This book is dedicated to two of my dearest friends, Rachel Fenn and Dr Martin Newbury both of whom lost their fathers during 2020, and who have both been in my thoughts even though they have not been in my presence as much as I would have liked.

Sharon Mallon

This book is dedicated to my neighbour, Rita. If you could ask her, she’d tell you I often work too hard (in her opinion) and should be able to visit her more often, disregarding COVID restrictions. She died in September 2020 and is fondly remembered by my family and me.

Erica Borgstrom
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It might seem paradoxical that Europe’s largest university also identifies itself as #OUFamily. At The Open University, we all share a common purpose to bring positive change into the world and into our students’ lives, but we also share in each other’s lives — in good times and bad times. This remarkable collection of short essays, which captures a moment in the Covid pandemic in intimate and profound terms, is an example of that sharing that is as moving as it is insightful.

Inspired by an earlier initiative by colleagues in their Faculty that was modelled on the fourteenth century Italian example of the Decameron, a book of tales exchanged between a group of men and women sheltering from the Black Death, Erica Borgstrom and Sharon Mallon of the University’s School of Health, Wellbeing and Social Care invited our staff and students to tell their stories of Covid-19. They have created a deeply human book about impossible choices, death and dying, regret and grief.

Some of the authors comment on how writing about their experiences, in often very personal and candid ways, was itself cathartic. I think many will also find that true of reading the
stories, whether reflecting on loss that is recent or long passed but still present. Some of the accounts tell of self-discovery as well as pain, and all of them remind us that death and bereavement are universal experiences but felt in many different ways, depending on our own biographies and circumstances.

In reading them, while there are experiences of Covid that I would prefer never to have had, I could not help but think back to many years ago now when my father died. I was in my second year as an undergraduate and received the news only a day after I had made the four-hour return trip to university after seeing him in hospital, apparently recovering from a heart attack. I look back now thinking I should have known he might die and should have stayed on. I remember the desolation I felt sitting in my college room having received the news and preparing for another trip home. As Erica and Sharon remark in the Introduction, there can be a lot more to grief than just the human loss.

What comes through in many of these essays is how feelings of grief can be so complicated by the circumstances, and how terrible Covid made those circumstances. Proper goodbyes have been denied on a scale never experienced since the second world war. Yet there is much that is positive amid this awfulness, from seeing the instinctive care about others that children have, to the replayed memories of times with parents that have also been part of making us who we are, long after their passing.

There is also much in the book to reflect upon regarding the wider circumstances of the pandemic. Many of us fortunate enough to have workspace and no children to home school initially thought how much better working from home is compared to regular commuting and site working, only later to feel our very nature as humans start to be undermined by not being around others. This disruption of connectedness and
relatedness has been far-reaching, but it has also brought new learning about ourselves.

There are deep insights in these essays into the lives of staff and students at the OU during this terrible period, but also very humanising glimpses into who they are: the qualified nurse who went back to the frontline, not having worked clinically for twenty years, the nurse consultant who recalls watching a hospital cleaner and thinking he used to do that job, or the long-lost postcard from a deceased father which reminds his daughter that hard times will pass.

As the Vice-Chancellor of our wonderful university, these are humbling stories to read. They are #OUFamily stories but, true to our open mission, are being made available to the world in this book. In doing so, they are also true to the motto on the University’s crest, ‘Learn and Live’.

Tim Blackman

Vice-Chancellor of The Open University
A book like this is unable to come into being by itself. From forming as an initial idea to being in your hands right now, there have been many people – named and unnamed – who have influenced the words on these pages. From the authors who contributed their words to those who edited and proof read the book, to those who physically make and ship it (or wrote the code so that you can read the electronic version). As academics, we are familiar with our traditional ways of publishing books and journal articles; this edited collection enabled us to be more experimental with styles, intents, and processes. Not only are we grateful for those listed below for making the book possible, but also for their encouragement and support for this creative community endeavour.

Firstly, we’d like to thank all of the authors who submitted their writing in response to our calls for contributions. For some, this was the first time writing with the intent to publish, for others it was the first time after a significant break or the first time writing about something personal. We do not underestimate the courage it can take to take this step, sending in one’s story and being open to selection and scrutiny. As
Preface

editors, we’ve been blown away by the sincerity of the accounts and how collaborative the authors have been in making changes to even the most intimate of details. We have shed more than a few tears upon reading these accounts. We are also grateful for all of the people who considered contributing but for whatever reason, did not in the end – we hope that even engaging with the idea of the project has been fruitful, knowing others are interested in one’s ideas and experiences. We acknowledge that for many the journey and experiences of loss associated with COVID-19 are too recent and too painful to reflect upon.

As part of the editorial process, we enlisted volunteers to help us long-list the initial submissions and to provide guidance on editorial issues. Largely, this group of volunteers came from Open Thanatology – the group for death-related research and education at The Open University (OU) – which has been most supportive of the project across the project’s lifespan. We’d like to thank (in no particular order): Joanne Jordan, Sara MacKian, Jackie King-Own, Becky Garcia, Korina, Laura Paterson, Kerry Jones, Claire Harris, Sam Murphy, Jane McCartney, Cass Humphries-Massey, and Marc Cornock.

We’d also like to acknowledge that the idea for the book was inspired by the work completed by our colleagues in the School of Languages and Applied Linguistics in 2020 which Sharon spotted in an internal newsletter. Using internal funding, Anna Comas-Quinn, María Fernández-Toro, Caroline Tagg, Lina Adinolfi and Emilia Wilton-Godberfforde solicited contributions from OU students imitating the Decameron. We are thankful that they’ve kindly given us many hours to learn from their project, from managing the process, to learning to enjoy the journey that editing such a book takes you on. We are also grateful for the colleagues who write these newsletters and have subsequently helped us to promote our own call for contributions, both within the Faculty and beyond, helping us
to navigate various university communication channels and encouraging others to share it on social media.

Like the *A Multilingual Decameron: Stories of a different world* project, the creation of this edited collection has been internally funded by The Open University, specifically financed by our Faculty’s Research Development fund. We were delighted and daunted (perhaps in equal measures) when we heard our bid had been successful, and are grateful that our colleague Dr Liz Tilley, who is instrumental within our school for managing research funding, could see our vision for the book in the short pitch we provided. There is also something very gratifying in knowing that this book is made up entirely of authors who are connected to The Open University and has also been produced with the financial backing of the university; it is thus both a symbolic and practical fostering of the OU Family that goes beyond our usual ways of working.

Making our vision into a reality required the expertise of Michelle Lawson. From front cover to fonts, she’s been invaluable in helping us realise our self-publishing dreams. Michelle is also an associate lecturer with The Open University, as well as having published her own work, including her PhD study of British migrants in the French Pyrenees. Michelle came to us by recommendation and we would also, in turn, recommend her to others embarking upon similar projects.

I (Erica) would like to thank Sharon for being a super collaborative co-editor. As editing goes, this has been a surprisingly smooth process as we fit this project around and within lockdown lives and intense workloads. The flexibility of self-publishing has also meant we’ve had to make many more decisions as we’ve not had the confines of a publisher to wrestle with and guide us. Being able to discuss these with Sharon and Michelle has kept the process exciting. Moreover, it has been incredibly useful that Sharon and I have been able to share the load of reading and processing the different pieces within the
collection. At times, reading them has been emotionally wrenching and draining; it was beneficial to have a colleague like Sharon who could understand that. I’d also like to thank my partner, Lukas, for bringing me cups of tea as I read and edited the collection and encouraged me to get out in the sunshine to help me process the vicarious grief.

Lastly, we want to thank you – the reader – for taking the time to engage with the narratives, reflections, and information within this collection. We don’t know why you’ve decided to pick up this book, but we hope that you connect with it. Perhaps you’ll see your own experiences of loss and grief reflected in the words and know you are not alone or perhaps you’ll be inspired by someone else’s narrative to think about your own loss in a different way or reach out to someone to share your experiences with them. Or, perhaps, you’ll even write your own story.
INTRODUCTION
DEATH, DYING, LOSS AND GRIEF DURING THE FIRST YEAR OF THE COVID-19 PANDEMIC
ERICA BORGSTROM AND SHARON MALLON

When we began creating this edited collection in the early months of 2021, the first-year anniversary of the COVID-19 pandemic was looming. As social science academics, who pre-pandemic were already interested in social understandings and experiences of dying, death, grief and loss, the pandemic had heightened our experiences of many of the issues we were already familiar with from our research. As a result, we had spent those early months of the pandemic reflecting both personally and professionally on these issues and how we might contribute to our longer-term understanding of them. We also saw that although death was highly visible in public discourse, individual accounts were also strangely absent, hidden, or sensationalised. Our personal experiences of COVID-19-related death came, thankfully tangentially, through deaths of friends and loved ones to COVID-19 or through the death of distant family members. Nevertheless, this compounded the chasm we felt was being created between those caught up in the reality of death during the pandemic and those of us who were left relatively untouched by these losses. At the same time, we were all experiencing losses of some kind; locked down in
our homes, for the time restricted by laws and moral duty from visiting friends and family, or even going to non-essential shops, much less visiting restaurants or cafés for social interaction even with strangers. These collective experiences and our desire to document them has led to this collection of narratives.

Some thoughts about the pandemic: death, dying, loss and grief

At the time of writing, it has been just over a year since the COVID-19 pandemic began in earnest across the globe. To date, according to World Health Organization statistics, it has caused or contributed to the death of over 3.4 million people (World Health Organization, 2021). The way people died during the pandemic often confronted societal norms and expectations about what, under typical circumstances, has come to be described as, a ‘good death’ (Borgstrom, 2020). Experiences varied, from death seeming sudden or unexpected, to deaths that were expected but took days to take place, with loved ones not being able to be at the bedside as people died. Media reports frequently highlighted the injustice of these deaths, especially as it became apparent that social inequalities – such as poverty and racial disparities – were connected with those who died from the virus or had more excess death during the pandemic (e.g. Anyane-Yeboa, Sato and Sakuraba, 2020; Bach-Mortensen and Degli Esposti, 2021). There have also been considerable debates about what ‘counts’ as a ‘COVID-death’ (either from or with the virus) and the resulting difficulties of accurately measuring the impact of the pandemic on mortality rates (Kiang et al., 2020).

Whilst on one hand, this may seem like a rather academic discussion about statistics, it is also important to realise that each number is an individual person who lived and was
Introduction

connected to family and community. It is important to remember that each death often impacts more than just that one person, sometimes having intergenerational impacts, and the effects of the loss can ripple out across the wider community affecting neighbours, work colleagues, and even acquaintances. It has been estimated that for every death, up to nine people are affected by a bereavement (Verdery et al., 2020). In many countries, during the pandemic, public health measures that restricted visits and access to medical and community spaces meant that, at various times, visiting those who were dying and/or usual funerary practices were restricted. In extreme examples, this has led to mass burials (BBC, 2020).

In other more common cases, significant restrictions have been placed by governments on gatherings and these have curtailed funeral and cremation services. Examples of these restrictions include reduced flexibility on deciding on the place and time of interment, as well as strict limits on the number of people allowed, so that only ‘close family members’ were allowed to attend. In addition, funeral attendees were required to observe strict physical distancing, thus preventing physical expressions of emotional support between mourners who, under usual circumstances would have likely hugged or physically held each other to provide support. Estimates from the UK suggest that up to 243,000 funerals were affected by these restrictions, with 9.7 million mourners being prevented from attending cremations and burials (Co-op Funeralcare, 2020).

The funerals of those who died during the COVID-19 crisis thus became reduced both in terms of the number of people who attended and in terms of the usual rituals that were practised. As a result, they were arguably more perfunctory experiences for those who were able to attend. During this time, the notion of a ‘Zoom Funeral’ and explorations of how death rituals moved online became part of the common social discourse (BBC World Service, 2020), with access to many
services also being provided online as a way for those who were physically unable to attend any ceremonies to participate. For others, there were hopes that the memorials that would be more befitting of the passing of their loved one, were only ‘delayed’ until restrictions were lifted.

The unusual circumstances under which these deaths took place and the restrictive nature of their associated funerals, means there is a great deal of uncertainty about the long-term social and psychological impact of these deaths on the bereaved. In one study, the majority of the UK adults surveyed felt that lockdown negatively affected their grief as well as a similar percentage noting that nothing has helped them grieve during the early periods of the pandemic when the survey was conducted (Co-op Funeralcare, 2020). Meanwhile, some have suggested that there could be a rise in complicated grief (Eisma, Boelen and Lenferink, 2020; Gesi et al., 2020) and long-standing trauma (Masiero et al., 2020). Others have been researching the variety of rituals that have been adapted during the pandemic to understand if, and how, they have benefited people and what they may say about cultural approaches to remembrance and mourning (e.g. Wagner et al., 2020; BRIC-19, 2021).

Throughout the pandemic, we have all witnessed how things have fundamentally changed – at some level, COVID-19 happened to each and every one of us. However, it has also become clear that these changes have not been the same for everyone, nor have they affected everyone in the same way. Some of this variation between our experiences has resulted from our personal circumstances. Those who live alone will have faced different challenges to those who have been surrounded by family members. Those who have been furloughed will have experienced different stresses to those who have been working from home or on ‘the frontline’ in care and supermarkets. Each of these experiences will again be distin-
guished by whether or not there were children who needed to be home schooled or other caring responsibilities to be fulfilled. There has also been much talk about the emergence of a ‘new normal’ (Berwick, 2020; Zinn, 2020), but also a realisation that we cannot simply return to the way things were; some of us have sustained permanent personal losses, others are continuing to struggle with the impact of the symptoms of long COVID and we have all been altered on some level by our experiences of 2020. The widespread nature of these deaths also means that, at some level, our ontological security — that is our sense of a stable mental state that can be linked to sense of continuity we have in relation to our lives (Seale, 1998) — is likely to have been affected at a deep and existential level.

In summary, the phenomenal structural, physical, professional, and personal changes caused by COVID-19 have had a yet untold consequence on us all. Yet, this is a good time to reflect and document where we are right now in terms of loss, death and bereavement. Doing so will allow us to reflect in times to come on our resilience and our emergence from what has undoubtedly been a transformative experience.

The making of the collection: editors’ reflections

In 2020, our colleagues in the School of Languages and Applied Linguistics self-published A Multilingual Decameron: Stories of a different world. In it, they mimicked The Decameron, a 14th-century book of short stories from a variety of experiences written during the Black Death, having solicited students’ written accounts in a variety of languages that reflected on the early weeks and months of the pandemic. Inspired by their work, we discussed how Open Thanatology (the research group at The Open University that focuses on death, dying and grief across the life course) could do something similar to capture experiences of loss, death and bereavement during the
first year of the pandemic. We reached out to our colleagues to discuss ideas, learn about processes, and finally bid for research funding within our Faculty to support the creation of this edited collection.

As we discussed our ideas, there were many decisions we had to make. Who do we want the contributors to be? How will we gather stories and reports, acknowledging the ongoing nature of the pandemic and that people are living with grief? What do we mean by ‘loss’ – is it limited only to when a person dies? Our answers to these questions at times developed organically, but they were also shaped by the demands of time-limited funding and our desire to capture this moment in time, as the narratives were at their most vivid in the minds of the contributors and before they got shaped by the passing of time and multiple retrospective interpretations.

One of the decisions we made was to call for contributions from the OU Family – students, staff and alumni. For those unfamiliar with The Open University, it was founded in 1969, predominately providing distance education, and is one of the largest universities within Europe. It has over 175,000 students, over 2 million alumni, and nearly 10,000 staff in a variety of roles. Although the majority of the students and staff are based within the United Kingdom – where The Open University has a four-nation model with offices in England, Scotland, Wales and Northern Ireland – the university has a global reach. We were conscious that this group, of which we are part, is massive and could provide us within many, varied contributions.

We were also keen to focus on the OU Family for another reason. Although the OU Family is familiar with connecting over great distances and online, we were aware that given the pandemic, many people were feeling socially isolated, even during their studies or while they were ‘at work’, and that nationally, there were concerns that many people were left to grieve alone (Selman, 2020). Moreover, people can be reluctant
to share ‘personal’ experiences in professional spaces, which can increase a sense of isolation or disconnect. In one way, focusing only on the OU Family enabled us to create a space in which people’s own experiences could be shared, recognised, and collectively acknowledged. Editing this book, therefore, was not just an academic practice, of curating a collection of accounts, but also generated capacity and spaces within the university for community during the pandemic.

Consequently, by February 2021, we had put out a call for contributions from within the OU Family asking them to share their narratives, reflections, and research related to the themes of the book. We were unsure how many submissions we would receive and recruited colleagues from within Open Thanatology to help long-list and sort submissions. And, as always when asking for voluntary contributions, there was the risk that we would receive nothing or very little. Luckily, our Faculty communications team and colleagues helped spread the word and we received short essays, poems, and narratives from a range of people, from first-year students and postgraduates, to staff from both academic and support backgrounds. To help readers understand the context of each essay or contribution, we asked authors to provide a short biography of themselves. You’ll find these at the end of each contribution. We worked with authors to develop their pieces, mainly to aid clarity for the reader rather than to change the style of their writing – we wanted to enable the authors to share their voice and story in the way that felt best for them.

After the first round of submissions, we assessed what topics were being covered and where the potential ‘gaps’ were. Part of this gap analysis was about looking at the themes that were present in the accounts as well as the variety of experiences being shared. We found that many people who wrote, had stories to tell about care homes – not being able to visit loved-ones in care homes and deaths. Where possible, we
approached people directly about writing a piece, or reached out to them via our networks within the OU. We also found that colleagues were working on COVID-related projects that we could also incorporate into the collection and we sought to include these where possible. Again, we worked with authors to help them showcase their accounts, and to add to the diversity of the voices in the collection.

A collection, however, can never be fully complete. As curators and editors of this collection, we are also aware that there will be ‘missing’ voices in this collection. These can be the people who didn’t manage to see the call for contributions in time, those who were unable to meet the writing deadlines, those who may have lacked the confidence to submit an item, and those who drafted items but never decided to submit them. We were aware that the short timelines for the project meant that many people who were interested in writing something for us were unable to; where possible, we provided extensions. We also know that some colleagues were unsure if their experiences would be ‘worthy of publishing’ – when we were able to have conversions with people, we encouraged them to write, stating that every story is worth being told. If we did this project again, we would want to enable more time for writing and this kind of encouragement.

One thing we found as we received and accepted submissions was how relieved people were that they had written. We had several emails about how therapeutic people had found the process of writing. Although some authors were surprised by this, we were less so as it is well documented that writing can help people process events and emotions (Zimmerman, 2010; Matthews, 2019); it is one of the reasons we wanted to do a writing-based project. We also heard from people who decided not to submit their writing but had found the process of engaging with the call for contributions beneficial, personally and socially, and how it had enabled them to recognise what
they had ‘gone through’ during the past year. Many were also honoured that their contributions were accepted for publication as this felt like it validated what they had experienced and how they had recounted this. Sometimes they also commented on how their essay was now part of the legacy of someone’s death or part of the memorialisation for them.

This project then, although primarily being about collating narratives, is much more than just some words on a page in a book. It’s about capturing a moment in time, different experiences and voices, generating and fostering community, processing emotions, and honouring those that have died. For each author, it may have done something different or more than one of these, and for us editors, it has been a privilege to be trusted with these accounts and to hold them in conjunction with one another.

**How this book is structured**

We spent many hours thinking about and discussing how we could structure this collection. We have opted for a thematically influenced focus that aims to grasp and draw out some of the common themes across the book. We have done our best to ensure that the dominant theme of each contribution is reflected in its position within the book; however, as might be expected, there are some cross-cutting themes that interlink the narratives and which run within them. For example, it is somewhat arbitrary to separate death during COVID-19 from grief, as any thanatology academic will argue the two are very much connected. However, we hope we have settled on a meaningful structure that will curate the reader’s journey through the accounts.

The first section deals with loss in its broadest sense. Narratives in this section vary from those that explore loss of self to those that explore the loss of wellbeing and mental health asso-
associated with the pandemic. Section Two explores the consequences of the restrictions in more detail and in particular those associated with the access to a loved one. It also deals with the very sense of an ‘ordered’ world in which choices are possible. In the third section, we focus on narratives that are related to death and dying during the pandemic and which were affected by its consequences. We also have a number of professional accounts of those caught up in supporting those who were dying and their families. In Section Four, we turn to consider those deaths that were brought about as a result of COVID-19, and one in which the death was attributed to COVID-19 but was not considered to be such by the family. This is a surprisingly short section, but we felt it was worth distinguishing these accounts because of the distinct impact it had on these families. Section Five continues to explore grief, loss and funerals as a result of deaths that took place during COVID-19, exploring also how limited social contact after the death impacted on bereavement. In the final section, we explore other experiences of grief during COVID-19, including those that were re-triggered or exacerbated by the lockdown and images of death in the media.

Note on content

Now that the book is in your hands (or on your screen), it is up to you how you read it. You may choose to read it from cover to cover or to pick it up and selectively read essays as you flick through it. We know some readers may gravitate towards accounts that may reflect or resonate with their own experiences, whilst others may avoid those.

As the title of the book suggests, much of the content is about death, dying and grief in some form. A few essays take the topic of ‘loss’ a bit more tangentially, as we understood that for many, the non-human losses of the pandemic – such as loss
of social contact, loss of freedom of movement – were met with feelings of grief (Berinato, 2020).

We are very much aware that the issues raised in this book are highly emotional and, in some cases, upsetting. While we are hopeful that reading other accounts in this book might connect with your experiences in way that you find helpful, we also wish to acknowledge that sometimes grief and loss are issues that become overwhelming.

None of the essays have individual content or trigger warnings as we cannot presume what each individual will find upsetting. However, below are a list of organisations that may be helpful if you find you need to either read more about your experiences or if you need to talk to someone about what you have read and/or the emotions or memories you experience.

**Support organisations**

If you are having a difficult time, there are various helplines available that can help to provide support. We have listed some useful ones below.

- Samaritans are there to listen; you can call Samaritans on 116 123 or email jo@samaritans.org
- Cruse Bereavement Care: Helpline 0808 808 1677. They also have a chat function that allows you to chat directly to a bereavement counsellor via their website (www.cruse.org.uk).
- Barnardo’s: More details on the different services they offer in different parts of the UK can be found via their website www.barnardos.org.uk
- Papyrus Hopeline: 08000 68 4141 exists to help those who are experiencing thoughts of suicide or are worried about someone else who might be suicidal.
- SOBS (Survivors of Bereavement by Suicide): National Helpline 0300 111 5065.
- Child Bereavement UK: Help for children and young
people aged up to 25. National Helpline 0800 02 888 40.

Notes on terminology

The terms COVID-19, Covid, coronavirus as well as others are all used interchangeably in this book. This is deliberate and reflects the language that is currently being used in relation to the virus and pandemic. ‘During Covid-19’ is often meant to indicate that something happened during the time of the pandemic (which during writing, was most of 2020 and early 2021). We have included a few clarifications on several terms that we know were used in the UK but not necessarily in other countries.

The term ‘frontline’ was used in the UK to describes people who were providing essential services and who could not ‘work from home’ during the pandemic. This included many health and social care staff, as well as workers in ‘essential’ (e.g. food) retail and logistics, schools, and public services. At times, the term ‘key worker’ was also used by the UK government to denote those providing key services. The key worker label enabled access to childcare, access to schools during pandemic closure periods, and earlier access to vaccines depending on roles.

The term ‘lockdown’ was used in the UK to denote the restrictions implemented by government to mitigate community transmission of the virus. Lockdowns were implemented as emergency measures and depending on the location, many weeks and months were spent ‘in lockdown’ in 2020 and 2021. At its most extreme, this included closing ‘non-essential’ shops and businesses, encouraging people to work and stay at home and minimise time outside the house (e.g. it was suggested only to go out for one hour per day for exercise), reduced social interaction with others not within one’s house, and reduced access to in-person education. Care homes and hospitals
Introduction

restricted visiting and there were rules about how many people could attend funerals. Travel restrictions were in place and access to social spaces was also impacted.

NHS refers to the publicly funded National Health Service in the UK. It covers healthcare from primary care in the community, to emergency acute care, and tertiary hospital services including Intensive Care Units (ICU). People who receive domiciliary care or live in a care home (or nursing home) may receive public funds to help pay for this care; this is often separate from NHS funding and referred to as ‘social care’. Within England, public health is under the remit of Public Health England which is separate to the NHS, although they often work in alignment.

In the author biographies, you will spot that some people are associate lecturers or tutors. At The Open University, this means that they support students as they learn and progress with their modules: marking assignments, facilitating group tutorials, and providing one-to-one support for students. Staff tutor is another role at the university; they supervise, coordinate and train Associate Lecturers.

About the editors: Erica Borgstrom and Sharon Mallon

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SECTION I

LOSS DURING COVID-19
Death. Dying. Bereavement. Grief. Loss. Words I often feel do not apply to me; words I feel I cannot connect with because I am one of the fortunate ones. I feel I have no right to claim these experiences because I am here, my family is still here. I have seen my parents and children come out at the other end of Covid. For now... I am grateful beyond words. Death has not set too close to heart and I feel ashamed to claim any pain.

But loss has. A feeling of mourning for hope and freedom. A painful feeling every morning when I slump out of bed and cannot bring myself to change from the timeless pyjamas, a constant reminder of endless hibernation. I remind myself that my pain is small in the face of the grief of parents and children and friends. I remind myself that I am the fortunate one. But the nagging pain is pressing my chest whilst I am forcing a smile. The invisible and unexpressed loss. A collective loss. The grief of all the others that have lost someone is dripping down and covers my heart with sadness and guilt. I feel guilty to weep for lost hope. The habitual checking of news and statistics and numbers looking for hope. I go through the day
with a numb, automatic push. The walls seem to close in every day.

An old friend died today. She was a mother just like me and now her children are without her and her own mother never had a chance to say goodbye and hold the hand of her dying daughter. Grief spreads beyond barriers of space, time and reason. A feeling that cuts my breath away whilst reminding me that I can still breathe. I am one of the fortunate ones.

**About the author: Simona Radu**

Simona Radu is originally from Romania, now living in Buckingham. She is a PhD student in the Faculty of Business and Law and an Alumna having graduated with a Bachelor of Science (Honours) in Psychology from The Open University.
As the world holds its collective breath, waiting for the pandemic to ease, this piece reflects, at both macro and micro level, on the broad and deep reverberations of this compromising of our systems. We are longstanding voice practitioners and members of the Natural Voice Network community of practice. This is a network of voice workers leading voice activities and singing groups in the UK, Ireland and beyond, who provide face-to-face and online opportunities for people to increase their joy and expression through voicework and singing. Catherine reflects on the wider impacts of Covid-19 and Louise then brings a personal lived experience of loss within her singing work. At the time of writing, the use of singing to support the breathing of people with long Covid is being explored.

Spring 2020 tilted the world on its axis in relation to both the pandemic and the death of George Floyd, one acknowledging the substantial risk to life from the Covid-19 virus and one resurfacing the global fragility of living within structural oppressions. Collective grieving in relation to the virus has been overlaid by communal grieving in relation to racism and
the multiple losses that this brings to many. A significant theme of the breath runs through these two immense phenomena. The combination of these ongoing events, and the deep global insecurities to which this gave voice, have been articulated in a powerful statement by academic Dr Errol Francis, who has reviewed deaths in similar circumstances in UK mental health institutions. He noted this time as one of: ‘a perfect storm of the Covid-19 pandemic and then the Black Lives Matter protests which, as the summer progressed, became inseparable from each other. This is because the social and public health inequalities that have been exposed by the pandemic – high infection and mortality rates for minorities and the socially disadvantaged – also reflect an apparent disregard for the value of Black lives by the criminal justice systems both in the US and the UK’ (2021, p. 1). Societally, many are uncertain whether we can continue to breathe safely; collectively we hold our breath, waiting for an indication that risk is reduced.

