

Executive Summary

The Bereavement Supporter Project –

Interim Evaluation Report
August 2019

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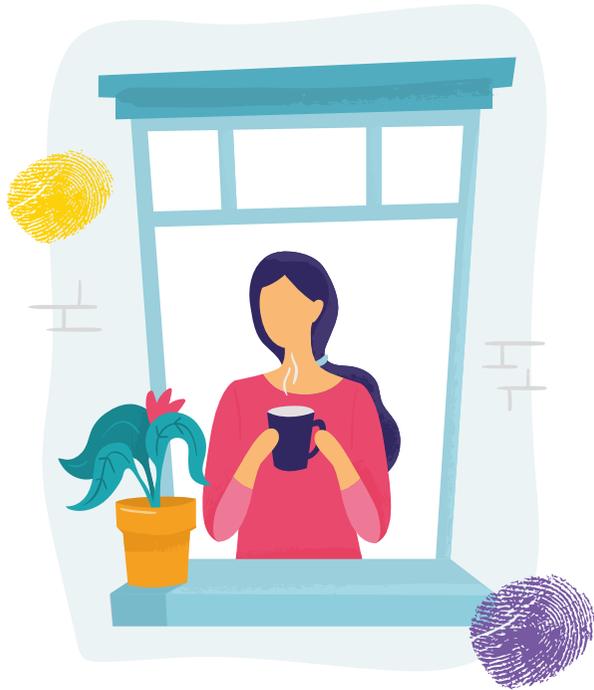
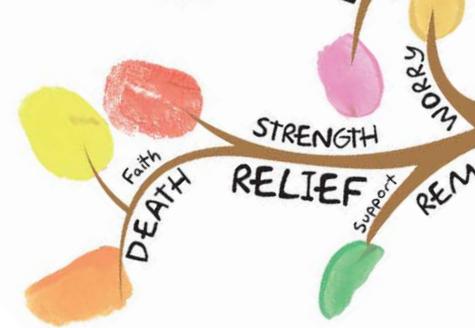


This tree was created by ExtraCare residents, using their fingerprints and words, to symbolise the many different 'branches' of emotions and challenges that can be faced following a loss or bereavement.



The Bereavement Supporter Project, a five-year partnership between Cruse Bereavement Care and The ExtraCare Charitable Trust, funded by the National Lottery Community Fund and commenced in 2017, is a pioneering public-health approach to bereavement support for older people.

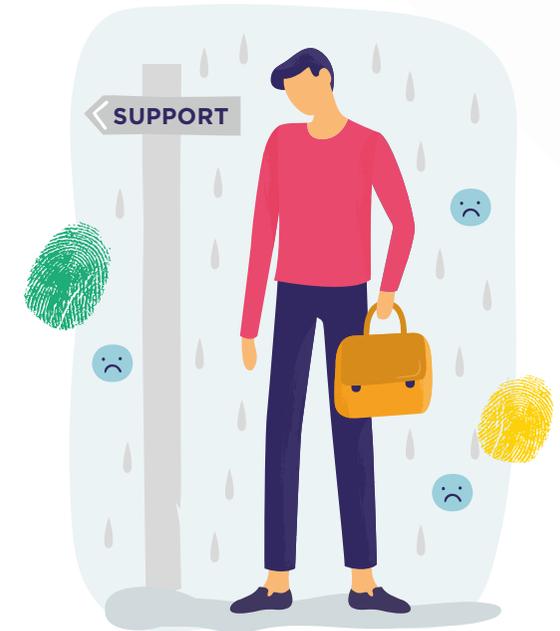
In recognition of the need to develop the capacities of communities to support friends, neighbours and family members through 'normal' processes of grief (National Bereavement Alliance, 2017), the Bereavement Supporter Project aims to:



- 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 Supporters who will act as first contact listening support to bereaved people in their communities; and

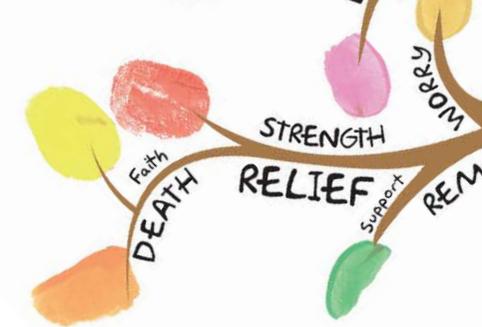


- Improve signposting and access to specialist bereavement and mental health support services.



