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An evaluation of the new pre-bereavement service developed by

Cruse Bereavement Support for people affected by dementia

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**“ Immeasurable
support at a time
of great darkness.
Light in a storm. ”**



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All the quotes and feedback are included verbatim from the transcripts or submitted questionnaires and reflect the language choice of the participants. The questionnaires were translated following permission from the authors with pre-testing and cognitive interviewing facilitated by [LLAIS](#) and fluent Welsh speakers – we thank them for their contribution.

The interviews were conducted by Gwenllian Hughes, Research Support Officer at the Dementia Services Development Centre Wales (DSDC), Bangor University, with additional input from Lois Williams a medical undergraduate at Cardiff University as part of her student selected component placement and Maria Caulfield, Research Support Officer (Centre for Ageing and Dementia Research). The team would also like to thank Teresa Davies for her generosity of spirit and insight in co-creating and co-delivering the Bereaved by Dementia module and for sharing her expertise on living with dementia to guide the design and presentation of the study documentation and online questionnaires.

Glossary

Carers refers to unpaid carers for people living with dementia.

Client(s) is used to refer to people that accessed the pre-bereavement service by Cruse. This could be people living with dementia, their unpaid carers or their family and friends.

People living with dementia (PLwD), people living with a diagnosis of dementia.

People affected by dementia (PaD) is a broad term used to refer to all those impacted by a dementia diagnosis, this includes the person with a diagnosis of dementia, their unpaid carers and family members and friends.

Volunteer(s) is used to describe the Cruse volunteers that undertake pre-bereavement training and provide the pre-bereavement support for persons affected by dementia.

Pre-bereavement support training pathway:

- 1. Bereavement support foundation training (BSF):** This training involves information on practical skills and the theory behind supporting people who are bereaved.
- 2. Module 1: Bereaved by dementia:** This module focuses on building awareness of the impact bereavement has on people affected by dementia and how the death of a person living with dementia affects their families and carers and how to provide appropriate bereavement support.
- 3. Module 2: Pre-bereavement:** This module aims to enable bereavement support volunteers to understand the experiences of people and their families living with dementia following diagnosis and build the confidence of volunteers and their ability to support the client with their feelings of loss and grief throughout their pre-bereavement journey.

Executive Summary

Background

Continuous losses are experienced by people living with a diagnosis of dementia and their carers before the physical death, resulting in feelings of grief (Blandin & Pepin, 2017). These feelings of grief prior to death are unrecognised by society (i.e., disenfranchised grief) meaning that the people affected by dementia struggle to resolve and come to terms with what they are experiencing, possibly leading to maladaptive coping strategies and complicated grief after the person living with dementia has died (Shuter et al., 2014).

Due to the length and challenging nature of carers' responsibilities it is important that support is available. Comorbidities such as depression and complicated grief have been experienced by carers especially spousal carers (Chan et al., 2013). Spousal carers experience losses in the physical and emotional relationship between them and the person living with dementia. This loss of companionship increases feelings of isolation and loneliness, which can be detrimental to well-being.

Webinar

A webinar, hosted by the Centre for Ageing and Dementia Research (CADR), describes the development and evaluation of pre-bereavement support service, and includes stories and discussions with Cruse volunteers and clients, the project partners, and the evaluation team.

 You can view a **recording of the webinar** and **watch a short animation**.

 The webinar recording is also available on CADR's **Youtube channel**.

Evaluation

The evaluation was conducted by Bangor University in three phases:

Phase one

Evaluating the impact of Cruse Bereavement Support Cymru pre-bereavement training on Cruse volunteers. This objective was met using two Joint Information Systems Committee (**JISC**) online questionnaires designed specifically for education and evaluation use. The questionnaires were completed by volunteers who had already attended specific training on dementia (e.g., Module 1: Bereaved by Dementia), and new volunteers who held no prior experience of supporting people affected by dementia.

Phase two

Evaluating the impact of the pre-bereavement support on clients via online questionnaires. Clients were invited, via the volunteers, to share their experiences of the pre-bereavement support using an online questionnaire. The aim of the questionnaire was to understand how the support helps them cope with their pre-bereavement loss and grief.

Phase three

Evaluating the impact of the pre-bereavement support on clients and volunteers via interviews. Clients and volunteers willing to be interviewed by Bangor University were invited to share their contact details at the end of the anonymous online questionnaire and an interview was arranged with a sample.

Key findings

From July 2020 to January 2022, Cruse has delivered:

- Pre-bereavement support to 151 clients. 17 clients were people living with dementia and 134 were carers or relatives/friends of the person with dementia.
- 124 clients were supported individually and 27 in groups.
- Pre-bereavement Module 2 training to 90 Cruse volunteers (18 were existing volunteers and 72 newly trained volunteers) and seven Cruse Cymru staff.

From March 2020 to January 2022, ten awareness training sessions delivered to 95 external delegates, the majority working within the field of bereavement support or dementia service delivery, in statutory and third sector organisations. These sessions raised awareness of the pre-bereavement service offered by Cruse Bereavement Support Cymru and complemented delegates existing skills and knowledge.

- The training increased volunteers' awareness of pre-bereavement support for those affected by dementia (100% strongly agreed - agreed).
- Volunteers felt they were better equipped with the knowledge and skills to support an individual with early to moderate dementia (95% strongly agreed - agreed), and they could support a carer for a person living with dementia (98% strongly agreed - agreed).
- At interview, volunteers reported the training had changed their perception of dementia and how to best support clients affected by it. Supporting clients over the phone had challenges, however, they found that it provided an opportunity to improve their listening skills and communication skills.
- At interview, clients reported feeling less anxious and not as lost after receiving support from Cruse. Many reported that they could confide in the volunteers and share their thoughts without fear of judgement.

- Speaking to volunteers was easier for clients compared to speaking to family and friends. Speaking over the telephone provided an extra level of anonymity which was welcomed by clients.

Conclusions

- The project has identified a significant unmet need in the support that people affected by dementia require to explore feelings of loss and grief in a timely way. Organisations, both statutory and voluntary, need to acknowledge the importance of this for people affected by dementia and prioritise embedding specific pre-bereavement support into future service commissioning and development.
- The strong partnership approach between Cruse Bereavement Support Cymru and the Alzheimer's Society Cymru supported the development, promotion, and delivery of an innovative and essential pre-bereavement service for those affected by dementia.
- In response to the COVID-19 pandemic, Cruse Bereavement Support Cymru demonstrated their agility and efficiency to continue to train volunteers and support clients.
- The feedback reported by clients and volunteers suggest Cruse have exceeded their expectations regarding pre-bereavement support and training, respectively, and this support is valued by those who accessed it.
- More work is required to ensure that people living with dementia feel comfortable to access this support following a diagnosis.
- Low numbers of bilingual / Welsh speaking volunteers that completed the evaluation needs consideration in terms of the language skills of volunteers.



A buddy system for volunteers as well as supervisors would be a sustainable mechanism for ongoing support.

