

Compassionate Communities for Extraordinary Circumstances:

Using diaries to capture bereavement support during the Covid-19 pandemic.

Authors:

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What we did

This project was carried out in partnership with the leading national bereavement charity, Cruse Bereavement Care, and a major provider of extra care housing, The ExtraCare Charitable Trust, together with researchers at the University of Bristol and Aston University.

Between May and September 2020 (during and after the first period of 'lockdown'), 8 bereavement support volunteers kept diaries.

The diarists were either Cruse Bereavement Volunteers (BVs) offering bereavement support to clients across the UK or volunteer Bereavement Supporters (RBSs) offering peer support to fellow residents within their ExtraCare retirement village communities in England.

The project was part of a much bigger five-year (2017-2021) partnership between Cruse and ExtraCare – [The Bereavement Supporter Project](#) - which is funded by the National Lottery Community Fund. It is a pioneering public-health approach to bereavement support for older people that recognises the need to develop the capacities of communities to support friends, neighbours and family members through 'normal' processes of grief.



Why we did it

To help us better understand the impact of the Covid-19 restrictions on ExtraCare residents and Cruse bereavement support services in relation to death, grief and the way a community supports bereaved people at a time when our experience of grief may be different and our normal rituals are affected or unavailable.

We were interested in the ways in which the Covid-19 restrictions affect grief and bereavement support regardless of whether or not Covid-19 was the actual cause of death and to learn about practices that could be helpful after the pandemic.



What we found

Presented in this booklet are the most powerful themes identified across the lockdown diaries, followed by key learning and recommendations to better support people through loss and bereavement during a pandemic; an extraordinary context that has heightened social isolation for many.



Theme 1:

Compassionate listening and peer-support were vital during 'lockdown'.

"We don't have the answers, but we can stand, or sit, alongside others... The fallout [from C-19] is immense throughout the Village and it's good to share that sense of loss of holidays, special birthday celebrations and short breaks. Being able to talk things through and share stories with others has been helpful." (27th August – RBS4)

Bereavement Supporter volunteers have instinctively complemented professional health and social care staff practices, which are primarily task-based in focus, with their (often overlooked) listening support. The primary gift or resource the Bereavement Supporters have been offering in emotionally supporting their community during 2020's pandemic has been listening.

This listening support has been self-organised and demonstrates the value of informal, locally-based, peer support whereby the Bereavement Supporters volunteered to use their skills to serve their community. They proactively communicated with fellow residents and staff and have provided essential continuity of social care at a time when it was not readily available elsewhere.

They achieved this by:

- Adapting their support to telephone and Zoom support and looking out for people known to them in their community. This is an important finding as it demonstrates that residents have adapted to new ways of working – such as switching to Zoom for online group activities – emphasising the often-underestimated adaptability of older people and their preparedness to use available technology.



- Organising 'chains' of telephone calls among residents in their own village derived from compiled lists of residents in order to listen and encourage fellow residents during difficult times, and deliberately taking every opportunity to talk to those they met.

"(We) have set up a kind of neighbourly scheme for ensuring that over 60 people receive at least one phone call each week." (RBS4)

In the process they were informally building support around those in their residential setting who were isolated, lonely, grieving and/or depressed or recognised as struggling through what has been a challenging year.

- Arranging appropriate socially distanced spaces to meet and listen, which included being willing to bring a folding chair outside a neighbour's apartment in the village and offer listening support whilst their neighbour sat at a safe distance in their doorway.
- One diarist went so far as to cook meals for another resident in their community!



Compassionate listening and emotional support were also valued by those in the general population who sought the bereavement support services of Cruse at a time when daily life in lockdown meant other support networks and activities for coping with a bereavement were suspended or not available.

"My clients have all been very grateful that I (we) have taken that time to just listen and be there for them in such uncertain and restricting circumstances." (BV1)



Across the diaries we learnt how active, compassionate listening and peer-support have been necessary and valued resources during the height of the pandemic in Britain, irrespective of whether the bereaved person was living in a retirement community or independently. We also learnt how regardless of where we live and our circumstances, 2020 united us all through the shared experience of multiple losses that were often not related to a bereavement.

Theme 2:

A shared community feeling of grief arising from many losses, that were not bereavement related.

"I wondered what was about to be taken away from us next." (RBS1 – 21st May)

The diarists reported that they had witnessed residents experiencing a great deal of loss and not all of it bereavement related. What links all the residents in the ExtraCare villages is the identity changes they underwent as they moved from their own home, owned or rented, to a residential setting where they did not have complete autonomy and choice in their domestic 'home'.