The public health model of bereavement care can be divided into three main components, as seen in Figure 1.

The Bereavement Supporter Project is most obviously located within component 1, but also contains elements of component 2, as support will be given by trained volunteers.



Component 1 (Universal)

1

- Information about bereavement and relevant supports provided to all bereaved people
- Support provided by family and friends



Component 2 (Selective/Targeted)

2

- Non-specialist support provided to some bereaved people (those seeking support and/or those at risk of developing complex needs)
- Support provided by trained volunteers, mutual-help groups, community supports



Component 3 (Indicated)

3

- Professional specialist interventions provided to a minority of bereaved people (those with high level needs)
- Support provided by mental health services, bereavement services, or psychotherapy



Figure 1. Demonstrates the public health approach and NICE guidelines adapted from National Bereavement Alliance, 2017.



Evaluating the Bereavement Supporter Project

An independent research team (based at Aston University, Birmingham and the University of Bristol) are evaluating the Bereavement Supporter Project.

Broadly, we are looking at:

- How the service is organised and delivered;
- The quality of information delivered;
- Outcomes for individuals (e.g. resident Bereavement Supporters, staff, and residents who have received support); and
- Wider impact

Our evaluation will be guided by the outcome measures agreed between Cruse Bereavement Care and the National Lottery Community Fund:

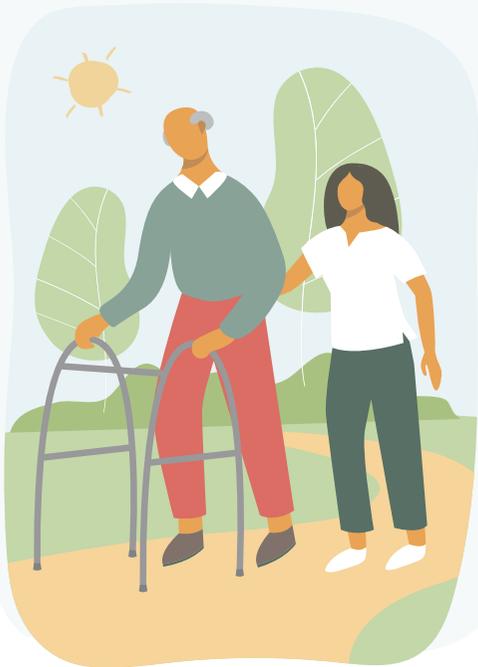
- Older people are more active, more engaged, more independent, less isolated and better supported after bereavement;
- Older people are able to live fuller, healthier lives with increased opportunities to volunteer and support each other;
- Older bereaved people with dementia and their carers have increased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



We have selected four ExtraCare locations to focus our evaluation:



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



The **ExtraCare**
Charitable Trust

We have collected a lot of detailed data by focusing our approach on qualitative methodologies (as depicted in Figure 2), and produced an incredibly detailed interim report.

This executive summary serves to present the most salient findings from our interim report in an engaging and accessible way. Participants are identified throughout using pseudonyms.

