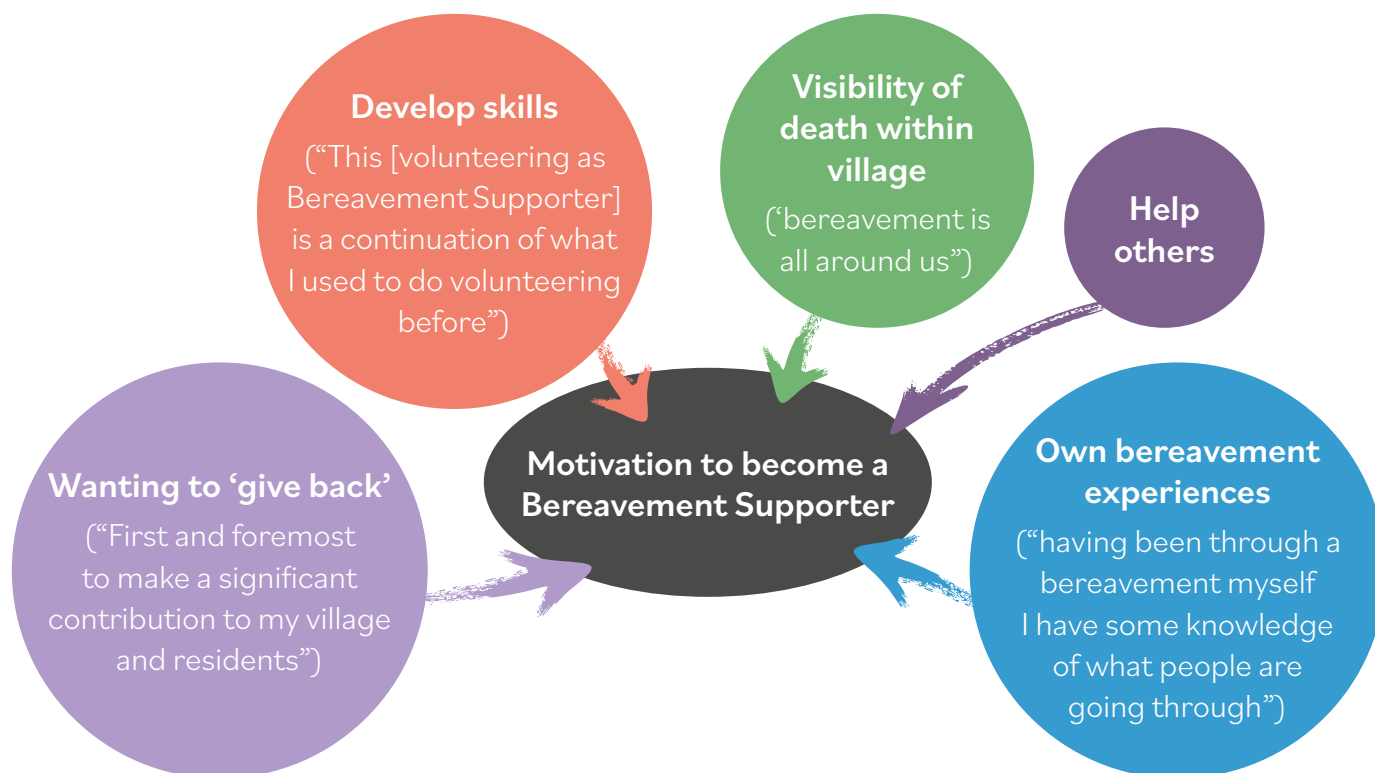


Figure 4: Depicts the main motivations for becoming a Bereavement Supporter

The Cruse training was well received by RBSVs and a large proportion of them (86%) agreed they felt comfortable offering bereavement support following it. Volunteers outlined how the training had helped them see how bereavement can be experienced differently, it had facilitated self-reflection, and helped develop their listening skills. ExtraCare staff found the training relevant to their role and helped them to think more deeply about bereavement, how to communicate with and listen to residents more effectively and confidently, and to think about the losses faced by residents in terms of bereavement. Nevertheless, there were mixed feelings about whether residents themselves were open to talking about death, dying and bereavement. Residents who had received support said it had helped them think through their feelings of being isolated or overwhelmed by their bereavement. They welcomed having someone non-judgemental to talk to. We were only able to interview three people who had received support at that time and within that small sample one person felt unfulfilled by their support experience, whereas another felt it enabled them resume activities previously enjoyed and to move on.

See Table 2 for a brief overview of the key messages identified in the interim report.<sup>5</sup>



Resident Bereavement Supporter Volunteer (RBSV) Training	RBSVs' Experiences of Support Provision	Support Provided	Issues for the Evaluation	ExtraCare Staff
RBSV Training was well attended and well received	RBSVs were highly motivated and some already had relevant expertise	RBSVs provide many instances of informal support	Accurately capturing support recipients posed a considerable challenge in terms of recording support referrals, numbers of contacts, and numbers of those who had received support	Training was well received by staff members from across various job roles
An unmet need for further support to manage the emotional labour of grief work was observed	RBSVs in post across the four evaluation sites	Many RBSVs felt the informal support they provided was more meaningful to those in need of support than more formal referrals	Capturing the experiences of receiving support was challenged by the small number of formal referrals and poor uptake of feedback surveys	Conceptualisation of bereavement in the training resonated with staff and facilitated a holistic approach to bereavement support

Continued overleaf.

<b>Resident Bereavement Supporter Volunteer (RBSV) Training</b>	<b>RBSVs' Experiences of Support Provision</b>	<b>Support Provided</b>	<b>Issues for the Evaluation</b>	<b>ExtraCare Staff</b>
<p>Trainee attendees enjoyed: visuals, activities, discussions to consolidate core messages, developing communication &amp; listening skills, learning about different experiences of grief, applying their learning to practice</p>	<p>The dominance of informal support was experienced as a challenge for some RBSVs</p>			<p>Further clarity was desired regarding the remits and collaborative working strategies between ExtraCare staff, Cruse, and ExtraCare RBSVs</p>
<p>Conceptualisation of bereavement in the training resonated with volunteers and facilitated a holistic approach to bereavement support</p>				

Table 2: Summary of findings from phase 1 presented in the interim report

## 7. Final Evaluation Findings

### Engagement with the Project (2017- 2021)

From available data collected to date, participation included:



- **49 Bereavement Supporter volunteers** trained and **18 residents** trained as part of the new 'Community Model' approach

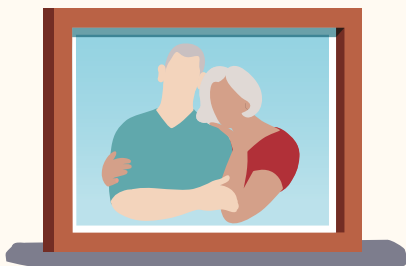


- **Over 390 staff** received Cruse Loss and Bereavement Awareness training; and over **210 staff** attended a Loss and Bereavement Information Session



- **Over 1290 individuals** accessed bereavement support (residents, family members and friends of the village)

- **Over 1500 residents and members of the wider village community** engaged with Loss and Bereavement Information Sessions, information stands or attended talks



- **Over 400 residents** took part in #IRemember week 2020

- **3975 copies** of bereavement and dementia resources distributed



The findings are presented here under the four headings that have been the main areas for focus of the evaluation:

- 1) How the service was organised and delivered;
- 2) The quality of the training and information delivered;
- 3) Outcomes for individuals (e.g. resident Bereavement Supporter Volunteers, staff, and residents who have received support);
- 4) Wider impacts, particularly in terms of how the project has facilitated conversations about death, dying and bereavement and developed general grief literacy among staff and residents in the villages. The findings build on the interim report, but are mainly focused on the data collected from phase 2 between August 2019 and September 2020. Key findings are extensively illustrated with verbatim extracts from interviews or focus groups with those who participated.

## 7.1 How the service was organised and delivered.

At the inception of the Project, the RBSV role was very much framed in quasi-professional terms of referrals, keeping formal records and peer review. It soon became apparent, however, that residents would not formally refer themselves to the RBSVs, or be formally referred by other members of staff, in the way originally envisaged. The original process-model, based on formal referrals, gave way to a far less formalised system, consisting of ad hoc and one-off conversations with other residents that may arise in the course of everyday conversation, or, in some cases, more regular interaction. As the following quotations from the volunteers illustrate:

*“...People in here that knew me put people forward to me “that she could do with a bit of counselling” or sometimes it was just that I met someone in the hall who had lost their partner and they needed support and felt that they were isolated so I just asked them their apartment number and asked if they didn’t mind me coming to visit them, and then I did.”*  
**(Cathleen, RBSV)**

*“Because I’ve seen people every day, people will tell you “I lost my brother” “I lost my husband” “I lost my sister” and so on and that gives you the opportunity to say “how are you getting on?” and so on and so forth and from one conversation you know whether that person might need help and support and I offer that help and support you know “I’m doing bereavement and if you would like me to come and sit with you and talk about it” and so on and so forth so I got a lot of referral self-referral.”*  
**(Marilyn, RBSV)**

This shift from formalised referrals to more ad hoc interaction reflects the way that residents themselves have responded to the service and is arguably more aligned with the compassionate communities ethos of the Project that RBSVs are essentially good neighbours with additional insight from formal training. In fact, a new Community Model in which a shorter 2.5 hour training session is offered to all residents to enable them to talk to others confidently about bereavement is being trialled across the villages. (We discuss this further in 8.2.1.) This new model also potentially addresses a number of organisational factors that have hindered the Project's objectives being fully realised in its original form. These are:

1. a clear and identifiable project champion;
2. trust in the Project and RBSVs;
3. vagaries of buy-in to the Project across the villages;

### 7.1.1 Project champion

There have been several iterations of organisational support structure over the life of the project, with the project initially sitting within the remit of the Locksmith (renamed as Enabler), but then transferred to the Volunteer and Activity Facilitator (VAF) whose role was then split into 2 separate roles Volunteer Organiser and Activity Coordinator. The project was passed to the Volunteer Organiser, who, we understand, had but 15 hours per week to coordinate over 100 volunteers across multiple roles.

In one of the villages, where the Volunteer Organiser, who had a very clear sense of the aims of the Bereavement Supporter project and had developed a good, supportive working relationship with the RBSVs, the Project appeared to be working well. The Volunteer Organiser had undertaken the Cruse training and had even worked for some time as a Cruse bereavement volunteer giving telephone support. In the interview she indicates a high level of trust and confidence in the RBSVs and a great deal of attentiveness to their needs:

*“...We meet every six weeks in the EOP room which is a really comfortable lounge setting ..., it was supposed to be an apartment but it's got a nice lounge and it's a comfortable setting, we just open the table and talk about feelings at first, sometimes we start a conversation with an exercise I use which is just say one word, one feeling word from this last six weeks and then we'll talk about it after, so somebody might say “satisfied” somebody might say “saddened” “heartbroken” but it's not always a negative, sometimes it's positive and like I said we then go back round again and say what happened, what made you feel that way. So we usually do that first, sometimes, we don't discuss names in the, because it stays between me and the volunteer ourselves, so we don't discuss names but they can discuss examples of what they've come across and how to, and then support each other with how they might move forward or support them or refer them ...”*

**(Volunteer Organiser interview, T2)**

At the time of writing this report, the project was being transferred back to the Enabler, with the support of the Dementia and Mental Wellbeing Supervisor. Given this rate of turnover of the coordination role, it has not been possible for us to come to a judgement about who is best placed to support the project and the RBSVs, but what we can say is that the lack of a clear champion within some of the ExtraCare villages has probably not been conducive to the development of the vital triangle of trust between staff, volunteers and residents. It is to this issue that we now turn.



### 7.1.2 Trust in the Project and the volunteers

In the example above, the Volunteer Organiser appears to have worked to develop trust and confidence among the care and wellbeing staff in the Project and the volunteers, which, in turn, helps to develop the trust and confidence of the residents. While a committed Project champion is important to the development of trust between volunteers and residents, it is possible that where RBSVs are already well known to residents and are trusted, staff are not needed to develop this. In another of the villages, the RBSVs had been well known members of the community for many years (even before the village was built), providing them with pre-existing legitimacy and recognition they could then bring to their Bereavement Supporter role. What we can say is that the Project seems to have worked best in villages where there is a high degree of trust and care among residents and where residents feel empowered to drive their own initiatives. In such conditions, the engagement of RBSVs and their reach of support seems to be most effective, as the following quotations illustrate:

*“Sainsbury’s and Marks and Spencer’s give us their out of date flowers instead of throwing them in the skip and that’s once a week, sometimes there aren’t so very many, but sometimes there are lots of bunches and Peggy, my wife, and Leslie who is also a bereavement counsellor go round distributing them to people who are ill, people who are depressed, people who are bereaved and very often there’s the opportunity to talk to somebody who needs support at the door when the flowers are offered. We also have volunteers from outside who do a lot of the distributing - a lady called Marilyn, but she’s not a Cruse counsellor [referring to Resident Bereavement Supporters].”*  
**(Charles RBSV T2 FG)**

However, it was more common in other villages, for RBSVs to be not so well known or, indeed, trusted. We found that this was a belief that was often reinforced by the very staff who were supposed to be working with the RBSVs to deliver the peer-support initiative in the first place.

*“I’ve tried to do two formal referrals, but both declined on the basis that they didn’t want to speak to someone within the village because they were worried about confidentiality and how far that goes.”*  
**(A Dementia and Wellbeing Enabler)**

*“I wouldn’t talk to the bereavement volunteers here because I think you know things that have happened in my life to do with bereavement. I wouldn’t want to share it with them because for me it’s too deep anyway you know I would want to see a professional, and have seen a professional so you know I think sometimes because the skills are lacking in that not everybody knows when to listen or what’s appropriate to say, or not to say.”*  
**(A Volunteer Organiser)**

*“I do tend to worry more about the Cruse bereavement volunteers because I do think that you’re putting them in the position sometimes where a disclosure could be made, there may be safeguarding concerns, I mean it could happen...”*  
**(A Volunteer Organiser)**

These three quotes from ExtraCare staff on the previous page, illustrate how staff can undermine, indeed block, the support offered by RBSVs. Staff are the primary gate keepers of fostering trust – some villages do this better than others. Trust is fundamental to the sustainability of this kind of project that requires overcoming the distrust among residents (gossip, cliques etc.) and the opinions of staff, which can ultimately make residents reluctant to come forward to talk about their bereavement experience and seek support:

*“...There are things that you want to talk about that you wouldn’t want to talk to a resident about? ...And you’d think, wonder, what they think what I’ve said to them and things like that. You would. 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.”*

**(P3 Resident in FG)**

The project and evaluation team acknowledge that structures of inequality and a highly challenging political economy of health and social care are, at heart, significant factors that are bound to influence and, in turn, challenge initiatives such the Bereavement Supporter project in extra care settings. It is not to say that care staff and, indeed, ExtraCare ‘fail’, so much as to acknowledge how the turn-over of staff on relatively low incomes in precarious, part-time, over-stretched roles that is endemic to the sector is a challenging foundation for any multidisciplinary, cross-sector partnership working to begin with, never mind trying to bring about a culture change to talking about death and instigating bereavement support.