Pearce et al. (2021) note the current ‘silent epidemic’ of grief in the wake of the Covid-19 bereavements in the UK and Ireland. I have noted parallel widespread sorrow and trauma accompanying the Black Lives Matter (BLM) campaign, throughout my social work client group and colleagues, in the BIPOC/BAME-led charity that I Chair, and in the participants in my singing groups. This sorrow shows up in specific and globalised anger and expressions of grief which can be verbal or behavioural. The trauma is also revealed through a diffused anxiety and alienation, the foregrounded risk surfacing many layers of fears about not being safe in the world despite small individual and societal progresses over the years. People seem to be dealing with renewed hopelessness, the strength of which surprises many. This has been compounded by worldwide news of repeated recent injustices – beatings and shootings of people of colour.

Bereavement literature identifies stages of grief and
mourning, the pathway through these being a loose iterative process. The experience of grief moves towards acceptance. Kessler (cited in Berinato, 2020) suggests that the search for meaning, as an important part of that stage, will assist people in coping with this traumatic experience. Often couched as a return to normal, it can be argued that no life affected by loss has the same normal to return to. In the fallout from both these paradigm shifting events, many-faceted types of mourning will be experienced. Grief psychotherapist Julia Samuel writes that, ‘The essence of grief is that we are forced, through death, to confront a reality we inherently reject’ (2017, p. xviii). It may be argued that collective mourning and seeking meaning can potentially support new responses to diverse aspects of chaotic, or unacceptable, reality. Emergence from the global shifts across 2020–2021 is likely to require a collective mental, cognitive and emotional agility, as societies seek to create new, more acceptable norms, new awarenesses, practices and permissions.

From the macro, we now refocus the lens onto the micro, through our projects that seek to make a difference to this person, this moment, in community arts. In planning this piece, we considered our experiences in our professional lives as voiceworkers, providing support to many diverse individuals through community singing groups and choirs. Our colleagues, our incomes and the small agencies with whom we work are all economically vulnerable during this time, experiencing multi-layered threats to our survival. Many of the people with whom we work, including informal carers, bereaved people and socially isolated adults, are digitally disenfranchised, as well as intersectionally oppressed (Pestano, 2021). Participation in online services is not possible for all of them, leading to the loss of a valued support system, not fully replaced by outdoor or telephone contact. The realities of death and dying enter our work indirectly but also directly. Below, Louise reflects on a
singing group related to bereavement, nested in its wider context of losses.

**A pause becomes an end**

On Friday 13th March 2020, I tidied up scattered lyric sheets, stacked chairs, sanitised my hands and stepped out of my choir rehearsal room. Had I known that nearly 12 months later I would still not have stepped back into that room, I would have taken a few more minutes to relish and reflect on the joy we had just created in that gorgeous little space on that otherwise nondescript day.

As I have come to write this piece in March 2021, I have been shocked and dismayed by the news that one of the people standing in that room with me that day is never to return. He was a stalwart of my choir. He had the most beautiful voice. Other singers liked to sit next to him as he learnt parts quickly and carried them well. He was quiet, reserved but strongly supportive, always kind, bestowing a tranquil yet charismatic presence.

Having my passion and livelihood ripped from me in the lockdown was violent and painful. It was, of course, compounded by the disruption to all aspects of my personal life. The losses of Covid-19 have been traumatic and complex as it has entirely upended our usual way of living, had a profound impact on all aspects of communities, threatened careers, financial security and left the future ahead feeling uncertain and unclear (Walsh, 2020).

Choirs throughout the world have survived the onslaught of Covid-19 through the use of various technological platforms. As described by Grushka *et al.* (2021), the usual social ecology of a choir providing friendship, support and the experience of singing together, has moved into a virtual realm.
Supported by the Zoom machinic, a new digital virtual choir ecology has been created.

With our choir, I did manage to achieve this digital shift. We resurrected some vestige of choir through the use of Zoom, YouTube, Facebook, sheer bloody mindedness, and the endless support of many choir members. As restrictions were loosened, I rode the punches of legislation as we moved through lockdowns to rules of six, to tiers to outside, inside and back round to lockdown. My aforementioned choir member sang on Zoom and ventured outside before making the decision to take himself back inside to keep himself safe as Covid cases rose.

As a choir, we have shown resilience. We have fostered an interdependence through supportive WhatsApp messages, Zoom and our meetings outside when allowed. Similar to what Imber-Black (2020) explored in their article about rituals and Covid-19, despite the threat to societies posed by the pandemic to usual rituals, I’ve noticed that through imagination and the human spirit, the choir have celebrated and recognised our usual life-cycles and created new rituals. These have included a regular morning sing-a-long and Zoom chats with a morning coffee.

Despite this, the loss of our usual life was never far from any of our thoughts or discussions. But we have plodded on, with the hope that the tide would turn, and normality would return.

I last spoke to my choir member on Christmas Eve when he phoned me. It was a long conversation. We discussed his health which he indicated was not particularly pressing but more of a mystery. We exchanged the usual pleasantries and expressed hope for singing once more in our usual room in our usual manner, without a care in the world.

His passing has bought into sharp relief that what has been lost. If I can ever enter into that small little room on a Friday morning again it will never be the same. He is forever gone, his
voice forever lost – his quiet sanguine presence never to walk in the door again.

I now realise that there is no normal to return to. While I long to enter that small rehearsal room and sing once more, there are losses contained therewithin which I have yet to face.

About the authors: Louise Blackburn and Catherine Pestano

Louise has been working as a community choir leader and musician in Birmingham and Walsall for over ten years. She is the Music Director of Voices Entwined, a non-auditioned choir of over 100 members who sing for the absolute joy of it! Louise graduated from The Open University in 2020 with a Master’s Degree in Music. Her experience of leading a virtual choir with the onset of Covid-19 formed the basis for her dissertation.

Catherine is an OU Alumna, visiting fellow and Associate lecturer. A social worker, she also runs a community music organisation in South London (Creative Croydon). Catherine is of Guyanese and Irish heritage, and is outgoing Chair of the diversity focused arts and heritage charity Culture&. Her professional doctorate explored intersections between anti-oppressive social work and community music practice.

Both are members of the Natural Voice Network. https://naturalvoice.net/.

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Waiting to exhale, together


‘We’re very lucky, really,’ I said. I repeated it many times, spread over many weeks, as the Covid-19 pandemic gripped the world and life as we knew it took a swift detour into uncharted land. I said it to myself as friends in the retail and hospitality industries were laid off or put on furlough, suddenly unable to make rent, and facing each day on tenterhooks, wondering which part of their newly fragile existence would crumble next. People work hard to survive and thrive, and what they had was taken away.

We’re very lucky. My job with The Open University was secure, the transition to home-working much smoother than that of many other employers. Even my team’s role remained the same – get our modules presentation-ready. There is something uplifting about producing a product which you believe will improve students’ lives, pandemic or no.

Kids were suddenly sent home from school for an indefinite period. My son came home halfway through Year 2, armed with an envelope of worksheets, bolstered by an app accessible from a tablet. At first, there was novelty in having him home – he hadn’t read all the books in the house fifty times by that
point, or built every possible permutation of track with his train set. Again, we were very lucky. My son had a tablet to use, unlike some of his classmates, who had to share devices with parents and siblings. My job was flexible enough that I could look after him while I worked.

We were so lucky, I thought, as entire sections of the economy went virtually dormant, as people’s lives ground to a halt. I was aware that dark threads of loss and hardship were weaving themselves rapidly through the tapestry of life, but they had not yet touched my corner of it. And there is something in feeling lucky which made me feel I must succeed at this new, strange way of being. What right do I have to fail? I know the precariousness of casual work, rental properties, and low wages. I’ve been there. If I survived during those times, I must do more than simply survive now that I have more resources.

The initial burst of energy and determination to adjust wore off after several weeks of school worksheets, buggy educational apps, and daily PE with Joe workouts. As the government’s terms of lockdown extended indefinitely, and information on the progress of the virus and our battle against it fell prey to political posturing and wrangling, hopelessness crept nearer. I was no more in control of my life than were the people who had lost their livelihoods. But I did not like to admit how distressing I found this.

I have battled with mental ill-health for years — with the darkness that resides inside, sometimes bigger, sometimes smaller; sometimes very present, sometimes merely skulking in the background . . . but always there. I have fought it with medication, healthy eating, mindfulness strategies. I have learned to distract myself from the internal spiral of despair which drags me in if I let it get too close. Daily routine is a large part of that distraction. I don’t have time to think unhappy thoughts when I am focused on school runs, going to...
work, grocery shopping, and entertaining my son. The spare corners of space where shadows might lurk can be filled with TV shows, reading, and gardening.

Then it all stopped. We lurked within the four walls of our house, shielding to protect vulnerable family members, leaving for nothing but the essentials. Anxiety attended every trip we did take — going to the supermarket because delivery slots were booked up everywhere, walking in the woods for daily exercise. If I forgot something in the weekly shop — my forgetfulness a side effect of stress — going back to the shop to get it became a daunting and dangerous journey. Fellow humans became ‘objects’ to be avoided by at least two metres, instead of sources of comfort and reminders of my own humanity. In fact, I had never noticed how much my ongoing identification as ‘human’ is supported and sustained by being around others, even strangers. Seeing the same few faces every day is not enough. The wary glances and mumbled apologies I exchanged with fellow shoppers whenever one of us thought we might have transgressed the social distancing barrier between us reinforced my sense of isolation.

I shrank mentally, withdrawing the reach of my daily life from the outer limits it usually occupies — the optional activities, like gardening and baking. They are nice-to-haves, expendable when my energy plummeted through fighting a darkness which had now grown larger than me. I shrank back to survival mode, which is bare basics: care for child, provide food, do work. And vegetate. Night-times are the worst, when, with no distraction at all, my brain battles subconscious monsters whose names I do not know, thoughts suppressed for so long that I don’t know how to access them. If I did, I would drag them into the light of day and have it out with them at last. I suspect they connect in some way with a sense of loss which I have carried with me for many years, ever since I left my home country of South Africa and moved to the UK. This
Shrinking myself was not just the loss of a familiar place and culture, but a loss of friends and of home. It was also the loss of a more carefree stage of life in which I was not plagued by anxiety. The pandemic has exacerbated these griefs, reminding me that the danger of loss is always present and that we rarely have a choice about when it strikes us. So, with poor sleep, daily vegetating time in front of the TV or with a book is vital to my mental survival.

Every time someone hints at the idea of lockdowns ending for good and life going back to ‘normal’, I wince. I cannot afford to let the hope that this will all be over in a few weeks allow me to lower my guard. Also, there is no going back to how things were. That is not how life works, embedded as we are in the flow of time. Everything changes – each day, every single one of us is forever changed, in some way, with no way to refuse it, even if the only change is that each one of us is a day older. That is rarely the only change, however. We often have the power to choose what the change does to us each as individuals, the ability to decide how we meet the challenge. We even have the power to choose how we act. But I have discovered, during lockdown, that this power can be weakened extensively by low energy, lack of options, and old mental wounds.

Eventually, there will be a new normal — a stable space where I can emerge from my survival husk, count my losses, and bind my wounds. I think this is what we are all craving. Trauma comes in many guises, and I suspect lockdown has given all of us fresh wounds, or reopened ones we thought were healed.

I am operating in survival mode still. And my survival is not in question. I am nothing if not resilient, weathered by the long struggle. But I am losing things too. Losing moments of connection with people I love, which I should enjoy but cannot. Losing out on opportunities for growth because I
haven’t the energy to take them. Perhaps I am losing things I don’t know about. Maybe my empathy is shrinking. Maybe I will become too cynical to hope. That would be disastrous – I consider hope to be a virtue. Hope: not a naïve wish for perfection in an imperfect world, but a defiance. A refusal to settle for stagnation in survival mode. A determination to grow despite opposition. Hope, I think, is like the life which returns endlessly from decay. All things on our planet die, yet life continually springs up, undefeated. Rejuvenated by the decayed matter itself.

I often forget that I am part of that life of our planet. Humans are also made of this stuff of birth and decay, living this cycle in which we are often more fragile than we would like to be, but also more resilient than we realise. Not all losses in life are permanent, but neither you nor I can say for certain which ones are. I suggest that the only way to live with loss is to learn to let go of whatever it is that has been lost, inch by inch or even millimetre by millimetre if that is all you can manage. I hope to learn, more and more, how to hold things lightly. Life not only takes, it also gives. Often, what it gives us is entirely new relationships and opportunities. But sometimes, it returns to us things which we thought we had lost forever.

About the author: Kirsten Jeffery

Kirsten was born and raised in South Africa before moving to Scotland at the age of 18. She studied Theology at the University of Manchester and currently works for the OU. Kirsten lives in Milton Keynes with her husband and son. She writes, draws, and reads to stay sane.
Introduction

We are, only slowly, learning the extent of the impact the coronavirus pandemic continues to have on various aspects of our lives. The pandemic is also changing how we experience and cope with these significant shifts as well as how we understand and relate to them. Our experiences of death and dying are no exception. We watch those dying turn into statistics. We attend socially distanced funerals where we are not allowed to embrace or even touch, and we are often left to cope in isolation. Children are included in experiencing these new realities, and yet since the beginning of the pandemic, while there has certainly been discussion about matters that concern children, there have been very little interest and few studies listening to what children themselves actually have to say and contribute. In this short essay, we will discuss our own study findings. We will carefully report on and respond to views and lived experiences of death, dying and loss as shared last year by a large cohort of English, Norwegian, Slovenian and Icelandic speaking 3- to 12-year old children.
We will add our reflections to the small body of studies on children’s very rich and complex understandings of death and loss, that are characterised by resilience, openness, and care for others. Our aim is to highlight that children and their important insights should be a fundamental part of our response to the pandemic as we learn how to support each other and thrive post-pandemic.

In this essay, we build on our collaborative work between The Open University’s Children’s Research Centre (OUCRC) and psychologist-led, Children Heard project, in which we analysed survey responses from 240 children from nine different countries on their thoughts, feelings and experiences of living through the COVID-19 pandemic. In the study, children discussed not only the costs of the pandemic, such as the losses they had experienced and sacrifices they had made, but also the wider impacts, both positive and negative, of the pandemic on their lives. Through their accounts, children showed that they were not only critical thinkers who actively participated in knowledge-making, they also offered unique perceptions on how the pandemic has redefined our lived experiences and relationship with various aspects of our lives, such as the way we experience death, dying and loss.

**The omnipresence of death and loss in children’s pandemic narratives**

Reflecting findings of other studies (Bray et al., 2021; Pascal and Bertram, 2021), children’s awareness and lived experiences of death, dying and loss was a prominent topic in children’s responses to what it was like living during the COVID-19 pandemic. Many children focused on the virus as deadly, ‘Lots of people dying from the coronavirus and it’s not nice’ and highlighted that ‘people die’ as being important to their experience of the pandemic. Children also talked about a sense of loss when
sharing that they were missing friends and family, ‘I am sad, not being able to visit anyone or go anywhere,’ ‘I am very scared in these moments and I have no friends with me’ and ‘I like to stay home, but I miss my friends, my teachers, and my grandparents and seeing the dog at my grandparents.’ Children reference death, dying and loss in particular when asked what they dislike about the coronavirus being around. Indeed, fewer social connections and death and dying were two of the most reported dislikes children talked about. As referenced in Table 1, 33.3% of children (aged 3–12) mentioned that fewer social connections were what they disliked most about the pandemic, and 29.2% of children in this age group stated they really disliked hearing about death and the rapid spread of illness.

Over 40% of the youngest children (aged 3–6) also talked about death, dying and spread of the virus when asked what they disliked about the coronavirus being around. This finding was particularly striking as we expected younger children would be, to some extent, shielded from knowing about these issues in detail. Instead, it reinforced Bray et al.’s (2021) finding that in spite of adult efforts to shield them, children were highly aware of the impact of the pandemic. Children’s responses also varied across their different countries of origin (see also Table 1). For example, concerns over death rates and the spread of the virus were more frequently cited in Icelandic-speaking responses and least cited in Slovenian-speaking responses. Children who completed the survey in English (mostly from the UK, but this includes children from other countries such as the USA, Canada) regarded both fewer social connections and the constant presence of death and illness as equally worrisome.
Table 1 What children dislike most about the coronavirus being around, by survey language.*

<table>
<thead>
<tr>
<th>Survey Language</th>
<th>Social Connections</th>
<th>Death Spread</th>
<th>+ Restriction</th>
<th>Missed Opportunity</th>
<th>Home-school</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>32.1</td>
<td>32.1</td>
<td>16.1</td>
<td>1.8</td>
<td>7.1</td>
<td>10.8</td>
</tr>
<tr>
<td>Slovenian</td>
<td>52.5</td>
<td>6.8</td>
<td>20.3</td>
<td>6.8</td>
<td>5.1</td>
<td>8.5</td>
</tr>
<tr>
<td>Norwegian</td>
<td>31.8</td>
<td>13.6</td>
<td>27.3</td>
<td>13.6</td>
<td>13.6</td>
<td>0</td>
</tr>
<tr>
<td>Icelandic</td>
<td>20.7</td>
<td>47.6</td>
<td>12.2</td>
<td>7.3</td>
<td>0</td>
<td>12.2</td>
</tr>
<tr>
<td>Total</td>
<td>33.3</td>
<td>29.2</td>
<td>16.9</td>
<td>6.4</td>
<td>4.6</td>
<td>9.6</td>
</tr>
</tbody>
</table>

*Percentages are reported in this table.

The experiences of death and dying children articulated were most often about the experience of a constant sense of danger of death and dying, rather than direct experiences with death and dying: ‘I don’t like that someone can die at this time when I’m having fun’ and ‘[I]t is very very dangerous because a lot of people can die.’ Similarly, children talked about loss, as more than passing of a loved one, but as a loss of closeness and presence of loved ones in their lives that negatively impacted upon their daily lives, ‘I dare not to hug or hold hands with anyone but Mum and Dad’ and ‘I did not get to be in a group with my best friend and therefore we have not met for a long time.’ This was related to some children discussing the general omnipresence of death, dying and loss in their lives at the time, ‘It’s big and lots of people are dying from it. Everyone knows about it’ and ‘You have to be careful not to hug or kiss.’

Many, although not all, children felt scared or threatened asking ‘Do children die from it?’ and ‘Is it dangerous to me?’ This sense of overwhelming threat could be discerned in some of
the participants’ responses such as ‘I never imagined it could be so bad’ and ‘maybe EVERYBODY in the world will get sick.’ Nevertheless, there were also children who appeared less alarmed but expressing frustration that it is taking, ‘quite a long time’ to learn how to combat the virus; ‘I wish I could talk to her [the virus], tell her to go away’. These children appeared reassured by the knowledge that the virus does not affect children, ‘[I]t does not have much effect on children and healthy people’ and ‘Not everyone gets it and not everyone dies.’

Relationships and resilience in children’s narratives of death and loss

Children expressed concern for their own safety: ‘I am scared even though they say the children get less sick’, but more often they were concerned for the safety and wellbeing of family and friends: ‘I am afraid my grandparents will die’ and ‘My worry is for my friends.’ This was particularly the case when a family member caught the virus, ‘I was afraid that my dad would die when he was sick.’ Thus, children appeared to be more worried about COVID-19 for its impact on others, which supports Weaver and Weiner’s (2021) finding that children may be very sensitive to the possibility of their parents or grandparents dying, and to the wellbeing of their wider community. Children were troubled that ‘someone in the family will get it and get sick’ and that they themselves were possibly a risk to their loved ones and might ‘infect a family member’. A child of a hospital-worker reflected that her Mum could ‘get more sick than others and needs to take care of herself.’ Similar concerns were also revealed by Idoiaga Mondragon et al. (2020, 2021).

Children showed an awareness of being part of a global event that affects not only them and their loved ones but also their community and the rest of the world, ‘Of course it is very bad that many people get sick and it is not fun but also that there are many
people dying in the world” and ‘The virus is happening; some people are dying because of it and there are a lot of infected people around the world and in Slovenia.’ Despite the toll of social isolation that negatively impacted children’s relationships with friends and family, some children highlighted the newly emerging kinships in communities when they talked about how their own health was vitally connected to the health of their community, ‘It spreads people to people and makes people sick;’ or ‘I think it is very important that we stay on lockdown for a while to prevent the spread of the virus because it has a huge effect on the country.’ Thus, children did not merely talk about themselves and their individual experiences of death, dying, and loss, they also talked about how their relationships, their family, school, community, or even the virus shaped the way they experience death, dying and loss during the pandemic.

Children not only openly expressed feelings of vulnerability, they also demonstrated resilience when they discussed how they coped during the COVID-19 pandemic as well as how they cared for their family and community, ‘At first I was a little scared but then I got used to it’ and ‘I want to help scientists so we can get antibodies as soon as possible so that the epidemic stops.’ Some children then reported that togetherness and kinships is what was helping them cope, ‘Coronavirus has made me feel upset and I am sure it has made everyone upset but my family and solidarity has helped me through it,’ and ‘In the beginning it was pleasant because I was at home in nature and I was with a lot of family outside.’ Many children shared ways they have been handling the situation and they also proposed ways they believe the situation could be handled and dealt with as we move forward, ‘I think that we should stay in lockdown until the amount of deaths decrease’ and ‘I think they should say more often to stay 2m apart.’ They not only expressed their need to protect their community but also their belief that their community will come out of the pandemic strong, ‘Maybe we [will] care more about our environment and our planet’, ‘We have more free time. This
Children’s narratives of death, dying and loss during COVID-19

has strengthened the community’ and ‘Everyone will be ready for a new epidemic.’

Conclusion

Children communicated rich and complex understandings of and insights into their lived experiences of death, dying and loss during the COVID-19 pandemic. Children reflected on their own social, emotional, and physical experiences that translated into very powerful and deeply personal narratives of death, dying and loss. These experiences were, more often than not, characterised by even the youngest children, through the omnipresence of the dangers of death and dying, loss of closeness and physical interactions, as well as narratives of resilience and emerging kinships. These narratives, while sometimes quite familiar and expected, as some children adopted adult rhetoric or common phrases from the media, were also often surprising and unexpected. Parents conducting the survey with the children also found their comments eye-opening and insightful, ‘Interesting to hear his answers and how much he knew for a five yr old,’ and ‘It was interesting, most answers as I’d have expected but a few surprises which were nice to talk about’ or ‘It was a nice experience listening to the answers of my child for things I haven’t asked him during this difficult period.’ For us, children’s insights generated new questions, such as: ‘How can we build on this knowledge?’ and ‘How can we strengthen our communities and relationships to cope with our experiences of death and loss during and after the pandemic?’ We therefore invite all adults to reflect on what children are telling us and ask questions. Moreover, we urge adults, both those familial and those in power, to work together, with and for children, and to act on the new ideas and issues children can bring forwards. By co-producing new spaces where children can not only contribute but be
supported, we can build kinships inspired by our children which can help us all thrive post-pandemic.

Ethics

The research protocol for data analysis was given a favourable opinion by The Open University Human Research Ethics Committee (HREC/3707/Chamberlain).

Project

The Children Heard project was launched in March 2020 in response to the limited spaces for children to share their views and lived experiences of the coronavirus pandemic. The online platform offers the opportunity for children to express and share their feelings and views both in written and art form. To date, the survey has collected the experiences of over 500 children aged 3 to 18. An analysis of survey responses from 240 children aged 3–12 collaboratively conducted by The Open University’s Children’s Research Centre (OUCRC) and the psychologist-led, Children Heard project demonstrates how children have varying experiences of the pandemic, both negative and positive, and shares recommendations to involve children and young people in the decisions that directly impact their lives. For the report and children's poster, please visit: http://wels.open.ac.uk/research/childrens-research-centre/research. The survey and a gallery of children’s artwork can be viewed at: www.childrenheard.com.

About the authors: Petra Vackova, Dr Stephanie Jane Bennett and Linda Plowright-Pepper

Petra Vackova (@petra.vackova) is a PhD Researcher at The Open University and a member of The Open University Chil-
Children’s narratives of death, dying and loss during COVID-19

dren’s Research Centre. Her work focuses on ethical methodologies, feminist new materialist theories, and educational justice.

Dr Stephanie Jane Bennett (@SJBBennett_Psych) is a Chartered Psychologist and works for The Open University as an Associate Lecturer in Psychology as well as being a member of the OUCRC. Stephanie is also a Lecturer for the University of Chichester.

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I have only recently returned from an island; from being shipwrecked, one might say, like Robinson Crusoe, that famous fictional castaway who spent decades alone on a desert island, so absent from what has been going on in the world. In this way, then, and to some extent, that island — my island — has sheltered me from the world around. The pandemic, therefore, has mostly evaded my path, and so my experience of it has been vicarious at most. However, make no mistake: my island was no reprieve. In lieu of one death, I faced another, and whilst I sit here now, returned from that figurative island, it is only in the act of writing that I begin to comprehend what I have been through, and what I have missed. I brought nothing back with me from my island — nothing to remind me of my experience; nothing to remind me of who I once was. Like Robinson Crusoe, I was stranded on an island surrounded by the sea, only the sea surrounding me was not simply a sea, but rather, the ‘big C’: cancer. Island life, for me, was a sojourn with Death. True, I escaped with my life, but I am no longer the same as when I first set foot upon its shore. Lost, then found; this is the story of my death.
The time of writing, March 2021, marks one year since I was cast onto that island. A recurring cough was masked by daily dozens of cigarettes smoked; it was only once blood appeared that I figured something was wrong. Post-flu season, or respiratory blackness, was my personal diagnosis; I brushed my tar-stained teeth too vigorously, and thus I bled. But the blood kept coming. This, however, was not the moment that I knew something was wrong. Instead, I recall sitting down to read and dropping a fresh cup of coffee, without cause or reason, all over the carpet. This was the moment that I knew, but how was I to know what awaited me? The pandemic had just begun to take hold in the West, and so, wherever I turned for help, I was met with trepidation — chest pains, coupled with haemoptysis, was enough to ring alarm bells in those early days of coronavirus confusion. I discovered that straight-talking honesty is hard to come by in the face of medical uncertainty due to the threat of potential liability, but that is just the way that it is, even though it does not help to stop you from drowning. Pulmonary embolism, heart attack, and coronavirus itself were early, popular theories of diagnosis, hence the GP was afraid and unable to help. The men in green, having raced to see me — blues flashing, siren wailing — reassured me against the latter two, but a trip to hospital was necessary to rule out the former. My journey had thus become ill-fated. I had entered into the storm, like a wayward ship battered into submission toward the desert island; man overboard, beaten down by wave upon wave of violent sea, and coughed out upon the shore. I had never been to sea before; I had never been ill before. The strawberry-blond, bespeckled nurse, patient, with kind words and a gentle disposition, sat cross-legged with sharp eyes fixed firmly in the moment and listened carefully, and in her softest voice tried to break through the tumult to reassure me, but my ship had failed, and my course altered. While the world turned, poised on the precipice of a
pandemic, I had become lost – marooned on an island all my own, facing a different kind of death. In March 2020, I was diagnosed: primary mediastinal B-cell lymphoma, stage IV with bulk and local infiltration to pericardium, right lung, and pleura.

My former self was a long-haired, foul-mouthed, smoking, misanthropic shadow of a person, content in isolation and hostile toward any well-meaning. To be sure, it was not all my own fault: I was scared of people, of places, of things. In fear of outwards, I turned inwards. You would probably think that, for someone who wanted to maintain a low profile, avoid detection, and go quietly about their business, thus keeping themselves to themselves, they would be a little less stand-out – it is not every day that you see a young lad with hair down to the top of his buttocks! Be that as it may: my mane was part of my identity. During this time, my principle means of solace was in books and study, occupying myself within other worlds of words. Ironically, it was on the island of Robinson Crusoe – studying the text as part of my master’s degree – that I received my diagnosis; that I, myself, became stranded on a desert island of my own.

