

The Bereavement Supporter Project

‘Learn and Share’ workshop

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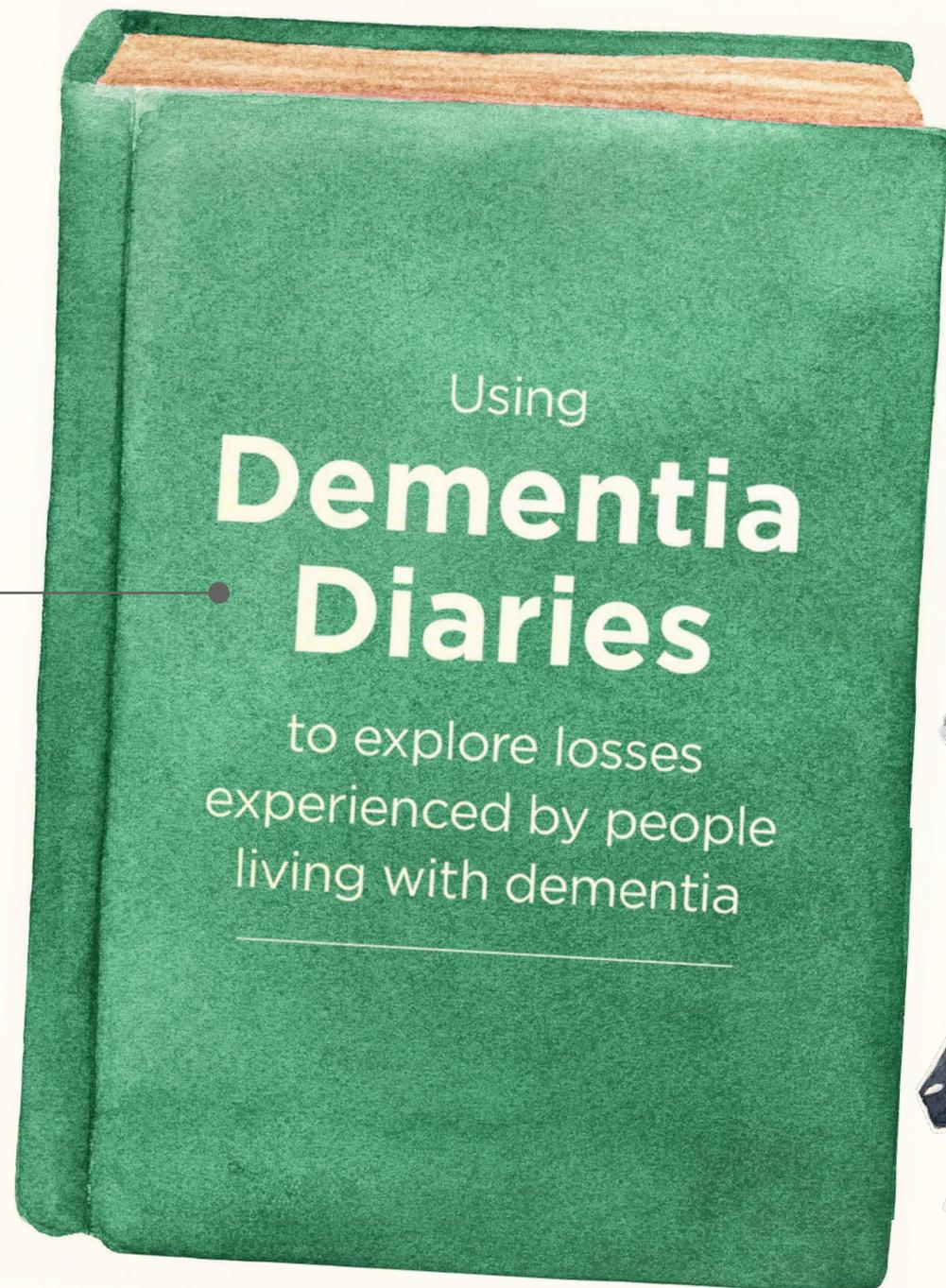
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Illustrations (excluding Diary cover & page) © Jane Hartley



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

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

Component 1 (Universal)

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



Component 2 (Selective/Targeted)

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



Component 3 (Indicated)

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



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

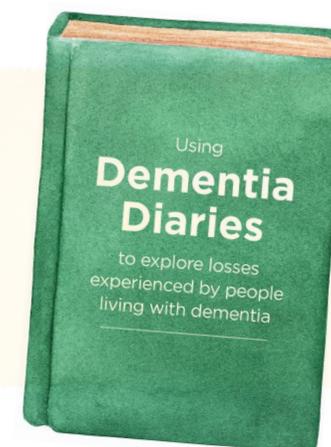
Learn and Share

The Learn and Share sessions and events are an important component of the Bereavement Supporter Project.

They were devised to:

- (1) Share learning and resources between the Bereavement Supporter Project and the Bereaved by Dementia Project www.cruse.org.uk/wales/dementia
- (2) Learn from people with a personal and/or professional experience of loss, bereavement, and dementia.
- (3) Use this learning to develop resources and/or to inform project delivery or evaluation strategies.
- (4) Share this learning with allied professionals, charities, and organisations.