### 7.1.3 Vagaries of buy-in to the Project across the villages

Nevertheless, we have to acknowledge the stumbling blocks to the ongoing sustainability of this project and that there was enormous variability across the villages in respect of the visibility and importance that was given to the Project by staff. As a RBSV in one of the villages commented:

*“I don’t think it’s visible enough and it’s not advertised enough [...] as I was saying the other day, the lady who is in charge of the volunteers, what’s her name again? I don’t remember. Anyway, she could do that! You know, just to remind people at the meeting that there’s a project, a bereavement project, and so if you need help and support, who in the village you can contact and make it a bit known all the time, so people will know.”*

**(Marilyn, RBSV)**

Aside from not visibly supporting the Project and being seen to be proactive in championing it, another common means of undermining the Project, even if unconsciously so, was for staff to keep suggesting that the RBSVs should receive further certified training. In doing so, staff were reinforcing and maintaining their perceived position and status relative to the RBSVs. The comments from staff suggest that some staff felt threatened by the RBSVs, who they might have felt were stepping on their professional toes. By referring to the RBSVs as simply a homogenous group of ‘residents’ or ‘volunteers’, ExtraCare staff were insufficiently cognisant of their former professional lives, qualifications and status; which might on occasion have seen a RBSV as more ‘qualified’ to offer bereavement support than the staff. Therefore, in ensuring the future success of similar peer-support projects, there needs to be some time spent with staff and RBSVs *together* in order to explicitly recognise the skills and experience residents bring to the role. If not, then attitudes such as this from a staff member who is supposed to be supporting the volunteers will persist and threaten to undermine future efforts:

*“It’s like basic first-aid, I’m a first-aider but anything other than what was covered I’m not...but I can do some things, and I have a bit of knowledge of what to do and that’s how I feel with the bereavement counsellors, I think they’re actually chucked in the deep end...we’re very active in promoting things like this but actually are we protecting them as well with some form of base knowledge and I think if people see them in more of a, you know in loose term ‘professional’ and that they have had some form of training to recognise things I think that people might approach them more knowing that.”*

**(Housing Support Assistant)**

*“I think what you said about staff not referring, I probably should hold my hand up because I haven’t done as many referrals as maybe I should...but it’s like what you said, if somebody is coming in to see me and I’ve managed to engage with them and they’ve managed to start talking about something, why would I then say “would you like to” you kind of stop them to send them somewhere else I just allow them, and if they want to come back and see me then they can come back and see me because obviously you’ve started something so I... because I see it as part of my role anyway so I wouldn’t sort of say “off you go” that’s part of what I do, if I can support them then I would.”*

**(A Wellbeing Advisor)**

The Wellbeing Advisor articulates a major hurdle in successful peer-support in the context of extra care and that is professional and volunteer boundaries. It was often intimated, but never so directly put as above, that staff felt their role was being taken away from them by the RBSVs. There was a lack of clarity of both purpose and roles between ExtraCare staff on the front line and RBSVs. Feeling confused, at best, as to the role and purpose of the RBSVs contributed to a lack of: staff buy-in, staff making referrals, and the perception that the RBSVs were not adequately trained for the role, even though some of them had not undertaken the training themselves. This also fostered a lack of continuity and resources given to the RBSVs to enable them to carry out their role and to promote the Project and service to other residents; be that a designated, appropriate physical meeting place or, more critically, access to supervision or mentoring for addressing the emotional labour and distress they did on occasion take on.

*“I’ve had one formal referral which was a bit of a disaster really...she was referred to me because the person who referred her thought I’d be the best one to deal with her but it turned out that she really needed a lot of professional help and she was a very, very angry lady [...] but it was an onslaught I felt very, very threatened by the situation and I think they thought because I was a nurse that I could deal with it because of my background but it wasn’t very nice and I don’t think that she should ever have been referred to me at all [...] it was the locksmith and she couldn’t deal with herself I don’t think although she wouldn’t admit that to me so she thought I could deal with it because I’d been a nurse and I worked in bereavement in the hospice and all that kind of stuff but [...] I found her very difficult and I really didn’t want to see her again! [...] I reported back to the Locksmith and I said that she needed, well I felt she needed more professional help outside of the village or any staff member but as far as I’m aware she hasn’t had it as far as I know, she may have but I doubt it (Meredith: did you have any help?) no, but I think because of my experience I was able to deal with that myself and let it go but at the same time I did also find it distressing at the time.”*

**(Lil, RBSV)**

*“I don’t know how appropriate it is to say here but you know I think there’s the right place to be able to feel comfortable phoning whoever, one of us, just to say can I offload because you know I’m thinking of, I worked in Relate and also with NHS family therapy and so on and there’s just times when there are certain folk that you know that if you say can I just blow this past you (a) it’s safe with them (b) they won’t remember it in a wrong way and but also it helps to bring things back to coz it’s horrible, because it’s been said to me “oh if you want to come and talk to me you can any time” but I didn’t feel comfortable going to talk to her, our locksmith, who is on maternity leave at the moment (I; yeah) and I didn’t feel confident to talk to her”*  
**(Meredith, RBSV)**

What these comments from staff and volunteers also capture is the lack of two-way learning between volunteers and professionals, which is a significant missed opportunity with the Bereavement Supporter project; although the training itself has had an impact on staff at various levels as we will discuss. Two villages have been quite successful at using the Bereavement Supporter project as another outlet for community development. Unfortunately, in other villages, volunteers seem to be stalled or their impact reduced either by staff or by disruptive residents. Volunteers are somewhat hidebound by the paternalistic structure and attitudes within their villages where staff view them as lacking necessary skills and experience:

*“...the skills are lacking in that not everybody knows when to listen or what’s appropriate to say, or not to say.”*  
**(A Volunteer Organiser)**

And yet, the RBSVs have a very clear idea of what is required in their behaviour and professional standards they expect of themselves in the role:

*“...At the end of the day, whether it’s Befriending or whether it’s counselling, everybody wants the same, they just want somebody to talk to, someone to offload on and they want to feel confident that you’re not betraying their trust and mentioning it outside.”*  
**(Cathleen, RBSV)**

*“It’s a long time ago about the training, I know the folder that we receive from the trainer was very informative and I know when I go into people’s home to be with them I use some of what I was taught and remember to do you know, you don’t take people it’s like, personal, you know, confidential you know and that is very important as well, sometimes when you go to people’s homes they really tells you some really important things and that is confidential and I need to be aware of that, you have to do that, it is very important.”*  
**(Marilyn, RBSV)**



Whilst the Bereavement Supporter project may have been valued and endorsed by ExtraCare’s senior management, it does not always mean that good rapport is fully established between the RBSVs and the ExtraCare staff they have to liaise with directly. One way in which rapport building and trust has been undermined is through communication from staff, even when RBSVs are trying to communicate with them in their role. It would, however, be unfair to blame members of village staff, who have themselves absorbed the Bereavement Supporter project into existing work schedules. Some staff clearly understand the aims of the project and are supportive of the RBSVs. However, some are not and if staff are not clearly seen to be supporting and valuing the project and the volunteers, residents themselves can hardly be expected to put their own trust in them. For many RBSVs, these organisational factors have not stood in the way of them getting on with the vital work of peer bereavement support as we will see more clearly when we report on the diaries project below, but for others, status and value is critical to them fulfilling the role successfully.

## 7.2 The quality of the training and information delivered.

In spite of some of the organisational challenges highlighted in the previous section, it is clear that the Bereavement and Loss Information Sessions and formal Cruse bereavement training were valued by both ExtraCare Staff and those residents who participated in them too. At the time of writing this final evaluation report, 392 staff from 21 villages and schemes, and head office teams, had attended the Loss and Bereavement Awareness training session. Of these, at least 95 staff members and 17 active RBSVs were from the four evaluation sites. In addition, 351 residents and 218 staff have also attended the one hour Bereavement and Loss Information Sessions.

Both staff and Resident Volunteer Bereavement Supporters reported a high level of satisfaction with the training materials and the training itself. For both staff and volunteers, feedback forms consisted of standard satisfaction questions and open responses to enable the exploration of what they found particularly useful.

### ExtraCare staff feedback – 3 months after Loss and Bereavement Awareness Training

I feel I would be.....	YES	NO	NOT SURE
More confident listening to and supporting a bereaved resident	88%	3%	9%
More confident communicating with a family following the death of a resident	88%	3	9%
Able to discuss bereavement and loss more than before	96%	3%	1%
More confident having a conversation with a resident about death, dying or Advanced Care Planning / end of life	76%	7%	17%
More confident supporting a bereaved colleague	88%	4%	8%
More aware of the physical and emotional impact of bereavement and loss on a resident	99%	1%	0%

Table 3: Q3 Since you attended the Cruse Loss and Bereavement Awareness training, have you noticed any of the following? (select any that apply).



Feedback showed that the vast majority in both groups thought that the training had enabled them to understand the impact of grief on emotions, body and mind and that they would know how to support a bereaved person. Despite the impact of covid-19 meaning that some of this training had to be offered online via Zoom to ExtraCare staff, the feedback was still hugely positive. For example:

*“Loved it - felt the trainer was brilliant and really underpinned by his real-life clinical experience. Would absolutely recommend.”*

*“I feel everyone should complete the training which can be used in your working and your personal life.”*

*“I really enjoyed this course, I feel I’m a very empathetic person and it really resonated with me. I would gladly attend the next phase of training. Thank you for allowing me to attend.”*

*“Very insightful course.”*

Following the Loss and Bereavement Training offered by Cruse, ExtraCare staff reported that:

*“I have applied the broader principles of loss to understand how the current pandemic is affecting us all.”*

*“I speak more confidently more about bereavement I’ve listened more (quietly) instead of trying to fix. Reassured resident that bereavement is normal and different for everyone.”*

*“I think that I have encouraged people to talk a bit more even when they seem to be ok. I feel much more confident about discussing bereavement with Residents. I have felt more confident to offer my support and empathy to anyone either in the village or around me suffering a bereavement.”*

*“I have more understanding of the different ways people can grieve and cope with bereavement.”*

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.

RBSVs, who all also received this training, but independently of staff reported:

*“I must say that because of the training and the process of meeting and sharing thoughts that has helped to give me confidence to sort of talk about what this is all about you know. It’s not a bad subject because that’s what a lot of people are thinking, it’s not a subject that we talk about, but now we’re more open, we’re sharing, and that’s much better.”*  
**(Nancy RBSV mixed site FG T 2)**

*“M: I think the training makes you more aware from my point of view because I’ve never done bereavement work before and so it has (L: you worked for the Samaritans) yeah I did work for the Samaritans but it’s not quite the same as bereavement, but it certainly makes you more aware of dealing with people and what people might be going through...”*  
**(Marcus and Lil, RBSV T2)**

Staff were motivated to attend the training so that they could better support bereaved residents (and in some cases their colleagues), while the motivation for resident volunteers were more varied and included wanting to ‘give back’ to their communities, wanting to use their own loss to help others, to develop skills, and to meet the 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 there was perhaps more emphasis on “*what is the right thing to say*” whereas for resident volunteers, listening, and sitting in silence, were the central learning points taken from the training.

### 7.2.1 Training fosters a broader understanding of residents’ losses

The training also encouraged staff and volunteers to consider losses other than death -related losses that might be relevant for ExtraCare residents, such as loss of family home or pre-death bereavement experiences associated with caring for someone living with dementia. This broader conceptualisation of bereavement resonated with both staff and RBSVs. Many reported that this has allowed them to view bereaved people more holistically in both a professional and personal context. We also learnt via the diaries project how the impact of the pandemic and the lockdowns that ensued allowed residents in those ExtraCare villages to acknowledge and come to understand a far more holistic concept of bereavement and grief. All residents had experienced multiple losses over 2020 and were grieving for missed opportunities, friends, family, loss of routines etc. See sections 7.3.1, 8.2 and Appendix 2 for more detail on this topic.

### 7.2.2 RBSVs’ training complements existing skills

RBSVs have not only used their Cruse training to develop a holistic understanding of grief and loss, but they also adapted it to their pre-existing worldviews and other roles. One example comes from the resident quoted below who supports people in her faith community as well as being a Resident Bereavement Supporter Volunteer:

*“This is where the bereavement from Cruse comes in so when you have what you study from Cruse then you can bring that into the equation or that conversation and you can go down that route if that’s, if they don’t want the spiritual side of that counselling.”*  
**(Marilyn, RBSV T2)**

One RBSV has adapted her Cruse training and role within the village to her pre-existing creative support roles and has therefore found herself informally facilitating bereavement support during book club and art classes as part of shared therapeutic activities:

*“I’ve got a group, I run a book club and an art club, as an art teacher and there’s quite a lot of us there where we share, we’re doing some art and we’re talking together so that helps as well as part of the bereavement and it’s very funny as well because I’ve found that when we’re talking to people who are in bereavement but are a bit closed sometimes a long-time bereavement but it’s still there so they’re able to talk while we’re doing something and I don’t think they even notice that they’re talking about the bereavement in that way while they’re doing something or other so in that way yes, it’s been good.”*  
**(Nancy RBSV mixed site FG, T2)**

'Singing away the grief', was incorporated into the provision of bereavement support for another RBSV; she sees the value of both bereavement support and group singing for finding strength through difficult times when grieving:

*"...We all are going through our bereavement and will sing it away. I hope other people will come and participate in our choir and we had concert and things like that, we have over 100 people to our choir, to our concert and things like that [...]and that is the reason why it encouraged me to be a part of that as well because I learn more so that I'm not only singing but I learn more than just singing and to deal with myself and to share with others as well too so really good [...] when I started doing it I felt "yes!" I felt the release and happiness coming inside of me and I thought "ok why not share it with somebody else and see how it goes" just for them to feel the same happiness that I'm feeling about myself, knowing that you lost somebody so dear and near to your heart and I, you know something, when my daughter passed away because I could not sleep I used to have like a glass or two of wine before just to see if that could make me sleep and I find that I was doing it a bit too much [...]and what I find when I was doing like that I thought "I don't want to continue to do that" but when this came into my heart, to sing away I felt good, it just stopped yeah! I could sleep and I felt better and I don't have to do it. Out of bad sometimes some good things can come out of it."*

**(Marilyn, RBSV)**

This RBSV then discloses how she not only supports other residents within her village, but also in the community beyond the ExtraCare village, but whenever she does and whatever time of day it is she will take her Cruse bereavement training folder so that the resources and insights mean she can "speak professionally":

*"I have people from next door, not in the village only but all around it I go to help as well. People call late at night "I need somebody to talk to" one lady called me 1:30 the other morning, Thursday, 1:30 in the morning (I: and you chatted with her?) yes, she said "I can't sleep, I'm worried about some things, please talk to me, please help me, can you come?" and we talk on the phone for a very long time until she feel happy and that she can go back to sleep now so you do get those things as well[...] I go along with my folder so that I can speak professionally [...] In everything I do I do it not only to make myself happy but to make others feel the same way so I enjoy what I do and I try to do it to the best of my ability and if I can't do it then I say "I'm not doing it."*

**(Marilyn, RBSV)**

### 7.2.3 Mixed attitudes of staff towards resident training

The training is voluntary and to date, as noted 392 members of staff (32 % of all staff) across most villages and schemes, and head office teams, have taken up the opportunity. However, in our phase 2 data collection with staff we saw that take up among staff was variable. While a majority of Volunteer Organisers and Enablers have had the training, uptake among other staff has been lower in some sites. Yet, understanding on the part of staff of the training is crucial to the success of the Project. In one location in particular, we found that some staff were highly sceptical of the training that volunteers had been given even though they themselves had not attended it.

*"I've been asked [by residents] "who are they?", "what training have they had?" and that's difficult because you know they're not trained counsellors..."*

**(Staff focus group, phase 2)**

This lack of 'buy-in' in some of the evaluation sites is unfortunate not only because, as noted, when staff have taken up the training it seems to have been highly beneficial to how they communicate with residents about death, dying and bereavement, but also, as the quotation above illustrates, this member of staff would have gained a better understanding of the aims and purpose of the Bereavement Supporter project. This lack of knowledge of the training and knowledge of the project's ethos and aims may go some way to explaining some of the frustrations experienced by the volunteers discussed in section 7.1. above.

When staff have taken up the training, there is better communication about death, dying and bereavement at all levels of the organisation, as the quotation below from a member of staff in the sales team shows:

*“Just the way I approach relatives who have lost a loved one. Some want to deal with things straightaway whereas others prefer to wait before dealing with formalities. I deal with end of tenancies so have adopted a slightly different approach when dealing with the bereaved relatives – understanding that they all react in different ways.”*  
**(Staff, Sales team)**

The training and information sessions have been widely taken up by staff and volunteers across ExtraCare. Feedback from staff and volunteers attests to the quality of these. We will discuss in section 7.4 the wider impacts that the training has had at all levels of the ExtraCare villages. Now, we will focus on outcomes of the project at the level of individuals.

### 7.3 Outcomes for individuals

In this section, we focus on three groups of individuals – volunteers, bereaved residents and residents with dementia. While staff are clearly another important group about which we have already commented in the context of the organisation of the Project and training, and whose input is vital to the success of the Project, the primary focus of the evaluation was on the volunteers and residents. It is also these groups that are of primary interest to the Project's funder – The National Lottery Community Fund. In this section, we will also draw on data from the additional diaries project (See Appendix 2), carried out between May and September 2020. We begin with the experience of volunteering.

#### 7.3.1 Volunteers

As noted in the interim report and in figure 4, we know that Bereavement Supporters have a variety of motivations for taking up the role. Some were motivated by their own personal experiences of grief and loss and simply wanting to give something back to the community.

*“I think it makes you feel good in yourself, in a good way, you know you feel you've helped somebody you know go over to the village, you meet someone and have a chat with them and they'll go off on their way and you'll go off on your way, but you feel like hopefully I did help that person a little bit [...] I think you feel you've given something to people and that you've given something back and err it makes you feel good about yourself in a good way you know.”*  
**(Lil, RBSV)**

Whilst there are no formal qualifications required to become a Resident Bereavement Supporter Volunteer (RBSV), there is a formal role description (Appendix 5). Volunteers interested in taking up the role are required to apply through ExtraCare's general volunteer recruitment process and to attend the 1-day Loss and Bereavement Awareness training. Residents who are deemed to be unsuited to the RBSV role might be directed to other suitable volunteer roles.

