

# The Bereavement Supporter Project

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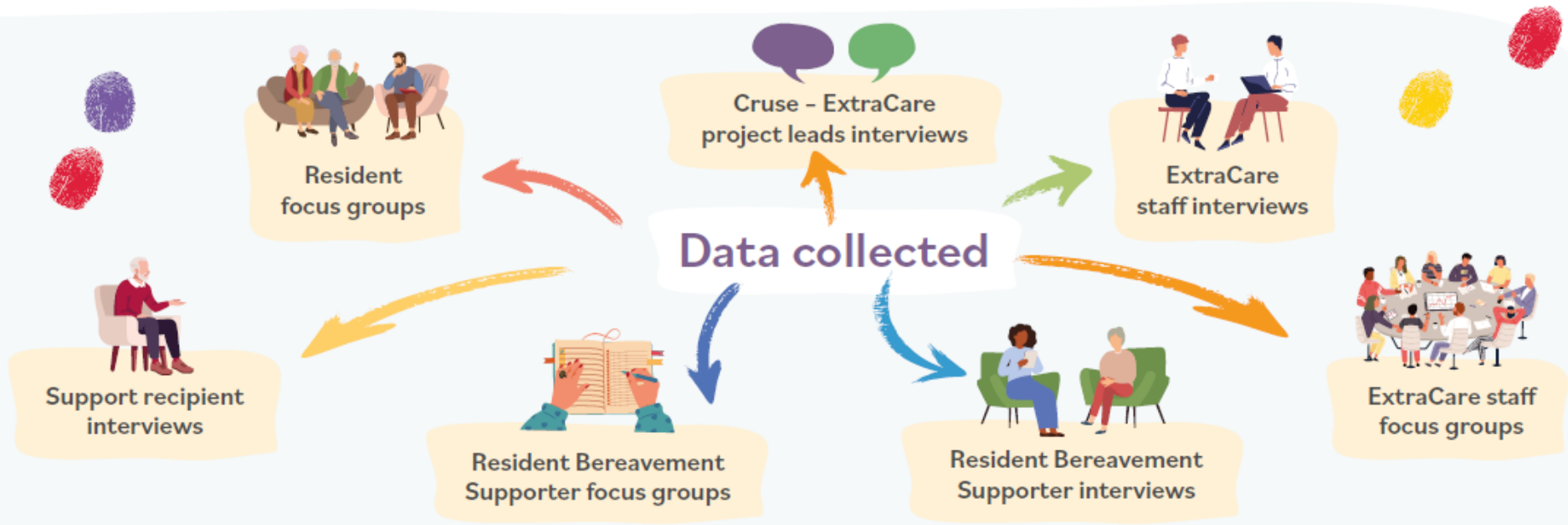
# The Bereavement Supporter Project

## Evaluation report Executive summary

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Data were gathered in 2 phases across the four sites.

Figure 2: Methods of data collection completed in the Evaluation of the Bereavement Supporter Project



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

# Bereavement Supporter volunteers



# Creating a bereavement friendly community



*“I learnt such a lot with the training... everyone is different with their bereavement journey” - Janet*

**975** residents and family members accessed bereavement support

**1,460** residents engaged with project activities



*“we’ve been able to open up conversations with residents” - Jenny*

*“...it’s about listening to their needs and giving them chance to talk ” - Kath*

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

**Introduced to  
ExtraCare in 2018**

**19 communities  
currently  
accredited**

**2 remaining  
undergoing  
training**

**Advance Decisions:**

A voluntary process to set a record of choices for end of life care

- **Focussed on a good death**
- **Enabling residents to die in their own home, if they choose**
- **Well planned, and with dignity**



# 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.

## Section 3

### Losses along the journey

#### Relationship and emotional losses

- Everyone's experience is different
- You lose the support of your partner because they can't support you anymore
- Your spouse can't always give you the empathy or support that they did before, I miss that in the relationship, it makes it hard
- Your partner reacts to you differently and may not understand if you explain that something is wrong or you are upset
- My husband still does pick up on my emotions as a carer
- You can feel lonely and isolated both when they are there with you and when they are not
- There are still moments of humour amongst the hard times
- The dynamics of the relationship have changed, we're no longer equal partners
- Like living a double life:
  - o One life when visiting my partner in a care home, learning to adapt to the change
  - o One life at home - a different life where I don't have to give care, can have 'me' time, and feel less exhausted

It can help to talk to others who understand the situation (see pages 30-33 for further advice)

- "My life is on hold" and how long for depends on the person with dementia
- "Loss of our relationship" - the loving relationship and intimacy changes, such as finishing each other's sentences
- It broke my heart not being able to share a bed anymore because of my husband's health and care needs
- I regret us having to sleep in separate beds and wish we could have done things differently
- No carer's experience is the same:
  - o my husband still recognises me
  - o my wife doesn't recognise me anymore
- "I lost my wife a long time ago" even though she is alive. I feel guilty having a life. I have started to grieve while she is alive because she's not there anymore, there has been a shift and I've already lost that person
- I feel bitter about how dementia has affected our life together



## 'We forget sometimes that people with dementia can also be carers'

A lot of attention (quite rightly) is dedicated to understanding the experiences of people caring for someone who has dementia, and how they might be better supported.

This diary entry challenged the notion that people with dementia are merely cared for – they can also be the carer of others.

This short clip was very emotional.

It demonstrated the range of feelings and losses that a person with dementia may experience whilst caring for a dying spouse:

- Witnessing the pain and suffering of a loved one.
- Loss of who their loved one used to be and the ways in which their relationship has changed.
- Fear of living life without them – both emotionally and practically.
- Feeling isolated and invisible as others do not recognise their ability to care for, and empathise with, others.



'Carers' Stories' is a guide for carers written by carers, telling their stories of loss along the dementia journey.

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

## 'That's It, I am now a non-driver'

Driving and dementia can be a complex and emotive issue, after all, driving is not merely a vehicle that permits travel from A to B. It can provide critical connection with services (e.g. shops, doctors or banks), family, friends and community groups, and may provide a person with routine and purpose.

Giving up driving is therefore bound in multiple losses and so can be difficult to give up and/or to be taken away. For many this can signal a loss of independence, choice and control, and can significantly change everyday life – practically, emotionally, and socially.

However, this diary entry provided a different perspective – that being in control of the decision and surrendering one's license freely can be an empowering act, one that marks a new life chapter as a non-driver.



*Thank you for listening*

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