

Bereaved by Dementia Project Evaluation (May 2019)

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Executive Summary

Background

While bereavement is considered to be a normal part of everyday life it can nevertheless be characterised as a period of intense suffering and adjustment (Stroebe, Schut, & Stroebe, 2007). Vulnerable people, such as older people, people with dementia, and their carers may be particularly susceptible to the impact of grief and bereavement. For example, bereavement among older adults has been associated with; an increased risk of suicide among widowers (Li, 1995); poorer perceived health (Thompson, Breckenridge, Gallagher, & Peterson, 1984); increased risk of depression (Alexopoulos, 2005); increased risk of complicated grief (Newson et al, 2011); and increased psychological distress (Thompson, Gallagher-Thompson, Futterman, Gilewski, & Peterson, 1991).

A diagnosis of dementia may also trigger feelings of grief and loss for both the person with dementia and their families and loved ones (Alzheimer's Society, 2017). Research suggests that carers who experience higher levels of pre-death grief are at higher risk of health complications post-death (Chan, Livingston, Jones, & Sampson, 2013; Givens, Prigerson, Kiely, Schaffer, & Mitchell, 2011; Sanders, Ott, Kelber, & Noonan, 2008; Shuter, Beattie, & Edwards, 2013, cited in Blandin and Pepin, 2017). Pre-death and post-death bereavement for people with dementia is a significant unmet need as well as an under-researched field of bereavement support (Dooley and Stewart, 2015).

The Bereaved by Dementia project, therefore represents a timely and potentially significant advance in supporting a growing group of vulnerable and overlooked people through their feelings of grief and loss. Funded by the Welsh Government Sustainable Social Services Third Sector Grant 2016-2019, Cruse Cymru and Alzheimer's Society Cymru joined in a partnership to address the bereavement needs of:

- People with dementia whose loved one/carer has died;
- People who have been bereaved through the death of someone with dementia.

Collaboration between partner organisations Cruse Cymru and Alzheimer's Society Cymru, Cruse Bereavement Volunteers (CBVs), and people affected by dementia

were critical to the design, development, and delivery of the Bereaved by Dementia Project. Over a period of three years (2016-2019), the Bereaved by Dementia Project delivered:

- A volunteer Recruitment Campaign – 131 new trained volunteers over 3 years (exceeding the target of 40 per year);
- A Bereavement Support & Dementia Awareness training module;
- A large proportion of the Bereaved by Dementia one-day training sessions were co-delivered by a person living with dementia and a Cruse Bereavement Care trainer;
- A jointly branded awareness raising/information resource booklet;
- Four information sessions per annum to statutory and third sector organisations;
- Raised awareness of Cruse services in the wider community;
- Bereavement support to 228 clients bereaved by dementia.

An independent evaluation of the Bereaved by Dementia Project has been conducted by a research team based at Aston University, Birmingham and the University of Bristol. What is presented here is therefore an executive summary of the wider evaluation the Bereaved by Dementia Project conducted, and delivered, by Aston University and the University of Bristol.

[Our Approach to the Evaluation](#)

The Bereaved by Dementia Project has been evaluated holistically. Broadly, the project has been evaluated in terms of; the content and quality of information delivered through training; outcomes for individuals – both CBVs and clients; and the wider awareness and impact across the networks of Cruse Bereavement Care and Alzheimer's Cymru. To do this, we utilised data collected by the evaluation team and data made available to us by Cruse Cymru. While some numerical data was collected in order to provide a snapshot of pertinent experiences, we focused our attention on qualitative methodologies (interviews and focus groups) which permitted rich and detailed accounts for how individuals experienced and made sense of their experience (Yardley, 2000). Aston University School of Languages and Social Sciences ethics committee granted ethical approval for this research.

Findings

What is presented here is an amalgamation of our wider findings. We intend for this to provide a snapshot of the Bereaved by Dementia Project, capturing the experiences of; CBVs, clients who have dementia and are bereaved; clients whose loved one has/had dementia (pre and/or post death bereavement); and the wider impact within the partner organisations. This will be achieved by attending to the three themes that encapsulate our main findings; training, support, and wider impact.

First, the design, development, and delivery of the Bereaved by Dementia one-day training was one of the core outcomes for the project. This training has been delivered in locations across Wales to 404 delegates, consisting of 241 CBVs and 163 external delegates (from public and private sectors). Overall, 96% of delegates reported that the training had met their expectations, and 91% reported that the training had increased their awareness about dementia and supporting someone close to them following a bereavement.

Furthermore, the majority of delegates commented on the quality and quantity of the information that was provided, and the awareness it generated. Delegates were particularly enthusiastic when the training was co-facilitated by a person who has dementia as this provided them with unique insight into how life, and loss, is experienced by a person with dementia. Thereby bringing the material to life, and humanising people with dementia through empathy and understanding.

Secondly, CBVs were better equipped to support clients who were bereaved by dementia through increased knowledge, empathy, and confidence cultivated through the training they received. CBVs and clients who are bereaved by dementia reported that bereavement support had provided a platform for clients' grief to be heard. An opportunity to share their experience, their pain, and their hopes for the future. Furthermore, clients reported examples of the ways in which they were reclaiming previously avoided activities, starting new activities, or looking to the future following bereavement support. Finally, there was evidence that clients' bereavement needs had been met on terms that were meaningful and valued by them.

The final theme captures the wider impact and learning generated from the Bereaved by Dementia Project. Delegates to the Bereaved by Dementia one-day

training –both internal and external delegates- reported that they would be able to apply their learning beyond the ‘classroom’ in their professional or volunteering role and/or their personal life.

Moreover, we received 116 responses to the impact and reach survey that was disseminated throughout Alzheimer’s Society Cymru and Cruse Cymru networks during December 2018 and January 2019. The vast majority of respondents (66%) were aware of the Bereaved by Dementia Project, and 92% believe that the project is important. Indicative that through the efforts promoting the Bereaved by Dementia Project an important step towards building awareness about bereavement and dementia has been made. Of those who has referred a client/family member to Cruse, 79% rated the process as either excellent or good. Respondents advocated for a dedicated and specialist bereavement support service that was sensitive to the needs and experiences of people living with dementia to be available and easily accessible. We argue the Bereaved by Dementia one-day training has, and could continue to, contribute to this recommendation through the development of CBVs who are sensitive to the needs of people with dementia who are bereaved.

[Conclusions, Recommendations, and Future Directions](#)

This evaluation has demonstrated that the Bereaved by Dementia one-day training increased delegates’ awareness of bereavement, dementia, and how bereavement may be experienced differently within a dementia context. Further to this, it has provided delegates with some core skills that will facilitate better support provision for people with dementia and their families as well as enriching how they understand and navigate their personal relationships.

Critically, we have observed a shift in how attendees to the Bereaved by Dementia one-day training understand, and relate to people with dementia. By focusing on the emotional integrity of people with dementia the training builds empathy and provides opportunities for connection. This is especially significant within the current climate of dementia discourse as a “living death” (Peel, 2014) which obscures individual experience and denies many avenues of support by giving the impression that people with dementia do not need, or would not benefit from, support.

The client and CBV narratives included within this evaluation illustrate the benefit of the Bereaved by Dementia project in supporting people through a variety of

bereavement journeys. Grief, and dementia, are experienced idiosyncratically, consequently the support needs of someone bereaved by dementia are likewise individualistic. Evidence from client and CBV interviews, and the 'impact and reach' survey demonstrate that there is a demand for bereavement services that are sufficiently flexible to meet the oscillating needs of people bereaved by dementia. The Bereaved by Dementia project has made an important step to address this significant and growing unmet need.

Further to this, through collaboration, Cruse Bereavement Care and Alzheimer's Society Cymru have played an important role in raising awareness and profile of bereavement and dementia. Through this effort, it is becoming increasingly apparent that the emotional toil, constant change, and loss experienced by people with dementia and their families is largely 'managed' in isolation. At present, while Cruse Bereavement Care recognise the significance of pre-death bereavement within the context of dementia fiscal limitations are a fundamental barrier to delivering this urgent service. We would like to see funds invested in furthering the scope of the Bereaved by Dementia project by enabling pre-death bereavement services – services that would have a significant bearing on the post-death bereavement experience - to be established, and evaluated.

Introduction

Research Background

Bereavement is a normal part of every life. However, vulnerable people such as older people, people with dementia, and their carers are particularly susceptible to the impact of grief and bereavement, but are often unseen and overlooked.

Dementia, both for people with dementia as well as those caring for or close to people with dementia, can complicate the grieving process. A diagnosis of dementia itself may also trigger feelings of grief, and, again, both for those with the diagnosis as well as those close to people with a dementia diagnosis (Alzheimer's Society, 2017). Research suggests that carers who experience higher levels of pre-death grief are at higher risk of health complications post-death (Chan, Livingston, Jones, & Sampson, 2013; Givens, Prigerson, Kiely, Schaffer, & Mitchell, 2011; Sanders, Ott, Kelber, & Noonan, 2008; Shuter, Beattie, & Edwards, 2013, cited in Blandin and Pepin, 2017). Pre-death and post-death grief and bereavement for people with dementia is a significant unmet need as well as an under-researched field of bereavement support (Dooley and Stewart, 2015). The Bereaved by Dementia Project, therefore, represents a timely and potentially significant advance in supporting a sizeable and growing group of vulnerable and overlooked people through the bereavement process as well as a valuable potential source of learning in this field.

Overall Aims and Objectives of the Bereaved by Dementia Project

The Bereaved by Dementia Project was funded by the Welsh Government Sustainable Social Services Third Sector Grant 2016-2019, Cruse Cymru and Alzheimer's Society Cymru joined in a partnership to address the bereavement needs of:

- People with dementia whose loved one/carer has died;
- People who have been bereaved through the death of someone with dementia.

The project has a special focus on, but is not limited to, older bereaved people with dementia and ways of working with this especially vulnerable client group.

The aim of the project was to deliver a successfully tested model of working which incorporates raising awareness of how bereavement affects older adult's mental and

physical health; improving access to support for bereaved older people; encouraging self-help and peer support in order to reduce loneliness and social isolation and to help safeguard and promote long term mental and physical health.

Over a period of three years (2016-2019), the Bereaved by Dementia Project delivered:

- A volunteer Recruitment Campaign – 131 new trained volunteers over 3 years (exceeding the target of 40 per year);
- A Bereavement Support & Dementia Awareness training module designed, developed and jointly delivered by the two organisations;
- A large proportion of the Bereaved by Dementia one-day training sessions were co-delivered by a person living with dementia and a Cruse Bereavement Care trainer;
- A jointly branded awareness raising/information resource booklet;
- Four information sessions per annum to statutory and third sector organisations;
- Raise awareness of Cruse services in the wider community;
- Bereavement support to 228 clients bereaved by dementia.

Glossary of Terms

ABC – Awareness in Bereavement Course, a revised version of the Cruse ABC training was introduced in August 2017 (Bereavement Foundation Training; BFT)

Ascentis – an awarding organisation of further, and Higher Education

CBV – Cruse Bereavement Volunteer

Our Approach to the evaluation

The Bereaved by Dementia Project has been delivered by Cruse Bereavement Care Cymru, and evaluated by an independent research team based at Aston University, Birmingham, and the University of Bristol. Broadly, the project has been evaluated in terms of: the organisation of the service; the quality of support and information offered; outcomes for individuals – both Cruse Bereavement Volunteers (CBV) and clients; wider awareness and impact. To do this, we utilised data collected by the

evaluation team and data made available to us by Cruse Cymru. We have used both quantitative and qualitative methods in order to capture the experiences and feedback of CBVs, external organisations, and clients both with dementia and anyone who has been bereaved by dementia in the wider sense. What is presented in this report is the culmination of the evaluation of the Bereaved by Dementia Project conducted, and delivered, by Aston University and the University of Bristol.

Data Sources for the Evaluation

- ABC/CORE training feedback form consisting of open and closed questions (data collected by Cruse Cymru).
- Bereaved by Dementia one-day training module for Cruse Bereavement Volunteers (Internal delegates) feedback form consisting of open and closed questions (data collected by Cruse Cymru).
- Bereaved by Dementia one-day training module for External delegates feedback form consisting of open and closed questions (data collected by Cruse Cymru).
- Focus group conducted with three CBVs to explore their experiences of the Bereaved by Dementia one-day training module (data collected by first author, acting as a representative of the Evaluation Team).
- Two CBVs, who were unable to attend a focus group, provided written responses (data collected by Aston University) to the questions raised during the focus group regarding experiences of the Bereaved by Dementia one-day training module.
- Three case study interviews with CBVs to explore their experiences supporting a client who was bereaved by dementia (data collected by Aston University).
- Three case study interviews with clients who were bereaved by dementia were conducted to examine their experiences of receiving support (data collected by Aston University).
- Impact and Awareness Survey distributed among the Cruse Cymru and Alzheimer's Cymru networks (survey designed by Aston University in collaboration with the research team and Cruse Cymru representatives).

- Learning from a Learn and Share Group, established to share learning between the evaluation team, Cruse Bereavement Care, Alzheimer's Society, and Cruse's sister project with the ExtraCare Charitable Trust.
- The first author attended a "Bereaved by Dementia" one-day training module (for external delegates) to gain a better understanding of the experiences of delegates and to inform interpretation.
- Preliminary findings were presented by the first and second authors at the Bereaved by Dementia Project Launch held at The Senedd (National Assembly for Wales) in May 2018.

Analysis of Data

Through the combination of quantitative and qualitative methods of data collection we will present an overview of experience more broadly, as well as detailed examples of lived experience.

Our strategy for data analysis was guided by the data generated. For instance, the open ended questions within the respective feedback forms and surveys elicited succinct responses, often characterised as listing pertinent features and/or expressing multiple aspects of experience within one comment.

"Informative and enjoyable...refreshed my knowledge and built on what I know"

As such, we used inductive content analysis (Elo & Kyngäs, 2007) to organise, code, categorise, and make sense of the written feedback provided by respondents. First, data was organised and analysed by question. This permitted a systematic approach whereby each individual written response was coded based on the content included within the comment. A single comment could therefore contribute to multiple codes. This procedure was followed for each of the open-ended questions in turn which produced a comprehensive and detailed summary of the data. Finally, this catalogue of codes was then further analysed to identify overarching themes to provide a holistic understanding of the feedback.

In comparison, the focus group and the individual interviews with CBVs and clients elicited rich data that the authors analysed independently and through discussion. Thematic analysis guided the data analysis; a method for identifying, analysing and reporting patterns within data (Braun & Clarke, 2006). Using this approach allowed

for a deeper analysis of the data which reflected the detailed narratives generated through the interview (or focus group).

Furthermore, our approach is sensitive to the way participants describe their experience. We have preserved participant voice, and used it as a vehicle for evaluation in two critical ways. Firstly, audio recordings were transcribed verbatim and so the extracts provided within this report mirror the patterns of spontaneous speech. While we have not ‘tidied’ participants’ responses, we have identified known errors that may hinder understanding using [sic], as well as providing additional contextual information in brackets. For example, *“If [only] all CPD [continuing professional development] training was as well planned and delivered.”* The provision of extracts from the data is used to both support our arguments and interpretations, and to bring the reader closer to the participants’ experience.

Secondly, the title of many (but not all) themes presented (for example *“Bridge of Communication”*) contain speech marks. This is to indicate that the title of this theme is drawn directly from the data. In other words, this is a quotation from the data that has been used to capture the essence of the theme. If the thematic title does not contain speech marks this means the title was generated by the authors to summarise the theme.

Finally, participants’ identities have been concealed using pseudonyms and by obscuring details (for example, locations, hospital names etc.) within their narratives that could potentially identify them and/or third parties.

The Structure of the Report

To do justice to the richness of the data collected, and the uniqueness of the evaluation we have produced this very detailed report. We have a chapter dedicated to each point of data collection (as described in the preceding section) with the aim of capturing the unique and the shared experiences of being a part of the Bereaved by Dementia Project. Core findings and recommendations are summarised at the end of selected chapters (see Chapters 1, 3, 5, and 6). These substantive chapters are bookended by the ‘at a glance’ chapter which provides a snapshot of our findings, and the ‘final thoughts’ chapter which draws together the findings and recommendations of this evaluation.

At a Glance

This section provides a snapshot of what is covered in this report. It presents some of the highlights from four main areas of investigation; CORE/ABC training feedback, Bereaved by Dementia one-day training feedback, case studies with CBVs, and case studies with clients who are bereaved by dementia.

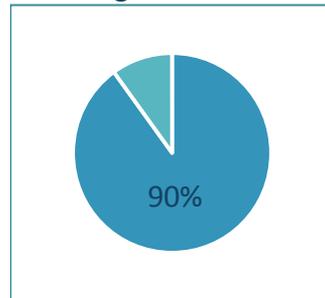
CORE/ABC TRAINING

Chapter 1 examines the feedback from the CORE (previously ABC) training completed by all Cruse Bereavement Volunteers (CBVs).

131 new Cruse Bereavement Volunteers recruited through the Bereaved by Dementia Project.



Of those surveyed, **90% were satisfied** (or extremely satisfied) with the training.



Respondents reported going on a **journey** developing their knowledge, skills, and confidence.



BEREAVED BY DEMENTIA ONE-DAY TRAINING

Chapters 2 and 3 use quantitative and qualitative feedback to explore the experience of internal and external delegates attending the one-day training.

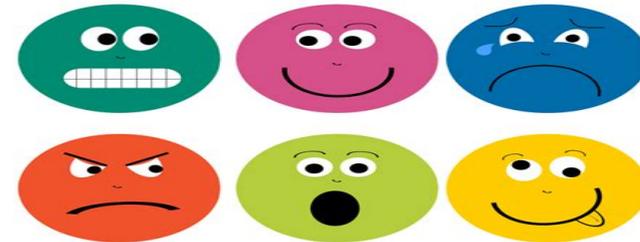
91% of delegates reported increased awareness of dementia & bereavement



Delegates agreed the training was “**a well thought through package**”



Realising that **people with dementia retain emotional integrity** was reported as the most **unexpected and impactful** aspect of the training.



CRUSE BEREAVEMENT VOLUNTEERS CASE STUDIES

In Chapter 4 we present three rich narratives of CBVs who have provided bereavement support to people who are bereaved by dementia.

CBVs agreed that the one-day training and personal experiences **prepare** them to provide bereavement



CBVs found it **difficult to assess** what **impact** bereavement support had on their clients.

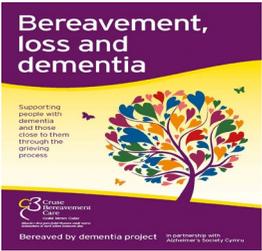
CBVs helped clients to **“grow a bit more life”** around their grief.