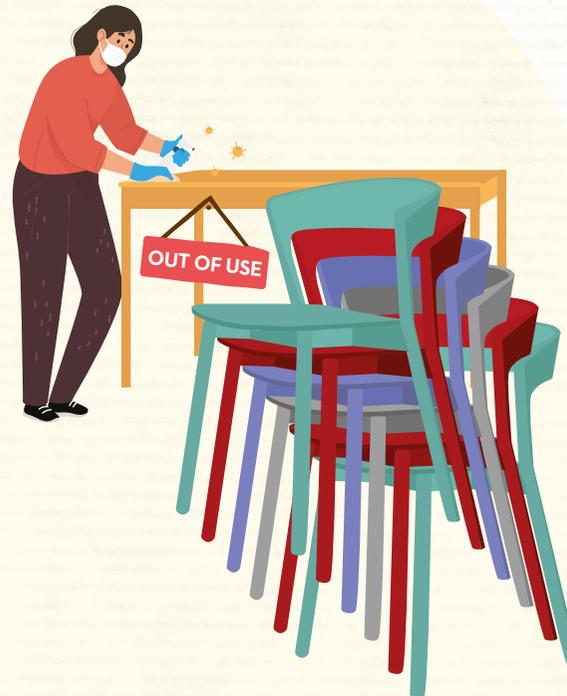
The ExtraCare diarists reflected on how lockdown had triggered, for some, a re-evaluation and sense of uncertainty about their decision to give up the autonomous space of home, and the additional support needs that this had given rise to.

The opportunities for activities, free movement, face-to-face social interaction were eroded or disappeared during 'lockdown' and few were replaced virtually so that the **"virus brought into effect a complete turnaround in many of our aims for living in a community setting."** (RBS4 – 27th August). There was a lot of 'loss talk' in the diaries, both individually and collectively articulated and felt.

"The reality of the virus came home to me as a gathering of restrictions, from 23 March. Every day a notice came on the tablet in the hall, or a letter through the door. No non-residents were allowed in for activities.

Then no one allowed in except delivery people, medical personnel, carers. The hairdresser's salon closed, exercise class instructors were barred, no meetings of Christian Fellowship group or choir. No family visits for Mothering Sunday. All outside exits/entrances locked shut except main entrance, where people had to sign in. No resident allowed to leave the site, not even for short walk to the Park.

Bistro only serving takeaways delivered to our own apartments...One of the bleakest signs of lockdown was the removal or stacking of all seating in the bistro, reception, lounge, even benches out of doors were removed. We were reminded of our own homes being stripped as we left to move to the Village...We had all moved to the Village with a hope, indeed a promise, of activities, social life and new friendships but now we shunned each other if we happened to pass on the stairs or corridors." (RBS1 – 21st May).



The combination of a new virus, Government guidance, and protecting residents and staff - many of whom were potentially vulnerable to the virus - required action contrary to ExtraCare's ethos. New ways of bringing people together and maintaining community had to be found and run parallel to the measures in place to protect everyone. This generated some inspiring scenes, some very visible like the balcony exercise classes or Thursday evening chorus of clapping for carers. Many other subtle forms of support came from one to one calls, doorstep talks or distanced walks for those whom had been brought to breaking point by loneliness. Although the measures were necessary the impact was not ignored, and all of the learning supported decision making as the pandemic progressed, helping to balance safety with the needs of a community.

It wasn't just about the impact of decreasing or losing physical or mental activity, but also the loss of habit of doing the activity itself that was keenly felt and missed. The impact of Covid-19 on residents was a collective feeling of uncertainty and losing confidence. A Bereavement Supporter volunteer noted that there was a lot of grieving going on with residents, but not necessarily about a recent death, rather, over other losses:

"Grieving of not seeing family, not seeing friends. Grieving for the losses that aren't death. All those little things make a lot of difference." (RBS3 – 11th August)



"Moving to our ExtraCare Village brought a massive amount of change to all our residents in the last 3 years.... this has been a shared community feeling of loss for 'what was life before ExtraCare' as no-one here understood us as individuals, knew intimately, were aware of our backgrounds or what our circumstances of living throughout life had been.

This was a challenge to us all to make an effort to work at becoming a new community, making new friends and getting to know each other as we attempted to break new barriers of friendship making... This Virus brought into effect a complete turnaround in many of our aims for living in a community setting. A relatively recent 'new life' still being formed has compounded the loneliness for us and many have tried to develop other ways of engaging and holding together the very tenuous ties which were beginning to develop pre Covid...

