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The Lived Experiences of People Bereaved by COVID-19

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&

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This study would not have been possible without the brave volunteers who came forward to share their experiences of losing their loved ones in such dreadful circumstances. We know how much courage that took. A massive thank-you for trusting us with your innermost anguish. It has been a truly humbling experience.

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This research is dedicated to the thirty COVID-19 victims whose stories comprise this report, their families who bravely told their stories, our own parents who we lost to this dreadful disease, and to all the victims of the pandemic and those who are still suffering so dreadfully.

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CONTENTS

		Page
	EXECUTIVE SUMMARY	1
	FROM THE AUTHORS	15
1.	INTRODUCTION	18
1.1	BACKGROUND TO THE RESEARCH	18
1.2	RESEARCH AIMS	20
1.3	STRUCTURE OF THE REPORT	21
2.	METHODOLOGY	22
2.1	ETHICS	22
2.2	PARTICIPANT RECRUITMENT PROCEDURE	22
2.3	SAMPLE: PROFILE OF PARTICIPANTS AND COVID-19 VICTIMS	23
2.4	DATA COLLECTION	32
2.4.1	Pathographies	32
2.4.2	Data Collection Processes	33
2.5	DATA ANALYSIS	34
3.	FINDINGS	35
3.1	CONTRACTING COVID-19	35
3.1.1	Doubt and Hesitation	35
	<i>Connecting Symptoms with COVID-19</i>	36
	<i>Recognising the severity of the situation</i>	37
	<i>Not Fitting the 'Profile'</i>	39
3.1.2	Slow Responses	40
	<i>Reduced GP/other medical services</i>	40
	<i>Delays in diagnosis</i>	42
3.1.3	Nosocomial Contractions	44
	<i>Care Home Contractions</i>	44
	<i>Hospital Contractions</i>	47
3.2	HOSPITAL ADMISSIONS	50
3.2.1	Saying Goodbye	51
	<i>Ambulance admissions</i>	51
	<i>Escorting people to hospital</i>	52
3.2.2	Waiting for initial news	53
3.3	COMMUNICATIONS	54
3.3.1	Communication with hospital clinicians	54
	<i>Pockets of effective communication</i>	54
	<i>Getting through on the phone</i>	55
	<i>Poor quality information</i>	57
	<i>Lacking two-way communications</i>	58
3.3.2	Direct communication with loved ones	60
	<i>Practical issues</i>	60
	<i>Problems due to COVID-19 treatment & symptoms</i>	61
	<i>Digital communication channels</i>	63

	<i>Help from hospital staff</i>	64
	<i>Lockdown & visiting regulations</i>	65
	<i>Hospital visiting and vulnerable patients</i>	67
3.4	CHAOS, CRISIS, CONFUSION & KINDNESS	69
3.4.1	A system overloaded	70
	<i>Overstretched staff</i>	70
3.4.2	Care standards	71
3.4.3	Confusion	72
	<i>Conflicting information</i>	72
	<i>Inappropriate delivery of difficult news</i>	73
3.4.4	Chaos	76
	<i>Poor infection control</i>	77
	<i>Breaking isolation protocols</i>	79
	<i>Discharging potentially infected patients</i>	79
3.4.5	Compassion fatigue and/or burnout?	81
3.4.6	Competence and kindness in the face of adversity	83
3.5	DNR AND CRITICAL CARE DECISIONS	86
3.5.1	DNRs	86
	<i>Processes</i>	86
	<i>Changing DNR/care plans when COVID is diagnosed</i>	91
	<i>DNRs without agreement of patient or family</i>	92
3.5.2	Critical care decisions	95
3.6	POWERLESSNESS AND FINDING AGENCY	98
3.6.1	Feeling powerless	98
	<i>Power imbalance</i>	99
	<i>Extra vulnerable</i>	100
	<i>Frustration with systems</i>	100
3.6.2	Finding agency	101
3.7	COVID-19 DEATHS ARE DIFFERENT	104
3.7.1	False hopes & rapid deterioration	104
3.7.2	Access to loved ones denied	106
	<i>Reunited in the final hours</i>	108
	<i>The final goodbye: via video and phone</i>	110
	<i>A dignified death?</i>	111
	<i>Newly bereaved and isolated</i>	114
3.7.3	Death in a pandemic	115
	<i>Practicalities</i>	115
	<i>A lack of understanding</i>	117
	<i>A society divided</i>	118
	<i>COVID-19 deniers</i>	120
	<i>The anti-vaxxers</i>	122
3.7.4	Elderly or with underlying conditions	123
3.7.5	The pandemic permeates every aspect of life	124
3.8	DEATH RITUALS	126
3.8.1	Funeral directors: The unsung heroes of the pandemic?	127
3.8.2	Restrictions to pre-funeral death rituals	129

	<i>Closed caskets</i>	130
	<i>Burial clothes</i>	131
3.8.3	COVID-19 funerals	132
	<i>Places of worship</i>	133
	<i>Funeral cars</i>	134
	<i>Coffins</i>	135
	<i>Flowers</i>	135
	<i>Singing</i>	136
	<i>Restricted numbers</i>	136
	<i>Time limits</i>	139
	<i>Comfort from an intimate funeral</i>	140
	<i>Satellites of sorrow</i>	142
3.8.4	Wakes and celebrations of life	142
3.9	COUNSELLING, MENTAL HEALTH AND SUPPORT	145
3.9.1	Counselling	145
	<i>Not accessed</i>	145
	<i>Inadequate services</i>	147
	<i>Receiving counselling support</i>	149
3.9.2	Mental health	150
	<i>Medical intervention</i>	151
	<i>Continuing struggles</i>	152
3.9.3	Complicated grief	154
3.9.4	Social media support	156
	<i>Social media groups: feeling connected</i>	157
	<i>Reciprocity</i>	159
	<i>Leading to real-life support</i>	159
	<i>COVID-19 social media groups: a double edged sword</i>	160
3.9.5	The importance of memorials	163
3.10	ANGER AND BLAME	164
3.10.1	Failure to protect care home residents	165
3.10.2	NHS	166
	Policies	166
	Individual hospital trusts	168
	No blame on NHS frontline workers	169
3.10.3	Government	170
	<i>International comparisons and shutting the borders</i>	170
	<i>Failures around PPE and vaccines</i>	172
	<i>Nightingale hospitals</i>	173
	<i>Lockdown failures</i>	173
3.10.4	Cynicism and distrust	175
	<i>Suspicion</i>	175
	<i>Contempt</i>	176
3.11	THE INQUIRY	177
3.11.1	Scepticism and mistrust	178
3.11.2	Pandemic planning	179
3.11.3	Comparisons to other public inquiries	180

3.11.4	What the bereaved want	181
	<i>Transparency and truth</i>	181
	<i>Accountability</i>	182
	<i>Lessons to be learned</i>	184
4.	RECOMMENDATIONS	187
	REFERENCES	191
	APPENDIXES	198
Appendix 1	Personal Recruitment Advertisement	198
Appendix 2	Ad Bereaved Families For Justice UK Facebook page	199
Appendix 3	Participant information sheet	200
Appendix 4	Participant consent form	205
Appendix 5	Distress protocol	207
Appendix 6	De-brief document	208

EXECUTIVE SUMMARY

There are already several important investigations recently published into aspects of the pandemic. Notably, Amnesty International's report into the UK government's failure to protect older people in care homes during the COVID-19 pandemic (Amnesty International 2020). The reports published by the Care Quality Commission (2021a) into care home deaths and DNRs (Do Not Resuscitate orders) (2020, 2021b) highlight the confusion and miscommunication about the application of DNRs and the unacceptable and inappropriate use of DNRs at the start of the pandemic. The very recent publication of the Government's own report (2021) by the Health and Social Care and Science and Technology Committees, finds that the UK's pandemic planning was too narrowly and inflexibly based, fatal errors were made regarding the timing of lockdown and the belief in herd immunity, reports problems with community testing, shortages of PPE, major deficiencies in Government structures, and acknowledges that failures in social care led to many thousands of deaths that could have been avoided. The latter report has been gravely criticized for ignoring the families of those bereaved (BBC 2021; Booth et al. 2021).

This research spotlights the lived experiences of the implications of these failings, the consequences of a wide range of further weaknesses in systems and processes, and the ongoing repercussions of being bereaved by COVID-19. Hence, it fills the gap left by the Government's most recent report. As one of our respondents sums up:

"This is a death, that unless you've experienced it, it's like no other death. I lost my own Dad when I was 17. He had a stroke. I went to work. I came back and he'd died. And gosh, that

was a shock to deal with. But you come – you came to terms with that. I don't know if you'll ever fully come to terms with this. It's just very different. And unless you've been touched by it in that you've experienced it yourself – I don't think people understand it, you know?"

[Amy]

This report is hopefully one small step in helping people to understand.

Research Aim

To investigate the lived experiences of families bereaved by Covid-19.

Research Questions

RQ1: What are the experiences of families during their loved one's final days?

RQ2: In the days and weeks following bereavement, what restrictions were there on normal bereavement and funeral rituals, and how did these make people feel?

RQ3: What factors are important to families bereaved by Covid-19?

Noteworthy, the findings go way beyond these three original research questions.

Methodology

After obtaining ethical approval for the research from the University Central Ethics Committee, an advertisement calling for volunteers who had been bereaved by COVID-19 was shared on various Facebook pages, including the lead author's own personal page and, with permission, the Covid-19 Bereaved Families for Justice page. It was then shared many

times. The lead author used pathographies (stories of illness experiences), to collect narratives of the experiences of 28 people who lost 30 relatives to COVID-19. Data collection took place between 7th and 25th June 2021. All narratives were audio recorded and later transcribed verbatim. We then conducted manual reflexive thematic analysis to identify core and sub-themes embedded in the data. These themes form the basis of the research findings. Of course, while placing the people who have experienced the phenomenon at the centre of inquiry, and are objective in that they examine actual experiences, qualitative narratives are subjective insofar as they rely on memory and feelings and perspectives.

Findings

Contracting COVID-19

An important part of people's stories relates to the ways in which their loved ones contracted COVID-19. Some of these ranged from bewilderment as to how their relative had contracted the virus, through sadness for those who felt their family member(s) had contracted it needlessly. Some expressed overwhelming anger at the lack of systematic processes to keep people safe. The research finds a perception among the bereaved that in the early days of the pandemic, many people in authority, including some healthcare practitioners, did not seem to take the virus seriously. We also uncover a belief that slow responses (from GPs, NHS 111, the ambulance service) caused delays in diagnosis, as did confusion around systems, processes and communications. Nosocomial contractions, in both care homes and hospitals, were sources of particular anguish for many families. Lack of PPE, a belief that some care homes had failed to prepare adequately, and perceptions of poor infection control in hospitals were blamed for these contractions.

Hospital Admissions

Throughout all narratives is the common theme that people could not be accompanied when admitted to hospital. This decree is universal throughout all experiences, even when the patient was deemed particularly vulnerable or to have cognitive impairments, which goes against published hospital visiting guidance. Narratives tell of extremely long periods of time (exceeding 24 hours in some cases) between a patient being admitted and the family receiving any communication about them.

Communications

These communication delays continue throughout the whole period in which patients are in hospital, and tales of desperation in trying to ring general wards for news are commonplace. When people did manage to get through to wards, the communication was often poor insofar that people wanted information about treatment plans and prognosis from doctors, while in reality the information received was mundane and often limited to communication with healthcare assistants. Several people felt that they had important medical conditions to communicate to doctors about their relatives, which could help the medical staff in making care decisions. Yet, this important line of communication, which would usually be open during hospital visiting hours, was cut off. The importance of digital communications channels to keep in contact with loved ones emerged as extremely important for many. There were, however, vulnerable patients who needed assistance with technology. Stories of kindness from individual healthcare staff emerged, where staff tried to help patients and families communicate. However, others often did not receive the help they needed and therefore direct communications between families were cut. Eventually, for many patients,

because of the nature of COVID-19 and its treatment, communication with their families became extremely difficult or impossible. Being denied access to their loved ones due to visiting restrictions, in hospitals and care homes, emerged as one of the most distressing elements in people's narratives.

A System in Chaos

A great deal of chaos and confusion became apparent in many stories. Tales of conflicting information, incorrect information, and an overstretched system that at times was unable to cope are interwoven among so many narratives that it would be impossible to suggest anything but chaos and crisis. Narratives describe some staff as harassed and pressured. These pressures led to some tales of observed suboptimal and even substandard care. A great deal of confusion led to families receiving conflicting information and receiving distressing news in inappropriate ways. Tales of lost tests, lost patients, poor infection control practices and discharging patients potentially infected with COVID-19 are commonplace. Despite this adversity, there are examples of extraordinary kindness and professionalism from frontline NHS staff.

DNR and Critical Care Decisions

The issuing of Do-Not-Resuscitate (DNR) orders has become an increasingly controversial issue both in the UK and internationally during the pandemic. Narratives tell of a lack of explanation or consultation with families regarding DNR orders, changed DNR decisions when COVID-19 was diagnosed, and the seemingly ad hoc ways in which critical care decisions were made. The issue of age and vulnerability emerged in the testimonies, with some family members expressing the feeling that their loved ones were treated differently

because they were older or had underlying health conditions. Consequently, DNR processes and critical care decisions often had a significant impact upon bereaved families, with feelings of guilt and helplessness enduring long after the death of their loved one.

Powerlessness and Finding Agency

The powerlessness experienced due to a lack of information, DNR decisions, frustrating systems, and being unable to visit or even communicate with loved ones, particularly at end of life, were major causes of families feeling helpless. A striking power imbalance emerged between the all-powerful system and the completely helpless patient and their family. This imbalance was felt acutely by the families of patients with specific vulnerabilities. When some families did attempt to participate in decision making, they felt as though they were 'pushing' and 'being stroppy' or 'kicking off'.

COVID-19 Deaths are Different

Participants were keen to explain the myriad ways in which COVID-19 deaths differ from other deaths, and how death in a pandemic brings particular issues that are absent during 'normal times'. One issue that emerged is the suddenness of deterioration for so many patients, meaning that relatives were unprepared to receive devastating news. Second, the suffering endured due to visiting restriction intensified as their relatives reached end of life. Though some 'felt lucky' that they were able to either say goodbye in person, others were not and had to experience saying the final goodbye by phone or video call. Third, not all deaths were perceived as dignified. Fourth, the newly bereaved had to endure social isolation. Additionally, a range of extra burdens were placed on the bereaved due to the pandemic. Lockdown and social distancing regulations caused issues with the practicalities

of registering a death and the official business that has to be completed. Strong feelings of being further isolated due to others being unable to understand what being bereaved by COVID-19 means emerged in many narratives. Attitudes among COVID-19 deniers make many bereaved families feel worse. Particularly painful was the discussion around COVID-19 deaths being higher in the elderly population and among those with underlying health conditions: many felt this conversation, and indeed events, made them feel as though the lives of their loved ones were somehow worth less than young, fit and healthy people. That the pandemic permeates every aspect of life, together with a sense of collective grief, makes bereavement more difficult, too.

Death Rituals

Throughout many narratives arose praise and a deep sense of gratitude that despite the many exceptional and severe problems the families had faced, funeral directors were one steadfast and positive element of the whole terrible experience. Despite support from funeral directors, many rituals and mourning practices, which serve to facilitate the grieving process, were denied due to the pandemic. Many families had restrictions such as their loved one not being embalmed, while the need for sealed coffins meant families were unable to visit the chapel of rest. Closed coffins also led to doubts that objects had been placed into caskets. Burial clothes, too, emerged as an important ritual that was denied. The numerous restrictions on funerals also added to people's grief. These restrictions included being unable to hold the funeral service at a place of worship, being denied funeral cars, being unable to touch the coffin, the coffin being wheeled rather than carried, singing being prohibited, being limited to a very short service, and the major restrictions on numbers allowed to attend a funeral service. On reflection, some families said they found comfort

from a small and intimate funeral service, though a major problem was that during funeral services, families could not give or receive any physical comfort. Social distancing, so acutely felt during funeral services, also meant families were denied a wake and an opportunity to be together and support each other while remembering their lost relatives.

Counselling, Mental Health and Support

Some respondents attempted to access some counselling, but came across inadequate or inappropriate services. Only a small number of people had accessed national and local charity counselling and found them useful. Most of the people who had accessed counselling had managed to do so through their employer or privately. Many respondents bravely shared some quite distressing stories about the ways in which their grief has impacted their wellbeing, with some requiring GP and medical intervention. Many tell of ongoing suffering with flashbacks, 'brain fog', and other trauma. Numerous participants shared feelings typical of complicated grief, where grief is debilitating and so severe that they are struggling to recover and resume their lives. Respondents also commented on the ways in which social media in general, at a time when they desperately needed some social support, actually amplified negative feelings. In contrast, most bereaved families found a sense of cohesion with others who had similar experiences, via the online COVID-19 support groups, though for some, the support groups have a downside, too, with them sometimes feeling too sad to read. The importance of memorials, especially the National Covid Memorial Wall, as a support to bereaved families emerged clearly.

Anger and Blame

A substantial number of narratives contained deep-seated anger as well as blame. Some of this is directed at some NHS policies and practices, as well as some individual hospital trusts, though throughout many narratives people stressed they did not blame the frontline NHS workers. Anger and blame is overwhelmingly directed at Government decisions that led to a failure to protect care home residents, a reluctance to close the borders, failures pertaining to PPE and the vaccine rollout, not using Nightingale hospitals sufficiently, and poor decisions regarding the first and subsequent lockdowns. Consequently, a great deal of cynicism and contempt for some figures in authority emerged, together with a belief that many in positions of power really did not care about lives being lost.

The Inquiry

Finally, most respondents stressed the importance of the Public Inquiry, due in early 2022. Though some were sceptic, and others concerned (the Hillsborough Inquiry was mentioned several times) people hope for lessons to be learned and never repeated in future pandemics. Transparency, the truth, and public awareness were also mentioned as incredibly important to bereaved families. So too is the need for disclosure regarding directives given by NHS England and issues with PPE shortages. Many want senior politicians to be held to account, with wishes ranging from an apology and an acknowledgement that things went wrong, through to criminal charges on the basis of corporate manslaughter. Most of all, these people want change so that in the future no one else has to endure the lived experiences of these families.

RECOMMENDATIONS

As a result of the findings of this research, we recommend:

Improved Pandemic Planning.

The report spotlights the implications on the bereaved due to the UK being inadequately prepared to deal with a pandemic. The NHS was overwhelmed, resulting in slow responses and reduced access to medical services. PPE was in short supply. Care home staff were ill equipped to deal with the magnitude of the pandemic. The frequency of pandemics is increasing (SARS, Bird Flu, Swine Flu, MERS, and Ebola) and pandemic planning needs to be a central part of Government, NHS, and social care strategy and this needs to be a wide-ranging and integrated strategy.

A root and branch investigation into NHS systems and processes during the pandemic.

This recommendation does not pertain to medical care: rather it refers to the systems, organisational management and protocols in place to record and communicate information pertaining to patient's whereabouts, their existing medical conditions, their current health status, and ways in which families can be updated. This research suggests that the NHS does not use technology to its full potential throughout the patient journey. Dissemination and sharing of good practice across and between NHS Trusts and all elements of primary and social care also needs to be enabled.

Communication channels between hospitals and families should be overhauled.

Waiting 24 hours or longer to hear any initial news of a hospitalised patient is unacceptable. Systems need to be revamped in order for families to receive regular updates, and the

nature of the information provided needs to be enriched. Doctors treating patients with underlying health conditions need to listen to families who can explain particular characteristics. Channels that facilitate communication between patient and family, particularly digital communications, need to be enhanced and help with technology should be available for those patients who need it.

Availability of current counselling services is expanded, that the levels of complex grief among COVID-19 bereaved is ascertained, and specialist bereavement services are developed in order to treat this particular type of grief.

This research finds many differences between being bereaved due to COVID-19 and being bereaved in other ways and during other times. Restrictions on being with family members towards and sometimes at end of life, enduring social isolation whilst newly bereaved, complexity of systems and processes due to lockdown, denial of many important death rituals and strict restrictions on others, negative attitudes among some groups in society, and the ways in which COVID-19 permeates every aspect of life makes bereavement particularly difficult. Yet, there is a lack of available bereavement counselling services, and a particular lack of specialist counselling and mental health services to help people deal with this specific type of grief.

A focus on the implications of cultural death rituals being denied during the pandemic.

This emerged as an extremely important part of the lived experiences of bereaved families, and denial of these seem to have made grief worse. This is an area that may well be

unheeded if someone has not lived through it. The importance of such rituals must not be overlooked, and must form part of the inquiry and future planning.

[The provision of permanent memorials to COVID-19 victims.](#)

This project spotlighted the importance of memorials in bringing some comfort to the bereaved, and the need to ensure COVID-19 victims are not forgotten. The research also uncovers the need to change societal discourse: permanent memorials will be one way to aid this. This research found that the National Covid Memorial Wall is a particularly important memorial, and it is recommended that the Government consults with the COVID-19 Bereaved Families for Justice Campaign, who founded and manage the wall, to make it a permanent monument.

[The Public Inquiry is brought forward, and processes are put in place to ensure it is conducted with diligence and integrity.](#)

This research reveals a clear need for the public inquiry to be held without further delay, the need for it to be transparent, the importance of bereaved families being an integral part of the inquiry, and for lessons to be learned so that many of the mistakes made in this pandemic are not repeated in the future. While this study includes bereaved people living in Scotland and Wales, it is acknowledged that some national practices did differ, and legislatures and executives are separate. Hence, the Public Inquiry should include inquiries specific to each of the devolved nations.

Changes to systems and processes are required in order to reduce nosocomial contractions.

Specifically, improvement to infection controls must be implemented. A review needs to be conducted and changes made to ensure, for example, adherence to infection control regulations, changes to systems in order to minimise the movement of patients around hospitals, better segregation of infected and healthy patients, and an end to the practice of discharging infected patients to places where they could infect others. Such a review needs to consider the very low usage levels of Nightingale hospitals, and whether they could have been used to administer palliative care for infected patients, thus potentially reducing the number of care home contractions and deaths.

Patients with cognitive impairments, learning disabilities or other vulnerabilities are allowed to be accompanied to hospital.

Despite this being a directive for hospital visiting within many NHS Trusts, it was not always allowed. This caused increased distress for patients and their families, and in some cases led to unnecessary interventions.

More training in end of life care for frontline staff.

Family support is an important aspect of end of life care. Many of the families interviewed felt that they had not been included in decision making. Staff development in the areas of specialist palliative care is important for health professionals, many of whom will have been expected to administer palliative and end of life care for the first time during the pandemic.

Processes for reaching, recording and communicating DNR and critical care decisions are overhauled to ensure consistency and transparency.

A central and integral aspect of Advance Care Planning (ACP) is to ensure people are at the centre of decision making and their beliefs and wishes for end of life are taken into account. This research finds evidence that this was not always the case. Consequently, DNR decision making needs to be overhauled to ensure patient's wishes are taken into consideration. In situations where clinicians overrule the wishes of patients and/or their families, the foundation and justification for this decision needs to be recorded and communicated clearly.

A (re)focus on person-centred care.

Person-centred care is a way of thinking and behaving. It aims to ensure that patients (and their families/carers) are involved in decision making. This research found that families were often not consulted. Such findings are in direct contravention of the NHS commitments made in the Five Year Forward View (NHS 2014) and the NHS Long Term Plan (NHS 2019). Consequently we recommend in-depth training for NHS staff in this important initiative.

FROM THE AUTHORS

Lynn Sudbury-Riley

I am a Professor of Marketing at the University of Liverpool Management School. My research focuses on improving services for the vulnerable. For the last decade I have focused on palliative and end-of-life care in hospices, hospital units, and for people dying at home. This work has received recognition, not least in an invitation to UK Parliament to give evidence on Hospice and Palliative Care services in the UK in 2018.

In late March 2020 my wonderful father, Ronnie Sudbury, had been in hospital for several weeks for a foot operation. While arrangements were being made for his discharge, he collapsed. Testing revealed he had contracted COVID-19 while in hospital. He died, alone, two days later, on 29th March 2020. After a life well lived, he did not deserve to die alone, before his time. He deserved more than 10 people at his funeral, and he deserved for his coffin to be carried high. A kind and generous man, he deserved a large wake so that the many people who loved and valued him could pay their respects. He got none of these. We will soon raise a glass to you, Dad, in proper fashion. I hope you approve of this work.

Benito Giordano

I am an Associate Professor (Senior Lecturer) at the University of Liverpool Management School. My research focuses on understanding how public funding can help create jobs, small firms and promote local and regional economic development. My interest is using academic research to try to make a difference to influence policy and help shape positive change for people and places.

On January 4th 2021, I took my 79-year-old father, Francesco Giordano, to his GP and she sent us to the local A&E. He had been feeling short of breath for a couple of weeks. My dad was of that generation that he didn't like to bother his GP and just soldiered on always. He was an immigrant to the UK, arriving from the south of Italy aged 23, not speaking a word of English. He made the UK his home, worked hard all his life, had a long and loving marriage to my English mother, Joan, and they had three children and then three grandchildren.

After 3 nights in hospital, I picked my dad up from hospital; I was told he was Covid negative and that he could go home to continue to care for my 76-year-old mother, Joan, at home. She had been shielding at home because she had had a knee and hip operation in the last couple of years. I was told to bring my dad back to hospital for an outpatient scan a week later. During that week, I started to feel unwell and I tested positive for Covid; my Dad's condition worsened at home and when my sister took him back to the hospital for his scan on Wednesday 13th, he could hardly breathe. He stayed in hospital and we were told that he had tested positive for Covid. A couple of days later, my mother started to feel unwell at home so we called an ambulance to take her to the same local hospital. She had got Covid too. Shortly after, my sister, her husband and daughter all tested positive for Covid.

My dad's condition deteriorated in hospital and he sadly died on January 25th; my sisters and I were allowed to be at his bedside and my mother was brought in a wheelchair from the adjacent Covid ward. That was the last time the five of us were together as a family. My mother had to fight the virus on her own whilst also grieving for the loss of husband. They would have celebrated their 50th wedding anniversary in Summer 2021. She fought hard against the virus but then on the morning of Saturday February 6th we were called to come into the hospital again. Unfortunately, we didn't get to say goodbye to my mother as she

sadly passed away before my sisters and I arrived at the hospital. We had a joint funeral for my parents on March 30th; the hardest day of our lives.

This work is for my parents and for the thousands of other families that have had their lives changed forever.

1. INTRODUCTION

1.1 BACKGROUND TO THE RESEARCH

As people who have experienced losing parents due to COVID-19 during the pandemic, Lynn as a result of her Father being infected while in hospital due to a foot operation early in the first wave, and Benito experiencing the terrible tragedy of losing both his Parents in the second wave, we knew that in addition to the grief experienced when one loses a loved one, being bereaved due to COVID-19 and during a pandemic brings particular difficulties. As social science researchers, we felt compelled to examine these differences. Hence, in March 2021 this research was launched.

At the time of launch, there was a great deal of speculative academic writing. The extra burden of grief on the families and loved ones of COVID-19 victims was predicted to be severe and enduring (Lee and Neimeyer 2020). The pandemic had already exposed injustice and inequality (Maddrell 2020; Warren et al. 2020; Winskill et al. 2020). Experiences during the last few days of life for families of COVID-19 victims were arduous to say the least. Difficulties endured in attaining information from hospitals and care homes. An inability to be with their loved ones added to the stress and trauma of dealing with imminent death. Due to social distancing measures, many COVID-19 victims died alone; the presence of family and friends prohibited. Families had traumatic experiences at every stage of the bereavement process. Many were denied the opportunity to visit their lost relatives at a Chapel of Rest. Normal and important funeral rituals were severely restricted: victims were not embalmed or dressed; coffins were closed and wheeled into crematoriums instead of

being carried high; families were unable to hold a funeral service in their chosen place of worship; severe restrictions were placed on the numbers of people allowed to attend the funeral. The funeral itself was severely constrained as people were unable to take and offer comfort to each other: instead they were satellites of sorrow, unable to even hug their families. Important social gatherings, where people came together to celebrate the life of their family member and give support to the bereaved, were also denied. Consequently, predicted increases in severe and persistent grief had been foretold (Eisma and Tamminga 2020; LeRoy et al. 2020; Lichtenthal et al. 2020).

As of March 2021, few empirical studies were yet to be published that deal with this crucially important issue. Eisma et al. (2021) conducted a survey in the Netherlands and found people bereaved due to COVID-19 demonstrated higher scores on a prolonged grief disorder questionnaire than those who experienced natural loss, but there was still an absence of studies focusing on experiences for people bereaved during the pandemic (Mayland et al. 2020; Stroebe and Hunt 2021). Some published academic research recognised that the grieving process for many will be complicated due to social distancing both during dying and death, diminished access to normal funeral rituals, and in social support since bereavement. Since March 2021 a handful of empirical studies have been published. These tend to focus on specific elements of COVID-19 bereavement including, *inter alia*, psychological distress (Joaquim et al. 2021) and depression (Wang et al. 2021), bereavement care provision (Harrop et al. 2021; Pearce et al. 2021), a study of the ways in which the pandemic is reported in UK newspapers (Sowden et al. 2021), and the use of social media during lockdown (Nguyen et al. 2021; Schoultz et al. 2021). We will revisit these studies in the corresponding sections of this report.

However, while there is much anecdotal evidence available, and the press have covered many harrowing individual stories, to date there is no known robust academic study that investigates the ways in which these traumatic experiences impacted, and continue to impact, bereaved families. Hence the bearing of these multiple traumatic events is yet to be fully understood (Aguiar et al. 2020; Khosravi 2020). Much is known about the importance of funeral rituals, but we are yet to understand how funeral restrictions impact the grieving process (Burrell and Selman 2020). We also need to understand the appetite for restorative justice (Cooper and Williams 2020) and address policy (Aguiar et al. 2020). There is also an urgent need to understand social support and bereavement support requirements (Breen 2021; Harrop et al. 2020; Moore et al. 2020; Morris et al. 2020; Simon et al. 2020). Against this backdrop, the current study was launched.

1.2 RESEARCH AIMS

The overall aim of this research is:

to investigate the lived experiences of families bereaved by Covid-19.

Specific overarching research questions include:

RQ1: What are the experiences of families during their loved one's final days?

RQ2: In the days and weeks following bereavement, what restrictions were there on normal bereavement and funeral rituals, and how did these make people feel?

RQ3: What factors are important to families bereaved by Covid-19?

Noteworthy, however, is that findings go way beyond these three original research questions.

1.3 STRUCTURE OF THE REPORT

This report comprises 4 major sections. Section 1 has provided the background to the project. Section 2 details the methodology used. Section 3 presents the results of the findings, discussing the major themes that emerged from analysis of the data, illustrated by excerpts from participant's narratives. Section 4 offers our recommendations.

2. METHODOLOGY

2.1 ETHICS

The central research ethics considerations of anonymity, confidentiality, voluntary participation, informed consent, and vulnerability took on elevated scrutiny for this study.

The study proceeded through the full University of Liverpool's Central Ethics process, which comprised attendance and defence of the proposed research to a full Ethics Committee comprising a range of academics and lay members, prior to Ethical approval being granted.

2.2 PARTICIPANT RECRUITMENT PROCEDURE

Recruitment took place via Social Media. The lead author placed an advertisement (Appendix 1) on her own Facebook page, which was shared many times. Sometimes the people this was shared with were members of various COVID-19 bereavement groups, others were not members of any groups, but received the advertisement via electronic word-of-mouth. A similar advertisement (Appendix 2) was shared, with permission, on the COVID-19 Bereaved Families for Justice UK Facebook page. The advertisements invited people to make contact with the lead author, via Facebook messenger or email, if they would like to receive further details about the study. Both advertisements were only live for a matter of hours: they had to be removed within 12 hours due to 41 people making contact. These 41 people were all sent a participant information sheet (Appendix 3) and an electronic consent form (Appendix 4). In all communications, potential participants were assured of confidentiality and anonymity, and it was explained that the research was opt-in and totally voluntary. All communications stressed that participants were free to stop their narratives at any point, either temporarily or to terminate the interview.

Of these 41 people, 32 expressed a wish to participate, and appointments for interviews via Zoom or telephone, depending on the choice of the participant, were arranged. In the time between arranging the interviews and conducting them, four people (one of whom had lost both parents) withdrew because they had begun to feel anxious at the thought of the interview, and felt their grief was compounded.

2.3 SAMPLE: PROFILE OF PARTICIPANTS AND COVID-19 VICTIMS

This procedure resulted in 28 participants who told the stories of 30 loved ones lost to COVID-19. Table 1 profiles these people. Data saturation was reached around 25 interviews.

Table 1. Profile of Participants (n = 28) and the People Lost (n = 30)

Bereaved Person		Lost Relation	COVID-19 Victim		Date of Death	Place of Death	Profile of Person Lost
Name	Profile		Name	Profile			
Adrian	54 year old Technical Author for IT systems	Mother	Sylvia	83 year old Homemaker and Voluntary Worker	17 April 2020	Care Home, after being discharged from hospital	<i>Born in 1937, Sylvia was a clever girl who got her scholarship to a Grammar School for Girls. Originally a legal secretary, she gave up her job to look after her family, and became a volunteer manager running a Citizen's Advice Bureau. She was a great people-person, gregarious, empathetic and willing to help others.</i>
Amy (P)	54 year old GP Practice Manager	Husband	Paul (P)	61 year old factory worker	8 December 2020	Hospital, in ICU	<i>Paul was a joker. His saying was, 'You've got to have a laugh, haven't you?' He had a fantastic 35-year marriage with Amy, & he doted on his kids. He was hardworking & handy, he could do anything around the house. He was always there for anybody and everybody, and was heavily involved in kid's football in the community.</i>
Ann	46 year old Senior NHS Nurse	Mother	Joan	68 year old Retired School Secretary	29 March 2020	Hospital	<i>Joan was fit & healthy & still did voluntary work at the school. She was also still a Brownie & Guide leader & had been for over 50 years. She was kind: she looked after her own Mother, her Grandchildren, & would go on the bus to get people's shopping for them.</i>

Anne	59 year old Local Government Worker	Husband	Ken	74 year old Retired Welder	10 April 2020	Hospital	<i>Ken loved holidays, food, movies & music & was a keen dancer in his younger days. He especially loved Christmas and decorated the house so much it used to drive Anne, his wife of 37 years, crazy!</i>
Annette	53 year old Housing Officer	Mother	Beryl	83 year old Retired. Housewife/ part time Dinner Lady	18 December 2020	Hospital, Nosocomially Acquired	<i>A typical family person: Beryl lived for her family. She loved her husband of 68 years, & was very proud of the letter from the Queen for their 60th Wedding Anniversary. She adored her Grandchildren, too. She was so funny, sometimes without knowing it, and made people laugh.</i>
Becca	39 year old Teaching Assistant	Father	Anthony	72 year old Retired Bank Manager	22 March 2020	Hospital	<i>Anthony was a devoted Husband, Father and Grandfather. His wife has dementia and he was her main carer, yet he still always texted his daughter every morning to check they were all OK. In the bit of spare time he had he used to do some voluntary work at the theatre and he'd go off out and meet friends when he could.</i>
Becky	48 year old Paramedic	Mother	Jan	71 year old Retired Retail Worker	5 November 2020	Hospital	<i>Jan & Pat were wonderful. Both really, really young at heart, they were loved by everybody. They were hilarious & such good fun. They were party animals: they loved barbecues & holidays & they loved their kids and grandkids, they had a very close-knit family. Jan could be a bit feisty: she had a look that was legendary, and you always knew if she liked someone or not! Pat was a gentle, quietly-spoken, witty, deadpan kind of guy. Jan was his best audience. Jan & Pat are best summed up as simply full of fun & full of life & full of love.</i>
&							
Father		Pat	71 Year old Retired Dock Worker	28 November 2020	Hospital, in ICU		

Charlene	60 year old Legal PA	Partner	Bill	62 year old Retired Metropolitan Police Worker	15 April 2020	Hospital	<i>Bill was very active. He loved running, and completed the London Marathon in 2016. He loved cycling, too, and in 2018 he did the London to Paris charity cycle ride. He loved climbing and walking. Anything active and outdoors, he loved it. He was a member of a running club, which is where he met Charlene back in 2007 and they'd been together ever since. He had a great sense of humour. He helped others: he did cycling for the disabled with specially adapted bikes and taught disabled kids to ride as part of a local wellbeing initiative.</i>
Charlotte	43 year old NHS Pharmacist	Mother	Christine	78 year old Retired Nurse	18 April 2020	Hospital	<i>Christine's health was stable before she caught COVID. Though she lived in a nursing home, Christine was active and independent: she still took herself out shopping into town on the bus or in a taxi. She used to take part in things, she liked going out for meals, and she was enjoying life.</i>
Claire	51 year old Medical Writer	Father	Len	81 year old Retired Shop Owner	29 Dec 2020	Hospital	<i>Len's family called him the Duracell bunny. He never, ever, ever moaned or complained he was unwell even when he was. He loved driving his car. He loved being a shopkeeper. He loved shops. He loved everything about shops. He would wear his wife out and she would complain that she couldn't keep up with him! Len was an absolute trooper and lived his best life. He was pretty amazing.</i>

Diane (P)	58 year old GP Receptionist	Son	Tim (P)	26 year old NHS Worker	24 March 2020	At Home	<i>Tim suffered with some anxiety issues, but this didn't stop him having friends or mixing with others. Tim was clever: he was very switched on. He worked for the NHS and was up to date with everything that was happening in society, but he did have some additional needs & was quite vulnerable. Despite his own vulnerabilities, he was well thought of in his place of work & was always enthusiastic & willing to help others</i>
Emma K	28 year old Homemaker	Grandmother	Enid	73 year old Retired Carer for the Elderly	16 January 2021	At Home	<i>Enid lived with Emma, her Granddaughter, & helped to raise her so was like a parent to her. She was a very fierce woman who was lovely and taught Emma everything she knows. Enid was very much a family person, & spent her whole life caring for others.</i>
Emma L	49 year old Milliner	Mother	Marylyn	80 year old Retired Team Leader for NSPCC	12 February 2021	Hospital, Nosocomially Acquired	<i>Marylyn & her daughter were called the twins by other members of the family, they were so close, & always together. Emma ran her business from her parent's house, & Marylyn used to come to Emma's shows for support. She was a lovely person who was Emma's best friend and was 'a proper Gran' to her Grandchildren.</i>
Fran	60 year old Funeral Director	Husband	Steve	65 year old Retired Police Officer	18 October 2020	Hospital	<i>Steve was just brilliant! He was Fran's best friend, and they had been inseparable for 12 years. He had even saved her life some years ago when he braved a house fire and carried her out. Steve was really popular, he knew so many people & they all loved him. Steve started showing symptoms of COVID-19 the day after his & Fran's wedding, and he died just 3 weeks later.</i>

Jackie	67 year old Seamstress	Husband	Peter	60 year old Office Worker	18 January 2021	Hospital	<i>Peter was an ex-Army soldier. Peter & Jackie had been married 29 years, & he helped to bring up her boys who thought of him as their Dad. They had worked really hard & he learned to help Jackie with her sewing business & would come home from work & help her. Pete loved Rock & Roll music, & they had just bought a caravan – things had been looking brighter.</i>
Judith	65 year old Carer	Mother	Eunice	94 year old Retired knitting machine demonstrator	23 January 2021	Care Home	<i>Eunice was a character. She was very independent & had lived alone long time after being widowed. It was only the last 8 years of her life that her mobility meant she needed to live in a care home.</i>
Liz	69 year old Retired Wealth Manager	Husband	Steve	70 year old Regional Trade Union Officer	19 December 2020	Hospital, in ICU	<i>Steve had only retired the year before he died because he loved the Trade Union so much: it was his life. Though retired, he still had his credentials and would still go to represent people because he felt he owed it to the members. Steve was also obsessed with politics. He was a very kind & generous person. Liz, Steve & Val all grew up together in the same street. Together for 30 years, Steve & Liz had been childhood friends.</i>
		&					
		Sister In-Law	Valerie	76 year old Retired Antiques Dealer	18 December 2020	Hospital, in ICU	<i>As well as being Steve's sister, Liz & Valerie were really good friends. Val loved Steve – he was born the day before her sixth birthday, and as a birthday present she was allowed to choose the name of her new baby brother. They'd had a special bond ever since.</i>

Lynn	58 year old Newsagent	Mother	Connie	85 year old Retired Accountant	29 January 2021	Hospital	<i>Connie was a Northerner who was a very strong woman. Married to her husband for 65 years, she was excited when she got 2 telegrams from the Queen! She was a happy-go-lucky person who was very family oriented. She loved her children & grandchildren: quite simply she was what everyone would want in a Mum.</i>
Lynne	49 year old Train Station Manager	Mother	Frances	69 year old Retired Post Office Worker	15 February 2021	Hospital	<i>Frances was just 20 years old when she had Lynne, so they were more like close friends. Frances had a really young outlook. Though she had had a brain haemorrhage when she was only 58 years old, she still liked to go out shopping, and having afternoon tea, and she loved going to the theatre.</i>
Margaret	60 year old Occupational Therapist	Mother	May	91 year old Retired Shop Worker	14 June 2020	Hospital, Nosocomially Acquired	<i>May was a feisty lady who called a spade a spade, but she had the heart of a lion. Widowed for many years, she was fiercely independent: she lived in her own home with no carers or helpers, she cooked all her own meals and still baked cakes.</i>
Pat (P)	56 year old Carer	Father	Peter (P)	80 year old Retired Technical Author	16 April 2020	Hospital	<i>Peter was a true gentleman. He was a funny, cheeky-chappie, always up to mischief, and always had a twinkle in his eye. He was gifted: he could play any musical instrument, and he loved music and had a massive collection of records. He had lots of friends and was involved in his local Church.</i>

Pauline	56 year old Nurse	Mother	Sheila	81 year old Retired Spot Welder	6 May 2020	Hospital	<i>Sheila was generous to a fault: and mad as a box of frogs! A widow for the last 15 years, she had many friends, & a great-granddaughter. Sheila had a great sense of humour, & refused to be called great-grandma, as that is for old biddies! She was known to her family as Grandma Senior.</i>
Sarah	66 year old Retired Care Home Quality Manager	Mother	Valerie	92 year old Retired Research Physicist & Homemaker	5 May 2020	Care Home	<i>Valerie was a very unassuming person. She was a very kind, very loving, very good person. She had a very strong Christian faith, & she lived her life by the principles of her faith. Valerie loved children, & had a great sense of humour. Valerie was amazing: she went abseiling at 80, white water rafting at 82, & gliding for her 85th birthday! She loved life & lived it to the full.</i>
Shelley	42 year old Shop Worker	Husband	Nick	48 year old Homemaker	20 April 2020	Hospital	<i>Nick was a die-hard football fan who loved Manchester United. Nick was also a big wrestling fan, & he liked Dr Who & James Bond. He and Shelley had been together for 25 years, & have a son. Nick loved to laugh: even at his funeral the poem was by Pam Ayres.</i>
Sian	55 year old Carer	Father	Brian	83 year old Retired Joiner	11 April 2020	Care Home	<i>Brian was a true gentleman who was kind and wise. He was intelligent and loved books and nature. Extremely hard working, he believed in justice, and fairness and doing the right thing.</i>

Sonal	42 year old Homemaker	Husband	Hayesh	48 year old NHS Pharmacist	2 March 2021	Hospital, in ICU	<i>Hayesh had been an NHS pharmacist for the last 25 years. He was dedicated: he worked in the community, in a local chemist, & was well thought of by his customers. He was passionate about his job & was extremely hardworking: during the pandemic he was working six days a week, sometimes until 830 at night. He was fit, healthy, & passionate about the NHS. Hayesh was a family man, & his two daughters are teenagers.</i>
Stuart	67 year old Retired Sales Manager	Wife	Pamela	72 year old Retired PA	15 February 2021	Hospital, Nosocomially Acquired	<i>Pam was very bubbly & didn't take life too seriously. She loved her family, her friends, but she was also a doggy person, and she bred and showed her dogs, even at Crufts. Pam's sister died relatively young, so Pam became a sort of surrogate Grandma to them. Pam laughed a lot, and laughed easily & often.</i>
Suzanne	63 year old University Lecturer	Husband	Brendan	88 year old Retired School Teacher	27 June 2020	Hospital, Nosocomially Acquired	<i>Brendan was a very fit and active person. He went walking every day, he cycled for 40 minutes every day on his exercise bike. He embarked on a Phi-Chi course just prior to lockdown, and continued that online. Brendan was active in mind and body.</i>

2.4 DATA COLLECTION

2.4.1 Pathographies

Pathographies were used to collect the data from participants. Pathographies are stories of illness experiences; they articulate hopes, fears, and occurrences, providing rich insights into diverse aspects of illness and death, and they place the person at the centre of the story (Hunsaker Hawkins 1999). Pathographies facilitate data collection from the individual's perspective rather than using predetermined questions, and enable a longitudinal perspective: they start prior to encounters with healthcare systems and incorporate the whole patient journey. These advantages are key to allowing the researcher to move with participants through their space and time (Burawoy 1998). Based on narrative theory's premise that most key information retrieved from memory is episodic (Woodside, Sood, and Miller 2008), participants were encouraged to narrate their stories starting by talking about the person lost prior to them contracting COVID-19, then moving onto contraction and their experiences with various healthcare systems. Pathographies then moved onto death, funerals, and grief. They ended with an outline of what these people would like from the Coronavirus Inquiry.