BEREAVED BY DEMENTIA CLIENT CASE STUDIES

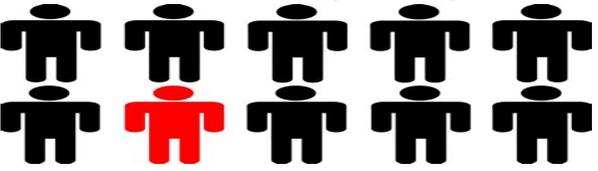
In Chapter 5 we present three unique experiences of clients who have received bereavement support through the Bereaved by Dementia Project.

“Sharing in the experiences of others was **greatest benefit** of bereavement support”



Resource helped **“breakdown experience of grief, stigma, and generational barriers”**.

Service responds to **individual experience** by providing support appropriate to **“where they are”** in their journey.



Chapter 1: CORE (formerly ABC) Training Feedback Data

The CORE (formerly ABC) training is a pre-requisite for anyone hoping to work with Cruse clients to ensure clients receive a consistent approach. The course comprises of both theory and practical skills delivered on a weekly basis over the course of eight weeks. Additionally, trainees are expected to complete a portfolio showcasing their learning through independent study. This training has been evaluated and accredited by Ascentis and approved by the National Counselling society outside of this project.

All volunteers recruited through the Bereaved by Dementia Project attended the CORE/ABC training and were given the opportunity to complete a course evaluation form (this is in addition to the session evaluation forms which are not presented here). Using a combination of open-ended and closed questions, the questionnaire captured respondents' feedback on:

- Whether their expectations had been fulfilled;
- How prepared they feel to provide support to bereaved people (with the option to comment further on this item);
- What they found *most* valuable and interesting about the course;
- What they found *least* valuable and interesting about the course¹;
- Suggestions for changes, omissions, additions to the course;
- Overall satisfaction with the course;
- Additional comments.

¹ This question was added following the pilot in North Wales. The aim of the pilot training was to evaluate an updated training package compared to previous volunteer bereavement training. The pilot training has replaced (as of April 2018) the previous training programme.

A total of 99 CORE/ABC training feedback forms were received over the period of 2017-2018, and have been included in the analysis presented here. With the exception of the item pertaining to feeling prepared to support clients², responses have been analysed collectively. The remainder of this section will explore the CORE/ABC training feedback in more detail. First by examining delegate responses to the closed questions, and then by exploring the delegate responses to the open questions.

Overall Course Satisfaction

As demonstrated in Figure 1, a sizeable majority of respondents (78%) reported being extremely satisfied with the course, a further 12% reported being satisfied with the course.

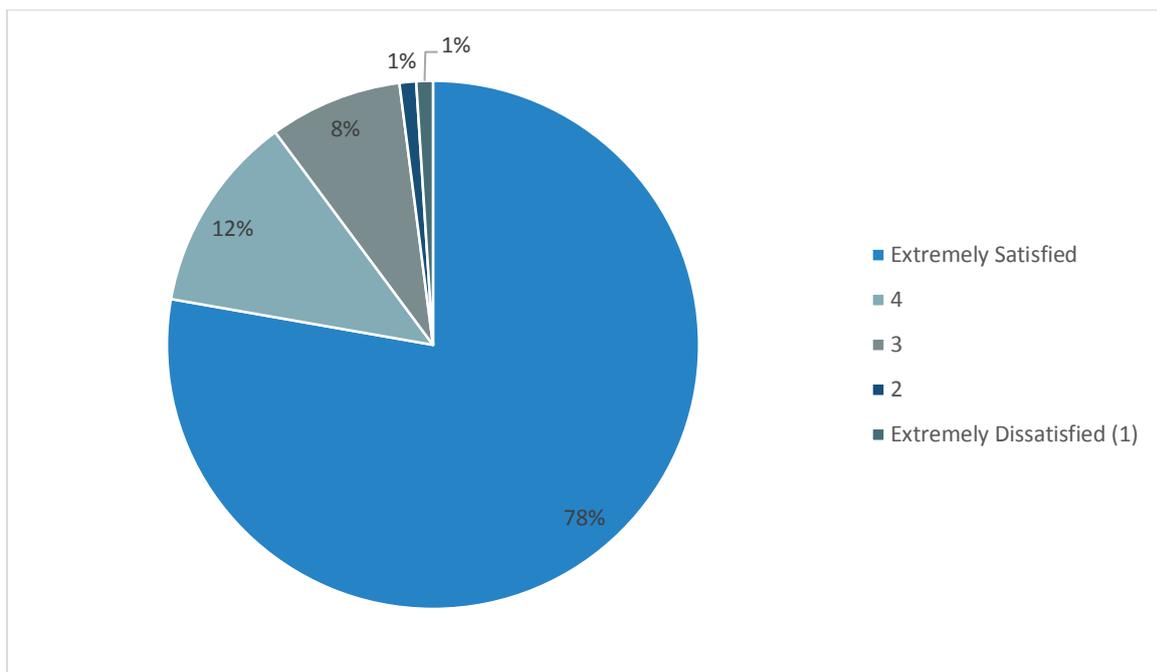


Figure 1. Demonstrates respondents overall satisfaction with CORE/ABC training

Overall, 90% of respondents reported being either extremely satisfied or satisfied with the CORE/ABC training.

² Delegates within one cohort of trainee volunteers received a slightly different version of the feedback form. While this form included an item examining volunteer experiences of preparedness, the response options were expressed in a way that prevented joined-up analysis.

How well has the course prepared you to support bereaved people?

As mentioned in the footnote above, due to different response choices, one cohort of delegate responses is presented separately. For clarity, this cohort will be referred to as Cohort B and all other delegates will be referred to as Cohort A.

Figures 2 and 3 provide a full breakdown of delegate responses. In summation, 56% of delegates in Cohort A responded 'very well' in response to the question 'how well has the course prepared you to support bereaved people'. In comparison, 87% of delegates in Cohort B reported being 'very well' prepared to support bereaved people, the remaining 13% reported 'well enough'. There were no delegates who responded 'very little' or 'not well enough'.

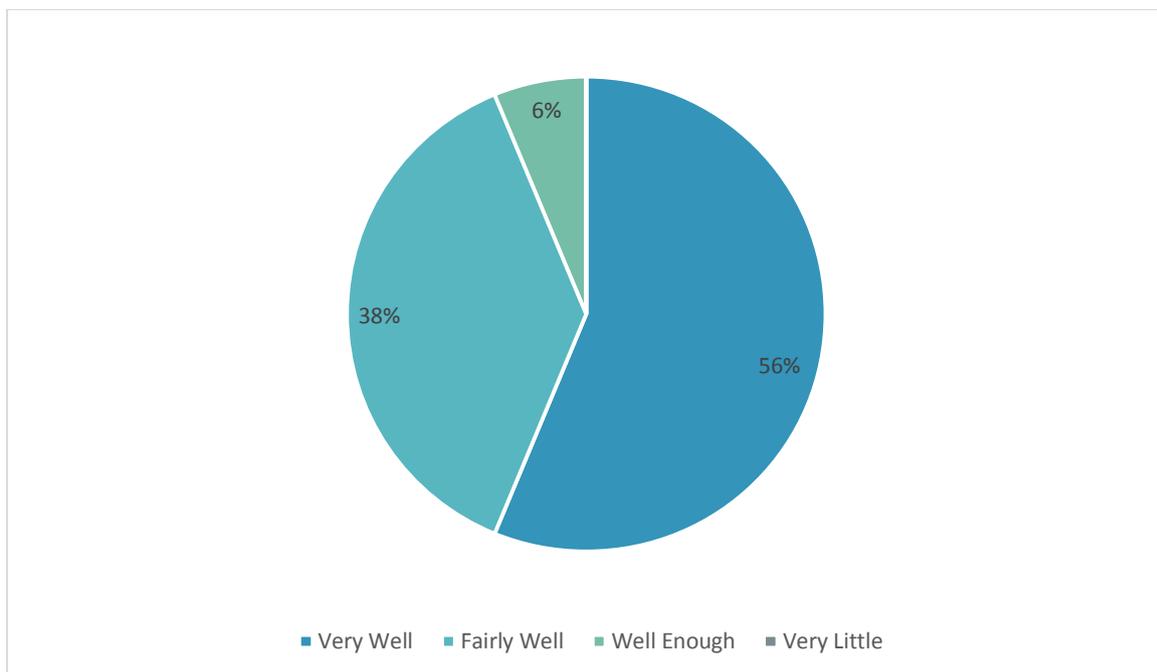


Figure 2. Breakdown of how well prepared Cohort A respondents felt to support bereaved people after completing CORE/ABC training.

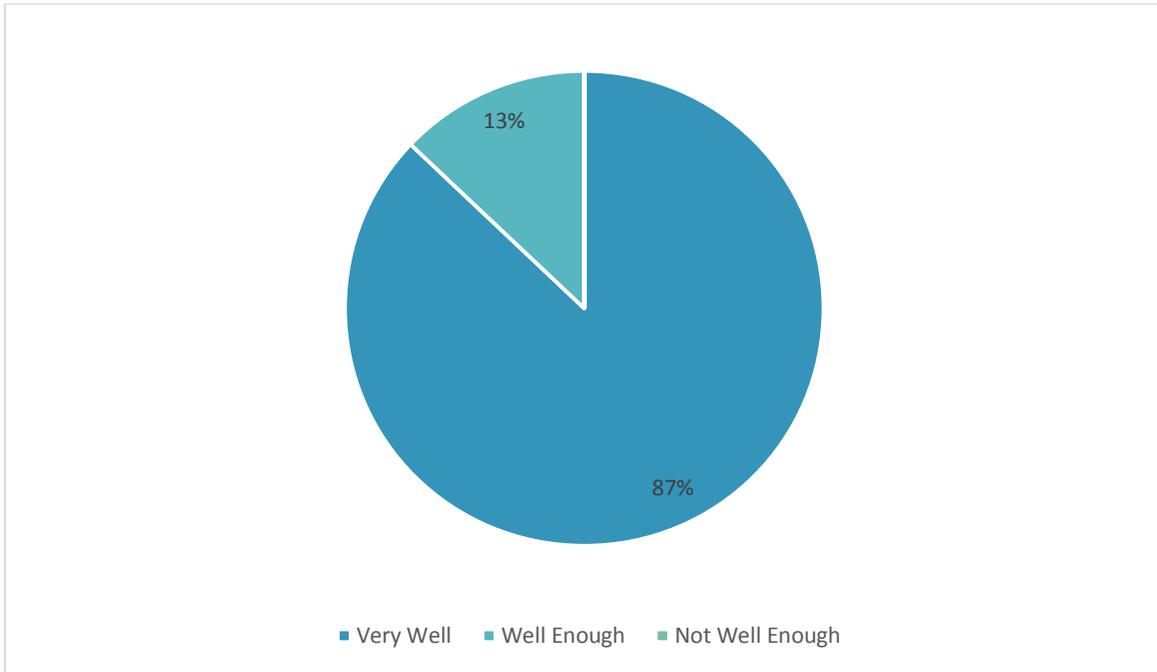


Figure 3. Breakdown of how well prepared Cohort B respondents felt to support bereaved people after completing CORE/ABC training.

Overall, 71% of delegates reported feeling very well prepared to support bereaved people after completing the CORE/ABC training.

- How well has the course prepared you to support bereaved people? Please comment;
- Additional comments.

The following overarching themes were identified through content analysis to provide a holistic understanding of the CORE/ABC training feedback.

“It’s been a journey”

Threaded throughout delegate responses was the sense that the completion of the CORE/ABC training marked the end of a journey, and indeed, the beginning of a new one for many of the respondents.

“I have learnt so much and feel that I have been on a journey”

“Also, the journey of self-discovery it takes you on in relation to self-awareness!”

“It’s really delightful to be embarking upon this journey with Cruse”

Embedded within delegates’ journey narratives are the distinct, but interconnected, themes of; knowledge/learning propelling their journey, the often unexpected self-discovery stimulated through the training process, and finally, their future horizons as they continue their journey by supporting bereaved people. We will examine each of these briefly in turn.

The most frequently occurring code (with over 70 unique comments) was ‘learning experience’. This code was consistently framed positively and expressed delegates’ gratitude and commendation of the knowledge and skills that had been imparted and nurtured throughout the training course.

“Overall [the] course [was] extremely thought provoking, great deal of knowledge gained”

“It has been excellent training given lots of useful information and skills practice”

Furthermore, the majority of respondents were confident that they could translate their learning (for example, grief processes, models, and theories) to real-life applications within their capacity as a Cruse Bereavement Volunteer. Developing counselling skills through triad³ and role play was frequently cited (54 unique

³ A specific role play format whereby trainee CBVs work in groups of three each with a specific role: (1) client, (2) bereavement volunteer, (3) observer.

comments) as being particularly apposite in nurturing respondents' confidence to deliver bereavement support.

"I thought the different scenarios we explored in group work and triad skills development were excellent and 'unpicked' the wide variety of cases we may come into contact with - this better prepared us for these situations, giving us skills to manage those presentations"

"The training supported and encouraged us to identify and practice skills and tools which will be essential when volunteering"

While the vast majority of respondents reported that through the development of knowledge and skills they were sufficiently confident to support bereaved clients there was a noticeable minority (7 unique comments) that voiced concern about taking on this responsibility. Continued support (and perhaps training in some cases) for Cruse Bereavement Volunteers is therefore an essential feature to mitigate obstacles on their journey to supporting clients.

"I would feel comfortable to work with bereaved people under supervision (I have also done levels 2&3 counselling)"

"No criticism of the course and the trainers however as completely new to social and bereavement work I feel the need for further training and practice on being a BV [Bereavement Volunteer]"

Finally, delegates reported that through personal reflection and class discussions they had embarked on a journey of self-discovery and personal growth. For many this involved being confronted by their own mortality and having the opportunity to reflect upon what this means to them within the context of their own lives, and for one respondent inciting change. Respondents also identified that increased self-awareness contributed to a greater empathetic capacity which they argued would be invaluable in communicating with, and supporting, bereaved people.

"I found a few things in my life I need to change, as it made me stop and think"

"As well as learning about bereavement care I have also learnt about myself and others within a supportive and encouraging environment"

“I've had to opportunity to reflect and build awareness of myself and my own bereavement experiences and as a result I feel more in tune with my feelings and thoughts”

“The trainers are a credit to Cruse”

Respondents emphasised the critical role of the trainers in supporting and guiding them throughout the course through their unwavering enthusiasm and wealth of experience (demonstrated through the 87 unique comments pertaining to the trainers).

“Trainer knowledge/experience has been essential to overall development/understanding”

“Trainers' input and ability to explain, and establishing a "safe" room within which we could ask questions, offer answers”

Indeed, the ‘additional comments’ section was primarily used as a platform through which respondents could thank their respective trainers for their ongoing support, and for sharing their experience and expertise.

“The trainers are a credit to Cruse and [I] thank them for my journey”

“The course and trainers have led me to feel that with their help and continuous supervision and development training I can now help others. Thank you”

As we examined in the preceding section, completing the CORE/ABC training programme is a significant commitment marked by meaningful personal and professional growth for delegates. This theme demonstrates the critical role that Cruse Bereavement Care trainers have to guide and support prospective CBVs on their journey.

[Suggested improvements](#)

Delegates were encouraged to offer suggestions for changes and omissions in the course and/or additional training. While the overwhelming majority of respondents emphasised the success of the training (characterised by leaving the space blank, or

responding with 'n/a' or 'nothing'), there were some notable recommendations to improve future CORE/ABC training.

The three most frequently cited suggestions related to: timing (12 unique comments), homework (7 unique comments), and further training (7 unique comments). There were mixed comments regarding the duration and intensity of the training programme, with some respondents requesting a shorter programme whilst others proposing a longer schedule.

“It would have been valuable if the course had been shorter, but I understand there is a lot of content to fit in”

“An extra day would help relieve anxieties/stress levels etc. Better closure possible re any issues”

For some the volume of work required for the portfolio was unexpected and “*overwhelming at times*”. While it was a valued component of their learning, some delegates made suggestions to redistribute homework assignments to make them more manageable.

“Maybe suggest not to volunteers complete 1 piece of the additional work with the journal each week, that way the extra work won't build up and become too much”

“A lot of homework perhaps instead of loads of homework on week 2 especially, could have less and do it week 3 when only have journal to do”

Finally, individual delegates registered interest for further training in: group facilitation, child bereavement training, dementia bereavement training, and general training for further professional development.

Evaluation: Learning and Recommendations

- The findings from this evaluation provide further evidence that the CORE/ABC training cultivates a learning environment that; promotes knowledge and understanding of core bereavement theory, develops counselling skills, and sufficiently prepares prospective Cruse Bereavement Volunteers to deliver high quality support to bereaved people.
- Additionally, this evaluation recognises the value that delegates place on the personal and professional journey experienced upon completion of the CORE/ABC journey.
- Our recommendations include; continued transparency regarding the commitment required to complete the programme successfully, and encouraging open communication during supervision to ensure new Cruse Bereavement Volunteers feel sufficiently supported and prepared to deliver appropriate bereavement support to clients.

Chapter 2: Bereaved by Dementia One-Day Training Feedback Data

The design, development, and delivery of the Bereaved by Dementia one-day training was one of the core outcomes for the project. It was designed over a period of several months in collaboration with Alzheimer's Society Cymru, Cruse Bereavement Care Volunteers, and through meaningful engagement with people affected by dementia. While the development time exceeded expectations it is recognised that working collaboratively requires flexibility and dedication to ensure the opportunity for all voices to be heard.

The one-day training session is an elective module for CBVs which contributes to their continued professional development. It could similarly be used for delegates from external organisations. The principal aims of the one-day training were to improve awareness regarding the impact of bereavement for families/carers following the death of someone with dementia, and the impact of bereavement for a person living with dementia. Additionally, it aimed to provide skills and confidence in supporting a person with dementia through a bereavement as well as increasing knowledge about how the physiological effects of dementia in turn impact on everyday activities, including loss of memory, independence, and confidence.

The feedback from the one-day training consisted of both open-ended and closed questions and was designed to elicit feedback pertaining to;

- Whether the training met their expectations;
- Whether the training increased their awareness of dementia and bereavement, and supporting someone close to them following a bereavement;
- Whether the exercises were useful and easy to follow;
- What aspects of the training were *most* useful;
- Suggested improvements.