Upon the commencement of treatment — I am alone; all alone, king of my own island — I obstinately persevered with my studies, and tentatively tended to my hair; frantic, yet resolute, in determination of holding on to those few things close to me. It was inconceivable to be without those worlds of words, or my mane, but as the fog of treatment and side effects descended — one of which is aptly denominated: ‘chemo fog’ — my efforts became untenable. Balding, bald, and fatigued, I reached out for help. I sent messages in electronic bottles that, to my surprise, received replies of hope, but no resolution. Reluctantly, resentfully, the old me resigned himself to his condition. I had succumbed to the reality of facing death, and therefore departed those worlds of words to focus on my
health; on crafting a raft, like Robinson Crusoe, to escape from my own desert island.

As I sit here now — writing, recovering, and consolidating becoming anew — I feel a vacuity. The past year has felt like no time: no forward movement, nor backwards; no progress, nor loss. There is simultaneously nothing and everything: death, and rebirth. I am returned from my island, but I am not who I once was. I am me, anew; reborn. Nor does this place seem to be the same as it was before I departed. I return from my island to somewhere different — somewhere scarred by a change from which I have been most absent. I find it hard not to wax philosophical about matters pertaining to time, death, remission, and rebirth. Having visited many literary worlds, the poetic and allegoric rise to the surface as a means of comprehension. I ask you, therefore, to humour me and my story; my new-found vigour and lust for life that is spurred on by rebirth, the recommencement of my studies, and my new-found acquaintanceship, which has manifest itself in this tale of shipwreck, island life, and rebirth. In amongst it all, what comes to mind is the perplexity of the opening lines of T. S. Eliot’s ‘Burnt Norton’, the first of a collection of four poems that are preoccupied with, amongst other things, time:

\begin{quote}
\textit{Time present and time past}
\textit{Are both perhaps present in time future,}
\textit{And time future contained in time past.}
\textit{If all time is eternally present}
\textit{All time is unredeemable.}
\end{quote}

I do not know where the past year has gone. I recall long moments of obscured stasis, punctuated by condensed eternities. Mechanical beeps measured an infinitude that stretched on and on in a wave of nauseating dependence, impatience, and feelings of flight. The day stretched endlessly as I
remained fixed in place and wired to a necessary poison, whilst the ladies in blue checked in every half hour or so. What followed was a daze of three recuperative weeks, regulated by towers of pills and the daily puncture of pain by those same heroes that everyone back home clapped for every Thursday. I was trapped in cycles where yesterday and tomorrow converged into a present that was neither wholly grounded upon the past, nor certain of any future. My plight was an eternity that was nothing but a short while.

I am once more returned to that island. Not my island, but Crusoe’s. I am studying once again: a year on, having deferred, the worlds of words are helping me to heal. The island reads familiar and reminds me of my own. One thing is for sure: once I am done on Crusoe’s island, I will not be returning — the poetic similitude of that castaway echoes too loudly with my experience and makes me nervous. As I turn the pages of the same book I held last year, I fear that they are dirty; tainted by the onset of death. Is there a difference in my touch now that I am anew? I wonder. Though I am recovering well, and learning who, exactly, this new me is, things are not the same, nor will they ever be. Echoes of my own island frequently resonate: a cough, a faint smell, a sensation of pain or discomfort, all reminding me of my time there. I struggle with concentration, and my stamina is still depleted; late effects, the lurking fog of treatment that comes and goes, unpredictable as the weather. But the ringing of the bell is growing more faint by the day, despite my vehement tolling at the close of last summer. The old me is dead and gone; I am here now. The faces of the scores of people I have encountered throughout my ordeal flicker by in moments of reflection; ghosts, of whom the old me would have been afraid. But I am no longer afraid. When Robinson Crusoe encounters people on his island — his first encounter in years — he is startled into a frenzy of feral activity that results in his constructing extensive defences in a
bid to conceal and protect himself from this perceived threat. It is only now, reborn as I am, that I perceive this to be absurd — an allegory for my old ways. It is only now, for the first time, that I am looking outwards, not inwards. To be sure, I am still me, but anew. Do I, therefore, grieve this loss, this figurative death? No. Of course, there are easier ways to achieve revival, but the carpet bears no stain, and all that has been lost is little but a short while. My hair grows back apace, so that, soon, you would never know.

About the author: Danny Lawson

Danny is currently convalescing at home in the North-East of England. Unable to work at the time of writing, he divides his time between his return to studies and his newly found outward perspective with his new best friend, Victoria. With her help throughout his illness and beyond, he is a new man, and is — and forever will be — eternally grateful. Danny is undertaking MA study in English Literature with The Open University for a second time, having deferred due to illness. Aside from (finally) completing his qualification, he is mostly looking forward to getting out and about in the fresh air and enjoying the little things.

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The perinatal period (pregnancy and the twelve-months following childbirth) is a time of major transition in a woman’s life, increasing vulnerability to emotional distress (Moustafa et al., 2020). Prior to 2020, approximately one-in-four perinatal women in the UK experienced a mental health difficulty (Howard et al., 2018); however, the prevalence of both anxiety and depression increased worldwide during the COVID-19 pandemic (Tomfohr-Madsen et al., 2021). In the UK, the prevalence of perinatal depression was reported to have reached rates of 43–49%, whilst perinatal anxiety was 49–61% (Fallon et al., 2021; Harrison et al., 2021a; 2021b). These increased rates of clinically relevant psychological symptoms may be explained, in part, by the loss of social support and extended periods of physical and social isolation that occurred during local and national ‘lockdowns’ imposed to reduce transmission of COVID-19 (Harrison et al., 2021a; 2021b). The considerable uncertainty experienced during this time, particularly around perinatal health care, may also have contributed to increases in perinatal depression and anxiety, along with the discrepancy between maternal expectations and
experiences, which have been associated with increased perinatal distress prior to COVID-19 (Harrison et al., 2020).

During the first national lockdown in May 2020, we (Dr Gini Harrison, Prof Michelle Moulds, and I) conducted an online survey of 456 perinatal women in the UK to investigate the impact that COVID-19 was having on perinatal mental wellbeing and perceptions of support. Psychological symptoms including tearfulness, worry, overthinking, fear, self-blame, guilt, and frustration were commonly described (Jones et al., in prep). Many mothers also reported feeling a sense of loss, illustrating the profound effect COVID-19 had on women during this time. Anonymised quotations from the study relating to the experiences and events associated with these distressing emotions are described below.

‘I felt helpless, like I didn’t know what to do with myself, my time, my baby. I felt I had lost myself and had nowhere to go and nothing to aim for or make plans for. I cried uncontrollably and had no energy to do anything but feed and hold my baby. I was stagnant — this was not what I envisioned new motherhood to be like.’

The theme of loss echoed throughout participant responses and, at times, was captured explicitly: ‘I felt a sense of loss and grief for all the things I was no longer able to do with my baby’. Women described feeling ‘isolated and cut off from society’ and ‘very alone and excluded’. They struggled with the ‘loss of regular contact and general chatting’, particularly in the postnatal period when women often rely on peer support for guidance on their mothering journey. Twenty-five percent of the postnatal women reported struggling with a reduction or total loss of peer support. They described how this made it difficult to understand ‘what is normal’. Many of the pregnant women were concerned by the loss of antenatal classes traditionally attended prior to birth. Ninety-four percent of the pregnant women had been less (or
not at all) involved in antenatal classes, and many described how this affected them.

‘I have not been able to go to things like antenatal classes and feel like I have missed out on the opportunity to socialise with people in similar situations to me. This has left me feeling isolated, and like I have no support network with the imminent birth of my baby.’

Perinatal healthcare was also affected. Birth partners and coparents were prohibited from attending antenatal appointments including scans. This led to considerable anxiety, particularly amongst women who had previously experienced a miscarriage and feared receiving bad news about their current pregnancy alone. Pregnant women also reported concern around the loss of opportunities for their coparent to bond with the baby at antenatal scans and during post-birth hospital stays: ‘I feel alone in the pregnancy as I am unable to take my husband to any scans, I feel worried he won’t bond with this child as he can’t be part of pregnancy.’

Several perinatal women described the loss of day-to-day freedom and autonomy, as well as a specific loss of control over perinatal experiences: ‘Not feeling in control about my choices with regards to prenatal care and birth choices.’ Many home-birth services were withdrawn, and home visits for perinatal care were severely limited. In some areas, Health Visitors were redeployed to attend to the urgent needs of COVID patients, leaving few to care for perinatal families. Indeed, Babies in Lockdown (Best Beginnings, 2020) found fewer than 11% of parents with young children saw a health visitor face-to-face during the first UK lockdown, and more than one-third of the postnatal women they surveyed had not experienced the birth they expected.

The mismatch between reality and women’s experiences of pregnancy, childbirth, and motherhood was another common
thread in our survey findings, as captured by this postnatal woman: ‘I found the essential loss of my maternity leave, as I knew and expected it to be, very upsetting.’ Women had expected to spend maternity leave enjoying time with family, attending baby classes, and making new friends, but these opportunities were lost because of lockdown restrictions. On a practical level, the lack of support proved challenging for many:

‘As a single new mum I expected to have my mum and sister to help me when I needed it. Instead, I’ve had to do everything alone and felt quite isolated.’

It was not until later in the pandemic that the UK government recognised these implications for perinatal families and changed guidelines to allow new parents to form a support group with another household. The loss of emotional support was just as difficult: ‘I am usually very happy to be alone but during lockdown is the first time I have truly felt lonely.’

Loss of contact with family was particularly evident during times of illness and bereavement.

‘My mum has dementia and only me and my uncles to support her; her partner died during this outbreak and she can’t watch the funeral as she can’t use tech. I’m too far away to call in and check on her and my husband doesn’t want me to because of the risk to us and the baby. I feel helpless and dependent on others I also feel I’m being judged as a bad daughter but unable to do what I want. This has frustrated me and made me cry’.

Loss of family contact was also noted at times of celebration. Birthdays brought sadness: ‘I wanted to see my parents on my birthday; I got very upset that they are missing out on my little girl’s life.’ Perinatal rituals became a subject of distress. Women withheld news of their pregnancy until they could meet face-to-face, and
uncertainty surrounded when extended family would be able to meet the new baby. Uncertainty was enhanced when relatives were outside of the UK: ‘My parents live abroad, and I don’t know when I’ll see them again.’ When families were able to meet, interactions remained difficult. As one woman said: ‘it breaks my heart not letting them hold or play with her.’

Of the 449 women who responded to the open-ended questions (see Harrison et al., 2021a; 2021b for demographic details and methods), 61% reported clinically concerning scores on depression and/or anxiety measures. This is far in excess of the rates usually observed in this population (e.g. Howard et al., 2018), but similar to increased rates reported in other UK studies conducted at this time (e.g. Best Beginnings, 2020; Fallon et al., 2021). Although causal links cannot be assumed, it is easy to imagine how the experiences of loss described here may have contributed to an increase in psychological symptoms. One-third of the perinatal women attributed their distress directly to the COVID-19 restrictions, including the loss of control and autonomy, loss of social support, restrictions on ‘non-essential’ activities, and changes to perinatal care. The distressing indirect effects that the COVID-19 pandemic is having on perinatal wellbeing are clear. It is likely that the loss of early motherhood experiences prohibited under pandemic restrictions and associated grief will continue to cast a shadow over family life for years to come.

About the author and Project information: Katie Jones

Katie is a part-time Economic and Social Research Council (ESRC) funded doctoral researcher in the School of Health, Wellbeing and Social Care at The Open University. Her PhD investigates perinatal anxiety risk factors, triggers, and trajectories from late pregnancy to twelve-months postpartum, as well as exploring the relationship between maternal anxiety and
mother-infant interactions, with the aim of identifying opportunities to reduce the prevalence, severity, and long-term implications of perinatal anxiety. Beyond the PhD, Katie works as a research consultant and chairs her local Maternity Voices Partnership.

This article draws on findings from research led by Dr Gini Harrison (Open University), in collaboration with Prof Michelle Moulds (University of New South Wales, Australia), and Katie Jones (Open University) — ‘Perinatal Isolation: Investigating associations between technology use, perceived social support, repetitive negative thinking, and mental wellbeing in the perinatal period during coronavirus.’ A total of 456 perinatal women (pregnant or up to twelve-months postpartum) in the UK completed an online survey during the May 2020 lockdown. The survey included a range of standardised measures of perinatal mental health, loneliness, and perceived social support, as well as open-ended questions regarding specific distressing experiences and access to support. Analysis revealed opportunities to support perinatal wellbeing, indicating that strategies such as increasing peer social support and reducing repetitive negative thinking may help to prevent and treat perinatal anxiety and depression. Further information can be found in the published articles: Harrison et al., (2021a, 2021b). An additional article relating to the feelings and experiences associated with perinatal distress is currently being prepared (Jones et al., in prep).

References


SECTION II

IMPOSSIBLE CHOICES AND RESTRICTED PRESENCE DURING COVID-19
I t is 4th February 2020, the day before my eldest son’s birthday, a week before my youngest son’s birthday and five days before we fly to Amsterdam for a birthday getaway. The phone rings. It is my brother-in-law. This is unexpected and I am immediately filled with anxiety. I was right to be anxious — my sister has had a brain haemorrhage and is being transferred to the Neuro Centre in Liverpool, half an hour from where they live on the Wirral. She is conscious but the scan shows a critical haemorrhage that needs surgical intervention.

I am in Hertfordshire and have to phone my dad to share this distressing news, he lives in south Wales and has been a widower since my mum’s untimely death ten years ago, so this is a really difficult call. Then I explain to my sons and husband that I won’t be home for birthdays and that Amsterdam might have to happen without me.

I drive to Liverpool in the early hours of the following morning knowing that Gill will have been to surgery and be in the intensive therapy unit (ITU) by the time I arrive. I pray and hope and hope and pray that the surgery will be successful but
I am an emergency nurse and I know the odds are stacked against her.

I arrive at the Neuro centre and immediately become a relative. Being a nurse makes being on the other side a strange and surreal experience; you know some things but not everything. It is my sister, not just a patient lying in that bed hooked up to all manner of drips and pumps and machines. My family look to me to fill in the blanks but I only have more blanks that need filling.

My sister has two children, young adults, the same age as my boys. My heart breaks for them watching them struggle with the reality of the situation. The news is not good and over the following days, it gets worse. She makes some progress but then things get worse again. It is an emotional rollercoaster and we are all hanging on waiting for this terrible ride to end. I make the return trip each week and by the beginning of March, there is talk of a transfer to the Neuro rehab ward where there is hope she may make some improvement from the ‘low awareness’ state that she is now in.

We make plans. I can work from a friend’s a couple of days a week, until we are able to find a more permanent second place on the Wirral. I want to give Gill as much time as I can to help with her rehab, to help ‘bring her back’. I want to support my niece and nephew through these shocking times. I want to spend time with her husband and my dad as we all go through this unfathomable loss.

Then COVID strikes. Visiting is reduced to one person once a week. Her husband is rightly given the visiting slot. There is some empathy for her children, and they get offered a special visit but then lockdown brings all visiting to an end. We are all lost in a world of sadness about what we know and fear of what we don’t know.

Hospitals are advised to discharge everyone who can feasibly be moved. Gill is transferred to a long-term rehab in
It could not have happened at a worse time

Chester. No visiting, no way of communicating with her, what must she think is happening to her? It was difficult to know what Gill understood; she was unable to speak and was often in a drowsy state but she had smiled sometimes when we were last able to visit. She knew who we were; Gill was still ‘in there’. So now we are left with the awful feeling that she may know nothing of the COVID virus and the devastation it is wreaking on the Wirral where she is, in the UK and across the globe. She must feel that we have abandoned her, left her to be cared for by strangers whilst we get on with our busy lives. The deep well of sadness and powerlessness is overwhelming. We start to shut down. We send messages to each other rather than calling; it is too painful to hear the wobble in the words and to know there are more tears, so hugs and love are expressed through Xs and Os and emojis.

No news; we have no idea how things are. The only communication from the Rehab centre is with her husband and it is cursory at best: ‘Slept well’, ‘Smiled at staff’.

Then the call – Gill may have COVID. She has been transferred to the hospital and is awaiting results. She is breathless and oxygen levels are very low. We all hold our breath. This could be it and we cannot even be with her: no visitors. She is not an ITU patient as it has already been agreed she is ‘not for resus’ but the rules are clear: ‘no visitors’, so we just wait. Relief, it is not COVID and she is back to the rehab place. This happens three times; it does not get any easier.

The pandemic news is getting better, visiting is going to start. I arrange to visit every two weeks; her husband and children will visit once a week. They get to go first, so I have been told what to expect. The reality is so much worse. We are outside, I have to be six feet away, in a gown, gloves and a mask. No touching, not even a squeeze of her hand. There is a member of staff on guard in case anyone should breach the protective bubble. Gill’s right-sided brain injury means she has
challenges with facial recognition – I am fairly sure she has little understanding of who I am or what is happening.

I am traumatised by the extent of her disability and can do nothing to help. Helping is what I do, professionally as a nurse, and in my personal life helping in my local community, at my children’s schools, supporting family and friends. Not being able to help only compounds the sense of abject loss and sadness. I visit four times and after each ghastly visit, I am re-traumatised by the impact of the brain injury, by the distance between us and by not being able to connect with her in some way.

Dad is still in Wales; different lockdowns mean we cannot co-ordinate a joint visit and he is so sad and lonely — another loss, another well of tears to be shed after each video call with him.

It is approaching Christmas; I work clinically once a week so I know the numbers and the shifts in patient presentations and the dread as a second wave is predicted.

I visit Gill on 17th December knowing that it is only a matter of time before visiting stops again. This time I am behind a Perspex screen; at least she can see me and there are smiles but the distance is immense, and I leave 45 minutes later, trying to hold back the tsunami of tears and frustration.

I get up close and personal caring for patients in my job, the nurses who care for my sister are up close and personal, we all go home to family, we all go to the shops, we all present a potential risk, but I cannot even hold her hand — the rules are the rules. Gill’s physical protection is absolutely paramount; all the guidance says so. But what about her emotional protection? The staff assure me that they support Gill and I should not worry. How do I explain that it is not ‘worry’, it is a need to be present, to share time, to show love, to connect with my sister at this time when she is not able to speak, not able to tell us how frightening it all is, not able to
It could not have happened at a worse time

ask, ‘What is happening? Where are you? When will things be better?’

I don’t know the answers, but I do know that the decision to protect physical health above and beyond any consideration for emotional wellbeing has had an incomprehensible impact on so many lives. Our future will attest to the emotional trauma these decisions have wrought.

And now we wait, for vaccine protection and visiting to start and pieces to be picked up. Millions of tiny pieces to try and put back together into something we might recognise as our lives, our new normal but all overshadowed by grief and loss and fear of what happens next. Life has taken on the façade of a stop start movie and we are playing the parts assigned to us, but it feels a long way from living a life.

Writing this has offered me a strange kind of therapy, a recognition of just how emotionally overwhelming this year has been. Work has offered distraction, we have ‘made the best of things’, we have ‘kept in touch’ but I can see now we have not grieved.

February 2021.

About the author: Jacky Price

Jacky has been an emergency nurse for over 30 years and a nurse lecturer for 20 of those years.

She has witnessed loss in all its forms, across all ages, and has always felt a professional responsibility to help junior staff and students to really understand the importance of the support they give when caring for patients and families suffering loss. Jacky has always focused on the immediacy of the emotional support given and the potential for us to create positive memories in these distressing times.

In the past 10 years, she has led on the development of advanced practice in nursing and the allied health professions.
Her work has focussed on promoting critical thinking as a vital foundation of the role; on enabling learning opportunities that reflect on the emotional and psychological impact on patients and families; and on our role in advocating and promoting their best interests in challenging situations.
When we hear the word ‘grief’ we automatically think of death – the loss of a loved one, whether pet or human. The human death toll has been at the forefront of our minds throughout the Coronavirus pandemic and our politicians constantly remind us that each Covid death represents a grieving family’s loved one. We have lived in fear for over a year, wondering when, how, or if we are going to be directly affected ourselves. However, one of the many things this pandemic has taught us is that it is not only death which causes intensely-felt grief.

I am writing this a year to the day since I last sat next to my mother in her care home happily doing some arts and crafts. As is so often the case when a shocking event happens, I remember the day with vivid clarity. We made a birthday card for one of mum’s carers and were looking forward to making my brother’s birthday card on my next visit — except that never happened. The following day, without warning, we became unwillingly estranged as the threat of coronavirus forced care homes across the country to go into lockdown. Overnight I became an unwitting danger to mum; a potential
carrier of a deadly virus that no one knew much about and keeping me away from her was considered the ‘safest’ thing to do. The separation was sudden and announced with no time to prepare or share comforting words with each other. We were unexpectedly plunged into grief — a grief with no precedent.

As a psychotherapist, I am aware of the complex nature of grief and, indeed, death. I, like many others engaged in the helping professions, have studied and revisited the work of Elisabeth Kubler-Ross and David Kessler many times.¹ These authors are famed for what has now become an almost legendary concept – the five stages of grief: denial, anger, bargaining, depression and acceptance. Such is the wide acceptance of these studies that people readily refer to there being different stages of grief without ever knowing the work of Kubler-Ross and Kessler directly. Their work covers grief that can be felt for all kinds of reasons besides death, too; for example, after divorce or some other life-changing event or significant loss.

Death is a definitive form of loss. However, there is such a thing as ambiguous loss, too.² This term was first coined by Dr Pauline Boss whose work focused on different kinds of more uncertain loss including that of ageing parents. I lived alongside ambiguous loss for many years with my father who had Alzheimer’s. It is a strange grief — one a friend of mine used to call ‘the long goodbye’ — and I found, in general, that people were often empathic and, at the very least, sympathetic about the grief experienced in watching a loved one disappearing mentally and physically before your eyes. People readily acknowledged the difficulty they perceived in coping with the loss of the father/daughter relationship whilst others seemed to acutely feel the tragedy of dad no longer knowing my name or what relation I was to him. Sometimes I think they felt it more than I did; imagining how something might be is often worse than being in the situation
A grief denied

itself. And I always felt the love between us which, for me, was the most important thing. All the other bits — the fatherhood, the daughternesship ... well, that was just ‘stuff’. Dad did not need to know that he was my dad to know that we were deeply connected. When his eyes lit up with recognition and he cried out ‘mammy!’, I did not correct him. I was proud to be the person he saw as safe and nurturing. It was love speaking.

There was another undercurrent of grief here, too: anticipatory grief. This is a quiet, rarely spoken grief that takes hold when you know that the only outcome for your loved one is death. It is a quiet grief because you keep it at bay not wanting the person to see you grieving for them. You want to make whatever time they have left of their life joyous and loving, and there is no time to let the grief that is already seeping through the very fabric of your being, start spilling out. You become a container in which you press the grief right down, covering it with extra special birthday celebrations, anniversaries, trips out, holidays and long-overdue visits to family and friends.

Although ambiguous loss and anticipatory grief somewhat resolved when my dad took his last peaceful breath, they were immediately replaced by another kind of grief. This next level of grief was what one might call a more ‘normal’ grief — an expected, public kind of grief — which involved arrangements, tears, a funeral, memory sharing, a gathering, a good spread, and a toast for a life well lived.

Of course, what I have just written is not a reflection of how it felt at the time. This is me, writing three years later at what might be called the ‘acceptance’ stage, a stage where I can look back with less pain and remember the fleeting, precious moments that kept us connected.

Grief never fully goes away, though, and now, for the first time since I lost dad, I find I am in a spiral of grief once again. The strands of ambiguous loss, anticipatory grief, and some
other grief I struggle to name, are twisting around each other again, rope-like and unforgiving, tighter and tighter.

When mum’s care home went into lockdown, I was understandably angry and I railed against what felt like an inhuman separation and enforced incarceration of my poorly and vulnerable mother. The rare neurological condition she lives with has already robbed her of mobility, speech, swallowing, continence, and is taking a hold of her cognition, too, and now she is separated from her most important lifeline — her family and friends.

When a decision is made for a loved one to move into a care home, it is a decision fraught with all kinds of denial, guilt, regret, and anger — it is a grief — and the transition from home to care home is such a tender and sensitive time. Mum made her own decision to make the move and, despite my best efforts to convince her that we could find a home together and I and my family would look after her, she was adamant that I was not to do that. She was understandably frightened, nevertheless, and my sisters and I promised her that she would never feel bereft and abandoned. This is a promise we have not been able to keep due to the pandemic and, believe me, we have tried. No amount of phoning, video calling or waving through a window could make mum feel any less abandoned and we have had to watch her diminish in physical and psychological stature at an alarming rate.

I am heavy with the grief of helplessness and powerlessness and, what is worse, it is a grief that, when expressed, has been rebuffed and denied numerous times. ‘Surely, you would rather your mum was protected from the virus?’ is the refrain I have heard repeatedly whenever I have spoken of the hurt and pain I feel about this situation. Of course, I want mum to be safe, but I wonder if forced separation from family and friends is ever ‘safe’. I am grateful that mum is still alive, yes, and I
remain hopeful that we will be reunited soon but I do not know where to place all these difficult feelings.

This part of my story has no neat ending because I am right in the middle of it. I am still trying to work out how to deal with the grief of a ‘lost year’ with mum — a grief that is denied expression because mum has not died — and, at the same time, I am holding that we are a whole nation in grief for so many pandemic-related reasons.

My hope is that, as we all recover and get back to some kind of normality, we will be able to acknowledge all the griefs of 2020/2021 and support each other through the collective and individual griefs that will inevitably emerge.

**About the author: Ruth Coward**

Ruth is a neuro-diverse, full-time family carer as well as a counsellor, life coach and qualified teacher in further, higher, and adult education. She is based in the East Midlands and lives with her husband, two daughters and family dog. Ruth is currently finishing an Open MA with The Open University and working on her last module for which she has chosen to study classics as something ‘different’ and non work-related! After completing the MA, Ruth hopes to turn her hand to more writing and public speaking projects on the topics that she is most passionate about which include neurodiversity, mental health, elder care, and living with grief. There is also a burgeoning performance poet in there, too.

2. There are many places you can read about ambiguous loss but this is my main source of information and support: www.ambiguousloss.com
3. Referencing the stages of grief found in the Kubler-Ross book mentioned in Point 1 above.
In 2019, in the very early days of the global Covid-19 pandemic, my mother’s difficulties with Parkinson’s Disease and dementia intensified after a long trajectory of decline. Her life at home with her wife was no longer possible and she moved into a care home, a car journey from where I live. For the next few months, I was able to visit a couple of times a week, popping over to sit with her, to talk to her, and to help as far as I could with bits of her care. There were no restrictions on entering the home, just a key code so that residents did not inadvertently wander, and a logbook of visitors for fire safety purposes. As the carers said, this was my mother’s home, and I was welcome any time. Her wife could spend hours there, accompanied by their golden Labrador, private in my mother’s room. My sisters could travel down from the north of England and visit for several days in a row. Her friends’ names appeared in the visitors’ logbook, and flowers and gifts from them were displayed on her windowsill.

In this new home, I met the other residents, and sat with them while they ate in the cheerful kitchen. My mother once steered me round this room by the arm, delightedly intro-
ducating me to carers and residents as if we were at one of the parties she so loved. Later on, I walked with her as she distractedly wandered the corridors, seeking something or someone she had mislaid. In this time, there was a sense of peace between us, in a relationship with its share of tension and conflict. When she saw me arrive, she often broke into a smile before I told her my name and that I’d come to visit her, her sight and memory difficulties temporarily overcome at a moment I was present to witness. I talked to my mother about her past, and the people we both know and knew, and about her interests in politics, current events, and the art she loved. She was already wandering in places and times to which I could not follow her, but sometimes we connected. I could interpret some of her spoken thoughts, drawing on the past we share. When she said she was living in hospital, I could link this to her nursing past in the trainee nurses’ homes of the 1960s. When I first told her about Covid-19, a new virus in China, I could connect this to her trip there twenty years ago to visit my sister who was teaching English in a Chinese school. When she then excitedly exclaimed ‘way, way’, I could realise she meant the Chinese dissident artist Ai Weiwei, a reference from my mother’s later life as an abstract conceptual painter and a gallery owner, embedded in the Cornish art scene but with a passionate interest in international art. Her face lit up as I made the link, and, briefly, we were back to the best parts of her old life.