Of course, while placing the people who have experienced the phenomenon at the centre of inquiry, and are objective in that they examine actual experiences, qualitative narratives are subjective insofar as they rely on memory and feelings and perspectives. Such narratives may be reconstructed (Charmaz 1999). Narrative research is therefore the study of how human beings experience the world, and how they assign meaning to those experiences (Moen 2006).

2.4.2 Data Collection Processes

Data collection took place between 7th and 25th June 2021. Four participants chose to be interviewed via telephone, while 23 elected to be interviewed via Zoom. One person, worried about the distress a live interview would cause, provided her pathography via a written document. A distress protocol was designed (Appendix 5) and all participants were sent an electronic de-brief document (Appendix 6) detailing links to several different support services.

Participants were encouraged to start the discussion by sharing some information about their lost relatives. Answers were incredibly rich and powerful, and enabled the profiles of each person lost that appear in Table 1. Starting the interviews in this way also seemed to put people at ease: many were nervous and anxious prior to the interviews. However, at the end many expressed their appreciation at the opportunity to share their stories, and many said how glad they were to have done it. The rest of the pathographies followed the stories in chronological order, from the point at which their loved ones contracted COVID-19, through to the present day. The pathographies enabled a deep-dive in terms of probing experiences, issues, examples, and feelings. Throughout, interviewer input was restricted mainly to questions such as, “and how did that make you feel?” or to clarify points that participants had made.

However, it is important at this point to acknowledge reflexivity and positionality of Professor Sudbury-Riley as the researcher who collected the data. It is acknowledged that reciprocity occurred during many pathographies, where participants also wanted to know about her experiences of losing her Father, and this information was shared openly. We

believe this made for richer discussions, helped build rapport between participant and researcher, and gave some confidence to participants that they were sharing their stories with someone who understood their perspective. Indeed, many made comments to this effect.

All interviews were audio recorded and later transcribed verbatim. The verbatim transcripts were then reduced (by the lead author who collected the data) in order to maintain full confidentiality of many issues. Full names were removed, as were the names of other family members and most place names and names of hospitals. The in-depth detail of family members lost was reduced to the pen-portraits provided in Table 1. Many participants requested that their names and the names of the lost loved ones be allowed to remain. Some did, however, choose to stay anonymous. Those people who chose to remain anonymous were given pseudonyms, which are noted in Table 1 with a (P) after their names. Once these procedures to ensure confidentiality and anonymity were complete, the reduced transcripts were shared with the second author.

2.5 DATA ANALYSIS

We conducted manual reflexive thematic analysis on the using the approach suggested by Braun and Clarke (2006, 2019). The two researchers separately identified core and sub-themes embedded in the data. Next, we shared these themes and reviewed them. Finally, the dominant themes with sub-themes that emerged formed the basis of the results which follow.

3. FINDINGS

3.1 CONTRACTING COVID-19

An important part of people's stories relates to the ways in which their loved ones contracted COVID-19. Some of these ranged from bewilderment as to how their relative had contracted the virus, through sadness for those who felt their family member(s) had contracted it needlessly, with some expressing overwhelming anger at the lack of systematic processes to keep people safe.

3.1.1 Doubt and Hesitation

Particularly during the first wave, many felt that they were protected from the virus:

"Towards the end of April she got what they thought was a chest infection, she very occasionally had chest infections in the past but usually in the winter, you know, when it was sort of flu season. Anyway, they said, the GP wasn't worried, he prescribed some antibiotics, but [name of care home]'s position at that time was that anyone with symptoms had to be tested. So, the GP said, "Oh, it's not going to be Covid, she's not got Covid, but if you want to test her, go ahead." And everybody was shocked when it came back positive." [Sarah]

Such shock was not confined to lay people, as Amy, a Practice Manager in a GP surgery, explained:

"Even though I worked in the environment. Even though you knew everything. You just never thought it would happen to me. Never ever thought it would happen to me." [Amy]

But even as the pandemic progressed, people were bewildered as to how COVID-19 had been contracted, particularly in light of their efforts to protect:

“My mum and my sister both caught Covid together, because they both lived together. They had been shielding, Mum was a borderline diabetic and my sister has health issues as well. So they were both shielding, so I was doing all the shopping and stuff. Taking the shopping to the house, putting it on the doorstep, stepping back. We did everything you were supposed to do. I never went in the house- because I also had to check with work what I could and couldn’t do.” [Pauline]

“And I sort of said, “Well” because I work in a primary school, we’d already decided that, and we knew that primary school was coming to an end that week. I sort of said, “Look I’m not going to come down to the house anymore because I don’t want to come in from school and come to you bringing something in.” [Becca]

Connecting Symptoms with COVID-19

Early in the pandemic, some people didn’t automatically connect symptoms with COVID-19.

“We’re down in [place name]. So there wasn’t really any cases here at that point..... Yes, so he was poorly. And then mum and dad weren’t, neither of them were 100%. But not awful if that makes sense. You know Dad was kind of like ‘well I have got a bit of a cough’.” [Becca]

“I mean you know I thought oh gosh he really doesn’t seem very well but I now think – I just think to myself ‘were we sleep walking?’ I don’t know.” [Diane]

It wasn’t just lay people who didn’t automatically connect symptoms with the virus. Some respondents felt that practitioners had been slow in making the connection between symptoms and virus:

“...the GP... on that day on the 12th of March [said] that his diagnosis was upper respiratory viral tract infection and that he sometimes got coughs. And so it was just to manage it at home and he wasn’t given any advice other than to manage it at home really. That’s the extent of the COVID denial at the time. Naivety? Lack of experience? Not sure. No open mind. No care. Yet our Son’s final weeks had been a cough and a chest that ‘hurts’ “[Diane]

Recognising the severity of the situation

Even senior healthcare practitioners did not always recognise the potential severity of the virus during the early days of the pandemic.

“I attended a medical conference at the beginning of March in London and I remember thinking at the beginning of March oh this is interesting you know I wonder whether anybody will think to maybe cancel it, and you know it’s kind of incumbent upon individuals as well so I suppose you could argue well I didn’t cancel my own attendance at that conference either. I think that was a bit pathetic in a way I suppose but you think well it was a medical community and they must be aware. So off I trotted to London at the beginning of March, I got on loaded double decker bus over to East London to attend the medical conference attended by may be about 50 medical people. So it hurts me to think about the context because you know on the one hand I think there was a feeling that there could be something serious happening, but then on the other hand there was that you know all pervasive sort of optimism that surely it couldn’t happen you know they couldn’t possibly be life changing. I don’t think that the issue of COVID at the beginning of March at this conference was mentioned once.” [Diane]

In contrast, some participants shared their memories of how they did recognise the potential severity of the situation, but this recognition was not always reflected by those in positions to do something about it:

“And I kept saying to the home, you know, it was on the news, it’s was that week 15th to 22nd March, I kept saying, because I have family working in hospitals, my daughter does as a professional and my sister is, and my brother. So I kept saying, “Well look, there’s a lot of cases, you know, it’s going up. Do you think you should close?” No they didn’t. Then I said again that week, I think the last day I saw him was 21st, because they said they were closing the following day because homes in that area had already closed.” [Sian]

In fact, not only did Sian’s pleas for the care home to shut down early fall on deaf ears, but she was later ridiculed by the manager after being told another resident had tested positive for COVID-19 in her father’s care home:

"I received a call from her one evening. And I thought, oh this is a bit strange. And she said, 'I've got some news. It's not that good...we've had a patient come out of hospital, come back to us, and they've got Covid.'" And I said, "What floor is she on?" And she said, "Your dad's." And I said, "Oh he's a goner then, he's a goner." Just like that because I knew. And she said, "Oh don't be so ridiculous," she said, "The media have made this out to be more than what it is." [Sian]

Others, while recognising the severity of the virus, felt they were given less than optimum information on how to stay safe:

"He was diabetic...And then February he started seeing the news reports coming through about COVID. And he said to me, he said, "If I get that," he said, "I won't survive." We didn't know anything about shielding. Nobody had said anything to us. [Shelley]

"I knew it was going on because I work in a GP practice and we're hearing some things on the television and things but you know the whole thing seemed to be happening at various levels and the levels didn't necessarily coincide you know - the problems at the very beginning of this pandemic and the confusion at many levels." [Diane]

For others, the realization of how severe the virus is, and how quickly people can become critically ill, came as a shock:

"And so, you know, what it's like [sob] you'd gone from, like your mum having a few like odd symptoms and doing all right to she's going to die and, so, yes, anyway, I then just, I just said to my husband, "She's going to die. I've got to go up there." So, I just jumped into the car and rang my dad en route and Dad answered the phone, "All right, lovey." I said, "We need to go up to the hospital, she's going to die." And he just, he went, "What?" "What?" You know, he, none of us were expecting that" [Becky]

Not Fitting the 'Profile'

Shock and disbelief were particularly marked among those who lost people without underlying health conditions:

"Absolutely nothing. No, nothing. He'd had no long term conditions. No chronic diseases. Nothing like that at all. No. He'd he'd really kept, you know, he was really kept himself safe, you know, so there was nobody more shocked than the four of us [herself and 2 children] when the test came back as positive." [Amy]

"It's awful because especially if like, you know my husband had no underlying health issues, because all this time we feel that, in the news we were hearing time after time that people with underlying health issues were most affected. And my husband had none. Absolutely none, fit, healthy young man. Absolutely nothing. I had to like even scratch my head and the last time when he went to the doctor's I can't remember, you know. So he was that fit. Nothing was wrong." [Sonal]

Even among healthcare practitioners, the belief that the virus only kills people with underlying health conditions was prevalent, as Ann who is a senior nurse explains:

"in those early days you weren't expecting, if there was no underlying condition, you didn't expect anything serious to happen because it was very much, and even in the Incident Control Centre, all the deaths that I was getting through all had a list of like COPD, cancer, Parkinson's, you know? So, even from working in there, the deaths that were being recorded still had underlying conditions and even though you'd go, "Oh, yes," you wouldn't expect to die from some of them so soon but there was still a condition there sort of thing." [Ann]

Not fitting the profile coupled with other vulnerabilities added to delays in recognising and diagnosing COVID-19:

"He had actually said to some friends that he thought it was a possibility that may be he'd got a little bit of this virus.... [but] I think unfortunately for my son because the focus was a little bit at that point in time on his mental health, you know he wasn't really listened to.... I think anybody who had any additional needs or vulnerabilities or mental health you know they... are people that were being overlooked - it's almost like discrimination really." [Diane]

3.1.2 Slow Responses

“Too slow” was a phrase used multiple times in multiple narratives to describe responses to many different facets of the pandemic. Severe reductions in GP availability and access to other medical services caused delays which ultimately for many had catastrophic results:

Reduced GP/other medical Services – which caused pressure points elsewhere

“The GP waiting rooms sort of closing doors and getting various directives from NHS England about changing telephone appointments and changing face to face appointments to telephone appointments. There was no proactive concern for any patient you know there was never a proactive oh we’re going into a difficult situation what can we do to reassure our patients that are under us, so whether they’re under the GP or whether it was under A&E or whether it was under mental health or whatever, it was almost as if everybody was quite pleased to say you know stay at home, our doors are closed, you have to play your role in not seeing anybody, not seeing your family, not turning up anywhere you know don’t turn up at any medical facility.” [Diane]

“And then all of a sudden later that day he was being discharged, and they discharged him [from hospital] he got discharged on the 10th of December. Over that coming few days he deteriorated and deteriorated, and on the- the GP was called multiple times. The GP in the end said look I can’t do anything for you, to mum, you need to call an ambulance. Called an ambulance on the 18th of December. The paramedic wanted to take dad into hospital. The on call doctor from the same unit that dad had been in with a few days earlier refused to accept him because his vital signs were okay. So, the paramedic wanted to try and arrange for dad to have fluids at home with one of the community teams, but the community team was too busy. So, they said wait for three days and contact your GP to get them to come out after the weekend, but the paramedic tried to give dad some fluid there and then, he couldn’t get a line in because dad’s vein- everything was collapsed. So they left him there. They left him.” [Claire]

“Brendan had a fall... So I rang the doctor and I said please could you send one of those- they have a team here which looks after elderly people so they don’t have to go into hospital - and I said could you please send those people along or a paramedic he doesn’t want to go hospital. You know and they said yes we’ll send somebody along- Well nobody came for a long time but in the meantime Brendan got worse and then suddenly he had a seizure ... So unfortunately - and I blame myself for that - I rang 999.” [Suzanne]

“And because of us working in the GP practice I was beginning in work to have to turn people away. You know there was an elderly gentleman that turned up and I had to ask him very politely if he would mind going home and making the call from home because he had such a dreadful cough, but he had a hearing problem as well so doing any telephone calls for him was a really difficult prospect so he’d been struggling and he had no choice really other than to turn up you know. And he was sent home” [Diane]

“My dad was really upset because the GP had said, “If she doesn’t go to hospital she’ll die with readings that low.” But they weren’t when I’ve looked at the stuff they weren’t that low. He just didn’t want to come out. And they weren’t that low because the ambulance crew were saying, “We don’t really need to take in” [Lynne]

“On the 12 of November last year he had gone in to have a heart stent done, he was telling us that his medication had been changed and when mum got him home and looking through his bag she could see they had put him back on a medication...that had caused him to have major stomach bleeds six months earlier, and it had ended up in him having a heart attack directly due to the blood loss. So, we tried contacting the path lab but nobody helped, they washed their hands basically. He’d been discharged. He’d gone home. Call 111 or your GP. The GP was well that cardiologist has prescribed it, you need to take it... within a number of days he had to be readmitted because he was haemorrhaging again. He ended with blood transfusions, and it left him with complications including explosive diarrhoea which went on for several weeks. [Eventually] the GP arranged admission to another local hospital on the 8th of December.... We took him there and he was made to wait five hours in a busy waiting room with no fluids and he collapsed in the waiting room.... this was an arranged admission” [Claire]

Pressure on services was particularly apparent for NHS 111 and the ambulance service:

“It was the day after the first clap for carers. I called into my mum and dad’s on my way home and saw through the window that my mum was slumped in the chair, abdominal breathing, so the deterioration in 24 hours was just like absolutely awful. But still, you’re trying to follow the rules and they were like, that “go home,” so still talking to her through the window. I was saying, “Oh, we need to get her an ambulance,” and she was like, “No, no, I don’t want an ambulance. I don’t want to catch Covid,” ...and I managed to talk her into saying, “If I phone 111 and they say you need an ambulance, will you go?”, and she was like, “You can do but I’m not that sick.” So, I dialled 111 and I was on the phone for an hour and a half and hadn’t got through to them.” [Ann]

After 1.5 hours waiting to get through to 111, Ann took alternative action:

“So then, I then went down to my friend’s house who is a senior nurse in [hospital named] and said, “Will you come and have a look at my mum?,” because being a nurse you can be a bit dramatic when it’s one of your own, do you know, and it’s like, “Well, am I being dramatic or am I assessing a patient as I would any other patient?” And so, he came with me to come and go look at my mum and as soon as he saw her through the window he was like, “Oh, she needs an ambulance.” So, he went in and checked her saturations using his phone and that’s when her saturations were only like 80%. So, she was already hypoxic. So, we then phoned an ambulance and then we waited two hours for the ambulance to come”
[Ann]

Ann’s experience of 2 hour delays was typical, with many more being much longer:

“And gradually he deteriorated, well we called an ambulance. It took four hours for a paramedic to come out by car who agreed that he needs to go into hospital. It took another five hours plus for the ambulance to come, so it was about 10 hours, we were waiting all day. We had a couple of check in phone calls from the ambulance service to see how dad was doing and I kept saying to them I’m worried about his breathing; his breathing has deteriorated.” [Claire]

It wasn’t just the ambulance service that was extra busy, as Sonal explains when she talks about how busy Hayesh, an NHS pharmacist, had been:

“He was an NHS pharmacist for the last 25 years. And he was, yes, he was a community pharmacist ...they were very busy all the time he was telling me. Very, very busy. Because since the pandemic started, you know, they were like- They had to go to work continuously. Some days even Saturdays because like the GPs were closed you know. The GP practice and everything. So they had more work.....” [Sonal]

Delays in Diagnosis

Many of those who did manage to speak to medical professionals told of being turned away or told to wait until the patient deteriorated – unfortunately this was often too late:

“He didn’t feel very well on 26th November. So, he phoned the doctor, and he said, “I’m a bit concerned because I’ve got COPD. Maybe I’ve caught Covid.” And the doctor said, “I think you need to phone 111. So, he phoned 111, and they said to him, “Have you got a temperature?” And I took his temperature, and no, he hadn’t got a temperature, no he hadn’t got a cough, no he hadn’t got all the three symptoms that they say. He just had the ones that he would have if he had a cold. But they said, “Oh no, you most probably haven’t got Covid. Just see how you go and then call us back.” So, then he started getting really ill, and then on the 30th, he said, “Liz, I think I really have got Covid, and I don’t want to die.” I said, “Don’t be ridiculous, you’re not going to die.” I said, “Go and have a test, and then you’ll know.” And then on the 1st, at 5pm, a text came through and it was positive. They need to upgrade their 111 system, because if someone phones you and thinks they’ve got Covid, and they suffer from COPD, that should ring bells.” [Liz]

“His GP appointment was 12th of March, whereas in actual fact he had become ill on the 24th of February, and it was recorded on his notes as an upper viral respiratory tract infection and the GP knew we’d had family over that had come in from China at the very end of January. I think him being him if he’d at least have been directed to you know A&E if it got worse or if he’d had been maybe given you know – I know that antibiotics don’t do anything for a viral infection but viral infections do turn bacterial. And in view of the fact that things were closing down I think people needed something other than just you know stay at home.” [Diane]

“So I phoned my dad [on the Thursday].. And he couldn’t speak to me. He couldn’t get his breath to talk to me. So I went down and I was watching him, looking at him through the window. And he couldn’t get up to get to the phone... I said, “Look I think I’d better ring 111 because you don’t seem right.”... The doctor said, “We’re going to send out paramedics to do a ECG.” They can just do it there... and give him some aspirin” So the paramedics came, checked him over, his chest was all clear, didn’t have a temperature, they were quite happy. And the ECG was normal for dad. And they sort of said, “Well probably the aspirin that you’ve given him maybe he got a bit stressed or what have you.” So they said, “We can take you in and do a Covid swab.” But because he didn’t really need to be, he wasn’t poorly when they, you know, they didn’t feel that he needed to be admitted. They said, “If we take you in to hospital we’ll do the Covid swab and then you’ll have to make your own way back...“even if you’ve got it, you’re not unwell enough to stay in hospital, you’ll still be sent home...” [Becca]

On the basis of this conversation, and taking into consideration his wife who has dementia, Anthony made the decision not to go into hospital. He collapsed two days later and died that night.

Confusion around systems, processes and communications also caused some delays in diagnosis:

“I ordered the Covid tests but the problem with it was I didn’t see you had to order two you had to go further down the page, it said ‘Is there anyone else in your household?’ so I assumed we would get two and we only got one. So he wouldn’t do that he was a bit stubborn and I did notice as well – I then booked and went to [name of place] and had a test on the Tuesday morning I think and on then on the Wednesday my result pinged on my phone that I’d got Covid. So he said I think I’d better do this then... his result come through on the 8th of January by which time he was already pretty bad” [Jackie]

“You know the stories coming out slowly from different places and the scientific community talking about it in one sort of way on the television. But you know I suppose if you see Boris Johnson shaking somebody’s hand in a hospital – I think everybody was – there wasn’t a coherent story and I thought it wasn’t very clear and I think people were questioning themselves as to whether they were over worried or under worried or did your family member have something that they ought to be worried about or was this just a normal thing and it was a bit silly to worry” [Diane]

3.1.3 Nosocomial Contractions

Care Home Contractions

Care home residents have been particularly impacted by COVID-19. The Care Quality Commission (CQC 2021) published figures in July 2021 pertaining to the number of COVID-19 deaths in care homes in England, though these were quickly disputed with the actual

number likely to be significantly higher (Sabin 2021). Many narratives reflected a belief that care homes had failed to prepare adequately and/or early enough:

“our group of care homes [where Sarah worked] locked down pretty early on, but we’d already put an awful lot of things in place which weren’t happening elsewhere, you know, Public Health England weren’t saying. So, for instance, one of the things I was concerned about at the home that my mother was at, was that staff weren’t wearing masks and because what we’d observed in our care homes was that staff, not so much doing personal care because that doesn’t, if you’re giving someone a bed bath or you’re assisting them with washing, you only spend a small amount of time face-to-face with them, but if you’re assisting someone to eat, you are very close to them and you’re probably chatting to them for a long period of time. And so, we identified, very early on, that staff should be masked when they were supporting people to eat.” [Sarah]

“...he’d gone downhill again. I asked her at the time, and I said, “Can he be tested then?” I said, “Because he’s not been very well. And he’s gone down- Can he be tested?” And she said, “No I’m sorry.” This is when I knew it was in the home, you know, there were other people in the home as well as this lady, because she said, “I’ve only got five tests.” I said, “Well can’t he have one?” She said, “I’ve got others unfortunately that-” So I knew then, I knew he was gone then because it’s obviously endemic in the home by then. It was obviously spreading in the home.” [Sian]

“Just the fact that you know I don’t know how we could have helped her to understand the situation better. And I also think even when masks were suggested strongly suggested in care homes they were coming out with them under their chin or hanging from ears or what have you. And there was me really being careful not to touch mum. I think – I don’t know that they quite had the right system in place. Don’t get me wrong, it’s a brilliant care home, she wouldn’t have been there eight years if it wasn’t, she liked it and she loved the staff and she thought of them as like family. But I don’t think they were really on top of it.” [Judith]

Lack of PPE emerged as a problem in care homes, with some finding ways to try to compensate for the PPE shortage:

“my brother, when he rang me, he said, “I don’t think much of their PPE.” So, I said, “Well, what did they give you?” He said, “A paper mask and an apron.” And, sure enough, a week later, he got Covid. And that’s the only place he could have caught it.” [Sarah]

“We couldn’t get PPE, so we got, and, you know, well I’m sure you know whatever Matt Hancock says is complete and utter rubbish but we got staff and relatives to make masks and we looked up, for obviously, you know we searched the internet for the safest way to make them and we had a pattern that we asked people to use. So, very early on our staff were wearing masks, so I asked at the care home my mother was at, which was a [name of care home] Home, so I asked if the staff there could wear masks and I was told, “No, we’re following Public Health England advice, as long as we do that, we’ll be fine.” And I was saying, “But their advice is not, it’s behind everything, they need to be ahead not behind.”
But they wouldn’t [Sarah]

Additionally, for some people there was a belief that other forces were working that obstructed the focus on keeping residents safe, yet requests to disclose information was refused. Sarah, who at the beginning of the pandemic was a Quality Manager for a group of care homes, explains:

Yes, [name of care home] closed pretty early, I think on the 12th of March, something like that, 11th or 12th of March. And, you know, they were pretty good about writing to us but one of the things that I’ve heard, through the grapevine, through one of the provider forums, was that [name of care home] had offered to take NHS patients, untested, for £3,000 a week. Now, I don’t know if that were true or not because, obviously, [name of care home] weren’t going to say that. But it has the ring of truth knowing [name of care home]. So, I wrote to the Chief Exec of [name of care home] and I said that I was concerned, that I knew that care homes were being put under pressure to take people from hospital without a negative test. And, you know, the homes I worked for, we were very lucky because most of our residents are self-funding so we didn’t have block contracts with the council, but in the teleconferences we had twice a week with the council and other providers, the council were putting a huge amount of pressure on homes to take people from the hospital untested. And my boss was in a strong enough position to be able to say, “No, I’m not doing it. My job is to protect my residents and I’ve got every sympathy for you and if you can get people tested, if they’ve had two negative tests, I’ll take them, but I’m not taking anyone who’s not tested.”
So, she was told, in a public forum, “You’re being very unhelpful.” And some homes, obviously, had to take them because they didn’t have much choice, really. Anyway, that’s by the by, but I wrote to [name of care home] and said, “I’m concerned about, we’re hearing about homes taking people from hospital, can you assure me that you’re not going to do that?” And they replied and said, “We are taking people in as per our admissions policy.” And I said, “Well, can I see your admissions policy?” And they said, “No, it’s an internal document.” [Sarah]

Many participants expressed frustration with the communications with care homes, as the following quotes articulate:

“they [the hospital] said, “We think she’s got Covid,” even though she wasn’t coughing or anything, they said, “We think it’s Covid, we’re going to do a Covid test.” So, they did the Covid test, and they had x-rayed her lungs and said it looks like Covid. And then the Covid test came back positive. So my brother rung the home to update the home and say, “Just to let you know, this is what’s going on, because they said that they think it’s Covid, but so far she hasn’t got any respiratory symptoms; she hasn’t got a cough”. And the home said, “Oh, we knew it was Covid, because we’ve already had two deaths from Covid in the home.”

[Charlotte]

“And what bugs me a little is when I was sat with my Mum the afternoon before she died, various carers came in and said ‘oh yes when I had it I felt wretched for weeks and when I had it – and I thought hang on a minute there’s too many people here they’ve all had it. I know it was tricky, very tricky, but we were having to stay away but they were able to go to their families, mix with people, go shopping you know for food or whatever and go into the home. And they kept it out for a year but then obviously it was rife but you don’t get to know these things - you’re not told.” [Judith]

Hospital Contractions

Many stories contain the issue of hospital contracted COVID-19. NHS data shows that between March 2020 and May 2021, over 32,000 people caught COVID-19 in hospitals. Of these, up to 8,700 died (Campbell and Bawden 2021). While there are myriad underlying reasons for this (Oliver 2021), our respondents explain that their loved ones, often after shielding for months, were admitted to hospital for unrelated problems and undoubtedly contracted the virus in hospitals:

“They did tell me that she had been Covid tested and that she was negative on admission, which was fine. And that the hospital had two pathways, one for positive testing of Covid and one for negative tests. So that was fine, she was on a ward which was negative, everyone was in it that had been tested was negative. She had tested negative on admission and was tested weekly, I think, after that, and she had three negative tests, and just in the middle of the preparations for her coming home, I got a phone call to say sorry, that Mum had tested positive for Covid” [Margaret]

“When she got to the hospital [after a fall] they gave her a CT scan and she’d got three broken ribs. they gave her some very strong painkillers... and I spoke to her on the phone... she said I’m fine don’t worry about me tell your dad I’m happy here... they said she’d had a Covid test and she was negative and so I felt quite comfortable you know? 12 days later, one afternoon, my daughter got a phone call from a sister saying your Nan’s tested positive for Covid and we’ve got to move her to a COVID ward. Well of course my daughter knew exactly what that meant” [Lynn]

“She was in a lot of pain. So, they took her in and they actually did loads of work on her so, they did loads of scans. They found that she’d got a bit of an infection in the bone and that’s what was causing the pain. They gave her antibiotics, they tested her for cancers, all her heart. She hadn’t got any underlying medical conditions...Anyway, while she was in she came into contact with Covid and they said that she’d started isolating with just this other lady....” [Annette]

“She had a fall just after New Year and her blood pressure was low, had dropped... we talked her into having the doctor. The doctor called for an ambulance and the ambulance took her in. She’d been convinced if she went into hospital she was going to catch it. That was the 25th of January, and on the 27th they moved her into [name of ward] Ward, which, she tested negative, so put her into [name of ward] Ward, and it- She rang me on the 29th, she was getting better, she rang me on the 29th because they’d been talking about sending her home, and said, “The patient in the next bed’s tested positive.” [Emma L]

“She was getting ready to be discharged and they must have tested her to bring her home. And on the 27th she tested positive for Covid. So that- A week. So she’d had three tests prior to going into the hospital. So she got tested at home, then she got tested when she arrived. They tested her in A&E. And so the A&E one was the proper testing the said. So they were all negative. So she got moved to a ward, when she’s getting ready to discharge, tested again and she was positive.” [Lynne]

“At the end of January, she fractured her hip and ended up going into hospital. And did really well, you know, had a friend in the next bed, you could hear them laughing and giggling and

being unruly, which was Pam's way. But you know that's where she contracted Covid, her and other people in the ward. She was doing well. She'd had an operation. It had mended well. And she was, you know, they were talking about the physio and getting her home. And when she could come home. And she was absolutely desperate to come home, absolutely desperate to come home. We'd lost her little dog just on the second day she was in hospital. So I bought her a new puppy. So she was desperate to get home to see this new puppy. And we were planning all of that. And then she just said, "Oh there's been a contact, a Covid contact on the ward." And she was in a general ward then at that place. And the ward sort of locked down. And it was actually just the bay, her bay, you know, which I think there was about five or six beds or whatever in this bay, rather than the whole ward. And that bay had been locked down. And her and her friend she was giggling and laughing with were both saying, "Oh we've been locked down now." Now obviously we had no idea where that came from. I don't think we'll ever know will we? You know we assume that staff had been vaccinated. But there was absolutely zero contact with the outside. Fortunately we have a niece who's a nurse in a different part of the hospital, so she managed to get a little bit of information. But yes I think they just said to her, I understand that she was tested when she arrived, you know, with her fractured hip. And that must have been negative, and anyway, she'd been isolating for over a year. She hadn't- The only people she'd had contact with was the ambulance drivers who came and took her into hospital. So at that stage she certainly went into hospital without Covid and then contracted it there." [Stuart]

The unfairness of contracting COVID-19 in a hospital, a place where people felt their loved ones should be safe, and after being so careful when they had been in control of their own COVID protection measures before admittance, emerged time and again:

"She'd been shielding: we'd kept her safe for the nine months previous you know she hadn't been out, And then she had a fall at home..." [Lynn]

"It's not fair, it's really not fair because look I mean he had underlying health conditions but none of those were in any way life threatening, they were very well managed" [Suzanne]

"For over a year, you know from the previous March, she'd not been out. Not seen family at all. No one had come to the house. You know, I used to get out walking the dog so at least I could get out into the countryside. But, and that wasn't really her thing. And her mobility wasn't great anyway. So yes, she- That's sort of the sad part really that, a year prior to her passing she hadn't actually seen or touched or, you know, she would speak to them on the

computer or the phone or whatever, but she hadn't been into contact with any of her family or her friends or anything, which is a bit sad." [Stuart]

Inadequate PPE and the number of moves around hospitals also caused some concern among several participants:

"I got there and they gave me a flimsy plastic apron, the paper mask and some blue gloves. That was it. I was shocked" [Pat]

"When dad got discharged on Christmas Eve he came through the hospital and he was always- he was very conscious about his mask, because he actually told other patients from previous admissions to put one on, but his mask was falling off his face. So, he was Covid positive at that time, wheeled straight through the corridor." [Claire]

"She'd been on A&E, MAU, she'd been on [ward name] and she'd been on the stroke ward. And that to me, in a pandemic, is too many places." [Lynne]

3.2 HOSPITAL ADMISSIONS

Among those who contracted COVID-19 outside hospital, stories of what happened when their loved one were admitted range from those who had a false sense of security, never imagining that they would not come home, through to sheer terror and the realisation that this may be the last time they would see them. Throughout all narratives is the common theme that people could not be accompanied.

3.2.1 Saying Goodbye

Saying 'Goodbye' took on a new meaning for those who had to watch their loved ones being admitted. Some said goodbye never imagining it would be the last time they saw each other, while others recognised that this may be final.

Ambulance admissions

"And it got to the point where I said, "Look, you need to ring 111". So my sister did ring 111. This was Monday morning at seven o'clock, on the 4th of May. One ambulance came out to see them and they actually called for back-up for a second ambulance to take them both in, in separate ambulances. And that was the last time my sister saw, well, that was the next to the last time my sister actually saw my mum, because they waved to each other in the ambulance and said, we'll see you later." [Pauline]

"The ambulance people came in, checked his temperature, he's got a temperature. And I went, "But I've just checked it." And they went, "Oh what- Oh yes, they're not very good." And it was like, "I bought it from Boots. It's not a cheap-" And he said, "Yes, yes, but-" And so they did some checks on him. And they said, "Actually can you put some stuff in a bag?" And so I did that. And it was the back of my mind, but I was still like, and I went, "Okay, so do I come with him? Or should I follow up?" And they went, "No you can't come." [Charlene]

"The paramedics said I think we'll take her but she'll be coming straight home. So we said okay I said can I come to the hospital, no you're not allowed Covid regulations blahdy blah. So I said well how will I find out about my mum so they just said you'll have to keep phoning and they'll let you know. So, my dad is not one for showing emotion and my mum was put on a stretcher and wheeled out and she was laughing. They said do you want to give her a kiss goodbye and he went no see you later Con and off she went and I went to the ambulance with her and I said I'll come and pick you up later mum you know because they don't think nothing's wrong with you. And that was the last I saw of her." [Lynn]

"And they took him in the ambulance, and I never kissed him goodbye because he had the nebuliser on. And he never came home." [Liz]

"The paramedics came and took him off to [name of hospital]. And that was the last time we saw him. No, that was the last time I physically saw him awake. Yes, physically saw him awake." [Amy]

“So, after waiting the two hours, the ambulance came and then decided they were going to admit her and they blue-lighted her then to the [name of hospital], so she got into the [name of hospital] like early hours of the Saturday morning. And my mum hated hospitals, she was crying going in saying, “Don’t make me go, come with me.” But she had to get into the ambulance and off she went on her own.” [Ann]

“It was horrible, it was horrible because then I couldn’t go with him you see, couldn’t explain what was happening. It was- It’s the most horrible traumatic situation, I still have those pictures in my mind all the time because then he was taken to a place, to the hospital in [place] which I knew from before was a very bad hospital with bad infection control and he went to accident and emergency there and from then it went from bad to worse.” [Suzanne]

“By the Monday of the following week, so this was the 5th October, so it was eight/nine days after we got married, I knew I couldn’t look after him – his breathing was really deteriorating. And I also knew that when I picked the phone up to call 111, that they would come and get him, and I didn’t think I would ever see him again. So, I’d been putting it off and putting it off. But I knew that I had to get help for him. So, I called 111, and they sent an ambulance. I asked Steve first. I said, “I need to get help, is that okay?” and he said, “Yes”. And they took him away that Monday. And I was isolating, so I had to stay at home. And he was gone. And I honestly did not think I’d ever see him again. I just didn’t. That was the worst day.” [Fran]

Escorting people to hospital

Equally traumatic experiences were vividly recalled among those who had been advised to take their loved ones to hospital:

“And they literally came out and scooped him into a wheelchair and off. And we barely touched fingers.” [Charlene]

“My mum was very, very reluctant to go to hospital... But the GP said, “No,” that she really wanted her to go up to the local hospital, and basically I had to leave her at the door. They wouldn’t let me in with her. I mean she didn’t have dementia or anything, but you know she was 91...and she had macular degeneration, so her eyesight was poor, and she was very deaf, and she wore two hearing aids. And she said, “If you just come in and settle me.” And I said, “Mum, I can’t, I can’t come in. I’m not allowed.” Then she started getting a bit upset

and said, "Margaret, don't leave me here because I won't ever come back home again." She was absolutely terrified. And that was the last kind of words that I spoke to her, kind of face to face, were, "Please, don't take me in here because I won't come back out." [Margaret]

"They [paramedics] told me to take him for an assessment. He wanted to actually drive. And I said, "No I will drop you." And I just dropped him, and that was it. He took his water bottle, mobile phone and his wallet, and that was it. After four months, yes, I saw his dead body. My girls and I. That was it." [Sonal]

3.2.2 Waiting for Initial News

After saying goodbye to their loved ones, often in the most terrifying circumstances, many people explained that the first day was marked by a total lack of communication which, of course, added to their worry:

"They took him in about 6 o'clock. And I think they were queuing that night at [name of hospital] to get people in and I never heard anything until 11 o'clock at night." [Jackie]

"None of us heard anything for the first day for 24 hours, and, oh, God, it was, it was awful. Dad was frantic" [Becky]

"We didn't hear anything for 36 hours....We tried repeatedly to get through, couldn't get an answer. We tried all the following day. I ended up having to write an email to PALS to say look you've got a vulnerable adult; we've got concerns about capacity to consent. We don't know whether- what's happened to him. [Claire]

3.3 COMMUNICATIONS

3.3.1 Communication with Hospital Clinicians

Pockets of effective communication

Unfortunately, few narratives told of good communication with hospitals, though there are a few isolated incidents:

“A nurse rang me then, about 5 o’clock, to say that they were admitting him. He was going up to HDU. But one of the ICU consultants was just going to come down and have a look at him, and give their expert opinion. And somebody would ring me in a little while, which they did. And they rang me back and said, he’s okay for the minute to go in HDU. The treatment plan that they’ll carry out, you know, and she told me what he’s on, you know, he’s going on the steroids, dexamethasone, you know, all the usual regime of medication, that they would be able to do that. And they – the ICU consultants would monitor from afar.” [Amy]

Another unusual experience was Lynn’s with one particular doctor:

“We then got a phone call from the doctor and the doctor said to us I think your mum’s got pneumonia I can’t tell if it’s Covid or pneumonia, that’s exactly what he said. He said we’ve given her chest x-rays. Then she’d got a catheter infection they’d been giving her antibiotics and this doctor I’ll give him his due he was the only one who spoke to us every day for four days and was giving us information every afternoon. He was the only person in the hospital”
[Lynn]

Pauline, too, had a good experience – though she recognises that her story is perhaps atypical:

“I then spoke to the hospital and they updated me and then they updated me three times a day. So I think I’ve had- I think I’ve had one of the better experiences - to be perfectly honest, because I spoke to them, in the morning once I got home. They rang me about four o’clock in the afternoon, and they also rang me Monday night, just to update me on Mum’s oxygen levels and stuff. We were kept in the loop- because I think a lot of people’s experienced was, they weren’t told anything. They didn’t know anything. I don’t think I’ve had the worst experience.” [Pauline]

Amy’s positive experience with communication continued once Paul had been taken to ICU:

“The consultant rang me later on, on that Saturday evening, when he’d been settled on the ventilator. She explained everything to him, you know, so she did at that point... after then he was ventilated she did ring. And then the story then after that is he’s, obviously – yes, we were, obviously, extremely worried about him. And they said there is a phone beside his bed and I could call this – they gave me a direct number, and that I could call that number any time of the day or night that I wanted. But again, knowing – having that bit of background knowledge, and knowing the ICU situation that they were in, you didn’t like to mither. But the second thing is, I was scared to death every time I did ring. So – and so what thread we fell into was, I knew the nurses and the staff did a 12 hour shift. That was 7:30 until 7:30. So what I would do is, I would ring at six in the morning and I would ring at six in the evening.”

[Amy]

Indeed, it seems as though communications were much better with ICU staff than when people were patients on the general wards:

“When he was in ITU they were brilliant, you know, I was ringing four times a day, and each time I was able to talk to his nurse and the doctors would ring quite regularly as well or I’d be able to speak to the doctors. So, I can’t fault the communication really. They were very, very good. We were getting regular updates, you know, I was, like I say, I was ringing four times a day trying to get, yes, lots of information” [Becky]

Getting through on the phone

Overwhelmingly, the story of trying to ring general wards for news is one of frustration, stress, and fear, which added to what was already a crushingly traumatic time:

“And I couldn’t communicate with the hospital, well, I say I couldn’t, I did try an awful lot. But I mean I went through 48 hours once where I couldn’t get any answer. And of course I kept thinking to myself well if there was a problem they’d phone me.” [Becca]

“So, yeah, he was in hospital then on the 25th. Every time we seemed to- it was a battle to get through to the ward. As you can imagine it was skeleton staff because it was Christmas.