The Bereaved by Dementia one-day training has been delivered in locations across Wales to both internal delegates (CBVs) and external delegates (individuals from public and private sectors). In total, 404 delegates have attended the one-day training, consisting of 241 CBVs and 163 external delegates. In response to demand, additional funding was secured by Cruse Morgannwg (local area) for a

further 12 CBVs and 89 external delegates to attend one-day training sessions that were delivered in 2018-19.

Feedback has been collected from a total of 253 delegates (response rate 63%), consisting of 140 internal and 113 external delegates (response rates 58% and 69% respectively). The data presented in the following section will examine the responses to the closed questions; with attention given to both the overall responses and pertinent differences between internal and external delegates.

The workshop met my expectations

Overall, 69% of respondents strongly agreed that the training met with their expectations, with a further 27% marking agree (see Figure 5).

When considered separately, 75% of internal delegates responded strongly agree, with a further 24% responding agree. In comparison, 61% of external delegates reported strongly agree, with 32%, 5%, and 2% respectively reporting agree, disagree, and strongly disagree. These findings indicate that external delegates' expectations were somewhat less successfully met than internal delegates.

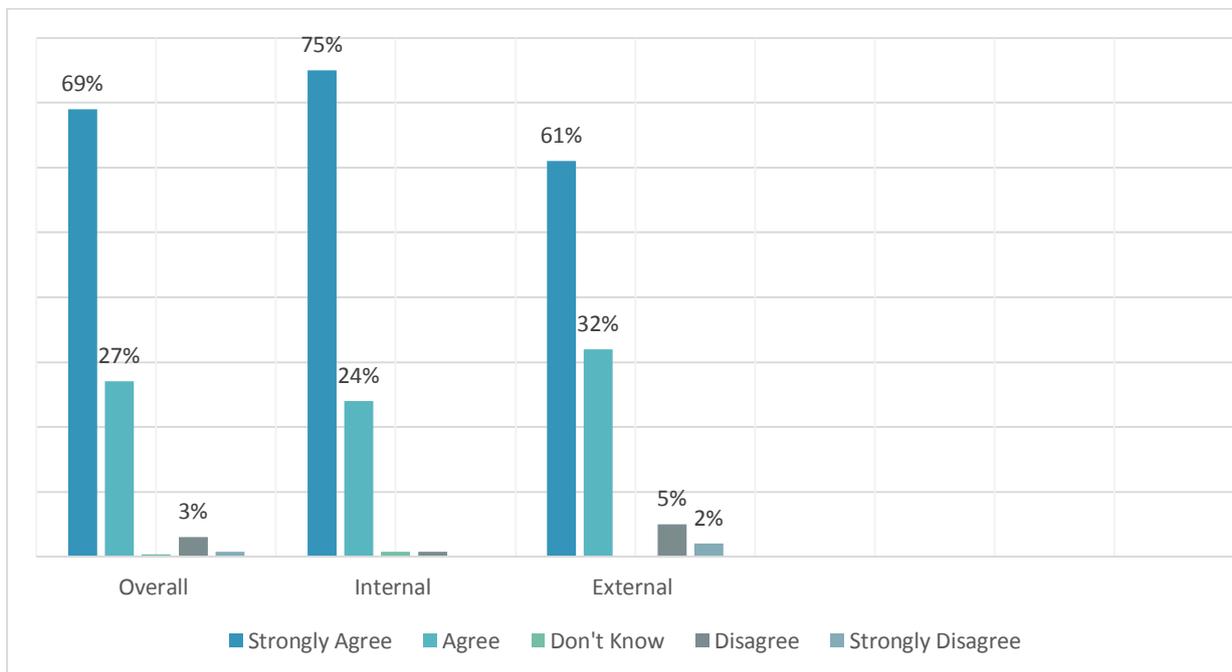


Figure 5. Comparison of expectation scores between internal and external delegates and overall scores

Overall, 96% of delegates reported the Bereaved by Dementia one-day training met their expectations

The workshop increased my awareness about dementia and supporting someone close to them following a bereavement

Overall, 65% of delegates reported strongly agree in response to this statement, with a further 26% responding agree (see Figure 6). The remaining 4%, 2%, and 2% responded don't know, disagree, and strongly disagree respectively.

When internal and external delegates are compared there is little difference in the number of respondents who reported strongly agree (internal; 68%, external; 62%) and agree (internal; 27%, external; 25%). The most notable difference between internal and external delegates' responses is that 5% of external delegates reported disagree, in comparison to 0% of internal delegates, and 3% of internal delegates reported strongly disagree compared to less than 1% of external delegates.

Overall these findings suggest that the one-day training substantially increased delegates' awareness about dementia and supporting someone close to them following a bereavement. With a small minority within both internal and external delegate groups whose awareness was not increased.

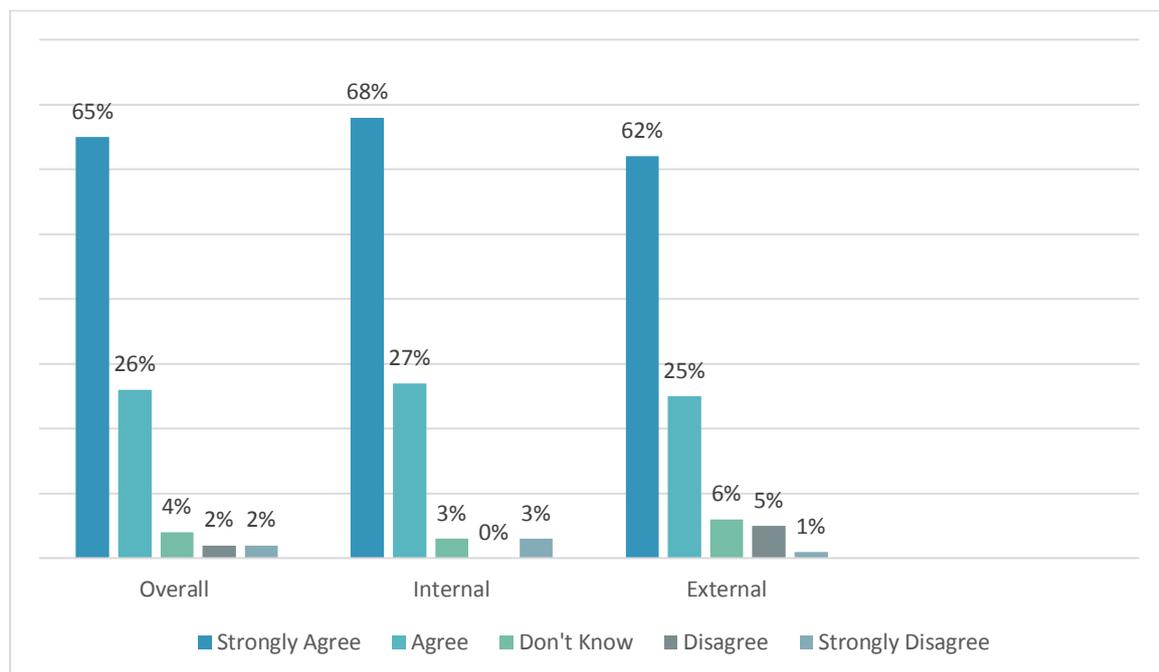


Figure 6. Comparison of awareness reported between internal and external delegates and overall scores

Overall, 91% of delegates reported that the Bereaved by Dementia one-day training increased their awareness about dementia and supporting someone close to them following a bereavement.

The workshop exercises were useful and easy to follow

Overall, 69% of delegates reported strongly agree, with 29% and 1% respectively reporting agree and don't know. Comparisons between internal and external responses revealed little difference (see Figure 7).

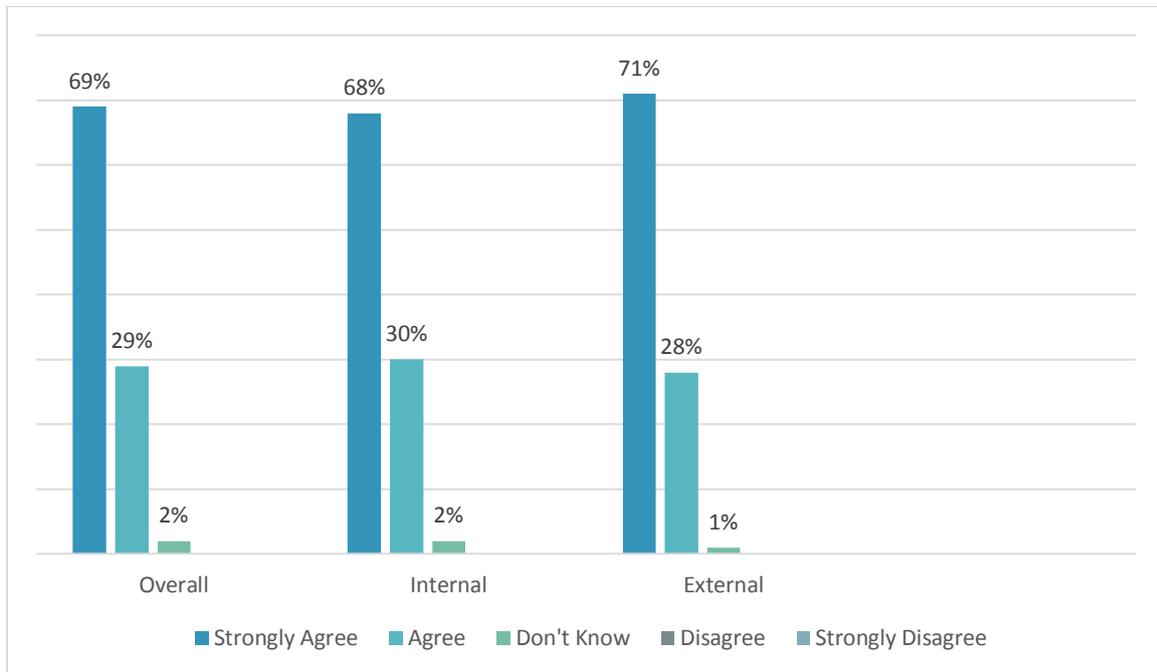


Figure 7. Comparison of the ease and usefulness of training exercises reported between internal and external delegates and overall scores

Overall, 98% of delegates reported that the workshop exercises were useful and easy to follow.

Open-ended Questions

Whilst it is not possible to discuss each category and sub-category in detail, the following sections will examine selected categories which were identified through the application of content analysis as being particularly pertinent.

“A well thought out package”

As the theme title implies, this section examines delegate experiences of attending the Bereaved by Dementia one-day training programme holistically. It demonstrates ways in which the training: increased knowledge and awareness; encouraged and facilitated meaningful discussion and thinking ‘beyond the self’; and provided practical skills which can be applied in the ‘real world’.

The sub-category ‘information and awareness’ was the most frequently cited aspect of the training day with over 60 comments relating to the quantity and quality of information that was provided and the awareness it generated. For some, it was an opportunity to examine a topic that they knew nothing about:

“Interesting to learn about dementia as I knew nothing”

While for others, it strengthened and built upon their previously held knowledge and beliefs and served as a refresher:

“My views are stronger than previously...day was brilliant”

“Enhanced my knowledge of how to deal and support patients grieving with dementia”

“Informative and enjoyable...refreshed my knowledge and built on what I know”

The module content and facilitated discussion, and in some cases the opportunity to examine the module content through the lens of a person with dementia permitted delegates to develop deeper empathy for people with dementia, and their family and carers. This is indicative that the training can elicit profound insight and evoke change in attendees.

“Learning about dementia from a person with dementia was insightful”

“I have more of an understanding of dementia and the effects on family and carers”

“Provided a chance to think more deeply about bereavement and dementia and about being human”

“Enabled me to look at things differently rather than just through ‘nursing eyes’”

However, for seven respondents the training session did not serve to increase their knowledge and awareness of dementia and bereavement. These responses all stemmed from external delegates who held dementia-related professional roles.

“The workshop didn’t increase my understanding as I work with people with dementia”

“Workshop too basic. I already knew most of the information. Nothing was useful”

For some it is evident that the training day had not met their expectations and needs. However, a large majority of delegates were able to see the value of the training, either as consolidation of what they already knew or as a gateway to understanding for those who are not as informed and/or experienced as themselves.

“This has not raised my awareness but was insightful”

“Already work in a CMHT [community mental health team] with clients with dementia so have a good knowledge base already. The course is excellent and set at a really good level for other[s] to learn/understanding who do not have the experience/knowledge of dementia”

Nevertheless, a sizeable number of delegates, both internal and external, emphasised that attending the training day had been a learning experience and provided them with valuable insight into dementia and the impact of bereavement within this context. Further to this, an external delegate (who works in a care home), described how the training had transformed the way in which they viewed people with dementia. The Bereaved by Dementia one-day training *“made us think of patients as a whole person”*, a significant achievement for a one-day training course. Finally, two delegates reported that attending the one-day training had helped them overcome personal anxiety and fear about working with clients with dementia (both were internal delegates).

“Something I would have found scary - but now feel better equipped to deal with - certainly will endeavour to get more knowledge! Build confidence”

“A very clear and informative presentation which dispelled anxiety about how to support a bereaved person who was diagnosed with dementia”

Respondents were asked to report specific resources and activities that they found useful. As one might expect, the aspects identified were varied and included; case studies, types of dementia, exercises, and communication and counselling skills. It is also noted that there were 35 comments that reported all of the content to be useful.

“The whole course brought an overall understanding and awareness”

“All were good- very well thought out package”

That being said, there were two aspects that were consistently cited as valued and important to respondents: (1) group work and discussion; and (2) emotionality, specifically the bookcase analogy. It is argued that these sub-categories serve the same function - to increase empathy with people with dementia. Both the bookcase analogy and the various group activities and discussion encourage delegates to consider life experiences beyond their own. To imagine and recognise the complexity of experiences, history, and emotion inherent within us all, including people with dementia. But further than that, they establish a channel through which a connection can be made. A shared understanding which, if explored sensitively, has the potential to transform the ways in which people with dementia are perceived and treated (by Cruse Bereavement Volunteers).

“Bookcase activity was very useful to show how to connect with a person living with dementia”

“Most useful session was sharing of experiences and live examples”

“Bookshelf with emotion. I hadn't realised that the emotions have not been lost”

“Sharing experiences together in a safe respectful environment”

Finally, whilst it is a laudable aim to deliver training that is informative and engaging, a central aim of this training was that the material would be applied in ‘real life’. It is therefore, of paramount importance that the message extends beyond the classroom by providing material and skills that can be applied in the ‘real world’. There were 27 comments stating that delegates would be able to apply the information and/or skills delivered in the training to a personally pertinent context, whether that was within their role as a CBV or within their professional role.

“It has helped me to understand how to tailor bereavement assistance”

“I will take the knowledge back to my team. Workbook will be very useful for staff training”

“Really interested in training as a bereavement volunteer...very good I will definitely use what I have learnt today”

“Two very inspiring ladies who offered hope”

Cumulatively, there were 65 comments pertaining to the trainers' experience, expertise, delivery, and engagement which in turn brought to life and connected the delegates to the training material.

“Led with enthusiasm which made a difficult subject easier to understand”

“Well presented, thoroughly enjoyed the enthusiasm of the trainers”

Particular emphasis was given to the value of having a facilitator who had personal experience with dementia. It is suggested that having a person with dementia co-deliver some aspects of the training orientates the material within the 'real world'. Through their access to the experiences of a person with dementia delegates were transported into her life. The examples and anecdotes provided illustrated how the world can be different for a person with dementia, but equally, the similarities in experience. In short, these personal stories permitted delegates to empathise, a critical feature of health and care provision. The incorporation of Linda's insight, as a person with dementia, was particularly valuable to delegates, the impact of which should not be underestimated.

“Trainers were inspiring...Linda's input was invaluable...very personal and much more encouraging than videos or DVD's”

“Linda gave some good examples of what she has experienced”

“Listening to the co-facilitator with dementia gives me insight into understanding how she feels”

Finally, it is noted that four respondents stressed the use of humour as the most useful aspect to the training day. This is considered to be particularly pertinent as

the discussion of, and immersion in, bereavement and dementia has the potential to be painful, frightening, and ultimately somewhat miserable. The challenges of using humour to lighten the load should not be underestimated and it is with great skill that the trainers in question have deftly utilised humour in their delivery.

“For what can be a heavy topic, it was a light hearted session with lots of humour and laughs”

“An enjoyable event with good humour in appropriate places”

“Heavy subject but light-hearted and enjoyable”

Relatedly, 20 respondents commented on the pedagogical approach of the training. In essence, this sub-theme captures feedback pertaining to the teaching style embodied within the training delivery. That trainers were flexible and inclusive, and that the content was diverse and encouraged active participation were thought to be central to the success of the pedagogical approach utilised. The result was, for the most part, a training day that was dynamic and enjoyable.

“Multi-sensory approach (PPT and activities) enabled embodiment of learning, interactive activities, fast pace, well planned and delivered”

“The approach used - it was fun and made an important point, good group cohesion and facilitation, different modes of teaching”

“Varied approaches to delivery provided insight”

Looking to the future

This theme draws largely (although not exclusively) from the question eliciting respondents' suggestions to improve the training. It is promising that the category containing the most comments (over 80) indicated that there was nothing that could improve the training.

“Nothing can be improved, very interesting and very well presented”

“One of the best training sessions I have ever attended”

“If [only] all CPD [continuing professional development] training was as well planned and delivered”

The inclusion of this item within the feedback form however, was to encourage delegates to offer constructive criticism as their experiences of the training, critical as well as positive, were welcomed. Similarly to the CORE/ABC evaluation, the most cited (12 unique comments) area for improvement related to timing. While one delegate thought the day would be improved if it was “*shorter, could be condensed into half a day*” the majority of respondents in this category welcomed more opportunity for discussion and practical skills practice.

“More time for the last exercise - case studies. It was a bit rushed at the end”

“Maybe longer session or over 1.5 days”

While these comments have been grouped under the category of timing there is noticeable nuance in delegates’ experiences here. For instance, some responses refer to time management within the session which could be improved through trainers reflecting on their classroom management, and implementing changes as required. While others requested for the training to be extended to permit deeper exploration and reflection on the subject material and skills.

As mentioned above, practical application of training material is essential these suggestions therefore offer potential avenues to explore in order to maximise the wider impact of this training day.

“More focus on practical ways of supporting a client”

“A small toolbox would be useful to a volunteer when supporting a dementia sufferer, something similar to the CYP [children and young people] have when supporting children”

“A little bit more on technique, on working with people with dementia - possibly the application of ideas around emotion”

To conclude this section, a short compilation of excerpts has been collated to illuminate suggested areas of improvement that were endorsed by relatively few delegates, but nonetheless are worth identifying and considering to improve the training session.