The level of experience and expertise among the resident volunteers was striking. A number had held professional and/or voluntary roles that either directly conferred relevant skills for the volunteer role (e.g. vicar, palliative nurse, or bereavement counsellor) or conferred skills that were certainly useful in the role (e.g. physiotherapist or family support for those with alcohol or drug addiction).

*“...I've been involved in counselling for donkeys years, training and enabling counsellors to be alert to the underlying issues that people may bring [...] I think probably because I bring so much work experience it's difficult to evaluate that to separate it out, there was certainly a feeling of satisfaction and I don't mean self-righteousness but a feeling of gratitude that I could actually use skills or that my skills were of use to somebody now that I find great [...] I felt that was good,”*  
**(Meredith, RBSV)**

*“Looking around us here now, how many of us are nurses? Or were nurses (three of the six)? So, you know, I find that it mainly tends to be the nurses that stick at it [Bereavement peer support] whereas the ones who have never done nursing are dropping out of it (Nancy: because you're caring, it's a caring and the whole point of bereavement is about caring) yes, and being able to talk to people...”*  
**(Hyacinth RBSV T2 mixed site FG)**

*“when I worked at the hospice we had volunteers [...] so I've always worked with volunteers and then when I left the hospice I worked at, well it's City Hospital now, and then I worked at Dudley, Sandwell and Wolverhampton teaching nursing and other professionals care of the dying person, the family, and bereavement so I actually taught all of that as well as working within the clinical area and then when I retired I worked in our local parish visiting bereaved families in the parish and the request from the parish priest who would suggest it to the family that I would visit, and then if they agreed then he'd ask me to go so I used to do that voluntary after I retired, so I was a volunteer then myself! [...] I've got a lot of background knowledge and experience.”*  
**(Marcus, RBSV)**

In the absence of other volunteering opportunities to deploy this particular skill set, the RBSV role offers a significant opportunity, which many residents across ExtraCare villages have taken up enthusiastically. As one RBSV explains:

*“I am a caring person you see and no matter what it is, as I've said, I will be and sometimes my husband says that I'm so caring I have to make an appointment to see you. He says “one day I'll go down and say I need a Befriender and hopefully it will be you”. I just like seeing people happy and I like doing, it doesn't necessarily have to be Befriending or counselling it could be like there was an old lady in here and she was on a little scooter and she used to go to bingo, and I go to bingo, I take another lady to bingo that's how I got into the bingo group.”*  
**(Cathleen, RBSV)**

This same RBSV went to extraordinary lengths to support the woman she refers to above before she died. The tasks she undertook in her voluntary support role were in addition to her bereavement peer-support role. Not only this, it is important to emphasise that she reports “just being there and making her life as enjoyable as possible” even while the person receiving her care and support was well known within the village for being “rude”:

*“At the moment I’m supporting a lady who’s dying and it’s quite a lot I have to do for her apart from supporting her, buying her items, getting her stuff online, getting her medication, sorting her medication out for her, and putting things together for her, taking her to bingo when she’s up to it, we used to go out but she won’t go out since she’s found out she’s dying, she just doesn’t seem to want to go out I’m trying to rebuild that up in her and I’ve got her taking the right stuff now so she is building back up because she wasn’t even eating or drinking so I’m making her meals [.....] it’s lovely to be able to help somebody and know that they appreciate it and she’s not one of these people that shows you too often that she appreciates it but I do know that as of late she is actually really appreciating it. I mean half the way through she said “I don’t know why you bother with me, I’m a horrible person!” and I said “no, no you’re not, you’re really nice, you just don’t see yourself” and I’m thinking on the other hand I know you are but I mean some people have taken offense, because she’d come out with anything she would, but I’ve had to go back to them and say “she doesn’t really mean it you know” and kind of cover up for her, but she can, she can be rude you know but you’ve got to look past that when you’re looking after somebody so I am just being there and making her life as enjoyable as possible.”*

**(Cathleen, RBSV)**

What this attests to is that the Project has made a role for residents who have particular skills and who do not shy away from supporting people in very challenging circumstances and even those who are not well liked by others. This is not the kind of role that everyone could take on, but does demonstrate how rewarding the role can be for the RBSVs and the kind of support that residents can give to each other when they themselves have the right support and the right skills.

As we noted in the interim report and in 7.1 above, the more formal system of referrals that was envisaged at the outset of the Project has gradually given way to a less formal system of ad hoc support, which latterly been brought within the remit of a Community Model. This has, however, not been without implications for the volunteers. First throughout the project, classifying and quantifying what ‘counts’ as bereavement support has been a significant point of contention for RBSVs and ExtraCare staff alike. For example, RBSVs were sometimes unclear about what they should note as ‘support’ and what they would consider as simply being ‘neighbourly’. We have discussed this at length in the interim report, so we will not discuss it in detail here, other than to note that the problem has persisted throughout phase 2 as the quotation below illustrates:

*“...With the majority of people I speak to is informal, what I would call informal and that is really the majority and as I’ve mentioned on many occasions I find it difficult to know what is supporting or just being neighbourly [...] I find it very much a woolly area between formal referrals and informal because sometimes you can’t separate the two [...] you don’t know whether you’re supporting as a Bereavement Supporter or whether you’re being, whether your character is that you would help anyway, or support anyway...”*

**(Richard RBSV T2 FG)**



Second, while for RBSVs like Richard above, straddling this formal/informal distinction, while challenging, is not an insurmountable problem. For others, though, there was a certain frustration that the more formal role they felt they had anticipated had been downgraded to a more informal role. While prior professional experience equips volunteers well to carry out the role, some volunteers have also expressed an expectation that the role be quasi-professional and have perhaps been frustrated when what they see as the kind of 'formal referrals' that they may have been used to in counselling roles did not materialise in the volume expected. Again, the strength of feeling on the issue did not appear to have abated in phase 2 of the evaluation.

*"I've been a Bereavement Supporter for two years and I've never had anyone referred to me."  
(Charles - RBSV T2 FG)*

*"I did say in the email that I wasn't very happy with the way things were going here at [...] with regards to the Bereavement Support Service...we weren't getting any referrals, none at all, and we felt we weren't really supported either nobody got us together and said you know, "how are you? How are you doing?" [...]so I felt that we were completely unsupported."  
(Marcus, RBSV)*

*"But that's the problem, we don't really know why people are not being referred or that's the way it was set up wasn't it that people would be referred, but it's not really worked out that way it's been more informal? [...] sometimes you just feel out on a limb, what am I supposed to be doing? [...] but very often a formal referral turns out you just turn out to be chatting like you would in the bistro or somewhere, you say "how are you feeling" and they will go into it but it's when you get one like the one lady that was referred to me and her anger was horrendous and she's a very complicated person anyway and half the time she isn't here she's off doing stuff but she was definitely someone who needed professional help (more so than what we could give) whether it was suggested to her or not I don't know I didn't hear any more about it."  
(Marcus, RBSV)*

*"...I haven't had any referrals and nor did we get any from the locksmith or any of them, it's just us talking around the village that pick things up and then you can chat to the person without saying anything about "I'm a bereavement counsellor for the village" sort of thing, just talking, because I think once you say that they might think "oh God do I need a bereavement counsellor?" (Lil: well basically we've all just been left to get on with it) yeah! (others agree) so we just talk you know..."  
(Hyacinth RBSV T2 mixed site FG)*





### 7.3.1.1 Inconsistent support for RBSVs

There is also a sense in which this feeling of being unsupported or being 'left to get on with it' as Hyacinth put it, is not merely about the transition from formalised system to less formal interaction, but also reflects some of the organisational challenges we discussed in 7.1 above.

*“I think volunteer person should get support for themselves as well, coz you keep giving, giving all the time you should be able to receive sometimes. I’ve never had any support [...] it would be nice, it would be nice for all the volunteers to come together and somebody minister us, not just teaching about it, but talk to us about our experience.”*  
**(Marilyn, RBSV)**

*“...It has been a bit messy and with having a new manager it’s been very difficult in the village - a lot of staff changes and so everything has been up in the air, people have been unhappy and [...] of course that impacts on what you do as a volunteer [...] (M: yeah coz the locksmith role is funded separately from ExtraCare yeah and so maybe she feels that if people see her delegating to people in the village like us then we’re in a sense a threat to her job)[...] so that impacts on us then and the attitudes that we’re picking up and sometimes we wonder why we bother you know, you know we’re trying to help people but if we don’t get the support, if they don’t want to be bothered with us you know, and especially when you don’t feel too great yourself, you think “ah just let them get on with it” you know which it not very nice, it’s a very negative attitude to have...”*  
**(Marcus and Lil, RBSV)**

### 7.3.1.2 Lack of visibility of the Project

This feeling of being unsupported was not everyone’s experience and as we noted in 7.1.1 above, in one of the villages, where the Volunteer Organiser has a clear sense of the role and the skills and contribution that the volunteers can make, the RBSVs did not express such concerns about lacking support. However, a common concern across all the villages was what they perceived to be a general lack of visibility of the Bereavement Supporters and the service within the villages:

*“Well from my perspective I think we are, how can I put this, we’re not visible for people [...] it’s not so much that I don’t think we’re needed, I think we are needed, but I don’t think we are visible enough to let people know that we are available if that’s what’s required and a part of that could be that we do a lot of this informally anyway and it could be that we could do this, and one of the things that I do find difficult with this is where do you take a person to talk to we do not have, I actually booked this, the lady who I was going to speak to was going to come in of an evening so I could book this room which is obviously far more conducive to having a sit down chat than in the bar or the bistro as far as you can be, because I did have one conversation in there with a lady and inevitably people recognise you, come up and want to talk to you, and obviously that’s not appropriate”*  
**(Richard RBSV T2 FG)**

*“I don’t think it’s visible enough and it’s not advertised enough [...] as I was saying the other day, the lady who is in charge of the volunteers, what’s her name again? I don’t remember. Anyway, she could do that! You know, just to remind people at the meeting that there’s a project, a bereavement project, and so if you need help and support, who in the village you can contact and make it a bit known all the time, so people will know.”*  
**(Marilyn RBSV)**

This lack of visibility and recognition manifests most obviously in the fact that the RBSVs struggle to find appropriate spaces in which to sit and talk with the residents they are supporting. This lack of provision of appropriate, private meeting space was a recurring theme in interviews and focus groups. Although by no means a universal experience, the quotation below is illustrative of a lack of respectful recognition of the work of the Bereavement Supporters in some locations:

*“4th June 2020 - During our private session, indicated by a sign ‘Meeting in Progress’ on the door, we were interrupted by a Care Worker who prioritised putting her cup in the sink over our privacy. Asked by lady if she was a Carer, then told off. Flippant response ‘get my wrists slapped’...She may put in a complaint?”*  
**(L2P1 - RBSV and Diarist)**

The volunteer training lays significant emphasis on values of respect and confidentiality and concerns about confidentiality and trust are given by some residents and staff as reasons why some residents might be reluctant to engage with the project, which we will discuss further below. The provision of appropriate meeting places is clearly vital to ensuring respect, confidentiality and trust and, therefore, to the sustainability of the Bereavement Supporter project, regardless of whether the RBSVs are accessed formally or informally.

### **7.3.1.3 Communication between staff and RBSVs**

A further challenge for the RBSVs, referred to frequently in the phase 2 data was a lack of information from staff about the health and wellbeing of residents that they have been supporting.

*“At the moment I am supporting a resident, and then the resident went into hospital I didn’t know, and then I went to look for the resident, not there, and I go to the staff and ask “where is Mr so and so” and it’s “no we can’t tell you”...”*  
**(Marilyn, RBSV T2 mixed site FG)**

It appears that bureaucratic processes, together with the general nervousness on the part of staff to imparting information about residents’ health and wellbeing, is impeding the Bereavement Supporter work. If the RBSV has already been privy to all sorts of ‘personal information’ from the person they are supporting, it is hard to understand why they cannot then be trusted with minimal information about the whereabouts of that same person.

*“The new manager - it sounds like I’m really getting at her which I’m not - but it’s what’s happening, so she doesn’t communicate with us she doesn’t think we should know anything and we shouldn’t be consulted and we shouldn’t be told of any new policies or anything like that [...] hopefully we will get a better structure, it’s the change in staff that has thrown quite a lot of things out in this village I think and a lot of staff have gone, have left.”*  
**(Marcus and Lil, RBSV)**

*“So it is a big problem around (Marcus; communication is a massive problem) communication and all the rotation of staff I think is one of the biggest (INAUDIBLE) and I think that demoralises [sic] staff because they’re always short of staff so that demoralises staff and you see it in the carers going around that they’re looking tired, they’re looking tired and before they used to sit down and talk to you say hello (Lil: they haven’t got time) no they haven’t got the time to do it...”*  
**(Nancy RBSV T2 mixed site FG)**

*“We cannot find out anyway, the staff they can’t tell us who is poorly and who isn’t because when you’re in a community such as this, you do know when you haven’t seen someone, for example I haven’t seen Elsa for a long time now but if was to go and try to find out from the staff if Elsa has been around they will just say “we can’t tell you...”*  
**(Richard RBSV T2 FG)**

Ultimately the RBSVs have found themselves limited by the multiple categories they find themselves being labelled with by ExtraCare staff – ‘resident’, ‘volunteer’, ‘client’, which can jeopardise the peer-support role they are trying to deliver.

*“...Because we’re seen as a resident so we shouldn’t be told anything and not seen as someone from Cruse who’s doing bereavement support...”*  
**(Lil RBSV T2 mixed site FG)**

At worst, RBSVs have felt they are being infantilised and patronised by staff. This could arise from the fact that extra care is an ambiguous setting – neither care home or nursing home – and yet, some staff, given their professional training in health and social care struggle to not infantilise residents and assume they are in need of care. As we have discussed in 7.1, an attitude of co-production between staff, volunteers and residents would be more helpful and, again, as discussed, we have seen evidence of some very good practice in at least one of the villages in this regard.

*“Somewhere we, there has been an attitude or somehow it’s been lost that actually we’re adults (Nancy: yes!) and that’s what bothers me that it’s rather like we’ve gone down the scale a bit now and I’m not sure whether I’m now a teenager or I’ve reached childhood!”*  
**(Meredith RBSV T2 mixed site FG)**

*“...It’s always “we have concern Nancy, can we have a meeting” and I’m thinking, so the thing is they underestimate the people and the skill and qualifications that they have got (ALL AGREE) and instead of using that (OTHERS AGREE) they’re trying to crush us and if we don’t watch it, it’s our home and we must know what we want (AGREE) we can stay in our apartments and do what we want but it’s a shared, we’re a family (SOMEONE: absolutely yeah) and if you don’t see someone tomorrow morning you think “where are they?” you’re concerned about them you’re not being nosy, part of it is being nosy (OTHERS LAUGH) but you’re concerned because it’s a family member.”*  
**(Nancy RBS T2 mixed site FG)**

### 7.3.1.4 The Bereavement Supporter role during the Covid-19 pandemic: evidence from the diaries project

Covid-19 presented challenges to the evaluation, but it also provided an opportunity for new data collection for the project team and the RBSVs, which over time produced rich descriptive data and key insights for both the project team and Cruse staff. The impact of Covid-19 meant that between May and September 2020 (during and after the first period of ‘lockdown’), 8 bereavement support volunteers kept diaries. The diarists were either RBSVs offering peer support to fellow residents within their ExtraCare village or Cruse Bereavement Volunteers (BVs) offering bereavement support to clients across the UK, and who receive a higher level of training. This together with an explanation of the methodology is given in Appendix 2 – ‘Compassionate Communities for Extraordinary Circumstances: Using diaries to capture bereavement support during the Covid-19 pandemic’.

The project team developed this additional project in response to Covid-19’s unforeseen impact as an opportunity to better understand the impact of the Covid-19 restrictions on ExtraCare residents and Cruse bereavement support services in relation to death, grief and the way a community supports bereaved people at a time when our experience of grief may be different and our normal rituals are affected or unavailable. We were interested in the ways in which the Covid-19 restrictions affect grief and bereavement support regardless of whether Covid-19 was the actual cause of death and to learn about practices that could be helpful after the pandemic. The key findings were produced into an illustrated learn and share booklet<sup>vi</sup> by Cruse to share with other stakeholders in relevant sectors.<sup>vii</sup>

One of the key learnings concerned the assumption that bereavements would necessarily be more difficult during the pandemic and that grief would be more challenging to deal with during a ‘lockdown’ when social distancing and self-isolation became standard practice. However, it was reported by diarists that some of those they were supporting during this time actually appreciated being socially distanced and facing their own grief privately during lockdown as this Cruse Bereavement Volunteer explains:

*“Father’s Day this week and a client grieving for her father is finding it very tough and painful. She is thankful however that pubs and restaurants are still closed because she feels angry and resentful when she sees other fathers out there enjoying family time when she has not got her father there to celebrate with. Therefore on Sunday when we are still not allowed out she is protected from that source of pain. She does not have to be so aware of the others . She intended to somehow bypass the supermarket Father’s Day promotions and cards. In many ways she is finding the lockdown helps her because it’s giving her an opportunity to withdraw without trying to find excuses. [...] Withdrawing and being sad is just where she wants to be and she can do this without feeling guilty about being a “party pooper.”*  
*(22nd June – BV2)*

*“Lockdown has provided some of my clients a space to privately grieve without the pressure of social norms. Being able to withdraw and feel sad is good and many seem to have said it’s been a benefit but so is socialising and its distraction, the jump after prolonged lockdown has been a challenge to explore.”*  
*(July 6th 2020 – BV2)*

vi See [www.cruse.org.uk/bereavement-supporter-project](http://www.cruse.org.uk/bereavement-supporter-project)

vii See [www.cruse.org.uk/about/blog/bereavement-lockdown-diaries/](http://www.cruse.org.uk/about/blog/bereavement-lockdown-diaries/)

This key finding is a valuable insight for bereavement trainers and subsequently written about in national media coverage<sup>viii</sup> by the project team, as well as documented in the Cruse learn and share document.