We were infected ourselves. We were feeling very poorly but we still tried to get through to the ward. We couldn't tell dad that we were infected. He didn't know." [Claire]

"It was very hard. You tried in the morning 'oh the doctors are with him' or you tried in the afternoon, sometimes you couldn't hear – get anything at all. Some days you couldn't hear anything or you just keep ringing and you get this one phone call a day and most of the time we found it was about 4 o'clock in the afternoon before we got anything - it was really bad."
[Jackie]

"It was terrible. I had to keep phoning. No one was phoning me to let me know how he was."
[Liz]

"they weren't phoning us, we were ringing the hospital day after day hour after hour what's going on.... we just couldn't get through. And when you did get through oh we can't give you that information blahdy blah you'll have to phone back. And you just could never get through no one would ever answer the phone it was terrible" [Lynn]

"At no stage did I have any contact, communication, feedback, info or anything from the hospital. So anything I found out was from her really. I mean if I rang the ward, most times no one would answer the phone. You know, I understood they were all busy, but..." [Stuart]

"The communication with the medical team was poor. I had to ring and go through the switchboard, and then the phone would ring, and ring, and ring, and ring, and nobody would answer. And I felt like I was a burden because they were all so busy. But equally, I needed to know what was going on with him. Under normal circumstances I would not have left his side. I would have been there when the doctors came round, and I would have known everything. So, it was really frustrating to try and track down the right doctor, to speak to somebody." [Fran]

Lynne explains the added pressure on families in this situation:

"I need to stress how traumatic it is on families that they can't contact anyone and get up to date information. When you're phoning a ward and it's just ringing and ringing. If we pulled mine, my dad's and my sister's phone records, and likewise probably yourself when your dad was in, we were probably phoning each 30 times a day to get one, maybe two answered."
[Lynne]

Poor quality information

Another consistent theme is that when relatives did manage to eventually get through to wards, the communication was poor insofar that people wanted information about treatment plans and prognosis from doctors, while in reality it was mundane and often limited to communication with healthcare assistants:

“When he was on the general ward. I’d have to wait for, you know, what it’s like, it would be, “Well, I’ve only just taken over, I need to find out, dah-di-dah-di-dah” [Becky]

“Couldn’t get through half the time, we couldn’t talk to anybody. If they did ring you ‘oh he’s had a bit of ice cream’ or ‘he’s had a bit of cake’.” [Jackie]

“He’s had a yoghurt. He’s had a bit of porridge.” It was dreadful. I was saying, “Has he got a temperature? Has he got a cough? Has he had a Covid test?” and it was, “Oh no, actually he’s got a low temperature,” so I thought that’s really good and then I researched the low temperature and it meant Sepsis. So, the next day I’d ring and I’d say, “Has my dad got Sepsis?” and they said, “Oh, yes we’re treating him for Sepsis.” I said, “Well, why am I not being informed? You know, he’s gone in with a UTI and I can’t speak to him and I’m just, I’m not really interested in yoghurts and things.” [Pat]

“The next morning at 6:30 I rang up and I was told that he was agitated and I said “What are his oxygen levels? What’s his respiratory rate?” And I was kind of fobbed off, you know?” [Suzanne]

“All day Saturday, even though I’d set up like their safe password to get information from them, I couldn’t get through. So, every hour on the hour, I phoned the Medical Emergency Unit to ask how my mum was and I just got through to the healthcare assistant who was telling us, “Oh, your mum’s comfortable. She’s fine, she’s fine.” But all day I kept asking, “Can I have clinical advice to see what the clinical plan was going forward?” And he kept saying, “Oh, the nurse is busy, you need to phone back in another hour. It was really difficult to find anything out. But every hour I phoned and all we could get to was the healthcare assistant.” [Ann]

“It was really hard to get through to the ward when I did, I was only told he was comfortable” [Anne]

“It wasn’t easy to get hold of the doctors. If I did get through to someone it was usually just a ward orderly or somebody. I think I spoke to the doctor more on the last day than I did in the entire week that he was in there.” [Shelley]

“When I would speak to the nurse, they told me “Oh he is actually fine, he’s eating, he looks okay.” They’ll just look at him like that, you know, on the phone call, the nurse comes and then looks at him. And so he looks okay. He has had something to eat. You know like that. So like, and whereas my husband never told me once that he was feeling better because and then why would he lie to me? He knew I was so stressed at home. He knew that I was always very anxious and I was worrying. One sentence he could have told me, I am feeling better. But no, in fact he told me so many times my lungs are finished, I can’t breathe.” [Sonal]

“And all the time, you know two or three days went by and I kept trying to find a doctor and trying to find out what’s happening. Nobody had rang me up to talk about his neurological symptoms, nobody rang me up to talk about his history, so I kept ringing, I tried to find somebody to talk to, sometimes I rang and I- Sometimes they didn’t know who he was, that was in the acute medical unit. Once they put me through to somebody and they said he’s going to be discharged today, they put me through to somebody who was the completely wrong person. You know so it was toing and froing, toing and froing all the time and then I kept on ringing and ringing and ringing and they said, “Yes they’ll be a doctor available at 12 o’clock.” So I rang back at 12 o’clock, “No the doctor is not available until 2 o’ clock,” so I rang back at 2 o’ clock, “No there is no doctor available until 4 o’ clock,” and I said, “Please could you please tell the doctor to ring me back.” But there was nobody ever I could talk to until the Friday afternoon, Brendan went into hospital on the Tuesday lunch time.” [Suzanne]

The ‘toing and froing’ that Suzanne refers to was typical for many families, as they tried to track their relatives down:

“I rang the hospital and I was pushed from pillar to post and they said, “Oh he’s in resus,” and I was like, he is in resus? And that was really frightening” [Pat]

Lacking two-way communications

Families didn’t just have trouble tracking down doctors in order to receive information.

Several people felt that they knew things about their relatives that could help the medical

staff in making care decisions, yet this important line of communication, which would usually be open during hospital visiting hours, was cut off:

"She had what I call white coat syndrome. If she ever went to the doctors because she'd got to have her blood pressure checked, her blood pressure went over 200 it was just the way she was. The physio said they couldn't walk her because her blood pressure kept going up. Well it would go up because that was just the way she was. They never got her out bed: she was in bed 12 days....I want to know why they didn't listen to us as a family" [Lynn]

"They didn't give antivirals as well. They said, "Oh your husband came out on the 11th day of the symptoms." So after the 10 days, but I actually told them my husband actually came on the eighth day not on the eleventh day because my husband was not on the 11th January he came, that wasn't the eleventh day of the symptoms you know. So they didn't give any antivirals and they said plasma was not according to government guidelines. And blah blah blah, whatever. So they did according to the government guidelines.... they told me clearly that look you are not from the medical profession, so do not question us." [Sonal]

"And then she got moved. She got moved the next day up to [ward]. But my thing is that if that nurse, and I kept stressing to her, I said, "Listen, she won't have had a stroke." I said, "That's how my mum is." I said, she said, "Well we're going to CT scans." I said, "Don't do any scans." I said, "Because we want her at home." Because we didn't want her in there because at that point of it being so high the Covid. And we'd shielded my mum from February before, before the country went into lockdown. And she said, "No she needs it." I said, "She won't have had a stroke. Lo and behold, long story short, she has, she didn't have a stroke. But they did MRI scan, CT scan, and lumbar punctures on her which I think were unnecessary. If they'd have let us in, or listened to us even, that was my mum, to me, if they'd have listened to us on that phone call, instead of telling me off that I was phoning and my dad had phoned in the morning, and said, hang on they're saying this is her normal behaviour? She does have a left side droop? But not just that. What is the cost of an MRI and a CT scan as well? It's a waste of money. My mum was confused.... They just never listened to a word we said. We couldn't get through to them. They just don't think. I just don't believe families get listened to. I think they think you mithering them and you're bothering them. And you don't know. And what they forget is you know them better than them." [Lynne]

3.3.2 Direct communication with loved ones

In addition to a lack of communication with clinical staff, many families had to endure being unable to speak to their loved ones directly. Underlying reasons for this range from practical issues arising from technology limitations, through to the severe directives pertaining to visiting.

Practical issues

The issue of vulnerable patients needing, and often not receiving, help with communications emerged as an important theme in many narratives:

“Dad couldn’t phone us because there was no mobile phone signal on the ward. This is something I’m really, really annoyed about because dad couldn’t phone us, we couldn’t phone him. We had to try and get through to the ward and even thought they had an iPad we had to phone the ward to ask to be able to use the iPad, so we couldn’t even book a slot or anything.” [Claire]

“We didn’t have FaceTime.” [Charlotte].

“Because he couldn’t text, he would try to ring and he couldn’t speak” [Jackie]

“You know I couldn’t do anything other than speak on the phone...you know, the communication was quite hard. She wasn’t great with mobile phones. I had to buy her one, a cheap one just when she went into hospital, because she didn’t have a mobile phone of her own. She liked Facebook and all that sort of stuff. But she wasn’t really- And it never really worked, the communication was difficult, she couldn’t hear me, I couldn’t hear her. The phone would go off charge, I’d lose contact with her for all day because she couldn’t reach the charging point and nobody would put it on her charging for her and all that sort of stuff. Her communicating with her relatives as they couldn’t see her was very important. But there was no, there’s nothing technical there, they didn’t have any iPads, they didn’t have any phones, they didn’t have anything. So you know, there could have been more help and more support, and whether that was through a lay person in the ward, it didn’t even have to be a doctor or a nurse, if they were really busy. You know, you think some volunteers could have helped the communication couldn’t they really.” [Stuart]

“So we sent a mobile phone in from A&E, we said, “Listen I’m going to send a phone in.” We sent it to her in [ward name]. We loaded my number in, my dad’s number in, the landlines as well, and my sister’s number and her landline. We sent it in, each day we’d phone and say, listen, because what she’d do, she’d talk to you, she’d forget you were talking, and she’d just go and put the phone down. So the phone would go down, but she wouldn’t charge it. But she’d like, because of the stroke, her left side was weak. But she had sort of limited vision just like that then. So if it was here she couldn’t see it. So a lot of the time she could hear it, so she’d start panicking. And so we’d say to them, but you couldn’t even get them to answer. But what really did upset me when I went into the ward on the Friday, she was in a bay in the corner ...And they had a healthcare assistant sitting at the end at the doors on a chair. And there were four beds. And we must have rang, I’d ring three times because I think the first time, she won’t find it. Second time she’ll be looking for it. And third time hopefully the staff in there will answer it. Never ever happened, barely ever got answered. And we’d have to phone the ward, all the rigmarole trying to get someone to answer the ward phone, and say can you answer her phone for her. So that’s how we were trying to communicate. Which is all stressful. When we went in that evening, there was a healthcare assistant sitting on a chair in the doorway, just sitting there like that. And that really upset me because I thought, we’ve phoned and phoned and phoned. And I know my mum would have been panicking trying to answer that phone. And looking for it. And you couldn’t get up and answer her phone.” [Lynne]

Problems due to COVID-19 treatment & symptoms

For others, the nature of the COVID-19 treatment meant they were unable to speak, or communications were at best extremely difficult:

“I messaged her and she said, “I want to talk to you but I’ve got an oxygen mask on so I’ll have to wait for that to come off.” [Becky]

“He tried to ring me but obviously because he couldn’t because of the breathing he had a CPAP on” [Jackie]

“They put her onto oxygen and that made communication even harder because there was this oxygen machine going on in the background and she was wearing a mask and all that sort of stuff.” [Stuart]

“He would do a sneaky phone call, and then get told off for taking his mask off. So, there was only a couple of quick phone calls.” [Liz]

Eventually, however, the symptoms of COVID-19 meant communication was almost impossible:

“We couldn’t get through to my mum at all because I think she was hypoxic still but she sent the odd text message that didn’t make any sense and then, when she did answer her mobile phone, she was talking about like her friend, her best friend from years ago that she still kept in contact with but not all the, you know, it just wasn’t sort of making sense. It was really difficult” [Ann]

“He had his phone with him. We had I think three video chats. Messenger and Facebook. But he couldn’t do that very easily because of the things they put on his fingers. But the hypoxia was making him very belligerent.” [Shelley]

“My dad was incoherent. He was actually incoherent for 18 days that he was in hospital, so I never spoke to him. I would ring and they would put the phone to his ear and I would sing Vera Lynn and I would sing ABBA and talk to him and they would say, “Oh he shook his head,” or “He raised an eyebrow.” That was all. Like, there was no face time. There was nothing and it would only be if a nurse, and when I say they put the phone to my dad, in 18 days I think that happened twice because I got the same nurse and she said it was her own private phone and they weren’t really allowed to do that. She also sent me a photo of my dad and said, you know, “I shouldn’t really do this either. You know, you need to please destroy my number,” but that was my only contact in 18 days.” [Pat]

The fear and isolation experienced by patients due to no visiting was particularly pertinent in Sonal’s and Stuart’s narratives:

“The last two days before he was taken to the ICU, he was actually on the verge of getting better. So he was actually, you know, feeling better, his oxygen was good, they were almost about to bring him down without the CPAP because two days he was without the CPAP. But then the panic attacks started. But that was his U-turn, yes. Imagine people dying in front of you, you haven’t seen your family for weeks. You have never been ill like this in your life, you know, you are so fit and capable of doing everything yourself. I felt that even if could reassure him, just once, if he had seen me physically, or you know, then he would have helped - I think it would be, it does mentally, it does help I think. Because imagine like, imagine him being alone that like, with just with the nurses and doctors and people dying in

front of you. And even in this WhatsApp messages he wrote to me how afraid he was. He was telling he was getting panic attacks and you know- And that was so awful, yes. It was like, that took the U-turn, because once the panic attacks started his oxygen demand increased, his heart rate, everything and that was when the doctors decided to, you know, intubate him and put him on the ventilator.” [Sonal]

“They were having to continue to increase the amounts of oxygen. And I think that was the issue. And then I was, I finally got, well, I was then told by her, I’m being moved to another ward. And she didn’t really know why or when or how, if they’d told her she hadn’t understood it. A lot of the staff were different nationalities which is wonderful. They do a great job. But she had quite a lot of difficulty in sometimes understanding what was being said to her. They were very kind but she couldn’t always pick up the full picture of what was being told. She was a little bit deaf. She had this mask on. So you can see the whole- She was becoming more and more isolated really. [Stuart]

Digital communication channels

The importance of digital communications emerged in many narratives.

“She FaceTimed a couple of my cousins. In fact, the last thing my mum said was to my cousin Helen, who’s a mental health nurse, was, “Well you sing that song better than your bloody mother”. [Pauline]

“And then that afternoon I had a WhatsApp call from him, and he seemed cheerful and fine. And we video called. We communicated for the whole 12 days by WhatsApp. I would watch to see if he had been online, and if he hadn’t been, then I’d message him and just say, “Hey, are you okay, are you asleep, and what’s happening?” [Fran]

“My son took a phone down to the hospital and we face timed Ken. When we were talking to him he opened his eyes as if he recognised us.” [Anne]

“He had his mobile with him and so I’d ring him a couple of times a day much to his disgust, he hates phones. But yes, so I’d ring him and actually, you know, we were able to talk for ages but once he had started to get more breathless it was harder because he had full face masks on and, yes, and as he got more poorly it was harder.” [Becky]

“We had an email thing that they do at [name of hospital] where all the family sent in emails and then the Friends Society or some society print them off and take them and read them.” [Jackie]

“Obviously, I only saw him when the mask was off for those little break times. He kept in regular contact with us by FaceTime and calls. He would ring really quite regularly. As you can imagine, you know, no visitors. Nobody there. It was really hard for him as well, so the phone was the lifeline and contact, you know. And in the evenings and everything, with all of us, he’d be ringing and FaceTiming all the time.” [Amy]

“And I texted him, and I said, “If you can get in touch with me, please...he then went onto a CPAP ward, and we still texted. We used to text each other a lot.” [Liz]

Indeed, as COVID-19 symptoms worsened and speaking became more difficult, digital messaging became more important:

“The thing is, because he was always struggling for breath, like you know, whenever I spoke to him I was not very- He was not very comfortable. He was losing oxygen. I could see. You know, he was struggling. So although everybody, all my family members told me, you need to video call him, video call him, he was, whenever I video call him he was struggling you know, to talk. I could see. And I could not see that pain, you know. So because he was losing a lot of energy, so we were all the time WhatsApp messages, you know. WhatsApp messaging. Yes, it was regularly WhatsApp messages. And in every WhatsApp message he wrote, he was not happy there. He was why did I come here? I should not have come here. He was so afraid. He was so afraid for himself and for us as well.” [Sonal]

Help from hospital staff

Several stories of kindness from individuals emerged, where staff had tried to help patients and families communicate:

“And so she passed me over to her nurse who was a lovely Northern Irish lady who basically told me, you know, how she was doing and that she was, you know, she was doing all right, she was on the CPAP, that she couldn’t talk because it was really noisy and then she did end

up passing me over to mum so we did end up having a little bit of a chat but it was quite hard to communicate because it's ever so noisy, isn't it? So, that was fairly short-lived"
[Becky]

"The doctors put the phone to her ear a couple of times...." [Charlotte].

"My mum couldn't work FaceTime. But she FaceTimed us once, a nurse in the last week of my mum being in, FaceTimed us" [Lynne]

Lockdown & visiting regulations

Window visits, particularly for those in care homes, were attempted but were often less than satisfactory:

"When I wasn't allowed to see her, I did have a couple of window visits, but because she was deaf, you know she couldn't hear me, and we attempted phone calls and- She couldn't hear."
[Margaret]

"For the year before she died previous to that I was seeing her nearly every day perhaps six times a week. All my life I've seen her almost every day and then Covid hit and I was only – well first of all I wasn't allowed to see her at all which was tough and then they implemented a situation where we could book a visit and we sat on a garden bench in the carpark and so I had to see my mum like that. And that went on for quite a while until they closed it down again. And then I was able to go and stand outside her bedroom window. Fortunately she was on the ground floor, I'd say to her it's a good job you're not upstairs mum. And so I'd speak to her through the open window which was problematic because she was very deaf and she didn't see very well so I was sort of stood in the flowerbed yelling at her, horrible. But that was – we sort of got through that but what bothered me particularly in the early stages when I was seeing her on the garden bench, she didn't really understand what was going on. That is my biggest regret, that mum – I'd try and explain to her she had no idea about the shops being shut or not being allowed to see people. And – well she didn't have dementia but she obviously didn't get a grip on life terribly well she lived there for eight years you know. And I'd say to her you know I'm not allowed to touch you mum. And then when the carers came to fetch her in because I wasn't allowed to touch her wheelchair and wheel her in, the carers would give her a hug and it was like – mum would say see they're not scared! And I said mum I'm not scared I'm not allowed to. And that was really horrible the lack of understanding of it all. So, then I was visiting her you know perhaps once twice a

week when they allowed me to talk through the window. I mean even Christmas Day I had to talk to her through the window and pass her presents in you know. [Judith]

Window visits sometimes happened at hospitals, too:

“We weren’t allowed in to see him but then just the day that he was going to be transferred to ICU I rang the hospital ...and I said, “Look, he hasn’t seen any of us since Mum died, you know, please, please can we come and see him? If we get all, you know, all the PPE on, please can we come and see him, I think it will do him the world of good?” And they said, “Well, the best we could do is you could see him through a window.” So, we went up to the ward and unbelievably he was in the same bed that Mum died. But we were waving to him, he was prone at that time, he was waving back and we were sending each other hearts and, you know, and we’d, my kids had written letters to him and we’d written a card and put some photos in and given him some snacks that he wanted but we didn’t actually get to see him. I said to the nurse, because they’re all, they’ve got the full PPE on and I said, “Can you give him a cuddle?” So, she did, she gave him a cuddle from us.” [Becky]

In some cases, physical distance meant families couldn’t attempt even window visits, as Margaret who is in Scotland explains:

“And my brother lives down in England, and he was trying to call her on the phone, but she couldn’t hear a word that he was saying. ... it must of been awful for him, he couldn’t come up because of lockdown, he wasn’t allowed anywhere out of England.” [Margaret]

While others were denied saying the final goodbye in person:

“They only let one person in once. The hospital that my mum was in, [name of hospital], they let one person in when they thought you were going to die. That was their policy. So, because [brother’s name] had gone in on the Thursday, that was it. So, when they rung us up and said she’s going to go today, this was the Saturday. They said she’s going to go today, and none of us could go in. They said they would put the phone to her ear. So, I was talking to her when she went.” [Charlotte].

“We decided which one of us would go, which would be my youngest brother and he would take with him recordings of each of us saying goodbye to her. So, that’s what we did and he went and he sat with her and he read what we’d said to her.” [Sarah]

Hospital visiting and vulnerable patients

In fact, despite some hospital directives which stated that particularly vulnerable patients could be accompanied, this did not transpire in any of the stories here. Becca's story is particularly poignant given that she had lost her Father to COVID-19 only a few days before, when her mother who has dementia was taken into the same hospital:

"She was in for a week, which was more traumatic than my dad being in because obviously dad had been a short amount of time and I'd lost him. So there was, in my mind thinking, I'm going end up losing both of them in very quick succession. But also my mum never had a phone, she couldn't- She wouldn't even be able to phone on a- You know she can't barely hold a conversation on a landline phone, so there was no way I could communicate with her." [Becca]

Margaret and Suzanne also tell of the distress caused by being unable to be with their relatives, even though they were extremely vulnerable:

"You see I mean I kept ringing up earlier, often I kept ringing the ward sister and said look can I not come in he really, really needs me because you know from time to time in the morning the nurse said he refused to take his medication and he refused to take pills and I said, well you know he needs me; he needs me to encourage him. "You can't come in," I'll wear the full PPE just like you do you know I won't stay long just to be able to get him you know if he's in an individual room it's very safe. "No, no we can't put him in an individual room and anyway no visitors allowed you can't come in." [Suzanne]

"The thing that haunts me to this day is that my mum must have been so frightened. She couldn't hear, she couldn't see very well, she wouldn't have known what was happening to her, and that just must have been awful. Absolutely. She would have been wondering where we were, because she wouldn't have been able to hear, and you know I said to the nurse, "Does she know she's got Covid?" "Yes." I said, "But how do you know she knows?" When it comes down to it, what's patient centred about leaving someone who can't hear and can't see, to die?" [Margaret]

Pat, on hearing that the regulations had changed for patients at end of life, found courage to visit:

“Well, what happened, I’ll go back a day. On the 15th [April 2020] the government said that anybody who was in palliative care, you could go and visit them so despite my anxiety and phobia, I got on the train and I rang the hospital and said, “I’m coming,” because I’d asked every day and they’d said, “No, no, no.” I said, “It’s on the news right now. I’m getting on the train. I’m coming.” [Pat]

However, even after the Government directive on 15th April 2020, many were still denied access to their loved ones:

“So why? Why? But end of life they should have called you in already if it was end of life. I thought that’s what it said once it’s an end-of-life situation visitors were allowed....there were some people who were allowed to go in at that stage, were allowed to go in but in can visit the relatives. There’s some people in that hospital who were allowed in all the time in the beginning -that’s not really good either because it needs to be adjusted to the local area but I think the rules were just arbitrary they weren’t you know there was no rhyme or reason that we had them.” [Suzanne]

Sonal, too, is puzzled by the seemingly arbitrary rules:

“But in the ICU, in the ICU funnily enough, when he was on his deathbed, the whole family was allowed to go. Anybody could walk in anytime in the ICU. In the ICU, when he was in the last week, this is I mean when he was actually, the doctor told me has one percent chance of survival, everybody was allowed in the ICU. That means his cousins, or you know, even not the immediate family. Anybody could walk in and go... I don’t understand these rules.” [Sonal]

Several participants felt guilt or regret that they hadn’t tried harder to persuade people in charge to let them visit their dying relatives:

“I keep, you know, sort of wondering whether I should have pushed harder to see her in the first place, because this is the time when Prince Charles went to visit Prince Phillip, you remember? Well that wasn’t- It wasn’t the time, it was after obviously, that was later on obviously. But you know, so some people seem to be able to visit their relatives. If I’d have pushed, if I’d have put myself out, if I’d have just but- I was never, I was always told I couldn’t go anywhere near. I wasn’t given the opportunity to see her. So I just assumed that nobody could and that was just the way it was. I understood the reason for isolating Covid, of course I did.” [Stuart]

“What I’m really angry about at the moment is that my dad and many like him have been stuck on wards with no form of communication with home. They’ve been held captive... I actually use the word captive because I can’t think of any other way to describe it. He couldn’t leave. He couldn’t phone. We couldn’t phone him. So, he was in effect captive”
[Claire]

Not being able to bring people home to die is a regret apparent in other stories, too:

“Once my mum tested positive with Covid we were begging to go in and we couldn’t get in. So every night I went to bed crying, broken hearted. So I’m thankful we got in eventually, because I know that not everyone did. But I just- we said can we bring her out? Let us bring her home? They were like no, you can’t take her out. She wanted to go home and she was scared. And when we got there she said, “I feel far better now, I’m not frightened anymore.” And I know that’s what she would have been.” [Lynne]

“He wanted to die at home, he didn’t want to be in hospital.” [Fran]

“He wanted to come home. And I wanted nothing more in the world for him to come home. And he kept begging me to go and get him from the hospital. And he got that in his head and he wouldn’t let it go, like a dog with a bone. And he was begging me and his mum to go and get him. Bring him home. And I wasn’t allowed to. He didn’t come home in the way I wanted him to. My head knows it’s not my fault, but my heart doesn’t.” [Shelley]

3.4 CHAOS, CRISIS, CONFUSION & KINDNESS

A great deal of chaos and confusion became apparent in many stories. Tales of conflicting information, incorrect information, and an overstretched system that at times was unable to cope are interwoven among so many narratives that it would be impossible to suggest anything but chaos and crisis.

3.4.1 A system overloaded

Perhaps this quote from Jackie, who was visiting Peter at his end of life during the second wave, sums up the situation in some hospitals:

“While me and [my youngest son] were outside the bay there were beds coming out with just sheets screwed up on them and oxygen bottles going down in the lift, because they put them all in the [name] Suite, the private suite on the first floor. So we were just looking at like these must be people that have died and in the course of that half an hour may be I don’t know how long it was, but five beds went down. And they were coming up with more people on.” [Jackie]

Overstretched staff

Narratives described staff as harassed and pressured:

“I would say that they tried their best that they could but they were very harried. Very busy. Very stressed. And I tried not to bother them, but obviously I wanted to know what was going on. And with Nick not making as much sense as he would normally do when he’s in the hospital. I mean when he found out I rang the first time, I got a really crappy message from him because he was like, “I’m telling you what’s going on” and it’s, “You don’t need to speak to them.” And I’m like, “But you’re not making any sense.” [Shelley]

“They said that they didn’t have enough single rooms, they were completely, what they were saying to me is that they were completely and utterly struggling. They were almost at the stage where the whole service was breaking down. They had staff who were off sick, off because they were shielding. They had staff who were off because they had been in contact and were isolating, they had staff that were off because they had Covid. They were rapidly running out of staff as well as ancillary staff.” [Margaret]

“The doctors were busy, maybe just one person to update. And I don’t know, but it was very difficult that time because in the HDU it was very difficult, yes, communication. Sometimes you know they were getting so angry as well, everybody was so busy.” [Sonal]

3.4.2 Care standards

Unfortunately, the situation described above meant many basic care needs were not met, with patients left vulnerable and without dignity or the pain relief they needed:

“I got a phone call at five past twelve at night and I was told your mum’s dying can you come... and my mum was really agitated she chucked off her mask....and then they started injecting her with – I can’t remember the drug to relax her and they kept giving her injections and every hour they did that and she was just in a normal ward, and my daughter said you’ve called us, she’s dying, can we have a private room? And unfortunately they hadn’t got round to moving the previous two occupants who had both died. [Lynn]

“When I came in that night I saw his bag and I noticed that his toothbrush and his shaver and his glasses had never been taken out I had put in [snacks] which of course it was all checked with nurses there on the ward. I told them what it was and they said, “Yes we’ve got it, we’ve got it,” it was never unpacked he never, never got the snacks you know never. And that was before he was on a Covid ward so it was just a normal ward, even there they didn’t give him the things. They never unpacked it they never bothered. Which was really bad because I thought a little bit from home his own clothes and everything would do him good.” [Suzanne]

“The hospital stripped the beds, stripped the room, she was in a bay – she was the only one in that room. They stripped it. Left her just a sheet, she phoned me upset. And I was saying, “You need to go and find somebody to get some blankets.” She managed to, but then later on, she rang me because had a drip in her arm by then and she needed the loo and they’d said, “You’ll have to wait half an hour,” and she didn’t make it.” [Emma L]

“About six o’clock my mum dislodged her cannula so that meant then that she couldn’t have any IV fluid, she couldn’t have her IV antibiotics, she couldn’t have any pain relief, and they didn’t actually put the cannula back in until two o’clock on the Sunday afternoon. And that was like just despite my going in and saying, “Please can we have a cannula? Please can she have IV medication?” because at that point that she was crying with the pain, she thought like the seagulls knocking on the window, like landing on the windowsill, she thought that was like a person cleaning the windows. Then she thought, when you looked out of the window you could see a new building being built, and she thought like the scaffolding was people trying to jump off. So, she was really confused, really, and so it was really difficult to see that she that she was really gasping for her air, she was on the maximum rebreather, 100%. “We’re too busy. We’re coming now. We’re too busy. Sorry, we’re too busy. We’re coming now, we’re coming now.” I was asking can she have IM pain relief, “We don’t need to do that because we’re going to give her a cannula.” They finally put it in at two o’clock on the Sunday afternoon” [Ann]

In some wards, it came to the point where patients were looking after each other, or where relatives, finally allowed to visit due to their loved ones being deemed end of life, having to administer personal care:

“I had a phone call from a lady who had been discharged... who was a nurse at a different hospital who’d been in there with mum. She’d been looking after her. There were two dementia patients in the room and her and mum, and the dementia patients were getting all the attention, calling them all through the night...And then, she was the one getting mum blankets. She was the one helping her eat. She was the one doing everything. And she turned round and said, “No one’s helped your mum wash for two weeks.” They’re saying she’s independent. The night before she went into hospital I had to shower her. And I’ve been following her round the ward, taking her to the loo, and everything” [Emma L]

“When we arrived on the ward at about quarter past twelve when they first phoned us, immediately they said to me and my daughter who’s the nurse? and my daughter said I am and from that moment we said that we were left alone, totally alone.... and my Mum was covered in excrement all over her hands and all over her face. My daughter cleaned her up, made her comfortable and changed her position. I got toilet roll and wet it all down and we washed her that way because that was the only way we could.” [Lynn]

“The trauma being, the biggest trauma was, that it wasn’t my mum passing away, that was horrendous, don’t get me wrong, my mum dying is horrendous. The trauma started the moment she went to that hospital to the moment she died.” [Lynne]

3.4.3 Confusion

Conflicting information

Perhaps due to staff pressures, some relatives had to endure conflicting information, and this emerged among both care homes and hospitals:

“The nursing home had six basically ways of contacting us... they went into lockdown at the end of March, like everywhere. I couldn’t see her, she was so-called locked in her room, so-

called we thought proper measures and control measures and all that. , the hospital phoned my brother on a Sunday, just phoned my brother, and said that she had been ill from the Wednesday with what they thought was a water infection. She had just been a bit delirious, high temperature, what they thought was a water infection, but she hadn't got better. So, she went into hospital on the Sunday. And then the hospital phoned my brother to say that she was in hospital. The home didn't contact any of us or tell us she was ill or anything, despite having all our contact details. My brother was liaising with the hospital, he spoke to the doctor that was looking after her. The doctor said the home had told them that they had had no Covid in the home. So, they'd lied to the hospital, when they'd already so-called told my brother that they had had two deaths from Covid in the home." [Charlotte].

"And we'd phone up and we might get told that dad was okay, he was not on oxygen but then when we'd maybe speak to him on the iPad he was on oxygen. We were getting told contradicting things. We got told that dad had been moved to a different ward. Spent all night trying to get through and find out where he was. He hadn't been moved; it was another patient they were talking about.

"We were then subsequently told that dad had tested positive on the 10th of December. I kept saying to the ward Sister, 'but nobody told us' it was the ward sister telling me this and she said well I can't possibly comment.... However, we then found out, she said to us, sorry I told you the wrong date, but she told us this three times, the 10th. It was the 22nd of December he tested positive. We were like, so I was like, so he's been on the ward... so basically he's had a positive test whilst he's been on the ward with other patients. They've ignored my dad's positive test. Dad's infected everybody else. It was very, very distressing. Later: "oh sorry, yes, we found out. Your dad was negative every single time he'd been admitted to hospital." So, every admission he had been negative, it was only when he was readmitted on the early hours of Christmas morning on the 25th, after he'd been home for those 12 hours, that he tested positive." [Claire]

Inappropriate delivery of difficult news

Chaos and confusion led to what can only be described as inappropriate ways in which difficult and distressing news was communicated to patients and families, or for patients to be told things that families had expressly asked to be delayed until they were with them:

"Mum passed away on the Friday morning as it was my dad's birthday. And they allowed my brother to go and tell him but then they had to come out and leave him. And then my

dad went downhill. He got put on oxygen that morning, they went to see him and talked to him about DNR and not being ventilated. Already. That same morning.” [Annette]

“On the Saturday a lady rang me up and she said, “We’re going to put your dad in a care home.” She said, “You can put pictures up of your dad. You can take all his belongings,” and she said, “You’ll be able to visit him. You can’t visit him here but it will be so much better in a care home.” I said, “Well, this is a bit of a shock.” I said, “I know he’s had a bit of yoghurt this morning but he can’t speak and he’s incoherent and he’s got Sepsis.” Wow, the lady wasn’t even a nurse and she said, “Well, it’s because he’s got Covid.” I said, “Pardon?” She said, “Didn’t you know?” and I said, “No.” I said, “Shouldn’t a doctor be telling me this?” and I said, “Can I speak to a doctor please?” So, she said, “No. It’s the weekend. You can’t speak to anyone until Monday.” [Pat]

“I found out because I rang to say – well I was a bit cross because I’d phoned up to say could I see mum and they said oh not at the moment. So I phoned the next day and they said – I said well can’t I even just talk to her through the window? No, we’ve got Covid in the home.”[Judith]

“I couldn’t really talk to him it was dreadful and then on the 18th of June, so that was nine days after he arrived I got a call and it says, “Hello this is the discharge nurse I’m ringing from whatever it was [place]”, and I thought lovely and I said, he’s coming home. You know what she said, “He’s tested positive for Covid.” Yes and she said she was discharge nurse; she didn’t say I’m ringing from the ward, Nothing she just “I’m the discharge nurse.” And I mean of course my world broke down because both Brendan and me knew that if he caught Covid in hospital that would be the end of him cause of his lung condition it wasn’t anything- He said, he always said if have to go to hospital I won’t come out, he’d always said that.” [Suzanne]

“My dad phoned me up and he said, “They’ve moved your mum.” I said, “Well why? Where have they moved her to?” And he said, I can’t remember what ward, going to the other side of the hospital. So she went over the other side. So I said, “Well what for?” And he said, “I don’t know. I can’t get hold of anyone.” So then we were ringing and ringing and ringing that number. Then my dad got a text message to his mobile it said, just confirming we’ve got to isolate - Frances [surname] has tested positive for Covid. So that’s how we found out my mum had COVID. Through track and Trace yes, yes. Why did nobody call? Why didn’t someone say Frances is now moving over to a Covid ward, Can someone tell her family we’ve tested positive? It should be some sort of protocol of how they inform people. Because telling my mum was no good, my mum couldn’t even use a phone. But then the next day when we’d finally got in touch with [ward name], they said ‘we don’t know why she’s moved and they did’. And they knew it was a Covid ward she’d gone to.” [Lynne]

“So we went in, they'd told my mum she was going to die. So, I said to the doctor, “Well, why have you told her that” he said, “Well, she's got capacity so we have to tell her”. .. my brother went in to see my mum and my mum said to him, “Well, am I going to die”? And my brother just said, “Well, we don't know mum”. So, then we swapped and I went in and she said exactly the same to me.” [Annette]

“We asked them not to tell her she had Covid. And they did. So I heard them, I'm sorry, she was on her mobile and she put her phone down. And I heard the doctor telling her. And then we said to her, “Don't tell her she's going to palliative care.” We didn't want her to know. We didn't her want to know she's dying. And they told her. And I know they told her because they walked in with her in the room and they're telling her, they'd already told her all this. Asking my mum did they have questions? So I knew my mum knew. And we didn't want her to. And my mum would have been on her own with that news. And then when she- I know there's hundreds of thousands- There's 130 odd thousand people the same.” [Lynne]

“Well, when we had the phone call to say dad had passed away... the ward sister, she called my mum, and she called my mum the wrong name. She got corrected and this was on speaker phone, and she called my mum the wrong name yet again. So, I did say it's not Sheila, it's Shirley, I got really angry. I knew what was coming, I knew she was going to be telling her my dad had passed away and I just thought it was so unprofessional. I understand people are busy and under pressure, but if you're not sure, if you're tired, don't use the name. You can skip past it. And she was, she wanted to give us all the information there and then straight away, and it was like she was reading from a script.” [Claire]

“My niece that's a nurse had spoken to the people that, the evening before or the morning, and they'd had a fairly positive, yes she's doing okay. She's responding, you know, she's holding her own. So I got this call at 6.00 am, you know, when the phones at 6.00 am your heart goes over anyway... And the woman said, “Well there's no easy way to tell you but your wife has passed away.” So I said, well I don't know what I said. But I said, “Well did she have a heart attack?” And she said, “Well no she just stopped breathing.” So “Oh okay.” I suppose that's how you die isn't it. But you know, so there was no, there was sort of no context to the whole thing. And you know she seemed to be in quite a hurry but she did say to me, “Oh is there anyone you can be with?” And I said, “Well we're in lockdown so not really.” [Stuart]

3.4.4 Chaos

At times, the situation became what can only be described as chaotic:

“And they would lose him. I’d ring in the morning and he was not where he was the day before and they’d go, “Oh he’s not here,” and of course, I thought the worst every time; “He’s not here.” I said, “Can you find him?” and they were searching and didn’t know where he’d gone to and I said, “Why has been moved in the middle of the night again?” He kept being moved in the middle of the night and they’d say, “Oh it’s nothing to do with your dad’s condition. It’s just to do with we’re opening up the beds.” [Pat]

“I unpacked his bag at the end and what did I find in the bag? I found a pair of slippers that didn’t belong to him. I found a watch in that bag that didn’t belong to him and I found a pair of dentures that didn’t belong to him he had no dentures. How did those things get into the bag? You know what does that say about infection control and about the way they were looking after him?” [Suzanne]

“On the 31st of January, I rang the hospital, rang [name of ward] Ward at 9:30 in the morning and was told by a nurse she was fine. She’d been in to see her, she’d had breakfast, and she was doing well. So at this point we didn’t know that she’d been tested and that she was positive. It was my nephew’s 17th birthday. So in the afternoon when he was with me, we rang the ward again and they went, “She’s not in here. We moved her at two o’clock in the morning to [Name] Ward.” I went, “Oh, [name of ward]?” Not realising my nephew had lost his other gran in the same ward to Covid, in that same ward, before Christmas. So the look on his little face, he just cracked and I was, like, “Right, okay, so why did no one tell me?” And they went, “Well, we wouldn’t have rung you at three in the morning.” I went, “No, I rang at 9:30 this morning and I was told she was still in here.” “Oh, it was probably an agency nurse.” [Emma L]

“He went in on the Monday and on the Friday they said that there was no, well every day I asked about the Covid results and they said, on the Friday they said that it had been lost because they still hadn’t got the results on the Friday.” [Pat]

“I got a call on the Wednesday evening and it was from one of the consultants, and they had been ringing me, but ringing me on Paul’s phone, which was down in ICU with him. And my number was on the file. So it was only by me ringing at six o’clock in the evening that I said, you know – and she said, “We’ve been trying to ring you today.” And I was absolutely panic stricken then” [Amy]

“On the Saturday a lady rang me up and she said, “We’re going to put your dad in a care home.”... Monday first thing... the only time I did speak to a doctor, and she said, “Oh, no

there's been a mistake," and I was like, "Ah, he's not got Covid?" She said, "No, he's got Covid but he's not going to be moved. He's not going anywhere. That was a mistake. He's not going anywhere." It carried on with the chaos and twice more after that they tried to put him into a care home." [Pat]

"And then we got a call, my dad was then getting poorly with Covid. And he didn't have breathing difficulties at that time, he'd got severe diarrhoea and was very poorly. So, my brother had called the ambulance and they took him in the same day we got a call to say there was nothing else they could do with my mum. My brother had said to the doctor, "My dad's on the way in, can you not tell him, we're going to come and tell him. But can you put him on the ward where my mum is" because we knew otherwise he wouldn't be able to go and see her. So, I drive down, get to the hospital and I get a phone call from my dad saying your mum's going to die - they'd told him." [Annette]

Poor infection control

Many stories told of a situation where overstretched staff and a chaotic system meant infection control standards were often not adhered to in hospitals:

"One of the admissions in November he went, do you know, he said there was a Covid bay opposite my ward and we were like, no, they wouldn't have been that close dad. And he went do you know what, he said, some of the staff were putting their heads in there without any equipment on as well. I was like no, dad, they wouldn't be doing that. I blooming well believe him now. He'd say as well that patients were going off the ward to the main entrances to collect their belongings from family or friends, or carers. Or whatever, because my dad thought they'd been shopping because they'd be coming back in with carrier bags. We used to see patients congregating having a cigarette from different wards." [Claire]

"I saw people coming out the Covid ward hugging each other with masks down under their chins" [Emma L]

"There was no supervision, you know I could see people running around with masks under their nose, some with no masks at all. People were moving from Covid ward to non-Covid ward all the while I was waiting there that night. You know you could see they didn't adhere to the rules, I think there are lots of systemic failings which had been happening before and then suddenly were brought to the fore by the pandemic" [Suzanne]

“So I had a phone call to go and take her a new dressing gown and stuff and when I got there they just handed me it, all the soiled washing in a bag, an open bag. No washing instructions. No anything. Didn’t warn me that actually on the 27th it had become – they’d had a Covid outbreak which is the day they moved mum into the ward.... my dad was driving me to the hospital, and he’s 80, and they were just handing it me in open bags. The nurses hadn’t got masks or gloves on. They carried it through the hospital using either the lift or the stairs and the doors, so they were touching everything. And when I actually questioned one of them about leaving it 72 hours, because as I said my cousin is a paramedic, and he – it came through his mum – the nurse told me, “You can if you want but you don’t have to.”