“When advertising course target audience should be stated”

“More about how to talk to carers about how to address issues surrounding death and fear at point of diagnosis”

“Personal experiences can be shared to aid learning, more time to sharing each other's experiences”

“Too much PowerPoint presentation”

“I don't think it could have been improved, but the whole day could be put on DVD - for other people to benefit as there was limited spaces”

“A film probably would have fleshed it out”

Chapter 3: Bereaved by Dementia One-Day Training Focus Group

On 23rd November 2017 the first author conducted a semi-structured focus group in South Wales with three Cruse Bereavement Volunteers (CBV) that had completed both the ABC/CORE training and the Bereaved by Dementia one-day training. The aims of the focus group were to explore CBVs; (a) perceptions of the training and support they had received, (b) challenges they (may) have faced, (c) how their training may have impacted their own personal development, (d) suggestions to improve the training. The Bereaved by Dementia one-day training was the primary focus of discussion, however volunteers were encouraged to discuss their experiences more widely if they chose to (for example, how the Bereaved by Dementia one-day training and/or being a CBV has impacted their professional and/or personal life).

What follows is an examination of the most salient themes identified through our analysis within the evaluation team (see Table 1 for demographic information).

Table 1. Demographic information for CBVs who attended Bereaved by Dementia Training (Focus Group and Written Feedback)

Name (Pseudonym)	Judith	Philippa	Anita**	Mary**	Laura**
Age	63	*	66	60	58
Gender	Female	Female	Female	Female	Female
Ethnicity	White British	British/Australian	White British	White British	White British
Employment status	Retired	Full-time	Retired	Part-time employed/ Part-time self-employed	Full-time
Occupation (if applicable)	N/A	Clinical Psychologist Assistant	N/A	Helpline Support Worker/Counselor	Mental Health Staff Nurse (working with people with dementia)
Time since training	*	October 2017	October 2017	9 Months	6 months
Client allocation	Group	3	6 & 2 groups	None	1
Family/friend with dementia	Yes	Father had dementia	No	Yes	No

*Left blank by participant

**Provided written responses to some or all of the questions

“It’s a learning experience”

Mirroring the findings from the feedback forms the three CBVs in the focus group likewise emphasised that the Bereaved by Dementia one-day training, and their continued role as a CBV was a learning experience.

“It was really informative and helpful (...) It gave me a lot of insight into dementia”

[Anita]

“There were some things that were a, a reminder for me (I: yeah) but other things that (.) if not completely new had a new emphasis” [Judith]

Both Judith and Philippa explained that their past professional and personal experiences meant that they had a good foundation of knowledge about dementia before completing the course. Nevertheless, the material delivered and the facilitated discussions provided them with insight and encouraged them to think about dementia, and bereavement, in a different way. Further to this, they argue that central to being successful as a CBV is an appreciation and acceptance that they don’t know it all and that their learning will continue to grow, both in and out of the classroom.

“You don’t ever get to the end of that learning curve either do you? (I: hmm) I think that that’s a really healthy attitude to have rather than “I have reached the counselling epitome!” [Philippa]

Philippa extends her argument by asserting that by being willing to admit you don’t know everything and having a drive to continually learn offers the potential to improve and that this is a meaningful expression of personal development that holds a lot of value to her.

“I think that’s a really positive thing to have that because then you’re improving all the time, your skills are improving, your knowledge base is improving and that makes life personally rewarding I think” [Philippa]

There was a palpable sense that being a CBV holds profound significance; each describe being motivated to embark on a volunteer role that would be worthwhile and make a meaningful difference to the lives of those they support and a reverence towards those that share their lives with them.

“I absolutely love doing what I do (I: hmmhmm) I absolutely love it erm and feel that it’s a real privilege” [Philippa]

“I was coming to the end of twenty years in social work (I: hmmhmm) wanting to do something worthwhile in retirement and I’m doing a counselling degree so I needed volunteer hours” [Judith]

“I had experienced bereavement myself and I just thought it was something it was something that you know that erm it was a way of helping people that erm suited my skills” [Anita]

All participants agreed that the Bereaved by Dementia one-day training was integral to developing their understanding about dementia and those bereaved by dementia. And as the following excerpt illustrates, Anita goes as far to say that everyone should do the training to gain a deeper understanding.

“But I came away from the day thinking “everybody should do this course!” (ALL LAUGH) regardless of what their role in life is so that they have some understanding” [Anita]

“Bridge of communication”

By far the most compelling feature of the Bereaved by Dementia one-day training identified through the focus group discussion (as it was in the feedback forms) was, the emphasis on emotional memory. All participants identified it as the singular most powerful, and unexpected, aspect of the training.

“It was the bookcase (I: yeah) analogy which stood out for me as being really helpful (I: yeah) to understand you know what, what was going on really and as you say that the emotional, emotional side is still there” [Anita]

“Yeah so that even if the logical bit has gone (I: yeah) there is still an emotional person there (I: yeah) so I think that was a really strong reminder” [Judith]

When reading and analysing the focus group transcript it is clear that these women have acute emotional intelligence as well as a wealth of personal and professional experience that equips them to be excellent CBVs. It is therefore even more striking that they needed a reminder that a person with dementia retains their emotional

integrity, in other words, their humanity. It is perhaps less surprising considering discourses in UK national newspaper articles (and elsewhere) represent dementia in catastrophic terms; ‘A time bomb ready to explode’, ‘a terrible affliction’, and ‘a harrowing descent into Alzheimer’s’ reflect but a sample of the phrases used to describe living with dementia (Peel, 2014). Bringing to the forefront the emotional experiences of people with dementia, bringing them to life as ‘real’ people, and eliciting empathy marks a remarkable achievement for the Bereaved by Dementia one-day training in that it represents a first step in dismantling the toxic rhetoric surrounding dementia.

The grounding in Kitwood’s (1993) person-centred approach to care, which conceptualises well-being in dementia in terms of emotion rather than sophisticated cognitions was a critical overarching message taken from the training as identified by participants. This was both explicitly and implicitly stated.

“I found it helpful that there was a framework that was talked about erm about person-centred care (I: yeah) a model for that (I: hmmhmm) and I think that was really useful (I: hmm) to consider the aspects of what’s important to a person’s needs (I: hmmhmm) so you know their identity and security and the five aspects that Tom Kirkwood (J: Kitwood, Kitwood I think) talked about (I: the petals was that?) hmm yeah and erm I think that was really useful because it gives a framework when you come into working as a bereavement volunteer with someone with dementia”

[Philippa]

As Judith perceptively articulates (below), the ‘problem’ with dementia or the ‘challenging behaviours’ a person with dementia may exhibit stem from our own problems; our lack of understanding and perhaps our lack of trying to understand. It is suggested that the inclusion of Kitwood’s (1993) approach and the incorporation of case studies has encouraged these women to think differently about people with dementia.

“Behaviour is a form of communication (I: hmm) so that behaviour might look bizarre (I: hmm) actually is the person trying to communicate something to you (I: hmm) and it’s our lack of understanding that makes it difficult (I: hmm) because we’re not getting it what they’re trying to express” [Judith]

Furthermore, introducing techniques to build a connection between a person with dementia and a CBV such as the significance of rituals, customs, and personal biographies has likewise been embodied by these CBVs. The title of this theme draws upon Philippa's discussion about the salience of the case study of Edna who she describes as having very little verbal communication, thereby representing a monumental challenge to establishing a connection.

“So then how do you find a place to connect with her? (I: yeah) That place of connecting through err (.) (I: yeah) erm and therefore being able to build, what I call, create a bridge of communication with them (I: yes) to find their world, a shared world” [Philippa]

Philippa's use of evocative imagery encapsulates much of what has been discussed here. It acknowledges an obstacle, and that to overcome this obstacle requires work, work that is built upon a solid foundation using varied and robust tools, but ultimately what is most powerful is that it suggests hope. That it is possible to bridge this obstacle and to share a connection with a person with dementia that is meaningful; both to them and to you. Recognising that a person with dementia has a rich and complex history again contextualises and increased empathy and awareness of their challenges, which in turn may provide an avenue through which a connection and support can be established. As Philippa again eloquently expresses you have to *“find the tracks in order to follow the trail”*.

“You've got to just bite the bullet”

This theme explores what it means to be prepared to support a client bereaved by dementia; the extent to which participants felt prepared, what contributed to their sense of preparedness, and suggestions for how to improve how prepared CBVs feel post-dementia training.

Within the first few minutes of the focus group Anita, without being prompted, addressed the issue of preparedness, something which she and the other participants returned to throughout our discussion.

“I certainly felt that if I need have a client you know, with dementia then I was more you know, erm maybe not fully prepared but more prepared (...)you know I don't

think that you would ever be fully prepared but you know better prepared maybe”

[Anita]

“You could have whatever training you like but there comes a point where (.) more is not going to make any difference (I: yeah) you’ve just got to bite the bullet really!”

[Judith]

“And so you’ve got to go with it in the end” [Philippa]

These excerpts illustrate participants’ understanding of the complexity of bereavement and dementia and the limitations of classroom learning. Their reflections indicate a solid grounding through the integration of information, discussion, and skills-based materials delivered through the training. But ultimately there is an assertion that sometimes you have to step into the unknown. This of course echoes the training material which emphasises the uniqueness of individual experience, of both bereavement and dementia which pre-empts an element of the unknown in bereavement work. However, there were suggestions, both explicit and implicit, peppered throughout the focus group that would serve to engender a greater feeling of preparation among CBVs.

First-hand, experiential knowledge was cited frequently as a pivotal way to bolster confidence and in turn a feeling of preparation. For example, Philippa was a former carer of a person with dementia to which she attributed her confidence in dealing with the unknown that is so inherent in bereavement and dementia work.

“I think that because I, I lived with it with my dad that helps to give me a, perhaps more of a sense, a greater sense of confidence as well (I: hmm) erm to be able to say that I know that everyone is different and dementia is very different” [Philippa]

Providing CBVs with a direct lived experience of caring for someone with dementia akin to Philippa’s is of course an impossibility, but facilitating indirect experience would be feasible. Indeed, Anita and Judith endorse the inclusion of personal experiences of carers:

“I felt that it would have been helpful to have someone like Philippa (LAUGHS) you know that, give, tell their experience of caring with someone with dementia and losing somebody with dementia (J: that’s a good idea) and how they felt during the

time while they were caring and the issues raised after the bereavement (...) And I think that that would've been really helpful to have someone tell their story" [Anita]

What form this would take clearly requires further consideration but participants' enthusiasm, both here and in the general feedback forms, for case studies and the subsequent group discussion seems an appropriate and feasible option.

In contrast, Philippa made a more hands-on suggestion; for there to be a second day of training which would deliver skills theory and practice, first within the classroom and then in a 'real world' context. She recommended establishing connections with local care homes that are known to provide exemplary dementia care in order to break down barriers, to observe care being done well, and for CBVs to get a real sense of what it might mean to support someone with dementia.

"It would be amazing to go in for a number of hours into something like a care home with something like dementia, with people with dementia (I: hmmhmm) and do some activities with them (I: hmmhmm) low-level activities (I: hmmhmm) in order for people to get a more of a, a realistic view of what dementia is (I: hmm) because you can talk about it until you're blue in the face and you can give some very good pointers that can help, but it's all in your head (J: hmm) but the minute you start erm relating to people with dementia (...)you will completely change your mind about how you see dementia" [Philippa]

It is acknowledged that implementing such a programme would require significant planning and resources. However it is argued that in addition to the benefits outlined by Philippa, engaging in this practical assignment may assuage CBVs anxieties about supporting someone bereaved by dementia. Respondents in both the focus group and the feedback forms have acknowledged that there is an element of not feeling fully prepared and indeed feeling anxious about supporting someone bereaved by dementia, it is also likely that they will have to wait a significant amount of time before being assigned a client. During which time their anxieties are likely to escalate. Having a programme such as this in place has the potential to attenuate some of those fears by permitting CBVs the opportunity to apply the information and skills they have learned and reflect upon their experiences ahead of supporting a bereaved person 'for real'.

As discussed in the previous theme, personal history is the crux of the person-centred approach and providing rich contextualised information is central to the case studies success as they draw out channels through which connections can be made. However, this detailed biographical history is not usually available to CBVs when they begin their assessments which perhaps for some contributes to their anxieties about the unknown.

“And you’re not necessarily going to know all of the history are you? For most, from a referral form? (A: no) and probably (A: no) the person with dementia wouldn’t be the one to refer themselves (I: yeah) you know, how much are you gonna, you know you might not have a lot of the information that you need, that would be helpful contextually” [Judith]

“We get erm, we get just a piece of paper (I: hmmhmm) and then we have to do an assessment. So, it just gives you the basics of whose died (I: hmmhmm), how old they are, how old the person it is that’s been referred, what they’ve died of” [Philippa]

It was somewhat surprising that CBVs entered their initial assessment with so little background to anchor them. Within our interim report (delivered in January 2018) we argued that this missing link of information was even more unfathomable considering Judith’s (who had been working on the referral line for eight months) comments that *“it’s, something that’s meant to take 2 hours can easily take 3”*. We had read and understood this to mean that a single referral can take over two hours (and indeed that it was expected to take at least two hours). We had questioned the efficiency of this as a process and recommended further exploration of the referral process.

During the intervening period Judith read the interim report and contacted us to explain that she meant the referral line was only open for two or three hours, rather than a single referral is expected to take this amount time. In light of this information we retract our previous timing-related concerns of the referral process. However, during the referral the CBV is likely to obtain a wealth of background information about the client that is not being captured, or at least it is not being passed on to the CBV who visits the client. So, how can this information be incorporated into the referral form in order to support the CBV who is assigned the client? It is beyond the

scope of this report to answer this question, however we felt it was important to raise this as an issue for further exploration.

The final contributing factor influencing CBVs sense of preparation stems from their ambiguity regarding 'breaking the news'; whether or not people with dementia should be told about a death(s) that they may have forgotten or will be unable to retain.

"I, was sort of hoping for a clear, you know, rather than a judgement call about do you tell the person (A: yeah) that so and so person has died (A: yeah) and how do you tell them and all that. I was wanting to get a sort of clear answer to that but I (LAUGHS) but of course there isn't a clear answer really (A: no, no) because it depends on the person and the situation and all of that (A: of course)" [Judith]

In the above excerpt we observe a dissonance between what Judith wanted and expected (clear guidelines), and her impression of the message of the training (it's a judgement call) regarding telling a person with dementia about the death of a loved one. There is the impression that whilst Judith is moving towards accepting this message and the unknown aspects of bereavement work (heightened when working with a client with dementia) the desire for clear guidelines remains. We certainly do not advocate discarding a person-centred approach to 'death disclosure' for dogmatic guidelines. However, it is argued that it would be valuable to explore channels to bridge the dissonance.

Following on from Judith's concern about death disclosure Anita suggests incorporating the experiences of carers who have/are experiencing this dilemma.

"I just thought it might be good to say "this worked for me!" do you know what I mean? Someone saying "this is how I dealt with telling them" (I: yeah) and you know, I know that might not work for everybody but obviously you know (LAUGHS)" [Anita]

Including the lived experience and decision-making processes of carers could provide critical insight into how death disclosure decisions might be resolved. As has been mentioned in previous themes, case studies, discussion, anecdotes etc. yield significant power in that they can transform the abstract into something real. It is suggested too then, that incorporating carers' experiences of death disclosure offers CBVs with a window through which they may observe a 'real life' situation which serves to contextualise the judgement and prepare for the unknown.

“Who’s the bereaved person here?”

This final theme, as the title implies, examines participants’ ambiguity over where the emphasis lies in this training: the person with dementia? Or the family member/carer of someone with dementia?

“I think I was confused about who’s the bereaved person here? Is it the person with dementia or is it their carer? (I: yeah) erm and actually I just looked back at the, the handouts we were given it’s mostly about the person with dementia, with just helpful hints for the carer (.) and I, it’s probably me but it wasn’t quite clear enough for me”

[Judith]

This excerpt reflects the disconnect between what participants expected and what the course delivered. Both Judith and Anita had anticipated a dual focus with equal attention to the bereavement needs and experiences of the person with dementia and their carer. Upon reflection however they assert that it is the former who takes the focus. Later on in the focus group Judith returned to this point to make recommendations for future training.

“So maybe going back to my confusion before (I: hmm) what we’re looking at is two training, two days’ training. One specifically the person with dementia who is bereaved (A: yeah) and one for carers (I: hmm) of people with dementia but I suppose for, for Cruse because it’s bereavement we have to wait for the person has died for them to contact us don’t we? But maybe the Alzheimer’s Society, I know they do work already with carers don’t they? (...)Because it’s still grief isn’t it? (I: yes) and it’s continuous grief, one loss after another, after another, after another, after another” [Judith]

Judith, and the other participants, recognised the necessity to support carers of people with dementia. Emphasising their continuous and anticipatory grief that precedes the death of their loved one. It is recognised that the Bereaved by Dementia one-day training does cover the feelings of loss prior to losing a loved one with dementia as well as after their death as experienced across family members, including children and young people, friends and carers. The challenge here is that the all-encompassing definition of bereavement that is presented in the training, one that incorporates this accumulation of losses then does not match up to the service that is provided as this uses the narrower definition of death.

Without further resources it is difficult to put into practice bereavement support in the wider all-encompassing sense. However, future training would perhaps benefit from a more explicit delineation between the umbrella term and what support is actually delivered by Cruse Bereavement Care, with relevant signposting where appropriate.

Bereaved by Dementia One-Day Training: Written Responses

The Bereaved by Dementia project manager provided the first author with a list of seven CBVs who registered interest in providing feedback regarding the Bereaved by Dementia one-day training but were unable to attend a focus group. In late December 2017, the first author emailed all of the aforementioned CBVs with the questions that had been previously asked during the focus group. Two CBVs responded, their answers have been analysed using content analysis (Elo & Kyngäs, 2007) and will be explored below. Additionally, one of the CBVs who attended the focus group (Anita) had to leave before the end of the discussion so she also provided written responses to the questions she did not have the opportunity to answer. Therefore, Anita's responses have also been included in the analysis presented below.

As there was a lot of overlap between the content of these written responses and what has been presented already only unique themes and/or perspectives have been selected for discussion.

What was most striking about these responses was that participants' advanced level of professional expertise in counselling and/or dementia care came to the fore. Mary for example is a professional counsellor, Anita had worked for many years in the public sector before retirement, and Laura works as a dementia nurse in a day hospital. Clearly, these women have highly specialised skills, training, and knowledge about bereavement and/or dementia. Despite this, there was a resounding enthusiasm for the Bereaved by Dementia one-day training evident in their responses, and further to this they all acknowledged that their understanding had been enriched by attending.