Recommendations

- ✓ Based on the feedback from both clients and volunteers we recommend that the support be extended beyond the initial ICF funding period (<March 2022).
- ✓ Further work with people living with dementia to address the relatively low uptake for this support with advocacy groups such as 3NDWG, Dementia Engagement and Empowerment Project (DEEP) and Lleisiau Dementia, should explore how the service can be promoted to *all* those affected by a diagnosis.
- ✓ Although the support is designed to be accessible at multiple timepoints after diagnosis, clients would value a 'roadmap' at the beginning of support if they are unsure of what they hope to achieve by the end of the sessions.
- ✓ Volunteers would appreciate more background information on clients where possible.
- ✓ The training has a lot of content. Discussion is a key component of the training and should not be curtailed because of the amount of content needed to cover. The time to deliver the training should be extended.
- ✓ There are opportunities for volunteers to discuss feelings of pre-death losses and grief with a person living with dementia.
- ✓ A buddy system for volunteers as well as supervisors would be a sustainable mechanism for ongoing support. Pairs should include volunteers who have just started supporting clients affected by dementia and those who have supported a few. This would provide an opportunity for advice and exchange of experience. Supervisors who specialise in supporting people affected by dementia could also mentor less experienced supervisors.
- ✓ The model of support has the potential to be expanded to the other countries of the United Kingdom and to support individual's facing life after a diagnosis of a progressive or terminal condition.

The Cruse Bereavement Support Cymru and Alzheimer's Society Cymru partnership

The partnership between Cruse Bereavement Support Cymru and the Alzheimer's Society Cymru predated the pre-bereavement service. The partnership was a continuation of a well-established relationship which continued to evolve following collaboration in developing the Bereaved by Dementia (Module 1).

The strong partnership was critical to the success of the project and has promoted a greater understanding of dementia and loss between the two organisations and enabled many people affected by dementia to benefit from support as they negotiate pre-death feelings of grief and loss.

As a direct result of close continuous contact between the two organisations, recommendations and improvements to the pre-bereavement service were easily implemented. Alzheimer's Society's expertise regarding dementia aided the formation of resources available for Cruse clients to use both during and after support sessions. Alzheimer's Society also promoted the training to Dementia Advisors and facilitated carers' support groups. Due to the increasing demand in response to the COVID-19 the pandemic, this service was felt to be greatly needed by the Alzheimer's Society Cymru to cater for clients' needs in relation to adjusting to pre-bereavement loss. To accommodate this need, members of the Alzheimer's Society team in Wales attended pre-bereavement training. This empowered individuals to implement their learning and understanding of pre-death feelings of grief and loss to their existing approach to assisting clients.



Introduction

Anticipatory grief, grief that occurs before death, is common among families of terminally ill individuals, for example, those with cancer (Patinadan, et al., 2020). Anticipatory grief can be characterised by the intense sense of loss and grief before physical death, giving rise to emotions such as frustration, anger, hopelessness, fear, and loneliness.



A type of anticipatory grief unique to PaD is Dementia Grief, distinguished by declining communication and awareness in the individual with dementia, even during the early stages. The main components of Dementia Grief are compounded loss, ambiguity and receding of the known self (Blandin & Pepin, 2017).

Specifically, losses experienced prior to death are compounded serial losses that increase in magnitude and severity as the dementia progresses. These losses vary from deteriorating communication to inability attending to basic everyday needs such as the ability to wash and feed without assistance. These ambiguous losses remove any possibility of closure because the individual living with dementia is physically present but may react differently as their cognitive abilities deteriorate. Receding of the known self refers to the changes to the persons' living with dementia identity, personality, memories, and abilities.

Becoming a carer for a person living with dementia can result in increased physical and psychological strain (Sullivan & Miller, 2015), including grief experiences due to continuous losses experienced by the person living with dementia before physical death (Blandin & Pepin, 2017). Chan et al., (2013) found carer anticipatory grief was positively associated with depression, and being a spousal carer was also positively associated with complex reactions to losses occurring before and after death. According to Shuter, Beattie and Edwards (2014), experiences of disenfranchised grief (i.e., grief which is not understood or acknowledged by society because the person is still alive) and ambiguous losses can increase the likelihood of carers developing maladaptive coping strategies such as avoidance and denial. Unresolved pre-death grief and the associated ambiguous losses can contribute to prolonged or complicated grief years after the death itself. This demonstrates support that helps resolve pre-death grief and losses at an earlier stage is needed.

Experiences of disenfranchised grief and ambiguous losses can increase the likelihood of carers developing maladaptive emotional coping strategies such as avoidance and denial.

A good deal of research has documented the challenges reported by carers supporting someone living with dementia (Chiao et al., 2015). However, it is important to note that, for some, caregiving also gives rise to positive experiences and the stresses and strains are juxtaposed with a sense of meaning, purpose, and identity (Lopez et al., 2005; McCann et al., 2015). Some carers report a sense of pride and accomplishment, the development of new skills and abilities, a sense of strength and resilience, and the opportunity to express their faith in a practical way. It is now recognised that individuals often emerge from stressful situations having made life enhancing and adaptive responses. Hence, to appreciate fully the lived experiences of carers and caregiving relationships, recognition of both the challenges and satisfactions is required.

Supiano et al., (2020) found that carers who were prepared for the physical death of someone with dementia resulted in a positive and more constructive grief experience, compared to carers who were unprepared. Fifty participants were bereaved dementia carers, and 50 were active carers. All participants completed an online survey including questionnaires on grief and complicated grief, as well as questions on death preparedness. Analysis of the responses evidenced themes associated with death preparedness including positive memory reconstruction; perception that death was ending the person with dementia's suffering; relationship resolution; a good understanding of dementia as a disease and shared understanding of the person with dementia's death with other family members. Themes associated with those reporting greater pre-death grief included perception of the dying process being traumatic; loss of the carer role; perceiving support as unavailable and loneliness after death. Those who demonstrated a healthy positive approach towards their grief demonstrated intrinsic resilience suggesting they were less likely to experience unresolved distress. With the help of therapeutic interventions before physical death, carers may be more prepared and less likely to experience the negative effects associated with pre-death grief experiences.

MacCourt et al., (2017) investigated the effectiveness of a coaching intervention for carers of PLwD on their levels of grief, empowerment, coping and resilience. Six coaching sessions, delivered by clinical counsellors, explored dimensions of grief, living with grief, maintaining self and enhancing resilience. The intervention was delivered individually or in group sessions, over the telephone, online or in person. Questionnaires were administered pre- and post-coaching for the control group (n=77) and intervention group (n=123). No significant differences between pre and post measurements were observed in the control group, whereas the intervention group showed significant improvements in coping, resilience, empowerment, and reduced levels of grief.

Despite these encouraging findings, the time frame between pre- and post-intervention was unclear. Symptoms may have been stable during the intervention period which would explain these improvements. Additionally, researchers did not discuss grief levels in relation to the stage of the disease amongst participants despite including a questionnaire which measured this. Despite these limitations, the study found the effectiveness of the intervention was not determined by the delivery method.