[Emma L]

“So I had to actually go to the ward where he’d, the medical assessment ward where he’d died to pick up the cause of death certificate and his belongings. And they handed me two bags double bagged, they said it’s all contaminated, double bagged like his clothing. And they’d listed what was, what was there. So there was his phone and his bank card and as it happens, he was wearing his rings, so they hadn’t taken them off. And then of course they said to me, “Well it’s contaminated. It’s double bagged. And you shouldn’t open the bags.”

So then it wasn’t until I’d got like, days later I said to my husband, “Why have they even given me this because it’s contaminated.” And it should have really probably been incinerated or something. They shouldn’t have just let me take it” [Becca]

“But what I witnessed, I went in on that Friday evening...They had my mum in a side ward, in a side room, but it was right by the nurses’ station. And I said to my husband, “It’ll never go away while these hospitals are like this.” And I witnessed, there was a porter at the nurses station, there was like, not the carer, you know the care assistants, they’re called something else can’t remember what they’re called now, but it was a girl, and there was a nurse. And I could see through the crack in my mum’s door. He was standing there putting the world to rights about Covid not being real. He’s on a Covid ward. About not getting a vaccine. The two others were saying they weren’t going to get vaccines. These are a nurse and a healthcare assistant. He had his mask up on his head, standing there, I’m seeing my mum fighting for her breath, knowing that she’s dying. She’s caught Covid in hospital. She’d been ferried round everywhere by them porters for different scans because that nurse didn’t listen to us on that day. So how will it ever go away? Because that’s the hospital. You don’t see it because you don’t get in there. It was shocking. Absolutely shocking. And I came back to my husband and I said to him, “It will never ever go away because the people who are meant to be practising it the most are not doing it.” I said, “I go to work, we practise it better than they are.” I said, “I’m a train operator. I’m not the NHS.” [Lynne]

Breaking isolation protocols

Isolation protocols did not seem to be considered by the people in charge in many

instances:

“After telling me my dad had died, at 215 in the morning, he said, “Oh you need to come in in the morning to collect the cause of death certificate. So I was like, “Okay, fine, right I’ll come in in the morning.” So then at some point during the morning I phoned up to the hospital, and I said, “I’m not really supposed to be going out because-” obviously I’d been with him on the Thursday. And by which point, by now he’s obviously been confirmed. They said, “Well we’ll only keep his belongings here for 24 hours.” So I said to my husband, “Well I haven’t got much choice really. I can’t not fetch his wedding rings and his, you know, his things.” So they said, “You need to come onto the ward.” The following day the hospital phoned up and asked me to bring it back....there was an error or something... I just said to them, “I’m not coming back again.” I said to them, “You’ve told me to come in. I’ve come in. I’ve fetched the stuff which was traumatic enough.” Walking into the hospital on my own. Going into- It wasn’t even like they’d taken it to a different ward. They could have just brought it to the front door or something.” [Becca]

“Then I had a phone call from my doctor asking me to go and collect a finger monitor, because my doctors is a different doctors to his he wouldn’t move I did. So they said you can go to [name] hospital and pick it up I said I can’t I’ve got Covid! And they still insisted I could go and get this thing” [Jackie]

Discharging potentially infected patients

“He rang me. And I said, “Oh what’s going on?” And he said, “Oh they’re sending me home. Can you come and get me?”... And I’m walking back and I’m thinking, well he can’t have it because surely they wouldn’t send him home. So I went and got him. Put him in the car. And I was like, “What happened?” Well, they did a chest x-ray and they said they’re 99% sure he’s got it. However, they thought he’d be better off at home because this is a local hospital.... And I wonder if it was 1) he had, that he had cancer and they didn’t want to deal with it. But 2) the test results take 72 hours. Had they tested him they’d have had to keep him in.” [Charlene]

“Basically two days before she died, she’s been sent to hospital. So, I got a phone call on the morning of the 16th to say that my mum had had to go into hospital. She’d been in there for a short period of time and then had been returned to the care home.... Yeah, in accordance

with Covid, even though she looked like she had it, it wasn't hospital policy to test her and therefore, they decided to return her to the care home because they considered that it would be best for her to effectively die there in somewhere that she was familiar with. They had 19 people in that care home out of 28 die that week." [Adrian]

"I said, "Well, if he's got Covid why would you put him in a care home?" because I mean, as we know now and I said, "My dad wouldn't want him or me to spread it," and she said, "Oh, no it's fine. He'll be in his own room and bring his belongings." [Pat]

"Mum ended up being really poorly, with the high temperature and like what looked like a UTI and she was quite, like disorientated and she ended up going into hospital on the Sunday, came home again that day and then went in again on the Tuesday and died on the Thursday." [Becky]

"They said that they'd found a blood clot on her lung so, I said, "You know that's obviously not good". So, anyway they then discharged her which I asked them not to do because she'd been off the oxygen for 24 hours. Took her off the drug, gave her the shitty antibiotics because I understand there's two and they gave her the amoxicillin which I think is probably the lower grade antibiotic from what I've read. Yes, yes so, and then they discharged her... she'd only been out less than 24 hours and she was back in because she couldn't breathe, she'd got sepsis and Covid pneumonia. My dad tested positive on the Thursday." [Annette]

"On the 24th of December in the morning my mum gets a phone call to say my dad is being discharged from hospital. So, we were delighted, we were shocked, amazed, delighted and quickly made arrangements that mum and dad were going to come back to my house because we had like a downstairs bedroom that they could use. So, we get in the house, it's about a 20 minute from the hospital to the house, it's not a long ride. So, we get in and then realise how short of breath dad is moving, even at rest he's very short of breath. And I phoned the ward to say look dad's not well. They went oh well hospital protocol is you either phone 111 or go to A&E. Well, I called an ambulance. The ambulance actually came quite quickly this time, I think we only waited about an hour or so for it. Took dad into hospital and following day we found out that dad was Covid positive. Found out that he hadn't been tested on discharge. We, the four of us, subsequently were infected with Covid. My mum, who was 78 at the time. My husband is 62. So, there was three of us straight away in the priority groups, I don't really count myself in that but my mum and my husband especially, and my 23 year old son was infected as well. [Claire]

3.4.5 Compassion fatigue and/or burnout?

Due to unprecedented pressures and severe emotional distress, the medical literature foretells and demonstrates elements of compassion fatigue and/or burnout among some healthcare staff (Alharbi et al. 2020; Franza et al. 2020). Unfortunately, some individuals told of incidents where they felt some staff had demonstrated less compassion than expected. Becca explains what happened when she went to collect her father's contaminated clothing the morning after he died:

"I went to wash my hands in a hospital sink. And then there was this chap, you know, kind of some cleaning guy that was there that was kind of like, you know, right in my way. And I think I was just sort of like heightenedly aware, and he was obviously totally oblivious to the fact, of what I was there for. But he was teasing me. It was kind of a bit like, oh I don't know, it was just sort rattled me a bit because you just think, you know, you're sort of laughing and joking about me washing my hands when..." [Becca]

Others, too, felt that the attitudes of some staff failed to live up to expectations:

"They're under pressures, I understand all of that but the attitude of some of the doctors was disgusting, there's no compassion." [Annette]

"At the beginning, when she tested positive, one of the nurses said, "Well I mean, she could have caught it anywhere. She could have caught it in the ambulance coming up." And I said, "No, she wasn't in an ambulance, she was in my car, and she hadn't seen anyone, for months." They were very, very defensive" [Margaret]

"The next morning they phoned us and said, "It's palliative care now for her." Now when we finally got in when she was so ill and they let us in, And [name] the ward sister or ward manager, whatever they call that, called my into her office and said to me, "You know your mum's dying." I said, I was upset and said, "I'm so angry with this hospital." I said, "We've shielded my mum since last February. No one's listened, she's been ferried round this hospital." I said, "The only place she'd been the day before was for her vaccine." She went, "Oh we've someone else in here with that." She said, "Where they'd only been for the vaccine." She said, "I've had Covid." I said, "Well I think maybe a lot of us have had Covid." She said, "Well I won't be getting a vaccine." So this is as my mum's dying and this is what she's saying to me." [Lynne]

“And this doctor said, “And if she needs more oxygen, well there’s really nowhere to go.” So you know, that was quite a- And then she said, “Oh but of course if she responds well to the medication and all that sort of stuff, then you know, hopefully-” So I said, “Well hopefully the medication will work.” “Oh yes let’s hope so.” And then after she said, “Have a nice evening.” And I said “Okay, thank you.” So that was the only contact I had. I think there certainly needs to be better- As I said I got the impression at least with that one conversation I had with that doctor on a Saturday evening, that well she’s old, she’s ill, what do you expect, you know. No she didn’t say those words, but that was really, that was really- You know, and to have that conversation in a matter of fact way. And then say to me, “have a nice evening!” There could be some better training there couldn’t there.” [Stuart]

“I think even after that my mum died, it was very much once I went and spoke to the nurses, “Oh, my mum’s now passed away,” and they said, “Oh, right, okay. Can you leave the body now? Can you stand on the corridor on the ward?” And so, then I had to stand on the corridor on the ward while they went to go and get the information that they have to give you, my mum’s belongings, as if life’s going on as normal. There was no offer to go into a room or anything. You’re there stood on a corridor waiting for them to sort everything out. And then it was like, “There you go, thanks very much. You’re not allowed to go back in to see the body now.” And it was talked about the body rather than my mum: There was no compassion then, even then. So, literally then within five or ten minutes of my mum dying, after being stood on the corridor, we’re being ushered out and then we’re like walking out to get back in the car to go home.” [Ann]

Striking was that within some of these recollections came a forgiveness, or at least empathy, with an overstretched system and workforce:

“I get it, they probably didn’t know what they were doing” [Becca]

“And that’s the thing. I mean from my own perspective, sending her back, so I can understand A&E would not have wanted her in A&E because it would have been hell on earth in A&E I would imagine at that stage, but sending her back to the care home as well, it would have been hell on earth trying to deal with three quarters of your clients dying in a week.” [Adrian]

“It was really hard because I felt for everybody. The staff were doing the best they could, they were frightened, they hadn’t been given the right PPE themselves, or the right training.” [Sarah]

3.4.6 Competence and kindness in the face of adversity

While the preceding sections tell of an overstretched system with exhausted staff, many stories also told of staff going the extra mile and providing outstanding care to their loved while demonstrating kindness to the families, too. Pauline and Amy sum it up when they say:

“I know there’s been a lot of bad practice over this, but there’s also been pockets of good practice. Personally I think the staff at the hospital where Mum was, they went above and beyond for me, I believe, for me. I mean, initially, the NHS was overwhelmed and it was just trying to keep going, trying to keep afloat...” [Pauline]

“And those ICU staff, you know, when – even before Covid when you – if that had been a case and he found himself in intensive care, whether he could speak or it would be – your family would be there and tell something about – whereas these were just people that they were caring and they knew nothing about them. So yes, they did try to make it personal, tried to simulate it as much as they could. But oh, gosh, they were run off their feet. They were absolutely run off their feet.” [Amy]

Many examples of good practice emerged:

“So, we got in there about nine o’clock and then we stayed with her right through. The care that she got off the night staff was really, was unbelievable, they were really good. They were caring, what you expect to receive” [Ann]

“The decision was to move him up to ICU, which they did. And, I mean, they literally had no beds and he was squashed between the middle of two beds with, you know, where the hand washing was for the team behind them. I mean, God love them, you know, those – that – the teams were just amazing. Couldn’t wish for anything better of care from them.” [Amy]

“The thing about the [cancer hospital], I cannot complain. The way, he was in a room there was a nurse there the whole time. And I guess she would get a break and someone else would go in. So he wasn’t alone.” [Charlene]

“And they were lovely – the staff were lovely.” [Fran]

“We were ringing once a day. So, one day my brother would ring, and then I would ring, because we didn’t want to mither them, because we knew they were busy. When I rung one day, the doctor said, “I’ve just come out of the ward. I’ve took all my PPE off. But don’t worry, I’ll put it all back on, and I’ll go back in and put the phone next to her ear.” But you couldn’t really speak to her. I’m hoping he was genuine, and I was hoping he did do that.”

[Charlotte]

“I spoke to the consultant and they said that they would like – did we want – we’d not – they realised we hadn’t seen Paul in almost a month. Did we want to go in and see him on – and it was arranged for on the Friday. So the children and I went on the Friday just after lunch, and before we were allowed to go in, the Consultant came and spoke to us, and the Nurse that was looking after Paul that day. So we had, you know, like I say, with having the contact of the Respiratory Consultant he’d asked – he’d given us lots of questions to ask, you know? Which in all fairness to them, they answered the majority of them before we asked them. But my question – my main question was then, you know, you’re not going to give up on him, and there was a resounding reassurance that, no, they weren’t. And they were querying at the time – they asked me a few more questions about him, like, had he a history of any respiratory disease, because they’d done a bronchoscopy on him, and they said that the lungs looked really unhealthy and pale. And I said, “No,” which not – I mean, he’d not smoked for a long long long time, you know? And he had regular checks via work and everything like that all fine. So they – and they were wondering if he had some sort of fungal infection as well. So the Microbiology Team were coming that afternoon, and they were hopeful that the cultures would have shown something. And if they weren’t treating him with the right antibiotics then, they’d change them. And the antibiotics were changed but I never found out if they, you know, I don’t think it was ever confirmed that, you know, they were just trying everything, to be fair.” [Amy]

Even within the narratives from people who had really negative experiences, praise and gratitude shone through for the pockets of kindness and professionalism demonstrated by some staff:

“My dad collapsed nine days later...So he ended up in there as well... to be honest, he was in a very specialised ward, and they were- We told the ambulance drivers. They told A&E. A&E told the ward he went into. So we were given the phone number. They rang us and introduced themselves. In the same building, in complete contrast to what mum had.”

[Emma L]

“The palliative care unit - they were lovely. I couldn’t fault them. Could not fault them. But I have issues with the rest of her care. You don’t even think you’re in The [hospital name]. It

doesn't feel like you're in The [hospital name]. Because we all know the bloody [hospital name], it is what it is isn't it.. But you go in there into the palliative care unit and it's very, very tranquil and it's very different to the rest of the hospital. You don't feel that you're in the hospital. And I couldn't fault the staff in there. They were so lovely with my mum. And they were so lovely with us and my dad. And I have no issues whatsoever with the palliative care unit." [Lynne]

Stories of staff going above and beyond emerged in many narratives, with the ICUs being singled out many times for special praise:

"They [ICU] were really sensitive as well. They gave him a knitted heart to put in his hand and gave us another one." [Becky]

"I honestly, honestly, couldn't thank them [ICU staff] enough for what they did for us. And you know when I'd used to ring in a morning, there was one particular guy, [name of ICU nurse], and I'd say, "Tell him we love him." And he'd say, "Do you want me to give you a kiss for him?" And just keeping the ICU station light, you know? And I said, "[name], if he woke and seen you giving him a kiss he'd have a heart attack. Don't be doing that." So, they were really, really nice." [Amy]

Perhaps Charlotte, who is an NHS worker herself, sums up the situation perfectly:

"It's like any job. I know nurses. I know good nurses. I know shocking nurses. I haven't got a nice thing to say about the care home staff, or the manager at the care home. Where my mum was in hospital, that doctor was really nice, and I'm hoping he was genuine in doing what he said. It's like the same everywhere. I think not all NHS staff are good – some are, and some are not, some are in it for the money, some are in it to be caring for people."
[Charlotte]

And perhaps, if this is the reality, it explains why such contrasts in care standards, attitudes and empathy emerged between and even within narratives:

“But there is a certain type of person, you can see the difference between them people, whether it’s someone just doing it because it’s half decent job and it’s half decent pay, and decent pension. Or someone who really wants to do it and really cares. And you can see that a mile away as soon as you go on a ward. Some wards are fabulous, don’t get me wrong. My mum’s had some fabulous wards. She’s had some shockers as well. One hospital, so why is that? So that to me is by the sister or the ward sister, whatever they call them, the matron. It’s how it’s run. So how can one of you be in [ward name], but you might be in, that’s fabulous, you’ll go down to [name] and it’s horrendous. So how is that?” [Lynne]

3.5 DNR AND CRITICAL CARE DECISIONS

The issuing of Do-Not-Resuscitate (DNR) orders has become an increasingly controversial issue both in the UK and internationally during the pandemic. Whilst our aim here is not to rehearse the debates about the combination of medical, ethical, legal and practical issues surrounding DNRs, it is pertinent to note that the literature on the subject is scarce, particularly in the context of pandemics (Sultan et al. 2021). Some countries adopted blanket DNR policies for certain age groups of patients, partly in response to healthcare capacity issues. In the UK, whilst NHS and other governmental health agencies (Neville 2021) have stated that there was no official policy for blanket DNRs when treating with Covid-19 patients, the lived experience of bereaved families interviewed is really very mixed.

3.5.1 DNRs

Processes

A number of participants explained how the DNR process for their loved ones was unclear, with a lack of explanation provided by healthcare professionals (HCPs) as to the issues at stake as well poor, or no, engagement with the families. Moreover, even when families

expressed their concerns about the signing of a DNR for their loved ones, often such views were not considered or simply even ignored in some cases. Along with the stress, angst and worry for their loved ones and their fight against Covid, families were confronted with having to deal with trying to navigate the DNR process, often being put under considerable pressure from clinicians and HCPs without fully knowing the implications of what they were agreeing to (or not). Some were told simply that DNRs were “hospital policy” and there was nothing that could be done.

“I mean what I, what I have struggled with is the use of the do not resuscitates without consultation, consulting on like family, or letting family know.” [Becca]

“I phoned about an hour after she’d gone into the [hospital] and spoke to them and she’d been admitted into Resus, but when she was in Resus, that’s when they said that they placed a DNR on her and she’d also been reviewed by Critical Care who said she wasn’t a suitable for Critical Care.” [Ann]

“The first person I got hold of, a doctor, they just said to me, “Has your dad got a DNR?” That was his first words. I didn’t even know what a DNR was but I certainly know what one is now.” [Pat]

“That Friday when the doctor first rang me, they talked to me about do not resuscitate order straight away right from the beginning when he didn’t even have Covid. And I kept saying well why is that relevant now? No, no it’s not relevant, I said he doesn’t want a do not resuscitate order he wants full treatment absolutely there’s no, you know why are you asking me that? I couldn’t see a reason. Why are you asking me that? I mean he’s not dying! I couldn’t understand it.” [Suzanne]

In contrast, for some families who had more experience of the DNR process, consent was much more straightforward because they knew of the medical implications.

“And mum also made the decision to sign the DNR form. She was asked, and to be honest, if they hadn’t asked Mum and they’d have asked me or Susan, we would have agreed to it as

well. Yes, because I've seen CPR. It's brutal. It would have made her death more painful and it would have been worse. It's cruel. I know it sounds horrible, but when you're seeing people, 81, 82, 83, they've been brought back. They've got- their ribs are broken, so they're in pain with that." [Pauline]

"I get a phone call from one of the doctors about a DNR. And I said, "Oh, there isn't one in place." But my Mum and I have discussed it and we had discussed it with the GP and I knew that Mum wanted, she didn't want to be left on machines and that. She used to say, "Oh at my time of life, why would I want that."... So, I agreed, so I phoned the doctor back and gave him my consent. And I said to him, I said, "Look, is anything that I should be concerned about here? Because as far as I am aware Mum is coming home soon?" "No, No, it is just procedure." Having worked in the care of the elderly for many, many, many years, I thought, well yes, okay, we do like to have anticipated care plans and this kind of thing. I didn't think too much about it." [Margaret]

Another issue that emerged was the way in which clinicians emphasized the point that a DNR was necessary because there was no other medical option. This was often the case with elderly patients or those who had underlying health conditions. The feeling of being powerless and angry at the ways in which DNRs were implemented, often with no formal consent from the families, is clear from the following quotes:

"The doctor rang. It was a female, I can't remember her name. I don't remember exactly what she said. But I heard her say, "Agreed to do not resuscitate." And I'm like, "What?" And she went onto explain that because of Bill's cancer, if he were- They couldn't do CPR because they would break all his ribs. So what I get from that is they, she said they had a long chat with him. He understood. So I said, "I presume he's signed something." And they had already sedated him and ventilated him. And I'm like, "What?" [Charlene]

"Oh yes, straight away. The minute they made contact with my brother, one the first things they said to him, "We're not going to resuscitate her. She's only going to get oxygen. We're not going to do anything for her, other than oxygen." They said that. They told him that straightaway." [Charlotte]

"[Annette's mum kept getting sent in and brought back out again] they put a DNR on her which I had discussed with the doctor and then when my mum came home I asked her about it and she said she wasn't aware of it." [Annette]

“I go to the hospital. And they tell me they’ve put DNR on him. And I can stay with him for an hour or so to talk to him constantly, or as much as possible, and squeeze his hand, rub his arm, do everything I can to try and let him know that I’m there. And I thought I’d heard people had said that it really helps, they can hear you. Sometimes it helps them really. The consultant said to me, “I have had patients as sick as Steven, who have managed to pull through, but what we won’t be doing is we won’t be turning him anymore. And we have put a DNR on him.” And I couldn’t work that one out.” [Liz]

“They phoned me New Year’s Eve night at seven-thirty and they said we’re going to move your mum and I said oh is she staying in and they said yes because of the pain she’s in [due to cracked ribs after a fall], but we’ve got to tell you we’ve signed a DNR. So I went sorry? I said she’s come in with a fall and you’ve signed a DNR? I said who do I speak to? So they went well you can’t speak to anyone the doctors have gone home, but because of her age and because of her condition we think that’s right. So I said well you know I thought she’d be home tomorrow sort of thing once she’d got the pain under control. So she said well you’ll have to phone back tomorrow and she was really – it threw me I just you know I didn’t know what to say I really didn’t know what to say.” [Lynn]

The DNR process had a significant impact upon the bereaved families because of the ways in which the decision was often taken out of their hands. The feeling of guilt and helplessness in trying to influence the DNR process endures long after the death of their loved one. The testimonies illustrate this point very powerfully:

“The doctor told us that he’d spoken to the consultant and the consultant agreed with what should happen, but it was just like they signed her death warrant the minute she went in. Do you know what I mean? It really was. They never offered her the jab while she was in there, nothing, it was horrible. And yes it’s - I can’t get it out of my mind I think about it every day.” [Lynn]

“They didn’t tell us they had a do not resuscitate. But they’d asked us that in the past and we told them no. Because when we mum got took in last year in June, July. And they the ambulance staff asked us that on the driveway. And I said no there isn’t and we’re not giving you authorisation for one. Where we weren’t even asked this time. We were in the whirlwind of everything. I didn’t even give that a thought. And normally I’m quite switched on and that, now I think why didn’t I ask that? [Lynne]

“They say assisted suicide isn’t allowed in this country but these doctors make these decisions and unfortunately if they’d have just listened to us as a family my mum would still be here. But they just wouldn’t listen.” [Lynn]

These feelings are exacerbated by the fact that face-to-face discussion about the DNR process were prohibited. Often, clinicians reported that the patient themselves had agreed to the DNR. The problem, however, is that close family members could not really feasibly either confirm or dispute this because it was hard to discuss such a matter with a person who was often fighting for their lives. Moreover, discussing the implications of such a sensitive issue were not easily done via telephone or digital communications.

“So I was then, I then sort of frantically rang the hospital to try and find out what was going on.... And the doctor said, “I have spoken to her. And we’ve agreed do not resuscitate.” So I said, “What?” “We’ve agreed do not resuscitate.” “And because she’s a, well she’s a heavy smoker and she’s a diabetic and she’s an asthmatic.” I said well she hasn’t smoked for 15 years to my knowledge. She’s a diabetic, she’s never been an asthmatic in the 40 years that I’ve known her.” So yes she had diabetes but, you know, in other words she was like painting a picture that wasn’t right....[and for days after she was] still saying to me, “Well when can I come home?” And “Can you find out when they’re going to let me out?” And I didn’t know if they’d talked to her. I didn’t know if they’d talked to her, if she’d understood completely what was being said to her. And if she had understood, would she be really frightened and worried? So I didn’t [mention it] because I thought that would make her feel--you know, she’s on her own. I mean bear in mind that I couldn’t go anywhere near her. I never had any contact with her, and nor did any of the family. Obviously we weren’t allowed in. So I can’t even say if that conversation took place. My guess would be that the doctor did speak to her but, and asked her a few questions, but that Pam didn’t really fully- I mean she was a very intelligent lady, but didn’t really fully understand what was being said to her because I think she would have immediately said it to me..... She didn’t think that. You know the day before [she died] she was saying, how is the puppy, can I come home? How’s she getting on? When can I see her? So she, you know, which I’m pleased about now looking back on it. That she wasn’t sitting there thinking, I’m going to die. She was thinking when I can go home?”
[Stuart]

“And also if they had had a conversation to her was it just, well a sort of a tick box: ‘well we’ve told the patient’. Now don’t get me wrong, I do understand that not everybody can be resuscitated. Would I have wanted her resuscitated? What would have been the outcome of

that? Would it have been a bad outcome? You know, so I don't know. I'm not medically trained enough to know, you know, all right she's 72, it wasn't old. But it's not young. She had some health issues so maybe, you know, maybe that was the right thing not to resuscitate. Maybe by resuscitating if they'd have got her back would she have been a bad state? You know, all- you don't know do you? So the difficult issue, but I just don't think it was handled very well. You know I have listened to a doctor on radio four talking about do not resuscitate. And it made an awful lot more sense to say that, yes okay if you're a young 20 year old rugby player of course we're going to resuscitate. But relatives expect all their loved ones to always be resuscitated. And it's not always the right thing to do is it. I mean yes, okay it was her decision not mine I suppose. But I'd spoken to her and she hadn't, well she hadn't said to me, "Well I've just spoken to a doctor." So you know I know the doctor hadn't got through. So yes, you know, I think they ticked a couple of boxes. And had a hurried conversation about it, told me, oh we've done that now, let's move on. And it didn't leave of us any of the wiser really I don't think." [Stuart]

Changing DNR/care plans when COVID is diagnosed

Another issue that emerged is the way in which DNRs were implemented following a COVID diagnosis, seemingly immediately. Once again, the testimonies illustrate how families were powerless to be able to influence such decisions. In some cases, this was even when the condition of the patients had improved slightly:

"Dad had a conversation. The doctors had said, if it had dropped to whatever point, or he was struggling, they would take him to intensive care. And they'd explained to him that you know, he had an option about that...and he'd said yes he wanted to, you know, he wanted it all. He'd wanted to be given every chance basically. And he'd signed that piece of paper and so that they had that there, that was quite early on in going into A&E. Now, from what I can gather he seemed to have rallied somewhat because he then came out of A&E and went into clinical, well medical assessment....And then when the Covid result came back, somewhere between you know, eight, half eight, something like this, he was by this point on the medical assessment ward. And the doctor there just crossed through the paperwork and attached a new one to say, not for resuscitation." [Becca]

Often, such decisions to implement a DNR were taken very quickly, in the space of a few hours, following a positive Covid diagnosis. Once again, there was little, or often no,

discussion with the families, with the paperwork being signed almost as a matter of course, in some hospitals:

“I get it to a certain extent. Obviously if they don’t feel like they can achieve anything with a patient, they have got to make difficult decisions haven’t they, so maybe they have to say, well actually ventilating this patient isn’t going to work. But what I don’t understand is how does that change in the space of four or five hours? Because if it was okay to ventilate him five hours ago, the only difference is he’s now got, you know, a confirmed Covid case. But actually if it could have been helpful five hours ago, why wasn’t it now?” [Becca]

*“It was only when he was readmitted on the early hours of Christmas morning on the 25th, after he’d been home for those 12 hours, that he tested positive. Dad’s notes show that a do not resuscitate was put on him as soon as he’d gone into A&E on the 25th of December. Bearing in mind there was no do not resuscitates put on him on all his other admissions.”
[Claire]*

DNRs without agreement of patient or family

The ways in which DNRs were put in place without any prior consent or permission given by the families caused a great deal of anger, hurt and confusion. This upset continues to have a profound impact:

*“It was discussed with him originally. And then it was changed seemingly without him being aware of it. So how do they get to make those decisions without even telling somebody?”
[Becca]*

“Within 2 hours of him being in A&E I received a phone call from a doctor who said, “if Ken deteriorated they would not put him on a ventilator due to his age” I begged the Doctor to give him a chance, and explained about his Parkinson’s and his fears and how scared he would be he said “he has made his decision” [Anne]

“Yes, and I just feel that by doing an assessment on them patients they were going in alone, confused, probably hypoxic, not feeling well, that you’re not going to get a true medical history and it should definitely be contacting family even if it’s through a phone call to confirm the understanding of that medical history.” [Ann]

As alluded to earlier, the testimonies here also demonstrate confusion:

“I was really quite shocked and I was asking, “Why have you put a DNR on her? I don’t understand why?”, and they just said, “Critical Care make that decision so we can’t discuss that with you because Critical Care aren’t down here anymore.” And I think being a nurse as well though I was really struggling to understand because I knew the assessment criteria that you use and I was like saying, “My mum, on the assessment criteria my mum would be a 3 and you should be giving one up to a 4, like 4 and under should be getting a Critical Care place. So, I don’t understand.” But they were totally, “It’s not our decision, Critical Care made it, we can’t explain that to you.” [Ann]

“I got another phone call from a different doctor who said “it is nothing to do with Ken’s age it was that a ventilator would not help Ken, he would be uncomfortable and he would probably not get off it ” I still said “He should be given the chance and I wanted him put on it. This was to no avail.” [Anne]

Another testimony emphasized the contradiction with patients, on the one hand, having difficulty in fighting the disease, being drowsy or confused, whilst, on the other hand, questioning how the same patients are fully able to understand the implications of signing a DNR form:

“The DNR says he’s got capacity to consent... and the nursing notes around the same time document saying that my dad is confused and anxious, trying to climb out of bed, saying he wanted to go home. But apparently he had capacity to consent? At no time we were told about the DNR and actually I wouldn’t want anybody jumping on my dad’s chest trying to resuscitate him, but it’s absolutely not the point.” [Claire]

Anger and hurt is further exacerbated by the fact that, in a number of cases, medical records do not accurately record the dissent and disagreement made by the families at the time in which the DNR decision was made:

“There was a preliminary enquiry by the Coroner (Which I can send you if you want a copy) that states there was a DNR was put on Ken at the A&E stage and says I understood and in a way agreed which I didn’t.” [Anne]

Others point to the fact that families were told that it was futile to not consent to a DNR being implemented because such a decision would be made in any case by clinicians:

“They told me what it was and they said even if they didn’t have my dad’s permission or my permission, they could overrule it because if someone was frail they could overrule it anyway.” [Pat]

“The ITU consultant rang me... He said that they weren’t going to move him to the intensive care unit, they weren’t going to intubate him and they thought he should have a do not resuscitate order on him. No they were not moving him to ITU, they told me quite clearly they were not going to put him into the critical care unit either and I kept saying but why not? Why not? You know there is no reason why you shouldn’t try at least to leave him in put him into critical, I don’t agree for the do not resuscitate order because Brendan wanted everything available, I said I do not agree.... And then he said to me and I kept you know fighting, fighting about this do not resuscitate and he said, “well there has to be an end to it sometime, there has to be an end to it sometime and we have to make the decision we’ll decide not to resuscitate.” [Suzanne]

“They told him [my brother]. They didn’t ask him, they told him. He was dead upset, because he said to me, “They didn’t even ask, I didn’t even have an option.” I said, “You won’t, that’s the way it is. They won’t. She’s 78, they’re not going to do anything for her.” [Charlotte]

Some don’t even know if a DNR was ever placed on their loved ones:

“Things like the do not resuscitate. I don’t know if there was one on him. He never discussed it with me. I don’t even know if he knew if there was one on him. He wouldn’t have wanted one.” [Shelley]

Others explain the clear inability to influence DNR decisions, with choice being removed and decisions made without the consent of either the family or the patient:

“I said to the consultant, “Yes, while you're on the phone about the DNR”, I said, “I asked my mum about that and she wasn't aware that she had signed anything or discussed it with you” and then he just went off the phone. So, then she got moved up into the respiratory ward and I spoke to another doctor and I said again about her not being ventilated. And they said, I said, “That decision has been made without proper consideration, you've just looked at her age basically” as far as I was concerned and I questioned the frailty. So, then they said well, they'd get the intensive care team to go, which they did. So, then I spoke to the doctor and I said, “Well, how have you put it to my mum” and they said, “Basically they'd just put it to her that she wouldn't survive anyway so what's the point of going on it”? I said, “So, basically you're playing God then”?” [Annette]

“And then no one phoned me the next day, so I phoned, and they said that they'd turned him. And I said, “Well, that's strange, because you told me you weren't going to do that anymore. Have you lifted the DNR?” And they said, “No, no, we haven't lifted that.” But they never asked permission, they just did it. Why would they put a DNR on him without actually asking if they could do that? That's what I don't understand. They told me from the very beginning, or they told Steve, that he was really strong and that he would be able to fight it.” [Liz]

3.5.2 Critical care decisions

Closely related to the issue of DNRs, testimonies also focused on the way in which critical care decisions were also made for Covid patients on a seemingly ad hoc way in order to limit and who got a critical care bed (or not).

In some instances critical care decisions were made quickly and in line with what family members and respective patients wanted:

“The doctor phoned me, and she said, “I've spoken to Steve, and he's very calm. His oxygen levels plummeted overnight, and he understands that his best chance is if he goes onto a ventilator. He's very calm, and he understands everything I told him. This will be his best chance.” [Liz]

“Val got to hospital and she phoned Mick [her partner] about 9am, because he had texted her. And she said, “Don’t you worry about me. I’m fine. Everything will be all right; I’m feeling a lot better now.” And he said then he never heard anything. And then later on that day, the early evening, he got a phone call from the hospital, and they put her straight on a ventilator, because she wouldn’t have the CPAP mask. So, she refused to have the full mask. And her oxygen levels were so bad that they actually had to sedate her and put her straight on a ventilator. So, Valerie was on a ventilator from the 3rd, all the way through to the 18th.” [Liz]

“I actually got a phone call to say that they’d both been taken in. My sister Susan was on a ward, and they’d taken mum to critical care. She went straight into critical care.” [Pauline]

“Mum was given the option of having the CPAP mask or to be ventilated. And mum opted for the CPAP mask, because it’s less invasive, and you can actually still speak while you’re on the CPAP. If you’re ventilated, you’re put unconscious.” [Pauline]

In other cases, the decision not to move into critical care was made by clinicians, and families accepted that:

“I managed to eventually get hold of people. And they told me that there would be a ceiling of care for him. He was not a candidate for ventilation. They didn’t have any treatment. All they could do was support him while his body tried to deal with the infection. And I understood that.” [Fran]

“I’d got a phone call from a doctor.... So, he said they didn’t think she was responding to the CPAP, “She’s not doing so well,” and they didn’t think she was going to get better on the CPAP. So, I said, “Well, what are you going to do then? Are you going to intubate her?” And he said, “No, we’re not. We don’t think that she will come out of this.” So, I said to him, “Are you telling me that she is going to die?” And he said, “Yes. We think you should come in and we want the family to come in.” [Becky]

“He just went down and down and down and each time they escalated, they did try every-, well, everything apart from - is it ECMO? He wasn’t eligible for that.” [Becky]

However, the issue of age and vulnerability emerged in the testimonies, with some family members expressing the feeling that their loved ones were treated differently because they were older and seemingly less likely to recover from COVID-19. The formal NHS policy is to treat all patients equally and this was communicated to family members:

"I contacted [name of city] CCG who informed me that all patients will be treated the same regardless of their age and that there were enough ventilators in the [name of hospital] Hospital." [Anne]

Some families, however, felt the reality was different:

"I spoke to the consultant on the Wednesday night and they said, "She's very poorly, we're not going to ventilate her because she's frail". And I said, "Well, can you explain frail to me, I know she's 83" and he said, "Well, she uses a stick". And I said, "Well, so if I come in, I'm 50 and use a stick are you going to class me as frail"? And she said, "Well, she's got high blood pressure" I said, "Well, that been monitored for all these years, that's not going to kill her". And then he said, "Well, we've got this blood clot on the lung" I said, "Yes, but they've said it's small again, they've assured us it would not kill her, she would get over this". So, they then, he just went, "Well, we're not ventilating her." [Annette]

"Yes, and I find it really, really difficult now because I sit in work and NHS England are patting themselves on the back saying, "Oh, we done audits and anyone who should have gone to Critical Care actually got a Critical Care bed," but what they're looking at is whoever done that assessment. So, it was like that lady or gentleman that done that assessment, so they scored my mum as a 6 even though she shouldn't have been a 6, she should have been a 3, she should have got the Critical Care bed. And so, then you're looking at it saying, "Oh, so the audit shows that she didn't deserve a Critical Care bed but no one's looking at that actual assessment." [Ann]

"If you were cold, and you were looking at it from another position and you weren't emotionally involved, and it was all about figures, you would look at it and go, you know what, it's going to cost this much money to save, what's the point? We do it in medicine. We look at old people on medicines, and we stop a lot of the medicines, because we go, right, that drug will stop them having a stroke in the next 10 years. They're 80, they're probably not going to last another 10 years. Let's stop that medicine. It's more expensive to keep that medicine on. What's the point? We do it all the time. So, I know that's how it works." [Charlotte]

“But at least if they don’t even have any frailty and don’t do proper frailty score and just decide on the spur of the moment. It’s not right. That can’t be- I mean there’s no rational decision behind it then. How can that happen?” [Suzanne]

“You know the sort of nagging fear that they’d given up on her. Was she getting the right treatment? I don’t know. I’ll never know.” [Stuart]

“She was thrown away. They’d decided that she wasn’t fit enough or healthy enough.” [Lynne]

3.6 POWERLESSNESS AND FINDING AGENCY

3.6.1 Feeling powerless

The helplessness and powerlessness experienced due to DNR decisions were also felt in many other aspects of care. Inability to be with loved ones, particularly at end of life, was a major cause of feeling totally helpless:

“I got this phone call saying we’ve told your husband, he’s going to die. And I went into shock I just like – and I’ve got – we have private healthcare so I kept thinking what can I do? What can I do? I felt so helpless” [Jackie]

“I mean I more or less, I started my grieving when my dad was alive. I have read that that is a thing because I thought, I’m never going to see him and that’s what my sister said as well. We’re not going to see him. He’s so poorly, you know, and he’s 80. He’s got a DNR on him and he’s just not going to make it” [Pat]

“Lack of control is, it is so disabling, it is so disempowering” [Margaret]

“I think at that time I was not that strong enough. I was, I think I wasted the whole month crying, that was it. I was just like- And now I feel I wish I had, you know, done something more. And you know, but we were so helpless as well because there was no way I could go there.” [Sonal]

Power imbalance

Despite the health paradigm of 'person centred care' where patients and their families are encouraged to actively participate in care decisions (NHS n.d.), a perceived power imbalance emerged between the all-powerful system and the completely helpless patient and their family.

"Just listen to what we are telling you because you won't understand, you are not from the medical profession, they told my sister. Like we had a right to know what his oxygen was, or what medication he was on. But the phone calls well they are, I don't know they were so busy, or what it was at that time in January, we don't know. But these are the kind of the answers we got. Please do not question us. And then my sister started getting very scared of asking any question to the doctors. Like, you know, we were all so afraid because like we felt all his life is now dependent on the doctors. So, we don't want the doctors to be frustrated with us. So we really trust them. We really, really trust the doctors because they were like God you know for us. And we were so helpless because if they let me even go once, because the rules were like no one was allowed to go." [Sonal]

Being afraid to question the clinical staff is apparent in Emma's narrative, too:

"I rang the hospital and went, "It's C. diff, isn't it?" I demanded to speak to a doctor and they went, "Yes. How do you know?" I went, "Well, I'm not stupid." And then, I actually said to them about, "No one's helped her. No one's helped her wash." Later that day my other – one of my sister's managed to speak to mum, and mum went, "Please tell Em not to complain again. I'm the one stuck in here." A nurse had gone in and gone, "Apparently you're not happy with how you're being cared for?" And I just, you know-? Yes, and my mum was, you know, your typical 80 year old gran, you know, lovely, quiet. I'm the mouthy one of the family, not her and she was scared. She was scared. And then, she just went downhill from then." [Emma L]

Extra vulnerable

Some felt the power imbalance was particularly acute because their loved ones had specific vulnerabilities:

“Which I think you know is another area of concern for me really because I think when there was a focus on may be one area of somebody’s health such as mental health or such as – as it emerged I think much later you know that a lot of people’s voices really were not always listened to and particularly people you know with additional needs or may be who found it more difficult to advocate for themselves or people with disabilities or you know people with mental health issues.” [Diane]

You know what, it was an absolute catastrophe the way they treated him; they didn’t care for people because they were a certain age. The whole thing about the fact that they didn’t put him into care, that they left him off the oxygen afterwards for no reason, that they didn’t try to administer the CPAP properly....they didn’t even try to give him a fighting chance because of his age. It’s systemic, it’s the treatment of the elderly where they do not get the proper care. [Suzanne]

Frustration with systems

Systematic changes which made little sense to families was another underlying cause of feeling helpless. The following quote illustrates this very poignantly, as Margaret explains the way her mother, who was almost blind, was left almost deaf, too, because her hearing aid tubes needed to be replaced:

“Maybe about two months ago now, and we got invited to actually come to the hospital.... I was telling them about my mum been frightened and they were visibly moved...and they said, “Oh, well, why did we close audiology?” I said, “Well you tell me?” And they said, “Well, we were told to re-deploy non-essential staff.” And I said, “Who made the decision that audiology was non-essential? Because there are some people that it’s absolutely essential for.” So, and you know I got very emotional, I said, “I felt like I had failed my Mum.” And the clinical director turned and said to me, “No, we failed her.” [Margaret]

Adrian, too, puzzles over some of the decisions that were made:

“Trying to segregate the healthy ones from the ones that had Covid would have been impossible. Why someone couldn’t have decided to use the [name], which was seven miles away and which was set up as a Nightingale hospital and they’ve just sent my mum there for, you know, palliative care and used that hospital, you know, used the resource that would probably have been available and taking the pressure off both the hospital and the care home? You know. I’m no healthcare expert but it occurred to me within about five minutes thinking of it.” [Adrian]

3.6.2 Finding agency

Even in the stories where people found courage and strength to question systems and rules, or at least attempt to participate in decision making, participants used phrases such as ‘pushing’ and ‘being stroppy’ or ‘kicking off’ to explain the ways in which they sought to reclaim some agency:

“I kicked off a little bit about half past ten, eleven o’clock on Wednesday morning, to say that, look, why can’t Susan [Pauline’s sister who was in the same hospital] come? She’s already got Covid so she’s not going to catch it. Mum is dying, you didn’t expect her to last this long. I think she’s hanging on to see Susan. To know that Susan’s there, if that makes sense? And they’d had to go through all the management channels because they had to shut off corridors to bring Susan down. Susan came down with two tanks of oxygen. She was told she’d get five minutes only. Susan got there at 25 past two, said to her, “It’s all right Mum, I’m here now. I’ll be all right, don’t worry about me, I’ll be fine,” and Mum died at half past.” [Pauline]

“I mean, it was bad enough for me and I know, I understand the pressures on people in care homes, I understand the pressures on the staff. But, yes, I felt I was pushing all the time and I thought I am just going to be stroppy and ring and say what I need to say because it’s my mum and I would do anything for her. The whole thing was awful. The GP seemed to be looking on it as a kind of oddity because he said to me, “Oh, your mum’s my first patient with Covid.” And then I talked to him about oxygen because her breathing wasn’t great and her Sats weren’t very good and I said, “I know she probably won’t survive this, but I want her to be as comfortable as possible. Is there any way that we can just give her some oxygen, not necessarily via nasal specs or anything but just around her, just to give her a bit more oxygen?” “Oh, no, no because we can’t, we don’t have oxygen in care homes.” I said, “Well,

obviously you do, you can. There's no reason why you can't, you just need to prescribe it." And he said, "Oh, there's no evidence." And I said, "There is evidence, there's new evidence come out about the therapeutic use of oxygen. I'm not expecting it to be a miracle, but I just want her to be comfortable." So, anyway, he was kind of, you know, feeling his way and, to be fair to him, he then went off to their palliative care consultant and got some advice from her and she was really helpful. But the care home were just awful, absolutely awful."