"I have been on many dementia courses in my line of work, but I have found this one more informative and effective than those in the NHS (...) I thoroughly enjoyed the

course and felt I had learned more and as a result felt more empowered to offer my help” [Laura]

*“Everybody there was extremely engaged in the topic and I learned a huge deal”
[Mary]*

“The dementia course was of tremendous help in understanding dementia and can only be of benefit in the future” [Anita]

Indeed, both Laura and Anita recommended that the Bereaved by Dementia one-day training would be beneficial to an even wider audience than it is currently being delivered to. Indicative of content that is (largely), mutually beneficial to both highly trained and novice delegates, which is an impressive achievement.

“Everybody needs to go on such a course” [Anita]

“It would be wonderful if all carers could attend as I feel a patient with dementia can be overlooked or their behaviour misunderstood while grieving” [Laura]

Relatedly, Laura repeatedly recognised the depth and breadth of the material covered during the Bereaved by Dementia one-day training.

“I was surprised how knowledgeable and well informed the leaders were, also how well presented the power point was. It touched on all of the main aspects” [Laura]

“I felt that the presenters had researched the dementias well and covered much of the different behaviours and approaches to to [sic] assisting a client with dementia through the grieving process” [Laura]

Given Laura’s professional expertise in dementia this is an excellent commendation. Laura emphasised the accuracy, depth, and understanding exhibited throughout the training materials. Indicative of content that reflects current professional best practice in dementia health and social care.

The salience of communication in supporting someone who has been bereaved by dementia were identified within all respondents’ feedback, mirroring the findings from the focus group (see “Bridge of Communication”). Thereby reflecting an integral facet of being a successful CBV.

“To be able to empathise and listen and help” [Laura]

“[I] am able to listen to very harrowing information from clients and be able to stay with that” [Mary]

However, these respondents identified a number of other characteristics that make for a good CBV that are worth considering. Perhaps unsurprisingly, respondents identified that having a genuine interest in people and the process of bereavement support offered by Cruse Cymru to be essential qualities for CBVs.

“A genuine belief in the process” [Mary]

“Having a genuine interest in people” [Anita]

These characteristics and skills (communication, interest in people and bereavement) are undoubtedly highly prized within the context of bereavement support to ensure that clients accessing the service(s) receive support from motivated and competent volunteers. What was striking is that, unlike any other respondents, two of the written responses contained features central to the lives of CBVs that would serve to preserve their well-being whilst delivering support. Here, Mary and Anita recognise particularly pertinent challenges that may stem from bereavement work and suggestions for overcoming and/or minimising them.

“Being grounded and comfortable with their own emotional issues (...) Good support from friends and family” [Mary]

“Able to keep a professional distance and remember to not self-disclose as it is always about the client not the volunteer” [Anita]

Mary highlights the need for CBVs to be in-tune with and comfortable with their own lived experience, particularly events that evoke an emotional reaction. This makes intuitive sense as CBVs will be, through the nature of their work, exposed to emotionally charged situations and conversations that may trigger their own experiences. However, to achieve this self-awareness requires tremendous and concerted introspection which may not come easily to some people.

Additionally, Mary emphasises the significance of the support of friends and family. Whilst Mary does not expand upon her response to explain her reasoning, both practical and personal interpretations are considered pertinent. As has been addressed during the examination of the CORE/ABC training feedback becoming a

CBV requires dedication to an eight-week training programme and independent study. CBVs then provide their time and effort in supporting clients, and attending refresher and further training sessions. The practicalities of this level of dedication should not be underestimated, and it follows that having supportive family and friends may contribute to ameliorating the challenges and consequences of this vocation. Mary's comment can also be interpreted in terms of the emotional consequences of being a CBV. Despite her assertion that CBVs need to be familiar with and comfortable with their emotions, it is perhaps inevitable that CBVs will, at some point, be affected by the emotionally charged environments within which they are working. Again, having the support of family and friends may help ameliorate the impact that this has upon CBVs own well-being.

Finally, Anita's comment recommends keeping a professional distance and avoiding self-disclosure as a strategy to prioritise the experiences of clients, rather than volunteers. It is noted however, that this strategy also serves to protect the volunteer's safety and well-being beyond their interactions with clients.

Evaluation: Learning and Recommendations

- In summary, this evaluation revealed 96% of delegates' expectations were met by the training, 91% of delegates reported increased awareness of dementia and supporting someone close to them following a bereavement, and 98% of delegates found the material interesting and easy to follow.
- In-depth analyses identified that the most striking feature of the training for delegates were activities, analogies, and discussion that demonstrated the emotional experience of people with dementia. For many, this was an unexpected feature to the training and gave rise to profound changes in perspective and understanding. This is a remarkable achievement for a relatively short training session considering the cascading impact this is likely to have for the delegates personally, professionally, and within the context of their role within Cruse Bereavement Care.
- The issue of feeling prepared to offer bereavement support to people with dementia was frequently discussed within the focus group as well as in the feedback data. The complex and nuanced experience of dementia and bereavement is not underestimated, nor is it suggested that a 'cookie cutter' approach be adopted. However, we recognise that trained attendees remain somewhat apprehensive about going into the 'real world' and providing bereavement support to a person with dementia. There is a recognition within participants' responses that a certain level of apprehension might be a 'normal' response and that classroom learning can only teach you so much, the rest you have to learn by experience.
- Moreover, participants in the focus group explored some thoughtful suggestions that, if implemented, may serve to engender greater confidence in CBVs to provide dementia-related support. They recommended the inclusion of more carer experiences of loss to broaden the scope of the material to reflect the dual experiences of a person with dementia and their carer, and classroom and 'real world' application of skills and techniques. Whilst we recognise that the training material includes carers' experiences of loss, as well as the experiences of family and friends through case studies and discussion, there was a palpable sense in the focus group that they had expected there to be a dual focus; with equal emphasis given to the bereavement experiences of carers and people with dementia. Redressing

this perceived imbalance and/or the expectations of delegates is perhaps worth considering for future training.

- Additionally, we recommend that the delivery of person-centred care may be enhanced by reviewing the telephony and in-person referral processes in order to better equip CBVs with the essential contextual information that can help build a *“bridge of communication”*.
- Moreover, whilst the majority of attendees provided positive evaluative feedback it is noted that for some, particularly external delegates their expectations and needs were not met. This is perhaps unsurprising considering dementia-care was instrumental to many of the external delegates’ professional roles. It is perhaps worth considering this when recruiting external delegates, or as one respondent in the feedback form suggested, to explicitly state training content in associated advertisements so (prospective) delegates can make an informed decision.
- Finally, we recognise volunteers’ concerns about ‘death disclosure’, that is, the often emotionally-charged decision regarding whether or not to tell a person with dementia about the death of a loved one. Again, we want to avoid rigid processes that erase individual experience and need, but argue that death disclosure remains an anticipated and/or lived dilemma for CBVs, as well as individuals caring for and supporting people with dementia. Prioritising dedicated discussion time to this topic within the training; trainers sharing their own experiences; and having case studies to explore in a group are tentative suggestions that could be feasibly incorporated into the training to elicit greater understanding and confidence in how to manage death disclosure.

Chapter 4: Cruse Bereavement Volunteer Case Studies

As well as examining experiences of the Bereaved by Dementia one-day training, we were interested in exploring Cruse Bereavement Volunteers' experiences of working with clients who were bereaved by dementia. We were guided by participants but wanted to explore:

- If, or how the training prepared them to support clients;
- If, or how they had applied their learning (from the one-day training) to a practical setting;
- The context and support needs of the client;
- Any challenges anticipated and/or experienced.

Critically, interviews with CBVs provided us with invaluable data about the client experience. As we will discuss in Chapter 5, recruiting clients who had received support through the Bereaved by Dementia Project was challenging. Having narratives which explored client experience through the lens of the volunteers has therefore furthered our understanding of how support is delivered, and how bereavement may be experienced by clients who are bereaved by dementia.

Two interviews were conducted by the first author, audio recorded and later transcribed; data for the final case study was collected by email, through written responses to questions pre-defined by the first author. Participants' and clients' identities have been concealed using pseudonyms, and identifying features (such as places, critical incidents etc.) have been obscured. What follows is an examination of the most salient themes identified through the analysis of the evaluation team.

Shirley

Shirley had attended the Bereaved by Dementia one-day training and provided bereavement support to Mr Mahoney, a man in his eighties whose wife died over a year ago (at the time of support provision). Mr Mahoney had held a professional position before retiring some years ago. Shirley described him as being “*fully aware*” but of limited mobility due to severe arthritis which she felt compounded his loneliness. Shirley explained that Mr Mahoney had tried private counselling while he was on the waiting list to be allocated support through Cruse. However, Shirley asserted that Mr Mahoney had found private counselling limiting because “*he found*

it was very cold and clinical, processes were mentioned (...) and just sort of factual events were gone through". What follows will be an examination of the three broad themes identified within Shirley's narrative; 'haunted by dementia', 'growing a bit more life', and 'opened my eyes'.

Haunted by Dementia

Throughout her narrative Shirley frequently used the word 'anguish' to describe both the direct experiences of Mr Mahoney, but also her own embodiment and internalisation of his pain (we will return to the latter in more detail in 'opened my eyes').

"This anguish lived and still lives with him erm much, much more than erm than I've found with [other] clients [where dementia is not part of the bereavement] (...) it's the anguish that pursues this man constantly"

Shirley described that within their sessions Mr Mahoney is particularly preoccupied by an incident whereby he pulled his wife and was called cruel by his wife's carers.

"He can't forgive himself for pulling at her, and we've talked quite a lot around that, so the guilt is huge around that particular incident (I: yeah) erm which the anguish the poor man feels which I feel, when I hear him"

Shirley's description of how dementia "*pursued its way through his wife*", and the subsequent rumination over his perceived misdeeds frames dementia as a malevolent force that has wreaked havoc, and continues to haunt Mr Mahoney. Evocatively, Shirley explains that Mr Mahoney was trapped in a "*ritual of apologising*" whereby he would apologise to his wife before he went to sleep each night. This stirring scene became the focus of their sessions and Shirley worked with Mr Mahoney to first unpack his experience, then gently counter some of his thinking, and finally explore more positive memories.

"The dementia meant that she didn't know him a lot of time but she would suddenly have a lucid moment and he went out of the hospital room one day and she pointed and said "there goes the man, the love of my life" (I: ohh) and I've just got him to replay that"

“Growin’ a bit more life”

Shirley was noticeably uncomfortable when asked to discuss the impact that the support she provided may have had on Mr Mahoney, emphasising that *“only he could truly say what impact”*. Nevertheless, Shirley did reflect upon the ways in which she personally gauged the impact on her clients generally, and Mr Mahoney specifically.

Firstly, Shirley recognised the significance of having the opportunity to talk freely to someone non-judgmental;

“To be able to freely admit exactly what happened was releasing for him because he does generally seem erm (.) a bit brighter”

While she is careful to clarify that what has happened *“will never go away”*, she nevertheless asserted that having a sensitive person to talk to has been helpful for Mr Mahoney to process his grief.

The title of this theme is how Shirley described her approach to *“open up his life”*. Mr Mahoney’s physical impairments to some extent limited his opportunities to engage in activities, nevertheless Shirley encouraged him to identify activities that were personally meaningful (as well as practically and physically possible) and begin to make changes to incorporate them into his life.

“[We’ve] talked about the kind of things that might be possible suggestions (...) and this man has taken on board what we’ve done, joined a bridge club and he goes out for his paper and he has his fish and chips”

An anecdote we found particularly salient relays how Mr Mahoney found Sunday to be the most difficult day of the week. When shared with his wife Sunday was characterised by getting the paper and enjoying a quiet shared time together. And her absence marks Sunday as incredibly painful and lonely. Shirley encouraged Mr Mahoney to reclaim Sundays through small gestures such as going to the shop for the paper.

“Maybe he will start to look forward to reading his Sunday paper again because that was the loneliest day for him a Sunday so I guess the impact it’s had on him is that he’s tryin’ to make that day good, or better again”

“Opened my eyes”

This final theme explores Shirley’s experiences of providing bereavement support to someone who is bereaved by dementia. Shirley acknowledged the fear she had, and to some extent continues to have, about dementia. She asserted that the one-day training was eye-opening, and claimed that she would not have volunteered to support a person bereaved by dementia had she not attended the training course.

“I don’t think I would’ve taken a client on without it to be quite honest (I: hmm) I would be hard pushed unless they were really stuck because I didn’t understand any of it and I was scared of it because I still am really”

She argues that dementia-related bereavement requires special consideration, sensitivity, and training akin to trauma-related bereavements.

“I think with that because it’s so specific (I: yeah) it’s a bit like a suicide, it’s a bit like a murder you need to have a bit more, a different understanding or trauma, if you don’t go in with some knowledge”

It was striking that Shirley described that the training had “armed” her to try to offer support to someone bereaved by dementia. Regrettably further exposition of her meaning was not pursued in the interview. A possible reading is that the training provided Shirley with information and skills practice that could be deployed in a real-life setting. In other words, the training material could be seen as protecting CBVs (e.g. preparing them for the emotional work involved supporting someone bereaved by dementia), and as preparing them to provide bereavement support that recognises and is sensitive to the needs of people bereaved by dementia. It also speaks to the pervasive global narrative of the ‘war on dementia’.

Supporting evidence presented elsewhere in this report (notably the Bereaved by Dementia one-day training feedback forms and focus group), Shirley emphasised how the training had encouraged her to think about how the world is experienced by people with dementia. Ultimately, she describes how she channelled this information to better support Mr Mahoney.

“So although she’s become totally different to him in this case, in my client’s case, the whole world around her has been completely changed”

Here, Shirley is referring to Mr Mahoney's difficulty understanding why his wife would get angry and try to hit him. This was very painful for him as his wife had previously had a very gentle disposition. Encouraging Mr Mahoney to reflect upon how the world might be experienced by his wife Shirley provides a discrete, and powerful way in which learning from the Bereaved by Dementia one-day training can be applied. And, indeed the impact that such an application can have on clients who are bereaved by dementia.

"I would say the times when we talked about that that made him feel a little bit of, I can't say it would be relief, erm let himself off the hook slightly (I: hmm) he didn't feel quite the pressure"

As alluded to above, Shirley commented on the inherent challenges of preserving one's self when engaged in demanding, emotional work. Although caught off-guard when posed with the question of how she feels emotionally about supporting someone who is bereaved by dementia, Shirley candidly explains how she *"finds ways to shut the door [to her emotions] when I shut the door"*. While acknowledging that she approaches all of her bereavement support work in this way she admits *"I emotionally take some of that on when I'm there [with Mr Mahoney]"* because she is witness to, and engaged with, his pain.

"Very, very, emotionally very hard to go (I: hmm) and knowin' you're, you're leavin' that lone, you know that loneliness, that you're leavin' such a lonely person erm really difficult"

Ultimately, Shirley admits;

"I don't think about it too much to be honest (...) Because otherwise it totally drinks you dry, you can get totally worn out physically and mentally by it and I can't afford for that to happen I'd be no use to man nor beast, or myself"

In summary, Shirley's narrative offered an incredibly rich account of her personal experiences being a CBV providing bereavement support to someone who is bereaved by dementia. But critically, she also provides insight into how learning from the one-day training can be practically applied, and can make a difference to the life of someone who is bereaved by dementia.

Moira

Moira has been a CBV for over 15 years, and attended a half-day information session about the Bereaved by Dementia Project (rather than attending the one-day training). She has been included in this evaluation because, uniquely she has provided pre-death bereavement support within the context of dementia. Mrs Piper contacted Cruse because her husband (who has dementia) had been taken to an assessment ward with the aim of evaluating how best to provide care. Mrs Piper was experiencing acute uncertainty and stress, culminating in *“feeling that she couldn’t cope”*. Although Cruse does not currently offer pre-death bereavement support, Moira was approached to see if she would be willing to support Mrs Piper given her personal experiences with caring for someone with dementia.

“No we don’t normally [offer pre-death bereavement] (...) dementia is a very difficult erm you know it’s a sort of different category really (...) because I could very much empathise with her (I: yeah) I know what she was going through you know”

Like Shirley, Moira emphasised that dementia belongs to a different category of loss, characterised accumulating losses pre-death.

“Everybody is different, but erm it’s not post-death that you grieve it’s before death”

Moira reacted to Mrs Piper’s in-the-moment bereavement support needs, and met with her on two occasions in this capacity to alleviate her distress. Moira explained that the geographical location of where both she and Mrs Piper live was likely to have compounded Mrs Piper’s isolation and grief because *“we are very rural here, very rural”*. Ultimately, Mrs Piper’s daughter and son-in-law had moved to the area and so they would be available to provide Mrs Piper with the help and support she needed. Moira recognised and respected that she had provided bereavement support that met the needs of Mrs Piper in the moment, while clarifying that *“if you need help again you can always come back”*.

Furthermore, while Moira championed bereavement support services for the family of people with dementia (in particular pre-death bereavement support as we have illustrated above), she was more hesitant advocating bereavement support for people with dementia.

“To me there was a little bit of erm uncertainty about what what the project was actually about because if you’re trying to support people with dementia it depends very much on erm the stage of dementia they’re in”

Using her experience caring for her husband Richard as an anchor, Moira argues that during the early stages of dementia bereavement support *“would be like supporting any other bereaved person”*, then during middle stages *“they’ve gone back to childhood (..) you know you’ve got to be where they are (I; yeah) and they probably don’t remember anything about being bereaved”*, and then in the final stages *“he [Richard] could hardly communicate so he lost his speech so I didn’t know what he could erm you know how much he did understand (I: yeah, yeah) certainly towards the end he, he didn’t I don’t think he recognised”*.

Shirley conveyed similar concerns about the efficacy of bereavement support to people with dementia in later stages;

“I would probably [provide bereavement support] if I were asked and it came my way go to someone who had mild dementia because obviously it would have to be reasonably mild, if there’s such a thing as mild because otherwise hmm (..) I’m not sure if it would be that helpful to the person as that’s what you want them to do is to come to terms with it a little bit”

Clearly, for Shirley (and potentially Moira too), *“coming to terms”* with and *“growin’ a bit of life”* around the bereavement are critical strategies to gauge the impact of the support provision. Such benchmarks are inevitably going to be disappointing when cognitive capacity is significantly impaired. Whether or not people with advanced dementia would benefit from an adapted form of bereavement support is beyond the scope of this evaluation. We encourage future research to explicitly examine this in more detail.