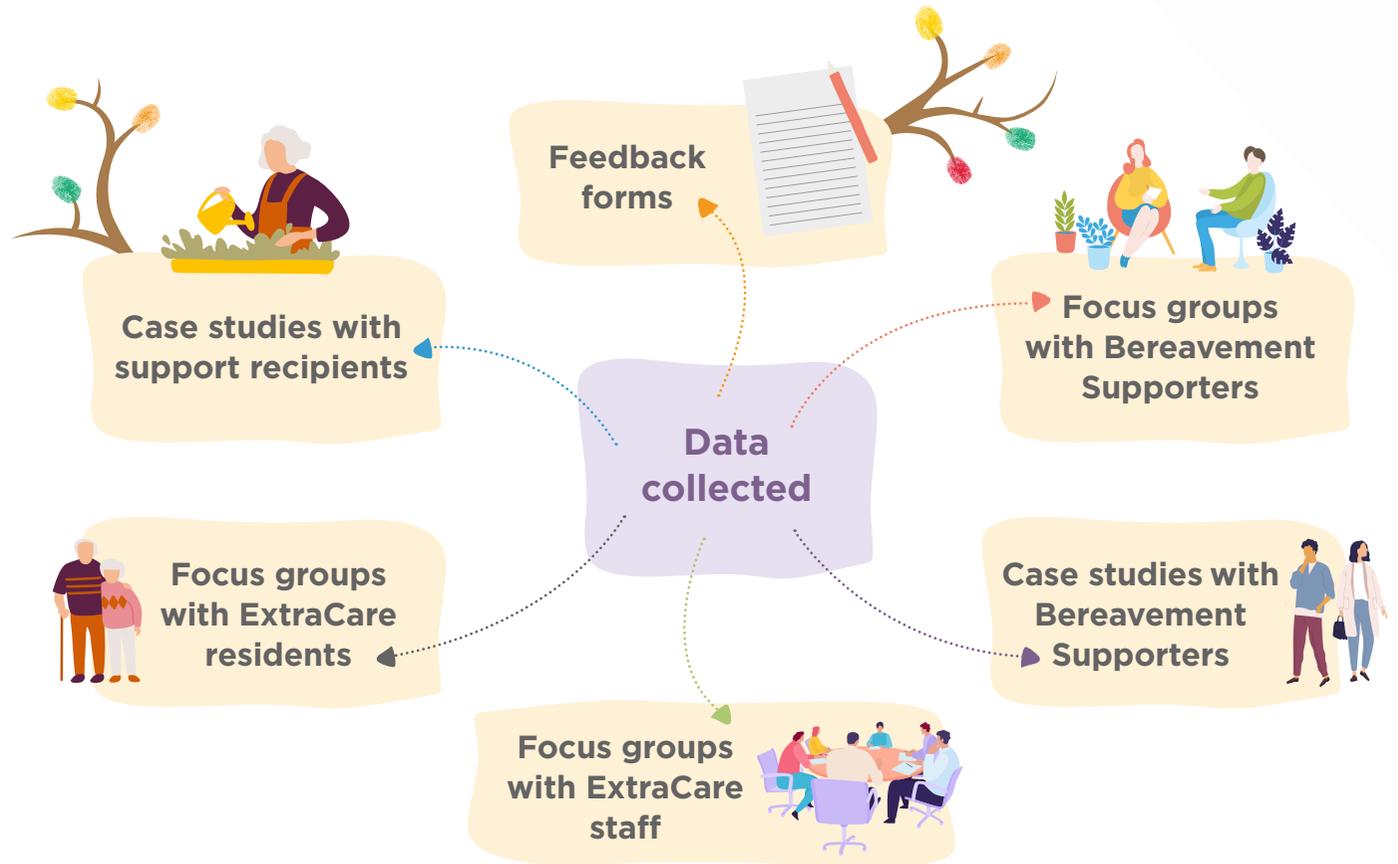


Figure 2. Depicts the methods of data collection completed as part of the evaluation of the Bereavement Supporter Project.



This diagram depicts the most frequently cited motivations provided by ExtraCare residents for becoming a Bereavement Supporter.

The level of experience and expertise among Bereavement Supporters was striking - a number had held professional and/or voluntary roles that either explicitly (e.g. vicar, palliative nurse, or bereavement counsellor) or implicitly (e.g. physiotherapist or family support for those with alcohol or drug addiction) involved loss, bereavement, and grief.

Others were motivated by their own personal experiences of loss.