[Sarah]

"When I sort of got myself together a bit [after the call to say Pam had died] I phoned them back. And I didn't get her, I got a different girl. And I said, "I want to see her for my own mental health really." "Well it will be very difficult, you'll have to put on PPE." And I said, "Well I don't care what I have to put on. I want to come and see her." And she went away and the phone was sort of dead for about five minutes. And you know, it was a little bit, "Well all right then." But you know. So I said, "Well I'm coming now." So I just marched, drove to the hospital, went up to the ward, got toggged up in PPE which was fair enough, I understood all of that. And then had 10 minutes with her. And I'm really glad I did. But that wasn't offered to me. And bear in mind, you know, we've been together 46 years. I hadn't been able to see her for three weeks plus because of her being in hospital with Covid. And we'd never been parted, you know, she lent on me and I was looking after her really. So I certainly needed to see her. And I did do that." [Stuart]

"They said you need to come in. I said we can't we're all positive. I said mum and dad need to say goodbye to one another via video, so I had to try and arrange quickly for them to say goodbye via video call, but was told got to wait because the nursing staff are doing a handover. Well, I thought death is not going to wait for a handover. So, I'm not usually this type of person but I kept ringing the iPad in the hospital until somebody answered it. I just wouldn't give up." [Claire]

"I said to them, "Look, I am sorry but I am in now and you're not stopping me hugging her." And I wiped her brow and her forehead" [Margaret]

Not all attempts to reclaim agency were successful, however:

"In the morning we talked on the telephone and he said, "There is something hard there I can't really breathe properly." So I rang up the doctor after this, I immediately created a fuss and I said, "Look that's not good enough he has problems breathing and I want to talk about treatment escalation plan." And again I think it was a junior doctor, I don't know whether they couldn't be bothered I don't know. He said "Yes, yes we'll do that tomorrow there's enough time for the weekend," when I wasn't happy but what could I do? ...I wasn't happy of

course I wasn't happy but I couldn't force them to do the treatment escalation plan could I, I didn't know what to do. It was absolutely awful." [Suzanne]

Noteworthy is that it was often those who had some medical knowledge who were able to have some input into their loved ones care, as Sarah (a retired Care Home Quality Manager) and Ann (a senior nurse) and explain:

"When my brother left the home, he rang me and he said, "Mum is very sleepy but she looks very tense and her breathing is very fast." So, I rang the home and said, "Has she had any morphine?" And they said, "No, she doesn't seem to be in any pain." And I said, "But I think she might be in distress because her breathing is very rapid and my brother says her neck is very tense." "Oh, do you want her to have some morphine, then?" So, I said, "Yes, please because she's dying and I don't want her to die in discomfort." So, they gave her some morphine." [Sarah]

"And I had to like actually say, "Oh, can you contact-," I asked her to contact the senior, like the Covid lead for the [area] to say, "Can you contact them because I'm telling you that I know that they will tell you that I am okay to stay," and so after that point, but I feel had I not been a nurse or had I not know, you would have just bowed to the ward manager because you feel that they know best." [Ann]

Lynne's insight therefore asks a very important question:

"I always think, what if people haven't got families? Many people haven't got families. What the hell happened to them?" [Lynne]

3.7 COVID-19 DEATHS ARE DIFFERENT

Participants were keen to explain the myriad ways in which COVID-19 deaths differ from other deaths, and how death in a pandemic brings particular issues that are absent during 'normal times'. Overwhelmingly, families agreed with Sonal's brief but powerful statement:

"A Covid death is not a normal death." [Sonal]

In this section, we look at the various reasons why.

3.7.1 False hopes & rapid deterioration

One issue that emerged is the suddenness of deterioration for so many patients, meaning that relatives were unprepared to receive devastating news.

"I think this is such a unique set of circumstances, and without dismissing other people's trauma and grief, and somebody that they love dies suddenly – which is what has happened to all of us, somebody that we have loved has died suddenly, and before their time, and from something that we weren't expecting – I do believe that there is a difference to being bereaved by Covid." [Fran]

"At eight o'clock I give them a ring, "She's comfortable." And then at 8.30 on the Saturday night, the ward staff phoned me to say, "Your mum's really deteriorated. We think that she hasn't got long so you need to come in." [Ann]

"And they said it's almost like a sudden death because you know, sometimes people go off out in their cars and they don't come home, you know, there was an accident or something, people drop down. And okay whilst he was in hospital it wasn't, you know, it's almost at that point of like that it's totally unexpected. But yes he was, you know, he was poorly, but it wasn't- We hadn't got that 'prepare yourself'. I don't know, sometimes I think it was better that way because we didn't have days and days to dwell on it and we couldn't visit. And other people who have had it where they couldn't, you know, they had days of waiting. You couldn't visit. So at least in that sense, you know, it was quick, and he didn't have days and days stuck in there, and us days and days sat worrying. But then on the flipside it was like, nobody at any point said this could be critical. Or he might not come home. There was no warning, no warning at all." [Becca]

"If he had had cancer then... you can say goodbye, you can talk about arrangements; we could've talked about my future on my own. All that was denied us, you know we didn't talk about those things. What makes it so worse is the suddenness" [Suzanne]

"And then on the 12th, it was a Saturday, and he phoned me up and we spoke on the phone for 35 minutes. And he said, "I'm feeling so much better, Liz. I think I'm coming home. I'll be home Monday," he said, "Monday or Tuesday at the latest. And then the Sunday morning, the 13th, I got a text from him, and he said, "Liz, really bad night, taking me to ICU in hospital. Stay strong." [Liz]

"Ken was doing well and they had put him on medication to keep him calm, the doctor said she was pleased with how he was. The same day I was told he had deteriorated.... Then they told us to come down as he didn't have much time, by the time I got there and actually got into the ward Ken had passed away, before I had a chance to say goodbye. I will always believe he would have thought I abandoned him and I know he would have been so frightened on his own." [Anne]

"I found him as if he was asleep in his bed." [Diane]

Others felt that they had been given false hope, or had communicated false hope to their families:

"At 1145 I was told by the hospital at "Oh he's quite stable". And then I had a phone call at quarter past two in the morning from the hospital to say he'd died." [Becca]

"So, following that, all day we were told, "No, no, she's comfortable, she's comfortable." And obviously, the kids were worried and I think I feel really guilty for giving the kids a real sense of like false security as well because I was getting told she was comfortable and the kids were worried and I was actually looking and going, "Oh, there's only 45,000 people in the whole world who've actually died of this," and I was using, I went, "that's less than how many people fit in [a football stadium]," I said, "and if you think of that, why do you think your nan's going to be one of them people of the whole world and-" because you're trying to give that reassurance. The kids actually remember that, you know, they say, "You said-." You just don't know at the time, do you know, you are really, and because we were told that she was comfortable and had improved that we were thinking, "Oh, yes, a bit of antibiotics and oxygen, she is improving." [Ann]

“The ambulance driver was actually my cousin, which is a bit of an issue now, and he promised her she’d be safe, and I wasn’t here and she rang me and said, “It’s [cousin’s name], it’s fine, it’s [cousin’s name], he’s promised me I’m going to be safe.” [Emma L]

3.7.2 Access to loved ones denied

We have already heard of the extra suffering that families had to endure due to visiting restrictions. This suffering intensified as their relatives reached end of life:

“So, that was on the like Saturday morning, like early hours of Saturday morning, and so they did say, “We’re going to monitor her overnight,” and even at that point I said, “Can I come in and see her then if you’ve got a DNR on her?” and they said, “No, you can’t come in,” even though like there’s a DNR.” [Ann]

“No. Nobody was allowed. The hospital policy at the time was a no.” [Shelley]

“Every hospital’s different, because in [name of another hospital], they were doing FaceTime, and they were letting the family in - every hospital’s different, but that was [name of hospital]’s policy. But bearing in mind, this was right at the beginning, and I think the hospitals got a bit more lenient towards the end of the lockdown, didn’t they. So, we were right at the beginning.” [Charlotte].

“But for me, it was knowing about what Covid was doing to his body was awful, and him being apart, being separated, which I suppose is the same for everybody if they’re in hospital – being kept separate from their families.” [Fran]

“A Covid death is not like a normal death. I was helpless. That is the worst bit.” [Sonal]

“My brother, it was an accident, a car accident. So he died instantly. It was horrendous. And I’ve had other people just die. And it is awful. But knowing that they’re dying and you can’t be there, its traumatic. Why weren’t we allowed in? When you go on their website, if they’ve got any of them conditions [cognitive impairments] a family member is allowed to go in if the patient is distressed without someone. Yes. So for three and half weeks my mum was fighting for her life on her own. Like many people were. But she was so confused as well.” [Lynne]

“We never did that [visited her at end of life] because only one of us – only one of us could go....- Mum would have rather we were all together, than one of us not, and when they rang us at seven and told us we can go then, she wasn’t responsive.” [Emma L]

“I don’t think people appreciate the trauma people have had. And it won’t be just Covid patients, it’ll be anyone who’s been seriously ill and died in hospital. But they don’t realise the trauma that causes people. Not being there, knowing your family member’s fighting for their life, it’s not like they’ve dropped dead because you can’t do anything then. But you know they’re fighting every inch, and you can’t will them on. People don’t know the trauma that causes you. [Lynne]

“I think what made Mum’s death so hard was the fact that we couldn’t be with her, that I couldn’t say goodbye to her in person. But when it came to the end, she died on her own, there was nobody in the room with her” [Sarah]

Even those who had people with them when they died, had to endure strangers in strange clothes:

“And these people he didn’t know the carers because most of the carers were off with it. So he didn’t know them. And they’re like in space suits. So I mean he didn’t have anybody he knew, and they looked strange, you know, all in this, it’s like space suits, you know, I couldn’t even see them” [Sian]

Even when families had travelled to be with their loved ones, they were denied this access, at least until the very end. Charlene, for example, had had to book herself into a hotel because Bill was taken into a specialist cancer hospital which was quite a distance from their home. Yet she was still unable to see him:

“And so I then stayed two nights in [a London hotel]. I wasn’t allowed in the hospital. So sometimes I would stand outside looking up and thinking is it one of these windows?” [Charlene]

Reunited in the final hours

Some respondents explained they felt 'lucky' that they were able to either say goodbye in person, and some were able to be with their relatives when they died:

"I'm so grateful, you know, I know that lots of people that lost loved ones in the first wave, didn't get to see their loved ones. I just can't, I can't imagine. Yes. So, thankfully we were able to spend the day, the afternoon with her and she was alert and orientated so, you know, we had lots of good chats and nothing was left unsaid, you know." [Becky]

"So I saw him. I was able to sit with him. I was allowed to hold his hand because I was gloved, masked, screen. I don't think they'd have let me kiss him anyway. But I kept saying to him, "I've got," I said, "This is me kissing you." Because I had the screen on. And I sort of talked to him and in the end I said to him, "It's fine, you can go and see your mum and your sister." And I told him that they weren't going to let me back into the hospital. And I left there, but it's almost like I'm floating in the ceiling and watching this going on below." [Charlene]

"And then I got a phone call about six o'clock that night to say, we've had to up it to 100%. We don't think- there's nothing- we don't think she's going to last much longer, would you like to come in? I went in. I went with a picture of my certificate to say which mask was okay for me to wear. And I actually was gowned up, you know, with the visor, the head dress, the gloves, the shoes the- everything that I needed to wear, I wore. I took a little bag in with me, a cloth bag, because I knew once I took it in, I wouldn't be able to take it out. I went to sit with her about half past seven Tuesday night, and Mum died on Wednesday afternoon at half past two. She gave me a list of instructions for what she wanted for her funeral. What song she wanted. I'm not to bury her in a shroud. So my mum was actually buried in a hospital gown because once she'd passed away, I asked them not to put her in a shroud, which is normal practice on the hospital." [Pauline]

"The Wednesday of the following week – so we're now on day eight or nine – I had a phone call to say come to the hospital now – come now. And I just dropped everything and went. And when I got there, he actually had recovered. They thought that he was at end of life at that point, but he seemed okay. I had the full PPE on, and I was allowed to go in and see him, and he was so happy to see me. And he rallied for two days, and then they called me back on the Friday. By that time, he was in a room by himself, and I just stayed there. And then I stayed with him from the Friday lunchtime through until the early hours of Sunday morning, when he died. I was just grateful to be with him...We'd talked about death, and we'd talked about him dying. And I promised him I would never leave him; I would be with

him. So, for those days when we were separated, I was devastated because I promised him I would be with him, and he's by himself. He was so scared." [Fran]

"And then on the 19th, they phoned me and said could I be there within an hour. And I went, and they said there was no hope, because he was on 100% oxygen, and no one could sustain that. He looked like he was just asleep. And they let me stay with him whilst they turned everything off. And I begged him to stay with me. And I hugged him. I couldn't kiss him because I had a mask on.... And then when he died at 11.22am, my world just came to an end." [Liz]

"They told me he wanted to carry on with the facemask for now but they would call me in when necessary... when they rang me to go in. They said we could all go in individually to see him. I went in – we all got gowned up and everything, we were just squeezing his hand he still had loads of strength in his hand but he was on 100% oxygen. And I still didn't believe he was going to go – sorry. I just didn't think – I still said well you better come out and eat my birthday cake. My son went in the eldest one and he was a bit more I don't know sensible. And he seemed to ask more of the right questions." [Jackie]

"Can my dad come in with us?" Initially, they said no because he had Covid symptoms but he was actually on day 8 by that time and so it was saying, "Well, he's actually day 8 now so he's clear and so they then said, "Yes, he can come in with you." So, luckily enough that both myself and my dad were able to go into the hospital." [Ann]

Though at times even this was a battle:

"They tried sending me home even though both myself and my dad had been there round about lunchtime that the ward manager came up to me and said, "Oh, our policy is that there's only one visitor so you need to go home because you're at risk of spreading infection." But I did say, "Well, actually, I've been here all night. Whether I stay here, I'm going to take home the same risk whether I go home now or whether I go home after my mum's passed away because I can see what's going to happen." And she was like, "No, no, no." She offered that we could do rotation, that I could go home and then I could come back and my dad could stay – that would be more of a risk" [Ann]

For some, the battle came not with clinical staff but having to make agonizing decisions about the risks involved in saying goodbye in person, as Judith, who is the mother of three severely disabled children, explains:

“And then it got worse because obviously January when she died was when we were right at the peak of the second wave and I couldn’t see her at all. And during that time they said to me they thought she was going down with a chest infection, fair enough so they put her on antibiotics etcetera and they were doing testing. But then she – I was ringing in because I wasn’t allowed to go because at this point there was Covid in the home and so I wasn’t allowed to even talk to her through the window. And eventually they said something – I said well has her test come back oh yes yes she’s positive, which was you know – and then I got the call that she was deteriorating and she wasn’t going to make it. But I was in a difficult situation because we were being very very cautious with [name of Judith’s severely disabled daughter] and the other two [disabled children]” [Judith]

The final goodbye: via video and phone

Others were not so ‘lucky’ and had to experience saying goodbye by phone or video call:

“So, mum and dad got to say goodbye through the iPad.” [Claire]

“And I was waiting for the call, and I knew with this call I had to be strong for him and hold his hand, you know as much as I could, over the video call.” [Sian]

“They said she’s going to go today, and none of us could go in. They said they put the phone to her ear. So, I was talking to her when she went.” [Charlotte]

“I just stayed on the iPad...And then on the Thursday night we stayed up all night with her. Because she’d asked for morphine, they gave her some morphine and then about 02:00 in the morning she got a bit agitated, she got very hot and she was throwing everything off of her. So, they gave her some more and then she didn’t wake up.” [Annette]

“As soon I started speaking he couldn’t speak and he was wailing, wailing at me. And that was horrific. That was horrific. He was just, he couldn’t speak, but he was shouting, not shouting, but sort of wailing, trying to speak to- And you could tell he was in distress. So I said to him at the time, I said, “Dad,” because is used to take him out a lot. And I used to take him to gardens and things, you know, from the home. I said, because he loved roses. So I said, “Dad,” I said, “Just think of us when we went to [name] Gardens.” And I said, “And we

sat on the bench.” I said, “I can’t be there physically but shut both your eyes and imagine we’re sat on the bench at [the] Gardens and I’m holding- Sorry- And I’m holding your hand,” I said. “Just close your eyes and think of me and I’m sat with you, holding your hand.” And I said, “I’ll come for you.” So he calmed down then. And yes, you know, and I said I loved him and things. And that was it really.” [Sian]

A dignified death?

A dignified death comprises multiple factors (Meier et al. 2016) and the pandemic has meant care of dying patients has in some instances been impoverished in ways that would once have been inconceivable (Chochinov et al. 2020). Unfortunately, many of the stories in this section spotlight such instances:

“It was just, it was horrific that she was in pain, to see your mum in so much pain and feel like, that you can’t do anything is really, and I think that’s really stayed with me that you feel like you should be able to help your mum and, especially when you know what she needs and, that I’ve seen, I’ve seen a number of deaths but I’ve never let anyone, any of my patients, ever, be in the pain and discomfort that she would have been in. And so, it was really, really awful.” [Ann]

“I saw my dad for ten minutes and what I saw was, I never want to see again and I wouldn’t wish that upon anyone.... that wasn’t my dad and I didn’t want, if he’d been like that for 18 days that was enough. That was enough for my poor daddy. It was enough.” [Pat]

And what upset me, I think, a lot was that the home weren’t proactive and it was only because I know what I’m talking about, so, it was on a Friday, I rang the home and she wasn’t getting any better and I said, “Have you got anticipatory medication for her?” And they said, “What?” And I said, “She’s very old, she’s got advanced dementia, she may die and she may die very quickly and she may be in respiratory distress, she’s going to need morphine or midazolam or something.” “Oh, okay, if that’s what you want.” And I thought, why hasn’t the GP thought of this? Why hasn’t the home thought of it? It’s a nursing home, you know, why am I having to do this? It was me often asking them things, like the anticipatory medication. Things like, you know, in the homes I work in, or worked in, if someone was end of life, then we would put their favourite music on in their room, we would put like an aromatherapy diffuser in there if they had any particular favourite scent or anything. We would try and make it as calm and peaceful as possible. And those weren’t

things they were doing, I had to ask and they weren't attentive. So, it was like all the time I was having to not just ask about things like medication but the nice things like that." [Sarah]

"We get a phone call to say, "Look, you can start visiting your mum." I thought, right. So, she must have lasted about four or five days, and they moved her into a side room, she was in the room on her own. She was on Oramorph, and some other medication, and they kept telling me she was peaceful, she was settled, and she was on oxygen. Every time I walked in that door, as soon as she was aware of my presence, because she couldn't have heard my voice, but she was so agitated. Every time I went in she was so agitated, and it was just utterly heart-breaking, seeing her like that." [Margaret]

"She was struggling a little bit to breathe so we rang our GP and they prescribed her some Valium to help her just calm down a little bit.... she wasn't very good we got the district nurses out and at the time they just said oh the Valium's sufficient she's alright at the moment. And then it started getting bad, she couldn't breathe so we called the district nurses again. They obviously checked with her that she didn't want to go to hospital and she said, "No I do not thank you". She was still very adamant she was not going. They came to give her the end of life injections basically, but by the time the nurse went in to give her the injection she'd gone. From all the things that I'm hearing I am glad she didn't go [into hospital], but obviously it was horrific for us seeing her like that and not being able to breathe and it's affected me and my mum quite badly. The steroids that you need for Coronavirus when you can't breathe were limited to only hospitals. The scaremongering all over the news made my Nan not want to go. You weren't allowed to see your relatives you weren't – the case isn't – I mean the care in hospitals anyway with the elderly isn't great but during Covid it was extra awful. So she was terrified she didn't want to go and they couldn't do anything because all the hospitals – all the medication for Covid was for only hospital use. I think the last part that I'd like to say is that she just spent her whole life caring for people and at the end if she hadn't have had us I dread to think how everything would have ended." [Emma K]

"They were then asking my husband if he still wanted to carry on with the facemask. So when they eventually came out they said he's decided that he can't go on anymore and we're going to get the palliative care nurses. ..they explained that they would give him one injection to calm him down so they could take the mask off. It's a bit like putting down a dog isn't it really when you think about it? Just what you do to animals. He didn't want us to stay so then 8 o'clock we got the message that he passed away at half seven." [Jackie]

"So at half past four in the morning we were moved to a private room and my mum was extremely agitated extremely agitated and they just kept injecting her and injecting her and injecting her....And eventually they gave her something else and then they sent the palliative nurse in and they said the syringe driver should go up. And then we sat there for 48 hours

because don't believe my mum was ready to die. Nobody should sit there for 48 hours gasping for breath. You know you don't even do that to a dog." [Lynn]

"When I arrived he wasn't on the CPAP anymore. So I went out again and said, "Please he hasn't got any oxygen" and they said to me, "Well just put the mask back on his face" So I tried to put the mask back on his face and then I noticed that the mask was not connected to the oxygen supply, it wasn't connected to the oxygen supply at all.... so I called them back in they gave him quite a lot of oxygen but by that stage he wasn't there anymore.... His eyes weren't open anymore and you could see that you know he was dying and nobody was doing anything... they just let him die without oxygen, nothing.... This was the most horrible, horrible experience you know the most horrible experience." [Suzanne]

"We managed to get two other members of the family to go in who weren't affected [other family members had COVID-19 themselves] but they described dad as being in the corner of a bay, I don't know if it was a six or eight bedded bay. The man in the next bed was having a bed bath. The men opposite him were watching TV. There were allowed to stay for one hour and then told to leave. Dad then died, I don't know, an hour or so later after they left and there was nothing to reassure us that anybody was with him, holding his hand, just a clinical last breath observed. And that was it." [Claire]

Thankfully, while still extremely difficult, some deaths were more peaceful:

"Then she looked at me and she looked at the nurse and she said, "Right, you can take this bloody thing off me now." Meaning the CPAP mask. So she'd said what she wanted to say. She got everything off her chest that she wanted to get off her chest. And then she went, right, I'm ready to go now. Susan got there at 25 past two, said to her, "It's all right Mum, I'm here now. I'll be all right, don't worry about me, I'll be fine," and Mum died at half past. I think they had put the syringe driver in for the anticipatory meds to just keep her settled and calm, and not have the secretions in the back of the throat. She was calm. She was peaceful, she was settled. It's the way to go, yes. I mean, we had to be double gloved all the time. We didn't have skin-to-skin contact as such. We were double gloved all the time but she knew we were there. I think even the staff needed a good, I know it sounds awful, but a nice death, because they'd seen so many horrific ones, to actually have a nice one- It was comforting to them." [Pauline]

"The doctor came in on the Saturday morning, and said to Steve, "We can't do anymore more for you, and I'm concerned that this is too much of a struggle for you, with this continuous pressure, and I think we should stop and just make you comfortable." And Steve agreed, but he also looked at me, and he said, "I don't want to die." And I said, "Of course

you don't want to die, nobody wants to die, you'd be mad if you did, but darling, this is just exhausting you, so we'll see what the doctor says." [Fran]

"And then we were called in the early hours, at quarter to six, to say that she was desaturating despite the CPAP and it, you know, it was as peaceful as it could be. She was still talking and it was her decision when to come off the CPAP." [Becky]

"When it was his time, we, me and my sister and my niece went in and we were able to be with him and they gave us unlimited time as well. They said, "You can spend as long as you want and when you're ready we can lower his oxygen." So, yes, we had control over it again and there was no rush to do anything. They were really good, really good." [Becky]

"I got a call in the morning to say they wanted us to go in. So we did and, obviously, they explained that they'd done everything that they could and that, you know, it's just, it was our decision now to be with him and make it as good a death as it possibly could be. But they were, the staff were amazing, they really really were amazing. They were so kind and so nice, and so - And I'm so thankful that we were able to have been with him." [Amy]

Newly bereaved and isolated

Many people told of the added sadness caused by isolation after bereavement.

"I think that the lockdown, the being on your own, not being able to hug people. The lockdown has massively intensified it" [Pat]

"It was just the general things about not being able to go anywhere, not being able to do anything... You are in your own little bubble and you could almost pretend that it hadn't happened. Which is probably not very healthy." [Margaret]

"It was a terrible Christmas on my own, New Year on my own. And the funeral wasn't until the 12th of January. I've never been on my own before." [Liz]

"We've got the crazy dog. So I had the dog." [Fran]

"Dad had to go home on his own, being Covid-positive after we'd took all the PPE off, that was it, he was then on his own. And knowing that, yes, he had to go home, losing his wife of 51 years, go home alone without his daughters for comfort. It's just horrific, isn't it?" [Becky]

3.7.3 Death in a pandemic

A range of extra burdens were placed on the bereaved due to the pandemic. These range from practical problems caused by lockdown, through to myriad issues within society:

Practicalities

Denied being able to visit, some participants also had extra practical burdens due to the pandemic:

“They keep on telling you, he is very unwell. He’s critical. The girls were at home, they were doing online school. My daughter is in her GCSE year. She was doing online mock exams. So my sister started taking the phone calls because after some time I was losing it totally.”
[Sonal]

Lockdown and social distancing regulations caused added stress with the practicalities of travelling, even to the funeral of both parents:

“So, where I live was Tier 4 at that time and where they lived and where the funeral was Tier 2. So, and that was the day before that they announced the tier thing, that we were going into Tier 4, oh, no, two days before, and I was just, I was frantic that I wasn’t going to be allowed to go up.” [Becky]

Other difficulties pertained to practicalities such registering a death and the official business that has to be completed:

“It was like, “Oh, we’re not sure what we’re doing because we’re working from home. We’ve not done this.” So, it felt like really the blind leading the blind. You were like really shocked at what we were going through but no one seemed to have any understanding of what was to happen” [Ann]

“After she died, he said, we’ll give you a little bit of time. We’ll ring back in about an hour to tell you what happens next.” And it was a Friday. No one rang us back. No one rang us back on Saturday. We kept the phone lines open. Nobody called us back. And finally, on Sunday, halfway through the day, I just decided to ring the hospital. And I got the site – I told the Receptionist, and I said, “I don’t know what I’m meant to be doing. I don’t know who I need.” She got the site manager. The site manager told me that the Bereavement Department would ring me on Monday” [Emma L]

“And unfortunately it wasn’t just the probate office, it wasn’t just HMRC, every single person you rang, you got a recorded message, due to Covid-19. So and you could hang on the phone waiting to get through for, I think the longest I ever waited for 55 minutes.” [Charlene]

“You then had to phone up each department individually and each department was dealing with twice as much workload as they normally would do and their number of staff had been reduced significantly because they were ill. So, you’d be on the phone for like, you know, an hour or two just for one.” [Adrian]

“I went in the bank, and the woman was dead snotty with me. I went in and I said, “Look my mum-.” She knew my mum as well, because my mum used to go in, and they all knew my mum by name. She went, “Ah yes, I knew Christine.” They knew she was in the nursing home. And they knew, obviously, it was a lockdown. And I said, “Look, Christine’s passed away with Covid, and I need a printout of her bank, because I need to know if she has got a funeral plan.” And she was like, “You shouldn’t be in here. You’re risking all our health by bringing Covid in here.” And I went, “How am I bringing Covid in here when I’ve not been near her? I’ve not seen my mum for weeks.” And she went, “Oh,” and just walked off. And I thought that was disgusting as well. I was going to put a complaint into the bank, but I never did in the end.” [Charlotte]

“Trying to get hold of universal credit, no chance. No they just say, “We’ll put a note on your account for your case manager to call you back.” And your case manager never calls you back because not only while organising a funeral, notifying everybody who needed to be notified, grieving, healing-... I then had a notification, well I went to get some, my son to get some money out of the bank for me, and my tax credits hadn’t gone in. They’d stopped them with no warning. No grace period. Nothing. So I then had to sort out universal credit in the middle of it all. And that was the biggest headache ever because nobody could tell me the information I needed to know. It was just another thing to deal with. I just think, the only thing that I think that maybe more could be done about for those grieving is regards to the availability on information with regards to the benefits that are available, the support that could be done.” [Shelley]

“Apart from the emotional side which, you know, we can talk about- Just the whole practicalities of having to sort out my mum’s house. Getting people in, get stuff taken to charity shops. So, all that practical thing was a complete and utter nightmare. So, you have got the emotional side of it, where it is just one of the hardest things in the world to ever do, because it was the family home. My mum had lived in for nearly 60 years, so as you can imagine there was a lot of stuff that we had to deal with.” [Margaret]

A lack of understanding

Strong feelings of being further isolated due to others being unable to understand what being bereaved by COVID-19 means emerged in many narratives:

“In some respects it’s nice that people don’t know because I mean if you they haven’t been touched by Covid, but equally I think if they truly, truly knew what had gone on they would be horrified and astounded. It’s definitely something that needs to be put out there because it’s an absolute scandal what’s going on.” [Claire]

“It’s just awful, isn’t it? I don’t think you’ll ever get those memories away from you, will you, because you’ve just lived it and you’re just, and I don’t think, unless you’re actually talking to someone who’s actually been through it no one really understands” [Ann]

“This is a death, that unless you’ve experienced it, it’s like no other death. I lost my own dad when I was 17. He had a stroke. I went to work. I came back and he’d died. And gosh, that was a shock to deal with. But you come – you came to terms with that. I don’t know if you’ll ever fully come to terms with this. It’s just very different. And unless you’ve been touched by it in that you’ve experienced it yourself – I don’t think people understand it, you know? [Amy]

*“It’s been really, really, really hard, very, very and I don’t think people understand it. And I don’t think people realise how serious it can be you know.... and then youngsters think well, I’m not going to die from it. So, it doesn’t really matter if I get it. But it’s not that, it’s who then you pass it onto and who they pass it onto. And you know I mean I’m glad we’ve never had to live through a pandemic before and I don’t think people understand what it’s like.”
[Annette]*

“I just feel people who’ve lost people to Covid are never going to be the same as people who’ve lost people to a car accident, or cancer. It’s just not the same. I think forevermore it’s like a taboo subject, and you’re never going to be allowed to discuss it. You’re never going to be allowed to talk about it. And I don’t think you get the same sympathy off people. It’s

weird. It's such a weird feeling. It's like you can't even talk about it or mention the Covid word. I don't know. It's really bizarre." [Charlotte]

"I'm very careful about who I talk to about it, because I don't want to get into a situation where I'm... in a situation where I'm in a 'I can't believe you said that to me conversation'. It's all a bit fragile." [Fran]

"And now they're all, you know, they all think they're fine, and they're all hugging, and God help anyone who hugs me next week on my birthday because I don't want one." [Emma L]

A society divided

Attitudes among some groups in society made many people feel worse:

"It feels terribly divided. And it feels quite hostile to me. So yes, so I'm finding it difficult at the moment. Yes I am. I think, yes as a society a lot of us have, but I think because of the way we're governed and things, we don't seem to have empathy and compassion and outward looking, you know, as a society." [Sian]

"I've lost my mum and everybody wants to party." [Annette]

"Well this is the other thing that's something which affects me very much too when everybody talks about holidays and we want our lives back and I'm so angry. And I think I could never have my life back, how dare you say that without a single mention of the costs getting to that stage." [Suzanne]

"It's the lack of respect for it, that's what's upsetting." [Amy]

"I don't get angry with people who are looking forward to opening up, because I can't wait to get away either. I can't wait to have some kind of normality back. But I get angry with people who break the rules. But the one thing that I do remember was that national day of reflection, I think they called it. I remember being absolutely furious at the BBC programme, that they did that night. Because it was all about when the pubs open and this happens, and I suppose there was a small bit about people who have been bereaved. But I was so angry that I actually emailed, and I am not usually the type of person who emails in to complain about programmes, but actually I emailed in to the BBC to say, "I think you have got the balance of this all wrong." It was almost all, "Fantastic we are going to get back to football

and we are going to be doing this.” And completely ignoring the fact that there were people, and a lot of people, whose lives are never going to be normal again.” [Margaret]

“But I just, people whinging and moaning that they can’t go on holiday abroad because of Covid, and oh Covid’s not real, it’s just the flu. It’s so not the flu. Until you’ve had Covid, even with a vaccine, it is not the flu. I would not wish it on my worst enemy.” [Shelley]

“I find myself getting quite cross sometimes with things that, I’m sure you’ve probably seen it in the press yourself, where people kind of belittle what’s gone on to a certain extent. Or they can’t wait, or you know, what pandemic? And you know, we’re sacrificing our pubs because we’re keeping in lockdown. And all the pubs will be shut and you sort of think, well, the pubs can come back. But your family can’t. It sort of heightens the fact that other people haven’t got the same- Which is great, I don’t- I wouldn’t wish it on anybody, but they haven’t got that same kind of thing to deal with have they? They’ve just got the pub to worry about. Or their summer holiday.”[Becca]

“What really upsets you is that everybody wants to move on now. And I understand why everybody wants to move on. Everyone’s a bit fed up with it aren’t they. And you know, you still get the people that don’t seem to believe it. Don’t seem to believe it’s real. Or think it’s just a bad cold. Or you know, that the old Trump thing you know, I had it and I’ve recovered and I’m stronger. You know, that left its mark; that hurt everybody I think didn’t it. Those sort of feelings that it’s only the very old that died and they were going to die anyway, you know what I mean. It’s all of that really.” [Stuart]

“I think people want to move on to be honest. Not me and people who’ve lost loved ones. I think overall it’s that type of thing, well let’s, you know, the sun’s out, we’ll soon be over this, let’s get on with it sort of thing. And with people, with people I get terribly angry, not angry, well I do sometimes, irate I would say, right from the beginning. Because there’s no social distancing now, we don’t, you know, the masks, everything. And I just thought, if only you knew what, or saw what I did and the pain that person went through, it wasn’t an easy death, you know. I just, oh I just don’t think people- And so yes, so I am finding it difficult I must admit.” [Sian]

“I find myself taking such a wide berth past people- and I’m, you know, I’m inherently a people person, I love being with people, I love, I don’t know. So, yes, I have, I’ve become, well, you’re different when you lose somebody close anyway, aren’t you- -but I have found I’m a lot more insular. I don’t want to go out, I want to speak to my little, my few close ones and- I don’t want to go out, the last place I want to be is in a crowded pub” [Becky]

“I haven’t been over to my local shop since this happened because I was constantly going in there and moaning at people when they came too close to me.” [Jackie]

“The wall. For ten days I was at the wall every day and I still now go and put people’s names on the wall when I can. That is full of love. The wall is just made of love and meeting people there was so good because being at home, all you hear about was the anti-vaxxers, the anti this, anti that and you felt there were two worlds. There was the bereaved world and those that weren’t bereaved but when we went to the wall the amount of people that came over, “Can I get you a coffee?” and, you know, just strangers walking by. It was really, it affirmed my faith in human nature but that was such a huge thing for me to go and do that. It was so lovely.” [Pat]

COVID-19 deniers

One particular group in society, the COVID deniers, were spotlighted for causing particular and unique stress among the bereaved:

“Then you’ve got people that deny it, that don’t believe in it, that dismiss it” [Fran]

“People were really like, your mum died of Covid? She can’t have, because it says in the [local newspaper], that [city] haven’t got no deaths or there’s one death, it was an MP or something from the [area], and it was like about a week later before they started acknowledging other people in [the city] were dying. Yes, and it’s that sort of like when you’re saying about it people had that disbelief” [Ann]

“The Covid deniers annoy me dreadfully. I can’t remember— oh I know I walked around a local park with the children on Sunday and there were stickers on all the benches you know Covid deniers and I thought this is bloody ridiculous and people had pulled some of them off and it did wind me up.” [Judith]

“I haven’t got any time for the covidiot’s that think that it’s all a, you know, all a lie and those that refuse to wear their mask because they’re not going to be told what to do and I, it makes me angry that, I’ve fallen out with several people on social media because of it, and I’m not a, I’m not a bolshie, opinionated person but I think people can be so insensitive, you know, I find myself, I don’t know, I find myself tutting at people [laugh] not wearing masks, I find myself, you know stepping back” [Becky]

“But you have conspiracy theories for everything these days, don’t you? And everybody’s an internet warrior. It’s scary, because people are believing it.... too many sheep and not enough thinking people.” [Pauline]

“People wouldn’t be anticancer. I mean I’ve had Piers Corbyn come up to me and say, “Your dad didn’t die of Covid.” I’m like, “How dare you! How disrespectful! How could you say that to somebody that’s grieving?” [Pat]

“I have to blame the people who don’t believe it’s real as well. I think they’ve got quite a lot to answer for, you know, the people who stand there and tell you it’s not real and you’re thinking, no! We’re a bit more wiser now but there’s still the people who won’t, who don’t believe the virus is real. They still think it’s a cold, you know, we’ve even had patients in the hospital where I work, saying it’s not real. Yes, you just- for me, I just think, thank God I don’t live in your head. You know, and I can walk away from you at the end of my shift. You can’t walk away from yourself. That’s how I justify it to myself.” [Pauline]

“I found all the conspiracy stuff and people’s attitudes- I personally feel like a lot of people see it like, we can’t talk about it. The mere mention of Covid, and it’s like, change the subject. Everything related to Covid, people change the subject. And I’ve had people actually tell me to my face. In lockdown, I’ve got horses, and I moved horse yards in lockdown, and had moved onto this new horse yard. And the first thing the woman come up to me and was asking about my mum. And I said, “She died of Covid.” And she went, “No, she didn’t.” And I went, “What?” And she went, “No, she didn’t, she didn’t die of Covid. Covid doesn’t exist.” I was like, “You’re actually saying that to my face.” And I’ve actually had three people now saying that to my face. You wouldn’t go up to someone and say, “Oh, I’m sorry, I heard you lost your mum at Christmas. What was it, do you mind me asking?” “Oh, she died of leukaemia.” “No, she didn’t.” And I’ve actually had people say to my face, “She didn’t die of Covid because it doesn’t exist.” [Charlotte]

“I’m very fortunate, I’ve only ever had one friend who disagreed about Covid.” [Shelley]

“I don’t feel like I can go back to things. Obviously, firstly because of the pandemic. I’m still worried about the different variants. However, I don’t feel like I can go because if somebody starts saying something that they dispute the pandemic, they don’t agree with the figures, or anything like that I don’t want to have to justify my dad’s death” [Claire]

The anti-vaxxers

In addition to the COVID deniers, the bereaved have to listen to the anti-vaxxers:

"I get angry with people who are anti-vaxxers, and are spreading all sorts of utter nonsense. I can't even read the comments on the BBC websites now, because you have got all these, Charlene, the beauty therapist from Glasgow saying, "Oh, no, you don't know what is in that." And most of them come across as just trying to be so intellectually superior to the rest of us because they have done their research. So, no, I reserve my fury like that." [Margaret]

"I've got people that are like anti – well I haven't got people, in the rock and roll scene there's one particular chap who's actually been over here and stayed here when he's played locally and he's an anti and doesn't believe it exists and he's a – I just said to my friend I was talking to I said if I actually see him in July you better not let me too near him because I might just smack him round the face. I'm not a violent person but he hasn't even sent condolences or anything so he's totally denying that Covid exists. And she said she doesn't know if her friend's going to have - no her daughter-in-law's going to have the vaccine and I said all these people who don't want to have things done when there's no reason for them to not have it done should be taken to see a Covid ward, Taken in there and let them see how people are lying there suffering and dying and then that might change their mind." [Jackie]

"I mean anti-vaxxers. Jesus, do they believe? So, literally a story that I have is I came out, I had to go to, get my second jab...came out and there was this lad running past in his running outfit and he goes, "Have you just had your second jab?" "Yeah." "Rest in peace mate." What? Yes, so I went, "What?" and he goes, "Yeah, I'll give you ten years mate." You know, "What benefit has it given to you?" and I'm like, I've just had that jab so I'm getting into the car because we're just about to go away for the weekend and I'm like, "Mate, you're talking to the wrong person. I've had Covid myself." "Oh, I don't think so mate," you know, "it's just government conspiracy." "Okay mate. My mum died of it." "Oh, she died of flu." My wife was there and my wife had to hold me back." [Adrian]

"And the anti-vaxxers bother me as well because none of us particularly want to put stuff into our bodies but you do it because it helps everybody else. And I've got carers well I haven't had them back yet because they're anti-vaxxers and I don't know how to pursue that. Because one of them – well she wouldn't have had it anyway but she donated a kidney and she said she doesn't want the vaccine because she's only got one kidney and you know what I mean this that and the other. Well I can't very well argue with that but equally I don't particularly want her coming into my house. I mean we've all had it even [name of adopted son] who's terribly autistic and then we've got the learning disability nurse that comes round and has practised for weeks and weeks and magically got one into him and he's having another one." [Judith]