As winter turned to spring in 2020, it became clear that Covid-19 was no longer a remote virus in China but was wending its way towards us in rural Cornwall. European countries were moving into lockdown. I started paying more attention to the moment of departure from my mother, ensuring that I left when she was awake and might be aware of my hug and goodbye kiss. I took more photos of her daily life. I knew she was moving towards the end of her life, and I also knew
this virus would threaten her, and perhaps my time with her. In mid-March, as I arrived at the home, a delivery man turned up with a clear container labelled ‘Isolation Box’ containing packs of gloves and facemasks. On a WhatsApp chat with my sisters that night, we discussed the idea of care homes ‘cocooning’, and rumours on Twitter about ‘quarantining’ all over seventies. A few days later, the government announced plans to shield people with serious health conditions, and my daughters’ school closed. There was a sense that a serious lockdown was coming. But the Sunday before the first full lockdown was announced was Mother’s Day. I rang the care home, and they were still accepting visitors. So, I drove over and sat with my mother in her sunny room full of spring flowers, conscious throughout the visit that I might not see her again for some time.

In fact, it was six months before I was allowed to visit again, and most of that time my mother spent with no visitors at all, not even her wife. The care home tried to compensate with technology: Skype sessions which felt like a form of spying on my mother as she deteriorated. We tried to atone for our absence, talking loudly into the online void as our mother stared blankly away from the screen, or fell asleep. The masked and gowned carers appeared on screen cheerfully trying to bridge the distances between us all. It didn’t feel like it was working, but these simulations of human contact were all we had. In autumn, my mother’s wife was allowed in, without the dog, and eventually I was granted an outdoor visit. I sat at the prescribed two-metre distance, in full PPE including a mask, and my mother, who had become immobile in recent months, was wheeled out to me in the garden full of traffic noise, swathed in blankets, a confused smile on her face. Her speech had deteriorated so it was now mostly incoherent even to people who knew her past. Her sight and hearing were already poor. I think at best she knew someone was there with her. We
Social death in the pandemic care home

were left alone, and I thought about breaking the rules and moving nearer, perhaps holding her hand. But the responsibility was too much, and I stayed at the regulation distance, trying to project my tearful voice across the space between us.

After that, there was the second lockdown. As it eased towards Christmas, one of my sisters made plans to drive down, and we booked visits with the home. But then the cases swooped upwards again, some of the staff tested positive, and all visits were cancelled as we nationally headed for the third lockdown. By Mother’s Day 2021, my mother had been without visitors again for three months, when my sister was allowed in on a special trip, justified under Covid regulations as an end-of-life visit. After that, my mother’s wife became the single designated visitor, and my other sister and I claimed end-of-life visits. Allowed into the home a year after the sunny Mother’s Day of 2020, the room was dim, the Mother’s Day flowers we had sent this year dry and dead in their vase. My mother’s eyes were unfocused. She was huddled in her chair on the sling which is now used to hoist her from bed to chair, her thin limbs twisted together and her face gaunt and immobile. I sat for my regulation hour, talking about random things which might spark something in her mind: hens laying, planting an apple tree, how cold it might still be in Yorkshire where she grew up. She said words now and again, in which I could discern no meaning. The opportunities of the year before, of sparking something about her former life and her identities, of making a connection between us based on our shared past, of acknowledging our relationship were gone.

In my academic life, I research aspects of personhood, kinship, and the beginnings and ends of life. What happened to my mother in the pandemic felt like a personal case study deeply connected to my research. Mulkay and Ernst (1991) have described care homes as locations in which persons at the end of life are segregated from others and begin the process of
social death, a form of death which can take place before, or indeed after, physical death (Borgstrom, 2017; Glaser & Strauss, 1965; Králová, 2015; Sudnow, 1967). Sweeting and Gilhooly (1997) have argued that dementia itself is an instance of the social death of the person. In my experience, however, the pre-pandemic care home was a place where my mother’s personhood could be reaffirmed by visitors in the face of increasing physiological and social difficulties produced by her illness. Staff maintained her personhood at a basic level, treating her with respect, kindness, and humour, but it was visiting kin and friends who could maintain a connection with her historic identities and who were able to shore up her personhood and relational agency, staving off her social death. It was the Covid-19 pandemic, and the political and structural deprioritisation of care home residents’ social lives which accelerated and enforced my mother’s social death.

About the author: Aimee Middlemiss

Aimee is an Associate Lecturer on DD102 Introducing the Social Sciences at The Open University. During the pandemic, she completed her Economic and Social Research Council (ESRC) funded Sociology PhD about women’s experiences of pre-viability second trimester pregnancy loss in England at the University of Exeter.

References


I am currently spending time with a friend who has recently been given a terminal diagnosis. All treatment has been stopped and she was given the instruction to go home and do what she wants to do until jaundice kicks in and she begins to lose weight. Sounds like a sense of freedom – do what you want.

She has a list of things she would like to do such as visiting the gorillas in the Congo, a Mediterranean cruise, wing walking and visiting places that she has never seen. It was quite exciting talking about her list and exploring the concept of the ‘bucket’ list. There is, however, a small problem in that we are currently in lockdown and no-one is going anywhere — no gorillas, no cruises, no visiting, no travelling not even being able to visit friends. Suddenly the sense of freedom dissipates as we realise that these are things that she will never be able do in the time she has left, and we are left with a feeling of disappointment and sadness and hopelessness.

I often wonder why, as a society, we do not give death and dying the true attention it deserves. It is, after all, one of the only things that we are certain of in life — that we will die, but
the notion is still treated like the diagnosis of cancer when my mother died over 40 years ago — you don’t mention it — you don’t say the word. Somehow, if you don’t mention it, it will go away.

Time moves on and attitudes have moved on. On receiving terminal diagnoses, there is now so much more support and people are encouraged to plan and do things they wish to achieve in their remaining time — to share their wishes and decisions, to choose where to die rather than simply facing the stark wards and routines of a hospital. Choice is something that the pandemic has tightened its grip on. My friend and I cannot choose to do much in these few short months of her life as they are taking place in the midst of a pandemic.

This leads me to think about choice at end of life, choice for those who do not have the luxury (if we can call it a luxury) of knowing that the sands of time are running low in their physical existence. What do we do? How do we react when events pounce on us out of the blue? Death and dying are then redundant concepts as we are forced to move on, to consider grief and the need to embrace loss. As I spend time with my friend, my silent thoughts gravitate towards the losses that I have experienced. A fond memory of parents and family members who had lived their lives and given life, but what of those who we feel were not given enough of a life — what of those who we feel were cheated of life — those who died young. I realise that the concept of being ‘young’ in this context very much depends on individual definitions. Young to some may mean some-one in their fifties, sixties or even, in this day and age, seventies. My mind is drawn to those I have known who have died in their twenties and early thirties. What choice for them?

The most painful, excruciating loss I have experienced is the loss of my son. He was 29 years old and only two weeks away from his 30th birthday, enjoying a week’s break in Berlin
after completing his Integrative Counselling Diploma. On the second day of his trip, he experienced a brain aneurysm and was sent to a hospital there: Krankenhaus Charite where he remained, mainly unresponsive, for the next three months. How we looked forward to our daily visits. In Berlin, visits are strictly monitored, only one hour per day and only after medical staff have completed their rounds. We chatted, we sang songs, we listened to his music — I say we, but the communication was only one way. It was just having the ability to be with him, to hold his hand, to whisper I love you in his ear, to read his books on existentialism to him, to massage his once very proud and now wasting muscles in his arms and legs. The physical presence, just being near him, the physical touch, his smell, listening to his breathing even though it was via a mechanical ventilator. He was there, but not there. What choice for him? We tried to help him make his choice. We reassured him that it would be ok to go — to please not stay as an obligation, to please do what he needed to do but to know that we loved him no matter what his choice.

What choice for people who cannot voice their thoughts? People on ventilators, people under heavy sedation, what choice for them? Choice then seems to move on and become the responsibility of those close to them, or those who do not know them at all. And what a responsibility that is — one that paradoxically doesn’t want you to make that choice. We were told Alex may have locked-in syndrome, may never regain consciousness, may never talk, never walk. We were asked to make a choice — the choice to turn the ventilator off. What kind of choice is that? I could not make that choice. That choice felt like I would be taking my child’s life away. But that choice ultimately needs to be made. It came when his condition deteriorated; he was experiencing seizures and we were called at five in the morning to the hospital. As the medics and his family were gathered in the room and his seizures were
getting more frequent, the consultant looked at me and no words were exchanged, just a single nod and then the medic removed the ventilator tube. We waited with Alex for over an hour until he breathed no more — the choice had been made.

My thoughts are disturbed by my friend rummaging through her wardrobe, choosing clothes to give to others and I am left with feelings of such sadness and loss and longing. Choice is still here with us in this room and my thoughts go out to those who because of the pandemic are unable to see, touch, smell, hear or talk to their kith and kin — those who did not have that choice to be together. Death and dying, grief and loss are shared by us all, as we have this certainty in life — that we shall all experience death and that we need to remind each other that we will never be alone in this certainty.

**About the author: Zenia Wainwright-Melnyk, BA (Hons), MSc.**

Zenia has worked in the field of health and social care since graduating in psychology in 1981. She has worked in statutory and third-sector organisations ranging from support services to project management. Zenia continues to be involved in service delivery and improvement from being a member of the Patient and Public Involvement Forum to undertaking investigative projects for the Elizabeth Nuffield Foundation, the University of Kent and Greenwich. She currently teaches K102 & K219. She remains a grieving mother.
SECTION III

DEATH AND DYING DURING THE COVID-19 PANDEMIC
Distance kept
Time suspended
A body in a bed, changing.
Not any body
Somebody.
Last breaths issue as quiet as peace,
In the way life exchanges this place, for that.

Nurse, her natural way of being contained by contagion’s clothes
The protection for the times
Feels the sting of the words she will soon speak.
Words not ready to be heard by those who must hear.
She steadies herself to say them, anyway.

‘I’m sorry…,’ she whispers
Confirming what they had witnessed and not wanted.
Her gloved hand reached across the bed and gripped hard the hand of the man
Who had been punched in the guts by her words,
A trembling man who had lost his love.

Daughters at the bed corners
Bent double, the squeal of grief caught in their throats,
Cries muffled by their dignity and the grateful recounting of a Mother’s blessings.

Driving home, her duty done
No distance can be kept from the thoughts that invade
Her closely guarded mind and heavy heart.
She surrenders, tears trickle.
No need to lockdown sorrow in this space
Now the mask is off.

About the author and background to the poem: Anne Coyle

Anne began her nursing career in April 1981 at the Royal Victoria Hospital, Belfast. She is now semi-retired and works with Marie Curie caring for people with life-limiting and terminal illnesses. She also works as a practice tutor supporting students undertaking The Open University’s nursing degree programme.

Most of Anne’s career has been in the fields of oncology, palliative, end-of-life and bereavement care and as such, she is no stranger to sad, emotional and moving encounters with patients, families and colleagues over the years. However, she reports there was something very different about nursing in these situations during the pandemic. Having to wear PPE, keeping distance from others etc, especially in situations where a hug would be the best medicine, really impacted on how she would normally relate to relatives in particular when in home-care situations.

Anne has used reflection on practice throughout her career to get her thoughts about nursing experiences on paper. This
poem began as a reflection of a particular situation: the first patient who died when she was on duty during the first lockdown of 2020. The family sacrificed so much of what would have been normal around the time of death for the culture in Northern Ireland. The patient’s daughters remained in their mother’s home to support their father. They decided not to have their partners with them to reduce the number present, and therefore, reduce infection risk, so the nurse caring for their mother would be safe.

With that and the many other changes the pandemic had brought to this situation, Anne reports this reflection helped her capture the atmosphere of the moment and its impact on her. It eventually became a pared down poem, a tribute to what she saw and how she felt. It is no doubt a scene repeated with similar emotions felt by nurses thousands of times in homes and hospitals across the world.
When the full effects of the pandemic hit us, in March 2020, it was soon clear that the impact on people with learning disabilities and autism would be severe. All of us were in shock: for people who find unexpected change difficult at the best of times, the sudden transformation of everyday life was even more dramatic. At a stroke, people with learning disabilities and autism were deprived of contact with friends and family and of the regular activities on which they depend for their quality of life — school, college, clubs, groups, volunteering, jobs, and leisure activities — and they were faced with a barrage of confusing (and confused) information.

Thankfully, organisations swung into action, within days providing high-quality easy-read information. Photosymbols, for example, produced at speed brilliant images that featured — as always — people with learning disabilities themselves to communicate key messages. Books Beyond Words provided social stories. These resources could be, literally, life-saving. Self-advocacy groups developed accessible information about the pandemic and how to keep safe. However, something was missing, and that something was a forum where people could
share their personal stories about what was going on — to help make sense of and come to terms with their experiences, to get a sense of perspective, to laugh, as well as to empathise with the grief and fear of others. Where were the stories of fun with Joe Wicks online; the fear when a family member became ill; the bemusement about what to do with yet another bag of turnips; getting to grips with working at home for the first time; joining exercise classes on zoom; the sense of community that came from taking part in clapping for the NHS and making rainbow pictures?

Sharing personal experiences is a critical life skill that needs careful consideration for people with communication difficulties. Storysharing®2 is an approach that was developed 20 years ago from working in schools and centres for children and adults with severe and profound learning disabilities. Over the years, it has been noticeable how often staff exchanged anecdotes about the individuals they supported — and how rarely they did so with those individuals themselves. When there was a conversation about past events, it usually took the form of question and answer, which could come to resemble an interrogation. Because of the challenges faced in remembering and in communicating the information, the ‘answers’ (the story) tended to emerge bit by bit, through a process of elimination. The process was completely different to what we see when people without such difficulties are engaged in reminiscence, where there is animated acting out, use of different voices, lots of gesture, use of objects and phones to share images, laughter, exclamation, and more often than not, co-telling if more than one person knows the story. Storysharing® uses all of these features to enable people to share not just the facts of an event, but what it means to them. In 2020, at the start of the pandemic, a collaboration with teachers from Three Ways School in Bath, Flo Hopwood and Katrina Arab, both trained Storysharing® tutors, led to the Surviving through Story Face-
book page\textsuperscript{3}, where we posted story scripts that families could adapt and use, together with suggestions and ideas, line drawings of signs donated by the Makaton Project,\textsuperscript{4} and symbols provided by Pictologue.\textsuperscript{5} We ran a series of free webinars, attended overall by some 300 people, exploring loss and bereavement (with Professor Tuffrey-Wijne), film-making and digital storytelling (with Mascha Legel Cam on Wheels (https://camonwheels.nl) and David Messer, Our Story (https://wels.open.ac.uk/our_story)), story massage, story and music (with Soundabout) and Storysharing for resilience and recovery, once children were back in school. We knew by the end of the summer that we had provided resources that supported families.

But we also saw that the stories of adults with learning disabilities and autism during the pandemic were still missing from public discourse — unless they featured as vulnerable victims. We knew many people who were so much more than this. They were holding down frontline jobs in supermarkets and post offices, they were helping with food banks, supporting their friends and neighbours — but these stories were not being heard. Even specific websites set up to support people with disabilities barely featured those with learning disabilities and autism. One person who was energised by the absence of personal stories was Craig Hart, co-chair of The Open University’s Social History of Learning Disability (SHLD) Research Group. He was desperate to hear how others were coping, particularly with loss and bereavement. Craig was also keen to share his own pandemic experiences, to help others who may be struggling. Craig’s vision, combined with the SHLD group’s long-standing commitment to including people with learning disabilities in history, aligned beautifully with the aims of the Surviving through Story project. Thanks to the generosity of The Open University and the charity Generate\textsuperscript{6}, which provided an administrator for the site, we built the
Surviving through Story website, which now features around 100 contributions.

This needed to be a space owned by people with learning disabilities themselves. We were able to recruit a dedicated team of nine self-advocates, representing a number of organisations (Mencap, RIX Research and Media, Foundation for People with Learning Disabilities, Openstorytellers, Social History of Learning Disability Research Group, Generate) but most importantly, bringing their own experiences to bear on helping us to see how best to challenge stigma and exclusion from the Covid-19 narrative. The site features images, films and written stories, and has a dedicated page for the celebration of lives lost during this time. One of our most thoughtful and generous contributors is Susie Gentry, whose story is told below.

My lovely husband Ronnie: Losing someone you love in a pandemic

Writing my stories

Sue and I have known each other a long time – nearly 30 years we worked out. Sue knew Ronnie all this time too. Since Ronnie passed away, I have ideas myself about the stories. I tell Sue and she writes it down. I tell my story and the words that I want to put and she puts them down as I say. I work it all out in my head before. I think about what I want to say and when Sue phones me (we can’t meet because of the virus), she writes it down and reads it back to me. I listen and make any changes that don’t sound right. Sue reads it back to me again and we keep doing it until I’m happy with it.

I always think about Ronnie and I like to write stories about him. I always remember the good times me and Ronnie had together. I like talking about Ronnie. He would be pleased with me and he would be proud of me for writing my stories.
Another reason I wanted to write the stories about Ronnie was that when I first met him he was a very nice man. We became friends at first and then we started talking and getting to know one another and fell in love with one another and then we became lovers and then we got married. We were together for 40 years. I was happy that I married him because I loved him very much and I still do.

Ronnie and Me: No chance to say a proper goodbye

I lost my husband Ronnie during the Covid pandemic. He died in hospital on 11 April 2020. He died because there were lots of things wrong with him not because of Covid. He didn’t have the virus, but he died after the pandemic had started. He died in the first lockdown.

He was with me at home on the Friday night. He fell on the floor at our flat and I called an ambulance. He went to hospital and he was very sad that I couldn’t go with him in the ambulance. I didn’t want him to go either but I could see he was very ill.

When I last saw Ronnie on the Friday night he was upset because he didn’t want to leave me for the hospital and I gave him a kiss and a cuddle and told him not to cry and said ‘I will see you when you’re well and better’. He passed away on the Saturday. I wasn’t able to say goodbye to him at the hospital before he died because I couldn’t visit. It was lockdown and the virus. So we never had a proper goodbye. When I said goodbye to him then I really thought he was going to get better and come home to me. I had no idea I wouldn’t see him again. The hospital phoned me up and told me that he had passed away. The nurses told me he was talking about his wife Susie in the hospital and asking to see me.
Our story

Ronnie and I got married in 2005. The reason why I married Ronnie was because I fell in love with him and I still love him. I fell in love with him the first time I met him at Sandilands [a residential home]. We had known each other for 25 years when we got married and moved into our flat. We lived together and had help from care staff who are very good to us. We live on the 10th floor and have our own flat with all our things. Since Ronnie died, I’m here on my own now. We would have been married for 15 years this year. We were very happy together. We had a good life together and Ronnie had a good life with me.

We went on holiday together, we went out together, we went to the pub together and we celebrated all our birthdays and Christmases together. He was a good man and a good husband to me. He looked after me when I wasn’t well and I looked after him when he wasn’t well. We had a good wedding. It was lovely. We have a lot of wedding photographs from that day. I loved him very much and I still do. Ronnie loved meeting people, making friends and talking to people. I miss Ronnie very much.

Not seeing other people has been hard

I had no idea he would die when I said goodbye and the people put him in the ambulance. We went from being together all the time to me being here on my own with the carers coming in. It’s been even more difficult to lose Ronnie when the virus is happening. This is because the funeral had to be smaller — 10 people — and I haven’t been able to see many friends.

This makes it more difficult as you are on your own more. I am still able to see my carers because they look after me but I haven’t been allowed to meet up with any of our friends to
have a drink and a toast to remember Ronnie and raise a glass to him. I would like to see friends and share memories and look at photos together. I feel it would cheer me up. I do speak to people on the phone and when my carer is here, I message people on Facebook but it’s not the same as meeting up with friends and going out to places like the cafés and the pub for a nice meal and a chat. I am lucky as I have a lovely neighbour who is my friend. Sometimes it’s very hard to be here on my own as I miss him so much. And each time it’s like the first Easter without him, the first Christmas the first Valentine’s Day.

To remember him I talk to him instead. I say good night to him and talk to his picture. I’ve got a new green plant and I call it Ronnie. This makes me a feel a little bit sad but when I look at it, it makes me feel like he’s here in spirit. I like to look at the photos in our flat. I remember when Sue’s daughter was small and he played with her and lifted her up in the air. I got that picture in our lounge and I look at it and it makes me smile. Ronnie loved children and he loved meeting people. I look at the picture of us outside Sandilands with Jenny our lovely dog.

**Deciding what to do with Ronnie’s ashes – having to wait**

It’s a big decision. I haven’t been able to collect them yet. It’s now a year since he died. I’m just waiting until the end of this lockdown (April 2021) and then I will collect his ashes from the undertakers.

I am still not able to do this because of the restrictions. You are not allowed to meet up with people. Ronnie was the best husband in the world and I will always have that. I need to think about what I want to do with his ashes when I have them.
About the authors: Nicola Grove, Susie Gentry, Sue Ledger and Liz Tilley

Nicola is a consultant and researcher in disability, communication and storytelling. She is currently an honorary senior lecturer at the Tizard Centre, University of Kent, and a member of the Social History of Learning Disability group at The Open University. She has authored several texts on sign language and augmentative and alternative communication, access to literature and storytelling for people with intellectual/learning disabilities.

Susie attended a boarding school for children with learning disabilities before moving to residential college in Wales. After leaving college, Susie settled in a seaside town in the south of England. In the 1990s, she worked in a charity shop whilst living in a residential care home. She married Ron Gentry in 2005 and together they moved into their own flat. Susie attended singing classes with her husband and together they performed in concerts and shows. Susie has previously written about songs composed and sung by people with learning disabilities in residential schools.

Sue is a Visiting Research Fellow at The Open University, UK. A member of the Social History of Learning Disability Research Group, she has co-researched with people with intellectual disabilities on a range of projects including institutional and community history, songs of resistance and life story work. Sue has over 25 years’ experience of working with people with intellectual disabilities and their families across health, social care and advocacy settings.

Liz is Senior Lecturer in the School of Health, Wellbeing and Social Care at The Open University. She co-chairs the Social History of Learning Disability Research Group, and has been researching alongside people with learning disabilities for a number of years. Liz has a particular interest in historical
perspectives and the role of history and narratives in sparking activism and change. Liz has recently led research projects exploring people with learning disabilities’ participation in heritage, and experiences of belonging across the UK and Japanese cultures.

2. www.storysharing.org.uk
4. https://www.makaton.org
5. https://www.pictologue.co.uk
6. https://generate-uk.org
7. As this is for a book not a website, Susie has chosen to use real names for herself and Ron, her husband.
My stepfather of 20+ years, Peter, had prostate cancer many years ago for which he received radiotherapy. He also suffered several strokes over the later years of his life but recovered well, though he was a little less strong each time. He also had heart problems and his hearing was poor. A couple of years ago, now in his early eighties, he felt unwell, and we were given the news that his cancer had returned and had spread to his abdomen. Due to his age and other conditions, it was decided to give him regular chemo injections, rather than other cancer treatments, and to review his condition on a regular basis. Appointments with the consultant were jolly affairs if you can believe that — Peter had a great sense of humour and made the care staff laugh each time we attended. Looking back, I don’t think he realised the seriousness of his condition. Or he chose to ignore it.

He and my mum lived in sheltered housing in a complex a few minutes’ drive from where I live. I would take them food shopping every couple of weeks. They came to ours regularly for meals and to celebrate birthdays or just for a coffee and a chat. I have fond memories of the laughter we all shared.
When the pandemic hit, and we were in lockdown, I continued to do their shopping online and would take it round. They would both come down to the car park for a socially distanced handover of the goods. As the weeks went on, Peter was quieter. Over time he stopped coming down and just waved to me from the window. Mum said he was noticeably quiet, which for a man usually so chatty, was worrying for us. He had four falls in as many weeks. The paramedics were called each time and the final time he was taken into hospital.

It transpired the cancer had spread to his spine, affecting his nerves. This was more than likely the cause of the falls. We were unable to visit him whilst he was in hospital because of COVID restrictions. Due to his various frailties, he wasn’t able to use a mobile phone or iPad to keep in touch with us. After two weeks, he was moved to a nursing home. Because of his instability he couldn’t come home but there was ‘nothing further’ the hospital could do for him. At first this seemed a positive step because we thought after a few days of physiotherapy he would literally be back on his feet and able to come home. But our initial feelings of hope were short-lived as the reality of his decline became increasingly apparent over the following days.

We were very lucky because the nursing home allowed visitors — the only nursing home I was aware of that did. Each room had French doors to the outside. So, we were able to sit in the open doorway, wearing masks. We weren’t allowed or supposed to approach him or touch him. At our first visit, it was a shock to see him. He had lost so much weight since we had last seen him several weeks before. At first, he apologised for all the fuss he had caused. He told us he was keen to get home and thanked us for visiting.

The physios tried to get him on his feet but his time in hospital had left him weak. He had a bedsore. He wasn’t eating, saying he would eat when he got home. We said he
couldn’t come home until he could walk. We encouraged him to eat because that would give him strength to enable him to stand to then walk and then return home.

With soup being the best option to try, the cook at the nursing home asked him what his favourite soup was and brought it to him in a beaker. The care staff would hold the beaker to his lips, encouraging him to take a drink, but after a few sips he would wave their hand away. We’d encourage him to try to take a few more sips but his face screwed up with the attempt, as if it tasted vile. We were so frustrated but no amount of encouragement from us (my mum sounding more and more angry with him) or the nursing home staff would persuade him to eat. It seemed so simple, but he still refused to eat and wasn’t strong enough to stand, let alone walk.

Over time, he stopped talking to us and he slept a lot. But we visited every day, spoke to him, and told him we loved him. We read him the cards from his grown-up children. Looking away, it was obvious he wasn’t really interested in anything. His children lived some distance away and couldn’t visit.

On the final day mum and I visited, he was agitated and wasn’t coherent. He wriggled around in his bed, waving his arms and attempting to kick the covers off his legs. His brow was furrowed as he moved his head from side to side, gazing into space, not seeming to realise we were there despite us talking to him. It was distressing to see him looking so troubled—I felt so sad for this previously strong, funny, loving man and what he had become. And it was hard supporting mum who was seeing the love of her life fading before her eyes.

We had a phone call to say he had died that afternoon. By now my husband (also called Peter) and I had become a ‘bubble’ with mum so were able to go into her sheltered housing complex. We went to mum; she looked surprised and pleased to see us, not realising the purpose of our visit. We gave her the news which was awfully hard. Mum is from Yorkshire and has
a very practical, stoical attitude. But over the days that followed, I found a scrap of paper on her bedside table – it was a love poem torn from a newspaper, with no author that I could see, that reminded her of the love they had shared. ‘Those we love don’t go away, they walk beside us every day, unseen, unheard, but always near, so loved, so missed, so very dear…’ I felt so sad for her.

Due to the pandemic, we couldn’t have a full funeral. Instead, mum opted for a cremation without a ceremony. He hadn’t seen much of his children although there was no ill feeling between them, so the decision was mum’s. We didn’t realise he would be taken to Aylesbury to be cremated and after discussion, mum decided that was fine and his ashes should be spread there as she had no intention of visiting. She figured, neither she nor he had any religious beliefs, so there was no reason to visit. But after a few days, she had a change of heart. She wanted his ashes brought to Milton Keynes’s crematorium in case she changed her mind about visiting his last resting place. Due to the pandemic, we had to collect his remains, so Peter drove her to Aylesbury to collect him and deliver the ashes to Milton Keynes.