Meanwhile, the documented impact of Covid-19 on ExtraCare residents manifested as a collective feeling of uncertainty and losing confidence. Some of the RBSVs recorded that they felt their role changed from a ‘supporter’ to ‘supporter and counsellor’, with a lot more listening and observing required on their part. For example, this RBSV recorded in her audio diary that there was a lot of grieving going on with residents but not necessarily about a recent death, rather, over other losses – grieving not seeing people, not seeing family or friends. Rather than grief per se, there was a shift to loss.

*“Grieving of not seeing family, not seeing friends. Grieving for the losses that aren’t death. All those little things make a lot of difference.”*  
*(RBSV3, 11th August – annotated from phone recording).*

Finally, as we will discuss in more detail in 7.4, we have seen some very positive signs of RBSVs developing their own initiatives for bringing about the cultural change necessary to making compassionate communities. The diaries showed us some powerful examples of RBSVs and other residents organising memorial events during the pandemic as the following excerpt from the learn and share report shows:

*“We had a funeral on Wednesday. Well, the thing about it, that girl she lost not only her mum, she lost her father and she lost her grandfather. So what Mavis and Heather did was they printed out some songs ... The staff came out to stand outside and by word of mouth I told some of the residents, ringing round saying to quite a few people that if they wanted to go down or stand on their balconies. They had a prayer and some songs, and they talked about her for about 15 minutes and then the hearse came round and stopped a bit. It was very moving, very, very moving and personal.”*  
*(22nd May, RBSV3)*

We have discussed above how staff in some of the villages are perhaps reluctant to recognise the skills and experience of the RBSVs and to treat them as peers, but what this example shows is that it is possible for the volunteers and residents to act on their own initiative and particularly now that the Bereavement Supporter project permits that broader change.

### 7.3.2 Residents

RBSVs provide many examples of the support they have given to the residents (ad hoc conversation and more formal and regular support). At the time of the interim report, 129 informal contacts had been recorded by RBSVs across the four evaluation sites. At the time of writing this final report, over 1290 residents, family members and Friends of village had accessed support through the RBSVs across all locations (see Appendix 4) and a further 13 residents had been referred further up the

viii West, K. & H. Rumble (2021) ‘What we’ve learned about bereavement during the pandemic.’

The Conversation <https://theconversation.com/what-weve-learned-about-bereavement-during-the-pandemic-153729>

Accurately capturing the number of people who have received bereavement support from a RBSV has been a significant challenge for the evaluation<sup>ix</sup> (and the Project more broadly). We know that RBSVs 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 RBSV explained; “*you’re not seeing, in my opinion, the true value because those conversations are not being recorded and probably never will be recorded*”.

Gaining access to residents who have received support from the RBSVs has been a persistent challenge. This we believe is for two reasons. First, and as discussed above, much of the support that is given to residents is of an informal and *ad hoc* nature. This kind of support is either not documented or, if it is, does not record contact details. It is also possible that residents would not even classify the interaction they have with RBSVs as ‘support’ as such, which is by no means to deny the benefits of interaction. Second, where residents are receiving more substantial and sustained support, emotions may still be raw, which may preclude their coming forward to talk about it. While we had plans in place to bolster the participation of support recipients in our 4 evaluations sites, the Covid-19 pandemic meant that we were unable to follow these up. We have case study data from two support recipients which provide the short vignettes in Appendix 1.

### 7.3.2.1 Support for residents through Covid-19

Albeit from the perspective of the RBSVs, the diaries data, discussed in 7.3.1. above, gave us some additional insight into the nature of bereavement support, from which we can infer benefits to the residents themselves.

*“We don’t have the answers, but we can stand or sit alongside others... The fallout [from C-19] is immense throughout the Village and it’s good to share that sense of loss of holidays, special birthday celebrations and short breaks. Being able to talk things through and share stories with others has been helpful.”*  
**(RBSV, diaries project)**

*“My friend Eunice, I told you her grandson was very ill [with the virus]. Well, he died. I did go round and see her. I didn’t break the rules. She was in the bedroom and I was in the passage just talking to her. I spent quite a few hours with her, because she was absolutely down, absolutely, absolutely devastated.”*  
**(RBSV, diaries project)**

*“We had a funeral on Wednesday. Well, the thing about it, that girl she lost not only her mum, she lost her father and she lost her grandfather. So what Mavis and Heather did was they printed out some songs ... The staff came out to stand outside and by word of mouth I told some of the residents, ringing round saying to quite a few people that if they wanted to go down or stand on their balconies. They had a prayer and a some songs and they talked about her for about 15 minutes and then the hearse came round and stopped a bit. It was very moving, very, very moving and personal.”*  
**(RBSV, diaries project)**

<sup>ix</sup> While we 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 Support revealed that less than 10% of client feedback forms are returned across the organisation indicative of a wider challenge capturing client experience.



RBSVs have been a vital source of support to ExtraCare residents in the following ways:

- Adapting their support to telephone and Zoom support and looking out for people known to them in their community. This is an important finding as it demonstrates that residents have adapted to new ways of working – such as switching to Zoom for online group activities – emphasising the often-underestimated adaptability of older people and their preparedness to use available technology.
- Organising ‘chains’ of telephone calls among residents in their own village derived from compiled lists of residents in order to listen and encourage fellow residents during difficult times, and deliberately taking every opportunity to talk to those they met. In the process they were informally building support around those in their residential setting who were isolated, lonely, grieving and/or depressed or recognised as struggling through what has been a challenging year.
- Arranging appropriate socially distanced spaces to meet and listen, which included being willing to bring a folding chair outside a neighbour’s apartment in the village and offer listening support whilst their neighbour sat at a safe distance in their doorway.
- One diarist went so far as to cook meals for another resident in their community

### 7.3.2.2 The benefits of being in the ExtraCare environment

A shared theme from both the focus groups with ExtraCare residents and the diaries kept by RBSVs concerns the perceived benefit of living in an extra care community when there has been a bereavement, as opposed to living in private accommodation and facing a bereavement alone. This became keenly felt during the pandemic:

*“I mean me moving in there six months, seven months ago with a company like this it is different, you meet different people and it does change your life...You meet different people, you sit in the restaurant, you’ll sit in the bar, you’ll meet different people at the reception and meeting like this people is different, but when you got a private tenancy or something different and are living on your own, it’s, it’s a killer. No wonder people kill themselves and suicide (Bernie: they have no one to talk to) yes, no one to talk to...”*

**(Rahul, a widower, –Residents FG)**

*“It was dreadful losing my husband and parents in such a short time, but it was even worse losing my daughter and in the way I found her, it was...it was awful and they were all just so lovely. They really were lovely and they all still are now. I’m really, really glad I live here. Really think it would have been different. If I’d been in a house, I don’t think I would have coped. I think I really would have a really bad nervous breakdown even with my family’s support. So yes, it’s a lovely place to live; I think so anyway.”*

**(P3, a widow –Residents’ FG)**





### 7.3.2.3 Men and bereavement

In fact, being in an extra care residential setting has a number of subtle advantages to reducing social isolation and loneliness in older adults more widely, not just those bereaved residents in need of bereavement peer support. This is true, especially for men, be they RBSVs or recipients of their peer support. Both the widow and widower quoted above have sought solace in the collective environment they are living in to draw strength in the face of loss and bereavement. Whilst ExtraCare Staff and a male RBSV have all commented that men are not engaging with the project as much as women (and only about a fifth of the volunteers are men), it is clear male residents seek support in other ways; such as bowling and social drinking. This does raise the question as to whether bereavement peer-support needs to be further tailored in its approach to appropriately meet the needs of different genders?

*“I’ve had .. informal chats with people who I know have been bereaved, maybe because I’m a bloke, people don’t open up to me as much! (LAUGHS) but I do try to talk to people, ... yes, I do talk to some male people who have lost their partners, but they don’t open up as much (LAUGHS) to be honest. They usually, one in particular, he is involved in bowling and I spoke to him a few times but he finds going out and playing bowling much more and he’s got this group of friends, the bowlers who I think he manages to cope through that.”*

**(Marcus RBSV in T2 Mixed site FG)**

*“... We do have a couple of men volunteers as well and that’s kind of, obviously this kind of generational stigma that it something me and my colleagues are working on at the moment trying to get these men’s groups off the ground because it’s a big massive aim here to try and support men with mental health issues and bereavement issues but it’s just proving really difficult with the age that they are ... they just don’t want to speak about their feelings, it’s just that stigma around the generation, you’re just a man, you don’t talk about your feelings... if you come into this village at about 9 o’clock on a Friday night in the bistro, in the bar area, there are probably a group of 20-25 men and they’re having men’s night and they drink loads of beer and they put the world to rights but that’s their therapy session it is their therapy session and it’s not that we want to infiltrate because we don’t but we want to make them more aware that there could be somewhere that they can, because there’s a lot of single men carers in here) that don’t have any help from any external care agencies and literally look after their spouses full-time that are suffering, that are going to the doctor’s with depression and things like that, that we could actually be helping them with but it’s just getting to them isn’t it so it’s just accessibility and it’s not, but we do have a couple of men bereavement volunteers very few and far between.”*

**(Volunteer Organiser)**

This staff member reports on the hidden issue of single male carers living in ExtraCare who live with the emotional labour and social isolation arising from the demands of care giving to their partner in later life. Certainly there is scope to explore the application of the peer-support model to address this resident population’s needs, but it would also be of value to also address the potential gendered stereotyping that appears to be imposed upon male residents by staff, such as the Volunteer Organiser quoted above. What is also important to note is that fewer men than women in the general population access bereavement support, so this is an issue that requires further investigation beyond the remit of the Project.



### 7.3.2.4 Equality, diversity and inclusion

Whilst the Evaluation did not focus on diversity specifically, the Project has adapted its approach to meet the diverse needs of all the community. Several Bereavement Supporter volunteers have a registered disability, including visual impairment. Training delivery and associated paperwork was adapted to meet those needs and, transport was provided for any volunteers who needed it.

At one of the evaluation sites, the majority of the population is from the BAME community. In order to ensure that events and materials were culturally appropriate, a coffee morning was held at the start of the Project along with a number of community engagement activities, including with community and church leaders, to help understand cultural and religious issues concerning bereavement. As a result, the Project contributed to events around dementia and mental health that were specifically tailored for the community and specific videos and resources were sourced.

These types of tailored approaches to meet the different needs of each community, will be equally as important as the Community Model continues to be rolled out.

We will discuss in 7.4. how the Project is achieving wider impact in terms of fostering the sort of culture change within the ExtraCare villages that enhances everyone's grief literacy. Now, however, we turn briefly to what has been achieved within the remit of the Project to enhance outcomes for residents living with dementia.

### 7.3.3 Residents living with dementia

The interim report provided insight into the experiences of supporting bereaved people with dementia, and the wider losses experienced by those affected by dementia.

Since the interim report, a number of resources have been developed by Cruse and ExtraCare to improve bereavement support and provide specialist information, for residents living with dementia, carers, and staff. To date 3975 copies of the below mentioned resources have been distributed both internally and externally to organisations including housing providers, and service providers working with older people, carers and people living with dementia.

#### **a) Factsheet**

One of the common challenges ExtraCare staff face is knowing how to correctly support someone with dementia who has forgotten about a bereavement due to memory loss, or is confused about what has happened. A factsheet was developed, "Responding to distress and behaviours that challenge", using specific real life examples relating to dementia and bereavement, to provide staff with guidance to respond to distress responses in an appropriate way.

#### **b) "Carers' Stories"**

Carers and families often experience grief from the point of their loved one's diagnosis of dementia, or even as symptoms start to appear. Following a series of workshops with carers who are ExtraCare residents, a new resource was developed called "Carers' Stories: Loss along the journey", describing the carers' experience of a changing relationship with their loved one, and including advice from carers themselves.

Susan, resident and carer from Longbridge village who helped write the guide said "This booklet will give other carers information about what it's really like being a carer from a carer's point of view, wherever they are on the dementia journey".

A PDF version of the guide can be found here:

[www.cruse.org.uk/bereavement-supporter-project-resources](http://www.cruse.org.uk/bereavement-supporter-project-resources)

Both the Alzheimer's Society and Carers Trust have positively received the resource and agreed to share internally and with their networks.

### **c) Dementia Diaries 'Learn and Share' report**

Collaboration with the Dementia Diaries project (also Lottery funded) enabled a face to face workshop to take place in February 2020 to explore losses experienced by people living with dementia, by listening to their in-the-moment thoughts, feelings, challenges, and reflections. A follow up report was published and shared widely

[www.cruse.org.uk/bereavement-supporter-project-resources](http://www.cruse.org.uk/bereavement-supporter-project-resources)

One researcher on social media commented: "This is such profound work. Reading it was moving, Such crystal clear insights into the experience of living with dementia. So helpful for all of us to appreciate, as human beings in this world together"

The Cruse Project Lead has also trained as a Dementia Friends Champion with the Alzheimer's Society and has created 143 Dementia Friends within Cruse meaning that the organisation as a whole is improving awareness regarding dementia and is better placed to support people living with dementia or bereaved by dementia.

## **7.4 Wider Impacts**

As we have already discussed, the Bereavement Supporter Project is partly about broader cultural change, which will take time. Here we discuss the wider impacts of the Project, particularly with respect to developing the 'grief literacy' necessary to bringing about that wider cultural change and to foster compassionate communities.

### **7.4.1 Recognising a shared culture of loss**

Whilst a programme of culture change takes time, one of the most striking findings from both the Bereavement Supporter project and the smaller diaries project during the first lockdown of 2020, is the evidence of recognition on the part of staff and the RBSVs of the wide range of losses beyond simply death-related loss that constitute a resident's sense of bereavement. This acknowledgement by RBSVs and staff has the potential to support the development of grief literacy that is central to ExtraCare's overall strategy for supporting end of life care. Since the RBSVs have been offering informal peer-support there has been more opportunity for addressing loss and recognising a shared vulnerability to loss that enhances empathy and understanding. The diary data suggests that the impact of covid-19 is that we will all be more readily willing to discuss loss with others, because we will have collectively experienced some form of loss over the last year.

*"Grieving of not seeing family, not seeing friends. Grieving for the losses that aren't death. All those little things make a lot of difference."  
(RBSV diary entry, 11th August 2020)*

There is also a shared loss for all the residents of ExtraCare villages that they may or may not acknowledge, regarding the losses that came with their departure from former homes and neighbourhoods to move into an ExtraCare village:

*“There are loads of services available and one of them is bereavement but .. could we widen it? Because I think you see that one or two folk are really grieving about having left their homes so that you know there’s a very able lady in her 90s, ex-headmistress, and you could imagine it too, she’s a friend of a friend actually so you know but she used to live in Moseley and she wishes that this was in Moseley well some of us think this would be better placed in Harborne! coz you know if we’re being absolutely honest being in this area ain’t a good idea.”*  
**(Meredith, RBSV)**

*“...there are all sorts of losses and that we sometimes just consider it as a death, but you know perhaps we should be looking at helping people other than the deaths, in conjunction with what we’re already doing in terms of support...”*  
**(Richard RBSV T2 FG)**

Not only has the RBSV quoted above, reflected on his practice and the forms bereavement can take, another volunteer discloses how her own understanding of bereavement has widened to recognise more than a loss incurred via mortality, which was crucially developed and enhanced via her initial Cruse training for her peer-support role:

*“...that people can go through different kinds of bereavement and that’s still bereavement it’s not all the death bereavement that you go through (I: so you mean like other losses can be experienced like a bereavement?) yeah, with your partner, or your husband, somebody leave each other (I: yeah, divorce or separation) I’ve been through that and it’s another bereavement for me [...] (I: did you think about them as bereavements before you had the training?) no, I was only thinking about just death, now during the training I learned there are different kind of bereavement and with the loss here like divorce .....”*  
**(Marilyn, RBSV)**

#### **7.4.2 Communicating death and talking about death**

We have discussed at length how members of staff who have taken the one-day Cruse loss and bereavement awareness training say that the training has helped them to overcome the anxieties of talking to residents about death, dying and bereavement. The most striking learning point for staff, has been in learning to overcome the impulse to act and to offer platitudes of comfort.