This booklet charts the discussion and learning from the most recent Learn and Share (February 2020) which used Dementia Diaries to explore the losses experienced by people living with dementia.



You can read more about the project here: www.cruse.org.uk/bereavement-supporter-project

Dementia Diaries

Dementia Diaries is a UK-wide project that aims to improve public understanding of what it is like to live with dementia, and how communities and services can best offer support (<https://dementiadiaries.org/>).

Diarists record voicemail messages that capture their in-the-moment thoughts, feelings, challenges, and reflections of living with dementia.

The clips are organised thematically (e.g. diagnosis and dementia, loss, public perceptions etc.), and are freely available via the Dementia Diaries website.



Giving up driving



Music and poetry



Having 'no goodbye'

What we did – February 2020 workshop

In a previous Learn and Share workshop we had identified and discussed losses that might be experienced by people living with dementia and their families as the disease progresses.

The Dementia Diaries clips provided us with a unique opportunity to consider in more depth the losses that people living with dementia identify as important. We listened to all the clips categorised on the Dementia Diaries website under 'loss' and selected five to discuss at the Learn and Share.

We wanted to include clips that were:

- Of a reasonable sound quality.
- Less than 3 minutes in length.
- Sharing different experiences of loss (e.g. death of a parent, loss of employment, grief associated with diagnosis, hope despite loss) from the perspective of different people.

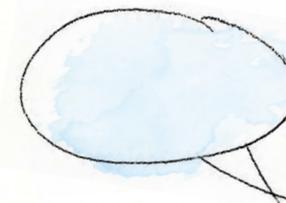
The Learn and Share was attended by 18 people which consisted of:

- Resident Bereavement Supporters;
- ExtraCare staff;
- ExtraCare resident who is caring for a loved one with dementia;
- ExtraCare resident living with dementia;
- Cruse Bereavement Volunteers; and
- The Bereavement Supporter management group (key personnel from Cruse Bereavement Care, ExtraCare, and academics evaluating the project).



We then split into three smaller groups to listen to and discuss the selected clips. Three broad questions had been prepared to facilitate discussion:

- (1) What losses can you identify in the clip?
- (2) What is your response to the clip? (i.e. how do you feel? what does it make you think about?)
- (3) What support might this person (and their family) need?



However, discussion was not limited to these questions – participants were encouraged to guide discussion and to share their own experiences if they felt comfortable. Support was available within every group and after the session for anyone whom painful memories and feelings had surfaced during the discussion. Each group were asked to make notes of their conversations which were then shared during a wider discussion with the whole group.

Presented in this booklet are the most powerful themes identified through group discussion for each of the selected clips, followed by key learning and recommendations that would allow us all to better support people living with dementia and their families through loss and bereavement.

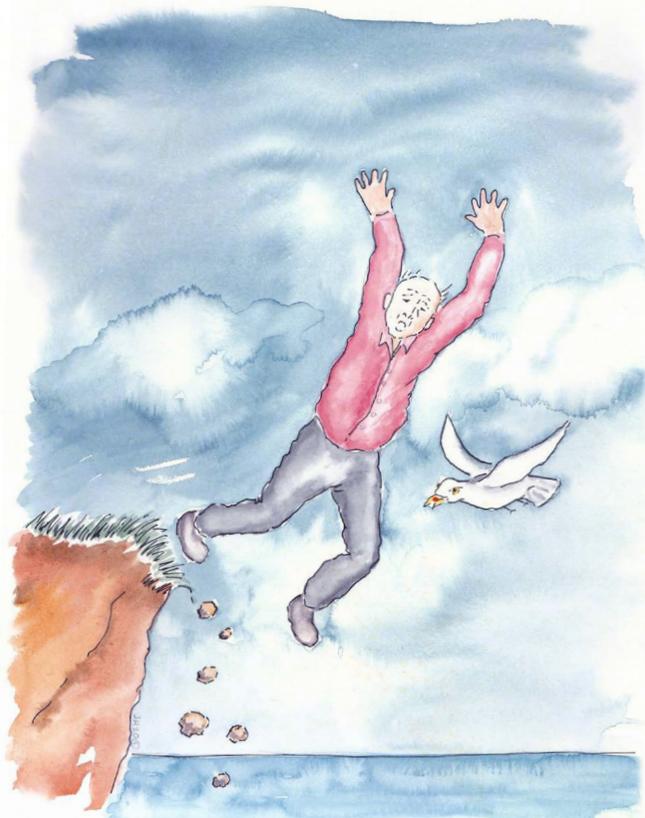
'Falling off a cliff'

'Falling off a cliff' was used in discussions to symbolise the feeling of abandonment that some people experience after receiving a dementia diagnosis.

You enter a void in terms of practical, social, and emotional support but have started the grieving process and are experiencing a range of emotions. While it was acknowledged there were many valuable sources of information and support available, signposting, personal resources, and accessibility vary.

Therefore, the experience of receiving a dementia diagnosis and the support systems that are available can be very different from person to person.