“The anti-vaxxers, the anti-vaxxers. I feel sorry for them, really, to be totally- They just, they don’t live in the real world, because look at the polio. They had polio in the fifties and look where we are now with polio. You know, it’s almost eradicated. And that’s because of the vaccine.” [Pauline]

3.7.4 Elderly or with underlying conditions

Particularly painful was the discussion around COVID-19 deaths being higher in the elderly population and among those with underlying health conditions. Many felt the conversation, and indeed events, made them feel as though the lives of their loved ones were somehow worth less than young, fit and healthy people:

“I don’t want somebody saying to me well he was old. Oh well he had underlying health conditions. I don’t want to hear that.” [Claire]

“I also want them to take back the “Oh this many people have died. But this many had an underlying condition.” Bill wasn’t going to die yet. A friend that I went to see last week lost her brother in November and her husband in January. Early 40s. Her husband had diabetes. Diabetes doesn’t normally kill anyone. Stop hiding behind the oh but they had an underlying condition” [Charlene]

“Just going back to my Mum at the beginning, when she passed way, people say, “Oh, but you know she was 91, she had a good innings. You can’t have her forever.” And I used to get so angry, and say, “Look, I am not stupid. I know, I just had her longer than most people had their mums, and you are never ready to let them go.” But the thing that will continue to haunt me forever and ever and ever, is that my mum probably died frightened, and the fact that we just didn’t have that human contact that we needed. And the guilt, that my Mum said to me, on that day, “Don’t take me in here, because I won’t come back out.” How can I ever forget that, because it was me who took her in?” [Margaret]

“What doesn’t help is when people say, “What age was he?” You know and I say “88”. “Well he was a good age.” You know whenever you tell people it 88, well that was okay you know he wouldn’t have lived very much longer anyway you know so who cares? Yes, he had the right to life just like anybody else you know, he had the right to be treated with dignity in the hospital as well. Not to be written off because of his age and that’s exactly what it feels like

and that is so wrong. He loved life he didn't want to die; you know it wasn't his choice. But in the beginning the media always said if so and so really desperate they all had an underlying health condition as if that was the reason to let them die." [Suzanne]

"There are those that just think that Steve had an underlying condition, so therefore he was less worth saving. It becomes a minefield that you have to navigate in conversations." [Fran]

"It's hard isn't it because I think anybody over a certain age is just discarded. I just think it was just an easy way out to let a lot of elderly people pass away early. And you know the consequences of it didn't matter" [Annette]

*"Those doctors made that decision for us, whether my mum was worthy enough to survive."
[Lynne]*

"You know, there is this conversation about 80 year olds weren't there, and it was all aging, you know. We seem to be a society where the elderly, we don't treat them with the respect or see them as people anymore. And I think this is where they were allowed to be dispensable if you like. And I think and people don't realise is that those are people, although they're in a body that may be 80 year old, they're like me at 50, I still feel like I'm 18. And my thoughts are still there and everything. The person is still in there. So they're still in there- And the way they died, it's not, you know, an injection in the arm like a dog and then they go to sleep quietly. It's just horrible, it was just awful. And you know, we're better to dogs than we are to people half the time, to animals to be honest." [Sian]

*"The people that lost somebody, like, in the care homes, I feel almost for those families, I feel like they were a bit, like, the – what the Germans did to the Jews in a concentration camps"
[Amy]*

3.7.5 The pandemic permeates every aspect of life

While people certainly did not want to forget their grief, they did find the ways in which the pandemic permeated every aspect of life to make things especially difficult. The media seemed to make things more difficult for some families, which is unsurprising in light of recent evidence (Wahl-Jorgensen, 2020) that spotlights the 'fear-based' ways in which the

UK newspapers have portrayed COVID-19 deaths, while providing little practical advice to the bereaved:

“If someone had died of cancer it wouldn’t be like, cancer, cancer, cancer. You wouldn’t turn the TV on and get cancer, cancer. It isn’t, it’s Covid, Covid, Covid. You’re doing everything because of Covid. You can’t get away from it. You can’t turn it off. You can’t, well I don’t watch the news. I haven’t seen the TV since before Christmas. I can’t, when it got to 100,000 I couldn’t” [Pat]

“In so many ways you can’t escape from it. Every day it’s on the news. It permeates everything to do with our lives. The government’s decisions. The restrictions that came into place. So, we were in November, and then we had a lockdown in November, didn’t we. And then again in January, we went back into lockdown. So, that whole isolation with Covid for everybody, is magnified when you’re grieving.” [Fran]

“I think that’s something else isn’t it, the fact that there’s no switching off from this, every which way you turn. Covid. Covid work. Covid home.” [Claire]

I’m just thinking lately, because I don’t know why I can’t- seems to be getting worse in some ways, the grief, you know, the sort of- It’s weird, it’s hitting me again lately. But I think that’s all with, you know, the media and the news now. [Sian]

And you just – yes, I can’t watch the news. [Emma L]

I don’t watch the news. I will read the headlines online because I can pick and choose what I open up to actually read. But I can’t watch the news. I haven’t watched the news since Nick passed away because I cannot stand listening to them prattle on about when we’re opening up, and how much people are suffering, because they’ve not got life back. My life’s forever changed. [Shelley]

A sense of collective grief made bereavement more difficult, too:

“I think losing someone in the middle of a pandemic is very different. Normally, if you lose a relative, you are kind of one person losing a relative in amongst an awful lot of people who are able to provide you with support, whereas this time round it’s been, you know, it’s just been all encompassing.” [Adrian]

“So, I think what makes this grief worse is that it’s a collective grief, it’s not just mine, there are millions and millions of people around the world whose loved ones have died and they needn’t have died. And I think you can’t avoid being part of that and, you know, you meet people all the time who, you meet people who go, “Oh, I don’t know anyone whose had Covid.” Well, lucky you, but I think when people know that something has happened to you, they then talk about what’s happened to them and you realise how many people have had such hard, hard things to deal with, much harder than I’ve had. And I think it’s that collective grief” [Sarah]

“I think it is just about the enormity of the global situation sometimes is so frightening, you know we are talking about very personal experiences, but look at the millions of people, in countries that aren’t as well- Well we weren’t well prepared at all, but you know? It is frightening. When I see my 21 month old granddaughter, picking up a mask that’s come out of the washing machine and putting her mask on, it is like a dagger through my heart. And people say, “Oh well, she is just copying.” She shouldn’t have to.” [Margaret]

3.8 DEATH RITUALS

While so-called death rituals, which are customs and practices that occur when a person dies, differ between cultures, it is well established that these rituals and mourning practices serve to facilitate the grieving process and support the healing process (Kagawa-Singer 1998). Many of these taken-for-granted rituals were denied due to the pandemic.

For one of our respondents, the service failures she received from her undertakers added to her stress and grief:

“I’ve had a terrible time with that. I unfortunately – in [place name] there’s a [name of funeral director] funeral service in [place name] Road and there’s also one in [place name] [place name] Road and I phoned the wrong one. I phoned the [place name] one and the woman well I’ve complained to them and they haven’t actually asked me for the balance yet because I refused to pay it with the way I was treated it was dreadful. You had to do everything yourself and you’re already going through this and then you’re ringing up sort of well have you done this have you done that and I kept thinking is there something I’ve

missed. I had to keep nagging all the time right through to the end it was dreadful. Yes because I'd always – I dealt with the [name] for my dad and my Auntie it's sort of an old fashion family thing they'd always gone to the [name]. But this woman she was like a gibbering – she was absolutely useless. And then I never got the video link sent to me so that was another thing. Everything was stress. It's just one thing that went wrong after another I could write a book on it really.” [Jackie]

3.8.1 Funeral directors: The unsung heroes of the pandemic?

Thankfully, Jackie's experience seems to be an isolated example of such poor service.

Throughout many of the narratives emerged praise and a deep sense of gratitude that despite the many exceptional and severe problems the families had faced, the funeral directors were one steadfast and positive element of the whole terrible experience.

“Absolutely amazing they were, yes. Wonderful.” [Amy]

“They were absolutely brilliant.” [Emma L]

“The first thing we did was we phoned the funeral director, because we thought that he would be the one to guide us through everything, and he was absolutely wonderful. He was so helpful, and told us all about the difference in registering the death, you were doing it all online, just all the practical details. So, we did that and then got the death certificate etc.”
[Margaret]

“It was 28th November and her funeral was booked for 11th December but when he deteriorated and went to HDU first they said, “We don't think he'll be out in time for your mum's funeral.” So, we decided to postpone Mum's funeral until the new year and give Dad a chance to, you know, to know whether he would get better from it. And so we'd booked her funeral for, oh, it, January sometime, I can't even remember now, but then after Dad died we decide-, we phoned the funeral place and said, “Can we do a joint funeral?” So, we did.” [Becky]

Many people felt that the funeral directors went above and beyond to support them:

“Mum wanted specific music, so, the coffin, as Mum was coming to the graveside, the undertakers had this piece of music that Mum wanted playing, so that was played on their CD player in their car at full belt. Yes, they managed. They did it” [Pauline]

“So I phoned them and I sort of said, you know, this is the situation. And they got the kind of boss chap to phone me. And he said, I said, you know, “I don’t know whether you can help me or not because it’s Covid. I don’t know-” I had this awful feeling that they might say, well he’s got to go from hospital to crematorium, because of what I’d sort of seen in the news. But they said, “No, we’ll fetch him.” And they weren’t sure about burial at that point because he already had a burial plot, they weren’t sure. But he said, “You know, I’ll look after myself for you.” He said, “You know he’ll be in good hands with me.” And he did everything and he kept me up to date. So from that point he was brilliant. Yes. Yes. But I really did genuinely get the feeling that he had fully looked after my dad, you know. He had done everything himself. He’d, you know, he meant what he said. It wasn’t sort of empty words you know.”
[Becca]

“They were nice with the funeral, and the way they were with all of us....They just looked genuine, and they were just nice to us and everything. And they weren’t being funny about Covid.” [Charlotte]

Indeed, many felt that funeral directors should have been included in the accolade that was reserved for carers during lockdown:

“I think that they have had a really, really difficult job and no one really, you know the NHS have been clapped for on the doorstep and what have you. But actually these people that are saying, “No we can’t take the clothes. No we can’t do, you know-” they’ve actually got a really tricky job to deal with I think. But I mean, and he, the amount of times he said to me, “I’m really sorry,” because he said, “I want to be able to meet you ahead of the service, I want, you know, this isn’t what I normally do. I normally would come and meet you, or you come to see me and we’d talk it through. And we’d, I’d get to know you.” [Becca]

“I mean, I think some of the unsung heroes are actually funeral directors. My funeral directors were a family business. They were lovely. They said to me, “Have a pauper’s funeral.” They said, “You know, there are so many things that you can’t do, that there’s no point, you know, and the coffin to me, didn’t look any different. It had handles and it was all nicely done” [Pat]

“Oh, yes. I mean, when they arrived with the hearse and I thought, my goodness, how amazing, they’re doing this, they must be doing this day in, day out, they’re putting themselves at risk because whatever they do, they’ve got to get that body into a coffin, haven’t they? And they were so respectful and so lovely and, you know, and that’s what broke me up, I think, when the woman who was in charge, she got out of the hearse and then she went round and she bowed and, you know, that was, I thought that was such a lovely thing to do. I know they do it, but their respect and for them that must have been unrelenting, awfulness, mustn’t it? Month after month after month.” [Sarah]

3.8.2 Restrictions to pre-funeral death rituals

Despite the kindness and professionalism demonstrated by most funeral directors, families were still denied a range of important death rituals. We will deal with the restrictions to funerals in the next section, here we listen to the added pain caused by restrictions to important rituals pre-funeral. As Margaret explains, such rituals are important:

“Normally you are constantly making tea and making sandwiches and doing all this, and it seems so incongruent to be sitting watching television, when I should have been going to a Rosary, or some ritualistic thing that is just what happens and it helps.” [Margaret]

Yet, many things that are normally allowed were denied to COVID-19 bereaved:

“I also heard he probably wasn’t embalmed. And I’d asked them for a lock of hair, and she’d said to me they would do that. And the afternoon before the funeral she said to me, “They’re going to put it in a little pouch and they’ll give it to me at the funeral the next day.” And then after the funeral when we came out of the crematorium, they then came over to me and said, “Oh I’m sorry we weren’t allowed to do it.” So I didn’t get it. But I’d asked the question and they said to me, “Yes.” it’s being done. So I don’t, because obviously people die, they send them to the morgue, which is cold so I don’t understand why they didn’t do that. Maybe it was a panic.” [Charlene]

Closed caskets

Many families lamented the need for sealed coffins and being unable to visit their loved ones:

"I never saw him in the chapel of rest." [Pat]

"We weren't allowed to see her, it was a sealed coffin." [Pauline]

"I was with him when he died. I saw his face after death when I stayed with him. But for his daughter and his son, that must have been really difficult." [Fran]

"I couldn't see my mum because it was Covid and not that I particularly wanted to but it's something my family always did, they always went to visit and I couldn't. Fair enough I accepted that it had to be a sealed coffin." [Judith]

"Dad had said that he wanted to see Mum, you know, obviously before he ended up going in hospital, he wanted to see Mum, so there was a lot of conflict as to whether he could see her and then when he went into hospital, they were saying, well, she'd need to be embalmed but, you know, we don't know how long Dad's going to be there and, you know, nature's not very kind to, in death. So, you know, but he didn't end up getting to see her" [Becky]

"So, you know, we- We don't even know it was her, to be honest. I mean, obviously, it was, but, you know, you go through, We're going to have a phone call from her one day going, what the hell, no one's rung me lately!" [Emma L]

"I couldn't go to the Chapel of Rest. And I'd wanted to – I'd really wanted to, not so much for myself, but when we – when Paul passed away and we were still with him, the Nurse asked, did she want – did I want her to take the tube out, and I said, yes. And when she – obviously, we had to go out, she's not allowed to do it while we were there. We went back in, he looked awful. I think because the tube there – and he looked like he'd had a stroke. Yes. So – but that really really really distressed [daughter] so much she was vomiting. And I wanted the peace of mind for me to come home to them and say, your dad looked absolutely fine. But they wouldn't let me. But [name] at the undertakers, I couldn't understand, because I said, he was – for two and a half weeks he was Covid negative and we were skin to skin. I lay on the bed with him. We had no gloves on. All right, we had masks on, but we kissed him, everything, we did. So I said I don't see why – I can't – he was negative [by the time he died], you know? And she – God love her – she tried and tried and

spoke to multiple multiple people, but they came back and said, because it's better to be safe, no. So I accepted that." [Amy]

Closed caskets caused doubt that things had been placed into coffins, too:

"We couldn't go and see her. We couldn't dress her. We sent things in and we don't know whether or not they went in with her because you just don't know do you?" [Annette]

"No, you couldn't have the coffin open. Her little dog had been cremated, and we had the little dog in his box. And he said, "I'm not meant to, but I'll open the coffin and put it in for you." And he said, "I'm not really meant to, but I will." Again, whether he did or not, or he just said it. He supposedly put a little dog in with her as well." [Charlotte]

Or that objects had been placed into coffins with dignity:

"When they laid her out, they [care home staff] just put the rings in the body bag because the undertakers weren't putting bodies in bags, they were supplying the bags for the home. So, they just seemed to have chucked the rings in with her." [Sarah]

Burial clothes

Being unable to provide clothes to dress their loved ones also emerged as an important ritual that was denied:

"It's just like the closed coffin, can't dress them, can't do anything." [Ann]

"Obviously I was told I couldn't see him at the funeral home. What they didn't tell me, and they're telling me it's a government directive, I didn't think about it then, I thought about it afterwards, that I hadn't dressed him. Apparently I wouldn't have been allowed. He was most likely in a hospital gown in a body bag [sob]." [Charlene]

"I wasn't allowed to dress him. He had to wear the hospital gown." [Pat]

"So, he was placed in the body bag, and I just gave [the funeral director] stuff that the children, the grandchildren wanted to put in the coffin with him, and various different things. And he just was placed in the coffin inside the body bag, which isn't what he wanted, and it's not what I wanted, but we have to protect people who are alive, and I wouldn't have

dreamed of asking to go and see him.... I wasn't allowed to dress him on the ward. I asked if I could, and they said, no." [Fran]

"I asked them [the hospital] to send her down in a hospital gown, and because she was Covid positive, once she was in that gown, they wouldn't change her because once she got to the funeral hall, they wouldn't dress her." [Pauline]

"We couldn't dress her. She just had to, you know, I don't even know what she was in, because we've got so many things that haven't come back from the hospital, that they've lost." [Emma L]

Again because of closed caskets, some people who were able to provide clothes are doubtful if their relatives were dressed in them:

"We took clothes for dad, but we've got no idea whether he was dressed in them or not. We were told that they would do that...., basically after we said goodbye to dad on the video call on the 29th, just before he died, and he was still telling us he was okay, as he was dying, we never saw dad again. Never saw him in the funeral home or anything. So, I don't know whether they did dress dad in his clothes. I've no idea." [Claire]

3.8.3 COVID-19 funerals

Just as the denial of many initial death rituals made grieving even harder, so too did the numerous restrictions on funerals. Emma and Emma sum this up when they state:

"The funeral was obviously really weird.... it was just – it felt like we didn't give her really the funeral that she deserved or that she wanted." [Emma K]

"Those limits on the funeral and – yes, having it on Zoom." [Emma L]

Some had delays due to sheer volume of funerals taking place:

"The funeral was a month later because there was so many people dying at the time." [Lynn]

And some had to endure a double funeral:

“We had a joint funeral. They couldn’t do them both at the same time, but they did one after the other. So, the people that went to Steve’s- Steve was first. So, we had Steve’s funeral, and then straight after, we had Valerie’s. But we had to come out and then go back in again.” [Liz]

“We did a joint funeral. God, I couldn’t have done it, I couldn’t have done two.” [Becky]

A number of different funeral rituals emerged as particularly important:

Places of worship

Margaret explains the importance of holding a funeral in a place of worship for some people, and how she felt ‘lucky’ to be able to do this:

“My mum wanted, my mum was very, very clear about the type of funeral that she wanted. She wanted a full Requiem Mass and she had her hymns picked out. She also had the pictures that she wanted for the Order of Service... But then came the realisation that she wasn’t going to get her last wish. She wasn’t going to get the service.... I contacted the priest, and he said, “Look, if you’re willing to delay the funeral for about a week, it is looking as if we are going to be able to open up. Still with restricted numbers, but we think we are going to be able to open up the Cathedral in [city in Scotland],” and that was where she was baptised, it is where she got married, it was where my Dad was buried from. It was our local church, I know it was a Cathedral, but that’s where she went all the time. So, we were truly lucky, and it turned out that yes, she was the first one in the area to have it in the church. I can’t even describe, I don’t practice religion at all but I can’t describe the comfort I got from knowing that my Mum got what she wanted. Because the thought of not being in church, I couldn’t have coped. But she got what she wanted.” [Margaret]

Others were not so fortunate:

“Mum couldn’t have a funeral. Because Mum wanted a funeral in a church and churches were closed.” [Pauline]

“We weren’t allowed a church so we had a graveside funeral. My mum and dad both went to church their whole lives. So they were very much church members, you know they were members of a Methodist church. So they would have, under normal circumstances, he would have had a church service.” [Becca]

Funeral cars

Being unable to have the usual funeral cars also emerged as an important issue for many:

“The one that caught me was, I was trying to arrange everything to be the same as dad’s funeral and then they said that we couldn’t have the limousine and that was the first moment I realised that things were really different.” [Adrian]

“The fact that you’ve got drive there yourself, no funeral cars” [Ann]

“We couldn’t have any cars. Like normally you’d get picked up in a car, you know, you’d travel together wouldn’t you? But as it was I went down to mum’s house and I literally, I got dressed and ready myself. Went down there. And I literally got her out of bed, put a jumper over the top of her pyjamas, brushed her hair, put a rug on her legs- And wheeled her out.” [Becca]

“It would have been nice if they could have included a car. We weren’t allowed to have a car. So I ended- Because I don’t drive, we ended up having to get a taxi over there. ... Well the thing is most of the limousines they’ve got leather seats. They’re easy to wipe down. And then most of them have got partitions between the driver and the back.... I think it mattered because it’s part of the ritual” [Shelley]

“There was no hearse, no following. The coffin was what they called, in situ.” [Pat]

The lack of a funeral procession had a knock-on impact for some:

“When we came up to the crem, the hearse had got there before us. And it was just sat on the corner waiting for obviously the service ahead to finish. And I wasn’t expecting it to be sat there. And I knew it was his because his Man United scarf was over the back of the coffin. And it hit me like a sledgehammer. And I just started crying. And I grabbed hold of my son’s

knee, I left him with bruises bless him. And he's like, "What's the matter?" And I just went like that. And he's like, "Oh." And then it just seemed so wrong for him to be sitting on the side of the road." [Shelley]

Coffins

Restrictions pertaining to coffins, too, added to the abnormality for many families, while for others it went against their expressed wishes:

"Then you get there, that you meet and then it's like, "Stand away while we move the coffin in, don't touch the coffin." Yes, that we had to stand away while it went on the trolley, while they wheeled it in. And again, I think the hardest thing is like that my daughter came with me it was the very first funeral that she's ever been to, she was like 17." [Ann]

"We weren't allowed to touch the coffin." [Pat]

"I noticed they didn't carry the coffin, they put it on a trolley...I didn't understand that." [Charlene]

"The only other thing, the thing I think she'll come back and haunt me for eventually- My mum was a great one for people's coffins being carried, she could not abide the trollies. She used to say, "Oh." I was taking her to her friend's funerals, and she would say, "Now remember Margaret, do not get me down that aisle on a trolley." She said, "They think it is ASDA in here." But sadly, although we were able to have it in the church, we weren't allowed to carry the coffin." [Margaret]

Flowers

Funeral flowers also emerged as important, and while none of our families were denied them, many expressed relief that they were allowed, at least, to have flowers:

"We could have flowers!" [Stuart]

“We just made sure that she had every flower because she loved her flowers every flower going.” [Lynn]

I was so lucky to even get flowers. There were no flowers around at the time but I managed to get some flowers [Pat]

“And I managed to get flowers as well because that was one of the other things, I thought how awful it’s going to look if this hearse comes along and there’s no flowers. And I know some people couldn’t have flowers. Then in my mind I was thinking it would just look like he’s unloved. Which, do you know what I mean? It doesn’t really matter what other people think because, what he knew and what I know, it doesn’t matter. But you just think, I just need to have some flowers. I said to my husband, even if I go to the supermarket and buy bunches of flowers I will have flowers.” [Becca]

Singing

“We couldn’t sing” [Annette]

“Obviously you couldn’t sing or anything. So I think that made it even harder to be honest.” [Emma K]

“We weren’t allowed to sing” [Emma L]

“So, we literally walked in and it was silent and we’re like looking at each other going, “What happened to the songs that we picked?” and then it was like, “Oh, they’re having problems with the music player today. It might and might not work for when you’re working out,” but it didn’t. So, again it’s things like that that the funeral, as you know, so not what it normally is anyway and then not to have the music as well, it just adds into another kick in the teeth. And you know like you feel like robbed anyway and so just like something else just then just, you’re like, “Oh, can this get any worse.” [Ann]

Restricted numbers

The sadness caused by restrictions on the number of people allowed to attend was apparent in almost all narratives, with most people mentioning this restriction. The following quotes are selected as ways of illustrating the added pain that this caused:

“There was no funeral because there was nobody there except me.” [Suzanne]

“One of the awful things about the funeral, was it was only myself and my wife that were allowed to attend and my mum would have hated that because she was very gregarious.”

[Adrian]

“We’ve got four children and he was the eldest so it was just us just five of us.” [Diane]

“And he’s done lots of volunteering. He worked for the local hospice, he worked for the local theatre, for Samaritans. He was in banking, you know, he knew loads of people. And he’d lived in the same house for 35 years, he knew a lot of people. So it would have been a fairly full house, you know. Instead we were limited to 10 people, and we had seven. It must be quite strange for other people who haven’t had, they know he’s died but they haven’t had any kind of long term family friends that are just, he’s just gone and they haven’t said their goodbyes.” [Becca]

“It was limited to 30. And we did have 30. We could only have 30 anyway. I mean Pam would have had- Pam would have had 300 at her funeral if it had have been the normal funeral, simply because of all the people she knew in the dog world, and you know, she was, as I said, well-known and well respected.” [Stuart]

“And so we only had seven people... it’s like my dad’s got three sisters so if you’d invited one of them, the other two would be upset” [Ann]

“It was up to 30 for a funeral but the crematorium that we were using it was only 20. And then 15 people for a wake. How do you do that? How do you decide?” [Becky]

Some families were unable to even meet the upper limit, either due to travel restrictions or the fear of not being COVID secure:

“We were allowed 30 but because of the travel restrictions no one could come really there were about eight people there.” [Emma K]

“Ken’s funeral took place about 2 weeks later, which at the time only 10 people could attend, friends and family came to the Crem outside, but a lot stayed away because of lock down.”

[Anne]

“We were only allowed five of us. My daughters live up country. They weren’t allowed to travel.” [Sian]

“We were allowed 10, 9 people plus the celebrant. I made a decision, because it was held at the beginning of May, that I could not put friends and family through the possible risk of picking it up and either losing them, or them passing it on to someone else and them dying. I couldn’t cope with that guilt. So the funeral was arranged through Co-op because I got my staff discount. And they arranged a web viewing.... so there was just me and my son”

[Shelley]

“I mean the difficulty was that a lot of the people that my mum knew and was friends with were of a particular age. They were either in [place name] and were too old and infirm to come, or even if they were local, you know, they were at risk and things. And we were in lockdown and things, so it didn’t make sense to put someone at risk just to simply, you know, pay their respects.” [Adrian]

“We were only allowed 30 at the church and we were allowed 10 at the burial. We done it by video link for her family who lived away because they couldn’t travel” [Lynn]

The issue of video links for those unable to attend, either due to travel restrictions or restricted numbers, also emerged as problematic for some:

“We had eight, but I think we could have had 30, or was it 15 or 30, I’ve forgotten now, there’s been so many different things going on. There was definitely eight. We had a webcast which kept dropping off apparently all the time, because we had quite a few family members throughout the world, and even locally dialling in, and the sound quality was poor or it kept buffering, or stopping, so it wasn’t great.” [Claire]

Some found ingenious ways to circumvent the restrictions on numbers:

“We were only allowed 10 people at the graveside but - there was more than 10 relatives, I’ll be honest, but because it was in a graveside, it’s a public area, so people were sort of walking round you doing laps” [Pauline]

“A restriction on numbers of 25... They were allowed to socially distance outside as well, and they were hundreds and hundreds. There was hundreds of people lining the street and hundreds of people outside crematorium. Yes, so – but again, they were all spread out everywhere and all really kept to the rules.” [Amy]

“He wanted to be buried in the burial ground which I used to manage, and they’ve got a beautiful building for the ceremony. And we were allowed to have 30 people inside the building. So, we had a guest list, and we had to be really strict about who could be inside and who couldn’t. But actually, people were allowed to stand in the courtyard outside. So, a lot of people were able to do that.” [Fran]

For others, restrictions on numbers didn’t matter; though the underlying reasons for this differ between people:

“It didn’t matter that there weren’t many people there because the people who mattered were there.” [Judith]

“Ten or twelve. Just us, me and my sisters and his parents and that’s it, and his brother. Nothing. I mean to be honest, I was- I could not believe it was his funeral. So it was the worst day of my life for me and my daughters. Because I could not believe this. And I didn’t even want a big crowd even if we were allowed. I wanted the day to go quickly, put it that way. I was not- I just could not believe it. I was in a state of shock. I just did not, could not put him in the past tense and you can imagine the impact on my girls, you know. No, it was the worst day of my life.” [Sonal]

Time limits

Others found the focus on short services to be hurtful:

“Straight in, straight out.” [Annette]

“The organising the priest to do like the crem, go to the crem, again that she was really not sure and she was really obsessed about the time we had in the crem, very much like, “Oh, you’re limited on the time. Don’t pick a long reading. Don’t make a big-,” do you know and you’re like that going, “You shouldn’t have to pick readings on their length”. And so you’re

then just like that going, you're then just thinking, it becomes time-oriented rather than, "What do you want for your mum". [Ann]

"Half an hour. The half an hour it just, it was rushed because you're waiting for the service ahead to get out. But if they're moving that holds you up. And then that holds everybody else up. So then you feel like you've got to get a move on." [Shelley]

"And because it was a burial, it was just a graveside service and it was only allowed to be 15 minutes long, which seemed like, well, if there's only four of us and we're socially distanced, why does it matter?[But] The vicar was lovely, and he said, once he'd finished his bit of the service he said, "You have as much time as you want here, there's nobody from the crematorium around, they're not going to bother you. You've got time for whatever you want to do to remember her." It made all the difference to do that." [Sarah]

Comfort from an intimate funeral

For a few families, the small funeral service unexpectedly brought some comfort:

"And you know and there are things, you kind of give yourself rules or how my Nan's funeral went, and obviously like my dad did a speech. And I was sort of thinking, at some point, you know when this, I'm in this situation that'll be me, I'll have to do this speech. And then afterwards I was thinking, actually it was just the seven of us and I didn't do a speech, and there was no expectation. I didn't have to sing while I was trying to hold back tears. You know there were bits about it that were actually, it was really a little intimate service that you never would have got with a church full of people." [Becca]

"To me, it was one of the best days. I spoke the eulogy. I could speak about my dad freely and openly. It was a celebration of him." [Pat]

"It was nice. It was good, and it was a nice day. I thought the same, because we were outside and we were open, people are not going to be as funny about, oh Covid, move away from me. It was just a nicer setting. You forget about COVID kind of thing." [Charlotte]

"The family were there. And some of her key friends. Some of my key friends. So the funeral was quite nice as much as one of those things can be quite nice. It was done in a tasteful way. We could have the people obviously standing out in the open. I was able to read a eulogy. And several of our family were able to say a few words. You know I have to say, it was quite, it was as nice as it could be." [Stuart]

“In all honesty the funeral I thought was beautiful. I thought to myself I don’t think I could have done that any better because it was only me because I’m an only one and planning it and everything and I thought it was dignified and beautiful and I just hope that if mum’s up there she thinks that too, you know.” [Judith]

So, the ceremony was beautiful. The day was beautiful. It was exactly as he wanted it. The people that he wanted to be there were there. It was all videoed, so I can watch it back on video. I think something like 2,500 people have watched it since the day. So, the funeral was amazing, and I felt like I’d done what he wanted for the day” [Fran]

“The best bit was the celebrant got his name wrong and my son’s name wrong by accident. Because he’d- we were his fourth service of the day. I was going to say something. He called Nick Brian at one point. And it was just like, what? And then he called Anthony Nick. And I was like, okay, did I hear that right? And I sort of side long looked at my son out of the corner of my eye, and he went, and rolled his eyes. And I thought, I’m going to say something. And then I thought no, he’s having a rough time at the moment. I’m just going to let it slide. And then I thought to myself, Nick will be killing himself laughing up there.” [Shelley]

“We were all dreading it, but actually, it turned out to be a surprisingly lovely service for several reasons. One of which was that we had put together an order of service, although we knew it was, what we wanted was to feel that people were supporting us, the four of us, my brothers and myself, and so we suggested that if family and friends wanted to, if they would light a candle at the time that the service started and we got the order of service with the eulogy, obviously there weren’t going to be hymns or anything it was just literally the burial service, and we also said that if people wanted things to be put in the grave then they could send them to us and we would do that. And so, what happened was that a lot of the grandchildren and her greatgrandchildren did some really lovely things. I mean one of my granddaughters is quite sort of hippy and she’d made two little potions, a sleep well potion and a peacefulness potion to go in the grave and others of them wrote little notes. And because there were only the four of us there, we were allowed to have our partners sort of supporting us but not with us, as it were, it felt really close, it felt really personal. I didn’t have to worry about, you know who is upset or who is not upset or are the children okay? You know, is there going to be enough food? And all that sort of stuff, all I had to do was just be there and weep for my mum. And it just stripped everything else away and really, although it was very bleak, it was lovely to just be able to think about her, talk about her with my brothers. and to know that there were, I mean we’ve got a very big extended family, there’s about 50 people of it, but also friends, people who’d known my mum. To know that there were all these people who were thinking about her and supporting us at the same time was just lovely, it really was.” [Sarah]

Satellites of sorrow

A major problem, however, was that during funeral services, families could not give or receive any physical comfort:

“Then you go in and you’ve got them seats, two metres apart, and even when I tried to move the seat so my daughter could sit next to my because you’re living together, she was in the car coming together like with my, and it was like, “Oh, no, you can’t move the seats. You can’t sit together.” And so, it’s that whole, “Oh, how can I support everyone?”, that we’d all travelled together. “Yes, you have to still them two metres apart.” And especially like then we had my Nan in the wheelchair because she’s 92 and so we brought her along and, do you know, and then for no one to be able to sit next to her as well. It’s just like, I think it just adds to the upset, doesn’t it?” [Ann]

“My sister and I said, “It’s not fair.” And she said, “You’ll be sat on your own because we can’t sit with you. There’s nobody to comfort you.” [Sian]

“We weren’t allowed to hug. We weren’t allowed to travel in cars together and we all had to be apart” [Pat]

“So the practical bit was difficult beyond words, but the emotional bit was just, because you couldn’t hug people.” [Margaret]

“And it was pretty rampant where I was as well so, you know, it’s terrifying. But I can remember going up there [to the funeral] and people wanting to cuddle me and I’m saying, “Please don’t, I’m in Tier 4.” I don’t, I’d hate for anybody else to catch it because of me” [Becky]

3.8.4 Wakes and celebrations of life

Social distancing, so acutely felt during funeral services, also meant families were denied a wake and an opportunity to be together and support each other while remembering their lost relatives.

“Not be sat by each other, no wake. I think the hardest part was then coming out, getting straight in the car. Going back to the house, getting in our car and driving back to [city], not seeing anybody you know.” [Annette]

“We didn’t have a wake. Literally, everybody left and when their own separate ways. And then we came back here, me and the kids, and we just ate cake. The lady who made us a wedding cake made us a funeral cake as well. So, we had a bit of cake and drank the leftover champagne from the wedding because it was only five weeks since we got married.” [Fran]

“We couldn’t have a wake because you were only allowed six people. ... And obviously you couldn’t have anyone come round not my friends or anything to give you a cuddle even or any of that, so that made it even harder because we all had to isolate for a week after her death as well.” [Emma K]

“So you see what happens is that the urn is sitting there on my sideboard as it happens in so many cases doesn’t it, just sitting there.” [Suzanne]

That isolation was felt acutely for some time after the funeral:

“My parents are 90 and I could not see them at this time, I was on my own in the house and spoke to my family and friends on the front step and they were down the path.” [Anne]

“I was already jumpy. I didn’t do eat out to help out. I refused to go to a pub last summer. I refused to do a lot of the things. And at Christmas in the end I said, I’m going to have to tell my son I’m not coming. I know he’s going to say you can’t do that. But you know, in the end I spent Christmas here on my own.” [Charlene]

“I couldn’t see my brother... I was here, not on my own because I have got a family, I have got a partner, I wasn’t on my own. But I had too much time just to sit and think.” [Margaret]

“The difficulty for me is that because I’m from [area], most of my friends are in [area], so when Wales locked down I wasn’t even able to see my friends” [Adrian]

There was, however, one ingenious even that got around these restrictions:

“In Scotland it is very traditional to have steak pie, potatoes and peas. That’s the staple funeral meal, and we knew that we couldn’t have it. But my wonderful son, her only grandson, came up with this idea. He went to the local butcher, and he said to me, “Mum, the 20 people that are coming, tell me who they are, and group them into families for me.”

And he ordered steak pies for everyone. He got bags of potatoes and tins of peas, put them in bags, little kind of parcels, and handed them out at the cemetery. And everybody at like six o'clock that night, was having my Mum's funeral dinner. Yes, and people were phoning me at the time saying, "Oh, the steak pie was lovely." And out of everything that is probably the thing that I remember, because it was so thoughtful of my son to do it, and I was just absolutely amazed that he thought of it." [Margaret]

Many others vowed that in time a social gathering will take place in order to try to make up for at least one element of the death rituals that they were denied:

"I was sad really for him, because - I was okay - I was - I think because it was such a traumatic - and a shock I wasn't bothered then, you know, today should have actually been the day we had a celebration for him. This afternoon. But because of the restrictions they still - even though the numbers increased to 30 it - where we were holding it wouldn't allow enough numbers so we've put it off now until September." [Amy]

"So I'm in the middle of arranging a celebration of his life now" [Chalene]

"We've got her wake planned for August" [Emma K]

"You know, we've said all along, "When this is over, which it will be some time, we'll have a big celebration of her life and we'll have a church service because that would have meant a lot to her." But it did help knowing that she was such a practical person and she would have, you know, it's not, she wasn't the sort of person that would have gone, "Oh, you haven't given me a proper funeral." It was." [Sarah]

"So, what I'm going to do, I'm going to do a garden party in my garden. So, it will still be socially distanced, but it will be outside. And we've got a garden room, which has got bi-folding doors, so we can open it all up. And it will all be part of that. And it'll be for Val and Steve together." [Liz]

"We'll get all the family and friends together in a nice hotel somewhere as soon as Boris allows us to do that. And then we'll have a meal and a glass of something." [Stuart]

3.9 COUNSELLING, MENTAL HEALTH AND SUPPORT

Undoubtedly, it makes intuitive sense that losing someone to COVID-19 amplifies psychological distress. This perspective is now receiving some empirical support (Joaquim et al. 2021). Given all we have heard so far in this report, it is unsurprising that many who took part have needed counselling, have experienced some wellbeing issues, and have reached out for support in other ways.

3.9.1 Counselling

The extra burden of grief on the families of COVID-19 victims, predicted to be severe and enduring (Lee and Neimeyer 2020) has recently received some empirical support with a study conducted by the Marie Curie Palliative Care Research Centre at Cardiff University, in conjunction with the University of Bristol. In a baseline report, the researchers (Harrop et al. 2021) explain that they identified high level needs for emotional support, with almost 60% of COVID-19 bereaved not having sought any support from bereavement services or their doctor. Of those that had attempted to access some support, more than half encountered barriers such as limited availability, lack of appropriate support, or a reluctance to ask for help. Vastly reduced support from family and friends, due to lockdown, exacerbated the situation. Our research supports and extends the findings of the Harrop et al. (2021) study.

Not accessed

A number of respondents had not been offered any counselling at all.