Bereaved by Dementia was a Welsh Government funded three-year project, with one year extension that ended in March 2020. This project was delivered collaboratively by Cruse Bereavement Support Cymru and Alzheimer's Society Cymru and provided person-centred bereavement support to people bereaved by the **death** of someone with dementia. An evaluation of the Bereaved by Dementia project, conducted by Roleston et al., (2019a, 2019b) concluded that pre-death bereavement services would have a significant bearing on the post-death bereavement experience. Accordingly, the development of additional bespoke training to provide a **pre-bereavement** service was subsequently developed by Cruse Bereavement Support Cymru.

Cruse pre-bereavement training programme

The aim of the pre-bereavement service is to provide support to people diagnosed with all forms of dementia as well as their carers and families, from diagnosis onwards. This will enable better coping with grief, and the individual pre-bereavement journey that each person will make.

This independent evaluation by Bangor University focused on the pre-bereavement service co-produced by Maxine Norrish, Project Manager for at Cruse Bereavement Support Cymru with the training team at the Alzheimer's Society Cymru. The project was funded from November 2019 to March 2022 by the Gwent Regional Board Integrated Care Fund (ICF) to be delivered across Wales.

Prior to delivering training or support, the pre-bereavement training programme was developed. This was done in consultation with four groups of PaD supported by the Alzheimer's Society Cymru to ensure support materials were dementia and carer friendly and provided emotional support for those affected by dementia following a diagnosis.

A Steering Group met throughout the life of the project on nine occasions. Members brought their specialist skills and knowledge to each stage of the service development and delivery. The core members of the group who attended every meeting included Maxine Norrish, Cruse Bereavement Support Project Manager, Christine Williams, Chair of Cruse Council, and Siân Bidder, Dementia Connect Local Services Manager, Alzheimer's Society Cymru (Cardiff and Vale). Together they maintained the necessary focus to achieve the project outcomes and in response to the COVID-19 pandemic made important decisions to ensure the project's successful delivery.

Cruse started delivering pre-bereavement training to Cruse volunteers in July 2020 and offering pre-bereavement support to clients from August 2020 onwards.

Bangor University was commissioned in September 2020 to conduct an evaluation of the pre-bereavement service.

Training pathway for volunteers

The pre-bereavement support training pathway comprised the following elements.

1. Bereavement support foundation training (BSF):

This training involves information on practical skills and the theory behind supporting people who are bereaved.

2. Module 1: Bereaved by dementia:

This module focuses on building awareness of the impact bereavement has on people affected by dementia and how the death of a person living with dementia affects their families and carers and how to provide appropriate bereavement support.

3. Module 2: Pre-bereavement:

This module aims to enable bereavement support volunteers to understand the experiences of people and their families living with dementia following diagnosis and build the confidence of volunteers and their ability to support the client with their feelings of loss and grief throughout their pre-bereavement journey.

Modules 1 and 2 were originally designed as a full day (Module one) and half day (Module 2) of in person training. In response to the COVID-19 pandemic, both modules were modified to be delivered via Zoom and work booklets were provided. Each module was delivered over two days, sessions lasting three hours each.

For Bangor's evaluation, Cruse volunteers were categorised into two groups. The first group of Cruse volunteers consisted of 140 existing volunteers who had already completed the BSF and Module 1 as part of the Bereaved by Dementia and were delivering post-death bereavement support to clients.

The volunteers from this group who chose to continue onto pre-bereavement support training therefore only received Pre-bereavement Module 2.

The second group of Cruse volunteers consisted of 72 newly recruited volunteers, recruited between March 2020 to January 2022 (n=72; 36/year). This group held no prior experience of supporting PaD or bereavement and received the BSF, Bereaved by Dementia Module 1 and Pre-bereavement Module 2.

Support pathway for clients

Referrals to the pre-bereavement service were made either through self or third party referral via a dedicated **email and telephone number** given on the Cruse Bereavement Support Cymru website.

Following an initial assessment phone call, each referred client is offered up to six support sessions, lasting approximately 50 minutes each, with a trained Cruse volunteer via a mode of their choice. Following the COVID-19 restrictions, from March 2020 the support sessions were delivered via telephone, one-to-one Zoom call or in group Zoom call.

Group support sessions were delivered in collaboration and co-facilitated by Alzheimer's Society Cymru and Cardiff and the Vale Health Board colleagues.

Following the initial assessment phone call, clients received copies of the project resources via post or digitally depending on preference. Clients may return to the service as their circumstances change following their initial referral.

Following an initial assessment phone call, each referred client is offered up to six support sessions, lasting approximately 50 minutes each, with a trained Cruse volunteer via a mode of their choice.



Method

The evaluation team was led by Dr Catrin Hedd Jones, Dr Diane Seddon (co-researcher), Gwenllian Hughes and Maria Caulfield (Research Support Officers) from Bangor University, and Lois Williams Cardiff University medical undergraduate on placement.

Ethics

Ethical permission was granted by the School of Medical and Health Sciences Ethics Committee on 18.08.2020 (Ref: 2020-16791).

Evaluation Materials

Bilingual evaluation materials were developed by Bangor University in partnership with Cruse. Further guidance was provided by Teresa Davies to ensure the surveys were designed to be user friendly. Questionnaires were hosted by the online Joint Information Systems Committee ([JISC](#)).

1. Cruse volunteers' pre-training questionnaire:

This questionnaire gathered demographic data and included the 'Approaches to Dementia Questionnaire' ADQ-GEN (Lintern & Woods, 1996; Popperwell, 2013) which assessed volunteers' beliefs and preconceptions on dementia. The questionnaire was translated into Welsh by Catrin Hedd Jones and [LLAIS](#). Participants were asked to select one response out of five on each statement; strongly agreed, agreed, neither agreed or disagreed, disagreed, or strongly disagreed.

2. Cruse volunteer's post-training questionnaire:

This questionnaire gathered demographic information and responses regarding how volunteers accessed the training, their ideal method of accessing the training, feelings on the pre-bereavement training content and the 'Approaches to Dementia Questionnaire' scale.

3. Client's questionnaire:

A recording was played during the training to encourage volunteers to invite clients to complete an online questionnaire at a time convenient to them, this could be between sessions or after the last session. This questionnaire included statements to assess feelings on the Cruse pre-bereavement support.

Participants

Participation in this study was voluntary.

Participants included Cruse volunteers and clients. All participants received a project information sheet and consent was gained. The responses in this report included volunteers who completed pre training questionnaires (n=70) and those that completed the post training questionnaire (n=37).

Seventeen clients completed the client questionnaire. In this study, all clients were relatives of the person living with dementia. Twelve out of the 17 were the main carer of the person living with dementia.

Thirty volunteers and eight clients shared their contact details to be interviewed, however, the study funding and resources involved individual online recorded interviews with eight volunteers and six clients (all carers).