The diarist also reflected that there was an expectation to *"live well"* with dementia, which in some ways had obscured the loss and grief she was feeling as she entered *"the right of passage into dementia"*. She felt like a step had been missed and hoped there would be opportunity in the future to talk through her grief.



'You're just going to be a liability'

This theme centred around feeling hopeless and helpless during a crisis.

It is not stated explicitly, but the group assumed that the diarist's (presumably grown-up) child had been rushed into hospital and they were told to *"stay at home and wait for news"*. She described this was *"the worst thing about dementia"* that she had experienced so far.

Multiple losses were identified during discussion: loss of control, feeling 'out of the loop', loss of an imagined future. But particularly powerful was the sense that this incident marked a shift in the diarist's experience of motherhood. They were no longer able to be there *"to help and support like they'd always done"* and so they felt a loss of purpose or role despite having the capacity to love and care for others.

'No goodbye'

Paid work is the way many of us support ourselves financially, but it can also provide; routine and stability, friendship and support, a sense of purpose and pride, a way to apply valuable skills and expertise (and so on).

Therefore, for many people, work can be an important feature of daily life.

One of the diarists spoke powerfully about how her dementia diagnosis triggered a rapid series of work-related losses.

While she reflected that she was no longer up to working, the suddenness of her resignation, where she received *"no goodbye, no going out, no goodbye cards"*, was a very painful loss and source of grief.



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

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

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

This short clip was very emotional.

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

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



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

www.cruse.org.uk/bereavement-supporter-project/resources

'That's it, I am now a non-driver'

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

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

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



'I'm just missing her a lot'

One of the diary entries was submitted shortly after the first anniversary of the death of the diarist's mother. The group discussed how significant, difficult, and painful the first anniversary of the death of a loved one can be.

The diarist explained that they were "*feeling it a wee bit*" and that their memory had gotten worse, perhaps because of their additional stress. This clip demonstrated that people living with dementia do grieve and that they are able to experience emotions. But it also showed that grief and loss may be complicated by dementia.

For example:

- Memory getting worse because you are feeling stressed and emotional.
- It can be confusing or frightening to feel the emotions of grief without the memory that would explain why you felt that way - you have lost the ability to make sense of your loss.
- Not being able to remember someone/ specific event that is important to you can be painful.



'Where would I be without music and poetry?'

One of the strengths of Dementia Diaries is that diarists are not restricted in terms of what form their entries take - this allows freedom of expression and creativity to shine through.

We selected a diary entry that celebrates the gift of music and poetry which sparked a lot of discussion about the power of music to (re)connect with people living with dementia.

This clip also served as a powerful reminder that creative outlets can be important coping strategies and tools through which we can better communicate with each other and can provide hope.



Learning and Recommendations

- These discussions served as a reminder that people with dementia retain their capacity to experience emotions and be creative, even when the source of the emotion(s) is not known or understood.
- Given that many people with dementia (and their families) experience multiple losses along their dementia journey it is important to recognise and validate feelings of loss and grief, and to signpost to appropriate specialist support services if appropriate. Further information about supporting a person with dementia who is grieving can be found in Cruse's 'Bereavement, Loss and Dementia' booklet www.cruse.org.uk/bereavement-supporter-project/resources
- Improvements need to be made in terms of post-diagnostic support so that people don't feel like they've 'fallen off the edge of a cliff' after diagnosis.
- Employers need greater awareness and understanding of how to appropriately respond if/when an employee develops dementia. This may include advice on what 'reasonable adjustments' to a job role might involve and how this could be implemented, or how to manage the transition to retirement in a way that is respectful.
- Critically, our discussion emphasised the importance of having people with dementia speak for themselves – about their frustrations, joys, and fears – and for us to truly listen and respond to their needs.

Conclusion

The clips that were chosen highlight that people with dementia, and their families, grieve for multiple losses (not only bereavement), and experience a range of emotions associated with each loss.

Listening to Dementia Diaries clips has provided a powerful and moving way to understand these losses further. Everyone grieves differently and it's important that these losses are acknowledged by professionals, organisations and employers, and that a person living with dementia can talk about these losses and be listened to and supported.

Thanks to all those who took part in this Learn and Share workshop, and to all at Dementia Diaries for providing such insightful and powerful diary entries.



Useful Organisations

Age UK

Advice Line: 0800 055 6112
(8am - 7pm every day)
www.ageuk.org.uk

Alzheimer's Society

Support Line: 0333 150 3456 (times variable)
Support Line (Welsh): 03300 947 400
www.alzheimers.org.uk

Carers Trust

Support Line: 0300 772 9600
www.carers.org

Carers UK

Helpline: 0808 808 7777
(9am - 6pm Monday - Friday)
www.carersuk.org

Cruse Bereavement Care

Helpline: 0808 808 1677 (times variable)
www.cruse.org.uk

Dementia UK

Helpline: 0800 888 6678
www.dementiauk.org

NHS Health Education England

Dementia e-learning
www.e-lfh.org.uk/programmes/dementia/

Samaritans

Helpline: 116 123
www.samaritans.org