Martin

As Martin’s experiences were collected through an asynchronous email exchange the data are less detailed. Martin had provided bereavement support to Mrs Little, a lady in her early eighties whose husband (who had vascular dementia) had recently died. Mr Little had been hospitalised because *“he had become too aggressive and*

was considered dangerous to himself and [to his] wife". Mrs Little found this difficult because "she had no say in him being held in hospital".

Contrary to the other CBVs we have included in this evaluation, Martin explained;

"Personally I do not believe there is much difference supporting someone bereaved by dementia or some other another cause. The therapeutic model we use –person centred therapy - is the same"

Martin was influenced by the Kübler-Ross (1970) model of grief which he claimed *"all clients will demonstrate some aspects of this model"* and so offers a platform from which explore clients' grief, irrespective of the underlying causes and mechanisms. It is unfortunate that it was not possible to interrogate Martin's perspective further. Nevertheless, his inclusion here is important because it demonstrates that there is not unanimous support for the inclusion of dementia-specific bereavement support among CBVs.

Moreover, Martin's comments in response to a question designed to explore what, if any, impact the support has had on the bereaved client were also striking;

"Not sure if support has any impact – it is not our practice to follow clients up"

Incorporating the client perspective within this evaluation was an on-going challenge. While we were able to interview three support recipients (case studies to follow), it required determined effort of the project manager to identify and recruit appropriate client stories. Informal conversations between the first author and Judith (the CBV included within the Bereaved by Dementia one-day training focus group reported above) revealed that there is a paucity of client feedback following support. We anticipate the findings of Judith's research which will explore in more detail CBVs reasons for not requesting client feedback, and her suggestions to elicit more feedback going forward.

Chapter 5: Support Recipient (Client) Case Studies

It was critical that the evaluation included the experiences of people who were bereaved by dementia and had accessed bereavement support through the service. An improved version of the Cruse Information System (CIS) has been under development, and is now live. One of the functions of the CIS is to integrate referral information across Cruse Bereavement Care which will make it easier to review and evaluate service provision across the organisation. The data provided by the CIS, cross-referenced against information received from each of the Welsh counties, revealed 228 clients who are bereaved by dementia have accessed the service in some way. Unfortunately, the CIS is unable to provide more detailed information at this stage (for example, the proportion of clients who were: (1) people with dementia who are bereaved, or (2) the family member of someone who had dementia who has died).

However, as outlined in the preceding section, identifying and recruiting suitable client case studies was a significant challenge. An internal audit within Cruse Bereavement Care revealed that less than 20% of client feedback forms are returned across the organisation. Which echoes Martin's -one of the CBV case studies presented in Chapter 4- assertion that *"it is not our practice to follow clients up"*. During discussion among Alzheimer's Society Cymru, Cruse Bereavement Care, and the research team, it has been suggested that as part of best practice CBVs should incorporate a basic measure that records mood pre-and-post session, irrespective of whether the client has dementia or not. In doing so, invaluable data capturing clients' experiences of receiving bereavement support will be recorded.

However, it is worth recognising that we did receive two feedback forms from clients who are bereaved by dementia. The content of each of these forms will be briefly report here. The identity of clients is not known so they will be referred to as Client A, and Client B respectively.

Client A reported a very positive experience in terms of: their overall experience; number of contacts they received; the frequency of contacts; and how helpful their CBV had been. They also indicated that they would recommend Cruse to others. They explained that having someone who was *"understanding, listening, and easy to talk to"* was the most helpful aspect of the bereavement support they received.

Furthermore, while Client A reported 'no change' in physical health, anxiety/depression, family relationships, or social relationships they reported their emotional functioning and everyday activities/self-care to be 'much better' and their self-esteem to be 'better'. Finally, the only aspect that Client A suggested could be improved related to the speed of response by Cruse which they indicated to be a 3 on a scale of 1 to 6 (where 1 = very happy and 6 = very unhappy).

While Client B's feedback form was not completed in full it nevertheless provides insight into how bereavement support is experienced by a person who is bereaved by dementia. Client B indicated that the number of contacts that they received was 'about right' and that the CBV has been 'helpful' and "*enjoyable*". They indicated that while there was 'no change' in their physical function and everyday activities/self-care, and their emotional functioning was "up and down" they asserted that they were "*holding up*", "*doing pretty well*" and that the bereavement support "*relieved stress*".

We can conclude, that for these two clients, the bereavement support that they have received from CBVs was valued and met their needs.

This remainder of this chapter will present three case studies that capture the experiences of; a family member of someone who had dementia, a person with dementia who is bereaved, and finally a person who is experiencing pre-death bereavement.

During the interview, we were guided by participants but wanted to explore:

- The nature of the bereavement, and if/how dementia impacts the experience;
- The process of requesting and accessing support;
- What, if any impact the support received has been;
- Suggestions to improve bereavement support for people bereaved by dementia.

John

John was the first client that was interviewed as part of the evaluation. The interview was conducted in his home (at his request) and lasted over an hour and a half. John shared an incredibly rich narrative of his wife Agatha's illness journey (which included but was not limited to a diagnosis of Alzheimer's disease) and his subsequent experiences of bereavement support. John attended group bereavement support approximately 12 months after the death of his wife.

There is simply not the scope within this evaluation to do justice to the complexity and depth of John's narrative. Instead, we present themes that were most salient to the aims of the evaluation; "Alzheimer's was a bit of a red herring", "helpful in an impossible situation", and "there is a positive outcome here".

"Alzheimer's was a bit of a red herring"

Following a period John described as a "*difficult memory spasm*", Agatha was referred to a series of specialists and was given a formal diagnosis of Alzheimer's disease in 2012. While there was some evidence of memory impairment from this point onwards, John was adamant that this did not significantly impact daily living. Rather, John focused on the deterioration of Agatha's movement and mobility which he strongly believed were symptomatic of Parkinson's disease.

"Her walking began to deteriorate, her movement. It was first walking, and, and balance erm, err and that got worse erm and it was from this point onwards"

For John, this marked the first of many missed diagnoses, which he argued were obscured because Agatha had received a diagnosis of dementia.

"I don't know whether because Alzheimer's was sort of on her record that nobody quite sort of thought of doing much, or doing anything"

John's frustration regarding missed opportunities through insufficient attention and/or action was palpable throughout his narrative. He was always careful to acknowledge that "*I'm not an expert of any of this so, it is only my assumption*" but there was nevertheless a trend that implied that Agatha's dementia diagnosis obscured her other symptoms, or that they were erroneously assumed to be symptomatic of dementia.

Ultimately, it was not dementia, or Parkinson's that caused Agatha's death. In 2016 it was revealed that Agatha had an inoperable brain tumour, for John *"the symptoms immediately fell into place"* following this diagnosis. The rapidity of Agatha's declining health and capacity was incredibly difficult for John, and contributed to him seeking out bereavement support.

"She wasn't too brilliant at Christmas 2015 erm and she dead by June 2016 erm and the thing sort of escalated and I think, that, that we found quite difficult and nobody could do anything and things just got worse and worse quite quickly"

"Helpful in an impossible situation"

It is difficult to pinpoint what John truly expected bereavement support would give him. At the point of the interview, which was several months after the bereavement support concluded, John explained *"my view is that so far I don't think anybody has got an effective way of dealing with this [grief]"*. He echoed the sentiments of Cruse that *"the bereavement you feel, is a sense of loss is entirely personal to each individual case"* and recognised that it's *"almost impossible for any organisation in a sense to offer the sort of solace that perhaps people expect from a bereavement service"*. Nevertheless, through our interaction with John, and subsequent iterative analyses, we suspect that there is a dissonance here. While John's discourse suggests that he recognised that grief is uniquely experienced and managed there remained a yearning for answers. We suggest that although John is moving towards accepting that there is not a person, or theory, or exercise to explain and erase the pain of his grief, this in itself is painful.

While the subsequent theme will discuss some positive aspects of John's experiences it would be remiss if we did not attend to some of the more challenging experiences he described.

In August 2016, two months after the death of Agatha, John attended an "understanding your bereavement" session in Cardiff organised by Cruse Bereavement Care which *"had a little lecture erm with some erm, some sort of graphs, not graphs, some (.) information put on a white board"* followed by an *"enrolment process which was frankly shambolic"*. John described:

“One of the lady volunteers took me into the kitchen and sat me on a chair and all sorts of people were around coming and going erm to ask me all these questions about myself that were put down on this form you see”

In an attempt to explain the chaotic, and insensitive treatment he experienced John speculated that perhaps the building used was temporary. He hoped that a more suitable venue would be found to improve the experience of future (potential) clients. Indeed, Cruse Bereavement Care have confirmed that since John’s experience the local Cruse area mentioned have moved into a modern, purpose-built space. We are confident that this will contribute to an improved experience for clients.

Furthermore, we were surprised that John waited 12 months to be allocated to a group. John voiced suspicion as to whether this was a deliberate strategy on Cruse’s part to manage the waiting list:

“It may be that they, they do the selection for further help on the basis of leave it twelve months, some people will say at that point “I don’t need your services anymore, I’ve in a sense, reconciled to the loss and I’m feeling OK” which I’m sure must happen erm and therefore that might relieve the pressure erm but certainly it was striking that I had to wait a whole year before getting my, my, my six weeks in this group you see”

While we appreciate where John’s suspicion comes from, we suspect – as he himself also suggested - that this waiting time reflects the crippling demand for the service and insufficient bereavement volunteers available to meet demand. We have come to understand that the time that John was accessing the service was particularly limited in terms of resources, and of course the additional CBVs eventually recruited through the Bereaved by Dementia Project were not yet in place.

Finally, John voiced some challenges regarding the delivery and dynamics of the group-based bereavement support he received which he described as follows;

“Very unstructured (...) the main, the main thrust of the group was to for us to recount our feelings and how we felt in a sense erm what had happened erm but (.) it erm (.) it was a bit strange (...) We weren’t given any sort of direction erm about how, about how we should go about this so we just, we were just asked to go around

in a circle and say a bit about ourselves and a little bit about what had happened you see”

Our (admittedly limited) experience of John revealed that as a person he responds well to structure, to chronology, and to explanation. Equipped with this knowledge it is perhaps unsurprising that he found it difficult to appreciate a situation which, on the surface anyway, is unstructured. Providing a rationale for the framework which the sessions are based may assuage concerns that the sessions are lacking in purpose, and provide people like John with the confidence that the sessions are not a ‘free for all’.

While John certainly valued sharing with and connecting to the experiences of others within his group (which will be explored more in the subsequent theme), he was evidently perplexed by the disparate experiences of those within the group.

“They [Cruse] knew who we’d lost and everything and thinking of it subsequently it did seem a (.) slightly bizarre mix of people erm (.) now whether the groups are made up entirely at random or whether there’s a system of choosing which group of eight or ten people get called together, I don’t know erm nobody ever told me and I have to say I never asked how they’re grouped but it did strike me how our little group was quite an odd mixture”

It was John’s feeling that his/the group’s capacity to “*help each other by discussion*” would have been enhanced if the group members were united in terms of who they were grieving – a husband/wife for example. We suspect that to maximise efficiency practical considerations drive how groups are established but, considering the salience of this feature of the group within John’s narrative we nevertheless bring it to your attention.

“There is a positive outcome here”

As the title of this theme conveys, John was quite clear that regardless of his critique of certain aspects of the referral process and delivery, the bereavement support he received was valuable and impactful. John explained that “*the way you talk to your family and friends about bereavement is quite different in my opinion*” and that having the opportunity to share his own experiences, and share in the experiences of others was the “*greatest benefit of the meeting*”.

What was most striking was that John revealed;

“Four of us are still meeting! In fact we are going to have lunch together on Saturday so since then we’ve been, we’ve been meeting up erm we don’t go all, all sort of bereavement discussion it crops up a little bit, but we’re just meeting up”

Maintaining their group relationship long after the ‘official’ support has ceased is really powerful, the significance of which cannot be underestimated, or indeed sufficiently articulated. Evidently they have developed genuine bonds, and provide each other a connection to shared experience but critically, an opportunity for future horizons.

James

James is in his early sixties and in the summer of 2018 his father (who is in his eighties) was diagnosed with Alzheimer’s disease. He described that he (James) *“became a focal point [in his family] of trying to create a level of calmness and a level of (.) sense about it all (I: hmm) but that became overwhelming for me physically (I: hmm) and made me unwell”*. Although John felt like he didn’t know *“who to turn to and potentially really understand what I was dealing with”* by attending to his physical reaction/symptoms John made an appointment with his GP. Subsequently, John explored counselling on a self-help basis, and then an Alzheimer’s Society local coordinator;

“suggested from what I was describing that I was actually dealing with erm (.) a level of grief which actually hadn’t significantly physically lost a loved and I was then sign-posted by the Alzheimer’s Society to, to consider speaking to Cruse”

While it is not possible to identify the Alzheimer’s coordinator that James spoke with and cross-reference to see if they had attended the Bereaved by Dementia one-day training, this anecdote displays a sensitivity to the unique bereavement experiences of people who have a family member with dementia. And moreover, the awareness of, and collaboration between agencies who have specialist expertise and so are best suited to offer support that meets an individual’s needs.

Through independent internet searching, James came across the Bereaved by Dementia Project and contacted Maxine Norrish (the project manager) directly. Maxine sent James the “Bereavement, loss and dementia” resource booklet, and

through a serendipitously crossing paths with Maxine agreed to be part of the evaluation.

Given that James did not receive traditional bereavement support (in a group or individual counselling for example) we were interested in exploring what particular components of the resource were valuable to James at this point in his journey.

“I found section four (I: hmm) which related to the journey through any loss and bereavement. Now, initially when I looked at it I thought it was quite simplistic (I: hmm) coz it’s very pictorial (I: yeah) but in terms of the, the pictures that you see it actually offers up erm a really simple way of breaking the whole thing down”

The presentation of simplistic, but evocative, illustrations to summarise the ways in which bereavement can affect; feelings, thoughts, behaviours, physical reactions, and relationships offered James a platform from which to reflect upon and discuss his own, and others’ reactions to his current, and prospective loss.

In the months following his father’s diagnosis James described feeling that;

“we were really free-falling into this, or spiralling into a level of no control over what we were dealing with and it was likening to being in a maze so that you would set off with such good intentions that you would get out of it but every time you went down one route you’d come against a barrier (I: hmm) but this really the pictorial elements of that section four actually helped to break down some of the stigma and some of the things that we were collectively experiencing”

Here, James eloquently and expressively demonstrates the impact that this resource has had in helping to make sense of his experience, the impact of which is incredibly powerful. Further to this, he explains that *“it’s helped break down some of those generation barriers that my parents, certainly my mum (I: hmm) has found difficult and we’ve only been able to do that by with the knowledge that I’ve learned, and shared experiences.”* Again, this illustrates the potential opportunity for impact that this resource yields – not only has it offered James a direct channel through which he can orientate and navigate his own grief, but he has also used it as a vehicle to help drive and guide his mother along her journey.

James was impassioned to encourage others to seek out informational and support services to aid them through their own journeys; *“people think that there isn’t any*

one to turn to there are! (...) well yeah I wish I'd just done that earlier!" He explained three things that he personally found helpful, and he believed would contribute to better support (including but not limited to bereavement support) for people living with dementia. Firstly, to be *"sign-posted in the direction"*. Secondly, to *"immerse yourself in sharing"* your own experiences, and listening to the experiences of others. Finally, *"the courage and conviction erm you know and not be frightened to step outside your comfort zone"*.

Mr White

Mr White was identified to participate in the evaluation to provide the perspective of a person with dementia who has received bereavement support. Through on-going dialogue between the Bereaved by Dementia project manager and Judith – a CBV who participated in the Bereaved by Dementia one-day training focus group.

Organising an interview that was appropriate and sensitive to Mr White's needs required dynamic communication between the first author, Judith, Mr White, and Mr White's son David. While complicated, this collaboration was essential to ensuring ethical practice. Some key decisions included; conducting the interview on the same day, and at the same time that Judith normally provided bereavement support; Judith would accompany the first author to Mr White's home to make the introduction; Judith and David remained in the room whilst the interview was conducted. This network was also invaluable post-interview and contributed considerably to our understanding of Mr White's experiences.

Mr White is in his eighties and was receiving bereavement support from Judith to help him process the death of his wife Caroline. He was interviewed a week before his final session with Judith. During the interview Mr White was quite reserved, and did not display the humour that Judith had observed throughout their bereavement sessions. He was reluctant to talk about Caroline, and could not remember receiving bereavement support from Judith. We recognise that Mr White's hesitancy may stem from unfamiliarity with the interviewer, and that sufficient trust had yet to be established. We also suspect that Mr White's unexpected trip into town the morning of the interview may have influenced his mood and energy. Responding to Mr White's obvious discomfort answering direct questions about Caroline, his grief, and the bereavement support he received, the interviewer reframed questions to explore Mr White's in-the-moment experience and concerns for the future. He spoke about

Caroline briefly, but the majority of the conversation was dominated by his current and future living situation.

Mr White described Caroline as the *“sort of person who everybody loved and wanted to know (...) she sort of glowed”* and to live without her felt like *“a hole to the head”*. Mr and Mrs White had been married for over fifty years, and Mr White had occupied a central caring role over several years leading up to Mrs White’s death. Mr White described how through his capacity caring for his wife he developed critical skills that have helped him maintain a level of independence in his daily living *“since my wife’s illness years ago (...) I got some of those skills under my belt while I had the opportunity.”* However, he was acutely aware that *“the problem I’ve got now is that my memory is going”* and that *“flavour of the month at the moment err which I’m looking at which is whether I should move into sheltered accommodation.”* Mr White spent a considerable amount of our time together exploring what his specific needs were in relation to his living environment, in particular what priorities would need to be met if he moved into sheltered accommodation.

“I suppose companionship is the erm the main one that you would get (...) because of the bereavement, that I could do with being around people (I: yeah) instead of on my own because erm I don’t want to (4) err go inward on myself and lose touch with everything (I: hmm) I still want to have a life erm that I feel is worth living”

Mr White oscillated between asserting that he still wants a life that’s worth living (as demonstrated in the excerpt above) and feeling that *“I’ve lived my life”* and that *“the future is just going to be a down-hill struggle”*. These discordant discourses help explain his preoccupation with moving into a retirement community. Such a move simultaneously offers the opportunity for a fuller life through companionship and organised activities, and mitigates his concern over being a burden on his family; *“I’ve had my life and they’ve still got theirs and they don’t want the millstone around their neck.”*

During a subsequent conversation with Judith, David revealed that from his perspective he had noticed an improvement in Mr White’s mood since the start of the bereavement support. Additionally, David noted his father was much more willing to communicate and discuss his residential needs and preferences. The latter of which was certainly evident in our communication with Mr White.