Nine clients and 57 Cruse volunteers shared their contact details with Bangor University to request a summary of the findings.

The three-phase evaluation:

Phase one

Phase one evaluated the impact of the pre-bereavement training on Cruse volunteers, in terms of equipping them with the skills necessary to effectively support PLwD and their carers with their pre-bereavement loss and grief. Since the first group of volunteers (n=140) had already completed the BSF and Module 1 and had experience of delivering bereavement support to clients affected by dementia, they were asked to complete the post questionnaire only. The second group of new volunteers (n=72) had no prior experience of supporting PaD as part of their volunteering work in Cruse and were asked to complete the pre and post questionnaires. All the questionnaires were anonymous.

The training questionnaire responses were sent directly to Bangor University for analysis, pre (n=70) and post (n=37). All volunteers that completed the questionnaire had the opportunity to share their contact details for a follow-up interview and /or request a summary of the findings.

Phase two

Online questionnaire feedback from clients that used the pre-bereavement service was collected between September 2020 and January 2022.

All the clients received an information sheet and link to the questionnaire directly from their volunteer. Clients had the option to complete the questionnaire online or printed questionnaires were available on request and posted to them. A free post envelope was included for clients to return their questionnaire to Bangor University. Data was stored on Bangor University's OneDrive secure system. Only clients wishing to receive a follow-up interview (Phase 3) or request a summary of the findings were asked to share their contact details with the evaluation team.

Phase three

Qualitative interviews were conducted with a sub sample of carers (n=6) and volunteers (n=8) to explore their experiences in greater detail. The interviews were conducted between February 2021 and June 2021. Participants who had expressed interest in being interviewed were provided with a copy of the Information Sheet and an interview Topic Guide. Interviews were conducted remotely, in line with COVID-19 regulations, using the online platforms Zoom or Microsoft Teams. All participants were assigned participant codes to maintain anonymity. Interviews were transcribed and anonymised and data was stored in compliance with General Data Protection Regulations on Bangor University's OneDrive secure system. Qualitative data was analysed thematically following the six-stage process suggested by Braun and Clarke (2006).

Two interviews were conducted with Alzheimer's Society Cymru to discuss the partnership working with Cruse Bereavement Support. These interviews provided contextual information about the development and implementation of the pre-bereavement service.

Findings

From July 2020 to January 2022, Cruse delivered pre-bereavement support to 151 clients. 17 clients were people living with dementia and 134 were carers or relatives/friends of the person with dementia. 124 clients were supported individually and 27 in groups. The Cruse team trained 72 new volunteers to deliver pre-bereavement support. This included completion of BSF, Bereaved by Dementia Module 1, and Pre-bereavement Module 2. In addition, 18 existing volunteers and seven Cruse Cymru staff members completed the Pre-bereavement Module 2.

From March 2020 to January 2022, ten awareness training sessions were delivered to 95 external delegates, the majority working within the field of bereavement support or dementia service delivery, in statutory and third sector organisations. These sessions raised awareness of the pre-bereavement service offered by Cruse Bereavement Support Cymru, provided referral information and complemented delegates existing skills and knowledge.

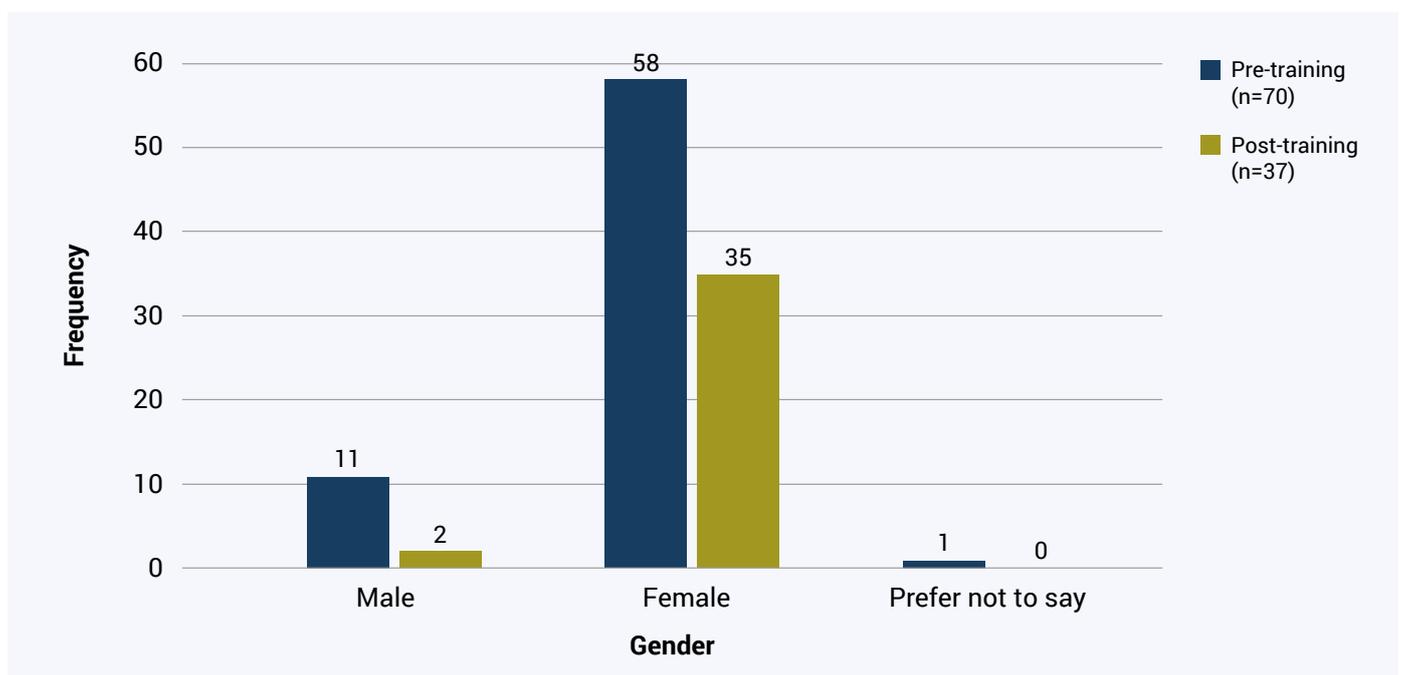
Cruse volunteers' questionnaire responses

Out of the 90 Cruse volunteers who completed the pre-bereavement training pathway and went on to support clients, 70 (78 %) completed the pre-training questionnaire. Of these 70 Cruse volunteers, ten had a relative diagnosed with dementia, five also held the role of Cruse Supervisor and five had a friend living with dementia. Only four volunteers expressed that they could support clients bilingually in both English and Welsh.

Out of the 90 Cruse volunteers who completed the pre-bereavement training pathway and went on to support clients, 37 (41 %) Cruse volunteers completed the post-training questionnaire. Of these 37 Cruse volunteers, 11 also held the role of Cruse Supervisor, eight had a friend living with dementia and five had a relative diagnosed with dementia.