“I wasn’t offered any” [Margaret]

“It wasn’t offered – there was nothing. There was nothing. I don’t think my GP even realised what had happened. I had no formal offer of support from anywhere at all – nothing. I think there was a letter from the hospital bereavement office, saying, we’re really sorry for your loss, and here’s the number for Cruse. But there was nobody that stepped in and said, “This is terrible, and when you’re ready this is what we can do for you.” There was nothing. And there still has been nothing.” [Fran]

Some didn’t feel this was a problem because they don’t feel ready, or feel that it would be pointless:

“I’ve not been offered any. I don’t know if I want counselling, I don’t, I just feel I should keep it to myself at the moment. [Lynn]

“Sometimes I think I need it but then I think, no, I’m not really, I’m my mother’s daughter, I’m much more a practical person so, you know, I was always brought up but I guess you can’t escape your upbringing, can you?” [Sarah]

“Oh no nobody. And I don’t think I would seek anybody actually because I think the only people who would really understand are the people who have gone through anything like this themselves.” [Diane]

Others felt that they would perhaps have tried it had they been offered:

“No one’s offered it. If it would help and it was offered, I probably would have taken it if they’d have offered it, to be honest, just to see, but I don’t know what they would actually help with or how they would help me with it. I don’t know. You can’t change it, it’s happened.” [Charlotte]

A further group felt that although they had not been offered any official counselling, they had sufficient support from friends and family:

“I’ve not been offered any counselling at all. But again, I’ve got – there’s – one of my colleagues in another surgery, she’s part of a bereavement group, she lost her husband a number of years ago, so she will ping me an email to join a Zoom call if I want. But to be honest, I did think about it a while ago but then I didn’t log on, but I, honestly, at the minute I’ve got such a fabulous family and so many friends around me, that I don’t feel that I need to [Amy]

“Well I’m aware that there is bereavement counselling, you know, I mean I’ve heard of Cruse, and you know I could have reached out to any of those sort of people. But you know, I was- As I said I have had a lot of support from friends and family, you know. A lot of love, a lot of support. I came home yesterday and there was some food on the doorstep. Somebody had left me a meal for- you know, I didn’t ask for it, but you know people are there for me. So I think I’m okay. It’s still a bit hard to talk about it as you can tell. But I think I’m doing okay... I’ve kept busy. And I am keeping busy.” [Stuart]

Inadequate services

A recent survey among healthcare workers from hospice, community, and hospital settings across the UK and Ireland (Pearce et al. 2021) uncovered not only increased needs for bereavement care, but major challenges due to stressed practitioners and the problems associated with transitioning to remote support. Our findings reflect the reality of this situation from the perspective of bereaved people themselves. Some attempted to access some counselling, but had less than satisfactory results:

“I did, you know, I did try to phone the GP initially. And even that was a nightmare as well because you know the GPs are not answering phone calls for one or two hours. You know sometimes in the morning you try to get an appointment, and finally they give me something. But then they said, “Oh it’s going to be like a Zoom with the group.” And I was not comfortable to go in a group. So I just discharged myself.” [Sonal]

“The counselling that I got through my doctor was terrible...It was a volunteer, and not very good – she upset me more than she helped me.” [Liz]

“And then they [GP] said, “Oh well we can refer you for counselling.” Which turned out to be more, it was a phone based thing. And they sort of were saying, “Well we can teach you how to do like positive thinking,” and this that and the other. And it was a bit like that isn’t really what I need because-, it’s not like I need sort of techniques to know how to- I need to process what’s happened. I don’t want to, I don’t need to find ways around coping at work or what have you because I’ll be fine at work once I’ve processed it. Or you know, it’s not that straightforward is it?”[Becca]

“I tried to access counselling last year because after my mum died I did become really, I was a really heavy drinker because there was nothing else and I sort of like. So, I was aware of that and I did try to access counselling and I had the first sort of like the triage session that you go through before you go through like the eight sessions and the person I spoke to after like telling them everything give my some like tips like, “Oh, don’t think you should be drinking so much and try and speak to friends on the phone,” this, that and the other, “but I don’t think you’re in a place to have counselling at the moment because I feel eight sessions will probably leave you in a worse place because it will bring up some of the emotions but there won’t be enough,” and it’s made me feel that I’ve not actually been able to go back because it’s hard to go through like especially when you’re feeling really like at the time to say how I’m feeling and this is what I’m, to then go, “Oh, you’re actually too bad to have counselling-,” you know, it’s just awful. So, it was just like, “Oh!” Really, they did offer like suggestions like, “Talk to your friends. Try and go out for a walk,” and you’re like, “I know what I should be doing but I don’t feel like doing that anyway.” [Ann]

Interestingly, two respondents were already counsellors themselves, and felt this put them in a particularly difficult situation:

“I actually was a counsellor myself for CRUSE, so it is a bit like physician heal thyself. I know the, yes, that would have been a difficult one. I have got a very good friend who is a psychologist and I have spoken a lot to her. I have got two dogs and two cats, and yes, you just have got to keep going for them, haven’t you.” [Margaret]

“At the time I don’t think I could even work out what I needed. Just rewinding a little bit, because of my background, because of my work, I am a trained Samaritan, I’ve done Cruse bereavement counselling. I’ve got bookshelves full of books about dying, death, and bereavement, and grief. In theory, I know everything there is to know about death and bereavement. For me, once it happened to me, the way that it happened, it felt like I’d gone through the looking glass, and I was in some completely different reality. And I didn’t know who I was, or where I was, or what I needed, or what would be helpful to me. All of my

knowledge was worse than useless, actually. I don't know if there's anything that would make things easier for me. I think I probably would benefit from one-to-one counselling with a very skilled counsellor. I can't afford to do that. It's not on offer anywhere, so I would have to seek it out. And I don't know if I've got the wherewithal to actually start interviewing different counsellors until I find the right person. I think the one thing I would say is that the absence of any kind of professional intervention or an offer of there being some support available when you're ready, if you feel you need it. I think that for me would have made a big difference. Because to identify that you need help is bad enough, it's difficult enough to do. But to then do something about being proactive to go and look for it is beyond my capabilities, and I'm a pretty competent person." [Fran]

Receiving counselling support

A small number of people had accessed national and local charity counselling and found them useful:

"I've had eight weeks of Cruise counselling, which helped a lot because I can't believe how it affects you because it makes you so angry doesn't it?" [Annette]

"The first lot of counselling I got through my church and it was group counselling and it was counselling for not just Covid. It was a general counselling. It was very good. A bit later on I then did the National Bereavement Partnership that, I think I had 12 one-hour sessions and the lady was so lovely" [Pat]

"I'm having counselling... My sister, one of her friends, works at the local hospice, and told me they were doing counselling. I rang our – we rang our doctors to find out about it and that's who they're doing the counselling through, so I've got [name of hospice] Hospice, I think they're doing about 14 weeks....You're walking round a supermarket in tears looking for someone else who's walking round the supermarket in tears. But they're arranging little groups to meet like on Zoom to start with, meeting up just – not to talk about this but just to do other things." [Emma L]

The majority of people who had managed to access counselling, however, did so through their work or privately:

“My work have done counselling for me. Yes, my work are quite good. But my dad and sister haven’t had any.” [Lynne]

“I was fortunate that because [my employer] have like a counselling, well a private healthcare scheme, I was able to access it through there. I did also, my wife did also arrange a particular counsellor privately because we didn’t necessarily want to be seen to be accessing counselling every five minutes.” [Adrian]

“I did pay privately to go for counselling because I just kind of thought, I need to do something to kind of try and release or work through what’s happened. So I did that off my own bat, which helped me because it kind of helped me think about things in a different way. And one of my daughters she went along to the same place but with a different counsellor because she just would find it very difficult to say anything about my dad at all. And they’d been really close. But I think she just didn’t know how to deal with it and what--what she was supposed to think or feel.” [Becca]

“I did take counselling very early on. Because of having that meltdown in the middle of the night, it really scared me. And then they [work] sent me links for a local bereavement service. And then followed up a week later to make sure I was all right. So I’ve had amazing support from work. I’ve gone back to counselling, but it’s once a month at the moment. I realised when I started unravelling around his anniversary that it might be time to reach back out. And I did. And I said to, I managed to get the counsellor that I had before, and she said, “How often would you like it?” I said, “Well can we start on once a month and see where I go from there?” And we’ve been doing that and it’s been helping.” [Shelley]

3.9.2 Mental health

Some respondents bravely shared some quite distressing stories about the ways in which their grief has impacted their wellbeing. Shelley and Adrian recall particularly upsetting events:

*“...various interventions including counselling, from work, medication from my GP and various treatments identified by my wife culminating in May 2021 when I attended the Priory and suffered panic attacks which caused me to attempt to leave (via a window)”
[Adrian]*

“When I had an absolute meltdown a few days before the funeral, middle of the night, I rung the counselling service and the lady stayed on the phone with me for two hours. I had an absolute meltdown... I, it’s only recently I admitted the thoughts that I had that night. And considered the options that were available to me. And I don’t ever want to be in that position again... I never want to feel like that again.” [Shelley]

Suzanne, too, feels that she needs more support despite having accessed a range of counselling services:

“I’ve had counselling, I’ve had I don’t know how many counselling sessions- -various places .. Then after that ended I really couldn’t cope and then there was an organisation called Sudden so I brought onto them and then I thought, okay now you’ll be able to manage but again at Easter I had a real breakdown.... And then I contacted the national bereavement service Covid bereavement service and they came through really, really fast. So far I have had nine sessions with them but again the councillor and me we’re both saying it’s probably not enough and you know at least in some not maybe every week but I need some support still so at the moment I don’t know where and how.” [Suzanne]

Medical intervention

A recent study (Wang et al. 2021) found COVID-19 bereavement is associated with significantly higher likelihood of reporting depression and reporting worsened depression among a sample of older adults across 27 different countries. Unsurprisingly, a number of our participants have needed support from their GP:

“I ended up going to the doctors because I was- I went back to work because my class is year 5, 6, so I went back to work the last six weeks, May into July, which was fine. I think I kind of needed the distraction if you like. And then when I went back in September it was almost like people had forgotten. And I’d be sort of stood there looking at people thinking, ‘I don’t know what I’m doing here.’ And it was almost like I couldn’t kind of- I don’t know how to explain it

really. But just everything was kind of going on around me and I just didn't feel like me- ... I'd just be stood there like, mmm. Just watching them all thinking, 'What am I doing?' It kind of just felt, which is not me at all, but I kind of got to that point where I just sort of thought, I don't know what I'm doing here. And so I spoke to the doctor at that point and just said, "I'm not- It's not a good place for me." Not that it's not a good place, I'm not in the right place to be in school. Does that make sense? So I had some time off." [Becca]

"I mean from my own perspective; it has been detrimental to my own mental health... I ended up going through medication from the doctor." [Adrian]

"I mean I think my GP knew what was going to happen because I'd rung the doctors on the Monday Nick died. And I hadn't slept for about three days. And I just wanted her to give me a few days of sleeping pills so I could- I needed rest. My body needed to sleep. But I was constantly waiting for the phone. And I think she must have spoken to the hospital because she immediately prescribed me with anti-depressants. So I think she knew what was going to happen. So and I have been on them since." [Shelley]

"I saw my GP I said look I find it really difficult to cope I kind of survive from day to today but I can't do a full-time job it's very difficult just to keep going. And he said, "Well, it's a whole year now so after full year I think you're suffering from depression I think I need to give you some antidepressants." And I thought well antidepressant it won't make any difference my life has fallen apart, there is nothing you know antidepressants make you maybe change your outlook into something more positive and I thought, well there is nothing here which is where my outlook can be more positive. Just need time and I need to work through the trauma I need have some answers and I just need to learnt to live with the grief I can't- Why should I- You know outlook more positive to do what? It's nothing I can focus at least on even if there's a more positive, nothing there you know it's nothing there. And then he refused even to put me a list to get some more psychological support. He said, "Better try those antidepressants." Easier isn't it?" [Suzanne]

Continuing struggles

Others are still suffering flashbacks, 'brain fog', and other trauma:

"It was just horrendous to be honest. It was just- yes it stayed with me. And the wail- Not to be able to be, you know, it's different if they reach that, you know, if he wasn't even- If he was sedated but he wasn't, wailing at me. He wanted help, me to help him. As soon as he

heard my voice, oh God and that, just not to be able to do that. I think that's caused me some trauma actually if I'm honest, because I keep reliving that." [Sian]

"Now more than for myself I'm worried about the girls you know. I've put my emotions on the side but I just can't see them- You know this is, it's very, it's like they're going through a trauma I would say. Mentally you know, my elder one especially. She just, at night, every day, she just breaks down. The trauma, the age, and they are not babies or they are not adults. They are in that age that is very fragile, yes, very fragile. And the younger one doesn't just talk anything about it. Like she's acting strong. So I don't know whether all the emotions are buckled up within her. She just doesn't express anything." [Sonal]

"At this moment in time I can't handle paperwork at all. Like, I have a lot of paperwork because my son's disabled, so I have to fill in paperwork and now I actually look at it and it terrifies me. Whereas before I was really competent and could do all that stuff before and now I look at it and I want to scream. I want to rip it up into little pieces and I want to hide away. I want to curl up in a ball and shut the curtains. I've definitely lost my sparkle. I can't do paperwork. I've got a completely fuzzy head. The anxiety of not going in shops has got better. Yeah, I've definitely got a low mood." [Pat]

"I'm an Executor of his will. But it's really difficult to deal with if your brain's fully functioning. But in the first few months, my head was all over the place. So, having to do practical stuff, I found that I could only do a tiny bit at a time." [Fran]

"I've not had any counselling, but I did speak to the mental health liaison at the hospital and had a chat with her and she offered some pointers which I have taken on board, and which have helped me. I'll be honest, I haven't been in a pub yet, since they've been opened. I don't want to. I don't want to go- I understand these football- I'm not a football fan, I'll be honest, but if these people want to go to these football matches, I personally wouldn't, because I wouldn't feel safe. So I suppose I have got a little bit of PTSD in that way, in that I don't like groups or crowds. When I'm out shopping, I'm going to where I'm going and I'm coming home." [Pauline]

"But no one can help me... The loneliness, the heartbreak. I just don't know what to do with the rest of my life now. I don't know. I'm completely lost." [Liz]

3.9.3 Complicated grief

Complicated grief describes a situation where grief is debilitating and so painful and severe that people struggle to recover and resume their lives (Mayo Clinic 2021). Unsurprisingly, the denial of normal death rituals and the inability to be with loved ones when they died can greatly increase the risk of complicated grief (Diolaiuti et al. 2021). Many participants shared such feelings of intense grief. Sian explains that because a COVID-19 differs from a 'normal' death, the grief also differs:

"You see we'd only lost mum the year before and they contrast in the deaths, in the passings. Because as I said to you, that's why I gave you the history of mum because it's hit me and I said I'd look after dad and make sure-, and I just, to, you know, mum we nursed, we bathed her, we were there that week, she has all her family round her. It was the most best possible death, you know, and we slept with her so that she wasn't afraid when she was passing. And her funeral, beautiful. She picked her own funeral. She picked all the songs, everything. So I mean there's not many times you get that. But then to Dad oh the contrast was so severe"
[Sian]

The isolation caused by lockdown has also made bereavement much more difficult:

"Because you've not even been able to see anybody to talk about it." [Annette]

"Socially, support was by phone and by letter" [Fran]

"Unfortunately, I'm on my own we didn't have any children; my relatives are not in this country they're in Ireland and France and Germany so you know there's nobody here. So all this year I've been on my own, I wasn't seeing anybody" [Suzanne]

For many, the intense sorrow appears to be rooted in guilt:

"It was the worst time ever and something I know I will not get over. I have had counselling in the early stages of my grief which helped a little, It could never take away my guilt, I should have done more, got him to hospital sooner, fought to be with him, or even left him at home at least he wouldn't have died alone and scared." [Anne]

"I really struggled with survivor's guilt. I couldn't be with him when he needed me. I always promised that I'd be there." [Shelley]

"And of course it's the amount of guilt as well which I say, alright even if he had to go to accident and emergency why didn't I take a taxi get him up there and just take him out?" [Suzanne]

"So I feel that I didn't phone up early enough to get him in. But he wouldn't let me. They said it wasn't my fault." [Jackie]

"And my daughter was in pieces because she said I'm a nurse I couldn't save her. I blame myself for sending her in but she had to go in she had to. I should have got her out." [Lynn]

"I wasn't with her when she passed away and I was with my dad I was with my Uncle I was with my mum's brother because there was no other family member and my Nan but I wasn't with my mum and that's the thing that gets me at the moment. You know grief comes in various cycles doesn't it, at the moment I'm feeling I've let mum down. And the funeral was – she'd left me a letter that said just like dad please, well I couldn't do it just like dad you know and so I just hope she knows that I didn't let her down on purpose.... I really feel I've let mum down." [Judith]

"It's all very raw, and my dad can't speak about it. My dad's now so guilty that he allowed her to go to hospital that he can't live with himself." [Lynne]

For some, the overwhelming sorrow prevents them from being able to find any positivity in their lives:

"I've got to find what my counsellor called new normal. Whatever that may be. And it really hurts" [Shelley]

"For me, it just feels like I've just got to get through this and get used to a life without the one person that always made everything better. I'd talk to him about everything. He'd talk to me about everything. We just shared our lives. And it's so strange, it's like all the clichés that you read about death that are actually so true. You feel like your heart is physically broken. I feel like half of me is missing. My little grandson wrote on the memorial wall, 'where are you?' And it just feels like that, where are you, because you're not here and I need you to be back here. So, I don't know if anything would help, really. I don't know." [Fran]

“My life has fallen apart, there is nothing you know antidepressants make you maybe change your outlook into something more positive and I thought, well there is nothing here which is where my outlook can be more positive. Just need time and I need to work through the trauma I need have some answers and I just need to learn to live with the grief. But I can’t. Why should I? You know – an outlook more positive to do what? It’s nothing I can focus at least on even if there’s a more positive, nothing there you know? There’s nothing there.” [Suzanne]

I’m quite open about it. I hate my life. I loved my life – I absolutely loved every bit of my life. And when I retired, I thought from the day I retired, I loved every minute of it. And lockdown for me was great, because I spent so much time with Steve, because we were always so busy with his trade union work and my job in the city. And for us to spend all that time together. And we had all those plans about what we were going to do. Now I wake up every morning- and think, another miserable sad day.” [Liz]

“It’s sad, it’s very, very sad because like my girls and I, we are left in the limbo, yes. Do you know we are just, the ones suffering. And, you know, to be honest, we can never be okay. So whether it’s tomorrow, after six months, after one year, we can never be okay with this kind of loss.” [Sonal]

3.9.4 Social media support

During lockdown, people in society became highly reliant on social media for perceived social connectedness (Nguyen et al. 2021). We have already heard how many of our families relied totally on social and digital media to communicate with their loved ones while they were in hospital. However, using general social media platforms during the pandemic has for some amplified negative feelings such as anxiety and panic, and caused frustration due to the sharing of misleading information (Schoultz et al. 2021). Respondents felt these negative impacts acutely, which increased their isolation at a time when they desperately needed social support:

“It does sometimes have its downsides. I find since Bill died, I’ve found Facebook quite hard to interact with. So much so that probably before I found the [COVID support] group I had a little clear out of the when it all started kicking off about Christmas and lockdown. And in the end it was like do you know what, I don’t need this. Delete. Because these were people that know Bill. So I had a little clear out.” [Charlene]

“I’m trying to stay away from a lot of social media because I accidentally went- well not accidentally, I went on something today and low and behold on one of the community groups for my local area, somebody has a freedom of information request answered disputing the overall number of deaths. So, there’s not a pandemic going on, they’re over exaggerating. Somebody else is going it’s flu, there’s nothing worse than flu. I thought what the heck? I usually try to avoid these things.” [Claire]

Social media groups: feeling connected

In contrast to social media in general, most bereaved families found a sense of cohesion with others who had similar experiences, via the online COVID-19 support groups. A feeling of being less alone, and part of a community that was understanding, emerged clearly:

“It’s really, really important. I think it’s the only place you can go where people truly understand what you’re going through. Nobody else truly gets it. So, yeah, it’s people that totally understand where you’re coming from. Where your concerns are. Why you feel the need to be there. And it makes you feel normal.” [Claire]

“I am on it quite a bit because I find I get support in a way that they understand. You know everybody else, even my other half, I think they think you should be over it. I do because they understand, they’re going through the same. So yes I do get comfort from it.” [Sian]

“I mean I don’t post a vast amount. I’m- But you know, I will comment on other people’s posts. But I’ll sorts see what other people have written, and I’ll think, ‘Oh gosh that’s just, that’s so, that’s- I do that. I do that. Oh that, I feel like that.’ And I’m thinking to myself ‘Oh gosh I feel like that.’ But I didn’t want to- You don’t necessarily verbalise it. But then when someone else says it, you think, ‘Oh God yes that is, that’s right, that’s how I feel. Oh yes, that’s it!” [Becca]

"[The Covid-19 Bereaved Families for Justice] is a wonderful support group. It has been very, very supportive. There's been no bitching, no backbites, no nothing, ever" [Adrian]

"I'm in eight different groups. To talk to other people that are going through the shared experience. I think that's really important to speak to other people. Without those groups, I don't know where I'd be without those groups." [Pat]

"It helps me, because it just makes me feel, well, I'm not the only person. There are loads of people who are going through this. So, that helps me just knowing that." [Charlotte]

"I think oh god yes, I know exactly how you feel. But also, it did help me understand that what I was feeling was normal. And then reading the stories at the beginning I thought that's exactly how I feel. So, it made me feel better in some respects." [Annette]

"Do you know, when I first joined the [Covid-19 Bereaved Families for Justice] group, I was really concerned that I would find it overwhelming, because I was in the middle of own madness of those early days and just not knowing whether I was coming or going, not sleeping. I joined the group, and one of my friends said, "Just be careful, don't over immerse yourself in this." But actually, what I found was like a family of people. It's like a family of- we all know. And when new people join, it's just like, now there's more people in this awful family that none of us want to be in. But it's so wonderful. There's so much support, and there's so much kindness, and there's so much understanding, just within this little Facebook group of people that I'll probably never meet most of them. ... We're social creatures, aren't we, us humans? And we need each other. So, virtually is better than nothing." [Fran]

"And it's nice just knowing that if I need to have a rant about something, I can put it on the group and it's a safe space that the majority of people on there will understand." [Shelley]

"I go on it sometimes, I don't post very much, what I do post is generally just when a story really touches me, just to say, "I'm so, so sorry." ... And so, from the group point of view, I kind of, it's a bit selfish in a way, but to see people and think, my God, I'm so blessed, really, my mother was old and she didn't die an untimely death and you can't help but feel part of that grief, can you, when, in the group, you feel the pain that so many people are carrying? And you want to support and you can't because you don't know them and you just, it's awful and I feel that it's something that only people who have been bereaved by Covid, even just sort of peripherally like me, as it were, can understand because it's so huge, it's so many people and it's going to impact on their lives forever." [Sarah]

"And a lot of people are like me, you know, affected. Because I've joined these widow groups. And I hate that word widow as well, it's horrible, it's awful. I have to get some sort of comfort because not many people understand the situation, you know." [Sonal]

I've got the Facebook site the Yellow Hearts Bereavement which is a beautiful website... you get upset sometimes when you read someone's story but you also know you're not the only one." [Jackie]

"I don't know the right word it's not nice to know that other people know what we're going through because obviously it's awful but they're other people that understand what you're going through at the same time. So I found that that helped me a bit more because it's quite an unusual situation. I think it's a different type of grief it's quite specific because of all the restrictions and things like that. Yeah I mean it makes me sad how many people died obviously and how they died, but it's almost nice to have people you can reach out to and that they're standing up against the government as well and saying actually no this is wrong. So it's not just you trying to fight on your own." [Emma K]

Reciprocity

Feelings of mutual support were clear in many narratives, as these quotes articulate:

*"You hear some awful stories and as I say because again, I lost my mum early on and it was expected and all that kind of stuff, I've not been affected as badly as someone who say, has lost their partner and things like that and so I feel like I can reach out and try and provide a degree of support and I get something out of that myself by trying to provide that...
Everybody is so supportive of each other." [Adrian]*

"I've found myself taking advice but giving it as well.... I've said, all of a sudden this complete group of strangers are closer to me than my friends are because I've got more in common with them, even though I haven't met anyone." [Emma L]

Leading to real-life support

A few families explained how the online support groups have led to them meeting up in reality for mutual support:

“I’d joined the charity you might have heard of them The Compassionate Friends. So The Compassionate Friends TCF for short are based in London it’s called The Compassionate Friends, it’s for bereaved parents. If you haven’t heard of them they are an absolutely amazing charity and it was actually a friend in Australia that told me about them actually funnily enough. Exactly. Sometimes it’s to road traffic accidents or sometimes it’s hospital negligence it’s for people who’ve lost their children in their 20s to things like you know road traffic accidents or sudden deaths in all sorts of different circumstances actually. And they are 20 out of 10 honestly they are a very very good. Well, since things have eased a little bit they organise small group walks in nature.” [Diane]

“Two women at the same time lost their husbands in the same ward in the same hospital to Covid and I met them and every time I meet them- Well one of them is still very much affected and you know it’s heart-breaking as well. The other one her husband was Irish as well and we managed to talk and go for a walk and kind of support each other a bit so that was quite good.” [Suzanne]

“There’s actually a lady I’ve made friends with who lives down the road, but she lost her dad rather than her spouse. And we’ve said when things calm down we’re going to meet up for a coffee. She’s an older lady compared to me. But I think she’s feeling lonely. And I periodically check in and she periodically checks in with me to make sure we’re okay.” [Shelley]

COVID-19 social media groups: a double edged sword

For some, the support groups have a downside, too, with them sometimes feeling too sad to read:

“So I’ve found it useful... but sometimes I do look at it and think- I’ll start to read something and then think, actually I’m not going to read that, I’m going to move on.” [Charlene]

“But as time goes on you have to think it’s breaking my heart again, I’m trying to mend, it’s not going to bring my mum back. And I don’t want to be feeling like it all the time because you have to get a bit of relief from it don’t you? Because it’s quite an intense feeling. Very upsetting, I don’t tend to read it now because I found that I was taking on everybody else’s grief. So, I scan at it you know because I don’t want to ignore people but I think for my own

peace of mind I know it's there..... Sometimes I find it quite distressing... if I read a lot of stories it gets me back on the roundabout." [Annette]

"I find it comforting I would say about 65% of the time, but when you read the stories on there they are so horrific and people – it's nice to be amongst people who understand what you're going through but I can't believe the stories that are on there: it's a weird mix, god some of them people have suffered and they lost both parents or they've lost entire families. And I know I've only lost my mum but my god some of them people lost five or six people it's dreadful, absolutely dreadful. And some of them are so young, so young. So I do find it helpful. I don't go on there every day, but it's nice to know there's people in that position as well who are there for you if you need it you know just somebody different who understands. Nobody who hasn't been through it understands" [Lynn]

"I did join quite a few Facebook support groups. Initially, they helped. Then I went through a point where I was, it was becoming obsessive. So what I did was, I set up another Facebook account just for Covid groups and stuff. So that I didn't have to look at it on my main Facebook page, if that makes sense? I had a second one, so it's not coming up on my newsfeed all the time. I could go to it when I wanted to, if that makes sense? And I do tend to go to it at least once a day. Just have a quick scroll through, and if I do see somebody who's struggling, shall we say, I'll try and put a positive comment on. You know, just try and, you know you're not alone. I think at one point, it did, it made things worse. Which is why I set up a separate account. To limit myself, if that makes sense? I sort of recognised that I was getting pulled in. And I needed to pull back." [Pauline]

"I mean, Father's Day, okay, I've still got my dad. But when you see the pictures of dads. A bit like Mother's Day. It's amazing how many of them have always got a glass, you know? Everyone seems to put a picture of them with a glass. Yes. And they all look so happy and jolly, and full of life. And it's so cruel. And it's not just ages, it's every age. The ones who've lost their children. There's ten year olds who have lost their parents. It's just – yes. So it's a bit of both, to be honest." [Emma L]

The support groups can also act as a reminder of the continuing damage of the pandemic, making people sad and angry that progress doesn't seem to be being made and so many lives are still being lost. This supports Wang et al.'s (2021) findings that, at least among women, living in a country with high COVID-19 mortality rates is associated with reports of worsened depression:

“The support that I have got from the group as well, I think is definitely worth mentioning. Just everyday people are, they are just being so kind and warm. But what does worry me is that we are still getting new members. Recently bereaved, and you are thinking, surely with inoculations and that type of thing. I remember this time last year saying, “If only we had a vaccine. If only we had a vaccine.” Now we have got a vaccine and we are not really that much further forward. [Margaret]

“It makes me cry, to think there’s so many people like me. So many people.” [Liz]

“There are some good points on there. Some of it’s sad. And some of it, you then realise you’re not alone. You’re just one of 130,000 odd thousand who’ve basically had the same experience. But it started from last January to now. Because it hasn’t changed. And I don’t believe for one minute it’s changed, because I know they tried to discharge my mum. So what have we learned?” [Lynne]

Others have come off all support groups, finding them too difficult at the current time:

“I did one of those groups through a Facebook page, where people had lost their partner to Covid but it wasn’t really right for me because it just increased my grief because everybody had bits from the very same dreadful experience and in the end all I could do was cry, you know it just magnified everything so I found it upset me, it upset me more. It was just like the Covid Bereaved Justice Facebook page which I try to keep in touch with, I try to keep in touch with but sometimes the stories are just so heart-breaking that every little scab comes over my mood seems to break up again and then it’s difficult. And because you can’t even be there and hug anybody you know.” [Suzanne]

“I have felt, over the last, I’ve been having some counselling with the local hospice and I’m probably at session number 10 or 11 out of 12 at the moment so I’m coming to the end of it and I’d said to her, I’d, this sort of coincided with a bit of a social media break. So, I came off for a bit and I said to her I feel like I’ve come out of a fog, you know, the clouds are lifting and I feel brighter and more positive, you know, it may have been a combination of things, the lack of social media, the counselling has helped, the sun had started to shine and, you know, a big combination of things that notoriously make you feel better and time as well, time was passing, we’d had a couple of like first anniversaries were out of the way, you know, so a lot of things. I’ve been back on social media now and I’ve gone back on to the groups and that and I feel the clouds coming down again and I, but part of me thinks, well, maybe I should, you know, I maybe I’ve just been distracted, maybe I should be focusing again on my grief and, or maybe I am being dragged down by it, I don’t know.” [Becky]

“I did go on the action site but I found it very upsetting and depressing. I found it, I suppose, reassuring that I wasn’t alone. There was a lot of people that had had similar circumstances. But a lot of them just seemed to be very angry....I don’t want to go down that road. It won’t change anything. And I want to stop thinking about the last four weeks and think about the last 46 years, you know. Yes but I think it just knocked me back slightly. So I have come off the group. Every story is a very, very sad one. You know, I’ll probably go back on it. But at the moment it’s just a little bit raw to read all of that.” [Stuart]

3.9.5 The importance of memorials

The National Covid Memorial Wall was mentioned often in narratives, with people getting a lot of comfort from having the names of their loved ones in a heart, as well as other memorials such as tree planting and the yellow hearts campaign which marks all deaths during the pandemic:

*“I’ve been to the wall, I’ve been down to where the wall is. And I’ve put my mum’s name on.”
[Lynne]*

“I’ve done everything, you know I’ve got my mum’s name on the wall, I’ve got my yellow badge, I’ve done the memory tree which is all lovely.” [Annette]

“I’ve got the metal badges. I’ve got a sticker on the car. And they’re doing a memorial at St Pauls” [Jackie]

Fran, a friend of the Wall, explains how being involved in that important memorial helps her personally:

“Being involved with the campaign group has helped me tremendously. And I can step back and see that that has made a real difference for me. Because I need to do something – I need to feel purposeful. So, getting involved with helping to create the wall...just being active has helped me to cope with this void that I’m living with. It’s given me a cause to put my energy

into. Whereas otherwise, I'd feel like I'd just be aimlessly trying to build a life and not really knowing what shape of life I'm trying to build." [Fran]

In fact, the need for a permanent memorial came up several times:

"The good part is that they did point me in the right direction to get her name put on the memorial wall in London. And I think you know, I think we need that now don't we? We need something from the government, from the country to acknowledge that this was a catastrophe that affected so many people. So you know, shouldn't have to be volunteers painting hearts should it? Yes I mean we even got a memorial garden to Diana haven't we, so I mean surely we can have something for 127,000 grieving families. So yes that would be nice" [Stuart]

"And I'm trying to get something round here to remember the people who we've lost here, because a lot of it is all very London based for the memorials, which is fine, obviously, Houses of Parliament, perfect place. But we need them here as well. But I think that's down to each area to -get going with it." [Emma L]

3.10 ANGER AND BLAME

The well-known (and critiqued) '5 stages of grief model' (Kübler-Ross 1969) includes anger as a normal part of grief, and indeed anger has been long-recognised as an important part of the grieving process (Cerney and Buskirk 2009). A substantial number of narratives contained deep-seated anger as well as blame. This anger and blame is particularly directed towards various institutions, predominantly the UK government and the NHS. As more and more families have gone through similar experiences, a lot of which has been shared via online fora, WhatsApp groups and other means, the levels of anger and blame have seemingly intensified. It is to those elements of anger and blame that this section turns.

From the outset, it is important to note that the anger from bereaved families is articulated in different ways and to differing extents. One person interviewed explained how she was angry at the way some of the blame was actually placed on the person who died:

“When the inquest took place - by Zoom of course - I was left feeling so frustrated because the doctor actually said “oh it’s such a shame that at the end of March, Timothy didn’t come back in to see me”. I was so gobsmacked by that statement that I couldn’t even you know respond to the screen. I just thought...she’s got to joking nobody could go back into a GP practice the doors were closed!” [Diane]

Another poignantly referred to her grief as sadness and wanted to share that she is not angry:

“I’m fairly philosophical and I’m not really angry. I suppose I’m just sad.” [Judith]

3.10.1 Failure to protect care home residents

The deaths of loved ones in care homes provoked a considerable amount of anger. Most of this blame was directed at Government decisions for failing to protect care home residents:

“And it’s also the anger at the government for, particularly, for leaving care home residents so vulnerable, and the staff, so vulnerable, so unprotected with no voice because they’re not the NHS, they haven’t got that power and they’re mostly privately owned so, you know, they really were left in the lurch.” [Sarah]

“PPE, it should have gone to the care homes as well. The care homes were sort of left behind. You know, those staff should have got it” [Pauline]

“I mean once I got the notes from the hospital that kind of, as I say, I can understand why they did it. They were following government policy that kind of changed on the 15th April, which is like the day that my mum was actioned. You know, the care home, what are they supposed to do, bar the doors from my mum when she’s sent back from hospital? So, again I’ve got no axe to grind with the care home for doing what they did.” [Adrian]

In contrast, Sian feels that there should have been more whistle-blowing among care home staff:

“You know, you have to do what’s right. You know, that’s my philosophy. And that was my Dad’s. I’d even lose my job over it to do the right thing. And I can’t understand how there’s so many of them wouldn’t stand up and do it, you know? Someone caught it in hospital, and that person came back from hospital in dad’s home. And then that was it, because none of the carers were wearing PPE at all at the time, nothing. Now if that was my care home... I’d be screaming from the rooftops... So I think it’s not just the government that needs to take responsibility, I think it’s care homes themselves.” [Sian]

Though Adrian has a different viewpoint:

“The Government were saying that people should be sent to care homes. It takes a very brave person in the NHS, for someone in that situation to have stood up to Matt Hancock and his ilk who were saying how wonderful a job they were doing and everything was ticked-boo and actually, go against their, you know, directives to come up with something alternative and even if that alternative was for a better solution, you know, this government doesn’t seem to be particularly well known for listening to anybody.” [Adrian]

3.10.2 NHS

Policies

Some anger stems from families feeling let down by NHS policy and practice during the pandemic:

“My mum, who I protected for, what, 11 months, did all her shopping, everything. Didn’t let her go anywhere and, you know, the second my back was turned that was it. Second she was out of my sight. And my mum was the sort of person that, if she had an accident she bounced back up from it. She never got sick. And we used to jokingly say, “It’s going to be something bloody stupid that takes you out.” And it seems to have been the NHS policies that took her out...and lots of things that we couldn’t do anything about.” [Emma L]

“I feel very let down by the NHS. I feel- I think as well because I have worked in the NHS, I feel a sense of betrayal as well. All those years that I tried to give patients good care, compassion, and my own dad didn’t get that and I feel very betrayed as well.” [Claire]

“I don’t want to be bitter because it’s a waste to be bitter with life. And I don’t want that. I am, I’m the first person to stand up for the NHS.... But I think it’s also apparent that the NHS have failed patients through Covid. I’m not struggling with my mum dying: I knew my mum was ill even before this, so I always counted every year as a blessing, every day as a blessing. I’m struggling with how we were dealt with before, the three and half weeks we fought tooth and nail trying to get information. Getting found out by a text message my mum’s got Covid is horrendous. That should never happen.” [Lynne]

“Was she treated properly? You know, why did somewhere where you should be being looked after and have a duty of care, allow her to catch Covid? And you know, that’s a very unpopular thing to say because we were out there clapping for the NHS like everybody else. And I still would. If they wanted us to clap tomorrow I’d clap tomorrow. But you know, it isn’t about the people, it’s just about all the systems and the processes. So you know, but I’m trying not to be consumed by that because it doesn’t help me. It doesn’t help her.” [Stuart]

“I’m really angry with the chemist, I’ll be honest with you. Yes and that is what I’m angry at- Yes I am with the amount of prescriptions that piled up, you know, in the evenings. And so this was like really a lot of pressure on them, a lot of pressure. And unfortunately, yes, and unfortunately they were not in the priority list as well for the vaccine which makes me more angry, you know, because what made them think that they were immune to this virus, you know. They were not. That was a breeding ground, you know, the pharmacies were a breeding ground... It was a breeding ground, that chemist’s was small, it was compact, there was- I mean it’s a chemist at the end of the day. It’s not going to be open space or you know..... Very small, one small toilet, everybody having lunch together. You know, come on it’s a breeding ground. But imagine how scared I was. I was so scared for him. And he told me that by law, anyway they were not allowed to close. I don’t know what the laws were, but they said that, I don’t know somehow the bubble, you are not supposed to isolate like, the rules somehow didn’t apply to them. I don’t know what it was.” [Sonal]

“And I think, which probably sounds awful, some of the people that are in management in the NHS, if they were put into the private sector they wouldn’t last five minutes. I have seen some gratuitous, ridiculous waste of money.” [Charlene]

Others recognised that the NHS was following government guidance:

“The government was providing guidelines that the NHS had to work to.” [Adrian]

“I know a lot of people are angry with the NHS. And I kind of feel like it wasn’t their fault, it was the government didn’t give them what they needed.” [Charlene]

Though, interestingly, the issue of whistle-blowing emerged here, too:

“You know at the end of the day the NHS is a government construct and the government has got the oversight, but on the other hand the professional bodies are in the NHS aren’t they.

They are also if they are the NHS bodies who are working together and they must have known that something was going wrong very early on if they had stood up together against the government they might have achieved something.” [Suzanne]

Individual hospital trusts

For some, their anger stems from the ways in which their loved ones were cared for in individual hospitals:

“Is it a government thing? I don’t think it’s a government thing at all. I’m more angry with the hospital.” [Lynn]

“I felt very much like my mum had been murdered, that’s, and my brother and my dad. Because if she hadn’t have got it she’d still be here and she caught it in the hospital where we thought she’d be safe. There’s no way she’d have gone in if we didn’t think she’d have been safe.” [Annette]

“I do think the NHS is the biggest jewel in the crown this country’s got. Because you don’t want it privatised and you don’t want it- But that hospital is managed dreadfully. Dreadfully. And they’ve saved my mum’s life in the past and I’m thankful for that when we mum first had a brain haemorrhage. But I’ve had 10 years of being in and out of there. And it is hit and miss with your wards...So some of them deaths are also at hospitals at local level”
” [Lynne]

“The thing was when it really came down to the brunt at least in my case I think most of the blame is the NHS and the staff and the particular hospital trust” [Suzanne]

No blame on NHS frontline workers

Despite the many examples of less than excellent care that many people shared, and a few respondents who are clearly angry with particular hospital trusts, a common theme to run through a substantial number of narratives was the need to explain that the frontline NHS staff are not to blame. In fact, several show empathy with the pressures staff were under:

“Even though my husband died, I can’t even blame the doctors to be honest because sometimes you know when the damage is done. The doctors, they didn’t know what to do, to be honest, you know there were so many people that time in the hospital, in January here it was the worst, you know. It was really bad. So I don’t know what was going on there. It was- I cannot say that the doctors were at fault, or you know, they didn’t do this or that, I cannot say that there was negligence there.” [Sonal]

“And then I know that people, obviously, it’s really sad that people caught Covid in hospital and that’s terrible, but it’s the government that are to blame, not the staff. Not the nurses, not the doctors, it’s the government.” [Sarah]

“I just don’t they could cope could they, they could not cope. I mean he was in a room on his own it was a beautiful private room but how long was he just lying in there with the other person outside having to go between two or three rooms and getting the care? And you know I know the doctors are busy but I did get told – he died on the day of the second highest deaths the next day was worse it was higher death rates the next day, but when I heard about them queuing up at the hospital to get in because I’ve got a friend who works there, she said to me the ambulances are absolutely queuing right out the road to get

everybody in. I don't know I can't blame the NHS but I think the government need to sort something out." [Jackie]

3.10.3 Government

Many people expressed anger at different government decisions throughout the pandemic.

I primarily blame the government. The government has made an awful lot of wrong decisions throughout this entire thing." [Adrian]

In addition to NHS directives issued by the government that we have already covered , these 'wrong decisions' stemmed mainly from international comparisons and failure to close the borders early enough, failures around PPE and vaccines, building but then hardly using the Nightingale hospitals, and failures around lockdown decisions.

International comparisons and shutting the borders

Many criticized the way in which the UK Government handed the pandemic compared to other countries:

"I think we should have closed the borders. And I worked for an airline. But we should have shut Gatwick. We allowed people to come and go as they please. I just think it was badly handled. I am absolutely disgusted- Sorry. Yes. I'm disgusted with Boris Johnson. I expected better. And we get to where we get to, and they fail even further, and they're excuse is, "Oh but you know, the UK is an international hub and lots of people come in and out to get to other places." Australia didn't care. Taiwan didn't care. There were- I mean Taiwan's had nine deaths. It's an international hub" [Charlene]

"My cousin lives in Australia, they shut the borders down straight away, they walk around normal, nothing has happened. Here, you know how many people have passed away?" [Annette]

"I mean, we're an island. I mean, Australia's had less than 9- About 900." [Emma L]

"I get even more angry about not locking down India's border when it was so obvious what was going to happen. That makes me furious." [Margaret]

*"If we'd have been like Ireland, like Australia or New Zealand or all these other islands that really imposed strict measures right from the outset. You know, we had that Liverpool game where the fans couldn't even they couldn't go and watch their own team in their own stadium. But they could come over to Liverpool and it was just like madness at the time."
[Adrian]*

"Most definitely the Government. Government didn't close the borders. We were in an ideal position as a nation because we're an island to close the borders. All right, Australia is huge. But it closed its borders. New Zealand closed its borders. Singapore closed its borders. Yes. The government solely to blame for the mess we're in, yes. it's on their shoulders because they didn't close enough, they didn't do enough to begin with." [Lynne]

"The decision not to do what New Zealand did and what Taiwan did, which was just, we are not going to allow this to decimate our people, we're not going to allow this. We're just going to shut the borders. I can remember last summer, those months of April of blue, blue skies, and still there were planes coming across, and people coming and going, and going about their business, and the virus doesn't travel by itself." [Fran]

"I am angry, absolutely I am, you know, because it – again, you know, you could, you know, had they taken a draconian approach as other places did we wouldn't be in this position. And I know, from documentation, that - or conversations, that there was an expected death amount. And if we kept within that limit it would have been a good outcome, because it's a global pandemic, there's always going to be deaths and you have to accept that. But, I mean, God the figure just is just ludicrous into what the actual number of deaths have been. So yes, and this Delta variant, Indian variant, now, that's made me really cross and angry at them, because of a trade deal and not shutting those borders, absolutely, the government have got something to answer to... that is where my anger lies" [Amy]

Relatedly, people expressed anger that these decisions continued to be made:

*"We're an island we should shut down. And this Delta one now has come in hasn't it?"
[Jackie]*

“And this, the latest one with India, we’re going to put India on the red list but we’ll let 30,000 people come in between now and then. So, they hadn’t learnt anything. And that’s what I find, you know, unbelievable. How can you not have learnt?” [Becky]

“They just don’t learn from their own mistakes... we’ve got the Delta variant because we didn’t shut down again and so we’ve got another month.” [Adrian]

“I just think it’s- I can’t even think of the word I want to use without it sounding wrong, but it’s such an insult to the people who lost their lives in the first wave that lessons have not been learnt, because they shouldn’t have lost their lives in the first place. It’s criminal.”

[Claire]

Failures around PPE and vaccines

“They had no PPE which is shocking. We had PPE in work, but the nurses never, which is awful. So that’s the government’s fault because they didn’t fund that, they didn’t top it up, they didn’t keep it in date. So that’s all their fault. So they are to blame. They’re to blame for the state the nation is now in. And the deaths we’ve had” [Lynne]

“Even the people in the shops should have got PPE, you know, the staff working in retail. They should have been offered a bit more protection than what they were given. The bus drivers should have been offered more protection than what they were given. All the key workers should have got more protection initially. I mean, I remember they were still going on the London Underground, weren’t they, construction workers and stuff, two and three weeks later. And they were still standing so close together.” [Pauline]

“And the PPE, all they [the pharmacists] got was that, you know the blue masks the disposable masks they got, that was the PPE they call it. That was all they had yes. The blue, the thin mask you know. That was good enough, you know. And they were like in the frontline, every time they were so busy, no there was a whole queue of customers, lines of customers. The pharmacists were always there, you know, they didn’t close even for one day. Even when the GPs had closed their doors, it was the pharmacists that were there. Why were they not in the vaccine priority list? I don’t understand, you know.” [Sonal]

“The anger, well, of the last few weeks of her life is still there. I’m angry with the government, with the way that they handled it. The NHS vaccinations have been brilliant, too late for her, that’s frustrating. You know it’s lovely to hear that everyone’s got their vaccinations, but she had none. And she could have probably if, you know, she was probably a couple of weeks late. We were still waiting to hear really, our area was a little bit slow to

get going. I suppose they were waiting for supplies. And I think because we live in seaside retirement place, I think they were getting through the over 80s, you know. We've got a lot of them. So that, you know, those sort of things that could it have been different if she'd have had a vaccination? Would it have been different? Would she have had a chance?"