*“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”*  
**(Phase 1 focus group with ExtraCare staff)**

*“When talking to residents in groups or in locations, I feel more confident to talk to them about their concerns, thoughts. I have also spoken to a family member about someone at end of life and felt able to talk more honestly and openly.”*  
**(Training feedback survey, ExtraCare staff member)**

*“This will help me to realise that as part of my role I don’t have to and am not expected to fix the situation. Grief is not something that can be fixed...”*  
**(Training feedback survey, ExtraCare staff member)**

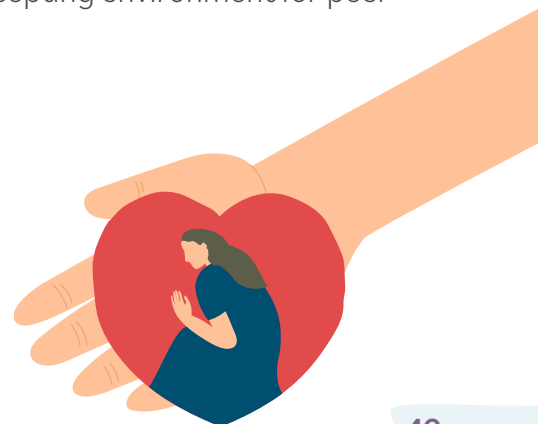
Changing culture and developing grief literacy is a process that will take time. The Bereavement Supporter project is certainly an important step in the right direction. As a postscript to the data collection, additional project activity has been undertaken to continue opening up conversations about grieving and bereavement, aimed at those residents who may not attend an information session due to the topic. Residents have been given the opportunity to read and review a selection of books (fiction, non-fiction, illustrated and autobiography) about life’s experiences including loss, grieving, loneliness and finding hope. Resident feedback will be used to create a recommended booklist for anyone bereaved that provides comfort, solace and time to reflect, which can be stocked in the village libraries across ExtraCare.

It is also worth noting here that RBSVs have experienced certain organisational barriers around the communication of the deaths of residents to both other residents and the deceased’s family. For example:

*“I don’t think staff actually do bereavement support to residents. I don’t think you know when somebody’s died.”*  
**(Lil, RBSV T2 mixed site FG)**

*“...They manage this village, they see everybody every day of the week and they know the funeral has been ordered, and the food and everything, but nobody ever tells the person that when there is a bereavement that this information should be passed on to the family, yes it would be a good idea to put up a notice and a photograph that kind of thing (I: and why do you think they don’t do that then as normal practice?) I just don’t think they think!”*  
**(Cathleen RBSV)**

We know that ExtraCare have gone to great lengths to explain to village staff and managers that there are no regulatory reasons why staff cannot let residents know when somebody has died. Nevertheless, there seems to be a persistent reluctance to open communication about the death of residents on the part of some staff. This is not an easy matter to address as there is a fundamental conundrum with ExtraCare in that some residents move in knowing they will only leave when they die, whilst others may not even recognise that and perceive the move into a village as a proactive step towards maintaining independence. This means that death becomes an uncomfortable truth that some try to mask or cover up through the use of idiomatic speech as an act of avoiding some hard truths. Death then becomes known only as ‘passing away’, which does nothing to help foster an accepting environment for peer-supporting residents who are grieving.



*“ExtraCare won’t allow any kind of benches, if a family wanted to buy a nice bench for outside with someone’s name on that’s completely a no-no with ExtraCare just generally, like at the moment a notice has just been put up because we’ve had quite a few deaths lately, and one man who has died has put “passed on whatever of December” there’s no “has died” it’s just not being used now - it’s all “he’s passed” and that’s general, on the television, on the news wherever that seems to have come in as a general thing and it’s almost a denial of death in a sense and you get that even with talking with some people they don’t want to know and one lady said last week that with the memorial book “it’s bad enough getting older and knowing we’re going to die, but we don’t want to be reminded of the grim reaper all the while” so there’s a lot of negative attitude towards death and bereavement here.”*

**(Lil, RBSV)**

In spite of this, though, as the quotations below illustrate, by no means all residents are reluctant to engage openly with death, dying and bereavement and some have a strong sense that the challenges lie in mixed understandings about what ‘extra care’ is:

*“We had a...somebody was coming from the John Taylor hospice to talk to us and there were notices put up and some people were so offended by it, by the thought of discussing death that it was all finished and I thought yes, 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 it just not come to the meeting? So it was all pushed under the carpet and I thought that was a bit...”*

**(P2 - Residents FG)**

*“It’s not a hospice because everybody isn’t probably terminal at some stage, we are living life here and we do look positively at different things about health and about physical activity and about getting involved in different things and entertainment and whatever and then maybe, if you had such a discussion relating to issues around death that could come as part of a series of things that were happening about older people but later life maybe, not end of life but later life and look at sort of different things that you can plan for the future.”*

**(P4 - Residents FG)**

Added to the ambiguity and conflict in attitudes arising from what extra care stands for, the reality is that residents come from many different cultural backgrounds, each with its own cultural heritage and expectations regarding care work and family duty following a death:

*“I’m, I’m a Muslim, I mean I’m from Pakistan and we have no such thing as bereavement support. We have nothing at all. No, none whatsoever, no we don’t, no, no seriously darling we don’t have this. “once he’s gone he’s gone” “once she’s gone she’s gone” With our culture and tradition and things like this the oldest son got to look after the rest of the family, the parents end of story. That’s your bereavement, you know “his wife will look after me.”*

**(Rahul, a widower-Residents FG)**



However, in spite of these significant challenges, we also saw some very positive signs that RBSVs, empowered in their role, had taken it upon themselves to overcome the organisational constraints of letting other residents know when a resident falls ill or dies. In one village they had organised an opt-out form whereby residents could let it be known to staff that if they go into hospital or die, they want other residents to know. Some had taken it upon themselves to organise collective memorial events (see Appendix 2 for examples). As the quotation below illustrates, some of the villages have a generally supportive attitude to bereavement, which residents themselves, together with staff, helped to create:

*“... We are so lucky here that everybody understands that, you know that somebody has had a bereavement and they may not be as they were obviously and it’s recognised within the whole village which is a good sense of the community that we have.... I can only class it to like we would all have lived in a street before and somebody down the road... had a bereavement, you probably don’t want to impose on them, you probably if you were to see them in the street say “sorry to hear of your loss” but here it is a little bit more togetherness.”*  
**(RBSV focus group, T2)**

It is hard to think of a more fitting way to describe the sort of cultural change that the Bereavement Supporter project aspires to and is achievable within all of the villages over time.

### 7.4.3 Collectively grieving

As mentioned, culture change takes time and more changes may be seen longer term, beyond this evaluation. As a postscript to the data collection, ExtraCare (supported by Cruse) provided locations with resources and guidance to actively participate in the Dying Matters initiative #IRemember week held between 26th October and 1st November 2020. This gave residents the time and space to collectively grieve for or reflect on a recent or historic loss, a chance to say goodbye in lieu of funeral attendance and a tangible and practical way to remember. Over 400 residents took part in creative and poignant activities such as memory trees, minutes silence, photo walls and socially distanced remembrance services. Both the Cruse and ExtraCare project leads felt this participation would not have been possible at the start of the project, because there was little interest amongst residents or willingness to engage with the topic.

*“I thought the #IRemember week activities were such a good idea. During the pandemic there has been little opportunity to remember those we have lost as a community.”*  
**(Resident who attended activities)**





## 8. Concluding Thoughts and Recommendations

### 8.1 Reflections from Conceptual Models

The successes of the Bereavement Supporter Project lie in the impact of the training on residents and staff at all levels of the organisation, which, in turn, has spurred the development of grief literacy across the organisation and opened up mature conversations about death, dying and bereavement. It has also afforded residents meaningful and challenging volunteering opportunities that deploy their experience, knowledge and skills. Although evidence of impact on support recipients is scant, we can infer from the cases that we have examined that when residents have needed bereavement support, RBSVs have been on hand to offer it. What we have also learned through the diaries project is that RBSVs have been pivotal in supporting residents through death-related bereavement as well as through other significant emotional challenges associated with other kinds of loss. In many ways the Covid-19 pandemic has proven the need for the Project and demonstrated the additional value of the RBSVs, who are uniquely attuned to other residents' bereavement-related needs and have challenged some unhelpful organisational practices around communicating the death and ill health of residents.

Where the Bereavement Supporter Project has encountered difficulties, they have arisen through poor trust, communication and partnership working between RBSVs and ExtraCare staff. There is a persistent reticence from ExtraCare staff to share information about residents' health and wellbeing status, even in the most minimal need-to-know terms. Further, the staff who have been designated to oversee and support the RBSVs at different points in time, for their part, have perhaps struggled to absorb the role into their busy working schedules, sometimes leaving RBSVs feeling unsupported and invisible. This raises questions about the support structure of the Project, particularly in its original quasi-professional form of referral to designated volunteers with a higher level of training, recognition and support.

The public health and compassionate community approach, upon which the Project is founded, suggests the deprofessionalisation of end of life and bereavement care. The most basic premise of both the GSF and the compassionate community approaches to end of life care is that death, dying and bereavement is everyone's business, not just that of professionals.<sup>6</sup> While there are hopeful signs of staff working within this general ethos, current organisational structures and processes in ExtraCare appear to be founded on residents' self-presentation or self-referral of need rather than a pro-active peer-to-peer looking out for each other that we have seen, for example, through the pandemic. We do not think it appropriate to single out particular villages for either praise or condemnation, but it does appear to us that the programme has taken off best in the villages in which there is a very basic understanding that the wellbeing of community members is everyone's business and, in which members of the community trust in, and consider themselves as part of, that community and not as individuals whose privacy is to be guarded at all costs.

We now reflect on the implications of the Covid-19 pandemic for the Project at the RBSV role and consider alternative models of peer bereavement support that could overcome some of the organisational obstacles we have discussed.

## 8.2 Alternative Peer Bereavement Support Models

In spite of the restrictions to daily life imposed upon the residents, the Covid-19 pandemic does seem to have given additional impetus to the kinds of community caring practices that are more conducive to a compassionate community approach to end of life. The RBSVs, as well as residents in general, have been forced to take matters into their own hands, organising systems of checking in and telephone support, organising memorial events and so on. Although a sad fact, Covid-19 has made it impossible to hide away from death. Even if the rate of Covid-related deaths in the villages has been low, the presence of death and bereavement is everywhere to be seen. RBSVs and staff who have attended the Cruse training have the necessary grief literacy to deal with the manifold losses that will surface once lockdown ends. Cruse training ought now to be mandatory for all ExtraCare staff.

### 8.2.1 A Community Model

Our Project partners' thinking on peer bereavement support in ExtraCare has altered somewhat since the Project was first conceived and partly as a consequence of the organisational challenges around the delivery of the original model. Alongside the recognised Bereavement Supporter Volunteer role, with its 1-day training programme and programme of staff referral and support, a new community model is being trialled in some of the villages. This, as already mentioned, is open to all residents and consists of a less demanding 2.5-hour training programme and does not carry the RBSV label. If we refer back to the pyramid of bereavement support in Figure 1, this new community model is aimed at the most universal and basic level of information and awareness to develop grief literacy across all villages and thereby foster an environment in which all residents can each speak self-assuredly about death, dying and bereavement and be compassionate neighbours. We have not been able to fully evaluate the implementation of the Community Model, although we have been able to glean some insights from residents' responses to scenarios of bereavement following the training. These would indicate that the Community Model is consistent with the compassionate communities model, fostering an environment in which all residents can each speak self-assuredly about death, dying and bereavement and be compassionate neighbours, and aligns well with the requirements of the GSF. Feedback from residents who've attended the training as part of the Community Model has been very positive. All rated the training 'excellent' or 'good', and all felt that after the training they were more comfortable in supporting somebody who is bereaved. Motivations for undertaking the training are also similar to those of the Bereavement Supporters, wanting to better support someone bereaved.

We received responses from 3 residents to a series of scenarios regarding different kinds of bereavement that fellow residents may experience and these revealed a genuine capacity for empathy and appropriate and sensitive support on the part of those residents who had put themselves forward for the training. Each respondent conveyed a sensitive understanding of grief, and that grief can affect everyone differently, there is no time limit on grieving and there is no right or wrong way to grieve.

*“I allow my neighbour to talk freely and understand her continuing distress with greater empathy.”*

*“Have not had the opportunity to talk with anyone.”*

*“Although I did the course have not been approached by the village or anyone in it.”*

Suggestions for how they would support a bereaved resident included:

- Posting a card to the bereaved person
- Inviting them for a drink
- Offering practical help
- Listening with compassion and without judgement
- Ongoing communication and contact with the individual

Responses to whether the training had been put into practice were mixed. However, as with the RBSV model, it was evident that some need 'permission' or expect formal referrals or recognition from staff in order to support a bereaved person.

*“I firmly believe bereavement support in <Village>; its members should have a ‘trusted volunteer status’ in terms of Resident privacy and confidentiality. Boundaries must be established.”*

*“The word ‘village’ is used loosely and we need to take care. It can mean small communities of people who live side by side for decades and in doing so get to know whom they can trust with their emotions and their experiences. This retirement village has not yet had the chance to develop this to the same degree, especially during Covid lockdowns. Natural carers need time to evolve and become accepted. Carers need to be organised into teams for mutual support, availability and accountability. Carers and those to be cared for need leaders who are identifiable, trained, and supervised.”*

While the Community Model may overcome some of the issues of formality associated with the RBSV model, there is nonetheless an underlying suggestion that residents feel further steps are needed to empower and activate the community. Support will not simply happen organically without an infrastructure of support from appropriate staff that embeds and legitimates the model. What is also evident is that both the more formal RBSV model and the Community Model require an organisational culture in which staff, for their part, feel able to share the news of resident deaths; and volunteers, for their part, feel that they have the backing and confidence of staff when it comes to offering support to other residents.

The Community Model is clearly a less formal model that, in many ways, is more consistent with the sort of compassionate communities advocated by the National Bereavement Alliance, the Irish Hospice Foundation and others. However, it is evident that a degree of formal recognition and organisational support will be needed to embed it in the villages. Furthermore, we would argue that there is still a place for the more formal RBSV role for three reasons:

- 1) It is evident that there are many residents with the kind of life and professional experience and skills that are conducive to such a role and, indeed, that there are few other volunteering outlets for these skills and experience. It would seem to us to be a pity not to utilise these skills across the villages;
- 2) As we have noted in the main body of this report, given their skills and experience, the RBSVs do seem to have a special role to play in supporting the bereaved that goes beyond ordinary neighbourliness as evidenced in their capacity to support those residents who are perhaps not well integrated or universally well liked in the villages;

3) As we have also seen, particularly in the pandemic, the RBSVs also seem to have the confidence to challenge some of the paternalistic attitudes of staff and have overturned some unhelpful organisational practices around death, dying and bereavement. Again, it would seem a pity to lose these capacities.

We recognise that the original RBSV model was open to all residents, but, in practice, it has been most enthusiastically taken up by those with prior skills and experience in counselling-, advocacy- and advice-type roles. One thought is, therefore, that there could be two strands – a quasi-professional RBSV role, but perhaps with more restrictive entry criteria, working alongside the open Community Model. In any event, we argue that to sustain the RBSV role, that certain conditions need to be fulfilled. These will discuss in the recommendations section at 8.4.

### 8.2.2 Telephone support as alternative to face-to-face peer support

Between October and November 2020, general Cruse clients were invited to complete a survey about their experience of accessing remote support during the pandemic, which prevented any face-to-face support taking place. All clients who completed the survey received telephone support, support via Zoom, or a mixture of both and were positive about the support they received. Remote support was deemed: convenient and accessible (especially for clients with mobility restrictions), of good quality during difficult times, reduced discomfort and embarrassment for the client in the absence of face-to-face support whilst still helping to normalise their grief. The results of this survey have been produced by Cruse as an infographic – see Appendix 3.

It is encouraging that 12 out of 17 respondents said they didn't have any suggestions as to how Cruse could improve their telephone service. The service was "faultless", "excellent", "worked well". Five respondents made some suggestions to how the service could be improved, and these were:

- "Reduce number of people the bereaved person has to tell their story to before being allocated appropriate [Bereavement Volunteer]."
- "The telephone service would work well if the counsellor had met the client in person before. This could even be with face masks and social distancing if required."
- "At times there was phone is ringing in the background and doors closing so I found that distracting at times and it must've been for the counsellor who would've been experiencing the noise at his end".
- Two people suggested video calling as an additional option.