The Milton Keynes Crematorium staff were brilliant and so kind. They showed mum the place where they would spread Peter’s ashes, which was near a bench. They asked her if she would like to be present when it happened. Mum was happy not to attend but was pleased to now have Peter back in Milton Keynes where she could visit if she felt the need to. I too was happy with this decision – initially, I thought it wouldn’t matter where his ashes were but knowing he was in Milton Keynes gave me some sense of comfort.

A few weeks later, our dog Jess had to be put to sleep. She was a rescue dog, a cross between a whippet and a Patterdale terrier. She was quite elderly and was on daily medication for seizures. She too had cancer which eventually spread. She was
a character, fine with us but didn’t really like people or other dogs, so walking her could be quite problematic as was having people over to the house until she got to know them. But she loved a cuddle on the sofa and had big, doleful eyes. She had been my constant companion since lockdown when I’d started working from home. She always sat near to me when I was working and followed me like a shadow whenever I left my ‘desk’ (really the dining table). Being a whippet, she liked to be covered with a blanket but often struggled to cover herself despite lots of digging in her bed. That’s when she’d look across to me as if to say, ‘Well, are you going to help me or not?’ and as soon as I approached, she’d curl round into a tight ball ready for the cover to go over her. As soon as I finished work, she would know it was time for a walk and would start jumping with excitement, straight up into the air at nearly chest height. We knew it was time to say goodbye when she was off her food and had stopped jumping and didn’t want to go for a walk. Because of the pandemic, we had to sit in the vet’s car park and wait for our turn to be seen. Our daughter, Emma, was able to travel up from London at that time so we all three sat in the car, watching several other cars and occupants waiting for their turn. At least two of them had their dogs put to sleep in the back of the car. It was awful to witness, so public, with nowhere to hide the grief and tears, but it prepared us for what we would experience. The veterinary staff were great, considering the circumstances they were working under. We were given the options of either one of us taking her into the building or they could give her the injection in the car with all three of us present. We wanted to be together at this time, so we folded the back seat down and I stood behind the car while Peter and Emma sat in the boot with Jess lying on her favourite blanket. After she had died the vet gave us as much time as we wanted with her then carried her, wrapped in her blanket, into the building. It was so sad
but under the circumstances was as good as it could have been.

It was a difficult few weeks with one death coming so soon after the other; the worry and fear caused by the pandemic adding to our grief. Whilst reflecting on this time, I can see similarities between the two events. Both had been of a good age despite various health problems. With advancing illness, they both slowly became more and more subdued, but it was such a slow decline it wasn’t until they stopped eating that we realised how far their health had fallen. We tried to encourage Jess to eat, as we had tried to encourage Peter. We bought different varieties of dog food and cooked her chicken and rice. In the end she would only eat cream cheese, which was fortunate as we could hide her medication in it.

I had not seen my stepfather face to face to talk to or to hug for several months because of the restrictions caused by the pandemic. In some ways, this made his death a little easier to cope with. He was of a good age and had had a great life and had many health issues. On the other hand, the loss of Jess hit me quite hard. Because of the pandemic I had been working from home for over eight months and was used to her company as she sat with me for most of my working day. She made me laugh with her antics such as getting her legs caught up in the wires for my laptop and internet connection or suddenly barking at a bird outside the window during an online meeting. I was surprised at how badly I was affected; after all she was ‘just’ a dog, but it is only now, six months on, that I can look at her photos and videos and smile rather than tear up.

Despite the sadness, we feel luckier than so many others who were not able to spend time with their loved ones before they died. The NHS staff were outstanding in their care of Peter and we shall be forever grateful for that.
About the author: Heather Fowler

Heather was born in Bradford and arrived in Milton Keynes (MK) by way of South Africa and Poole. She met her husband, through a mutual friend. Peter had a business in MK and her job in Dorset was just that, a job and not a career, so it made sense for her to move to MK and start their new life together. That was 32 years ago. They have one daughter, Emma, who lives with her boyfriend in London. She has been a member of OU staff since the 1990s on either temporary or permanent contracts. She started as a temp in what was then the Summer School Office, typing up reports on access requirements for students with disabilities attending summer school, and her last role was that of a Curriculum Coordinator in the School of Health, Wellbeing and Social Care.

She left the OU at the end of March 2021 to spend more time with her family – her elderly mother, now living on her own, is in poor health and her husband is semi-retired.

The pandemic has caused Heather to reassess her life and what is important to her. Life is short and Heather intends to make the most of what time she has left to do the things she enjoys.
Thirty-three years ago, I read *Une Mort Très Douce* (*A Very Easy Death*) by Simone de Beauvoir. I have never wanted or needed to read this book again until now — now, when I need the company of another daughter who is going through what I am going through. Now, when my own mother has cancer and is dying.

I was 17 years of age when I found Simone de Beauvoir. I imagined her in a café in Paris, smoking an unfiltered cigarette, engaged in intellectual conversation with her lovers and peers. I was keenly awaiting the start of my undergraduate degree in Philosophy, and desperate to absorb everything about the French existentialist writers, and the intellectual world they inhabited. I had read a lot of populist philosophy before being initiated into the ‘hard core’ works I encountered as an undergraduate. *A Very Easy Death*, at less than 100 pages, led me to expect a very easy read. Not so.

Written in 1964, a year after Mme Françoise de Beauvoir’s death, *A Very Easy Death* explores the intensity and complexity of Mme de Beauvoir’s relationship with her daughters in the weeks leading up to her death, as she is ravaged by cancer and
Finding comfort and truth in *Une Mort Très Douce*

made still sicker by the complications arising from treatment. Kadish (1989, p. 631) describes it as an ‘intensely moving autobiographical work in which a daughter pursues the goal of lucidly describing her aging mother's debilitating illness and eventual death’. Brennan (2004, p. 85) suggests that its ‘themes are universal — love, ambivalence in family ties, loss, and bereavement … At its heart, the book is about a mother and daughter. But it is also a reflection on suffering, family, faith, and mortality’. Reading this for the first time, I appreciated the power of literature. I remember hardly breathing as I read the book from cover to cover — not wanting to make a sound in case I unwittingly entered the hospital room where Mme de Beauvoir lay dying. de Beauvoir says, ‘In the night the slightest sound seemed huge to me — the rustling of Mademoiselle Cournot’s paper, the purring of the electric motor. I walked in stockinged feet in the daytime. The coming and going on the staircase, and overhead, shattered my ears’ (p. 64). These words drew me into that sorrowful space and compelled me to remain quiet.

In some extraordinary and intimate way, *A Very Easy Death* spoke directly to me about the relationship I might have with my mother in the future when the time inevitably came that we approached her final days of life. I think the word presentiment might be fitting. I experienced a shocking, physical response to de Beauvoir’s writing, the shadow of which remains today and takes me back over three decades. It may be a cliché, but I felt that time stopped as I read the book. Aside from the content, the memory of myself physically reading the book is so strong that I can bring to mind my then 40-year-old mother, younger and more full of life than I am now; beautiful, glamorous, sociable and happy, with a clarity so sharp and clear it hurts — a woman I am not ready to lose, and who isn’t ready to be lost to me.

I connected immediately with the women in this book.
Something about the quality and nature of de Beauvoir’s relationship with her mother was mirrored in a younger and less mature relationship that I had with my mother, and I knew back then that, at a future time, I would reach out to this book for greater understanding of this relationship, of myself, death and grief. Since then, at intensely emotional points in my life which have brought me in contact with questions about motherhood and mortality — the birth of my daughter and the devastating loss of my paternal grandmother — I have felt what I might describe as an aura or vibration of the emotions evoked when I first read de Beauvoir’s words. I recall crying uncontrollably when my daughter was born, thinking of the joy and agony of her being a daughter to a mother who is the daughter of my mother.

Brennan (2004, p. 87) tells us that Mme de Beauvoir had an unhappy childhood, and that she brought at least some of that unhappiness into her role as a mother. Without doubt, my mother’s childhood experiences have coloured her relationship with me, and mine with her. She brought a deep need to be loved, and to love more deeply in return, into her role as a mother. I must confess that I have resented the former and struggled with the latter at times. Our relationship is complicated. My mother is a complicated woman who has lived much of her life unknowingly buried in layers of secrets, deception, hypocrisy and lies created by her own mother.

This may be why my mother is a complicated woman, and I believe partly explains why we have such an intense relationship, and why at times, I have felt like the parent in this mother/daughter dyad. McDonald (2010) identifies one narrative strand of _A Very Easy Death_ as ‘a retrospective of the mother/daughter relationship — in which each made the other suffer — and the attempt to change the relationship through caregiving’ (The Death of Maternity? Simone de Beauvoir’s _A Very Easy Death_, para 5). This is the strand which resonates most
with me, and the one I struggle with as I have become the care-
giver; the stable and consistent ‘parent’ my mother never had. I
have tried to compensate for the lack of love, respect and
honesty from my maternal grandmother, and I have also
colluded unwittingly in my mother’s selective reframing of the
past, and false recollections of ‘good times’ to make her feel
better.

A re-write of autobiographical history is understandable
perhaps given her circumstances, but I now struggle with
anything less than speaking the truth. I am blunt and factual
about our history. By speaking only the truth, I can cause
distress and disappointment in my mother. She tells me that I
am cold and unkind. Perhaps we can reach a place of common
understanding in the days and weeks ahead, something de
Beauvoir found with her mother at the end, a re-connection
and tenderness: ‘I had grown very fond of this dying woman.
As we talked in the half darkness, I assuaged an old unhappi-
ness; I was renewing the dialogue that had been broken off
during my adolescence and that our differences and our like-
nesses had never allowed us to take up again’ (de Beauvoir,

My world has diminished. Being with my mother now is all
consuming. Brennan (2004, p. 88) notes that with Mme de
Beauvoir in her hospital bed, de Beauvoir wrote: ‘The world
has shrunk to the size of her room: when I crossed Paris in a
taxi I saw nothing more than a stage with extras walking on it.
My real life took place at her side...’ (p. 64). Kadish (1989, p.
635) observes that there is not only a shrinking of the physical
world but of the psychological distance between mother and
daughter as de Beauvoir moves from a position of ‘freedom as
an independent adult to an awareness of the deep-seated ties
binding her to her mother’. I feel this too. The events and
people in the outside world are becoming proportionately less
significant as my mother’s health deteriorates, and her physical
and emotional needs grow exponentially. Existing within a devastating worldwide pandemic, we are both shielding and shielded. We are in a terminal-illness bubble; we share our bubble with an ugly, malignant cancerous tumour.

Everything that happens in this bubble concerns illness. Living in lockdown while knowingly dying means that my mother has been cheated out of having the end of life she deserves. There has been no bucket list; no time spent with her many friends during these last long months of isolation; no respite.

For me, this waiting time is a liminal space. Liminality, as classically advanced by the French ethnographer Arnold van Gennep (original 1909; English translation 1960) suggests that the major role of the liminal period is ‘to enable a transition in the individual from one status to another in society; and to supply a psychological, social and territorial “space” in which the individual may be prepared for their new role and status’ (Evans and Kevern, 2015, p. 3). It is somewhere betwixt and between, a place of uncertainly and discomfort, at the threshold of another phase of life. Once crossed, this threshold cannot be ‘un-crossed’. I will deeply, painfully, miss having a maternal figure.

After this is all over, separated from my mother, I worry about re-assimilation into a new phase of life. It will be an unwelcome rite of passage to the role of elder female in the family. I worry about re-connecting with the outside world, the world beyond our bubble with her cancer. I’m not so sure that I will be ready.

**Epilogue**

18 days after finishing this essay, my mum — my friend — died in hospital.

Covid-19 visiting restrictions denied us our final conversa-
Finding comfort and truth in Une Mort Très Douce

tion and our final chance to say goodbye. I am beyond sad, and troubled by all the things I didn’t do, and the time I didn’t give to her, and to us. In de Beauvoir’s words, ‘I fear the regrets that will accompany my grief perhaps more than the grief itself. When someone you love dies you pay for the sin of outliving her with a thousand piercing regrets … you feel that she should have had more room in your life — all the room, if need be’ (de Beauvoir, 1964, p. 82–83). I have found both comfort and truth in these words. Whatever regrets I carry, I was the only daughter I could be to her, and she was the best mother she could be to me.

About the Author: Claire A. Harris

Claire, daughter to Bernadette, mother to Izzy. She is also a Staff Tutor in the Faculty of Wellbeing, Education and Language Studies (WELS) working within the School of Health, Wellbeing and Social Care (HWSC). As a Registered Mental Health Nurse she practiced within a diverse range of clinical areas in her early career and later specialised in Veteran’s Mental Health and post-traumatic stress disorder (PTSD) for many years before moving into higher education as a Senior Lecturer in Mental Health. After 10 years lecturing within brick universities, Claire joined the OU in January 2020.

Her first academic love is still Philosophy, but with good helpings of educational theory and all things mental health on the side. Claire is currently working on the production of the L3 Nursing Practice module, L1 Social Work module and remake of the L2 Health and Social Care module focused on mental health.
References


February 2021

It has been a long and tiring 12 months, for everyone. As a counsellor in a hospice, and a nurse returning to the frontline after 20 years, this is our story:

The unseen enemy was closing in on our worlds, more and more people dying, more and more people infected, and more and more staff becoming unwell. Masks covered the face, aprons covered clothes and scrubs became the new fashion.

Within the hospice, the immense fear present was palpable. You could feel it and see it in the eyes of patients and staff left at the hospice. Suddenly, staff were furloughed or working from home, and the rest of us were separated by the need for social distancing. Strategies we used to employ, which promoted self-care and resilience, were no longer possible as staff were separated. The loss of physical contact between colleagues and patients meant we could no longer touch or hold and could not comfort or respond to each other’s human and everyday needs. The loneliness and isolation became an everyday reality. In the Hospitals, staff were being redeployed,
often to unfamiliar settings, with health-care staff going back to the frontline line after many years, all wanting to do something to help care for patients, their families and fellow staff members. There was a sense of real camaraderie in hospital, that feeling that we are in it together — but that fear of the unknown was always bubbling under the surface. How long would it go on for?

The phrase ‘I will never forgive myself if I take this home’ became the foundation for fears expressed by staff who were torn between duty and commitment to their profession versus keeping their families safe. The fear of COVID-19 was tangible. As a counsellor, the psychological impact of bearing witness to these stories had become the most distressing and emotionally traumatic experience of my career; I heard these daily from the staff, the patients and families I worked with.

Death — the very end of life — is finite; it cannot be replayed or revisited later. The effect on families who couldn’t be present for those final moments has proven to be the catalyst for further trauma and anger that has manifested more strongly in the grieving process as the choice about whether to be present at the bedside was taken away. Although some families have been able to be present when a loved one died, the restriction on the number of visitors has meant that others have reported having to watch those last moments through a window or not at all.

Nursing staff have found different ways to support visiting, facilitating heart-breaking video calls and listening to the final intimate words between loved ones, leaving them with mixed emotions of privilege and intrusion. The individual cost of that emotional experience has been heavy for everyone involved, and why wouldn’t it be? This is the life journey of patients and their families, their lives entwined. Many partners and families want to be there in the final moments; the last thing they can do for their loved one being to hold their hand as they die. The
What did we see?

nursing staff responded by providing a presence if loved ones could not be there so patients did not die alone, easing the minds of the families, soothing the end of life for our patients, working with utter commitment and total compassion.

The daily sharing of stories between the nurses, health-care assistants and doctors about the lives and deaths witnessed, and how COVID-19 changed these, was honourable to listen to. Their ability to hold each other emotionally and carry each other through the day, despite the restrictions of the pandemic, showed courage and tenacity, compassion, care and empathy. They showed a new collective spirit to find a way to simply get through this and to maintain hope that things would be different again.

Brené Brown writes about vulnerability: she says

‘Vulnerability is not winning or losing; it’s having the courage to show up and be seen when we have no control over the outcome. Vulnerability is not weakness; it’s our greatest measure of courage.’ (Brown, 2017, p.4)

Each and every member of staff, no matter what their profession, showed this courage.

It was, without question, hard. The outside world was becoming a place of fear rather than enjoyment or a place to feel the sun, a walk in the park renamed as essential exercise, once daily, no more … frightening to think that whatever we had perceived our lives to be, changed overnight. Fears exacerbated by COVID-19 sometimes overspilt into anger at how life had changed, and the future lost its clarity like muddy water, but those days were the days that colleagues carried each other emotionally. Of course, they made sure that Personal Protective Equipment (PPE) was on correctly, keeping each other as physically safe as possible, but above all, they showed each other tenderness and concern, with a mutual respect for staying committed to their beliefs as health-care professionals.
For us both, one very powerful image on social media was of two nurses stood head to foot in PPE, their heads down, eyes closed, just taking a moment to be still and to emotionally hold each other in the momentous tasks that they were carrying out daily. This was a reflection of the images we were seeing at the hospice and hospital where there were times when words simply were not adequate to hold people’s fear and bewilderment at the pandemic. Nothing was going to take away the rising tide of exhaustion, and nothing would be able to answer the question of ‘When is this going to end?’ but they carried each other, and we bore witness to that.

Distress is something we encounter regularly within our roles in the hospice and hospital palliative care team; death and dying our context. We talk with others about grief as being about the loss of a life which has been shared with another, not just about the loss of the person. During the pandemic, this has become magnified unrecognisably by those who are bereaved trying to understand this new world, while in the midst of their grief. Support from families, which comes only by telephone or video, is not always enough to cut through the pain barriers that grief presents, but contact with loved ones has been restricted beyond recognition for the bereaved.

In response to this, the hospice counselling team have seen significant changes to their ways of working, moving to working from home which has necessitated the delivery of telephone and video counselling. The counsellors listen to stories that are heart-breaking and breath-taking, but they carry on from their homes finding a way to be present, and to offer the best of themselves to provide the aftercare that is exceptional. They have ensured the counselling service continues to provide a specialist psychological service through an intensely emotional time for the clients and patients whom they now may never meet in person, yet still need to develop a human connection with. It is that connection which has enabled
patients and their relatives to find some sense of understanding of their existential process of loss and grief through this pandemic, what it means to them and how they can find a new way of living.

During this pandemic, we have observed the distress of our patients and their families, and we recognise our own vulnerability in doing this day after day. It can be hard to discuss vulnerability, but not to acknowledge its presence would be to dishonour the professionals around us who have fought every day to continue to bring a sense of peace to the dying, and understanding to their relatives. This pandemic has offered us different things. Exhaustion yes, but more so a time when colleagues have come together and built something that will never be forgotten and will continue to have an impact. Over the last year, we have seen friendships and companionships built from adversity which foster resilience, with a combined sense of internal power that can’t be defeated because we, and those we worked with, stood together and faced something we had never known. We have been sad and cried, got home and felt lucky to be alive, but we carry on because the combined philosophy of the nurses and Health Care Assistants, doctors, and all the staff who faced adversity is to be there for those who need us, when they need us.

Our support and specialism allow patients to die with dignity, and for those who grieve to have space to be supported. Focusing on the little things enables them to become the big things and delivering care with human kindness and compassion becomes a priceless and critical component in care. (National Palliative and End of Life Care Partnership, 2015). We would not have thought that Covid would have the impact on our lives in the way that it has, nor that the length of time we would endure it would even reach the summer, let alone a year later.

But it has and still we rise.
About the authors: Claire Henry MBE RGN BSc(hons) PGDip and Tracey Hughes MBACP Accredited

Claire has over 30 years’ experience in clinical, managerial and quality improvement within the NHS and third sector, working predominately in palliative and end-of-life care.

Claire has led national programmes and independent reviews including the NHS End of Life Care Programme which supported the implementation of the National End of Life Care Strategy for England and National Choice offer for end-of-life care ‘What’s important to me’.

Claire has been actively involved in community engagement and developments nationally including Dying Matters.

During Covid Claire went back to the frontline at her local acute hospital having not worked clinically for 20 years. Claire has been part of a team from the Palliative Care Team and Emergency Department developing and delivering Time Critical Telephone Conversation Training to staff during the pandemic.

Tracey is the Counselling and Bereavement manager/Lead Counsellor for LOROS Hospice in Leicestershire. She has been a practicing integrative counsellor for 12 years, specialising for the last 6 in Palliative and end-of-life care. She strives to change the language in bereavement and psychological intervention, and to honour the existential process of grief and loss, both for patients and their families.

Tracey is passionate about teaching and psychological education, being able to share her learned experiences of both peace and trauma in death and how the grief process changes. She has taught care homes about loss and grief through Covid-19 and how to manage the distress separation has caused, and is currently teaching bereavement volunteers and enabling them to facilitate bereavement hubs virtually.

Tracey is a reflective practitioner and guides her colleagues
through the complexities of death and dying and supports them to recognise the need for self-care and understanding of what’s meaningful to them; this has been especially poignant and needed through the Covid-19 pandemic.

References


On the day the lockdown was announced, the doors to the hospice closed for good. This had been some time coming, a move to a community hub with fewer rooms, a cosy beamed space, rural setting, chickens roaming with a café on site. Endings of any sort often trigger a high level of anxiety and so it was with the staff team who said goodbye to colleagues, who had opted for redundancy or new positions; goodbye to the roomy corridors, the baby grand piano around which carols were sung, the peaceful reflective rooms in which relatives had cried and grieved. A deep mourning was felt when the ward’s giant windows, which looked on to nature and ponds and ducks, a place and time that had often offered a certain dignity and care and expanse to the dying, were finally shut to the outside world. It was a sad day all round.

But against the backdrop of a rising death toll and the rapid spread of the coronavirus, coming to terms with the loss of the workplace, in tandem with the loss of any known certainties at a wider societal level, was a slow process. The sudden absences of all sorts of secure bases, in the words of John Bowlby (1979), left many of us, as professionals, in need
of one another in a way that we had perhaps not as consciously or intensely recognised before. Anxiety was impossible to deny, as was a sense of numbed shock. The impact of a collective, powerful grief paralleled the processes of individual grief. Once the aftermath, the shock, began to dissipate, the felt-sense of ‘missing’ allowed us to think clearly about our value to one another. And exciting, innovative ways of regrouping took place.

As a palliative psychotherapist, faced with a rapidly changing family and working set up — children now at home for the foreseeable, partner sent back from London, a shift to Zoom and telephone counselling for people ageing, dying, grieving — it was important to join and to continue to belong to reflective, thinking spaces throughout the pandemic. Assimilating one’s own sense of precariousness, internal and external, while being invited to contain the overwhelming fears of clients (no longer able to access the service face to face in the sanctuary of the counselling room, or within their own homes) was a daunting prospect. A question would linger, ‘Whose anxiety belonged to whom; was it located now in the client or the practitioner?’ While the disentangling of transferences and counter-transferences is par for the course in psychodynamic practice, being plunged into this curious online crisis-based counselling meant that attending to one’s own processes as separate from the client’s was ever more important. However, owing to the perpetual fears, the sheer pain and suffering reported each day (through news channels and from colleagues) and that experienced in my day-to-day world, this task demanded considered, careful and concentrated focus, helped by peer support networks.

A certain sense of homelessness lingered, which was paradoxical to the injunction to stay at home. Where could home, then, be found in this cut-off disconnected place of working through video link, unable to encounter the bodies and minds
in the rooms with us? Psychotherapy relies on words, of course, but we also make contact with the non-verbal, the way that a body manoeuvres itself in space, the way the movement of a foot, the raising of an eyebrow speaks. Our clients, many of whom are dying, notice that the cleverness of words — and the way they can at times defend us from ourselves — may be ebbing away; what then of the work of palliative psychotherapy and our understanding of one another? How, then, do we continue to see, and to hear, and to touch through the screen?

Reminded of the words of Julia Kristeva (1985, p. 152), when she points to a form of care, for her, maternal love, which gives the ‘speaking subject … refuge when his symbolic carapace shatters to reveal that jagged crest where biology transposes speech: moments of illness, of sexual intellectual passion, even death’, it seemed that we would have to become more attuned to sound, to tone, to acknowledge the paradoxical distance between — yet sharing virtually of each other’s physical space. Silence, pause, listening and looking would hold clients as a kind of womb-space, one hoped, in the rushing chaos of the pandemic. Kristeva reminds us that language acts for the speaking subject as a protective shell, an armour, out of which we construct notions of ourselves; that via language we engage with others as subjects who are never fully articulated. Kristeva speaks of the unconscious language of biology. In the absence of physical space in which bodies (and minds) meet to establish a therapeutic alliance, practitioners continued to try to be alert to the disconnect between words uttered and the tone of voice, the body positioned or screen, a background changed to outer-space, the fidgety pressing of the mute button. Together there had to be an acknowledgement of the multiple layers of uncertainty, and a way of finding words that compassionately revealed our collective vulnerability, rather than those which may have hidden it.
Finding a home in the homelessness

While it became clear that the most unwell clients would benefit from home visits, donned as we were in PPE, both a barrier and an opening – a strange experience of recognitions and misunderstanding and humours – the adaptation to online counselling has also taught many of us what can be done in this context, what has also been lost in terms of human relating, and what we need as people. Long-established therapeutic relationships, pre-pandemic, adapted well. There were combined and co-constructed memories between that could be drawn from; we had a relational frame already in place and a wealth of meetings in the physical space of the counselling room to use as an anchoring reference point. Those moments of awkwardness of frozen screens and poor links could survive because a constant, consistent earlier set of shared understandings had already been in place in the work within the hospice. The dynamic shifted considerably: patients who had perhaps felt frail or weaker or vulnerable in comparison to the healthy-bodied therapist now noticed that the therapist too also had a reality of some struggle to assimilate; many, in fact, were more technically able. And a vital question hung in the air – who is now helping whom, who is caring for whom? Something of greater mutuality emerged, the capacity for seeing and taking back projections of any sorts on both sides was of great help to the therapeutic relationship. It moved people on, in the relief of becoming whole in the face of dying.

Within the organisation, it became apparent that – the ward now empty, even the new hub spaces barely used – institutional community was vital. Virtual wards, virtual corridors for reflection, virtual groups for carers and the bereaved all sprang up. The pandemic precipitated actions at high speed that had, before, been slowly germinating, ideas alone, in the abstract, growing and evolving in talks. Now they existed — all these thinking spaces to combat isolation and the sense of being locked down and locked in with thoughts and feelings.
that had no outlet. We need, as human beings, community. To remove us from the collective, the gathering, the possibility of moments of mutual recognition is too much.

The sheer capacity for connectedness and relatedness that I have borne witness to, personally and professionally, during this pandemic is what I will hold on to as those of us well enough — possibly — return to something approximating the lives once known. Systems of care, the value of care and of community, have been systematically eroded in our neoliberal times, through often destructively narcissistic ideologically driven policy. The language within such policy — and the simultaneous under-resourcing of care provision — splits off and disavows our deep-seated need for one another, our dependency and interdependencies, to provide support in times of upheaval through the lifecourse. I have known this throughout my time in palliative care — no time is more uncertain than those days and months in which we face of an endpoint — but the rate of change, the stepping in and stepping out of life and lockdown (which in many respects parallels the trajectories of a terminal illness) has brought this much closer to the surface for those of us who consider ourselves reasonably well.

As I visited a dying client, part way through lockdown, the reality of the depth of the ways in which we can touch each other hit me, as she asked me — covered in visors and plastic — to sit alongside her in her bed, wrapped an arm around me, and said, ‘I don’t know why I like you so much.’ With that we talked about trust, about how much had been shared, about our joy at mischief-making.

This moment alerted me to the real value of the therapeutic relationship, for both client and therapist, and a fear that the collective adaptation to online work will lead to a convenient rationale for organisations further to cut corners in providing for much-needed psychotherapeutic services. And that the procedural technical imperative of doing the task and
Finding a home in the homelessness

getting the job done must always go hand in hand with a valuing of the relational, and the implied interdependencies therein.