The reasons that many of us chose to come to the Village were suddenly negated and taken from us. Everything seems to have been put on hold... or 'a big STOP sign' introduced into our lives."
(27th August – RBS4)

What was apparent from the diaries was how residents and Bereavement Supporter volunteers in retirement communities used their resilience, derived from diverse and extensive life experiences, in order to face the physical, social and emotional implications of these losses:

"Most of our residents delved deep inside of themselves and found the resources they needed to get through by using the strengths they have learnt through the past experiences of life."
(27th August – RBS4)

Theme 3:

Acknowledging and communicating a death in residential communities remains challenging, especially during 'lockdown'.

"I don't think this village, residents or staff, have worked out how to deal with deaths. A few families have held wakes in the village hall, and sometimes the flowers from the coffin have been given and laid on a table by the front door, once or twice a notice has been put up at reception with a photo and date of funeral, but this has not happened for many months. I get the feeling that death is not a nice subject and should not be mentioned in a place where so many old people are living, or funeral flowers might put off people who are thinking of moving here." (RBS1)

Finding appropriate ways of acknowledging and communicating the death of other residents is a persistent challenge in ExtraCare villages, but this has been compounded by Covid-19 where the usual word of mouth channels for communicating the death of residents are unavailable. Covid-19 and 'lockdown' made it harder to identify when people were in need of bereavement support because there is no longer any one around to pick up information or receive referrals from staff. In an attempt to try to address this, some diarists focused on checking in with people they already knew. However, much more needs to be done to better serve a community of bereaved people in residential settings in the event of a future lockdown.

What did emerge and surprised us, was the role that balconies can play in bringing together a community of mourners and supporting individual and collective grief at a time when usual social customs and cultural rituals that support bereaved people are no longer available or possible.¹

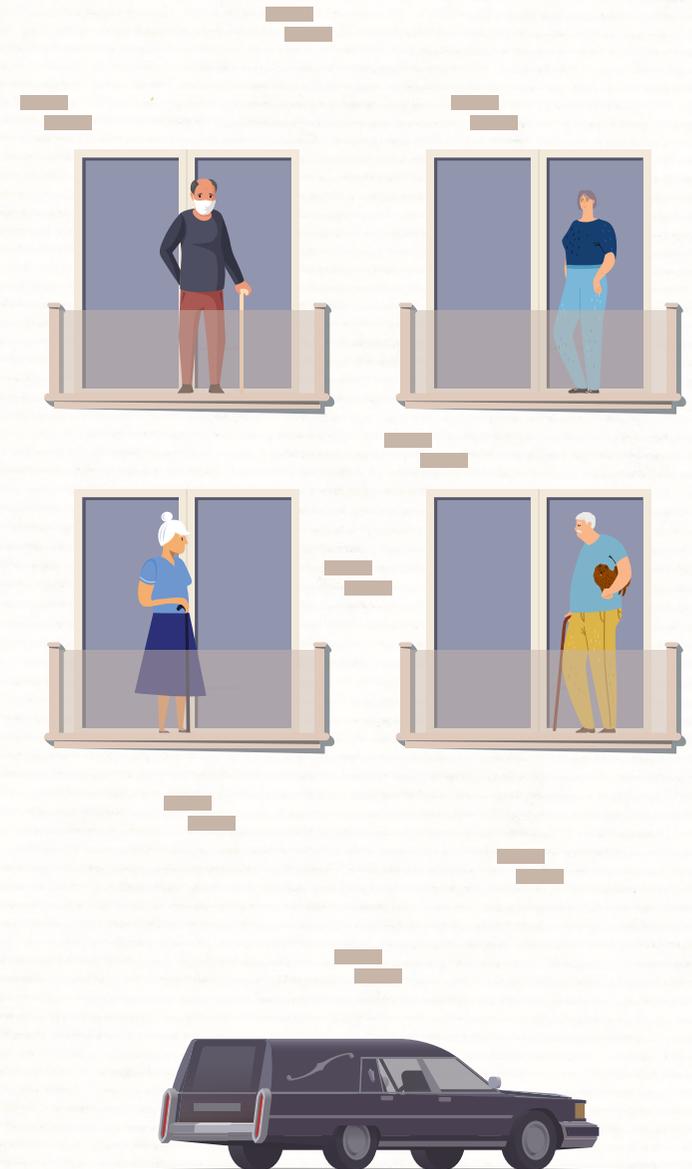
"We said farewell to one of our residents yesterday... many of us from our balconies as the hearse moved off to the very small, family funeral." (RBS4 - 7th May)

Bereavement Supporter volunteers noted that when there was not an opportunity for collectively grieving and acknowledging someone's death, then the grieving process was arrested:

"Some of us haven't started grieving because we haven't come together yet... that conversation is still on hold." (RBS3)

In response ExtraCare staff, supported by Cruse, actively participated in the Dying Matters initiative #IRemember week held between 26th October and 1st November. This gave many residents a chance to have a recent or historic loss recognised at a time when it was not possible to collectively grieve.