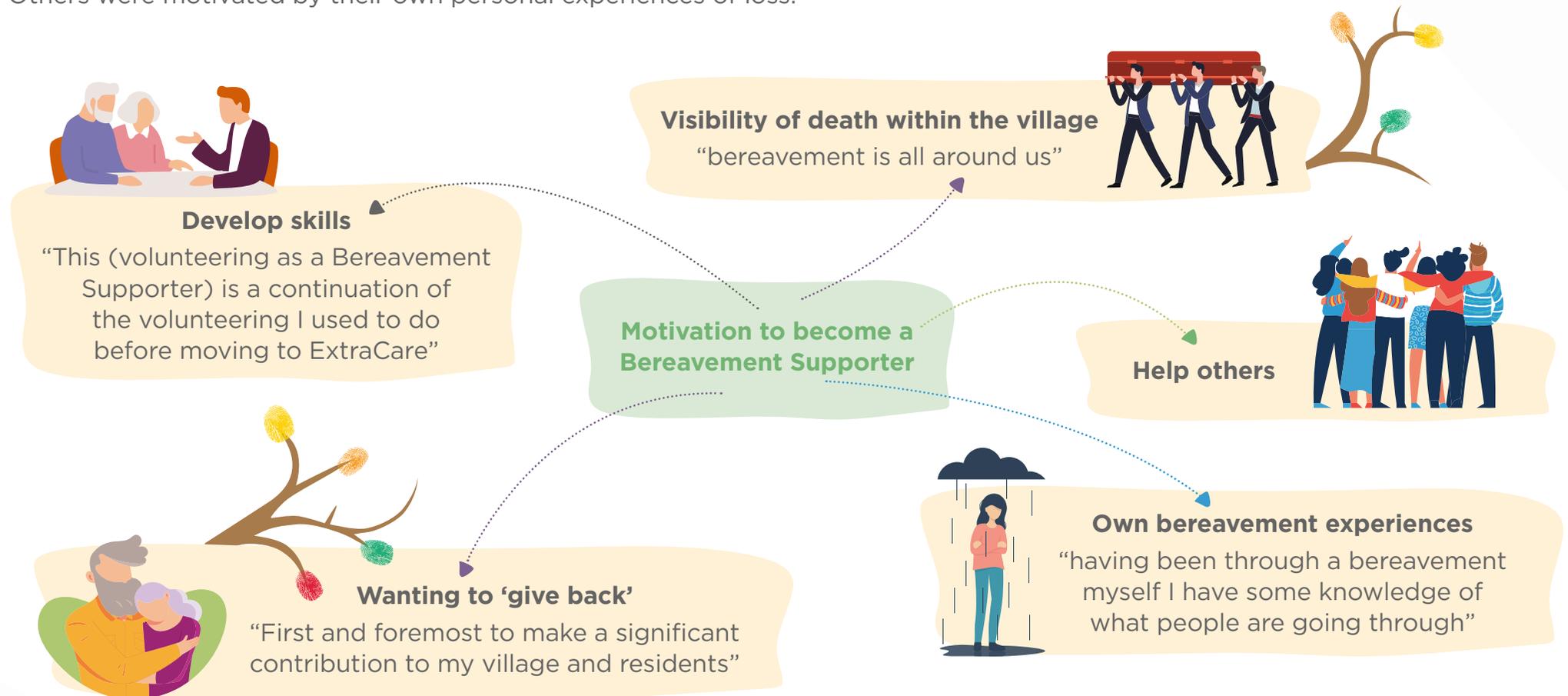
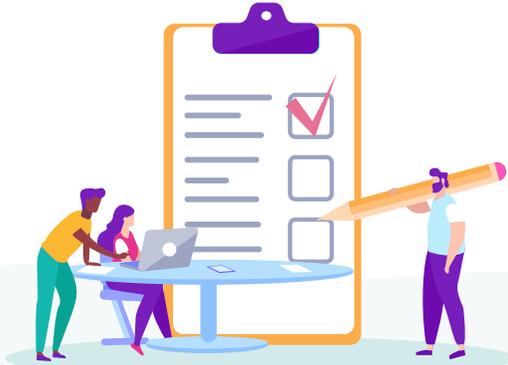


Figure 3. Depicts the main motivations for becoming a Bereavement Supporter.

Bereavement Supporters' Training Feedback



- All residents thought the training was either excellent (61%) or good (39%)
- All residents agreed they now understood grief better
- 86% agreed they were now comfortable supporting bereaved people



- Residents commended the training for how much they had learned about bereavement and grief - in particular how everyone experiences it differently



Facilitated an openness to talk about the "dark stuff"