Despite misgivings by some Cruse Bereavement Volunteers about the transition from face-to-face support to remote support, those Cruse Bereavement Volunteers who kept diaries during the first lockdown in 2020 noted some surprises and changes in their attitude towards remote support that warrants quoting here:

*"Some of my telephone sessions, with disabled or unwell clients, would never have taken place in our rooms. I am learning to work with clients who are slower in their process during the session and to measure, pace and weigh the silences. I do find it challenging and for some of these clients I would like to give more sessions because they are slow and very low so the progress we make together is in tiny little steps. Giving telephone support in isolation is different from doing it in the office where there is a team of people about. A general sharing of frustration or pleasure or just general comradery makes a huge difference in the work I do."*  
**(Early August - CBV2).**

So whilst there were some Cruse Bereavement Volunteers who missed giving face-to-face support because they liked to ‘read’ their clients body language and felt it enabled better rapport and more comfortable silences, a number of others were pleased at the potential reach of their support if offered remotely. As one Cruse Bereavement Volunteer also noted, if support was offered remotely, then adults with physical disabilities that meant they had limited mobility could also become Cruse Bereavement Volunteers. This was encouraging and positive learning during a period of rapid change in how Cruse delivered their support. Although not a strong theme in the Bereavement Supporter evaluation data, volunteers and staff also wondered whether telephone peer support might work as a complement to the face-to-face peer support across the villages. As they saw it, this would enable more opportunities to put their experience and skills to use and may overcome some of the barriers to residents taking up face-to-face support, particularly among men.

### 8.3 Limitations of the evaluation

We recognise the following primary issues as limitations to our Evaluation of the Bereavement Supporter Project:

1. Data collection, as originally planned, was curtailed by the pandemic. This therefore explains why there is a conspicuous absence of interview and focus group data with ExtraCare staff and recipients of resident volunteer bereavement peer support. The plan had been to conduct interviews with both these cohorts of participants in order to understand their experiences and needs. This absence may have somewhat skewed our perspective towards the RBSVs. However, on the positive side, the lockdowns that accompanied the Covid-19 pandemic provided an opportunity for the team to gather different forms of data and experiment with other methodologies for data collection. Out of this came the diaries project (see Appendix 2), which was able to gather very rich, personal accounts of residents’ daily life during ‘lockdown’, albeit again from the perspective of the RBSVs.
2. The research team were hampered by an inability to access residents who had received support from the RBSVs. We acknowledge that their experience and views of the peer support service are lacking in this evaluation therefore.
3. The informal nature of this Project’s peer support and the recording thereof hampers formal evaluation, since many instances of bereavement support were not recorded or recognised by the RBSVs.
4. We acknowledge that only four locations were involved in the main part of the Project. Whilst this is clearly not a representative sample from across ExtraCare’s locations, what is lacking in breadth is more than compensated for in depth. This is especially true of the unexpected delivery of the diaries project in response to the pandemic in 2020, which also gave us access to RBSVs in two additional locations.

## 8.4 Recommendations

Our evaluation findings suggest the following recommendations for Cruse and ExtraCare:

### 1. A clear and consistent member of staff to act as Project champion and RBSV liaison

Success of the Bereavement Supporter Volunteer role requires ‘buy-in’ from ExtraCare staff at all levels and especially where the RBSVs are not already well known to residents. The role needs to be proactively integrated into the communities for it to be implemented appropriately. Close communication is required between staff and the RBSVs for it to fulfil its objectives. As noted, the role of Project champion and RBSV liaison has moved from role to role and currently sits with the Volunteer Organiser. Whichever member of staff takes this on, it must be consistent and with ring-fenced time for the champion and liaison task. Ideally it should sit with a member of staff that is most closely aligned with bereavement support and who understands the RBSV role and the volunteers’ training, experience, and expertise.

### 2. Mandatory loss and bereavement awareness training for staff

To be serious about approaching the goal of becoming a compassionate community requires a commitment to train staff. We found high levels of satisfaction with the training among staff and residents, and fully endorse the quality of the training provided by Cruse. We recommend the training is mandatory for staff and perhaps that staff and volunteers could attend joint training and peer groups or forums to foster collaboration and integration.

### 3. An environment of collaboration and co-production

At a Project Management level Cruse and ExtraCare collaborated with residents and staff at every stage of the project, which directly impacted on project development. For example quarterly Project Reference Group meetings, involving RBSVs and staff, led to: changing the volunteer role name; co-designing project paperwork; and co-creating a tree image which has acted a symbol for the project and has been used by volunteers as a communication tool. However this same spirit of collaboration and co-production did not always seem to be replicated at a local level. Local staff in some locations were reluctant to take ownership of the Project making it difficult to progress the Project without the input of Project Leads.

To facilitate close working partnerships between ExtraCare staff and RBSVs, we recommend moving towards an environment of collaboration and co-production at a local level. ExtraCare is very good at collaborating and positively utilising skills wherever they exist. We suggest that this collaboration go further by fully recognising the skills and wisdom of resident volunteers (in any role, but in the context of this report, the RBSVs). Involving resident volunteers in the development of roles or projects, as stakeholders, at a local level would afford them further responsibility and, thus, ownership of such projects. Ownership comes from fully understanding the need for an initiative and is more likely to result in effective uptake.

This could involve setting up an equitable forum at local level, led by a specific local staff member, where staff and resident volunteers can get to know each other, where they attend shared events (meetings, training, discussion groups), and where they can forge productive working relationships.

#### **4. Clear protocols on data sharing between staff and Bereavement Supporter**

Any role requires boundaries within which to function, but it appears that boundaries between staff and RBSVs have been too rigidly interpreted by some members of staff when it comes to sharing even basic information about residents that could aid them in their role. A clear protocol needs to be established across the villages about what can be shared with RBSVs about residents' health, wellbeing and whereabouts.

#### **5. A supportive forum for RBSVs**

We noted that some RBSVs have suggested that they would like the kind of clinical supervision that is normally given in professional counselling roles. We also understand that this is probably not practical or necessary within the remit of the Project. Nonetheless, we recommend that some sort of supportive forum is established in which RBSVs can discuss the support they're providing, any problems experienced with support recipients, and any issues they have found difficult to deal with. The emotional cost of bereavement support needs to be recognised and ExtraCare needs to fulfil its duty of care to its residents in providing them with appropriate and on-going support. We understand that the initial service model placed onus on the Volunteer Organiser to have monthly peer meetings in their village with RBSs but this does not seem to be consistently applied. This needs to be revisited.

It is likely that ExtraCare staff would also benefit from the provision of such a forum; they are certainly not immune to the emotional labour inherent in grief work. It may be beneficial to further pursue the relationship between ExtraCare and Cruse in the provision of said supervision.

#### **6. Open death dialogue fostering grief literacy**

The Gold Standards Framework (GSF) for End-of-Life Care promotes open dialogue about death and advance care planning. As an organisation, ExtraCare has signed up to the GSF and offers expert End-of-Life Care. As part of that endeavour, and to develop grief literacy among staff and residents, there is a need to bring death conversations into everyday living in ExtraCare villages. We have seen some very positive signs that the Bereavement and Loss Awareness Training, and Information Sessions, have started to develop the grief literacy of both staff and residents. We have also seen how the RBSVs have challenged and modified entrenched practices around communication about ill health, death, dying and bereavement and organised collective memorial events and so on. These practices need to be strengthened and generalised across the villages to fully embed the ethos of the Bereavement Supporter project and to foster compassionate villages.

We also found euphemisms for death in common usage; language may seem unimportant, but the way we talk about (or don't talk about) death can significantly impact on the way people think about it and behave around it. The covid-19 pandemic has brought death and grief into the open somewhat. This offers an opportunity to capitalise on the shared experiences of grief residents and staff have had during the various stages of lockdown in 2020-21 by continuing conversations about loss, death, and dying.



## **7. Telephone support**

Despite expectations of the former, RBSVs' experiences of providing telephone support were largely positive and they were well received by support recipients. Telephone support fosters anonymity, which can encourage some to seek support who would otherwise avoid it, perhaps men in particular. It also encourages wider uptake of bereavement support across villages; volunteers would not be restricted to supporting those living in their own village. It may be that telephone support is supplemented by use of other technologies (e.g. video call software) if desired by residents.

## **8. Appropriate spaces for bereavement support**

On several occasions the lack of space was identified as a problem for Resident Bereavement Supporter Volunteers. Existing spaces had been commandeered by volunteers which worked well, but they were not always available. Some support sessions were interrupted by residents who were unaware they were being used as a private space. Space needs to be culturally appropriate to recognise the different ways in which people grieve and make sense of death.

## **9. Compassionate communities training**

The Cruse Bereavement and Loss Awareness training is arguably one of the most successful elements of the Project, so we see no reason to alter that. That said there seems to be little in the training about how to apply that knowledge of bereavement to the development of compassionate communities. We have seen some very good practice from the RBSVs in terms of working supportively with bereaved residents to reconnect them back with the wider community with which their bereavement has temporarily caused them to lose touch. However, we have also seen how there is perhaps also a tendency to see the role as becoming a special and exclusive friend to the bereaved. There is a fine line to be trodden here and some of the ideas from the compassionate communities model may help to supplement the training in terms of a better understanding of the end goal of peer bereavement support.

## **10. Further exploration of the Community Model**

Although we have not carried out any formal evaluation of the new Community Model currently being trialled in some of the villages, we think there is merit in exploring this further. First, it is very much in line with the public health and compassionate communities approach that asserts that in most cases of bereavement nothing more is required than a neighbourly, sympathetic ear. Second, it has the potential to overcome some of the organisational and resource barriers to the more formal and quasi-professional RBSV role. That said, we do think that it will still require that staff recognise that the support of good neighbours who have been prepared to undergo the training can be as legitimate and important a source of support to bereaved residents as their own professional support.

**Special thanks go to The National Lottery Community Fund for their support and guidance, without which the Project would not have been possible.**

### Appendix 1 -

#### Vignettes of two bereavement peer support recipients

Mrs Carter, a woman in her sixties, who had suffered multiple bereavements in her lifetime, approached the Resident Bereavement Support service on the recommendation of her friend. Evidently she had withdrawn from community life and events, following an incident. As Mrs Carter herself put it: she “*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”*

Mrs Carter 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 motivation 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, because of the support of a Resident Bereavement Supporter:

*“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.”*

Two other support recipients sought support for more recent spousal bereavements. They noted that they had reached out to the volunteers because they felt their grief was becoming over burdensome for their families. In one case, support had not been continued at the time of the interim report because other family matters had intervened. In the other case, support had not continued because, in the words of the recipient, **Mrs Laverty**: “*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 and to start to build a life of her own:

*“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.”*

Mrs Carter's case provides clear evidence of the lasting value that peer bereavement support can bring. The evidence from Mrs Lavery is less strong, but does attest to the need for support either when residents are suddenly faced with bereavement as a result of the death of a close relative or spouse, or because there are past bereavements that residents keep to themselves for fear of overburdening family members.

## Appendix 2 -

### Compassionate Communities for Extraordinary Circumstances: Using diaries to capture bereavement support during the Covid-19 pandemic.

Both Cruse and ExtraCare learnt a great deal from this methodology and were impressed by the enhanced engagement of RBSVs compared to previous focus group and interview activity. The success of the diaries approach was due to two factors. Firstly, the research team and partners were agile and flexible in how these diaries were kept and collected in order to accommodate the preferences of those taking part. Therefore, whilst some diaries were kept as word-processed accounts that were emailed to the team on a weekly or monthly basis, other diarists chose to keep handwritten records and attach them as scans to an email at regular interviews. One diarist requested that her diary was a recorded telephone conversation on a bi-monthly basis. Irrespective of how these diaries were kept and submitted, they were all thematically analysed by the research team and project partners at Cruse and ExtraCare. Secondly, part of the successful engagement and commitment to this project by diarists must be attributed to the fact that they could take ownership of their diary; not only in its format but also in its content. The project team never overly directed what diarists could document and reflect on, other than to stipulate that we were interested in their experiences and observations of the pandemic in their day-to-day lives. Subsequently, whilst the diaries cover far-ranging topics, they are rich in description and highly evocative. On occasion they describe death announcements, collective village responses to a death or departure of a resident in a hearse, informal resident-led support activities and collective anxieties about death and the pandemic.

**Compassionate Communities for Extraordinary Circumstances:**

*Using diaries to capture bereavement support during the Covid-19 pandemic.*

**Authors:**  
Hannah Rumble, Karen West and Ailsa Cameron from the University of Bristol; Rachel Shaw and Caity Roleston from Aston University; Eve Wilson from Cruse Bereavement Care; and Michael Spellman from The ExtraCare Charitable Trust.

University of BRISTOL  
Aston University  
COMMUNITY FUND  
Cruse Bereavement Care  
The ExtraCare Charitable Trust

January 2021

# Compassionate Communities for Extraordinary Circumstances:

*Using diaries to capture bereavement support during the Covid-19 pandemic.*

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January 2021



# What we did

This project was carried out in partnership with the leading national bereavement charity, Cruse Bereavement Care, and a major provider of extra care housing, The ExtraCare Charitable Trust, together with researchers at the University of Bristol and Aston University.

Between May and September 2020 (during and after the first period of 'lockdown'), 8 bereavement support volunteers kept diaries.

The diarists were either Cruse Bereavement Volunteers (BVs) offering bereavement support to clients across the UK or volunteer Bereavement Supporters (RBSs) offering peer support to fellow residents within their ExtraCare retirement village communities in England.

The project was part of a much bigger five-year (2017-2021) partnership between Cruse and ExtraCare – [The Bereavement Supporter Project](#) - which is funded by the National Lottery Community Fund. It is a pioneering public-health approach to bereavement support for older people that recognises the need to develop the capacities of communities to support friends, neighbours and family members through 'normal' processes of grief.



# Why we did it

To help us better understand the impact of the Covid-19 restrictions on ExtraCare residents and Cruse bereavement support services in relation to death, grief and the way a community supports bereaved people at a time when our experience of grief may be different and our normal rituals are affected or unavailable.

We were interested in the ways in which the Covid-19 restrictions affect grief and bereavement support regardless of whether or not Covid-19 was the actual cause of death and to learn about practices that could be helpful after the pandemic.



# What we found

Presented in this booklet are the most powerful themes identified across the lockdown diaries, followed by key learning and recommendations to better support people through loss and bereavement during a pandemic; an extraordinary context that has heightened social isolation for many.





# Theme 1:

## Compassionate listening and peer-support were vital during 'lockdown'.

"We don't have the answers, but we can stand, or sit, alongside others... The fallout [from C-19] is immense throughout the Village and it's good to share that sense of loss of holidays, special birthday celebrations and short breaks. Being able to talk things through and share stories with others has been helpful." (27th August – RBS4)

Bereavement Supporter volunteers have instinctively complemented professional health and social care staff practices, which are primarily task-based in focus, with their (often overlooked) listening support. The primary gift or resource the Bereavement Supporters have been offering in emotionally supporting their community during 2020's pandemic has been listening.

This listening support has been self-organised and demonstrates the value of informal, locally-based, peer support whereby the Bereavement Supporters volunteered to use their skills to serve their community. They proactively communicated with fellow residents and staff and have provided essential continuity of social care at a time when it was not readily available elsewhere.

### They achieved this by:

- Adapting their support to telephone and Zoom support and looking out for people known to them in their community. This is an important finding as it demonstrates that residents have adapted to new ways of working – such as switching to Zoom for online group activities – emphasising the often-underestimated adaptability of older people and their preparedness to use available technology.



- Organising 'chains' of telephone calls among residents in their own village derived from compiled lists of residents in order to listen and encourage fellow residents during difficult times, and deliberately taking every opportunity to talk to those they met.

**"(We) have set up a kind of neighbourly scheme for ensuring that over 60 people receive at least one phone call each week."** (RBS4)

In the process they were informally building support around those in their residential setting who were isolated, lonely, grieving and/or depressed or recognised as struggling through what has been a challenging year.

- Arranging appropriate socially distanced spaces to meet and listen, which included being willing to bring a folding chair outside a neighbour's apartment in the village and offer listening support whilst their neighbour sat at a safe distance in their doorway.
- One diarist went so far as to cook meals for another resident in their community!



Compassionate listening and emotional support were also valued by those in the general population who sought the bereavement support services of Cruse at a time when daily life in lockdown meant other support networks and activities for coping with a bereavement were suspended or not available.