Evaluation: Learning and Recommendations

- This evaluation has drawn evidence from three unique client perspectives; the family member of someone who had dementia and has died, a person with dementia who is bereaved, and someone currently experiencing pre-death bereavement.
- All of the client narratives show clear evidence that bereavement support has had a significant impact on their grief experiences. Examples include; ‘growin’ a bit of life’ (to use Shirley’s words) around their grief, using the ‘Bereavement, loss and dementia’ resource to make sense of grief and to share this understanding with others, and to begin a discussion about how future needs might be met.
- Our findings suggest that enabling people to retrospectively understand the process(es) of dementia, and how it might be experienced are critical to how loss and grief are managed within the context of dementia. The one-day training, and the ‘Bereavement, loss and dementia’ resource are therefore critical strategies to build awareness, and equip CBVs and individuals with the necessary skills and information to support people who are bereaved by dementia. We also suggest that if people are supported through the stages of pre-death bereavement the complexity of their grief post-death (for example, overwhelming guilt, regret, anger etc.) may not be as acute. This of course requires further investigation.
- We have demonstrated some of the challenges both supporting people who are bereaved by dementia, and evaluating such support which include but are not limited to; ensuring appropriate support is dispatched in a timely manner; open dialogue with clients about the structure and function of the bereavement support service they have accessed; sourcing services that are available and appropriate to an individual’s ‘stage in the journey’; the flexibility required to respond to the in-the-moment experiences of a person living with dementia.

Chapter 6: Impact and Reach Survey

In order to evaluate awareness, reach, and impact of the Bereaved by Dementia Project within, and beyond, its partner organisations we devised a brief online survey. The survey was disseminated throughout Alzheimer's Society Cymru and Cruse Cymru networks during December 2018 and January 2019.

In total we received 134 responses, of which 116 contained sufficient detail to analyse. Respondents were affiliated with 16 different organisations, most notably; 38% Cruse Bereavement Care, 32% Alzheimer's Society, 11% Aneurin Bevan Local Health Board, 3% Hospice of the Valleys, 3% Age Connects, and 3% Cardiff and Vale University Health Board. Figure 9 (below) provides a full breakdown of organisational affiliation of the survey respondents.

The job description of respondents were likewise varied; 11% Alzheimer's Society Dementia Adviser, 21% Alzheimer's Society 'other role', 35% Cruse Bereavement Volunteer (including managers and trainers), 3% Cruse Bereavement Care 'other role', 11% nursing, 19% 'other' (which included administrative, managerial, and practitioner roles within the respective charities and/or health and social care providers).

Within these job roles, 48% worked with people with dementia on a daily basis, a further 16% reported working with people with dementia on a weekly and monthly basis respectively, and finally, 19% reported never working with people with dementia. Unsurprisingly, respondents working for Alzheimer's Society or memory clinics dominated the 'daily' response, whereas respondents working/volunteering for Cruse Bereavement Care dominated the 'never' response.

The vast majority of respondents (66%) were aware of the Bereaved by Dementia Project, and 92% believe that the project is important. Indicative that efforts to promote the service has been effective and worthwhile.

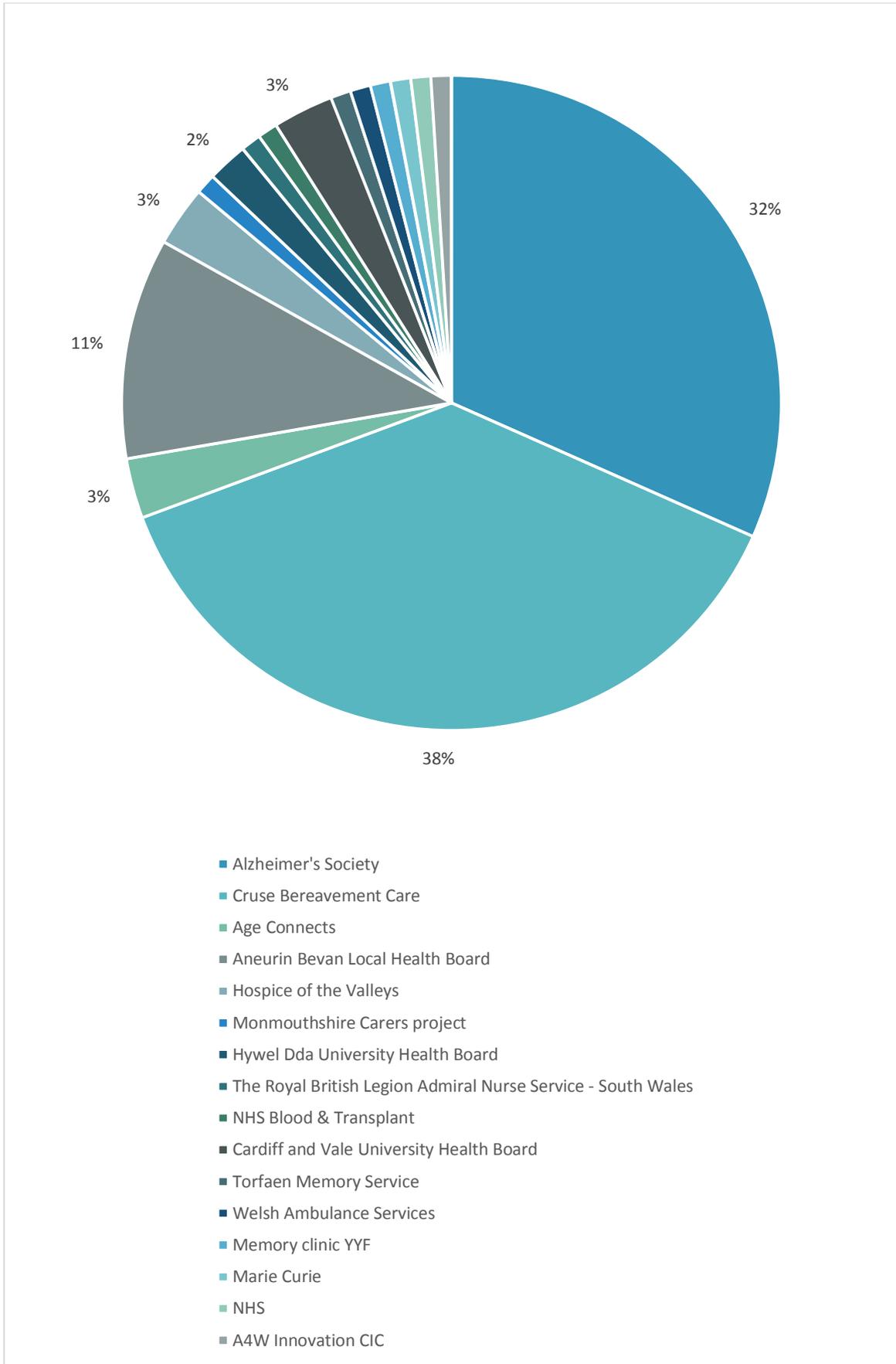


Figure 9. Breakdown of organisational affiliation of survey respondents.

33% of the 76 respondents (who answered this question) indicated that they had referred a client/family member/friend to the service. As depicted in figures 10 and 11, of these 54% rated the referral process as excellent, with a further 25% and 31% rating it 'good' and 'average', respectively. Furthermore, 80% reported they would refer someone in the future, with 1% and 19% reporting that they would not refer in the future, and they were not sure, respectively.

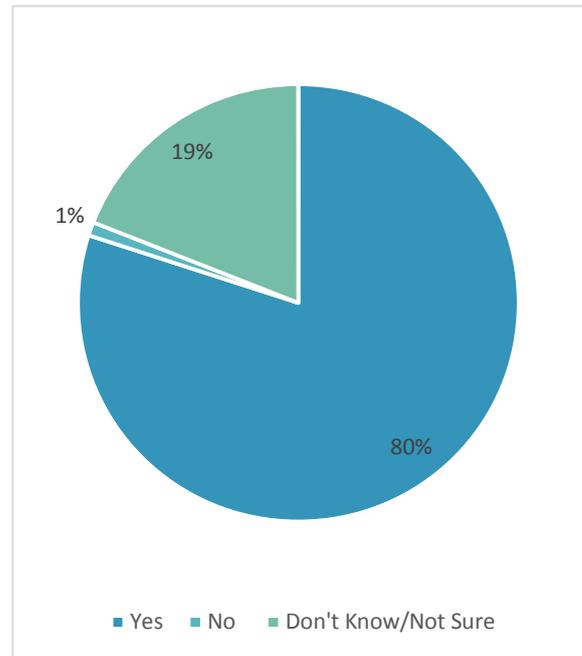
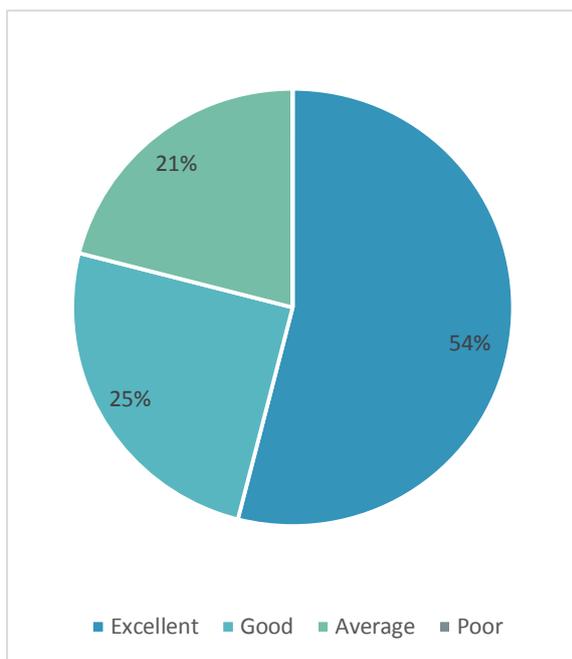


Figure 10 (left). Respondents' rating of the referral process.

Figure 11 (right). Depicts proportion of respondents who would refer to the service in the future.

Additionally, 11 respondents provided additional comments regarding their experience of the referral process. Most notably, two explained that their referral had satisfied the in-the-moment needs of their client(s):

"I have provided information rather than make a direct referral as this was what the bereaved person wanted"

"Individuals and their carers are pleased to have the opportunity to discuss their feelings of loss with others"

While two respondents praised the efficiency of the referral process, three of the comments were critical of how long it took to respond to the needs of the client. Unfortunately, the comments are brief; *“long wait to be allocated support”*, and do not contextualise the situation making it impossible to investigate particular incidents further.

All participants, irrespective of whether they were familiar with the Bereaved by Dementia Project, or whether they had referred anyone to the service were given the opportunity to provide written comments about how they think (a) people with dementia, and (b) the family of people with dementia can be better supported through bereavement. Inductive content analysis (Elo & Kyngäs, 2007) was used to organise, code, categorise, and make sense of the written feedback provided by respondents. Whilst participants’ recommendations shared some thematic similarity, with the aim to respect the nuance of participants’ suggestions, we present discrete suggestions for how (a) people with dementia, and (b) the family of people with dementia can be better supported through bereavement.

[How can people with dementia be better supported through their bereavement\(s\)?](#) Overwhelmingly, the majority of responses (42 unique comments) advocated for a dedicated and specialist bereavement support service that was sensitive to the needs and experiences of people living with dementia to be available and easily accessible.

“More specialised support with empathy for the dementia and its impact”

“Supported to access relevant support as required”

“Understanding the complexities of dementia and how memory loss impacts on their understanding of loss”

An understanding of dementia, and how this may impact an individual’s experience of loss and grief was identified as being of paramount importance if the support is to be appropriate. Respondents suggested that this could be achieved through more specialised training. We argue the Bereaved by Dementia one-day training has, and could continue to, contribute to this recommendation through the development of Cruse Bereavement Volunteers who are sensitive to the needs of people with

dementia who are bereaved. In other words, the one-day training generates the skills and/or knowledge among delegates that equips them to be responsive to individual situations and provide person-centred care in-the-moment.

“Supported to access relevant support as required”

“Ongoing support for a time that is appropriate for them”

This echoes back to data reported elsewhere within this report (most notably in the Bereaved by Dementia One-Day Training: Focus Group section), whereby Kitwood’s person-centred care was identified as a valued approach for CBVs to maximise their capacity to ‘meet participants in their world’. In other words, the Bereaved by Dementia one-day training cultivates an appreciation that when delivering bereavement support, particularly when supporting people with dementia, flexibility and sensitivity to individual experience and expression are essential.

Finally, respondents recommended that the provision of bereavement support to people with dementia should, where possible, be delivered by a consistent person to maximise familiarity and rapport and to minimise distress.

“On-going support and a named contact that will support the person to cope with and understand their feelings/what is happening”

“Regular support and familiar faces who they feel at ease with”

The other two most salient themes, capture the respondents’ recommendations for further awareness (10 unique comments) and training (10 unique comments) of bereavement support services. These themes interconnect both with each other and to the previous theme.

With regards to ‘awareness’ respondents argued that both service providers and service users should be made more aware of the availability and eligibility of relevant services. While publicity was identified as a meaningful way to promote services, respondents also suggested that inter-organisational cooperation will be essential to disseminating appropriate provision.

“Wider public knowledge of support systems, splinter groups formed from other care associations”

“More publicity and joined up thinking about the various support services”

“By all the statutory bodies being aware and having the funding to help”

Respondents recognised the necessity of providing health and care professionals with on-going professional development training with the aim to improve the care and well-being of people with dementia, as well as meeting the bereavement needs of people with dementia. One respondent specifically identified the Bereaved by Dementia One-Day training as a vehicle through which professional development training could be delivered.

“In care homes -caters need to be offered training re bereavement and living with dementia”

“More education/ training for professionals”

“By providing more bereaved by dementia workshops/information days”

[How can people bereaved by someone with dementia be better supported?](#)

The majority of respondents (28 unique comments) likewise recommended that the provision of, and access to, bereavement support that is sensitive to the needs and experiences of a person who has been bereaved by dementia is critical.

“Every person is different but I feel they need help to understand and deal with their loss”

“By having specific support from someone who understands how bereavement following dementia can differ from the experience of bereavement from other causes”

Furthermore, respondents reiterated the importance of increased publicity, awareness, and inter-agency cooperation (18 unique comments), and greater provision of training (11 unique comments).

“Better link of dementia support agencies with cruse etc.”

*“Better information about *local* bereavement services be provided by register offices, better training for financial and other organisations in their treatment of the bereaved”*

“Providing knowledge to the carers / family members of what to expect and how to cope”

Rather than examine the overlapping themes in more detail, specific attention will be given to the unique themes that were identified to improve bereavement support of the family of people with dementia.

Respondents recognised that pre-death bereavement (15 unique responses) is fundamental to the experience of families of people with dementia.

“More specialised support with understanding that they may have been grieving before the actual bereavement”

“Ensure support/information on support is provided before death”

“By recognising their specific needs and circumstances; for example they may go through two losses or bereavements - one when if the dementia is severe when they “lose” the person and one when the person dies”

It is recognised that loss, and accumulating losses, are experienced in families who receive other chronic and degenerative diagnoses, and so pre-death bereavement is not an experience unique to dementia. However, the loss(es) and adjustment to loss(es) experienced by the family are invariably experienced alone as their loved one loses capacity to share experiences in the way they once could. The provision of pre-death bereavement within the context of dementia therefore seems particularly apposite.

Specifically, respondents recommended that support groups are a valued source of support and information for the family of people with dementia (8 unique comments).

“By having someone to talk to and others in a similar situation on a regular basis”

“Provide more support groups for individuals and carers”

With the additional recommendation that support not be withdrawn at the point where their family member dies.

“By not cutting them off immediately, let them go after a few months”

“To be permitted to keep attending group activities for as long as they need to”

While we acknowledge one Cruse Bereavement Volunteer’s comment expressing concern over the trend of pathologising grief by condition:

“Do they need better support? Surely we don't need specialised support for every kind of illness or condition?”

The evidence we have collected and presented within this chapter indicates that there are unequivocal similarities in the loss and grief experienced by people bereaved by dementia. Nevertheless, there remain significant differences in how loss is experienced by the person with dementia, and their family, both before, and after death that require further consideration.

Evaluation: Learning and Recommendations

- 66% of the respondents from either the Alzheimer's Society Cymru or Cruse Cymru were aware of the Bereaved by Dementia Project, and 92% believed the project is important.
- 75% of those who had referred a client to the service reported the process to be either excellent or good, and 80% would refer someone in the future.
- Without knowing more about the specific referrals (i.e. the geographical location, how long into the project it took place, how long the referral took etc.) we are tentative in our recommendations regarding the referral process. However we echo the respondents' assertion that timely bereavement support is critical.
- We argue that the continued provision of the services captured within the Bereaved by Dementia Project would contribute to the fulfilment of respondents' recommendations that people bereaved by dementia would be better supported if there was appropriate and accessible bereavement support information and provision. Continued collaboration between Cruse Cymru and the Alzheimer's Society Cymru, and their extended networks is essential to maximising the reach and impact of the services provided by the project.
- As has been reported elsewhere in this report, evidence from the 'impact and reach survey' suggests that pre-death bereavement remains a priority for the advancement of bereavement support for people who are bereaved by dementia.

Chapter 7: Learn and Share Group

While the design of the evaluation was iterative, in that our methodological approach was adapted and refined throughout the life of the project in order to more accurately capture the nuance of experience and impact of the project, we were resolute in the value of including a Learn and Share Group. As the name suggests, the primary aims of the group were to share information, learn about the project, the evaluation, and perhaps more importantly to share in the rich experiences and expertise of the attendees.

We held two Learn and Share Groups; February 2018, and October 2018. Attendees included; the evaluation researchers (as named in this report), the Bereaved by Dementia and Resident Bereavement Supporter project managers, director of Cruse Cymru, operations manager of Alzheimer's Cymru, Cruse Bereavement Volunteers, Bereaved by Dementia one-day training trainers, ExtraCare resident supporters, ExtraCare Enrichment Opportunities Programme Lead, and ExtraCare's head of innovation and wellbeing. A large number of attendees had been involved in the Project Steering Group and/or the Project Advisory Group which had been meeting since 2016. Members from these groups joined the Learn and Share Group as it evolved to embrace the learning across the two Cruse Bereavement Care Projects (the Bereaved by Dementia Project and the Bereavement Supporter Project respectively), along with their respective partner organisations (Alzheimer's Society Cymru and the ExtraCare Charitable Trust).