70% of volunteers 'strongly agreed' and 30% 'agreed' that the training has improved their awareness of pre-bereavement support for

Table 1: Gender of volunteers responding to the pre- and post-training questionnaire



those affected by dementia. 57 % of volunteers 'strongly agreed' and 41% 'agreed' that they felt more equipped to deliver pre-bereavement support to a client who cares for someone living with dementia. 41 % of volunteers 'strongly agreed' and 54 % of volunteers 'agreed' that they felt better equipped to deliver pre-bereavement support to a client with early or moderate dementia.

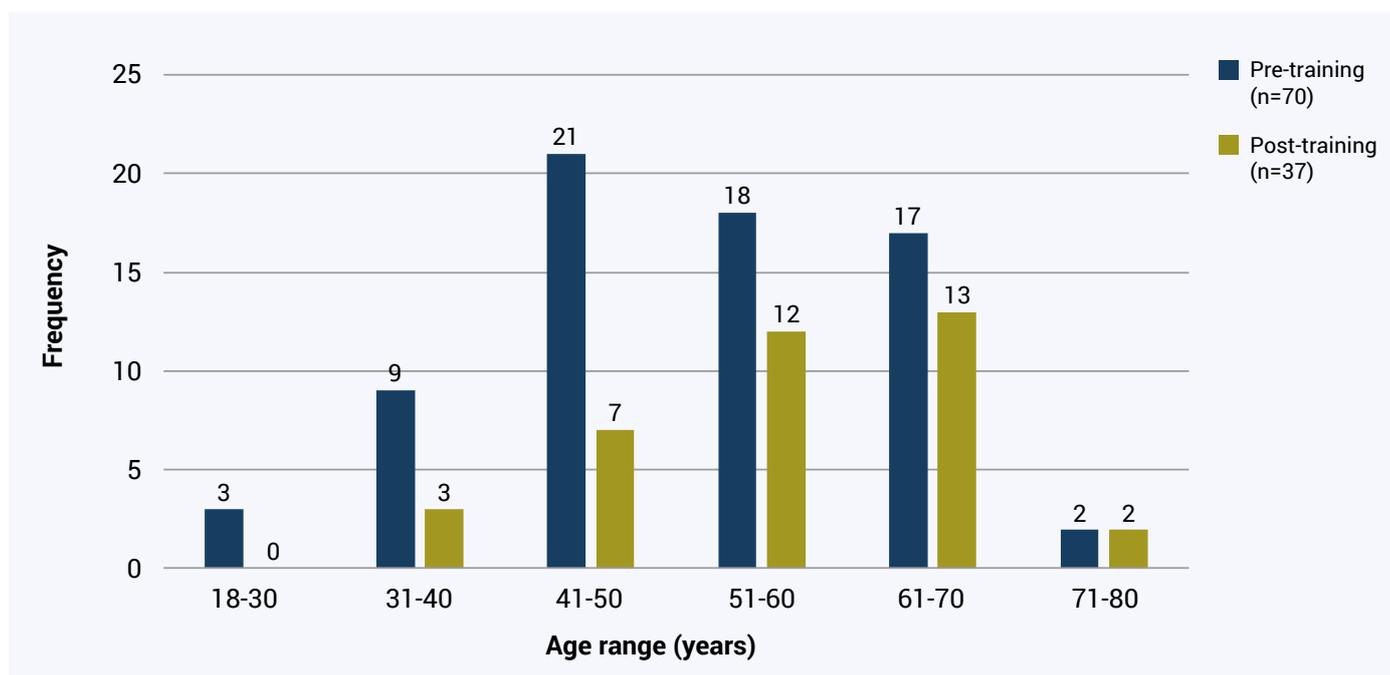
The training was a good balance of theoretical and practical learning and offered thought provoking and powerful ways for volunteers to appreciate the complexity of losses and grief experienced by PLWD, their families and friends. Volunteers valued the collaborative and interactive elements to the training which allowed opportunities for the sharing of experiences, points of view, and knowledge. The variety of training resources including videos, case studies, role play, discussions, storytelling, and a range of creative and interactive exercises made the training engaging and interesting. Practical exercises were complemented by recommended readings and work booklets with a wealth of material for volunteers to refer to in their own time and to continue their learning.

Having the time to meaningful engage in group work, in-depth discussions and debate was important for volunteers to help them learn from others and process the content.

To sufficiently cover the breadth of the training content, volunteers stated that they would like more time for each training session. They would also benefit from meeting or hearing more from people with lived experience of dementia to explore with them the support they have found helpful (or not) and why. Refresher training was also recommended to give volunteers the chance to reflect on the support they had provided, to share what worked well and areas they would like more support with. Having feedback from the clients themselves, where possible, would be helpful for volunteers' continued learning and development. As most volunteers had experience of supporting carers only, they expressed an interest in learning more about how to communicate with and support PLWD, particularly people with young onset dementia and those living with comorbidities. Volunteers would also liked to be kept abreast of new support approaches and relevant local or national support services and resources they could signpost clients to.

Volunteers felt the training facilitators were professional and knowledgeable and excellent at making sure the discussions were inclusive and supportive. 85% of volunteers expressed an interest in attending future training.

Table 2: Age range of volunteers responding to the pre- and post-training questionnaire



Clients' questionnaire responses

Although the service is designed to support all those personally affected by dementia all the 17 clients that completed the online questionnaire were relatives of a person with dementia. Eight of the respondents were wives and one was the husband of the person with dementia, seven were daughters, and one widow (supported into her post-death bereavement). Twelve out of the 17 were the main carer of the person with dementia. For nine clients, their relative had a diagnosis of dementia for 5 years or more (Table 3).