**"My clients have all been very grateful that I (we) have taken that time to just listen and be there for them in such uncertain and restricting circumstances."** (BV1)



Across the diaries we learnt how active, compassionate listening and peer-support have been necessary and valued resources during the height of the pandemic in Britain, irrespective of whether the bereaved person was living in a retirement community or independently. We also learnt how regardless of where we live and our circumstances, 2020 united us all through the shared experience of multiple losses that were often not related to a bereavement.

## Theme 2:

# A shared community feeling of grief arising from many losses, that were not bereavement related.

"I wondered what was about to be taken away from us next." (RBS1 – 21st May)

The diarists reported that they had witnessed residents experiencing a great deal of loss and not all of it bereavement related. What links all the residents in the ExtraCare villages is the identity changes they underwent as they moved from their own home, owned or rented, to a residential setting where they did not have complete autonomy and choice in their domestic 'home'.

The ExtraCare diarists reflected on how lockdown had triggered, for some, a re-evaluation and sense of uncertainty about their decision to give up the autonomous space of home, and the additional support needs that this had given rise to.

The opportunities for activities, free movement, face-to-face social interaction were eroded or disappeared during 'lockdown' and few were replaced virtually so that the **"virus brought into effect a complete turnaround in many of our aims for living in a community setting."** (RBS4 – 27th August). There was a lot of 'loss talk' in the diaries, both individually and collectively articulated and felt.

"The reality of the virus came home to me as a gathering of restrictions, from 23 March. Every day a notice came on the tablet in the hall, or a letter through the door. No non-residents were allowed in for activities.

Then no one allowed in except delivery people, medical personnel, carers. The hairdresser's salon closed, exercise class instructors were barred, no meetings of Christian Fellowship group or choir. No family visits for Mothering Sunday. All outside exits/entrances locked shut except main entrance, where people had to sign in. No resident allowed to leave the site, not even for short walk to the Park.

Bistro only serving takeaways delivered to our own apartments...One of the bleakest signs of lockdown was the removal or stacking of all seating in the bistro, reception, lounge, even benches out of doors were removed. We were reminded of our own homes being stripped as we left to move to the Village...We had all moved to the Village with a hope, indeed a promise, of activities, social life and new friendships but now we shunned each other if we happened to pass on the stairs or corridors." (RBS1 – 21st May).

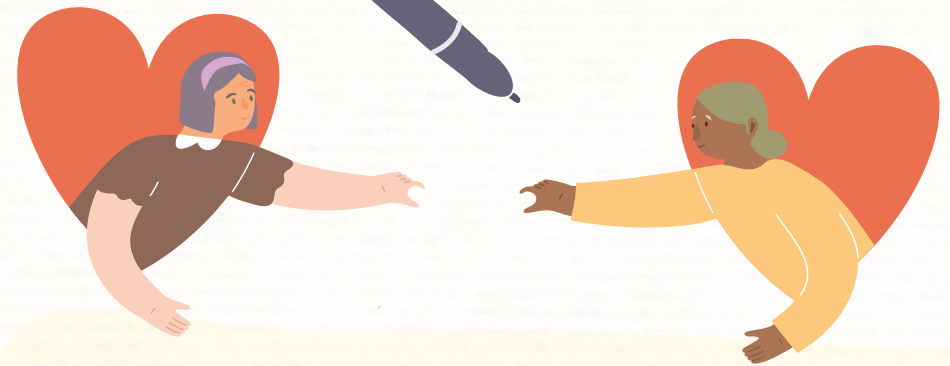




The combination of a new virus, Government guidance, and protecting residents and staff - many of whom were potentially vulnerable to the virus - required action contrary to ExtraCare's ethos. New ways of bringing people together and maintaining community had to be found and run parallel to the measures in place to protect everyone. This generated some inspiring scenes, some very visible like the balcony exercise classes or Thursday evening chorus of clapping for carers. Many other subtle forms of support came from one to one calls, doorstep talks or distanced walks for those whom had been brought to breaking point by loneliness. Although the measures were necessary the impact was not ignored, and all of the learning supported decision making as the pandemic progressed, helping to balance safety with the needs of a community.

It wasn't just about the impact of decreasing or losing physical or mental activity, but also the loss of habit of doing the activity itself that was keenly felt and missed. The impact of Covid-19 on residents was a collective feeling of uncertainty and losing confidence. A Bereavement Supporter volunteer noted that there was a lot of grieving going on with residents, but not necessarily about a recent death, rather, over other losses:

**"Grieving of not seeing family, not seeing friends. Grieving for the losses that aren't death. All those little things make a lot of difference."** (RBS3 – 11th August)



**"Moving to our ExtraCare Village brought a massive amount of change to all our residents in the last 3 years.... this has been a shared community feeling of loss for 'what was life before ExtraCare' as no-one here understood us as individuals, knew intimately, were aware of our backgrounds or what our circumstances of living throughout life had been.**

This was a challenge to us all to make an effort to work at becoming a new community, making new friends and getting to know each other as we attempted to break new barriers of friendship making... This Virus brought into effect a complete turnaround in many of our aims for living in a community setting. A relatively recent 'new life' still being formed has compounded the loneliness for us and many have tried to develop other ways of engaging and holding together the very tenuous ties which were beginning to develop pre Covid...

The reasons that many of us chose to come to the Village were suddenly negated and taken from us. Everything seems to have been put on hold... or 'a big STOP sign' introduced into our lives."  
(27th August – RBS4)

What was apparent from the diaries was how residents and Bereavement Supporter volunteers in retirement communities used their resilience, derived from diverse and extensive life experiences, in order to face the physical, social and emotional implications of these losses:

**"Most of our residents delved deep inside of themselves and found the resources they needed to get through by using the strengths they have learnt through the past experiences of life."**  
(27th August – RBS4)

# Theme 3:

## Acknowledging and communicating a death in residential communities remains challenging, especially during 'lockdown'.

"I don't think this village, residents or staff, have worked out how to deal with deaths. A few families have held wakes in the village hall, and sometimes the flowers from the coffin have been given and laid on a table by the front door, once or twice a notice has been put up at reception with a photo and date of funeral, but this has not happened for many months. I get the feeling that death is not a nice subject and should not be mentioned in a place where so many old people are living, or funeral flowers might put off people who are thinking of moving here." (RBS1)

Finding appropriate ways of acknowledging and communicating the death of other residents is a persistent challenge in ExtraCare villages, but this has been compounded by Covid-19 where the usual word of mouth channels for communicating the death of residents are unavailable. Covid-19 and 'lockdown' made it harder to identify when people were in need of bereavement support because there is no longer any one around to pick up information or receive referrals from staff. In an attempt to try to address this, some diarists focused on checking in with people they already knew. However, much more needs to be done to better serve a community of bereaved people in residential settings in the event of a future lockdown.

What did emerge and surprised us, was the role that balconies can play in bringing together a community of mourners and supporting individual and collective grief at a time when usual social customs and cultural rituals that support bereaved people are no longer available or possible.<sup>1</sup>

"We said farewell to one of our residents yesterday... many of us from our balconies as the hearse moved off to the very small, family funeral." (RBS4 - 7th May)

Bereavement Supporter volunteers noted that when there was not an opportunity for collectively grieving and acknowledging someone's death, then the grieving process was arrested:

"Some of us haven't started grieving because we haven't come together yet... that conversation is still on hold." (RBS3)

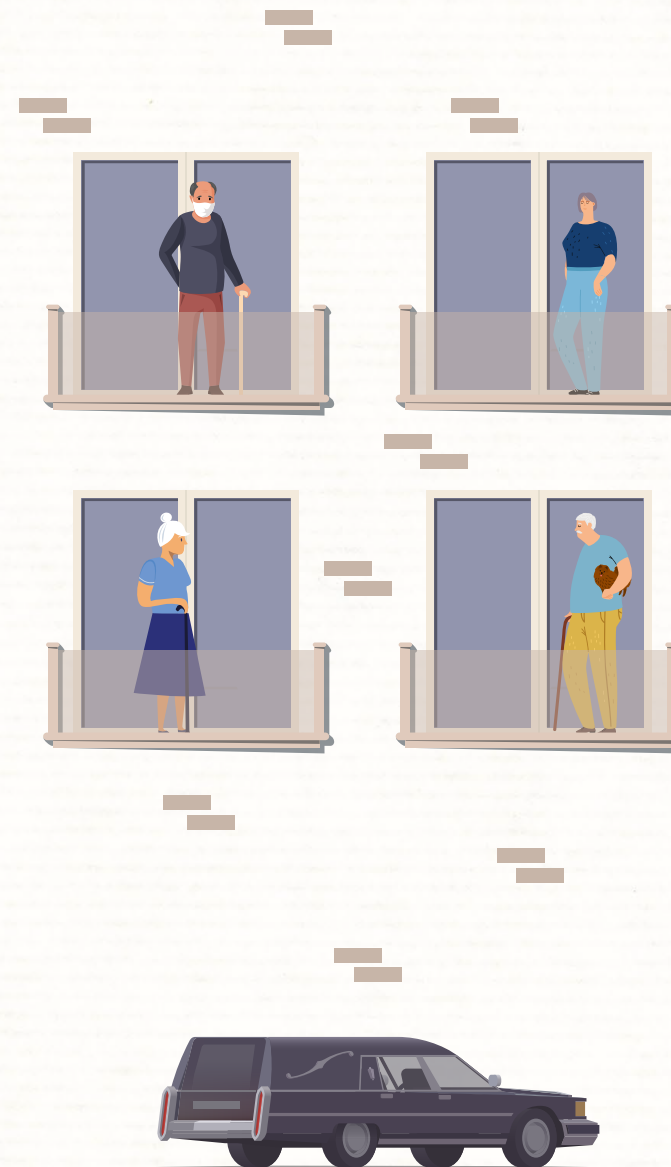
In response ExtraCare staff, supported by Cruse, actively participated in the Dying Matters initiative #IRemember week held between 26th October and 1st November. This gave many residents a chance to have a recent or historic loss recognised at a time when it was not possible to collectively grieve.

Over 400 residents took part in activities such as memory trees, minutes silence, photo walls and socially distanced remembrance services.



Dying Matters

Let's talk about it



<sup>1</sup>See 'Balconies and Community Space in Extra Care Housing: Covid-19 and creating HAPPI outdoor space' on the Housing LIN blog (28/07/20) - [www.housinglin.org.uk/blogs/Balconies-and-Community-Space-in-Extra-Care-Housing-Covid-19-and-creating-HAPPI-outdoor-space/](http://www.housinglin.org.uk/blogs/Balconies-and-Community-Space-in-Extra-Care-Housing-Covid-19-and-creating-HAPPI-outdoor-space/)



The initiative highlighted the long-term emotional importance of such an acknowledgement; a function usually fulfilled by funerals and other traditional rituals following a bereavement.

And Bereavement Supporters took it upon themselves to organise opportunities for staff and other residents to grieve together when attending funerals was not possible:

"We had a funeral on Wednesday. Well, the thing about it, that girl she lost not only her mum, she lost her father and she lost her grandfather. So what Mavis and Heather did was they printed out some songs ... The staff came out to stand outside and by word of mouth I told some of the residents, ringing round saying to quite a few people that if they wanted to go down or stand on their balconies.

They had a prayer and some songs and they talked about her for about 15 minutes and then the hearse came round and stopped a bit. It was very moving, very, very moving and personal." (22nd May, RBS3)



# Theme 4:

## Grief and bereavement during 'lockdown' and a pandemic; a complex and very mixed experience.

"Some have benefitted from the time and lack of pressure during the lockdown... Some of my clients have been relieved of pressures from family traditions which they sometimes find overwhelming...Another client has been, very much, missing the reassurance of friends and family ..." (early August – BV2)

Again, another surprising finding from the diaries emerged from those written by Cruse BVs who noted that while some clients had keenly felt the loss of restoration activities, some were finding bereavement somewhat easier to manage during the pandemic because they felt liberated from the social pressure to appear 'normal' and OK.

During lockdown some bereaved people reported that their grief was easier to bear because nobody was enjoying life, at least not visibly/openly and this made anniversaries and special occasions easier to cope with.



"Father's Day this week and a client grieving for her father is finding it very tough and painful. She is thankful however that pubs and restaurants are still closed because she feels angry and resentful when she sees other fathers out there enjoying family time when she has not got her father there to celebrate with.

Therefore, on Sunday when we are still not allowed out she is protected from that source of pain...In many ways she is finding the lockdown helps her because its giving her an opportunity to withdraw without trying to find excuses.

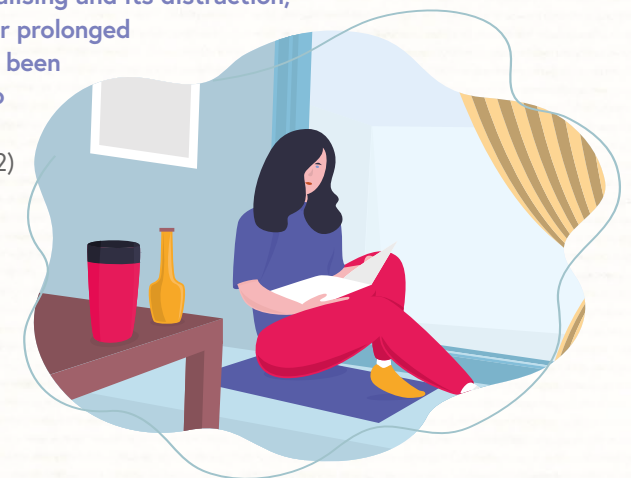
Her best friend certainly does not get it and wants to change the subject when she talks about her dad. Withdrawing and being sad is just where she wants to be and she can do this without feeling guilty about being a "party pooper." (22nd June – BV2)



Lockdown has provided some of my clients a space to privately grieve without the pressure of social norms.

Being able to withdraw and feel sad is good and many seem to have said it's been a benefit but so is socialising and its distraction, the jump after prolonged lockdown has been a challenge to explore."

(July 6th – BV2)





However, not all bereaved people that the Cruse BVs were remotely supporting found bereavement during lockdown easier.

"My client...is finding the lack of community activity very challenging. It is also difficult for signposting because so many groups are not meeting and she does not have access to a computer. She lives alone in a house and has unhelpful neighbours. She would like to live in a more caring community. Her life before her mother died was all consuming with her mother's health her main occupation and her only source of social interaction was by being part of that caring team of people involved. Covid-19 has really reduced any of those restoration after loss activities for her." (13th July - BV2)

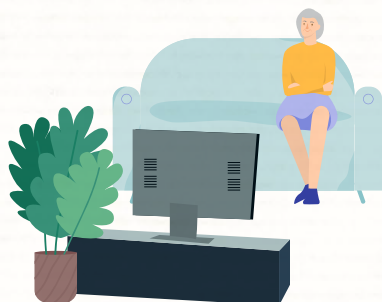


Yet, it is not only the loss of restoration activities during lockdown that made bereavement challenging; loss of support networks, activities and social isolation compounded some clients' grief and a feeling of being overwhelmed or unable to cope.

"Learning to live alone in lockdown was a huge chaotic struggle for her. Becoming aware of the neglected house and garden, as all her time and energy had been attending to her husband's dementia needs.

This new acceptance and reality seemed to be 'on pause' and her chaos was really overwhelming because she wanted and needed all sorts of people in her life; family, friends, solicitors, church members, plumbers etc. the pandemic and lockdown took away so much of her support and left her in a much more vulnerable and frightening place than it should have been."

(early August – BV2)



Whilst the absence of usual social, care and support networks has made bereavement even harder for some, and the restrictions on funerals meaning bereaved people could not come together necessarily at a funeral, there have been some alternative displays of support and acknowledgement that have proved to be valued by bereaved people.

"From a number of clients there has been a sense of community though.

Whilst social distancing has prevented 'wakes' some clients have left the home onto the chapel and found their neighbouring street to be lined with people.

Often the clients speak of this being overwhelming and they will remember these scenes forever.

They have found a sense of community that they didn't know exists and have been surprised by the acknowledgement and support of those neighbours; their level of help and support and the level of compassion."

(BV3 – 25th June)



# Theme 5:

## Bereaved people and Cruse Bereavement Volunteers have adjusted to telephone-based support and learnt new ways of working to support the community.

"Using the phone has been a simple transition for me. My clients have all been very grateful that I (we) have taken that time to just listen and be there for them in such uncertain and restricting circumstances." (BV1)

Diarists reported that they were adjusting to telephone-based support and learning new ways of working:

"I am learning to work with clients who are slower in their process during the session and to measure, pace and weigh the silences." (BV2)

Diarists also saw distinct advantages in adopting telephone support as a regular feature of Cruse volunteer-based bereavement support:

"Some of my telephone sessions, with disabled or unwell clients, would never have taken place in our rooms." (BV2)

Another diarist was surprised and heartened at the bond that she was able to establish with a client through telephone support: "I had one gentleman whose regret was that he hadn't met me. He's invited me to a music event that will go ahead when restrictions ease. It will be in honour of his beloved father. I was flattered." (2nd August – BV1)

Diarists commented on the volunteering opportunities that telephone-based support might afford volunteers with a disability given they could now offer support remotely and therefore mobility is no longer a barrier for skilled volunteers. However, with regards to referred clients, the BVs recorded an increase in mental health needs arising from the impact of lockdown and social distancing measures:

"During this time of lockdown I am taking on seven client appointments per week and ... there are a larger proportion of clients with mental health challenges which isolation has exacerbated. I have two clients with OCD who find cleanliness and infection all consuming."