Development of skills - particularly listening skills was valued among residents



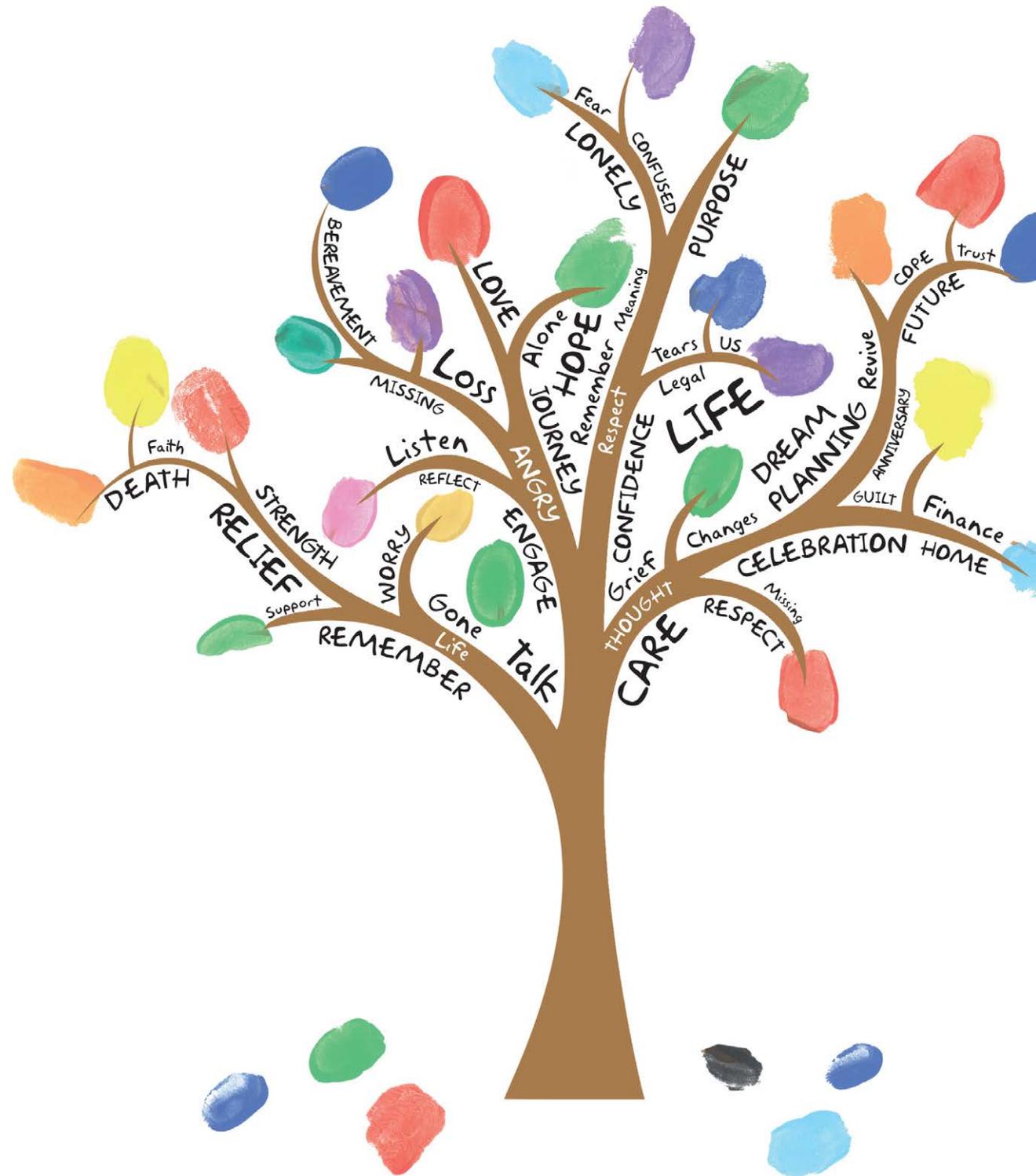
Training had encouraged self-reflection and increased confidence supporting bereaved people



While referral protocols were embedded within the project design that would allow residents to discretely self-refer themselves or for staff to refer consenting residents to Bereavement Supporters, the overwhelming majority of support provided by Bereavement Supporters would be considered 'informal'.

Informal support takes many forms but may include a bereaved person contacting a Bereavement Supporter directly to access either one-off or on-going support (as required), but is often a "casual conversation" initiated in a communal space (e.g. corridor or restaurant) that may cover many topics of which bereavement is one.

This section summarises Bereavement Supporters' main reactions to bereavement support being delivered in this way.



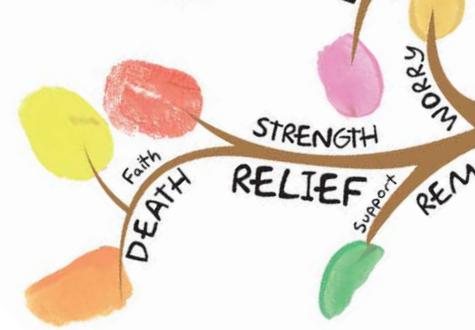
Bereavement Supporters' Reactions to Informal Support