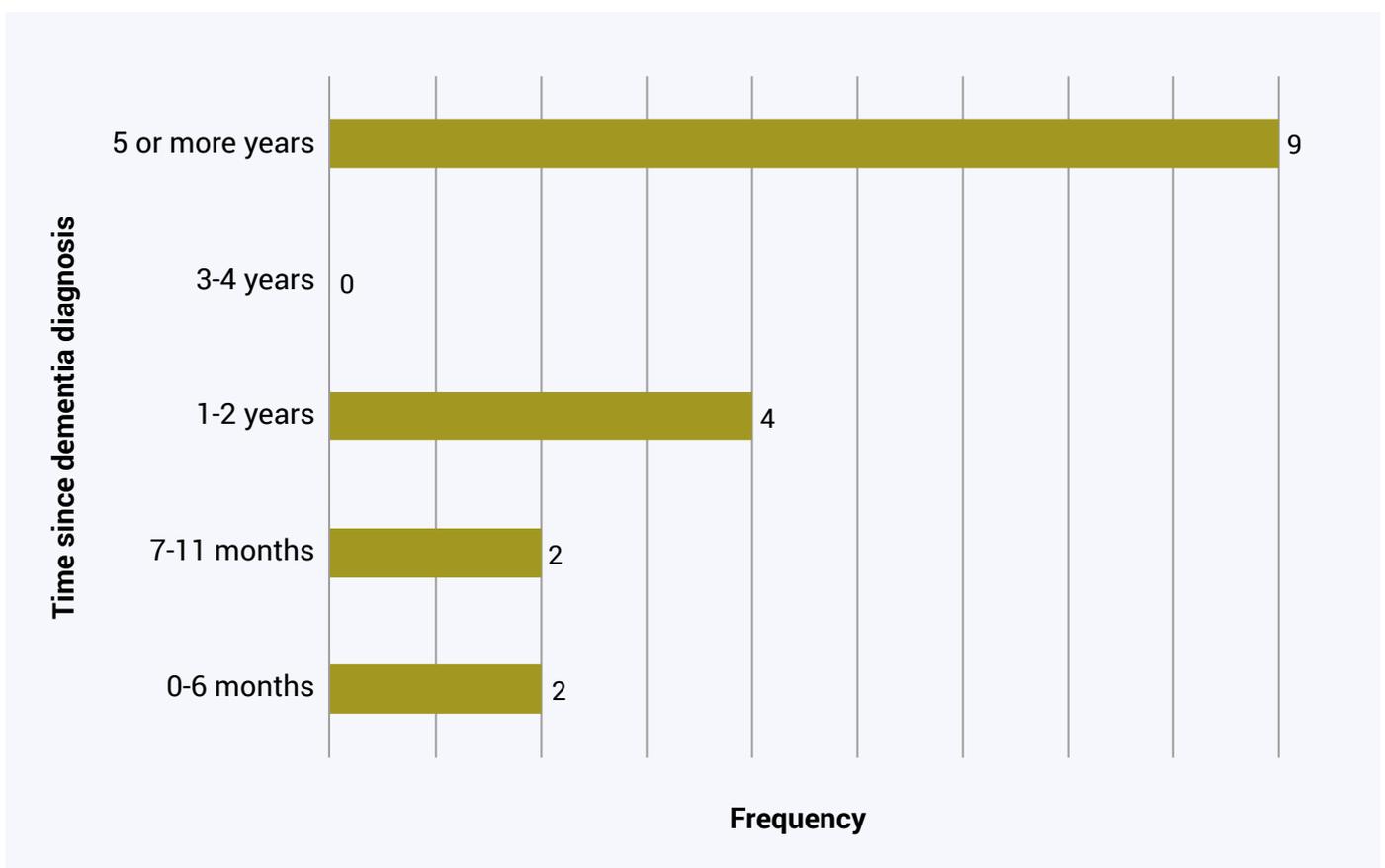
11 clients were recommended to Cruse by Dementia Support Workers employed by the Alzheimer's Society Cymru. Ten clients were between 61 and 80 years of age, 5 were between 51 and 60 years of age, and two were over 81 years of age. None of the respondents were Welsh speakers and therefore accessed the service in English. 10 clients were supported

over the telephone and 8 online or via Zoom, (one client was supported by both methods).

For future support, six clients would favour in person support, eight preferred support to continue online or over the telephone, and three held no preference. Only two of the respondents reported they had used the resources provided by Cruse, these were the booklets, carer stories, and guidance on communication. Five clients reported that they had contacted others for support since talking to Cruse including friends, family, Social Services and third sector organisations.

Based on the 17 client's questionnaire responses, 11 'strongly agreed' or 'agreed' that the support had made them feel more hopeful and improved their ability to cope. 11 clients 'strongly agreed' or 'agreed' that the support had increased their sense of being understood, and 13 clients 'strongly agreed' or 'agreed' that the support had increased their awareness of their feelings.

Table 3: Length of time since a dementia diagnosis was confirmed



Interviews with Cruse volunteers and clients on their experiences of pre-bereavement training and support

All the quotes are included verbatim from the transcripts and reflect the language choice of the participants. Eight volunteers and six clients were interviewed; all clients were carers for a person living with dementia. Quotes are coded as 'V' for volunteers and 'C' for clients.

Providing training and support online

The COVID-19 pandemic meant Cruse had to adapt how they delivered training to volunteers and how they supported clients. All training was held online over Zoom. Volunteers felt that Zoom was a good substitute for face-to-face training, as more people could receive the training and did not need to organise travel or accommodation;

"It's a good back-up if anybody couldn't get to face-to-face (training) because of childcare arrangements or something like that." V4

However, many volunteers would like to return to face-to-face training in the future. During the online training, some volunteers struggled to gauge how others were feeling. They also missed opportunities for informal discussions to consolidate learning and to get to know others. Some volunteers felt the extent to which they could engage with different types of material was limited and that more time was needed to work through the training content;

"The timing is quite tight which is good in one way, but I think it's one of the downsides with Zoom." V6

Volunteers supported clients over Zoom or the telephone. While on the telephone, the lack of visual cues meant volunteers had to refine their listening skills and *"know the quality of silence" V8*. Interestingly, because of increased anonymity over the telephone, some clients were more open with volunteers;

"Clients are disclosing quicker and deeper because there isn't a physical presence." V6

For carers, the connective fabric of the group sessions, particularly when discussing difficult and sensitive topics, was challenging online;

"A hug or an arm over the shoulder or somebody holding your hand... it is a big thing we've lost, and we've had to find ways of showing sympathy, empathy in other ways. I think the session worked in a group because you have the challenge of a how you get out on your own to meet people, so it's been good for that." C3

Holding the group sessions online has meant that support could be extended to more vulnerable and isolated clients, those confined to their home due to caring responsibilities or disability. Carers noted that this could potentially bring together a greater diversity of perspectives and allow for a more energised discussion;

"I think Zoom has drawn a lot more people in; people who can't get out, families who can't accompany loved ones to these sessions so Zoom has been a help." C5



Volunteers' reflection on pre-bereavement support training

Alongside the clinical perspective of dementia, training discussed the pre-bereavement experience of people affected by dementia, including the different ways grief and loss may manifest on a day-to-day basis. Different tools and approaches (e.g., conversation cue cards) were discussed to build a rich repertoire of resources for volunteers to draw on, depending on their client's needs and circumstances. The breadth of content covered was judged to be excellent and extensive. Many volunteers expressed a preference for more time to explore a diversity of case studies and work through example scenarios in greater detail;

"I think perhaps listening to more caregivers, interviews with them on how they deal on a day-to-day basis, which would give us some tips on how to support clients when we're speaking to them." V7

In response to COVID-19 pandemic, pre-training work booklets were developed. Volunteers found the workbook extremely useful in providing context and could look through material at their own pace;

"The pre-coursework is excellent. It's really thorough. I loved the fact that I didn't have to keep finding a handout on the day." V6