Over 400 residents took part in activities such as memory trees, minutes silence, photo walls and socially distanced remembrance services.



¹See 'Balconies and Community Space in Extra Care Housing: Covid-19 and creating HAPPI outdoor space' on the Housing LIN blog (28/07/20) - www.housinglin.org.uk/blogs/Balconies-and-Community-Space-in-Extra-Care-Housing-Covid-19-and-creating-HAPPI-outdoor-space/

The initiative highlighted the long-term emotional importance of such an acknowledgement; a function usually fulfilled by funerals and other traditional rituals following a bereavement.

And Bereavement Supporters took it upon themselves to organise opportunities for staff and other residents to grieve together when attending funerals was not possible:

"We had a funeral on Wednesday. Well, the thing about it, that girl she lost not only her mum, she lost her father and she lost her grandfather. So what Mavis and Heather did was they printed out some songs ... The staff came out to stand outside and by word of mouth I told some of the residents, ringing round saying to quite a few people that if they wanted to go down or stand on their balconies.

They had a prayer and some songs and they talked about her for about 15 minutes and then the hearse came round and stopped a bit. It was very moving, very, very moving and personal." (22nd May, RBS3)



Theme 4:

Grief and bereavement during 'lockdown' and a pandemic; a complex and very mixed experience.

"Some have benefitted from the time and lack of pressure during the lockdown... Some of my clients have been relieved of pressures from family traditions which they sometimes find overwhelming...Another client has been, very much, missing the reassurance of friends and family ..." (early August – BV2)

Again, another surprising finding from the diaries emerged from those written by Cruse BVs who noted that while some clients had keenly felt the loss of restoration activities, some were finding bereavement somewhat easier to manage during the pandemic because they felt liberated from the social pressure to appear 'normal' and OK.

During lockdown some bereaved people reported that their grief was easier to bear because nobody was enjoying life, at least not visibly/openly and this made anniversaries and special occasions easier to cope with.



"Father's Day this week and a client grieving for her father is finding it very tough and painful. She is thankful however that pubs and restaurants are still closed because she feels angry and resentful when she sees other fathers out there enjoying family time when she has not got her father there to celebrate with.

Therefore, on Sunday when we are still not allowed out she is protected from that source of pain...In many ways she is finding the lockdown helps her because its giving her an opportunity to withdraw without trying to find excuses.

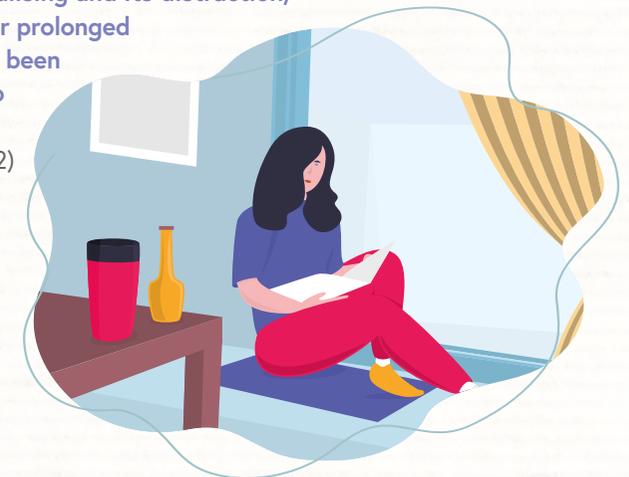
Her best friend certainly does not get it and wants to change the subject when she talks about her dad. Withdrawing and being sad is just where she wants to be and she can do this without feeling guilty about being a "party pooper." (22nd June – BV2)



Lockdown has provided some of my clients a space to privately grieve without the pressure of social norms.