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About the author: Esther Ramsay-Jones

Esther is an associate lecturer on the Death, Dying and Bereavement course at The Open University. She was awarded her PhD from the OU in 2018, and has since written ‘Holding Time’, based on her research in dementia care, and ‘The Silly Thing: Shaping the Story of Life and Death’ following her mother’s death from brain cancer. She is a practising palliative psychotherapist, counselling tutor and mum.
My mum moved into a care home on 18\textsuperscript{th} December 2019. Throughout 2019 her health deteriorated and in October 2019 she was admitted to hospital. While in hospital it was agreed by all concerned that it would be best for my mum to move into a care home. Prior to this, although I worked full time, I was her sole carer. My mum had capacity and was happy to move as she did not want to be in the house on her own while I was out at work.

I had a close relationship with my mum and visited her every day in the care home. We both enjoyed shopping so on Saturdays we would mooch around the local shopping centre, looking round the shops, and enjoying coffee or lunch together. My mum liked to dress nice, sometimes buying herself a top on these trips to cheer herself up.

Then lockdown came in March 2020. I was no longer able to visit my mum. This was exceedingly difficult as we had a close bond and my mum relied on me for support. It was heart-breaking to no longer be able to visit her. I can only imagine how difficult it must have been for my mum – she was used to my daily visits. Speaking to her on the telephone was out of
the question as she was hard of hearing. Such conversations would have only been frustrating for us both. Instead, I wrote to her regularly. I handed in magazines, toiletries, and gifts to the nursing home to pass on to her. Items which were my attempt to keep connected to her and keep her connected to the outside world.

Events like Mother’s Day and her birthday in April were especially difficult. Still unable to visit, I ordered flowers to be delivered to her. On her birthday, I spoke to the care home staff - they said kitchen staff had baked her a cake. It was a comfort to me that the staff were doing something for her that I was unable to do.

My mum’s health deteriorated both physically and mentally. The home phoned me about various incidents since lockdown. She fell out the chair a couple of times, fell out of bed and was refusing to let staff get her out of bed in the morning. It was so difficult to only be able to listen to what they were saying and not being able to do anything. The only way I could reconcile myself to the situation was that it was out with my control. However, it was also worrying as, prior to lockdown, my mum had not experienced any of these issues. These were changes in mum that I could only hear about, unable to see for myself how she was doing.

In June I was informed she had a small blood clot in her leg. This led to her being admitted to hospital for a couple of days before returning to the care home. Again, due to the restrictions, I was not able to visit her either in hospital or in the care home. It was excruciating to not be there to comfort and support her.

Visiting restrictions were eased in July and I was able to visit my mum outside for 30 minutes every two weeks. The first time I visited was very emotional and we both cried. However, I still had to physically distance from her and wasn’t allowed to hug or touch her. It was good to see her but the decline in her
mentally and physically was obvious. Eventually indoor visiting was allowed enabling me to visit for 30 minutes every two weeks in a designated room with several other residents and their families also present. Due to her hearing and the lack of privacy it was difficult to have any meaningful conversation. However, it was nice just to see her and spend some time in each other’s company. Visiting stopped in the middle of October as the care home had a Covid outbreak.

In November, the care home called. I was advised that my mum’s health was deteriorating. The doctor had written an Expected Death Certificate. Within the next few weeks, she twice had chest infections and it was unknown if she would survive. However, as always, she was a fighter and pulled through both times.

Then on 10th December 2020, I was advised my mum had tested positive for Covid-19. I was surprised - I was not expecting it as she had previously recently tested negative even through there was an outbreak of Covid-19 in the home which had been going on for weeks. I knew right away that this was it: she was going to die. I prepared myself for the worse. She had fought so hard previously; however, she was now very frail and did not have the strength to fight this.

The care home had advised previously that I would be able to visit if she was dying. I thought she was now dying and asked if I could visit. I was advised I could. This confirmed my worse fear.

Sadly, by the time I could visit, my mum was not awake. Therefore, I was not able to speak to her and let her know I was there for her. Staff assured me, although she was not conscious, she would know I was there.

Visiting was difficult; although you see images on the news nothing can prepare you for the reality. I have enormous respect for care home staff going into work each day knowing what lies ahead. I had to wear full PPE and staff could not
come into the room unless they were wearing PPE. Staff were stationed in the corridor outside the room and were not allowed to go anywhere else in the building. Although I was wearing PPE, I was aware that my mum had Covid-19 and there was a live outbreak in the home; I was scared that I would also contract the virus. Nevertheless, I wanted to visit and be there for her and I visited for a short while every day for the next five days.

As I sat in the room listening to my mum’s laboured breathing, I started breathing in time with her, almost as if to encourage her to keep up the effort. It was an extremely harrowing time as I knew she was not going to get better, and these were the last times we were going to spend together. Sadly, in the early hours of the morning of 17th December 2020 she lost her fight. It was almost a year to the day since she had moved into the care home.

Friends and colleagues had been incredibly supportive throughout the whole pandemic. However, I was overwhelmed by the number of heartfelt messages, flowers, and gifts I received when my mum died. The funeral took place two weeks later on 31st December 2020. I appreciated the effort made by everyone who attended given the climate we were living in. Mixing with other households, when it was allowed, had been very limited since March. Therefore, to gather together as a group felt quite daunting. Friends, relatives, and neighbours attended despite their own health issues and concerns about the pandemic, as they wanted to show their support. However, the rules at the time were that we were not allowed to hug and it was not possible to have a reception after the funeral service. People have been amazing, and their support, thoughts and prayers are what have sustained me through the dark days since my mum and best friend passed.
About the author: Jo McGee

Jo McGee is an OU student currently studying K102 Introducing Health and Social Care. She lives in Scotland and works as an Admin Assistant within Social Policy in a Local Authority. From March 2020 to June 2020 she was redeployed to a Local Authority care home to provide administrative support.
SECTION IV

DEATH AS A RESULT OF COVID-19
Covid took everything away from my mum in the last months of her life.

My mum had Alzheimer’s — she was 79 years old. Prior to the first lockdown in March 2020, she was losing her ability to communicate and needed help with her personal care. But she enjoyed spending time with her loved ones, and they cherished making memories with her. She still recognised her family and friends, greeting them with a huge smile and outstretched arms.

All that stopped on 16 March when the first lockdown began. Both my parents were shielding and did not leave their house. My sister brought their shopping for them, speaking to them only through the closed front door. I live two hours away from my parents and was not allowed to travel to visit them. I spoke to my mum every day on the phone but each day she responded less; I could feel her slipping away from me. My dad is not tech-savvy so Skype calls with him were out of the question.

When the first lockdown was lifted, I went to see my parents. I walked into their lounge where mum was. There was
no smile from her nor outstretched arms reaching for a hug. I sat next to her, and she looked at me and asked, ‘Who are you?’ The bottom dropped out of my world — I knew it was likely that this moment would come but to be faced with it is heart-breaking. I held her hand and told her I was her baby and she smiled — though I knew she did not know who I was.

Deprivation of social communication and contact during lockdown had an enormous impact on mum’s condition. She had deteriorated considerably during isolation — so much so that in August 2020, she went into a care home as my dad could not provide the care she needed at home. The day my sister and I took her to the care home was the worst of my life. I should imagine it is a difficult experience at the best of times, but COVID makes it unimaginable; a surreal experience and one that unleashes a whole tide of distressing emotions. We were not even allowed to take mum into her room and settle her down – we just handed her and her belongings over to the staff at the front door and had to walk away.

Due to COVID restrictions, we were not allowed to visit mum — not even visits through the window. The care home had previously tried ‘window visits’ but it had distressed the residents. So, the care home was converting a bedroom into a visitor’s room to allow family to meet their loved ones. Sadly, we never got the chance to use this room. Mum was taken to A&E at the beginning of November. We were not allowed to accompany her to hospital — how frightening that must have been for her to be in a strange environment and not know what was going on. She had a kidney transplant eight years before and as she had not been eating and drinking properly, her kidney was failing. The doctors told us there was nothing they could do, and mum was put on end-of-life care.

Mum was transferred to a ward and my sister was allowed to visit. I arrived the next day to see her and was taken to one side by a nurse and told that mum had COVID; there had
been an outbreak at the home; mum had tested negative on the Monday but was positive when tested on the Wednesday. Mum was then transferred to the COVID ward. The ward staff were amazing and said that one family member could visit each day, providing we met their COVID-free criteria. I wanted to visit mum to say my goodbyes but was advised that although I would not need to self-isolate, it was recommended that I did not then see my dad, as he has chronic obstructive pulmonary disease (COPD) and would be considered ‘at risk’ of having complications if he contracted COVID. My sister was already self-isolating as she had spent the day with mum before her test was returned. I was faced with the decision to either see my mum for what I knew would be the last time or comfort my dad as he lost his wife of nearly 60 years. This is a choice that no-one should have to make. The staff allowed my sister to visit our mum every day. This act of kindness meant that my sister was with our mum when she passed away.

However, COVID had not finished wreaking its torment on us. The coroner contacted us and said there would be a delay with issuing the death certificate as mum had been admitted from a care home — then the coroner decided that the main cause of death was COVID. We argued that this could not have been the case as mum had not had it long enough for it to cause her death. All the news reports state that those dying of COVID were infected at least four weeks before — mum was only infected a matter of days before. We were told that as mum had COVID, the hospital would not perform a post-mortem and if we contested the coroner’s verdict, the funeral would be delayed. We decided not to contest the verdict — this would have been an added pressure at an already challenging time.

As mum had COVID, the funeral director had to seal her coffin at the hospital, so we were unable to see her at the funeral home. There was no wake — such a crucial part of the
funeral process for our family where people would have gathered to comfort one and other and reminisce about the times they spent with my mum. COVID took away the opportunity to say goodbye to mum properly; only 30 mourners were allowed at the funeral, so many of mum’s relatives and friends were unable to attend.

COVID took away so much from us as a family; the ability for mum to spend her final months and moments with her family and friends, our opportunity to grieve as a family and the true cause of her death – anyone in the future investigating our family history will discover that mum died of COVID but this was not the case.

COVID has not finished with us. My dad has just been diagnosed with terminal bowel cancer — he has six to twelve months to live. He is in a support bubble with my sister and if I follow the current lockdown restrictions, I should not visit him. How have we come to this — where a parent must choose which child to see, leaving any other children feeling isolated and helpless? I missed out on spending time with my mum during her final months and COVID is dictating that I do the same with my dad. Having lost precious time with my mum, I cannot bring myself to let the same thing happen with my dad. At the time of writing, Mum passed three months ago — the pain is still raw that I could not be with her in her last moments nor comfort my sister when mum had gone. I would challenge anyone to look me in the eye and tell me that it is not essential or necessary that I see my dad when I know that his time is limited.

About the author: Julie Williams

Julie is 52 years old and lives in rural Cumbria with her husband, though she is originally from Manchester. She loves walking the fells and cycling and has a penchant for good food
and wine. Julie also loves travelling and experiencing different cultures. She is currently studying an Open degree with The Open University, specialising in social sciences, and is due to graduate in summer 2021. She is studying her degree for pleasure and to prove to herself that she can!
On 27 March 2020, my aunt died in the Royal Gwent Hospital, Newport, south Wales, having contracted coronavirus there around a week earlier. My uncle had been able to make one visit the day before she died, but was, to his lasting sorrow, unable to be with her for her final moments. The end for my aunt was seemingly mercifully swift; within a week of being diagnosed with COVID-19, she and her husband were told that her death was imminent, and within little more than 24 hours of that, she had died. Thinking back now, very nearly a year later, three things strike me. First, how my initial response, with so little understanding of the virus’s impact, inevitably failed to grasp quite how long a haul the pandemic would be; second, that the language used by many who seek to downplay the seriousness of the virus fails to respect the reality of COVID-related death and grief; and third, that a year on, the lingering sense of loss remains hard to grasp. This short reflection expands on each of these three observations, tracing the different stages of grief I have shared with my family.

After the initial sadness on hearing the news of her death,
and subsequently reminiscing with family members about my childhood, in which my aunt had been very present, I sought to understand her death in the context of what was at the time a new national and global situation, and one unlike any that I had experienced before. These were early days in the pandemic, as we adjusted to the strangeness of the first lockdown and attempted to process emerging information about the nature of the virus and its effects. On 28 March, the day after my aunt’s death, I felt compelled to share the following on Facebook:

Yesterday’s coronavirus death-toll included four people in Wales. One of these was my aunt. I’m not seeking sympathy by writing this post, but I hope that it might help bring home that this virus and its effects won’t just happen to other people.

I know that you’ll already be adhering strictly to the government’s guidance and rules on social distancing and isolation; please stick with it for as long as it takes.

I wanted to communicate that this virus wasn’t simply something that could or would happen to other people, unlike other health scares of recent years that can easily seem remote to us in the UK, such as the Zika virus. Inevitably, I got a lot of sympathy, but also a great deal of appreciation for the wider context of my remarks as friends shared their hope that the general public would take collective responsibility for their actions. I didn’t really know what ‘as long as it takes’ meant back then, but I didn’t really imagine that it’d be a year and more. I think I had already had months rather than weeks in mind, but even that seems naïve now. Looking at my Facebook post, I can’t help but notice the death toll that is recorded. Four deaths in one part of the UK didn’t sound that many, even then, but again, I could not have imagined how small that
number would end up seeming in relation to the overall numbers of deaths that would eventually occur.

As time wore on and I became aware of the dissenting voices of conspiracy theorists claiming that the impact of the virus was being overstated and other lockdown sceptics, their rhetoric brought my aunt’s death back to the forefront of my mind. In particular, the prominent bandying about of the phrase ‘underlying health conditions’ in relation to the death toll hit home. From the mouths and keyboards of those using this to rail against the persistence of social restrictions, this sounded harshly dismissive. Yes, my aunt was in hospital being treated for another illness from which she was highly unlikely to recover and doctors had advised that she would not survive much longer. However, coronavirus not only brought about her death more abruptly, but it also radically altered the conditions of her death, most importantly for her and my uncle, but also for her extended family. Her death, in isolation, rests heavily on us all, and most especially on my uncle; I suspect the sense of remorse, though futile, will never entirely disappear. The casual dismissal of deaths such as my aunt’s as those that ‘would have happened anyway’ rides roughshod over the experiences of so many families, while the emotional strain on those who died will never be known. The bringing forward of these deaths by days, weeks or months was not some mere inconvenience, but the robbing of precious final moments of intimacy and dignity.

My aunt’s funeral was necessarily attended by only a very few people; those of us living further away were unable to be there. In communicating with family members around that time, there was a general sense, shared by my uncle, that we would find a time to gather together in due course, once restrictions were easier, so that we could reminisce, laugh and cry together. We didn’t speak of when this might be, but I doubt that any of us imagined that we would still have been unable to do this a year later. Talk of this event has now gone,
and there is still no clear sense of when such an event might be possible. I wonder whether it will happen at all. Far from indicating that the circumstances of her death have been forgotten, it is a tacit acknowledgement of the extent to which everyday life is still affected by the same virus that took my aunt’s life. The rawness of grief has faded, and living with the restrictions on social gatherings has become increasingly normalised. Herein, for me, is something that’s hard to grasp; just as an end to the pandemic feels difficult to imagine, so too does finding a way of commemorating its indelible effects.

About the author: Martin V. Clarke

Martin is a Senior Lecturer and Head of Discipline in Music at The Open University. He was born and brought up among a large extended family in a tight-knit community in the south Wales valleys. He joined The Open University as an Associate Lecturer in 2008, becoming a member of the central academic staff in 2014.
MEMORIES OF MAMMAW
ROB WILSON

Rose Barron Wilson — 4th February 1928–14th January 2021 (92 years old).

My grandmother (Mammaw) passed away with Covid-19 in January 2021 along with 3,979 other Americans on the same day. Like any of the millions who have died, she was so much more than a number and the numbness with which I now note the daily tragic figures sometimes feels like I’m not honouring her life and death appropriately. I was so excited to see her on my next visit home as soon as the pandemic eased. Instead, my family and I joined those grieving the loss of a loved one.

Grandparents have an enormous impact on our lives. I’ve always known that I would go home for Mammaw’s funeral and so, two days after her death, I drove to Heathrow in the snow, paid for a rapid Covid-test and boarded a near-empty flight to the States. My brother picked me up in New Orleans and we drove the many miles home to Mississippi. Despite not having seen my parents for more than a year, I could not stay...
at their house because my dad was feverish with Covid. I had flown home but could not be at home.

Four days after her passing, my dad, a minister by profession, did the service, masked and coughing outdoors at the graveyard with about 20 close family members spread out. Most of those present had already had Covid. The disease has taken so much out of us and so much from us.

I’ve found the grief comes in waves. I’ll see my daughter on Facetime with her grandparents and know I’ll never see my own grandmother again. I’ll see the last text I sent to Mammaw, saying ‘We love you’, and know why she never responded. I haven’t removed her from my contacts list.

Since her death, I’ve found writing cathartic. The days after she died brought a flood of memories that I wanted to record so that I never forget. They may not mean much to others but they are shared here, snippets of images, feelings and times that I can grasp on to, and that tell of who Mammaw was to me.

**Childhood**
- Shelling mountains of peas
- Watching the Jungle Book and sleeping on the fold-out bed in the back room of her house
- Making scarecrows with Pappaw’s old clothes and hats and faces on paper plates
- Popcorn in wooden bowls
- Brushing my teeth with my own labelled brush in the cup of all the cousin’s toothbrushes

**Boyhood**
- Traveling to Vermont and Lake Placid, New York with Mammaw and Pappaw
- Catching snakes in Vermont and wearing the clothes that Mammaw had brought along for me all week because it was colder than I expected for summer
- That trip instilled a love for travelling and extra stops along the way. We went to Gettysburg and Hershey Chocolate World and Amish farmlands. We also walked across a bridge into Canada at Niagara Falls and I remember Mammaw negotiating with the Canadian Border Police to let me enter with them because I did not have a passport and they were not my parents. A wallet family photo did the trick. That was the first time I ever left the country.
- Not sleeping at all one night in Lake Placid because Mammaw and Pappaw listened to white noise while they slept, and it kept me up literally until the sun came up. I moved rooms the next night.
- Making birthday/holiday cards and playing pinball on Mammaw’s computer
- Mammaw contributing to my foreign currency collection with coins and notes that soldiers had gifted to her at the hospital in New Orleans

**Young adulthood**

- Mammaw joined Facebook while I was at Ole Miss and I was not sure about being her friend
- Looking back at our messages she kept me updated on the family while I was away and was not afraid to call me out if I seemed out of line, whether it be a status with foul language, a photo involving alcohol or tattoos. She always told me she loved me.
- She loved reading my blogs from my travels in Europe and Australia
- One time I posted a status about getting back to work at the sawmill to earn some money to leave Australia. Mammaw
commented that all I had to do was ask and the check would be in the mail. Luckily, I didn’t need her help, but it was comforting to know that she would fly me home if I ever did need help abroad.

- I didn’t write much in Vietnam because I got more into photography, but she loved those photos and asked for updates regularly. Mammaw sent Jess and I cards and presents no matter where we were in the world.

**Adulthood**

- When I came home from Vietnam, I wanted to spend a lot of time with Mammaw and Pappaw. I remember one day going out to their house and watching Sunday afternoon football and looking at old photos with Mammaw and she gave me lots of old cameras that she had used over the years. One of my favourites is on my desk in England. It is a micro-camera that says ‘made in occupied-Japan’.

- I would go to visit Pappaw at the Veteran’s home and then Mammaw and I would go to eat at Newk’s in Clinton. One time I was following her there in Pappaw’s truck and she swerved way into the other lane. I was worried that she was texting and driving but then I nearly bottomed out in a crater of a pothole that she had cleverly swerved to avoid!

- Mammaw was so pleased to be able to attend mine and Jess’ Mississippi wedding ceremony with Pappaw and each year since sent us a card on our initial anniversary.

- One time a Dutch friend of mine told me how nice it was to see my grandmother comment ‘Love from us’ on all my Facebook posts. Other friends told me this as well and I realised it really was special to be so connected with Mammaw even though I was far from home. And nice that my friends knew who Rose Wilson was. I don’t know many of my friends’ grandparents’ names.
- When Jess and I brought Ella to America for her first Christmas, Mammaw couldn’t wait to see us and drove straight over on the first day to meet Ella.

- We did a family photo shoot on that visit and Ella was photographed with Mammaw. She wore a baby gown that belonged to Mammaw’s mother (from c. 1890). They were both so happy.

Mammaw was such a generous and thoughtful gift giver and obviously put a lot of energy into caring for other people and keeping up with loved ones. I will miss her so so much but I have countless amazing memories and ‘love from her.’

About the author: Rob Wilson

Rob is from Brandon, Mississippi but has spent most of his adult life away from home, working in Australia, teaching in Vietnam and most recently establishing a home in England with wife, Jess, and daughter, Ella. He works at The Open University Graduate School supporting research students and is studying towards an MBA with The Open University Business School.
I remember the blue and red flashing through the curtains of the nursing home. I’d been unwell for days, couldn’t catch my breath. I was made to wear a mask in the ambulance. The siren screaming made me think: this must be serious.

I could see from the stretcher, along the corridor. A cleaner was bringing a brightness in straight lines to one side of the floor. I used to do that job. I saw doctors and nurses with lines on their cheeks, where the masks dug deep. They look like they’d just been punched. I passed two porters talking. One said, he’d pushed the long box to the mortuary more in one day than they did in a week.

I saw my heart briefly running up and down the steep hills of a cardiac monitor. Then it was disconnected. I heard the words ‘ceiling of care’ spoken by a doctor through a mask.
I could see my son through the window, nervous, standing on his own. Looked like an extra from Star Wars. One nurse said when working long shifts she needed the bladder of a whale; made me laugh. The Tic Toc on the nurse’s I-phone lightened the atmosphere, turning everyone into a dancing queen.

I’d been on this ward many times before, but this time the buzzers were strangely quiet. The ward clerk, in gloves, mask, kept wiping everything twice. I overheard the doctors saying they were becoming experts in hospice care. One nurse said if her breath came through the mask, making a cloud on the inside of the visor she’d probably catch it.

I felt better, then something changed, felt even worse, utterly exhausted; that was when I was somewhere that didn’t have anything to cling on to; where the oxygen couldn’t reach me.

About the author: Mel McEvoy

Mel McEvoy was born in Liverpool in 1959 to Irish immigrants. He spent five years in Catholic religious life. He is a Nurse Consultant in Cancer and Palliative Care. He has nursed for 38 years, focusing on end-of-life care in a Teesside hospice and an acute NHS hospital. He was an Associate Lecturer for The Open University (North). His first collection of poems was called ‘An Emptied Space’ published by Mudfog (2012). He recently achieved a Master of Arts in Creative Writing with The Open University (2019). He has three poems in ‘These are the hands’ NHS Anthology March (2020). He is currently involved in collaborative research with the OU promoting creative writing for wellbeing in acute hospital settings.
SECTION V

GRIEF, LOSS, AND FUNERALS DURING COVID-19
For all our faults, if we really are guilty, we look for someone or something to blame. For me that has been my engagement with death.

Growing up, my first encounter with death was of utmost joy.

I still remember I was in class, possibly aged 10 or maybe even less. It was a typically hot north Indian summer day and the temperature was above forty degrees. With fans that twirled apologetically as if doing us a favour, sweaty smells all around and teachers who yelled and beat (the boys) for no reason (at least in our view), the only thing that one looked forward to was the end of the day. Every day I dreamt and willed the powers that be that something would happen; maybe the train on the track right outside would have a crash and I would be able to trudge out to see the spectacle, or the riots I heard about in the distant city centre would descend upon the doorsteps, or nothing as morbid, just the building crashing down would be good enough to give me respite from this institution.
And one day it happened; sometimes some wishes do come true.

All of us students were summoned by the siren to assemble in the dusty playfield that doubled up every morning as the assembly ground. In regimented lines, we waited to hear why we were there, worried about what collective punishment would be meted out to us, desperately juggling our memories to ascertain our past crimes and misdemeanours. Was it the smashed glass panes, or the broken chairs or the yelling? The Headmaster took the mic and started to read out some lines — it did not seem to be going the way I imagined.

The part I remember, very clearly even after all those years, was: ‘with profound grief and sorrow, we regret to announce the demise of Mr X; as a mark of respect to the departed soul, we are suspending all further classes for today. Please observe two minutes’ silence.’

Those two minutes did feel like eternity, not because of the grief that had dawned on us, but because they were the last two minutes of captivity. And then, with a roar we all broke our lines, cheered and celebrated our freedom. May God bless the soul. The Glorious Dead — they gave their lives for our freedom.

And so it was, every day, we wished, we hoped, we prayed, for someone to die; for us to be free, for them to escape and for us to escape. Death was something we looked forward to, prayed for, something we celebrated, something we wanted all the time.

This disposition held me well, especially as my father was a fighter pilot, and death visited quite often, but it was always for us a celebration. The Glorious Dead — they gave their lives for our freedom. The grand funerals, the missing man formations, the flares in the sky and most importantly an empty house meant a chance of an upgrade (houses in the Air Force were allotted by rank and post; a death meant someone had to move
out, and someone had to move in). And in this grand-standing and mundane positioning of life’s troubles, grief and bereavement had no place. Luckily, I did not have to find out as well, since my father survived his tenures, intact.

And so, it was, whenever I met someone who had lost a near and dear one, I had no words, not because I understood that silence is the most comforting at that time, but because, that loss was something so alien to me, and not because everyone I knew was alive but because I never viewed a departure in that frame of mind, ever.

So, it went on, with age that nonchalant treatment of death led to an acceptance of the fact as a mere fact. What a weird way to become a Stoic — factually coming to the same conclusion from a completely reverse standpoint. My father and I freely talked about dying as a matter of fact, something not very common in Indian society. We discussed that I will not cremate his body, but just give it to the medical school to be used as a cadaver. But there was an element of hollowness to it. Mine on account of the weird spectacles growing up. And in my father’s case, his parents were both orphans, so he did not see his grandparents die, and his parents were still alive well into his sixties (they only died in 2018 and 2019), and then being a fighter pilot, he also looked at death as something that happened to the unlucky or the incompetent. He did mention once though, that as a young newly-minted fighter pilot, when he heard about a crash for the first time and realised that the pilot was his mentor’s nephew, he realised fighter flying wasn’t all glamour and show, but was actually a risky life-taking business — that’s when he claims he started to drink alcohol. Sometimes I think it was just a story he told to claim a moral
upper hand to not be judged for his alcoholism. I don’t know the truth, possibly won’t.

Till one day, death came close. Yet, remained distant. I was away from my home for some meetings, and I got a call late into the night from a friend of my wife’s brother — it seemed he (the brother) was no more. My first thought wasn’t of the loss, or to reach out to my wife for comfort, but was — I hope he has not died in a stupid accident. Slowly the fog lifted, my phone started buzzing and the story started developing. He was in the Army, he died in service, with his men, leading his men. *The Glorious Dead* — they gave their lives for our freedom.

So, it was all again, grand. A grand funeral, the last post and missing-man formations. The celebration of a hero, the attempted absence of tears and grief (they were there, but in private); you do not mourn a hero — you celebrate him. It was a celebration, and to me, close yet far, in my mind there could be no grieving, there should be no grieving. I must add, my wife does not say it, but somewhere she does feel that my conduct (and incidentally my father’s) had and has obvious gaps in helping her with her grief.

And then, it inched even closer. My favourite grandmother, old enough to have seen a great grandchild — so having lived a full life — eventually reached a stage where any day could be her last. It started in December 2020; she inched along, and then it went to January and then suddenly she was gone. What a time to die. Due to the pandemic, there was no grand funeral, no celebration, no crowds, and no sweets. No choices, of crematoriums, clothes, timings, nothing. It was what was.