[Stuart]

Nightingale hospitals

"What I don't get is we opened the Nightingale hospitals, then we didn't use them?"

[Charlene]

That's what I don't understand you know. I mean they never used some of these Nightingale hospitals. Why did we have them? Because you know you just think well, they could have used them for the Covid cases and they might have got better treatment. But also, say, like my mum had been put in the hospital, she'd been in there two weeks before there was an outbreak. So, they knew my mum was clear so, then why put somebody in, they needed another isolation?" *[Annette]*

"Why someone couldn't have decided to use the [name], which was seven miles away and which was set up as a Nightingale hospital, why not just sent my mum there for, you know, palliative care and used that hospital, you know, used the resource that would probably have been available and taking the pressure off both the hospital and the care home is, you know. I'm no healthcare expert but it occurred to me within about five minutes thinking of it."

[Adrian]

Lockdown failures

In terms of lockdown, the government were blamed for acting too late in the first wave:

"He's [the PM] done the failings by allowing it to carry on to this point and not locking down. He didn't follow the science and he didn't follow the data. To me you follow the scientists, they know best. We don't as normal people, as a prime minister he doesn't know. He should have followed the science and instead he never. So he's responsible for the whole picture of the country being in the state its in....he didn't lockdown and he should have locked down in

October. He should have shut in the half term and things. We all knew that. But for some reason our government didn't. For that I blame them." [Lynne]

"We didn't shut down soon enough." [Pauline]

"I know prior to the first lockdown [name] was due to go to Crufts with my two friends they'd got tickets and I felt really bad because I said I don't want her to go and they said in honesty I don't think we want to go either. Because when you think about it people were coming from all over the world to Crufts and I just thought that would have been such a stupid thing to do. I think that's where the government were wrong, they weren't quick enough and proactive enough in the early stages were they because wasn't there a race meeting as well?" [Judith]

"But if we'd locked down earlier, we wouldn't be as bad as we are now. I don't believe the economy would be as bad." [Charlene]

"I agreed with the lockdown. I think, you know, this government has been far too slapdash and it's come back. They've tried to protect the economy and all they've done is sacrificed the economy." [Adrian]

"I blame the government for reacting far too late. You know the fact that they reacted too late when it was in Italy already and it was the holiday season and lots of people were in Italy and they just didn't, just let it go you know. That is something which I find quite bad, very, very bad." [Suzanne]

People were also furious at subsequent decisions pertaining to lockdown:

"And now I think, why, why were we so careful. And other people weren't, because they did lift the restrictions and everyone was going mad, weren't they?" [Liz]

"Well, the Christmas thing as well, what was going on then? It was like he didn't want to be the bad guy, you know. I'm going to make people happy even if, you know, I don't know. It's so short-sighted, isn't it?" [Becky]

"Last Christmas was an absolute joke when they were going, oh but for five days and people were putting memes on Facebook going, because Covid's going to go, no five days I'm going to have a break. And in the end he ummed and ah'd and ummed and ah'd and then put London into 3. I sat and watched the news and what people did was because he said, I don't

think you should travel after Sunday, so they all packed their bags and went to St Pancras. It was packed.” [Charlene]

“The other problem we had was the big government slip up where we live. We live in [name of place] which is [name of place] which borders us with [name of place] that borders us were all shut down so everybody came into [our area] for their Christmas shopping. And I remember quivering in the Card Factory trying to get cards for my mum who’s in a home and this woman came up she said what’s the matter and I said I just can’t be in here with all these people. Because I’d been so careful because of his vulnerable side. So she went and collected all these cards for me but that was about the middle of December. But we all then got Covid around New Year’s Eve.” [Jackie]

“I know it’s a pandemic, and we didn’t know how the virus behaves. But certain things could have been avoided, definitely... See in the first wave maybe they didn’t know enough, you know. But the second time? Come on, you know!” [Sonal]

3.10.4 Cynicism and distrust

Within narratives emerged a great deal of cynicism, a belief that many in positions of power really did not care about lives, and contempt for some figures in authority.

Suspicion

“Personally, my belief is that they deliberately looked at it. They’re not stupid, they obviously knew it was going to spread like wildfire in the nursing homes. They’re not thick, they know the situation. And I think they just thought, it’ll take this amount of money to go in and stop that. No, it’s not worth it. And I think someone up there looked at it and went, it’ll take these many million pounds to protect all these nursing homes, not worth it, they’re only old people. They’re going to pass away soon anyway. They’re draining the NHS. They’re draining us, we’re paying the money, paying for them, for the care in the nursing homes. And if they pop off, we can have all their pensions as well. Honestly, I do think that decision was made. But they’re never going to admit that.” [Charlotte]

“And it’s either incompetence or, I mean I do remember the very first day that Boris was elected and he said, “I’m going to sort out the social care system,” and he pretty much has because anyone who’s old who is on a pension, anybody who is poor and is on benefits,

anyone who's sick and on benefits, you know, a huge chunk of them are dead so they're no longer claiming, so he has sorted it, just in not the way that we expected." [Adrian]

"To a large extent at least in my area here, and I don't know what it's like in London you know I remember before Brendan got ill we saw those films in hospital I think was it the Royal Free Hospital in London or something you know where some people survived some people didn't. But they were on all those monitors they weren't in intensive care but before they went in they were monitored, there were people ringing up the relatives every day. A completely different situation to what happened, what a difference you know." [Suzanne]

"I just think that this government is so desperate to open, they won't tell people the truth anymore." [Liz]

"So, the fact that they are saying now that they were never, well Michael Gove was on TV tonight saying that they were never short of PPE. Well, why the hell were people wearing bin bags?" [Adrian]

"It was all about the money and not about the people. And if I'm honest, I look at it as that we've not had a world war for many years now, they're quite happy to lose 130, 140,000 people." [Lynne]

Contempt

"This government were too busy rolling their hands together that they'd got us out of Europe and putting Brexit first. And that's all they were worried about. They didn't care. Well he said it didn't he? He said, "Let the bodies pile up." That's the man, that's the government. And they all blame one another. Cummings and all. He's running like a rat throwing them all in the mix now. They're all as bad, they've all got blood on their hands. But Boris is in charge of this country. Boris Johnson. He's the Prime Minister, it's Boris Johnson. He acts the fool to get away with his shortcomings. He's killed a hundred and odd thousand people. And the country will be in debt for another hundred years because of it. Yes. Yes." [Lynne]

"And they are quite reluctant to tell you how many people have died. And people are still dying. And they don't tell you how many people are in hospital anymore. And the Tories are just so smug about everything. I just can't bear it." [Liz]

"All this back biting now with Dominic Cummings, whatever's coming out, what you want is for that – if that's true, that somebody is held accountable and take responsibility, because from the outside looking in, from an educated perspective, they haven't got a – they clearly don't know what they're doing, or – and they've not taken the advice from the right people.

Those professionals who know what they're speaking about, just because, it doesn't align to some – well how do I say it-? Doesn't align to some box that they need, you know, to keep things going, keep things open.” [Amy]

“I think it's that impotence you feel because you think, even if we had an election tomorrow, he'd probably be re-elected because for some reason people seem to like Boris Johnson. And it's this feeling that they're not being held to account and they never really will be, they'll slide away from it. Matt Hancock will be the scapegoat.” [Sarah]

“And like Dominic Cummings and what, I don't know how you feel, but what they said Johnson said about you know, so many liars. I forget what he said now the actual words that they said. But and I thought, my dad was such a different person to him.” [Sian]

“I was livid about Cummings, you know. Someone in that position and a professor who broke the rules as well, who was advising the government. Driving up to Barnard Castle to test your eyesight? Pardon my French but fuck off, with the kids, the family in the back. I'm sorry, you've got no excuse for it.” [Adrian]

3.11 THE INQUIRY

Claire makes an incredibly important point when she notes that whenever she asks questions of public organizations, they are dismissed because she is grieving, rather than these questions being taken seriously because they legitimate:

*“One thing I find quite intriguing is when you contact anybody, because obviously invariably you want answers, you want to try and justify- not justify, why did this happen. And trying to stop it from happening again, that was my motivation. But every time I contact maybe a public organisation, professional organisation, they want to suggest bereavement counselling. Now, they don't know whether I'm having bereavement counselling or not, but it comes across because you're contacting us you're not coping. You're not coping. When somebody doesn't know me and then they just dismiss my concerns, and they're telling me this is the bereavement counselling links I think that's when I start getting really annoyed.”
[Claire]*

The UK Government has agreed to a Public Inquiry to investigate the decisions made during the pandemic, the details of which have still to be decided in terms of the timing, who will Chair the Inquiry etc. Whilst these decisions will be made (or not) in due course, the families of those that lost loved ones to COVID-19 are key stakeholders in any Inquiry process that takes place. Moreover, the Inquiry could potentially provide some answers, and perhaps some closure, as to what happened during the pandemic which, in turn, may (or may not) help the grieving process of the bereaved families.

3.11.1 Scepticism and mistrust

One person explained that she was unsure what she would like to see from the Inquiry:

“I suppose I don’t know, it’s hard because it’s almost like if they tell you there’s things they could have done differently, then it will make me feel, it’ll make me feel like- Well it won’t change anything. It won’t make anything worse.” [Becca]

Many other people expressed their concerns and indeed scepticism about what any eventual Inquiry into the pandemic will deliver for them and their families:

“What I want and what I think will happen are two questions.” [Emma K]

What are we going to get out of it? Are we going to get anything? [Lynn]

“They’ll try and cover up come next year.” [Lynne]

“To be honest I have no hope for it, not with this government, not at all. No I don’t have any hope for the Inquiry. I don’t think, I wouldn’t say justice, but any learning from it. Because they’re not, personally, they’re not honest and upright like my father. So I think there’ll be cover ups.” [Sian]

Sian went on to contrast how her father was and what the Inquiry would achieve (or not):

“That’s what I mean. He was such a gentleman, everybody loved my father. And he was so upright, he’d never lie, he was so honest, he would help anybody. He was about justice and fairness. And we certainly, I don’t think we’ll get that with the public enquiry, no I don’t.”

[Sian]

“No, course not. No, they’re like schoolboys at the moment, aren’t they, bitching about each other.” [Becky]

“I don’t want to pin too many hopes on it, because ultimately, I’ve got to focus on keeping on going.” [Fran]

“I’m just concerned now because we’re in a devolved nation how it’s going to pan out with the enquiry here. Wales has just gone really quiet about enquiry and I’m sure they’re going to try and hide behind the UK government, and then just blame them, but Wales is a devolved nation. They’re responsible for their own NHS and social care so I can’t see how they can do it but I’m sure that they will, because it will come down to politics in the end, won’t it.” [Claire]

3.11.2 Pandemic planning

Many people mentioned the planning that already exists in the UK for dealing with pandemics:

“But I kind of already know there’s stuff that they must have planned. I know they sort of had done like a trial what happens if there’s some big, you know, some big pandemic or illness or what have you. And it didn’t go so well. But they didn’t sort of do anything to change it. And I suppose having that written down won’t necessarily change the fact that I kind of know that anyway.” [Becca]

And as I understand it, we had a kind of- We had a pandemic force, or there was a pandemic plan in place. And now I can’t remember when it went in place. But they started cutting back. They didn’t replace staff. They then did a pandemic exercise which they failed.” [Charlene]

“I blame the government that they you know stopped those pandemic plans which were supposed to have been carried out when was it in 2019 there were some plans.” [Suzanne]

“We’ve even had like the, what was it, the 2016 sort of exercise then to learn lessons and we didn’t learn those lessons, I’m actually watching back episodes of Yes Minister at the moment and it is just, you know, that phrase about, you know, it’s too early for us to do something. Well, we should do something but we don’t know what we should be doing. We ought to have done something but it’s a bit late now and we’ll learn lessons for next time. Ideally, I would like to see the people who, I mean I think it’s gone beyond the fact. Anyone can make a mistake. However, only a fool doesn’t learn from their own mistakes. We should have learnt from the mistakes or the experiences that other countries were having. ... the people that should have been there at the controls were asleep at the wheel, or were just, you know.” [Adrian]

3.11.3 Comparisons to other public inquiries

Striking was the number of people who mentioned other public inquiries, and worried about the timing and outcome of this one:

“Yeah, but unfortunately, you know, we have Hillsborough as an example.... It’s going to be 10 or 20 years down the line before we have anything.” [Adrian]

“And I think the inquiry, I hope, will begin to explore some of the circumstances that have led to us all being in this situation. If it doesn’t, if it becomes a whitewash, then that will be destructive. But I haven’t got 30 odd years, I don’t think, to push for the truth to come out. Those Hillsborough families have gone through so much, and they still haven’t had the satisfaction of what they should have done. And I worry that this is much huger than the tragedy of Hillsborough, and there are so many vested interests, and there are so many complicating factors, that I don’t know if we’ll ever get what we want. But I think the process of fighting for something is really helpful. Even if we don’t get the end result, I think the actual process of pouring my energy and other people’s energy into doing something to try and stop other people experiencing this. I would like to know the truth about why decisions were made. I think we’ve been lied to, and the truth has been hidden about the reason for decisions and the choices that were made, and the decisions not to close the borders. Nothing’s going to change anything as far as my life is concerned. Steve’s dead, and I’m never going to see or hear from him again, and that’s what I’ve just got to live with. But if it can possibly be avoided, I don’t want other people to have to go through this. And I think the inquiry is the only way of beginning to make that avoidable.” [Fran]

“You watch all these other inquiries: Hillsborough look at them, they’ve fought for justice for over 30 years and they’ve still not got justice. You can’t keep blaming everything on Covid and everyone you talk to at the hospital oh it was a pandemic, it’s Covid, we didn’t have staff, it’s Covid. You can’t keep making excuses. Yes it was a pandemic, yes it happened but they’d been dealing with it a year before I lost my mum. If my mum had gone probably in the early stages I probably wouldn’t feel this way but I watched my daughter work through it and the heartbreak she went through having to be with families, and I just feel well what can you ask at an inquiry why did you let them all die and why are they still letting them die because they are.” [Lynn]

3.11.4 What the bereaved want

Transparency and truth

Transparency, truth and public awareness were much hoped for outcomes of the Inquiry:

“I would like some transparency for public awareness and I’m sure that it’s available under the freedom of information or whatever anyway about what you know akin to the same sort of directives that were given by NHS England to the GP surgeries about when to close doors and when to switch to telephone appointments and things like that and when to try and source PPE, but what were the guidelines for pathologists and testers testing for unexpected deaths during that period.” [Diane]

“I think it’s the recognition of the Government made mistakes, that they were really too slow in acting initially and I think by that being so slow at the beginning, that’s affected not only deaths, it’s about the lives of them staff who have had to care for them patients in such high numbers and I don’t think we’re even like looking at the number of people who’ve committed suicide, the mental health side of things of people who’ve had to endure such long, so I think I’d like to see it opening up and actually seeing the wider impacts of what Covid and the lockdown have done because you look back and you just think it was ridiculous having the Liverpool game with Madrid coming over here when they were in lockdown but they literally came over and partied, didn’t they, because they couldn’t do anything back at home so it was like as if that’s not going to spread anything. And I think when you go back even sooner, my husband was 50 in February last year, so we had a cruise that was booked going from Hong Kong to Singapore in February and we didn’t want to go because at that time Covid was there, Hong Kong had shutdown, the numbers were rising, deaths were happening and we were saying, “We don’t want to go on holiday, we’re too, we really don’t

want to go,” but the insurance company said, “You can cancel but you’ll lose your money because we’re not giving you any money back because the Government say it’s safe to travel so it’s just you worrying about nothing.” And so, at that point you’re saying why aren’t the Government putting on, saying it’s not safe to travel, it should be essential travel only to these countries?” [Ann]

Pauline sums up this section and speaks for a lot of people when she says all she wants from the Inquiry is:

“The truth.” [Pauline]

This need was echoed by others:

“The truth. Yes. People to be held accountable for making this, you know, I mean, everyone makes mistakes, but my mum wasn’t at the beginning, she was a year later really. So we kind of should have learnt by then and the mistakes are still being made. I mean, they definitely are round here. We haven’t even got any pop up vaccination thing, so I’ve only had one jab, and that’s because I’m my dad’s carer.” [Emma L]

Accountability

There is a hope, or perhaps even a need, from bereaved families that the UK Government accepts its responsibility and be accountable for the mistakes that were made. This would go some way to helping with grieving process and to provide closure for many:

“But what I would love, I know they’re never going to, but even if they just said, look sorry we’ve made mistakes. Even if they didn’t know the full- But just, you know, that would be enough for me. But no, it’s a kick in the teeth this government for me I’m afraid. Especially from my, you know- With all that’s gone on with Covid and things. And what has been said, and it’s just horrific, it’s just awful. And that adds to the trauma I’m afraid.” [Sian]

“I want Boris and Hancock to be held to account. I want people to realise, particularly the ‘Covid isn’t real’ people, I want them to see that we are real people. That we didn’t lose a number. We lost partners, husbands, fathers, grandfathers, mothers, grandmothers, girlfriends, boyfriends, wives. I want people to- It needs to be acknowledged. I don’t know what else they’re going to say. I know they’re never going to pay any sort of compensation because I think that would bankrupt the country with the amount of dead we’ve got. I just want answers. I want them to be held accountable. [Charlene]

Feelings and anger are strong on the issue of accountability and whether the senior people responsible will be sanctioned or not:

“Yes its corporate manslaughter yes that’s because there was many knowing- Yes there was an intention, it’s intentional.” [Suzanne]

“So, people who were at the top who should have been in a position to make sure that we were well prepared, as far as I’m concerned, it’s corporate manslaughter and it should be treated as such and they should be potentially going to jail. So, yeah I mean in an ideal world what I’d like to see is that the people who are to blame for these unnecessary deaths to be treated as causing corporate manslaughter and therefore, going to jail. The reality of the situation is I very much doubt that’s going to happen, so the best I can hope for is that they learn the lessons and make sure that we are prepared for the next one, you know.” [Adrian]

“I want some acceptance of responsibility. If they’d locked down sooner we wouldn’t have gone to that GP appointment. He may still be here. We may not have picked it up. And I just think that there was a lot more that could have been done. And all these delays where, like with the Indian variant, we’re going to lockdown the borders, but we’re going to give you 10 days to get in without quarantining. What the hell man? No lessons learnt.” [Shelley]

“I want, well, I’ve been thinking about this quite a lot because I think that if Matt Hancock, Boris Johnson, anybody in the cabinet said, “I’m sorry, we got it wrong. We should have listened to the other people, not just Public Health England, we should have listened, seen what was happening in Italy and learned lessons from it. We did cause countless, unnecessary deaths and we’re really sorry, but we were dealing with something the scale of which was unimaginable.” It’s that failure to just, you know, the Mid Staffs inquiry, when I was working at CQC, obviously, that had just reported and that was all about people not acknowledging what was wrong and the whole thing that came out of that, the duty of candour stuff, and you think, if only the government would listen to that and actually do it. Of course people make mistakes, nobody knew what they were dealing with but to just go on

blindly pretending things were okay, I just would like people to acknowledge that and apologise like you or I would if we made a mistake. We'd say, "It was a genuine mistake but I am so sorry." [Sarah]

Indeed, receiving an apology emerges as a key theme:

"I want an apology, I want an acknowledgement that mistakes were made, and I want learning. I want learning. I want experiences really reflected upon and I want things to be done differently in the future. Nothing is going to bring them back, and if anybody dares suggest that there is anything at all financial about it, I won't be responsible for my actions. I want acknowledgment. I want an apology, but I want lessons to be learned and changes to be made." [Margaret]

"I want them to admit that they could have done things better, that they made mistakes, but just, you know, it's not going to make anybody come back is it, so just an admission that they made mistakes again and again and that's all I would want really." [Becky]

"I want them to admit it, I know they won't. I mean I'm not going to sue or anything, my dad wants an apology, that's all he wants. He wants an apology and them to admit that they caused her death." [Annette]

Lessons to be learned

People expressed a desire that the Inquiry process brings about real change and ensure that that lessons are learned to avoid further tragedies taking place in the future. Some want the Inquiry to include a focus on the NHS in order to get to the bottom of what actually happened in the hospitals:

"I want the NHS to first of all admit to the fact the because of lack of infection control there were more hospital acquired Covid cases than there should have been. I want an investigation into why that is? Why that didn't happen to that extreme degree in other countries, compare it with other countries it didn't happen. Is it because of staff not properly trained? Too many agency nurses? Is it the hospital organisation itself the way the wards are arranged?" [Suzanne]

The same person went onto express her sadness about what happened in the hospitals and that the Inquiry needs to help to get proper accountability:

“So I think there was a systemic injustice that’s one of the things I want to see from that. I know Covid affected different groups of people in different ways but I’m just interested in those hospital acquired Covid infections. I want to see that addressed because at the moment quite frankly I’m so frightened of having to go into one of those hospitals for whatever reason. You know just thinking about it makes me break out into tears and makes me have a panic attack. I think in the end looking at it now it might even be a human rights thing. I don’t think whoever made the decisions and implemented them I don’t think they should be allowed to get away with it, without a slap on the knuckles at least because nothing else will happen. [Suzanne]

“I want to know why they didn’t send someone to him sooner or organise something. When he phoned his doctor, his doctor knew he had COPD. And they [GP and 111] should’ve tried- I don’t know if someone had seen him sooner it would have helped – I don’t know that. But I’m sure it would’ve helped a bit.” [Liz]

“I want the hospital to be exposed. I don’t want anything off them. I want the truth. And I want them to know the truth. I’m not all for that, I’m not going to sue the hospital. I’m not. Not for that. Because the NHS isn’t there for that. They’re there to try and save us at the end of the day. And I don’t want to take out of that, that budget that they have. But they need to know, the staff lie. And they failed my mum. How I put it to them is, no one cared enough to care for my mum. And that’s how I put it. And that’s what, it’s exactly it. They didn’t care enough to care for her properly because they didn’t listen to us who knew her best.” [Lynne]

But, most of the learning wished for was directed at the Government:

“I think what I would like to see out of this, and what I will be fighting for is a change in the social care system. Because that has to be overhauled. I was shocked...it all needs overhauling. It certainly does.” [Sian]

“So, we’ve learnt a lot of lessons and, you know, another lesson should have been that we should have been locking down a lot harder, a lot sooner. So, that’s the best I can hope for is that someone updates the book.” [Adrian]

“I want lessons to be learnt. I don’t want anyone else to go through this, I don’t want any money or even accusations or anything. I mean they’ve all made huge mistakes. They’ve all, you know, got blood on their hands, all of them, but the most important thing is it should not happen to anyone else and to take note from other countries, to look at our statistics, our data. Like, they keep saying that on the 21st it’s all going to go ahead, it’s all going ahead but you can’t say that. If there are more deaths and there’s more Covid you’ve got to change your plans. You’ve got to, you know, yeah I want things to open up and go back to normal the same as anyone, well more than anyone because I want to be hugging people and to get out of this more than anyone but I don’t want anyone to go through, you know, what you and I are going through.” [Pat]

“If they’d have been draconian, people – I think, people were so scared and they were so compliant they’d have done anything. In the early days they did, didn’t they? People – the streets were deserted, people complied, and people wanted to – and they had an opportunity there to minimise the deaths. There was always going to be deaths, sadly and horrifically, but they had an opportunity and they didn’t do it. And I do want them to be – to answer some of the failings, and for somebody to take accountability and responsibility, that’s what you want out of any enquiry, you know?” [Amy]

“I’d love Boris to be out and Hancock to be honest I think there should be charges against them for everything that they’ve done. What do I think will happen not much. They might make Hancock a scapegoat.” [Emma K]

So important is that lessons are learned in order to avoid others going through these lived experiences:

“I just want something that none of these people are forgotten, because I feel other than – I think everybody’s forgotten them already in some ways. If there is ever another pandemic, of whatever sorts, even if it’s in a 100 years time, if there’s lessons to be learned about this then, even if there’s one or two elements from it, if it makes a change, you know, then It’s worth it.” [Amy]

“it isn’t going to bring them back it’s not going to make it that we could do things better – as long as they can do things better in the future that’s what I would want to see. Now we know more about it that we can make better plans and help for people going through it then.” [Judith]

4. RECOMMENDATIONS

As a result of the findings of this research, we recommend:

Improved Pandemic Planning.

The report spotlights the implications on the bereaved due to the UK being inadequately prepared to deal with a pandemic. The NHS was overwhelmed, resulting in slow responses and reduced access to medical services. PPE was in short supply. Care home staff were ill equipped to deal with the magnitude of the pandemic. The frequency of pandemics is increasing (SARS, Bird Flu, Swine Flu, MERS, and Ebola) and pandemic planning needs to be a central part of Government, NHS, and social care strategy and this needs to be a wide-ranging and integrated strategy.

A root and branch investigation into NHS systems and processes during the pandemic.

This recommendation does not pertain to medical care: rather it refers to the systems, organisational management and protocols in place to record and communicate information pertaining to patient's whereabouts, their existing medical conditions, their current health status, and ways in which families can be updated. This research suggests that the NHS does not use technology to its full potential throughout the patient journey. Dissemination and sharing of good practice across and between NHS Trusts and all elements of primary and social care also needs to be enabled.

Communication channels between hospitals and families should be overhauled.

Waiting 24 hours or longer to hear any initial news of a hospitalised patient is unacceptable. Systems need to be revamped in order for families to receive regular updates, and the nature of the information provided needs to be enriched. Doctors treating patients with underlying health conditions need to listen to families who can explain particular characteristics. Channels that facilitate communication between patient and family, particularly digital communications, need to be enhanced and help should be available for those patients who need it.

Availability of current counselling services is expanded, that the levels of complex grief among COVID-19 bereaved is ascertained, and specialist bereavement services are developed in order to treat this particular type of grief.

This research finds many differences between being bereaved due to COVID-19 and being bereaved in other ways and during other times. Restrictions on being with family members towards and sometimes at end of life, enduring social isolation whilst newly bereaved, complexity of systems and processes due to lockdown, denial of many important death rituals and strict restrictions on others, attitudes among some groups in society, and the ways in which COVID-19 permeates every aspect of life makes bereavement particularly difficult. Yet, there is a lack of available bereavement counselling services, and a particular lack of specialist counselling and mental health services to help people deal with this specific type of grief.

A focus on the implications of cultural death rituals being denied during the pandemic.

This emerged as an extremely important part of the lived experiences of bereaved families, and denial of these seem to have made grief worse. This is an area that may well be unheeded if someone has not lived through it. The importance of such rituals must not be overlooked, and must form part of the inquiry and future planning.

The provision of permanent memorials to COVID-19 victims.

This project spotlighted the importance of memorials in bringing some comfort to the bereaved, and the need to ensure COVID-19 victims are not forgotten. The research also uncovers the need to change societal discourse: permanent memorials will be one way to aid this. This research found that the National Covid Memorial Wall is a particularly important memorial, and it is recommended that the Government consults with the COVID-19 Bereaved Families for Justice Campaign, who founded and manage the wall, to make it a permanent monument.

The Public Inquiry is brought forward, and processes are put in place to ensure it is conducted with diligence and integrity.

This research reveals a clear need for the public inquiry to be held without further delay, the need for it to be transparent, the importance of bereaved families being an integral part of the inquiry, and for lessons to be learned so that many of the mistakes made in this pandemic are not repeated in the future. While this study includes bereaved people living in Scotland and Wales, it is acknowledged that some national practices did differ, and legislatures and executives are separate. Hence, the Public Inquiry should include inquiries specific to each of the devolved nations.

Changes to systems and processes are required in order to reduce nosocomial contractions.

Specifically, improvement to infection controls must be implemented. A review needs to be conducted and changes made to ensure, for example, adherence to infection control regulations, changes to systems in order to minimise the movement of patients around hospitals, better segregation of infected and healthy patients, and an end to the practice of discharging infected patients to places where they could infect others. Such a review needs to consider the very low usage levels of Nightingale hospitals, and whether they could have been used to administer palliative care for infected patients, thus potentially reducing the number of care home contractions and deaths.

Patients with cognitive impairments, learning disabilities or other vulnerabilities are allowed to be accompanied to hospital.

Despite this being a directive for hospital visiting within many NHS Trusts, it was not always allowed. This caused increased distress for patients and their families, and in some cases led to unnecessary interventions.

More training in end of life care for frontline staff.

Family support is an important aspect of end of life care. Many of the families interviewed felt that they had not been included in decision making. Staff development in the areas of specialist palliative care is important for health professionals, many of whom will have been expected to administer palliative and end of life care for the first time during the pandemic.

Processes for reaching, recording and communicating DNR and critical care decisions are overhauled to ensure consistency and transparency.

A central and integral aspect of Advance Care Planning (ACP) is to ensure people are at the centre of decision making and their beliefs and wishes for end of life are taken into account. This research finds evidence that this was not always the case. Consequently, DNR decision making needs to be overhauled to ensure patient's wishes are taken into consideration. In situations where clinicians overrule the wishes of patients and/or their families, the foundation and justification for this decision needs to be recorded and communicated clearly.

A (re)focus on person-centred care.

Person-centred care is a way of thinking and behaving. It aims to ensure that patients (and their families/carers) are involved in decision making. This research found that families were often not consulted. Such findings are in direct contravention of the NHS commitments made in the Five Year Forward View (NHS 2014) and the NHS Long Term Plan (NHS 2019). Consequently we recommend in-depth training for NHS staff in this important initiative.

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Appendix 1 Personal Recruitment Advertisement



**Would you like to take part in a research study about
The lived experiences of people
bereaved by Covid-19?**

I am a lecturer at the University of Liverpool and I lost my Dad to Covid-19.

I am conducting a study into the experiences of people who were bereaved by Covid-19. It is designed to find out the experiences of families during this dreadful time. You will be asked to tell your story of how your loved one got sick and then died due to Covid-19, and your experiences of the days and weeks before and since their funeral. There are no right or wrong answers – we know that everyone is individual, so this research is about finding out your feelings and beliefs and experiences. Hopefully the findings will help to shape policy in the future.

- If you agree to take part I will arrange to have an 'interview; - a chat for about half an hour. You can choose if you want this via video (Zoom) and you can choose if you want your camera on or off (I will have mine on) or if you prefer you can have your interview over the phone. [I'm collecting a few interviews at a time, so don't worry if you see this message disappear and then reappear again next week].
- All interviews are in complete confidence, and will be anonymised if you so wish. If you would like to find out more about the study and decide if you want to volunteer, please don't hesitate to contact me. You can message me via social media, or contact me via email or telephone, details below:

Dr Lynn Sudbury-Riley

University of Liverpool Management School, Chatham Street, Liverpool L69 7ZH

Tel: 0151 795 2553

Email: L.Sudbury-Riley@Liverpool.ac.uk





Would you like to take part in a
research study about
**The lived experiences of people
bereaved by Covid-19?**

**Group Approved – please see
details below**

Appendix 3 Participant information sheet



Participant Information Sheet

V2 25th April 2021

The lived experiences of people bereaved by Covid-19.

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask me if you would like more information or if there is anything that you do not understand. Please also feel free to discuss this with your friends, relatives and GP if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Thank you for reading this.

1. What is the purpose of the study?

This study looks into the experiences of people bereaved by Covid-19. You will be invited to tell your story about how your loved one got sick and the experiences of that very difficult time. You will be asked to share your story of the dreadful day when your loved one passed away, and the events from that terrible day up to their funeral. You will also have the opportunity to tell your story of how you have felt since. There are no right or wrong answers – we know that everyone is individual, so this research is about finding out your feelings and beliefs and experiences.

2. Why have I been chosen to take part?

You have been invited to participate because you lost a family member due to Covid-19. I am hoping to chat to about 30 people about their experiences of losing a loved one to Covid.

3. Do I have to take part?

You do not have to take part. Participation is completely voluntary and you are free to say no, or to withdraw your participation (up to the point of transcription – see point 10 below), without explanation, and without incurring any disadvantage. You are free to ask any questions about the study before you decide if you would like to take part.

4. What will happen if I take part?

If you agree to take part, I will arrange for a mutually-convenient time for a research interview – which is basically a chat about your experiences of being bereaved due to Covid-19. You will have a choice on whether you prefer the interview to be over the phone or by video (Zoom). If you decide to have a video interview then I will have my camera on so you can see me. You can decide if you want to put your camera on too, or if you would prefer your camera to stay off – the choice is yours. The chat will probably last about half an hour or so – it will last as long as it takes for you to tell your story in your way.

My name is Lynn Sudbury-Riley and while I am a University researcher I also lost my Dad to Covid-19, and only I will be conducting the interviews.

5. How will my data be used?

The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of "advancing education, learning and research for the public benefit.

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The Principal Investigator (Dr Lynn Sudbury-Riley) acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to her (contact details appear at the end of this sheet).

Further information on how your data will be used can be found in the table below:

How will my data be collected?	The telephone or video interview will be audio recorded.
How will my data be stored?	The audio recording will be stored in a password-protected secure file on the University's mainframe server. After 1 week, the audio recording will be transcribed and then destroyed. The transcription will be stored in the same way - in a password-protected secure file on the University's mainframe server.
How long will my data be stored for?	The audio recording will be stored for 1 week. The transcription will be stored for 10 years, in line with the University's data policy.

What measures are in place to protect the security and confidentiality of my data?	All data (audio and transcribed) will be held securely in password protected files on the University's main server.
Will my data be anonymised?	Yes, if this is what you wish. Some people may prefer to keep in the names of their loved one, or names of their family, and that is fine. However, if you prefer, at the point of transcription your data will be anonymised. This means that your name, the name of the person you have lost, and any other people you refer to in your story will be removed. Any other information that appears in the interview that may be able to identify you will be removed.
How will my data be used?	Your data will be merged with the data collected from everyone else in the study, and used to search for common themes. These themes will form the basis of academic reports and articles. Even if a quote is used in these publications, if you have chosen your data to be anonymised then neither you nor your loved one will be identifiable from it.
Who will have access to my data?	The only people who will have access to your data are the Principle Investigator, named on this sheet, and the transcription company which is authorised by the University. A full confidentiality agreement is in place with the transcription company.
Will my data be archived for use in other research projects in the future?	No.
How will my data be destroyed?	Transcriptions will be completely deleted after 10 years.

6. Expenses and / or payments

There are no payments available for taking part in the study.

7. Are there any risks in taking part?

While there are no physical risks to taking part in the study, I understand how upsetting losing someone to Covid-19 is. I know that it is likely you will get upset during our chat. If, during or after your interview, you experience any discomfort then please let me know. We can pause the interview, or stop it completely – and either postpone or cancel. If you prefer, you are of course free to have a friend or family member with you during your interview.

8. Are there any benefits in taking part?

While there are no direct benefits to you for taking part, your participation will be used in publications which are designed to advance knowledge and hopefully help to shape policy, procedures, and services in the future.

9. What will happen to the results of the study?

It is hoped that several academic journal papers will result from the study. I will be happy to give you a copy of these if you wish. Additionally, I will produce a report that is available to anyone who would like a copy. If you would like a copy of the report and/or the journal articles then do contact me (details below) and I will be happy to supply. Remember that unless you have chosen to use your name or the name of your loved one, you will not be identifiable in any of these publications.

10. What will happen if I want to stop taking part?

Before, during, or up to one week after the interview (if you have chosen for your data to be anonymised) or up to 3 months after the interview if you have chosen your data not to be anonymous, you can withdraw your participation in the study at any time, without explanation. Just let me know, and any data already collected will be destroyed.

After one week, the audio recordings will be transcribed, and at this point the data will be anonymised, if you have so requested. At this point, it will not be possible to withdraw your data, as it will not be possible to identify which data is yours.

11. What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let me know by contacting me (details at the bottom of this sheet) and I will try to help. If you remain unhappy or have a complaint which you feel you cannot come to me with then you should contact the Research Ethics and Integrity Office at ethics@liv.ac.uk. When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so that it can be identified), the researcher involved, and the details of the complaint you wish to make.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

12. Who can I contact if I have further questions?

All questions about any aspect of the study to be directed to me:

Dr Lynn Sudbury-Riley
University of Liverpool Management School
Chatham Street
Liverpool L69 7ZH

Tel: 0151 795 2553

Email: L.Sudbury-Riley@Liverpool.ac.uk

Appendix 4 Participant consent form



Participant consent form

Version number & date: V2 25th April 2021

Research ethics approval number:

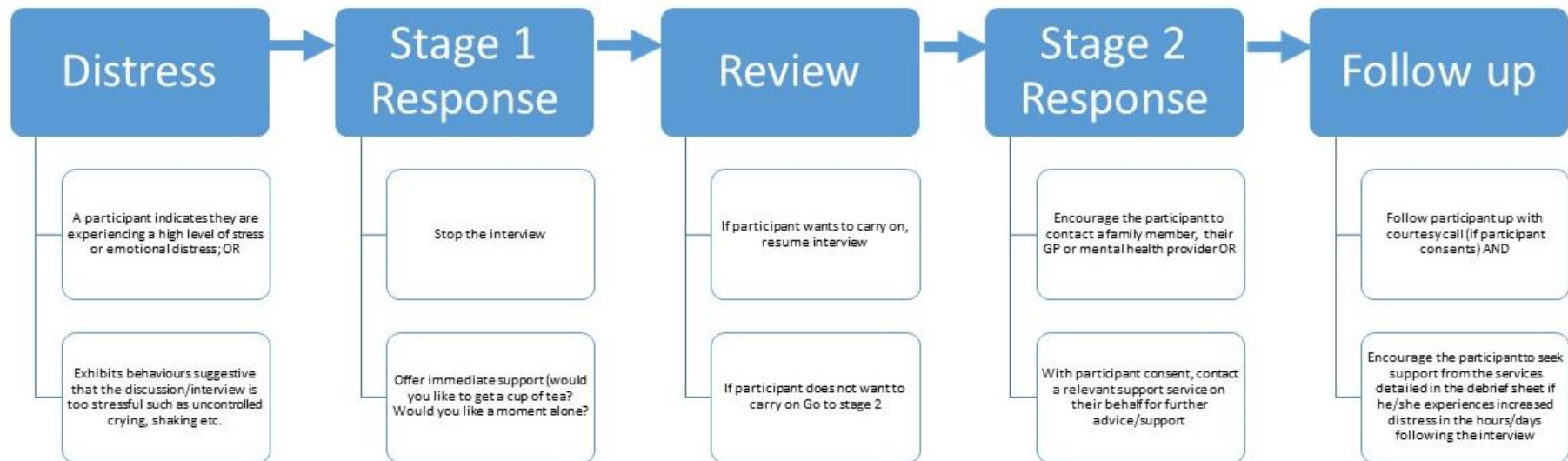
Title of the research project: **The lived experiences of people bereaved by Covid-19.**

Name of researcher(s): Dr Lynn Sudbury-Riley

- | | | Please
initial box |
|---|--|--------------------------|
| 1 | I confirm that I have read and have understood the information sheet dated 25.4.21 for the above study, or it has been read to me. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2 | I understand that taking part in the study involves an audio recorded interview | <input type="checkbox"/> |
| 3 | I understand that my participation is voluntary and that I am free to stop taking part and can withdraw from the study at any time up to the point of transcription (1 week after interview, if you have chosen the option for your data to be anonymised), or up to the point of publication (3 months after interview if you have chosen for your data not be anonymised) without giving any reason and without my rights being affected. In addition, I understand that I am free to decline to answer any particular question or questions | <input type="checkbox"/> |
| 4 | I understand that I can ask for access to the information I provide and I can request the destruction of that information if I wish at any time prior to the point of transcription (1 week after anonymised interview, 3 months after non-anonymised interview). I understand that following these cut-off times I will no longer be able to request access to or withdrawal of the information I provide | <input type="checkbox"/> |
| 5 | I understand that the information I provide will be held securely and in line with data protection requirements at the University of Liverpool. | <input type="checkbox"/> |

Appendix 5 Distress protocol

Protocol for managing distress in the The lived experiences of people bereaved by Covid-19 interviews



Appendix 6 De-brief document



Participant Debriefing

Version number & date: V2 25th April 2021

The lived experiences of people bereaved by Covid-19.

Thank-you for taking part in the study and sharing your story. I understand how upsetting this is, and I know that while sharing experiences can actually help, it can also make us feel even more sad and lost. Below are some support services that you may want to access.

National Bereavement Partnership

Provides a support helpline, counselling referral and befriending service for all those suffering from bereavement, grief, living loss, mental health issues, and those affected by the COVID-19 pandemic.

Telephone Helpline: 0800 448 0800 (7am - 10pm, every day)

Text Helpline: 07860 022 814 (texts are charged at your standard rate)

Alone Together Covid-19 Support Network

A private group on Facebook. A support network for people who have lost someone they love to Covid-19. <https://www.facebook.com/groups/550762382237414/>

Cruse Bereavement Care

Coronavirus Online and Helpline resource for dealing with coronavirus related bereavement and grief.

Telephone Helpline: 0808 808 1677

Monday + Friday 9.30am - 5pm; Tuesday - Thursday 9.30am - 8pm; Weekends 10am - 2pm

Online Chat: <https://www.cruse.org.uk/>

Monday - Friday 9am - 9pm

NHS Bereavement Helpline

Offers guidance, support and advice to families dealing with loss and grief of a loved one.

Phone: 0800 2600 400, 10am to 4pm, Monday to Friday.

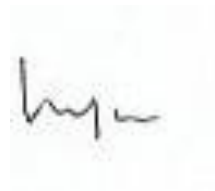
www.nhs.uk/conditions/coronavirus-covid-19/social-distancing/bereavement-advice-and-support

I will be putting a report together for everyone who took part in the study.

This will take several months to put together. If you would like a copy do drop me an email on

L.Sudbury-Riley@Liverpool.ac.uk or message me via Facebook and I will send you a copy.

Once again, thank-you for taking part.

A handwritten signature in black ink, appearing to read 'L. Sudbury-Riley', is positioned in the lower-left area of the page.