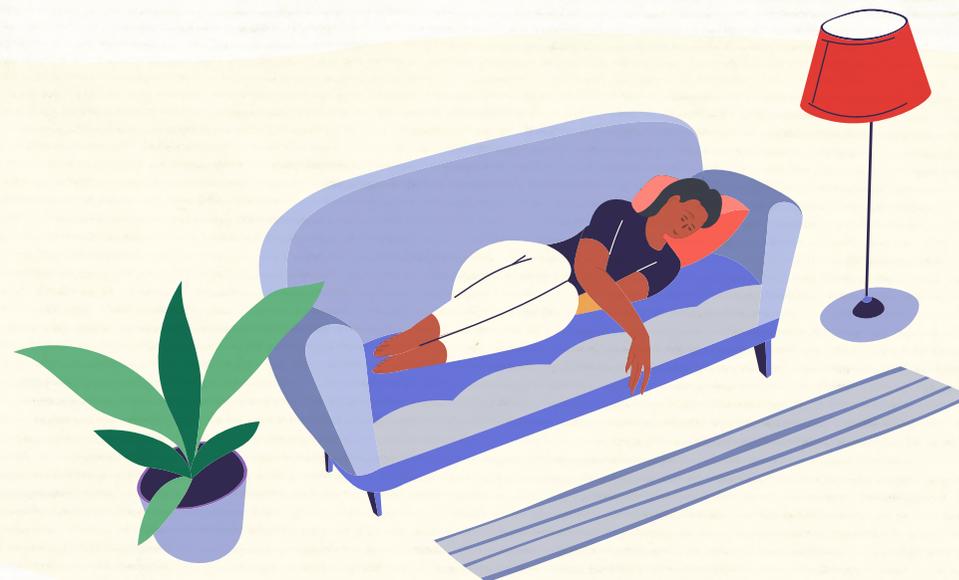
Being able to withdraw and feel sad is good and many seem to have said it's been a benefit but so is socialising and its distraction, the jump after prolonged lockdown has been a challenge to explore."

(July 6th – BV2)



However, not all bereaved people that the Cruse BVs were remotely supporting found bereavement during lockdown easier.

"My client...is finding the lack of community activity very challenging. It is also difficult for signposting because so many groups are not meeting and she does not have access to a computer. She lives alone in a house and has unhelpful neighbours. She would like to live in a more caring community. Her life before her mother died was all consuming with her mother's health her main occupation and her only source of social interaction was by being part of that caring team of people involved. Covid-19 has really reduced any of those restoration after loss activities for her." (13th July - BV2)



Yet, it is not only the loss of restoration activities during lockdown that made bereavement challenging; loss of support networks, activities and social isolation compounded some clients' grief and a feeling of being overwhelmed or unable to cope.

"Learning to live alone in lockdown was a huge chaotic struggle for her. Becoming aware of the neglected house and garden, as all her time and energy had been attending to her husband's dementia needs.

This new acceptance and reality seemed to be 'on pause' and her chaos was really overwhelming because she wanted and needed all sorts of people in her life; family, friends, solicitors, church members, plumbers etc. the pandemic and lockdown took away so much of her support and left her in a much more vulnerable and frightening place than it should have been."

(early August – BV2)



Whilst the absence of usual social, care and support networks has made bereavement even harder for some, and the restrictions on funerals meaning bereaved people could not come together necessarily at a funeral, there have been some alternative displays of support and acknowledgement that have proved to be valued by bereaved people.

"From a number of clients there has been a sense of community though.

Whilst social distancing has prevented 'wakes' some clients have left the home onto the chapel and found their neighbouring street to be lined with people.

Often the clients speak of this being overwhelming and they will remember these scenes forever.

They have found a sense of community that they didn't know exists and have been surprised by the acknowledgement and support of those neighbours; their level of help and support and the level of compassion."

(BV3 – 25th June)



Theme 5:

Bereaved people and Cruse Bereavement Volunteers have adjusted to telephone-based support and learnt new ways of working to support the community.

"Using the phone has been a simple transition for me. My clients have all been very grateful that I (we) have taken that time to just listen and be there for them in such uncertain and restricting circumstances." (BV1)

Diarists reported that they were adjusting to telephone-based support and learning new ways of working:

"I am learning to work with clients who are slower in their process during the session and to measure, pace and weigh the silences." (BV2)

Diarists also saw distinct advantages in adopting telephone support as a regular feature of Cruse volunteer-based bereavement support:

"Some of my telephone sessions, with disabled or unwell clients, would never have taken place in our rooms." (BV2)

Another diarist was surprised and heartened at the bond that she was able to establish with a client through telephone support: "I had one gentleman whose regret was that he hadn't met me. He's invited me to a music event that will go ahead when restrictions ease. It will be in honour of his beloved father. I was flattered." (2nd August – BV1)

Diarists commented on the volunteering opportunities that telephone-based support might afford volunteers with a disability given they could now offer support remotely and therefore mobility is no longer a barrier for skilled volunteers. However, with regards to referred clients, the BVs recorded an increase in mental health needs arising from the impact of lockdown and social distancing measures:

"During this time of lockdown I am taking on seven client appointments per week and ... there are a larger proportion of clients with mental health challenges which isolation has exacerbated. I have two clients with OCD who find cleanliness and infection all consuming."