In that helplessness, I felt a very weird sense of grief for the first time.
About the author: Nishant Beniwal

Nishant is currently a PhD student at the Faculty of Business and Law, Open University researching alternative mechanisms for enforcing climate change obligations in a South Asian context. Prior to commencing his research, Nishant was a renewable energy lawyer advising clients on projects across Asia. Other than law and climate change, Nishant’s interests include theatre, philosophy, and history.
Dr Graeme Edward Hobson was, and is, my dad. He was funny and clever, with a quick wit, a unique turn of phrase and with a form of gentleness rarely seen. ‘When I fall off me perch’ was a favourite of his, and always preceded an assurance that it was only a photo that needed affixing to the pre-prepared funeral service sheet that was kept safely with his own handwritten eulogy. With a BSc, MSc, PhD and DSc, he described himself as a ‘real’ doctor throughout a lifetime invested in the genetic engineering of fruit. But his ability to alter genomes couldn’t stave off Parkinson’s in his late seventies or prevent his two subsequent heart attacks. It was so fortunate that just one week prior to the first lockdown we were able to hold a joy-filled gathering in celebration of my dear dad’s 90th birthday.

A fortnight after the first lockdown, dad’s low blood pressure meant a hospital admission. Covid rules dictated that he went in alone despite being confused and rather deaf. My heart hurt for him as I considered his loneliness. He was moved onto a ward, but staff rarely answered my calls and abruptly advised me that there was no facility to speak to my dad. I was
constantly left wondering and worrying. In desperation, I telephoned the hospital chaplain, and her daily visits provided comfort for him and a lifeline to me at a bleak and fear-filled time. A few days post-admission, a doctor rang to say they’d spoken with dad and he’d agreed to a ‘do not resuscitate’ order which left me confused. Only days prior to that admission he had expressly stated a wish to be actively resuscitated, despite his age.

I sat with this information, an angry child feeling desperate at the thought of coercion to manipulate my dad to agree not to be resuscitated, coupled with my adult understanding, aware of the Covid crisis and the need for a sensible approach. In hindsight, I can see that even in those early days of Covid, the NHS were in the business of managing their resources carefully.

A second call from a senior doctor came the following day. ‘We are very sorry to tell you that the man in the next bed has Covid, and we’ve been nursing them both without PPE.’ I was furious. My heart shattered into a million small pieces — this was what I had dreaded. Dad was tested and moved to isolation in a side room. I wanted to scream and rage at Covid and at God but in the end, all that lay before me were fourteen interminable days of waiting and praying. Each day without a call perversely signified a blessing — no news is good news, isn’t it? After ten days, with promises that I’d find carers for him at home and would nurse him myself despite living 120 miles away, the hospital agreed to transport him home. With just one carer willing to take the risk, and both of us in PPE, she and I waited at my dad’s house for the ambulance to arrive.

The Covid-delay had taken its toll. His wit, fierce determination and dogged resilience had gone, to be replaced by the shell of a frail old man who was incoherent, incontinent and immobile. The Covid crisis appeared to have created a system of neglect for those unlikely to survive. And so, I worked whilst
the carer slept, and she worked whilst I fitfully slept. And whilst the changing of soiled pads and warm flannel bed baths felt like a pitiful reflection of our father/daughter relationship, these were the very last acts of love I could bestow on him. It sometimes came as a relief that masks, gloves and aprons hid the fact that it was me performing such intimate tasks.

There were some brighter times. Once, we dressed him to sit unsteadily for his soup at a table in his bedroom and he reminisced coherently about old friends. That day I took one final photo of him, smiling. Another time, he woke up and asked about progress with my PhD and I was able to reassure him that I too would be a ‘proper’ doctor one day, like him. These times gave us a glimmer of hope.

We moved dad into the lounge to overlook his beloved garden. I collected a prescription for morphine from the pharmacy, not recognising its significance. The ‘end-of-life’ district nurse visited daily, regaling us with stories of life and laughter in better days with my dad, which warmed my heart. I would leave the house only to weep uncontrollably because even in my denial, I knew the end was coming.

As the days passed, gradually he stopped eating and would only accept teaspoonfuls of water. I cajoled him, bartered with him and begged him to eat and drink. Something in his refusal belied a conscious decision to expedite his end, because his joy in life had gone. It was when he stopped swallowing his medication that things really changed. He knew that biological processes would perform their duties, and minus sustenance or medication, he became master of his fate — this, his last act of resolve. His breathing shallowed and his vital organs suffered for their lack of oxygen. He fell unconscious, and that infamous death rattle signified liquid-filled lungs. Gaps between breaths grew longer and there were countless times I was woken to attend to dad in his dying moments, only to find that he rallied.
Dad lay with a look of peace, eyes shut, mouth open, and despite my protestations in his ear to ‘please let go’ because ‘it’s ok, it’s ok’, he doggedly took his time. His tenacity and resilience persisted in his determination to have one more breath. This interminable wait for death to arrive made me wonder if leaving would help him take that final breath. I told his carers of my intention to travel home, but first, I picked out his funeral clothes, with feelings of guilt because he hadn’t yet died. I packed my bags and after a wrenching and tearful goodbye, I left. Minutes after leaving, the carers rang to say dad had chosen his time to slip away, that same calm look upon his face and no morphine needed to speed the end. I drove on home.

My dad’s body was taken away that day. He was dressed, and they tucked a clean, white handkerchief into his breast pocket — he never liked to be without. He left from his house, and I drove to mine, with a searing emptiness and untold loss in my heart. I arrived home and everything and nothing had changed. One week later, the ‘eight’ of us permitted under Covid regulations gathered at dad’s house for the last goodbye. I ran out as his coffin arrived and the sight of it broke me; my sadness spilled out in sobs. My middle brother heard my cries and hesitated, the social distancing rules were clear, but he put compassion before risk, and held me as I wept on his shoulder. My sobs quietened as we took a slow and sombre short walk to the church dad loved.

A collection of his friends gathered in disparate, solitary groups near the church. There were no hellos or hugs, just waves of sad acknowledgement as we followed the coffin to the graveyard’s edge — eight of us distanced for a shortened service of sorts. My husband live-screened it to my eldest brother, unable to attend the death or funeral, mourning abroad and alone.

I said my final farewell to my parents, reunited in death,
and hopped over the flint wall (as my father would have done) to wander home. Just eight of us in his garden — two families sat apart from one another — a picnic in the sun and game of croquet. Dad would have loved it. Nearing the day’s end, I called dad’s gardener to give him the news. He told me his own father had recently died, in hospital, from Covid. His father had been nursed next to mine. Unbidden anger rose up and dissipated, because the irony of the situation was clear — we both found ourselves in the same grief.

Now, ten months have passed and the pain explodes in waves; grief feels so like fear. Having no parents is like being lost at sea, abandoned and alone. As a reflex I go to call, to hear his warm voice and to lap up his interest in my life and in his ‘little children’ as he called the grandchildren, despite their age. I yearn for him and mourn for me. A secret part of me is grateful that he died as he did, overlooking the beautiful blooms of the yellow rose that he planted, that blew gently in the breeze on that final May day. I want to tell him about my studies, give him news of my son’s football matches and university offers for my daughter, but I can only whisper them at my parents’ grave and hope they hear and are proud.

My dad’s death won’t feature in any Covid-related statistics, though it played a substantial part in his demise. And in the end, what does it matter? For those who mourn a Covid-death and for us that don’t, the ache and tragedy remain. For the gardener and I, our loss is the same, with an inability to mourn and grieve as we would want, no chance to fully celebrate the life lost and no loved ones to comfort us as we cry.

Covid deprived us of that.

About the author: Laura Patterson

Laura is a second year, part-time PhD student at The Open University, researching adolescent suicide. The rest of her time
is spent as a Senior Adoption Social Worker and running a Wellbeing Café on the high street where she lives. She grew up near the sea on the south coast of England and now lives in Towcester, Northants. Laura is married with two teenage children and loves to read and walk in the countryside; she sells Body Shop goods to raise money for the café.
When I tell people I lost my dad in the summer of 2020, they tilt their head and ask, already sure of the answer.

‘Covid?’

No.

While the world was distracted by a pandemic, stomach cancer took over my father’s body, robbing him of the ability to absorb nutrients. When others lost their sense of taste or smell, he lost the ability to digest. Eating became first unenjoyable, then painful, then impossible.

Terrified of taking a deadly disease into my parents already poisoned home, I spent the spring of 2020 delivering their shopping and chatting through the window from the driveway, me leaning on the bonnet of my car, them safe behind the glass. Beyond treatments and potential and hope I can’t remember what we talked about; the changing world I suppose. How my kids, their grandchildren, were coping with (loving, actually, in those early days) being at home.

By the summer, I was visiting inside the house, without heed to government guidance. These were special circum-
stances in unusual times and the need of our family to spend
time together overwhelmed the risk introduced by the global
health crisis. A small part of me yearned to be challenged; a
nosey neighbour reporting us, or being stopped by the police
on my way home. Imagine explaining the situation. Imagine
how angry I could become if I were told not to go into my
dying father’s house. Imagine how righteous I could be in my
fury.

But still I was sensible. I sat across the room while they
huddled on the sofa, my mum supporting the mug of tea to his
mouth as she had with her 92-year-old mother the year before.

It was the last time I saw him out of bed.

Father’s Day 2020 was the last time I saw him alive,
although he lived for longer. I simply couldn’t face seeing him
again, so weak and frail, so old before his time. My mum
understood. I went to the house to visit her, to help her, but
when I said I didn’t want to disturb him by going into the
bedroom she didn’t ask again.

We were all there on Father’s Day. My sister and I sitting in
opposite corners of the bedroom, mum holding his hand at the
bed. He couldn’t talk much, but he enjoyed hearing us chat
about the old days, when we were young. The family dog, holi-
days we had been on. I made his card that year, like I had as a
child — ‘Best Dad’ in bubble writing, elaborately coloured.
When your father is dying, high street cards are not appropri-
ate. He will not drink beer, drive a car, do DIY or any other
father tropes again.

He died on a sunny Thursday afternoon. The cancer
nurses saw it coming; during their morning visit they took
mum aside to say they didn’t think he would be here much
longer. She called my sister who went straight there. She called
me and I said, if she didn’t mind, I wouldn’t come. She said
that was fine. She didn’t go when her mum passed away, so I
believed her.
Covid meant no funeral and I was glad. I didn’t want to grieve in public, the pressure of putting on an event piling into our heartache. On the day he was cremated, his pilot friends flew over the house in convoy and the eight of us – Mum, my sister, our husbands and his grandchildren – waved from the garden, like we had waved at him in his plane so many times. We walked together in distraction at a family favourite woodland, smiling and remembering.

I updated my will not long after. No funeral for me, thank you. No ceremony around my cremation; ritual has no place in my life and is unnecessary for my death. Save your money. Take a trip to the coast and scatter my ashes into the sea, my favourite place. Then have an ice-cream, and fish and chips on the beach. Feel the salt air in your lungs, and remember the happy times.

**About the author: Sarah Alcock**

Sarah is in the last year of her MA Online and Distance Education with The Open University, and achieved her first degree, BSc Psychology, with the OU in 2006. She lives in Milton Keynes with her husband and two children and works in learning design. Sarah’s hobbies include writing and planning the next family holiday to the seaside.
This is a personal journey through the experience of loss of my mother Diane, during the first wave of the pandemic that began in the United Kingdom in March 2020. Diane was born in Stratford, East London in 1930 and at the outbreak of World War Two she was evacuated to Duxford, Cambridgeshire to live with her grandmother for the duration of the War. In 1948, she met my father John, married and both had long careers as trained nurses. They were married for 26 years but separated after the death of my older sister Angela in 1974 who was studying to be a nurse in Brighton. At age 19, Angela had contracted Hepatitis B; a blood-borne liver disease, following an accidental injury with an injection syringe needle. I was a teenager aged 16. At the time, her death did not appear to have a significance upon me, in the way that the more recent death of my parents did. However, long buried feelings about the death of my sister have emerged. These were entwined with my more immediate feelings about the loss of my mother. Perhaps, in retrospect, the early experience of the loss of my sibling has influenced my reaction to the loss of my parents in later life. This early life experience of loss could be viewed as
consistent with published work in which acknowledgement is made of the way early life ‘loss experiences’ can ‘shape’ psychological reactions to grief and loss in later life (Block, 2019). Furthermore, Lobb et al. (2010) debate and are equivocal about whether early life experience of loss is a ‘protective’ or ‘risk factor’ in the development of complicated grief reactions. I remain unsure about whether the death of my sister has ‘shaped’ my reactions to the loss of both of my parents or presented any significant risk factors to me. However, it has rekindled memories and feelings of regret about the teenage rivalry between myself and my sister. This may be connected to my emotional distress related to my mother’s recent death given that how I responded as a teenager to her death may have placed considerable pressure on my mother.

In more recent times, I lived 220 miles away from my mother. During 2019, I was a regular visitor to Lincoln, where she lived as she was frequently admitted to hospital. She had a long history of ill health which included type 2 diabetes, recurring chest infections and increasing immobility due to her age and frailty. Towards the end of the year, it was clear to the family and her friends that she was unable to care for herself at home. Despite her desire to receive home care for as long as possible, because of increasing ill health, she was admitted to a local care home. My brother and I have had long NHS careers and we both knew that her prognosis was very poor and again she was admitted to hospital. Following another journey to Lincoln during the winter, and after receiving medical advice, the family agreed that she would begin receiving palliative care and active treatment was to be withdrawn. Remarkably, my mother then recovered from pneumonia and was discharged from hospital back to the care home in late December 2019. Within a few weeks, she again developed a chest infection requiring further hospital treatment, and on 31st January 2020 I travelled up to Lincoln to celebrate her 90th birthday whilst
So close, yet so far — lockdown and loss

she was in hospital. At the time, I didn’t know that this would be the last time we would be able to be together. All remained well for a few weeks and I was in regular contact with my mother by telephone whilst she was in hospital, until she was discharged back to the care home to receive on-going palliative care. On 1st May 2020, while in the residential care home, mum died peacefully. If it had not been for the overwhelming support offered to my mother by care home staff and local family members who, due to Covid-19 restrictions, had very limited access to the care home, my feeling is that her final days of life may have been a profoundly lonely experience for her. I was unable to support her.

The first wave of the pandemic had struck in early March 2020 and restrictions for visiting residents in care homes were put in place. At the time of her death, we were notified that she had succumbed to a recurrent chest infection which, in retrospect, had all the hallmarks symptoms of Covid-19. However, we were told that this was not the cause of death and Covid-19 was not mentioned on the death certificate, despite many of the symptoms being mentioned by the care staff prior to her death.

After my mother’s death I experienced profound personal feelings of distress, reminiscent of the experience of losing my father two years previously. Hidden in the depths of my memory, feelings, regrets and distress generated about my sister’s death 46 years earlier also emerged. However, my distress about my mother’s death was exacerbated by what I can best describe as a ‘surreal depersonalised’ experience, compounded by my frustrations about being so far away from her because of the impact of Covid-19 national restrictions placed upon me. It did not feel as if the experience of my grief was real but was somehow happening elsewhere and to someone else and at a distance, quite literally. I knew that my mother had died but it could well have been a million miles.
away on another planet entirely. It felt frustrating being only a few hours’ drive away. Being unable to travel left me feeling powerless and angry. Being unable to travel to Lincoln to see my mother for the last time left me feeling that her death was unreal. It contrasted with the experience of the death of my father where I felt that his death was tangible, visible and free from frustration. Although he had died in Ireland, I had still been able to have an active role in planning his funeral.

When mum and dad had separated in 1974 after my sister’s death, my father moved to County Kerry, Ireland. At the time of the separation, I felt abandoned by him but in later life, I established an ongoing relationship with him by regularly visiting him in Ireland. Immediately prior to his death, I was unable to get to Ireland, but I was instrumental in making all the arrangements for his funeral. This act gave me a profound sense of closure, knowing that I had been able to say goodbye to him in a tangible way. He had a very public, community-focused and meaningful funeral that helped me to come to terms with his death. In contrast, the pandemic and national travel restrictions and the opportunity for a family and community-focused funeral was profoundly absent for my mother. After her death, I began experiencing a degree of unreality and depersonalisation with a sense that her death was somehow ‘suspended in time and place’ and I could not fully comprehend that I was dealing with the death of my mother. My immediate thoughts were that the funeral ceremony would provide me with an opportunity to come to terms with the experience of loss, but the restrictions built in a set of complexities that I had not even considered. On reflection, I also thought that my expectations about the funeral process were shaped by my strong Irish heritage in which there is an expectation that a funeral takes place within a very short time following the death of a loved one, often within a few days. This is clearly not the case in Great Britain
and this delay may have also contributed to my distress at the time.

Despite my own thoughts about what a funeral should or should not be, the funeral was arranged and delivered according to her wishes and so I had to suspend my own feelings and cultural values about how the funeral should be conducted. I am not alone in believing that a funeral service provides an opportunity for family, friends, and acquaintances to personally and publicly recognise the death of a person who is loved. It also presents an opportunity for individuals to openly grieve before beginning, or in some cases as part of the process of completing the initial transition towards facing the death of a loved one.

However, during the first wave of the pandemic, with large numbers of people dying, it was perhaps inevitable there would be challenges with the timing and arrangements for funerals to take place. For our family and despite the ‘formulaic’ restrictions in place, we were fortunate that the funeral took place three weeks after her death. The national restrictions that were in place included limiting the funeral party to 15 people, not arriving into the crematorium any earlier than 15 minutes beforehand. Only very limited private gathering in groups was permitted beforehand — no hugging, social distancing and we were required to leave the crematorium promptly after the funeral. Nevertheless, the Humanist eulogy and funeral delivered at my mother’s funeral was meaningful and sensitively delivered to meet her last wishes, but as a Roman Catholic this also challenged my personal, cultural and faith beliefs around death, dying and the funeral as a ‘rite of passage’. As I lived so far away from where the funeral was held restaurants and hotels were closed and my journey on the day included an exhausting five-hour journey each way journey to attend a 20-minute funeral ceremony. This left me with a feeling of an overwhelming sense of incompleteness and exhaustion, but I
felt compelled to do this essential journey as it was my only way to say goodbye to my mother.

After my return home from the funeral, I continued to experience a sense that something was missing. On reflection, I sense this was about being unable to say goodbye to my mother in a way that helped me come to terms with my loss.

My Irish heritage through my father tells me that there was a need to celebrate my mother’s life by holding a ‘wake’ but again, national restrictions on family gatherings restricted this. The term ‘wake’ is of Celtic origin. It is now widely used to describe a social gathering after a funeral when family and friends gather to celebrate the death of a loved one. Historically, it is described as a social gathering where the body of the deceased person was present in the home prior to the funeral and it still occurs in Ireland. The family view was that there may be an opportunity to hold such a gathering when her ashes were interred in September 2020 but again, the pandemic restrictions at this time limited gatherings to six people. Understandably, my sister marked the internment of my mother’s ashes with a gathering of her own family. I made another long round trip journey to spend time alone with my mother on a beautiful late summer’s day in the Lincoln Crematorium Memorial Garden where her ashes were interred. In some ways, the experience of being alone with my mother at her grave side had a greater emotional impact upon me than the experience of the funeral which it seemed, had, alongside my personal feelings of distress and loss, been characterised by procedure, bureaucracy and limitations.

To conclude, the personal experiences I have described may be similar experiences to the thousands, if not millions, of people worldwide who have experienced loss, separation, and grief during the 2020–2021 pandemic. My recollections are unique to me; the death of my mother during the pandemic evoked feelings of acute personal distress, as well as igniting
long-forgotten memories of the early death of my sister. It also connected with a sense of loss and separation that occurred in a dispersed family over a period of 40 years or more.

About the author: Rory Bowe

Rory is a Staff Tutor at The Open University in London and the South East and has previous experience in a wide variety of NHS education and training roles.

He is a dual qualified Adult and Registered Mental Health Nurse, a qualified teacher, and holds post-graduate qualifications in Nursing, and Sociology. In his role with The Open University, he has teaching and management responsibilities for student nurses recruited within the School of Health Well-being and Social Care Studies. He is currently responsible for the tuition delivery of the Level 2, 60 Credit Module — K220 Death, Dying and Bereavement.

References


Foreword

In 2019, my husband and I each completed a doctorate as part of our phased retirements. To celebrate, we planned a global sight-seeing ‘trip of a lifetime’, departing from the UK in late November 2019.

Our first stop was to China’s ancient capital, Xi’an, in Shanxi Province. This place has historical significance as it is the home of the world-famous Terracotta Army, the burial place of China’s first Emperor, Qin Shi Huang. Our visit had personal significance, as Xi’an was also the venue for a family wedding between our Australian nephew and his Chinese wife. After the celebrations on 1st December, we and various family members undertook a whirlwind 1500 mile ‘bullet train’ sight-seeing tour through south-western China. Unknown to us at the time, the first casualties of what would come to be known as COVID-19 were being identified in Wuhan, about 500 miles east of our itinerary.

In mid-December, we flew from Kunming, China, to New Zealand to visit other relatives, then on to California, USA, to
A pandemic narrative

spend the festive season with our son and his family. It was only after our return to the UK in January 2020, that the world began to realise a pandemic was developing in its midst (Blackburn, 2021a).

Introduction

In this essay, permit me to share some of the stories of the lived experiences of three close family members and friends who died from either COVID-19 or non-COVID illnesses over the 15-month period the pandemic raged. To date, ten family members or friends have died, as well as our family pet, with all the impact of personal grief, loss, and bereavement. There was also some learning of coping strategies during this time. Names are anonymised and the information is shared with the prior knowledge and permission of those involved.

The Narrative Diary

January 2020: I returned to the UK from the ‘trip of a lifetime’ and became extremely unwell from what I thought was a tick bite. I experienced symptoms similar to those of COVID-19, which were beginning to be publicised in the media. I contacted NHS 111 and my GP, fearful that I might be one of the first COVID-19 cases in the UK, and that following international travel, I might have inadvertently caught or spread the virus. The health staff dismissed COVID-19 and were more concerned about potential Lyme disease from the tick bite and prescribed antibiotics. After a few weeks, I recovered. At the time, there was little COVID-19 testing, and it remains unclear to this day whether I was an early COVID-19 victim or had seasonal flu.
March 2020: Several residents in our apartment block also presented with COVID-19 symptoms. My husband was one of them and he became extremely unwell. We immediately self-isolated from each other in our flat and from the world at large. He ultimately recovered but presented with long COVID-19 symptoms. Subsequently, we have both become actively involved in the King’s College London research study (2020). As part of that research, we set up the Zoe app on our phones and, with others, provided the healthcare system with critically valuable information about the symptoms of COVID-19 and the hotspots where it occurs. Participants record their symptoms daily.

Two neighbours and I, all with a clinical background, set up a COVID-19 Advisory Team (CAT) for our apartment block, and together we developed a strategy and newsletters for residents and leaseholders. These specifically focused on the risks, impact, and implications of COVID-19.

April 2020: My elderly cousin died from terminal cancer in a care home. Her death was expected, on account of her age, frailty and cancer but was not related to COVID-19. I last saw her in February 2020, just before the first lockdown. Since her death, I have remained in regular contact with her husband and daughters using social media. This was really important as we could not meet face to face. Physical visits to the care home were eventually banned in accordance with government guidance. The virus was spreading nationally at an alarming rate. Even as we emerged from the first lockdown, no family members were permitted to visit her widowed husband in the care home garden and give him a virtual hug. This increased the pressure and sadness for my late cousin’s husband, all our family and care staff.

At that time, only four people from my cousin’s immediate
family were permitted to attend her funeral, socially distanced. Attempts were made to live-stream this event, but the crematorium and funeral directors were so overwhelmed with the number of deaths, that they declined the request, while acknowledging that infection control procedures would not permit a dignified service for the deceased or her family. There was no fanfare, no ‘wake’, no floral tributes from the extended family; just the photos and memories, we all committed to paper and shared or spoke about and continue to do via regular Zoom sessions or phone calls.

April 2020: It came as a shock to learn of the death of a close medical colleague — my first friend to die from COVID-19. His widow, also a close friend, and I trained as nurses at the same hospital 50 years ago. The last time she saw her husband was four weeks before his death, when the ambulance crew loaded him into a wheelchair and then into the vehicle. Waving farewell, the ambulance crew drove off to an intensive care unit. As my friend looked into the distance at the fading yellow vehicle, she realised that she would never see her husband again. He spent the next four weeks on a ventilator. Before he died, his wife was occasionally permitted to see him via video access, either separately or with other family members. The funeral, like that of my cousin, permitted only some, but not all, immediate family members. After the funeral, my friend’s wife, two daughters and a son who were locked down together held a small wake in their garden with the two family dogs.

On the day of the funeral, close friends, including myself, joined a family ‘sitting shiva’ via Zoom to commemorate and celebrate our medical colleague’s life. In the Jewish religion, this provides a time for spiritual and emotional healing where mourners join together and pray or pay their respects. My husband and I prepared a pictorial book and gathered senti-
ments, photos and mementos from his medical and the nursing fraternity and presented this to the family, following the first lockdown.

**February 2021:** My Australian nephew’s wife – whose wedding we had attended in China – had an unexpected still birth at 28 weeks gestation. This was their first child, heralding a tragic sequel to the colourful wedding celebrations we had shared together in China in 2019. They had a small funeral which we would have joined via live-stream, had technology permitted. Unfortunately, the internet failed us. Instead, we shared pictorial flowers, Messenger video chats, and tears after the event.

**March 2021:** Our beloved Siamese cat of 18 years slipped unseen into our garden and was found dead the next morning. Nicknamed the magnetic cat marsupial, she cuddled up to us every night during the pandemic and was a source of particular comfort during that time. So unexpected was her death and so great our loss, we produced a photograph album and my husband wrote a poem including the following stanza:

> Gently into that good night she went. No rage. No fuss.  
> She spread herself upon the path.  
> And soaked up death as once she’d soaked up sun.  
> *(Dennison, 2021)*

So, what can we interpret from these narratives?

Globally, the pandemic has changed all our lives, including my own. We have had to learn how to socialise and communicate
differently, usually at a distance, whilst exploring new ways of living safely and in harmony with each other. During the pandemic, I have discovered additional social media platforms, such as Whereby, where I have enjoyed chatting and enjoying a meal with family and friends together, without always having to wear a mask, and learned how to touch and express love and affection in a safe and meaningful way. I believe the pandemic may, in the future, change the way we receive and access health care, how and where we learn, where and how we work, how we care for those approaching death, and how and where we grieve for family, friends (Jones, Mallon and Bergstrom, 2020), as well as our pets. Most of my medical consultations have taken place by phone. Work has been conducted via social media platforms. A Jewish memorial was held online. We were unable to attend the funerals of any family or friends, on account of the pandemic. My husband and I held a small funeral for our cat, whom we buried in our garden, placing flowers around her burial site. It enabled us to remember our cat but also reflect on those whose funerals we had been unable to attend.

As individuals, we have had to learn resilience. The pandemic continues to challenge our emotional well-being, concentration, and productivity. When permitted, we shall need to re-learn how to express fellow feeling and proximity with others, without having to draw apart.

So how should we consider or anticipate loss in the future? As we move from ‘lockdown’ to ‘unlocking’ and the potential for other COVID-19 surges, how do we retain the ‘good will’ that has been generated over the last year or so and withstand the challenges and requirements to maintain a caring community? COVID-19 knows no boundaries and is unlikely to disappear in a hurry. Has the roll out of COVID-19 vaccine programmes enabled us to mix more closely with our loved ones? Does it prevent mutations and continue to reduce
deaths? There are no easy answers. As a former nurse, I question whether, if alive today, Florence Nightingale would have offered practical solutions that could have brought the pandemic under control sooner? As a statistician, social reformer and a nurse, Florence Nightingale’s understanding of health, infection control and data analysis (Nightingale, 1859) might have provided a welcome contribution to the UK government’s scientific advisory teams. Her practices are still relevant today (Nightingale, 1859), in the fight against COVID-19. 2020 was intended to be a significant year for Nursing, marking the ‘International Year of the Nurse and the Midwife’ but also corresponding with the 200th anniversary of Florence Nightingale’s birth on 12th May.