(15th June – BV2)





# Learning and Recommendations

1. In the absence of being able to gather a community of bereaved people together at the time of a funeral (i.e. no face-to-face contact with family members and enforced limited or non attendance at funerals), our diarists suggest that having a hearse drive through the community *en route* to a chapel or crematorium had been extremely comforting.

It served to acknowledge their bereavement and gave anyone who wanted to, an opportunity to show their last respects and stand in mutual support. In ExtraCare community settings, the balconies of individual apartments that overlook the main entrance or driveway have proved to be invaluable for such public displays of support and condolence.

A gathered community, be they standing in their residential doorways or balconies, can also sing together, pray, make speeches and pay tribute in whatever form is appropriate and meaningful to them.



2. Due to the increased intensity of the client/supporter relationship arising from the pandemic and associated social distancing regulations, bereaved clients have fewer sources of bereavement support between sessions and fewer distractions from bereavement.

Meanwhile, bereavement supporters also have fewer outlets to distract them from what are intense encounters. Therefore, extra support needs to be given to those who are supporting bereaved people under such intense circumstances. This should include strategies for maintaining boundaries and timekeeping when delivering telephone or video call support, as well as usual distraction activities following the delivery of a support call.



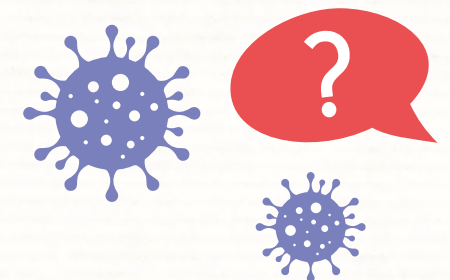
3. The importance and value of listening in a non-judgmental manner, and how this benefits a bereaved person, cannot be overstated.
4. Bereavement support should remain open to listening and responding to all losses; not to narrowly focus on issues arising from death related loss.
5. It is important to give people the space and time to grieve and that in 'normal times' people feel too much pressure to return to cheerfulness and fulfilling social and family obligations.



6. Nobody denies the importance of face to face support, but we can adapt to new ways of offering meaningful support - even people in advanced age and living in ExtraCare can adapt. New remote ways of communicating can make support more widely available and enable a wider variety of people to play supportive roles.



7. Whilst 2020's pandemic has been hugely challenging it is also an opportunity to engage more readily with questions, concerns and issues of death and dying across all populations, irrespective of age, gender, ethnicity, social class, belief and identity.



# Conclusion

In conclusion we would like to briefly comment on using diaries – be they written, typed or voice-recorded accounts (we used all three approaches) – as a method for capturing people's lived, subjective experience and thoughts and feelings during the pandemic. Using 'lockdown' diaries to capture bereavement support certainly gave us a snapshot and insight into people's daily lives during these extraordinary circumstances. The diaries distinctively captured a tiny part of history in the making. But admittedly, there were some limitations as keeping diaries relies on people's willingness to participate.

However, this has always been an issue for any research that requires voluntary participation. We were flexible and allowed our diarists to keep written, typed or voice-recorded diaries, depending on what mode of technology they had access to and were comfortable with. Likewise, we were not overly directive about what was recorded during lockdown, which meant diarists did not always reflect on issues and activities that were primarily of interest to the research team.

Despite the limitations, we think that diaries give us deeper and more subtle reflections and insights into how people support each other through bereavement than we have been able to capture through other methods, for example through surveys and forms.

By being flexible and allowing the diarists to take ownership of what they wanted to record during these extraordinary times, we received wonderfully descriptive, evocative portraits of people's working, psychosocial and daily private lives that contribute to a fascinating historical record.



**Funders** – The work was supported by the Elizabeth Blackwell Institute, University of Bristol and the Wellcome Trust Institutional Strategic Support Fund and Cruse Bereavement Care. We are grateful for their support.

**Links to further organisations and support** – can be found on the Cruse website [www.cruse.org.uk/get-help/useful-links](http://www.cruse.org.uk/get-help/useful-links)

<sup>1</sup> Ethical approval of the project was granted by the Research Ethics Committee of the School for Policy Studies at the University of Bristol. Any queries on ethics or research design can be directed to Karen West, project lead ([karen.west@bristol.ac.uk](mailto:karen.west@bristol.ac.uk))





DIARY 2020

## Appendix 3 -

### What Cruse clients say about the value of telephone bereavement support

# What Cruse clients say about the value of telephone bereavement support



As part of a research project to understand the experience of bereavement and grief during the pandemic, between October and November 2020 clients were invited to complete a survey about their experience of accessing remote support from Cruse.

All clients who completed the survey received telephone support, or support via Zoom, or a mixture of both.

- 19 client responses - 2 male, 17 female



- 7 responses from clients aged 26 - 55 years old;

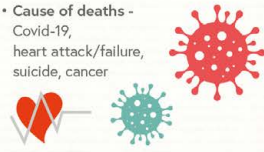
- 12 responses from clients aged 56 - 75 years old



- Relationship to the person who died – sibling, mother-in-law, partner, son, daughter, parent, spouse, uncle



- Cause of deaths - Covid-19, heart attack/failure, suicide, cancer



## Survey responses

### *Theme: Normalising their grief*

"My experience with Cruse support was excellent, I was given the time and freedom to express myself at every stage and encouraged to bring up memories with my mother that made me feel better and brought a smile to my face and a sense of beauty into the grieving process for the first time since her death."

"It met all my expectations, the compassion and support was amazing the lady I spoke to helped me understand what I was feeling and that it was a normal way to feel no right or wrong way to go through this and that everything I was feeling was a natural, normal way of dealing with grief, she listened with no judgement which help me a lot."

### *Theme: Reduced discomfort or embarrassment*



"I was happy with my telephone support especially when I got upset during many of the sessions as I didn't feel probably as embarrassed as I would've been if it had been face-to face, plus I was sat in my own home which made me feel more at ease."

"I really had wanted face to face contact but that was not possible (apart from the initial assessment) and I found that to start with I wanted just telephone support as I suddenly needed for it to be anonymous."

1



# What Cruse clients say about the value of telephone bereavement support

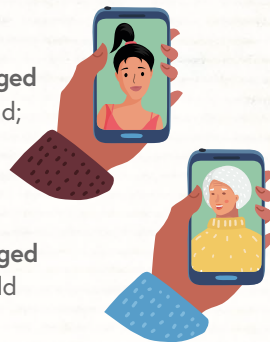
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- 19 client responses -  
2 male, 17 female

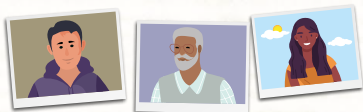


- 7 responses  
from clients aged  
26 - 55 years old;

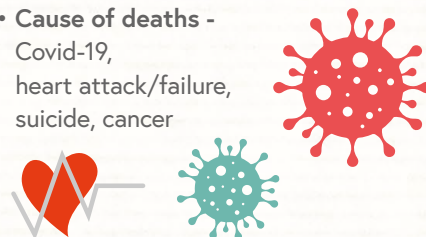


- 12 responses  
from clients aged  
56 - 75 years old

- Relationship to the person  
who died – sibling, mother-in-law,  
partner, son, daughter, parent,  
spouse, uncle



- Cause of deaths -  
Covid-19,  
heart attack/failure,  
suicide, cancer



## Survey responses

### Theme: Normalising their grief

"My experience with Cruse support was excellent, I was given the time and freedom to express myself at every stage and encouraged to bring up memories with my mother that made me feel better and brought a smile to my face and a sense of beauty into the grieving process for the first time since her death."

"It met all my expectations, the compassion and support was amazing the lady I spoke to helped me understand what I was feeling and that it was a normal way to feel no right or wrong way to go through this and that everything I was feeling was a natural, normal way of dealing with grief, she listened with no judgement which help me a lot."

### Theme: Reduced discomfort or embarrassment



"I was happy with my telephone support especially when I got upset during many of the sessions as I didn't feel probably as embarrassed as I would've been if it had been face-to face, plus I was sat in my own home which made me feel more at ease."

"I really had wanted face to face contact but that was not possible (apart from the initial assessment) and I found that to start with I wanted just telephone support as I suddenly needed for it to be anonymous."

## Theme: Convenient and accessible

Over **57%** preferred telephone support to face-to-face, or had no preference.

"No preference, the telephone support worked well for me."

"Me personally I don't mind either I've never had any kind of counselling before I was just so happy that I was given the opportunity to speak to someone."

"No preference. Call or video as good as in person"

Almost **70%** said there were no barriers to seeking telephone support.



## Theme: How Cruse could improve their telephone service

"At times there was a phone ringing in the background and doors closing so I found that distracting at times and it must've been for the counsellor who would've been experiencing the noise at his end."

"Reduce number of people the bereaved person has to tell their story to before being allocated appropriate bsv."

"video call"

"Having to do things over the phone was restrictive as in we couldn't always tell when each other were finished speaking amongst other non verbal cues that allow conversation to flow easily."

"I prefer face-to-face as it is more personal. The other person's face (listener) also gives you something to focus on."



## Theme: Quality support during difficult times

"... my experience was a lovely one I felt supported throughout the entire process."

".. I think it was very good how it has been adapted."

".... counsellor was amazing. Clearly the training she had been given along with her genuine care and personality was very supportive and positive."

"Given that there was no other option but a telephone service in current circumstances, I have no suggestions to improve it. The volunteer communicated well, checked that I could hear and was comfortable, and the warmth of her personality was obvious, even though she remained professional in her approach."

"... it worked really well for me. My counsellor was amazing and I think I did use the service at the right time"



This research project was carried out in partnership with The ExtraCare Charitable Trust, together with researchers at the University of Bristol and Aston University.

The work was supported by the Elizabeth Blackwell Institute, University of Bristol and the Wellcome Trust Institutional Strategic Support Fund and Cruse Bereavement Care.

The project was part of a much bigger five-year (2017-2021) partnership between Cruse and ExtraCare – [The Bereavement Supporter Project](#) - which is funded by the National Lottery Community Fund.



## Appendix 4 -

### The National Lottery Community Fund Outcome Measures

#### The National Lottery Community Fund Outcomes, Indicators and Timescales - Bereavement Supporter project

Outcome One:			
Older people are more active, more engaged, more independent, less isolated and better supported after bereavement.			
Indicators:	Indicator Level:	Timescale:	Progress:
Attendance and participation with engagement activity.	1500 residents attend engagement activity (e.g. information sessions, talks and stalls) and encourage others to attend. 300 in each year.	End of Project	<p>Total attended 1 hour Information Sessions: 351 residents, and 19 people from the wider village community.</p> <p>Total attended information stalls: 60 residents and 3 people from wider village community.</p> <p>Total attended short talks at Street Meetings/events: approx. 1068 residents.</p> <p><b>Total of the above 1501</b></p>
500 individuals access bereavement support.	Evaluation of the service (which will include experiential data from a number of sources) demonstrates that receiving bereavement support has a positive impact on residents (e.g. they feel better supported after bereavement, less isolated, more engaged etc.).	End of Project	<p>Through Bereavement Supporters: <b>Total 1298</b> (residents, family members and Friends of village)</p> <p>12 residents and 1 family member also supported by Cruse Bereavement Volunteers following a formal referral.</p>

## Outcome Two:

Older people are able to live fuller, healthier lives with increased opportunities to volunteer and support each other.

80 older people recruited and trained as Bereavement Supporters	Older people equipped with skills to signpost and offer peer support with 16 older people trained each year.	End of Project	49 Bereavement Supporter volunteers trained and an additional 18 residents trained as part of new community model' approach.
Older people recruited and participate in project reference group	A minimum membership of 4 older people as residents will be members of the project reference group throughout the project timescale.	End of Project	Attended by an average of 8 volunteers per bi-monthly Peer Group meeting.
Older people report increased levels of personal wellbeing through volunteer activities	Resident Bereavement Supporters will report that participating in the project has been personally meaningful (e.g. supporters may report improvements in their mental and/or physical well-being, feel like they are making a difference, developing new skills etc.).	End of Project	Some responses from volunteers to the question 'How does volunteering as a Bereavement Supporter make you feel?': <i>"I feel valued because my skills are useful. I also feel very grateful for my own life"; "wellbeing"; "It makes me feel good listening and befriending others"</i> .

### Outcome Three:

Older bereaved people with dementia and their carers have increased access to appropriate bereavement support.

Development of resources and materials to support older bereaved people with dementia and carers	Effective resources produced with the input of older bereaved people and carers.	Year 2	1500 copies of Carers Guide disseminated throughout 2019 (within ExtraCare and to wider sector).  ‘Responding to distress...’ guidance factsheet distributed internally and externally.
Dissemination of resources, good practice and stakeholder event	Improved awareness and access to information for those supporting older bereaved people with dementia.	Year 3	1475 copies of ‘Bereavement, Loss and Dementia’ booklets distributed within ExtraCare to support families, carers, staff and people living with dementia.  Stakeholder event October 2019 and 2 x webinars in 2021, to share resources and good practice.
Older bereaved people with dementia will access support	Monitoring of clients who access support from Cruse volunteers.	End of Project	
100 Cruse staff/volunteers signed up as Dementia Friends	Improved awareness regarding dementia amongst Cruse staff/volunteers.	End of Project	143 Dementia Friends created within Cruse.
Develop a new model of working with older bereaved people with dementia	Production of resources to assist/enable everyone (staff, carers, family) to support older bereaved people with dementia, and monitoring of feedback.	Year 3	‘Responding to distress...’ guidance factsheet distributed and ongoing comms plan in place.  ‘Carers’ Guide’ booklet created and disseminated.

**Outcome Four:**

Increased awareness of impact of bereavement on older people's mental and physical health.

<b>Indicators:</b>	<b>Indicator Level:</b>	<b>Timescale:</b>	<b>Progress:</b>
750 ExtraCare staff will have access to Loss and Bereavement awareness training and/ or Information Sessions	Staff are equipped with skills to support older bereaved people.	End of Project	<b>Total 610 staff:</b> 391 staff members, and 1 external volunteer, have undertaken Cruse Loss and Bereavement Awareness training, and 218 staff members have attended Information Sessions.
Residents and staff in ExtraCare sites can discuss bereavement	Evaluation report highlights increased bereavement awareness and improved mental and physical wellbeing for older people.	End of Project	Ongoing
Staff will access bereavement support	Monitoring of staff numbers who access support from Cruse.	End of Project	24 ExtraCare staff (combination of ad hoc support and formal referrals).



## Appendix 5 - Bereavement Supporter role description



# Volunteering Opportunities

The  
**ExtraCare**  
Charitable Trust  
Better lives for older people



### Volunteer title: Bereavement Supporter

Hours: Variable

Location:

At ExtraCare our vision is simple; we want to create **better lives for older people**. We want to broaden horizons, not limit them. We seek to foster independence, not simply deal with dependence. We aim to **help older people stay active in body and mind** for as long as possible and **volunteering is at the heart of what we do**; we rely on the support of thousands of valued volunteers to ensure our services remain affordable for all.

#### Purpose of these roles:

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

#### The Bereavement Supporter's 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

#### Key skills needed for this role:

- Awareness of the importance of confidentiality
- Trustworthy, honest, reliable and flexible
- A good listener with a friendly and welcoming personality and ability to communicate with a variety of people
- Are empathetic and non-judgmental
- Caring approach to bereaved people
- Ability to work as part of a team and under own initiative
- 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

#### Training and Development:

- Attending Bereavement Supporter training
- Acquiring experience supporting people
- Ongoing direction and support provided

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

**How to apply:** If you would like to apply for this role then please contact XXXXX at XXXX@extracare.org.uk or call XXXX on XXXXXX. Alternatively, please visit our website: XXXX



- <sup>1</sup> Independent Age (2018). Good Grief. Older People's Experiences of Partner Bereavement. Independent Age/ILC.
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- <sup>3</sup> Breen, L. Kawashima, D., Joy, K., Cadell, S., Roth, D., Chow, A. and Macdonald, M.E. (2020). 'Grief Literacy: A call to action for compassionate communities'. *Death Studies*. doi/full/10.1080/07481187.2020.1739780
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- <sup>6</sup> Brown, L., & Walter, T. (2014). Towards a Social Model of End-of-Life Care. *The British Journal of Social Work*, 44(8), 2375-2390.