Following the training, volunteers reflected on their improved understanding of dementia, including variations in the types of dementia and severity of symptoms and the confluence of losses with disease progression. A central aspect of the training was that PLwD and their carers were not defined by their diagnosis, reinforcing person-centred approaches to support. Volunteers reported greater cognitive and compassionate empathy, which improved their confidence to communicate and support clients;

"I learnt that people living with dementia are first and foremost people and not an illness." V2



Client's reflection on pre-bereavement support

In the initial support sessions, the emotive responses of many carers implied a degree of desperation, characterised by their emotional turmoil and relentless caring responsibilities;

"I felt so lonely, and I was really tired. The expression I had was "I feel like a grease spot on the floor". It just felt like everybody else was getting on with their lives and having a fun time, doing what they wanted." C2

Carers alluded to the losses in their relationship, fading companionship and their sense of identity. Carers were acutely aware that the person with dementia was gradually changing;

"A description I came across the other night, every time you go to bed, the tide goes out and every morning the tide's back but never back in quite the same way...there's always a bit less of him and a little bit less...it is excruciatingly painful because the person you love is just ebbing away." C2

Talking to Cruse volunteers was a form of cathartic release, permitting clients to share their thoughts or anxieties, something they felt they were unable to do, to a certain extent, with friends or family;

"It was very cathartic to get a lot of it off and, you know, talk about how I felt, how I was feeling, and I dealt with a lot of guilt really... she just allowed me to explore" C6

As an alternative to stopping the pre-bereavement support after the sixth session, a phased discontinuation of support was suggested by some clients. However, volunteers reminded clients that they could reconnect with the service at any time if they needed to. For those clients who attended group support sessions, the reciprocity of peer support was invaluable. Clients identified and empathised with others in similar circumstances, and learnt new coping mechanisms;

"We're all going through the same thing and at different stages and that's the beauty of talking to other people... I just felt like we were not alone. There's other people going through lots as well." C3

The resources and prompts used to steer and stimulate discussion during group sessions were positively received by clients and helped them to articulate their experiences, identify and own their emotions;

"The flashcards that they gave us meant you could revisit on your own to think about things...the discussion cards really did prompt...they really are very well designed by Cruse. In terms of how it's been for support, it made a difference. I've been able to visualise and vocalise some of the emotions." C3



Qualities of Cruse Volunteers

Volunteers aimed to create a safe psychological space for the clients to talk openly and honestly without fear of judgment. Volunteers focused on using their time effectively and flexibly, *“You adapt to the person in front of you” V1*, and were respectful of the extent to which clients wanted to share on the day. Volunteers aimed to stay present with clients through periods of upset and did not try to rush the conversation on. Clients were encouraged to talk about whatever they wanted and were not led down a particular path by the volunteer;

“Get on board with their journey and take them as far as needed.” V4

The absence of judgement from volunteers was referred to in the context of discussing their feeling and thoughts. The opportunity to change volunteers if the match was not deemed suitable reinforced the client-centred approach to support in which the client has full autonomy in session adjustment;

“Just being able to talk to someone that understood what was going on with me. Completely non-judgemental, completely understanding really.” C4

The volunteer’s breadth of knowledge of dementia, their appreciation for the many complex losses and experience of pre-death grief was noted by clients;

“I really believe they know what they’re talking about, and you trust in them and go with them because they know what you’re going through. You feel comfortable with it.” C5

Volunteers compassionate and empathic communication and active listening skills helped establish good rapport and trust with clients to facilitate a constructive therapeutic relationship;

“I didn’t feel like I was being manoeuvred into behaving a certain way...I got the sense that I was being treated as an individual rather than a number or whatever in the system.” C6

Volunteer support network

For volunteers to effectively support clients, they were mindful of maintaining appropriate boundaries and taking care of themselves. During a support session, a volunteer can absorb a lot of emotion expressed by the client. Many reported the need to do something completely different to ground themselves;

“Some of the phone calls take everything out of you... and there’s a lot of thoughts going around in your head while you’re on the phone.” V3

Volunteers also practiced self-care by using their support networks. Supervisors were available to discuss any concerns volunteers had about a client or anything they were finding difficult;

“You would always be able to get hold of either your own supervisor or another supervisor or the safeguarding officer if you had a concern.” V6

External organisations, such as Alzheimer’s Society Cymru or Carers Charities were available to answer questions, mostly relating to the behavioural and psychological symptoms of dementia and provided information on local or national support services and resources.

Conclusion

“I am so struck by the simple fact that within the everyday lives (of the clients) they have no meaningful opportunity to share these most difficult of emotions”

Mark Jones, Young Onset Dementia Team Lead, Cardiff and Vale University Health Board

The pre-bereavement service provided clients with protected time and space to talk in confidence about their experiences of pre-death losses and grief. Clients appreciated being listened to and felt understood by volunteers who whole heartedly wanted to offer support and showed compassion and kindness.

Through group sessions, clients were comforted by learning they were not alone or isolated in their experience of pre-death losses and grief. Importantly, the pre-bereavement support validated client’s emotions, supported them through their own journey of acceptance and helped them to relinquish intense feelings of impending losses and complicated pre-death grief experiences. Most clients reflected that they wished they had known about and accessed the support sooner in their journey.

The feedback from volunteers regarding the training was overwhelmingly positive with 100% of respondents strongly agreeing – agreeing that the training has improved their awareness of pre-bereavement support. Volunteers felt better able to support clients following the pre-bereavement training and most had an interest in future training (85%). Volunteer’s key ‘take home’ points from the pre-bereavement training included a greater understanding of pre-death grief experiences and dementia related losses at different stages of disease progression for PLwD, their carers and families.



of respondents strongly agreed that the training improved their awareness of pre-bereavement support



of volunteers felt better able to support clients following the pre-bereavement training

Although there are commonalties in the experience of living with dementia or caring for someone with dementia, grief is as individual as the dementia.

In response to the COVID-19 pandemic, the project was adapted in several ways. The training modules originally planned for in person face-to-face delivery were adapted to be delivered virtually, meaning more volunteers could be trained to meet the growing need for client support. Sessions were also delivered to Alzheimer’s Society Cymru Dementia Support staff, providing them with a greater understanding of the pre-death losses for PaD which they could utilise in their role. This also meant that they could refer potential clients to Cruse pre-bereavement service with a far richer understanding of the benefits they may experience.



Delivering pre-bereavement support using a virtual platform or over the telephone had both advantages and disadvantages. Group support sessions, originally intended for in person delivery, took place via Zoom. This meant that client support was not restricted by the location of volunteers and the waiting time for clients to receive support was reduced. A disadvantage, however, was that sessions could not be accessed by those without IT equipment or perhaps limited IT skills. Clients were still able to benefit from support over the telephone despite, from the perspective of volunteers, it being a more challenging method of delivering support. Interestingly, many clients valued their sense of anonymity and therefore preferred support via the telephone.