Benefits

- Bereavement Supporters provided a number of examples of residents and family members who they had supported (informally) which they believe had been helpful;
- Some suggested that Bereavement Supporters are receptive to talking about the “dark stuff” which residents pick up on – what may seem like a “casual conversation” may be more strategic;
- Argued that “it isn’t formal counselling but is equally important for their development”;
- Furthermore, some argued that the informal route may be the only way residents feel comfortable discussing their grief – “the fact is, she needed help and that’s the only way she could do it”;
- Bereavement Supporters argued that informal support offers the opportunity to bypass ‘officialdom’ which may be particularly challenging for older adults (i.e. expectation for older adults to have a “stiff upper lip”);
- Finally, it was argued that “the informal is actually more important (...) they’re almost taking the top off the pain and upset and they get rid of that by chatting to us and then they can go about their daily lives”

Challenges

- Support being informal was identified as a challenge in almost every research encounter with Bereavement Supporters;
- Not what volunteers were expecting (perhaps because of previous work/volunteering experience);
- Belief by some that the project “has not taken off” in their village because so few formal referrals have been made;
- Some “felt like a failure” because formal support had not been delivered;
- Some may withdraw from the project as a result of their expectations not being met;
- However, we argue that for some Bereavement Supporters the informality of support is a challenge because they are expected to record their support cases for the evaluation

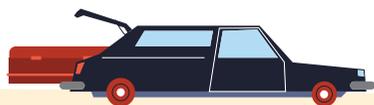


ExtraCare Context

This diagram captures the ways in which Bereavement Supporters identified the ExtraCare context to be pertinent to their experience, and specifically what barriers they perceived to the 'success' of the project in their village were.



The ExtraCare Charitable Trust



Death and bereavement are visible within the village - a service is needed to address experiences of grief



Lack of appropriate spaces



Staff engagement critical to 'success'



Lack of project visibility within the village



Overloaded staff - who is responsible?



GDPR/ Data Protection



Figure 4. Presents the ways in which Bereavement Supporters identified the ExtraCare context to be pertinent to their experience.

Findings from ExtraCare Staff



Staff members from across job roles within ExtraCare have attended the bereavement and loss one-day training and all reported the material was relevant to their role and encouraged them to think more about bereavement more broadly.

“So we’re all dealin’ with different sort of bereavements really, she’s in care, you’re in housing, and I’m in reception so we’re dealin’ with it in different ways” (Marnie)



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

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

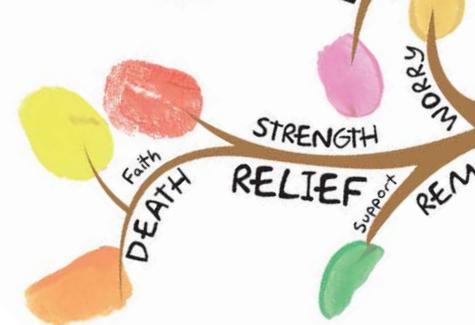


Staff were divided about whether residents were open to talking about death, dying, and bereavement.

“Not absolutely every resident is in a place where they want to engage with this agenda (...) but there was definitely others who wanted to get involved and subsequently did” (Dan)



Findings from ExtraCare Staff



Many staff members reported feeling bereaved when residents die, and felt that more could be done to support them.

“And before now we have had PSAs (Personal Support Assistant) where a resident has passed away and they’ve actually been so close, that for months afterwards it affected them” (Shireen)



ExtraCare Locksmiths (senior staff who work closely with residents with dementia and their families) reported that within the context of dementia “it’s bereavement on diagnosis” (Lisa) for the person with dementia and their families, and that as the disease progresses many experience “constant losses all the time” (Mary).

The Bereavement Supporter Project has developed a number of resources to better support residents living with dementia



Findings from Support Recipients



Residents reported feeling depressed, isolated, and overwhelmed before contacting a Bereavement Supporter.

"It overloads me and I can't cope. So I end up in tears all the time, I don't wanna do anything" (Mrs Carter)



Residents welcomed having someone trained, caring, and non-judgemental to talk to.

"I feel that the volunteer who visited me was experienced and she understood how to help me. I felt comfortable in confiding in her in view of her experience" (Anonymous Resident)



One resident reported that the Bereavement Supporter she turned to has encouraged her to resume activities she had previously enjoyed.

"I'm startin' to go back now. My life is now better than it was before." (Mrs Carter)



However, some residents reported that the match with a Bereavement Supporter had not been fulfilling for them.

"I just didn't feel she was the right person to speak to" (Mrs Laverty)