Florence Nightingale is recognised as the founder of modern nursing and the principles that she championed, first in the Crimean War, then at St Thomas’s Hospital, London. These form the bedrock of nursing and arguably some of the main defences against COVID-19. When Florence Nightingale arrived in the Crimea with her small team of nurses, she discovered unsanitary and poor hygiene standards in the military hospitals. The soldiers were dying of severe diseases and infections, rather than their war injuries. She promoted hygiene and cleanliness to combat infection. She insisted on frequent handwashing, fresh air, infection control, and clean and sterile surfaces to treat injured soldiers. These are still the methods utilised to prevent transmission of COVID-19 today (Vanderbilt School of Nursing, 2021).

The initial shortage of adequate personal protective equipment (PPE) for health and social care staff in the UK during the early stages of the pandemic exposed them to higher risks. Florence Nightingale recognised the dangers that health professionals faced in combatting disease. As her career advanced, she used statistics to highlight the risks of exposure to diseases like cholera. She was a pioneer in many areas, such
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as epidemiology, where she used data to improve hygiene standards in hospitals to protect both staff and patients. She believed that accurate data was essential to informing and bringing about change and was the first woman to be inducted into the Royal Statistical Society. She used infographics – creating coloured charts and pie charts to convey facts about diseases and infection control that are still used by medical experts and advisors in conveying information to the public about COVID-19. Let us hope that Florence Nightingale’s legacy remains to help overcome COVID-19 and the loss of loved ones that many of us have experienced since 2020.

About the author: Dr Maddie Blackburn

Maddie is a (retired) solicitor, senior health professional, a retired Florence Nightingale nurse, midwife, health visitor and lecturer with extensive background in policy development, research, management, law, ethics, and performance auditing and inspection. She has developed considerable experience in national and international children’s and young people’s policy and legislation both as a Chief Executive and Director(s) across health, social care, criminal justice, legal, regulatory and the charity sector. More recently, her work has focused on young people with life-limiting and/or life-threatening conditions. Maddie completed her PhD at The Open University in 2019: ‘Sexuality, relationships and reproductive choices in young adults with life-limiting and/or life-threatening conditions’. Since then, with Dr Sarah Earle and members of The Open University Sexuality Alliance, Maddie has helped complete the Let’s Talk about sex, intimacy and relationships project (see publications). Maddie is currently working with Dr Sarah Earle on a COVID-19 study related to young adults with life-limiting and/or life-threatening conditions.
References


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SECTION VI

OTHER EXPERIENCES OF GRIEF DURING COVID-19
I still wave at lorries. If I spot the red and white logo of a British Oxygen Company (BOC) vehicle carrying cylinders round the ring road or turning into a hospital, I can’t help it. They don’t wave back but that’s all right.

My mother, Betty was a telephone order clerk at BOC Margam, just down the road from Port Talbot steelworks on the industrial belt on the south Wales coast. Her job was to write down the orders and make sure the oxygen cylinders were delivered to the right place at the right time. The weekly schedules were done by hand, way before online ordering or globalisation.

This was the seventies and her workplace had a canteen, a savings scheme for bus trips to London shows, a social club for Christmas parties. Betty was the social club organiser, blonde, busty and full of quick wit. The office clerks were the girls and the drivers were the boys.

It was easy for her to sort the delivery rounds with her local knowledge. She didn’t need a map. She was in charge of arranging the medical gas deliveries to small pharmacies up and down the valleys from Merthyr to Maesteg. She shone on
the telephone, always charming, yet firm. She could sort out all
the local chemists who knew her by name and sometimes
would plead for a couple of extra cylinders.

You can’t send out a half empty lorry if it’s not on the list.
The computer would have said no. But she knew who the
oxygen was for: the old miners with dusty lungs and faint
breath. So, she’d pop into the yard and chat up one of the
delivery boys to do a detour. At Christmas, the chemists sent
her chocolates and talc sets.

When her dementia began to tangle everything up in her
mind, I brought her to live near me. She never belonged, she
never settled, chucked out of three care homes for so-called
‘challenging behaviour’. They could have tried harder to get to
know her, to work out that she was just frightened by institu-
tional corridors full of strangers, her sense of direction and
telephone charm long gone.

She took her last breath in peace in Vale House, a beautiful
dementia hospice. I am grateful she got a place and for the
well-trained carer who held her hand that night and told her
that her daughter was on the way but if she wanted to go, she
could. I did not make it, but that’s all right.

It was all sorted, so I thought. The forms, the photographs,
the organ donation, the funeral, the feelings.

But years later in COVID-19, when I see the news item
about the oxygen shortage in Brazil, I am furious. The families
are clubbing together to buy their own cylinders and lugging
them to the hospital doors for their relatives trapped and help-
less inside.

I ache to ring her up. She wouldn’t stand for it. She would
organise a collection, a whip-round, she would have a word
with one of the boys. She would tell that President Bolsonaro
to bugger off. Challenging behaviour? Bring it on.

And the news is like a tidal wave: more graphs, more
photos of loved ones, nurses in tears and carers in bin-bag
Gas and air

aprons and then grannies pressing against glass. It is not right. I want to put my fingers in my ears when they announce the numbers of care home deaths. I must not imagine the old people confined to rooms or restrained. There must be a kinder way.

I switch it off.

Someone should do something — let them out, take them to the park, to the pub, to the beach, flush away the tablets, give them gas and air, hold their hands, tell their story.

The border with Wales is closed. This year I cannot take flowers to the cemetery.

With so much death in the news, I find myself thinking back to when I was arranging her funeral. I know she would have preferred a BOC lorry to a hearse for the journey back to Wales. She would have known who to phone. Instead unconventional to end, the coffin glides into a beautiful white converted camper van and co-cocooned we play Tom Jones all the way down the M4. I try to teach my English-born children a few lines of Calon Lân¹ so they don’t mouth the words like fish at the funeral. It is hopeless. She would have roared in laughter.

The crematorium at Margam is restful, with gardens full of daffodils and benches facing the mountains. It is right next door to the British Oxygen Company. The plant is bigger and noisier than I remember. It keeps working 24 hours. I always thought those pipes and chimneys were magic. Some lunchtimes, the girls would escape from the office and sit at the crem with their sandwiches and crisps in the fresh air.

At the crem, on the day of her funeral a gang of work colleagues from decades ago appear. I am in awe that they want to pay their respects to Betty after all this time, that they still remember her laughter and that my cousins come to carry her.

Afterwards, I think of her particles in the air all mingling,
dancing, charming their way into a cylinder or two. Gas and air. For someone else’s birth or death.

I still wave at BOC lorries and sometimes I just wink.

About the author: Deborah Cooper

Deborah is a lecturer in International Education at The Open University and has been an associate lecturer and student.

She took a long career break to care for her mother and aunt who had dementia. She found examples of some good care and some bad care and wishes for a time when there will be a more positive way to support people with dementia.

During that time away from academic writing, she rediscovered the power of creative writing and storytelling in the oral tradition and now trains others in these methods. Many of her stories are set in the landscape of south Wales where she grew up. The story presented here is true. Her daughter, a midwife, helped her with the title of the story when she said she thinks of her grandmother whenever she sees oxygen in hospital.

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1. Calon Lân is a popular hymn and means pure heart:
   
   *I don’t ask for a luxurious life*
   *The world’s gold or its fine pearls,*
   *I ask for a happy heart,*
   *An honest heart, a pure heart.*
text from my sister in lockdown: ‘Aren’t you glad that Mum didn’t have to live through this?’

Mum died in October 2016, a time that was both years ago and five minutes ago. Grief does that. It concertinas the months into something outside time. My mind is still stuck in the darkness of that August, long hours sitting by a hospital bed waiting for results. She spent her final weeks in the garden, on an elaborate nest of cushions. She couldn’t eat, and there was always a table of drinks by her side, like an Edwardian garden party, only with Ensure instead of gin slings. She liked to watch the birds and smell the autumn air. She liked to be outside, so outside is where we looked after her.

She didn’t have to live through lockdown. If she had, she would have been a key worker. She worked in residential care for much of her life, cooking endless meals, all tailored to the residents’ needs. She worked from early morning to mid-afternoon, right up until she was dying. She spent her life looking after people at the end of theirs. They got a longer life than she did.

Cancer ate her up from the inside. She weighed six stone
when she died; you could see the tumours through her skin. She turned pale, then yellow, then grey. She refused most medications, because she didn’t want to waste her last days in a fog of opiates. She refused to go to a hospice. She had seven children, then aged between 37 and 15, and seven grandchildren. Two more grandchildren were born during her illness. There was no lack of life around her, no lack of laughter. Time froze and crystallised around her; her death seemed an impossibility.

But she died anyway, on her own terms, in her own house. She died and was cremated, and we were left in the aftershock, wondering what came next.

For me, what came next was weeks, then months, then years of shock. I was my mum’s nurse, her interpreter, and her advocate, as the eldest daughter, the one with medical knowledge, the bossiest. I was the member of the family who acted as the spokesperson, interpreting and explaining her illness to anyone who had questions. I absorbed every moment of her illness, not out of martyrdom, but out of a desire to protect my siblings and my dad. The last thing I did for my mum was sponge her bed clean after her body was taken away. I sponged up all the trauma and I took it with me.

Fast-forward to 2020. Coronavirus has closed the country down. Not fast enough, not hard enough, not financed enough to fix it, but enough to make everything step sideways out of time. The buses are advertising movies that came out in March, but it is September. People are afraid of their groceries, hoarding toilet roll that they sprayed with Dettol. The death toll rises, falls, and creeps back up again. It’s hard to remember that every number is a person. The streets are quiet, but inside is a constant wave of noise and chaos, the children too loud, needing so much attention.

The streets are quiet.

I go to the streets, walking miles around the same block of
suburbs that I call home, relishing the fresh air, the quiet and
the subtle changes in the season that give some idea of time
passing. My walks take me through the churchyard, on
purpose. My mum isn’t there — we spread her ashes on the
cliffs in Norfolk, in the liminal space between the land and sea
— but hundreds of others are. I take my time among the
graves, noting the ones that are still cared for after 50 years, the
abandoned ones, the broken ones and the newer cremation
memorials; the parents buried with children, the spouses
together in death, some reunited after decades.

I rage as I walk, furious that she died, furious about her
pain and about her continued absence in my life. I remember
minutiae of the last months, things I thought I had forgotten,
like sitting by her in the garden as she tried to do crosswords in
the back of magazines. Up goes the step count, and up come
the memories. Up come the tears, and I’m glad of the people
keeping their distance, unable to tell if it’s weeping or hay
fever.

In the quiet of the endless, timeless lockdown, I begin to
grieve.

She would have hated lockdown. No seeing the family
except at a distance, but still having to work? She’d have been
livid. No holding her grandchildren, the youngest of whom
was born between lockdowns? No holidays? No haircuts for six
months? She’d have been beside herself. Daily Boris Johnson
on the television? She’d have thrown away the remote.

Covid has been a time of grief, unreality, and loss. Losing
people, losing lifestyles, losing time; grieving those losses. Time
has concertinaed — an eternity of Tuesdays. But the loss of
time, the cancellation of appointments and holidays and sports
days and parents’ evenings, the loss of all the anchors to the
calendar of reality that we take for granted, gave me back the
time I needed to grieve.
About the author: Sophie Michell

Sophie lives in Peterborough, juggling her children, writing and history. She is a post-graduate researcher at The Open University, studying Victorian inquests. This piece is dedicated to her mum, Joanne (1961–2016), who would have hated lockdown.
In February 2021, a postcard sent by my dad 77 years ago arrived out of the blue. With it came strong memories. The postcard message was short:

Dear Uncle Fred
Well, I am in Blue at last.
I did not think it would be like this.
You don’t get much time for yourself, do you? but I like it alright.
I will write when I get half a chance so will you hold on a bit.
I have 19 weeks here yet.
Give my love to everyone
Love Bill

To make sense of this, you need to know more about my story and relationship with my dad.

Like many, I have found the third national lockdown (Jan-April 2021) to be the most challenging. The shorter winter days and the poor weather have created less opportunity to get
outside and the novelty of the ‘slowing down of life’ has begun to wear thin. Isolated from friends and family, our world has become smaller. Or maybe it’s the enormity of what we have all been through in the last year is catching up with me.

However, the more honest and personal reaction to why I have been struggling more in this lockdown is linked to my own grief journey. I am heading towards ‘Mourning March’, the month where I mark some tricky dates, where I need to plan carefully and try to navigate my way through it. My mum died on 3rd March 2012. Mother’s Day usually falls in the middle and on 30th March is the anniversary of when my daughter Fi died suddenly in a car accident at the age of 17. It feels unbelievable that in March 2021 we will be marking the fifth anniversary and the second one in lockdown without Fi, my very precious daughter and middle child. Five years without her smile, sparkle and her physically enriching my life as her mother. The anticipation of knowing these anniversaries will again take place during social isolation and lockdown restrictions is hard. In any other March, I’d draw on the kindness of others — my grief support network — and spend time with others missing the same loved ones.

In February this year, we felt brave. We shared Fi’s gift of organ donation and our experience of supporting her decision to become an organ donor at the end of her life in support of National Health Service Blood and Transplant (NHSBT) ‘Leave Them Certain’ campaign. This important public awareness campaign has followed a law change in England introduced on Fi’s birthday in May 2020. The law now presumes consent to organ donation unless an opt out has been registered.

It was a big step for us to share our very personal story within the national media. We knew Fi would approve: the campaign is aligned with her strong principles in life of being kind, helping others and making the world a better place by
raising important social justice issues. However, alongside the immense pride in telling Fi’s story, the week had also left me feeling emotionally drained, grief exposed. Any steps that involve being brave involve a risk of further vulnerability.

On the Friday evening, it was with much relief I switched off from work and started to connect virtually with friends and family. I couldn’t believe the messages that were being shared within my sibling WhatsApp group. A postcard sent by dad, aged 18 to his uncle Fred in the first week of naval training in Plymouth had been delivered to the family home in Liverpool. It had finally arrived in the post after it was written in 1943. It was such a shock to get a written message from dad who had died 25 years ago and was never a letter writer in life. Luckily the family home remains within the extended family, so the postcard’s arrival was shared by my cousin. So much excitement and speculation surrounded its unexplained arrival and why it had turned up now after all these years. For me, its arrival brought joy and the much-needed energy boost. It was an opportunity to reflect deeply on my relationship with my dad and what he had taught me in his life and following his death.

My dad, who didn’t have an easy life, always lived with hope. He encouraged us, his six children, to work hard, to be positive, use our talents, be resourceful and take advantage of each and every opportunity and to continue to learn from life’s experiences. I have parented my own children to live life with hope and nurtured the same family relationships that were so important to my dad. The postcard felt like such a wonderful gift, timed to connect me with dad’s spirit and values of promoting resilience, choosing hope, and making a positive contribution.

Leaving home and joining the Navy during the Second World War was such a significant, and much anticipated, time in my dad’s life. He wrote to Uncle Fred, who was a few years
older and was a surrogate ‘older brother come mentor’ after dad’s older brother died in childhood. It clearly tells how the first week away from home was a huge adjustment and that he was thinking of his family.

Dad faced many challenges as an Able Seaman during his war years. He was on a mine sweeper preparing for the D-Day landings in June 1944 and was on the first ship to arrive in Nagasaki after the devastation of the dropping of the second atom bomb in August 1945. Dad’s ship then went on to take Australian prisoners of war back to Sydney at the end of the war. The Second World War was an incredible difficult period in history and a reminder that hard times do pass and can result in the building of brighter futures.

My dad died a week after the birth of my first child in August 1996. He had been so ill for so long and spent his last summer receiving end-of-life care in a hospice. Those weeks spent with dad when I was heavily pregnant on the cusp of parenthood were so precious. He was hanging on to see his fifth grandchild at the same time I was hanging on to remain pregnant. I knew that as soon as I became a parent, I would lose him as my parent. I knew I was going to struggle navigating this life transition without my dad there physically ready to catch me, guide me and provide reassurance and unconditional love and protection when I was needing it most.

So many emotions, such sadness when dad died and matched also with such joy at becoming a parent and meeting my baby daughter two weeks after her due date. The grief of losing my dad and early parenthood just merged. It was hard to unpick the exhaustion of early parenthood with the heavi-ness of grief at this time. I do know my first born became a very special baby in our extended family. Everyone was grieving and the sadness of dad’s death and the love felt was positively channelled and redirected to the grandchildren. My daughter, born at this point, became a focus for much of the
outpouring of love. I saw her being held close and the comfort this provided especially to my mum.

Dad’s death triggered other big life decisions for me and my husband: a year later we moved cross-country to be near my mum and siblings, a relocation decision that would have made dad smile. Fi and my youngest child were born as we settled back in the village community I grew up in. The village dad loved and often proclaimed was ‘the best place in the world’ was the same one I couldn’t wait to leave in my teenage years. I had found the village stifling, insular, dull and boring and here I was returning with a young family to a community that felt safe, caring, welcoming and nurturing. It takes a whole community to raise a child, and indeed to grieve the death of one. The outpouring of love and the kindness shown following Fi’s death has confirmed dad’s sound judgement that our home village is the best place to live. Dad was so often right and I still hear his words of wisdom when I am struggling or need to make important decisions.

It is probably unsurprising that it was my own parents that I took inspiration from as I faced that difficult day in the hospital following Fi’s accident, hearing that her head injury was not survivable and being approached about organ donation at the end of her life. Neither of my parents were alive at the time. My parents’ third child (my older brother Michael) died of childhood cancer aged six years in the 1960s. I knew, because I had experienced it first-hand, that it was possible for a family to survive and thrive following the death of a much-loved child. I knew that immense grief and sadness could sit alongside joy and laughter and that families had the ability to keep living and moving forward while holding the memories of loved ones close. What an incredible legacy and gift that has been passed on to me by my parents. They provided the road map, showing how to navigate grief and sadness and use it to
find a new and better way of living following the death of a loved one.

The postcard arrival during the third lockdown has been a reminder of the challenges and difficult life events my dad faced. This included the death of his older brother in childhood, the suffering and hardship he witnessed during his war years and the death of a child from cancer that he worried had been caused by his own exposure to nuclear radiation during his time spent in Nagasaki. Dad continued to live with hope. Dad’s approach to life continues to inspire me and his family values have been grounding and provided much reassurance. He has shown me that hard times will pass and it’s possible to build better futures by drawing on support when needed, and that working together with others can have impact. Look at what has been achieved during the pandemic by all the key workers.

My relationship with my dad continues. In life I wasn’t the best listener when he ‘shared his life lessons’. Since his death I have found a new closeness and awareness of his energy, ability to focus on what is important and his encouragement to learn from opportunities and experiences. Some of the hardest times bring the greatest life lessons. I now know how precious life is and every day needs to be lived fully and appreciated. The third lockdown and the Covid-19 pandemic will pass. What will I have learnt from this period and be able to pass on to future generations in a short postcard message?

About the author: Vicki Caldwell

Vicki is a regional OU Social Work academic with a specialist interest in work-based learning, employer collaboration and apprenticeship delivery.

Following the sudden and unexpected death of her daughter in March 2016, Vicki has become interested in ‘active
A postcard from my dad

grief’: activities that don’t make your grief worse and can help with finding a new way of living with hope following a loss. Some of Vicki’s active grief strategies include walking challenges with friends, a regular yoga practice, spa visits, journaling and involvement in community-based activities that have been inspired by her daughter’s memory.

Vicki is the founding Trustee of FEES Fund (https://www.feesfund.org/) an education charity set up in memory of Fiona Braidwood awarding grants to remove financial barriers so young people can take part in enrichment activities. Vicki has shared her experience of organ donation in support of NHSBT ‘Leave Them Certain’: a public awareness campaign around the importance of having conversations about wishes for organ donation. The recent law change to opt out means families remain at the centre of the decision-making process and are still approached to support this decision if no objection has been registered.

Vicki is a member of the Open Thanatology research group, North Bristol organ donation committee representing the views of donor families and part of NHS Blood and Transplant ‘National Donor Families advisory group’. The latter is a group that ensures donor families’ perspectives are included in research, policy development and have influence within service improvements.
Remember the joke about buses? You wait for one and then three come at once. We have that with illnesses and death. We don’t have one death, we have at least three and it is the same with illness … and medical appointments.

Covid didn’t start for my family in March 2020 with lockdown. It started a few months before, in January.

It started with my mum being admitted to hospital, after what was thought to be the last of her triple seizures. Before her admission, she’d had chronic fatigue and a dry cough for two weeks. In the hospital, she had a high temperature and a blood oxygen level of 85%. She was only allowed home after three days in hospital because she was given a DreamStation Pro CPAP breathing machine to use overnight. A week later, my dad, after having a routine operation, had to stay in overnight because he had a blood oxygen of 85% … Sound familiar?

At this point in 2020, Covid wasn’t really known. I thought
mum’s was an infection and my dad’s a bad reaction to the anaesthetic. I didn’t even register what was going on in China. I had two sick parents and a diabetic dog who had a specific routine. Even when I developed a cough and fatigue, I put it down to being asthmatic and running myself into the floor in all different types of weather. I nearly collapsed one time. I had a sudden onset of nerve pain down one side of my head which felt like someone had broken my skull and face. Yet, I had to carry on; there was no one else for mum, dad and my dog.

February. Suddenly, Covid was everywhere. You couldn’t escape it. We were trying to work out coping strategies and we received a phone call. My great uncle Ken had been taken into hospital. Due to Covid restrictions, nobody could visit. His children received updates from his doctors over the phone. It wasn’t Covid, but it was a mystery. Over the next few weeks, he was in and out of hospital while they tried to diagnose what was wrong.

The week before lockdown, we had the answer to great uncle Ken’s mystery: aggressive stomach cancer. The hospital wanted him out as soon as possible, so that he could die at home with his family. As I was trying to process the shock, the Covid chaos meant I was frantically trying to prepare for the inevitable lockdown. All the stress and anxiety it brought with it felt magnified as I was still the main carer for my family. A few days later, we received the call that Ken had died in hospital; his sons hadn’t got there in time to say goodbye.

Numb. That is how I felt. Even when I knew it was coming, I had no time to accept or grieve for a great uncle who was always a part of my life. And everywhere in the news, there were families crying and begging loved ones not to die; they couldn’t die of a virus. And I knew exactly what that felt like.
Nearly 12 years ago, we were in the same position. My Uncle Roger, who had just turned 50, suddenly became very ill. No explanation why. For 13 weeks we said the same thing as the families on the news: he can’t die of a virus. But he never recovered and died in hospital. None of us have recovered from that …

A funeral in lockdown is a nightmare. My grandfather wanted to go to his brother’s funeral. Because of his age and health status, he was in the ‘vulnerable category’ for Covid risk. We told him it may not be possible for him to go. Covid restrictions. He insisted; he didn’t want his brother to go alone on his final journey, because their sister couldn’t go to the funeral. Luckily, my dad managed to contact the crematorium to arrange for my grandfather to go. He went but he had to sit outside and listen over loudspeakers.

I had no time to grieve or reflect on his passing. Within hours of Ken’s funeral in April we received another phone call. My great aunt Julie had died in a care home, possibly due to Covid-related symptoms, but the diagnosis got lost in everything else that happened the next day. Another phone call: my great aunt, Anne, Julie’s sister-in-law, had died of heart failure. Lockdown meant that no one could attend the funerals because of not being able to travel. Three deaths. No chance to say goodbye or have time to grieve or remember happier times.

It felt like everything in my life was turning upside down. And still it went on and on.

My great aunt Mary, who is Ken’s and grandfather’s sister, was admitted to hospital with potassium level problems. My cousin gave birth to her son, who ended up in the NICU, because of rhesus-negative blood issues that had been missed during her
pregnancy. He nearly died. His own father was told that due to the Covid restrictions, he could only see his son if he was ‘end game’. Fortunately, my cousin was allowed to stay, even when the Covid regulations were very strict.

It was terrifying answering the phone. Who was going to die next?

May. The phone rang again. Lorraine, a very close cousin was admitted to hospital with sepsis, arising from underlying health complications.

She nearly died. My grandmother had my great aunt sobbing on the phone, because my great aunt couldn’t visit while Lorraine was so sick, due to Covid restrictions on visitors. She would only be let in if and when Lorraine was dying, which was a major possibility. Morning and night, we exchanged phone calls trading updates on her health and hoping that the strict Covid rules inside the hospital would prevent her from catching it. After all, the news was full of stories of people contracting Covid inside hospitals.

Stress upon stress. I couldn’t take much more death and illness.

And the week she came out of hospital, another cousin, who had had cancer suddenly died.

And this is how it was all through the year of Covid. Nothing but health scares, death and stress.

My 98-year-old grandmother had to be admitted to hospital in November. We thought she would be safe, but unfortunately, she was exposed to Covid. Twice. Fortunately, she didn’t become infected, probably because she was left in a side room
and forgotten. I wish I was exaggerating, but there were painful conversations where she cried and begged over the phone to be taken home. It was traumatic because she has always been such a strong, capable, and reassuring presence in my life. But to hear her like that, whilst being powerless to do anything, was just heart-breaking. It did also cross our minds that there was a possibility she could die there and none of us would be able to get to her.

Covid testing — quarantine periods. Time and lockdown shaping. She went into hospital reasonably well, considering her age. She came out a shell of who she had been before. Her memory issues have turned into dementia. We can’t visit because of the lockdown, so she believes we’re all dead. Last week, she thought that I was eight years old. It’s hard being told by my father that I shouldn’t participate in Zoom calls, because she won’t know that I’m her granddaughter.

It feels like it will never end. I haven’t had time to process what has happened, or grieve for those who have died or are dying around me. My grief has turned into anxiety and depression. I have exhaustion, insomnia, stomach issues. I become anxious very easily and suffer from random crying fits. I can’t process that fact that my mother nearly died of Covid, long before it was known to be in Britain. Both of my parents could have died within a month from Covid. They are both ‘fine’ but my mother has lost two thirds of her left lung capacity, so she has to do a lot of lung exercises to get them to expand, and my father’s lungs were damaged but to what extent we are not sure yet. And it has left me with long-Covid symptoms that affect every part of my health.

I know a lot about grief; I’ve grieved a lot over the past 12 years. Since my uncle Roger died, I have lost six relatives including him and two dogs, but right now, I’m numb to grief. It's like losing your childhood piece by piece. I don’t feel that I can begin to grieve for one person, before another member of
my family either dies or becomes ill. My mental health is suffering and I can’t see it changing. I no longer see positives in any part of my life. It should be a positive that my parents have both had the first Covid vaccine. Yet, I sat in the car park in tears, with anxiety, terrified that the ‘mild dose’ it gives the recipient would trigger more health issues. And I can’t cope. Every mention surrounding Covid raises my anxiety. It consumes me, and leaves me feeling like I’m being smothered and unable to move. Sleep is impossible. I colour pictures and look for ways to free my body from tension. Some days, I stop listening and reading the news because it’s too much to cope with.

I look at other people who share good news and have irrational anger thoughts over their happiness and mourn why my life has nothing but death and illness. Hopefully, sometime in the future, I will get time to grieve for those I have lost and for what has happened to my life.

I am stuck in a Covid world and I can’t see a way out.

About the author: Emma Buckley

Emma has been with The Open University since she was 18 years old. She has a BSc (Hons) in Science and is currently studying for either a diploma or degree in social science. She is a carer and also a student rep for The Open University Students Association (OUSA). She lives in Shepshed, Leicestershire. Emma would like to point out that she does not live in a Catherine Cookson novel, this is just how things have happened.
Between the prayers
and unsung hymns

a photo-montage blurs
to shadow and shape.

I try to make things out
then let them be, drift

amid the smudges —
we are back in Paris

the char of *Notre Dame*
the promise of rising.
About the author: Karen Littleton

Karen is a coach, poet and Professor of Education at The Open University. She currently supports academic professional development within the Faculty of Wellbeing, Education and Language Studies. Karen is a member of the ‘Hornet Press Poetry Collective’ and as a former writer-in-residence, at Westbury Arts Centre, she founded ‘Time to Write’ — where writers gather to share, develop their craft and, crucially, write.