Approximately one year after clients first received pre-bereavement support, Cruse started to receive client re-referrals back into the service. Cruse advise clients that they cannot guarantee that the same volunteer will be available should they return to the service. Fortunately, for many re-referrals, Cruse were able to ensure the same volunteers for clients. Reconnecting clients with their original volunteer with whom they had a strong therapeutic relationship enabled the continuation of effective and timely support.

The low uptake from PLwD to Cruse's pre-bereavement service is an area for development. Alzheimer's Society Cymru noted that during the last two years, it was predominantly carers of PLwD requesting support. In turn, this meant that most referrals to Cruse's pre-bereavement service were carers. The low numbers of bilingual / Welsh speaking volunteers that completed the evaluation who could provide support in Welsh needs consideration in terms of the language skills of volunteers.

This evaluation has identified significant unmet need; people affected by dementia need to be able to access support in a timely way to explore feelings of pre-death losses and grief. Organisations, both statutory and voluntary, need to acknowledge the importance of this for people affected by dementia and prioritise embedding this specific pre-bereavement support into future service commissioning and development.

The subject of grief due to personal losses experienced as a direct result of ill-health is an identifiable feature in all life-changing progressive conditions. Pre-bereavement palliative care is especially relevant in the efforts to decrease complicated grief and depressive symptoms (Nielsen et al, 2017).

The movement towards the integration of pre-bereavement services into clinical practice is strong evidence of the growing appreciation of the value of this support (Grande et al, 2017). There is considerable potential to adapt this model of pre-bereavement dementia support to assist a wider demographic of clients.

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Contacts

Cruse Bereavement Support

Grief can be overwhelming. You don't have to deal with it alone.

Cruse Bereavement Support is the UK's leading bereavement charity that supports people across England, Wales and Northern Ireland – helping people through one of the most painful times in life, with bereavement support, information and campaigning.

To make a referral please email:

lossanddementia@cruse.org.uk

Pre and post bereavement by dementia information can be found at: **www.cruse.org.uk/?s=bereaved+by+dementia**

We have over 80 local branches delivering services locally. Contact your nearest branch to find out about grief support or volunteering: **www.cruse.org.uk/get-support/contact-your-local-branch**

Cruse Helpline. You can call us for free on **0808 808 1677**.

Opening times:

Monday: 9.30am-5pm

Tuesday to Thursday: 9.30am-8pm

Friday: 9.30am-5pm

Saturday and Sunday: 10am -2pm

Alzheimer's Society

Alzheimer's Society is here for everyone affected by dementia.

If you are living with dementia or are concerned for your loved one, please contact Dementia Connect and speak to our Dementia Advisers who will provide information and support 7 days a week. We can support people with a diagnosis and those waiting for a diagnosis.

Call us for support on **0333 150 3456** or our Welsh-speaking support line on **03300 947 400**.

Support line opening hours:

Monday to Wednesday: 9am-8pm

Thursday and Friday: 9am-5pm

Saturday and Sunday: 10am-4pm

You can also access the service online **www.alzheimers.org.uk/dementiaconnect**

Further information about research, our factsheets and other support is available on our website: **www.alzheimers.org.uk**

For Professionals

We provide information services, resources and specialist training for health and social care professionals working with people affected by dementia.

To find out more and what we can offer visit: **www.alzheimers.org.uk/dementia-professionals/refer**

Bangor University

Since it was established in 1999 the Dementia Services Development Centre Wales (DSDC) at Bangor University has been engaged in developing and evaluating ways in which the well-being and quality of life of people affected by dementia can be supported and maintained **<http://dcdc.bangor.ac.uk/supporting-people.php.en>**.

With an international reputation for interdisciplinary ageing and dementia research, researchers work collaboratively with colleagues, including people living with dementia and their unpaid carers, to focus on developing new ideas, writing research proposals, publishing research, and sharing knowledge.

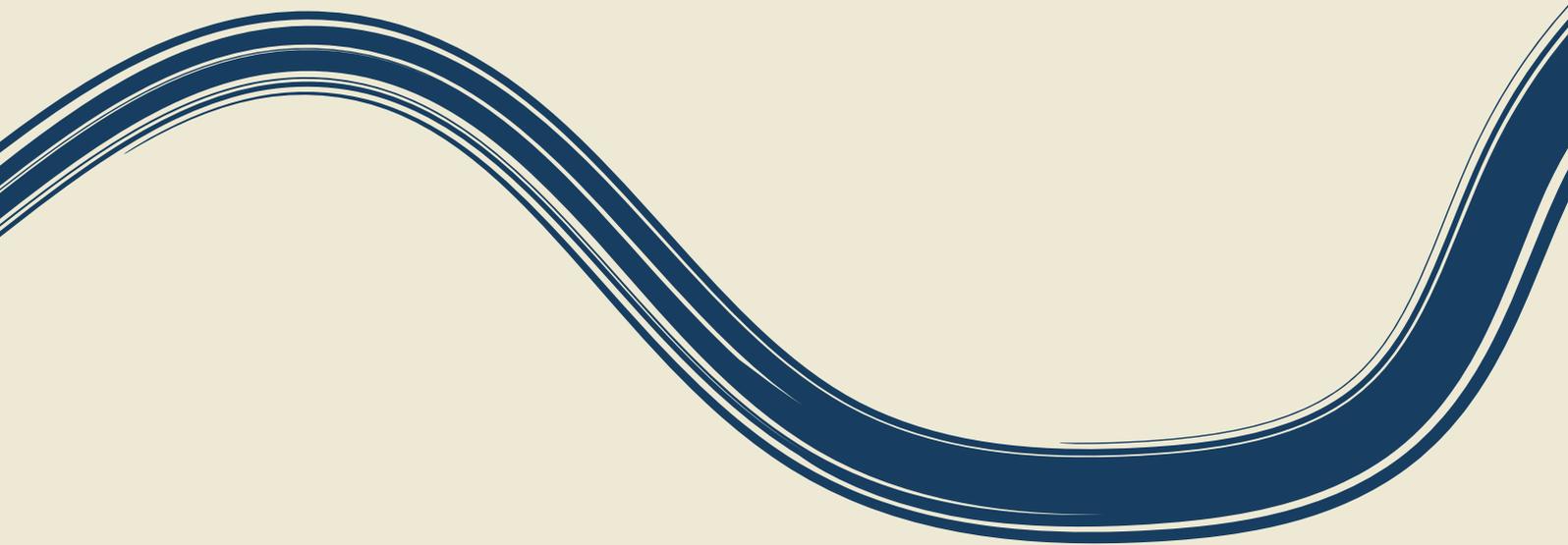
Supported through infrastructure funding from Health and Care Research Wales, DSDC, together with Swansea University, contributes towards the Wales Centre for Ageing and Dementia Research (CADR), which aims to improve the lives of older people living in Wales through the integration of research policy and practice. To learn more about CADR please visit **www.cadr.cymru**.

If you would like to discuss our work to support Healthy Ageing and living with dementia, please contact Dr Catrin Hedd Jones, School of Medical and Health Sciences, Bangor University, Bangor, Gwynedd.

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