(15th June – BV2)



Learning and Recommendations

1. In the absence of being able to gather a community of bereaved people together at the time of a funeral (i.e. no face-to-face contact with family members and enforced limited or non attendance at funerals), our diarists suggest that having a hearse drive through the community *en route* to a chapel or crematorium had been extremely comforting.

It served to acknowledge their bereavement and gave anyone who wanted to, an opportunity to show their last respects and stand in mutual support. In ExtraCare community settings, the balconies of individual apartments that overlook the main entrance or driveway have proved to be invaluable for such public displays of support and condolence.

A gathered community, be they standing in their residential doorways or balconies, can also sing together, pray, make speeches and pay tribute in whatever form is appropriate and meaningful to them.



2. Due to the increased intensity of the client/supporter relationship arising from the pandemic and associated social distancing regulations, bereaved clients have fewer sources of bereavement support between sessions and fewer distractions from bereavement.

Meanwhile, bereavement supporters also have fewer outlets to distract them from what are intense encounters. Therefore, extra support needs to be given to those who are supporting bereaved people under such intense circumstances. This should include strategies for maintaining boundaries and timekeeping when delivering telephone or video call support, as well as usual distraction activities following the delivery of a support call.



3. The importance and value of listening in a non-judgmental manner, and how this benefits a bereaved person, cannot be overstated.

4. Bereavement support should remain open to listening and responding to all losses; not to narrowly focus on issues arising from death related loss.

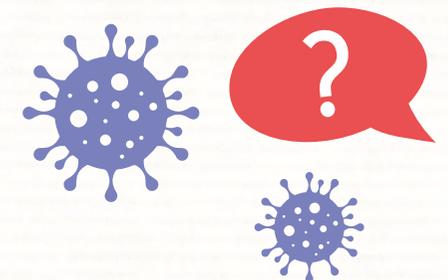
5. It is important to give people the space and time to grieve and that in 'normal times' people feel too much pressure to return to cheerfulness and fulfilling social and family obligations.



6. Nobody denies the importance of face to face support, but we can adapt to new ways of offering meaningful support - even people in advanced age and living in ExtraCare can adapt. New remote ways of communicating can make support more widely available and enable a wider variety of people to play supportive roles.



7. Whilst 2020's pandemic has been hugely challenging it is also an opportunity to engage more readily with questions, concerns and issues of death and dying across all populations, irrespective of age, gender, ethnicity, social class, belief and identity.



Conclusion

In conclusion we would like to briefly comment on using diaries – be they written, typed or voice-recorded accounts (we used all three approaches) – as a method for capturing people's lived, subjective experience and thoughts and feelings during the pandemic. Using 'lockdown' diaries to capture bereavement support certainly gave us a snapshot and insight into people's daily lives during these extraordinary circumstances. The diaries distinctively captured a tiny part of history in the making. But admittedly, there were some limitations as keeping diaries relies on people's willingness to participate.

However, this has always been an issue for any research that requires voluntary participation. We were flexible and allowed our diarists to keep written, typed or voice-recorded diaries, depending on what mode of technology they had access to and were comfortable with. Likewise, we were not overly directive about what was recorded during lockdown, which meant diarists did not always reflect on issues and activities that were primarily of interest to the research team.

Despite the limitations, we think that diaries give us deeper and more subtle reflections and insights into how people support each other through bereavement than we have been able to capture through other methods, for example through surveys and forms.

By being flexible and allowing the diarists to take ownership of what they wanted to record during these extraordinary times, we received wonderfully descriptive, evocative portraits of people's working, psychosocial and daily private lives that contribute to a fascinating historical record.



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Links to further organisations and support – can be found on the Cruse website www.cruse.org.uk/get-help/useful-links

¹ Ethical approval of the project was granted by the Research Ethics Committee of the School for Policy Studies at the University of Bristol. Any queries on ethics or research design can be directed to Karen West, project lead (karen.west@bristol.ac.uk)



DIARY 2020