The event in February prioritised establishing the dynamics and purpose of the group. The emphasis was on sharing our respective roles in relation to the Bereaved by Dementia project, and providing a platform for the research team to present preliminary findings of the evaluation. While this was an informative and valuable approach we were keen for future groups to be more interactive, and to more actively draw out attendees' personal and professional experiences to inform the evaluation.

We devised a 'Dementia Journey: Losses and Labels activity' to use as a catalyst for discussion. The management group⁴ designed a (simplified and 'idealised')

⁴ Which consisted of the evaluation team, Cruse Bereavement Care representatives, and ExtraCare Charitable Trust representatives.

dementia journey (Appendix 1) which could be used as a framework to explore points that attendees identified as significant in terms of the loss(es) experienced and/or that were salient in terms of how this period/person/place is labelled. Attendees were encouraged to use their personal and/or professional experiences for the activity and the group facilitator (the first author) emphasised that all voices were equally valuable and respected.

As anticipated, attendees reported multiple, and accumulating losses along the journey. Much of the discussion focused on the losses experienced by people with dementia and their families' pre-end-of-life. In particular, having or choosing to retire and to stop driving were identified as being significant sources of loss for people with dementia as this is experienced as a loss of autonomy and independence. Additionally, the 'loss of self' was felt powerfully within the group, with one group member stating "*I miss me*". The group reflected on the loss of previous role(s) and relationships within their family, and how the subsequent shift in dynamics can be very challenging for people with dementia, and their families. Compounding these losses is the expectation, perceived or otherwise, to hide one's feelings and put on a "*brave face*".

While the group displayed an openness to talk about loss, death, dying, and bereavement, some individuals explained that although they find these conversations empowering, they are afraid to discuss these issues with their families. Indeed, it was proposed that dementia - not death – is the last taboo.

We devised the dementia map to act as a catalyst to conversation about people's experiences of living and working with dementia. The discussion revealed that loss is experienced by people with dementia and their families throughout the dementia journey, and that the language we use to frame and explain dementia can have a significant, and detrimental, impact on how dementia is experienced. We hope that the findings from this exploratory conversation will be examined further by exploring the experiences of loss and labels throughout the dementia journey with different groups of people. It is suggested that through such work a tool could be developed for CBVs to elucidate the possibilities for loss and bereavement experienced by people with dementia and their families.

Final Thoughts

The Bereaved by Dementia Project has successfully delivered against the principle outcome measures: (1) 120 new Cruse Bereavement Volunteers have been recruited, trained, and deployed; (2) Bereavement Support and Dementia Awareness training module was designed, developed and delivered; (3) developed an awareness raising/information resource booklet; (4) four information sessions per annum to statutory and third sector organisations were delivered; and (5) raised awareness of Cruse Bereavement Care services in the wider community.

By incorporating in-depth lived experience of CBVs, clients, and third sector organisations, our evaluation also demonstrates the impact that participating in the Bereaved by Dementia Project has had upon individual lives – both professionally and personally. Critically, we have observed a shift in how attendees to the Bereaved by Dementia one-day training understand, and relate to people with dementia. By focusing on the emotional integrity of people with dementia the training builds empathy and provides opportunities for connection. This is especially significant within the current climate of dementia discourse as a “living death” which obscures individual experience and denies many avenues of support by giving the impression that people with dementia do not need, or would not benefit from, support.

Additionally, the one-day training increased delegates’ awareness of bereavement, dementia, and how bereavement may be experienced differently within a dementia context. Further to this, it has provided delegates with some core skills that will facilitate better support provision for people with dementia and their families as well as enriching how they understand and navigate their personal relationships.

The ‘Bereavement, Loss and Dementia’ brochure was co-designed by people living with and/or affected by dementia based on their lived experience and suggestions. It is therefore an invaluable resource to support people with dementia and their families begin to make sense of their loss(es) and better prepare them for their journey. Conversation with Maxine Norrish, the Project Manager for the Bereaved by Dementia Project, revealed that there is already a demand for this resource to be shared more widely - 200 copies have been ordered by a nursing home provider in England for example. Furthermore, the resource booklet has been well received and

used by Resident Bereavement Supporters within ExtraCare Charitable Trust villages. Residents have reported that the resource was “*very useful*”, and, in relation to the pictorial thoughts, feelings, and physical reactions that it was good to know they were “*not the only one*” to feel this way. Demonstrating that the resource can be used as a meaningful supplement to listening support, and help residents make sense of their grief. Additionally, a church education organisation in Wales has expressed an interest for it to be included in training church ministers, as well as training for Imams within the Muslim community. Demonstrating that the resource is considered appropriate across a spectrum of religious and cultural beliefs. Furthermore, through extensive engagement the Bereaved by Dementia Project has raised the profile of both bereavement and dementia across communities who have vested interest in the topics. It follows therefore that community leaders will continue to promote the Bereaved by Dementia resource booklet and bereavement support within their own communities. Contributing to the sustainability and impact of the Bereaved by Dementia Project. Finally, the resource booklet has been submitted to the 2019 British Medical Association patient information awards, the winners are scheduled to be announced in May 2019.

While we acknowledge that the evaluation would have been strengthened had we been able to draw on a greater number of client experiences, it is critical to recognise the shared, and unique, challenges of collecting client feedback within the context of the Bereaved by Dementia Project. As discussed in Chapter 5, a recent audit within Cruse Bereavement Care revealed that less than 20% of clients returned feedback forms across the organisation. Examining the reasons behind this relatively low response rate, and strategies to increase the quality and quantity of client feedback in the future are current priorities for Cruse Bereavement Care. The challenges in collecting data from people with dementia that require reflection on experiences - which may be more difficult due to short term memory loss - should not be underestimated. In other services, evaluation can be gauged by proxy, for example by capturing the carers’ perspective. However, in cases where the person has been bereaved, there may not be a carer or family member to get feedback from either. Future research is required to develop and evaluate a more robust evaluation tool in order to capture the experiences of people with dementia who are bereaved and have accessed bereavement support.

The case studies included in this report, together with the narratives of CBVs, illustrate the benefit of the Bereaved by Dementia Project in supporting people through a variety of bereavement journeys. Grief, and dementia, are experienced idiosyncratically, consequently the support needs of someone bereaved by dementia are likewise individualistic. Evidence from client and CBV case studies, and the 'impact and reach' survey demonstrate that there is a demand for bereavement services that are sufficiently flexible to meet the oscillating needs of people bereaved by dementia. The Bereaved by Dementia Project has made a significant step to address this significant and growing unmet need. Further to this, through collaboration, Cruse Bereavement Care and Alzheimer's Society Cymru have played an important role in raising the profile awareness and profile of bereavement and dementia. Through this effort, it is becoming increasingly apparent that the emotional toil, constant change, and loss experienced by people with dementia and their families is largely 'managed' in isolation. At present, while Cruse Bereavement Care recognise the significance of pre-death bereavement within the context of dementia fiscal limitations are a fundamental barrier to delivering this urgent service. We would like to see funds invested in furthering the scope of the Bereaved by Dementia Project by enabling pre-death bereavement services – services that would have a significant bearing on the post-death bereavement experience - to be established.

Furthermore, we propose the Bereaved by Dementia Project Launch event hosted at The Senedd (The National Assembly for Wales) demonstrated good public engagement practice. The event was attended by representatives from: statutory and third sector organisations; Welsh government; the general public; the research team; and critically, the event was co-hosted by people living with dementia who shared their stories. The Bereaved by Dementia Project has demonstrated a genuine commitment to ensuring that the voices of people with dementia and their families are included in the design, development, and delivery of the project. Indeed, feedback from a delegate revealed that attending the launch, and observing how the Bereaved by Dementia Project actively engaged with people affected by dementia throughout the project journey, had been an important learning point for them that would elicit a meaningful change in practice. In sum, the dedication to inclusivity demonstrated throughout the Bereaved by Dementia Project has produced training,

resources, and learning that are even more powerful because they have been designed and endorsed by people affected by dementia.

The evaluation has also identified aspects of this new service that could be improved. Specific recommendations are provided at the end of each chapter within this report so we will not repeat them in detail here. However, through the Bereaved by Dementia Project, and our evaluation of it, we have a better understanding of what CBVs and third sector providers' value and require from training, and how bereavement support is experienced by both clients and CBVs. Essentially, our recommendation is that the Bereaved by Dementia Project continues, but with slight modifications. In particular: greater clarity about how and who the service is pitched to; training to have clear dual focus – people with dementia and their families; and more opportunities within the training to have difficult discussions, including but not limited to, death disclosure and how to prepare CBVs to support clients who have dementia and are bereaved.

Finally, both the Bereaved by Dementia Project and its evaluation have yielded important learning. We are increasingly, and quite rightly, being encouraged to incorporate and collaborate with people with dementia and their families when designing, implementing, and evaluating health and social care. However, there are often practical and ethical implications that should not be minimised or overlooked. For instance, during the design of the training and resource there were occasions when service user representatives, who had dementia were unable to, or did not want to, discuss this aspect of their experience at that time. These sessions were consequently rescheduled. It is apparent therefore that flexibility, patience, and adaptability are fundamental when designing and delivering inclusive services and in evaluating such a service.

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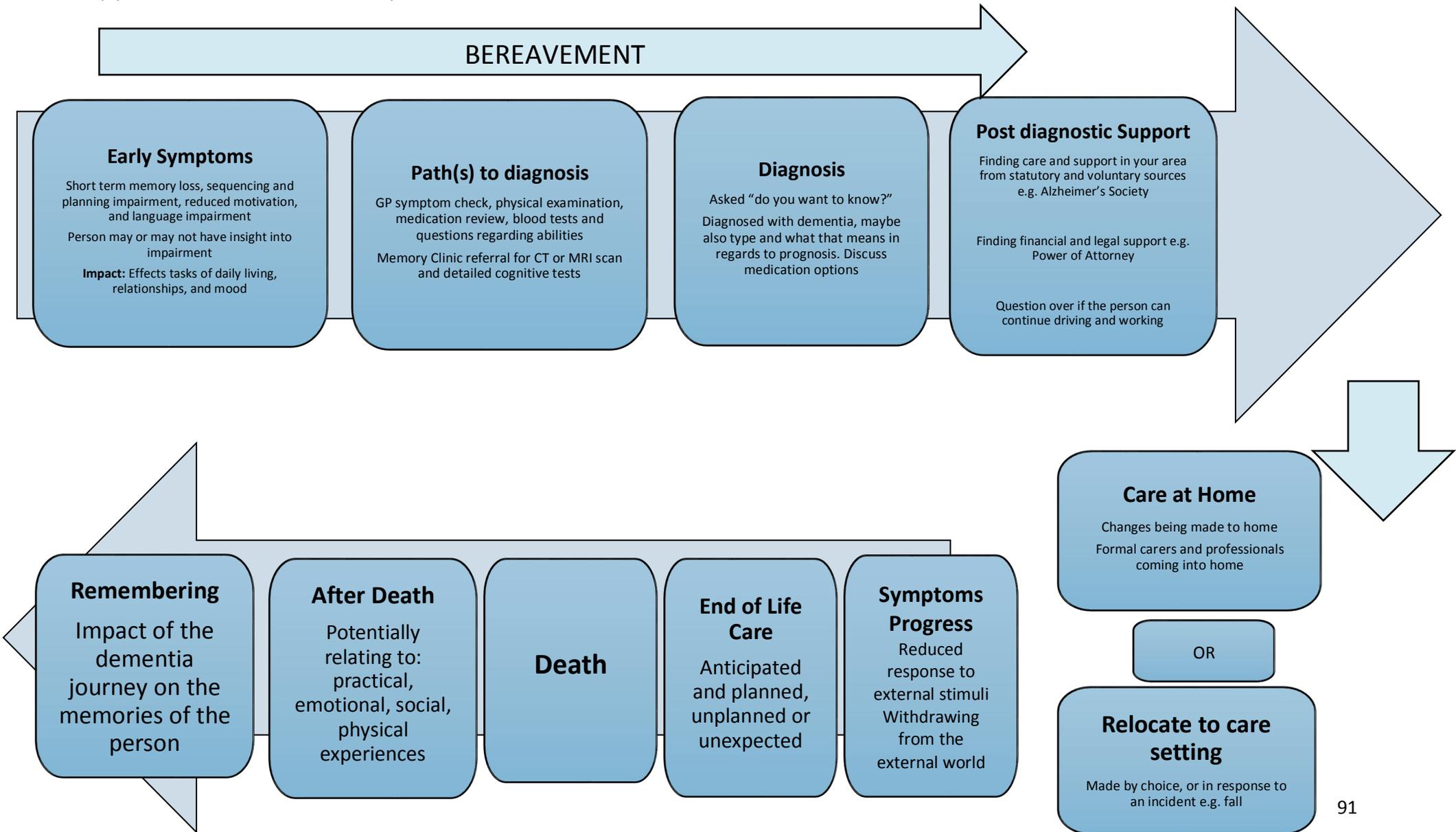
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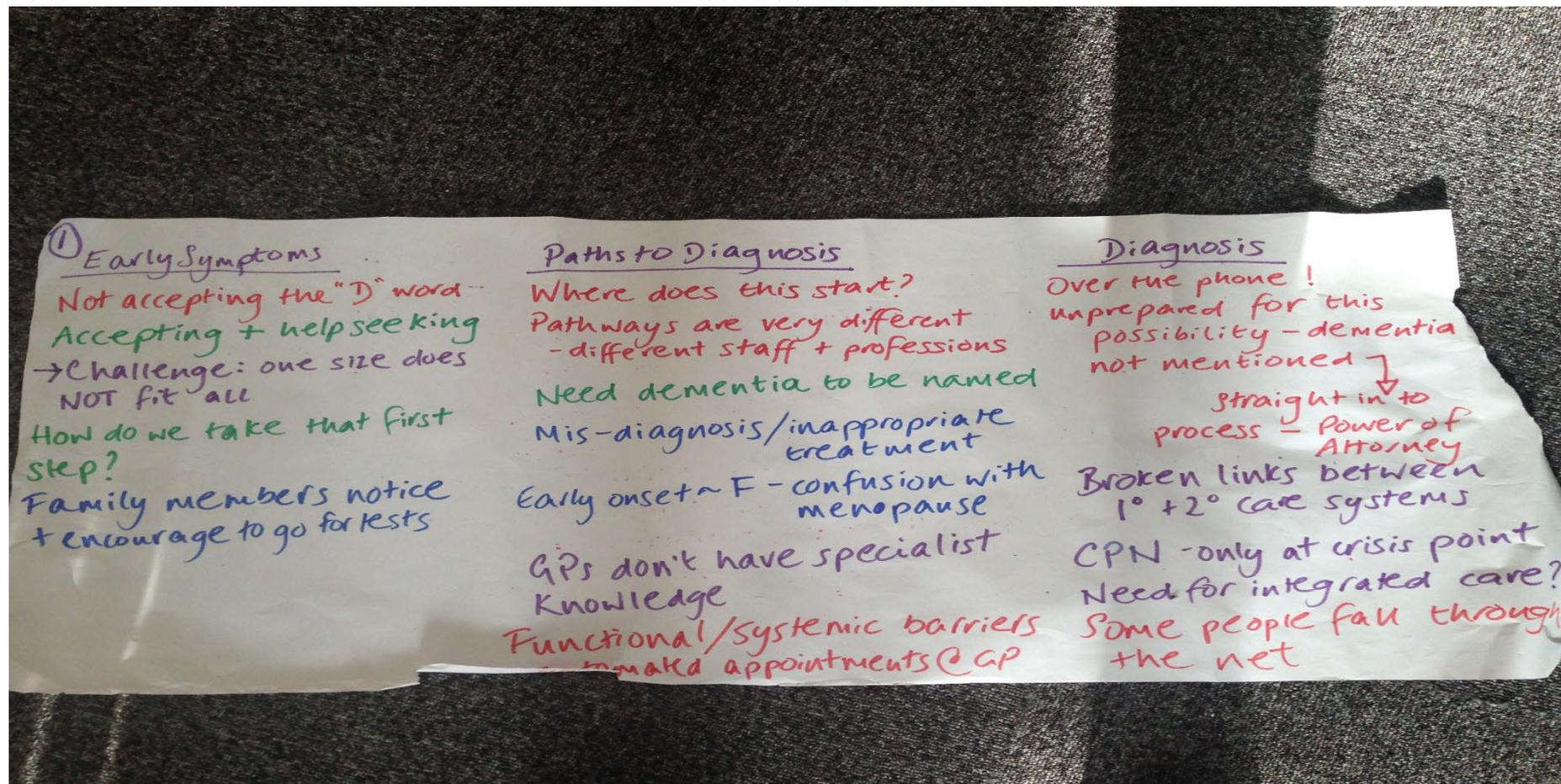
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Appendix 1: Dementia Map



Appendix 2: Documentation of Dementia Journey Mapping



Post Diagnosis Support

'Desire' for integrated care/
Communication between
Services + 3rd sector

→ Challenge: funding
sources / access

Family ability to provide
support variable +
dependent on dynamics

Denial - across family
members - Fear
Responsibility for care

LOSS

Experienced by family
"I miss me"

Family don't want to
burden - loss of role/
sharing problems/
spending QT with
all family generations

Hide feelings - "brave
face"

Family Support

Family members don't
know how to adapt
in a productive way to
maintain independence
+ safety / distract
from agitation

Family help with
finances to prevent
future problems

④ Symptoms Progress

Work! Driving → loss
of autonomy / job /
independence

Disciplinary @ work
Lack of understanding
by employers

Advanced care Planning

Need to create them
while able to make
decisions (agency)

Family needs to talk
through ACP

Early conversations
about end of life

→ empowering

Afraid to raise it with
family members

It is never too early

End of life

Intergenerational
conversations about
death - carers + older
adults

Can now talk about
death

Getting the language
right: dying, death

Dementia is scarier
than death: Living de
Death is not the last tabo
it's death

(x)

After Death

Capture lovely memories
as work through journey
in the memory jar

The Book of You: happy
memories for family members
to use in the future

Guilt of family members
about who relative had
become

- Actively NOT
losing these
memories

Living with dementia
can be good
You've taken the fear
away: only someone with dementia
can do that

Remembering the
characteristics that
may have been
lost

Diagnosis

Diagnosis can be
liberating

Need for early support
Identify as someone
with dementia

Stigma: We don't
have dementia here!
You don't look like you
have dementia