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## “Untold Distress” – How did the COVID-19 pandemic affect those who had previously experienced an epilepsy-related bereavement?

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### ABSTRACT

**Purpose:** This study explores the impact of the COVID-19 pandemic and lockdown on people with lived experience of sudden bereavement as a consequence of an epilepsy-related death.

**Method:** We developed an online survey with fixed choice and open-ended response formats to collect data on grief symptoms and well-being during the pandemic. A total of 275 people bereaved by epilepsy-related deaths between 1980–2020 participated in this study: with 79 participants providing free-text responses for inductive thematic analysis.

**Results:** In total, 84% of participants reported a bereavement following a sudden death of a person aged under 40, with 22% aged 19 and under. The majority (77% of participants) reported they had been thinking more about the person who died compared to before the COVID-19 outbreak and 54% had experienced more distressing flashbacks to the time of death. Additionally, 61% reported more difficulties falling asleep and staying asleep and 88% of participants reported that the outbreak and response measures had negatively impacted upon their mental health. Medication was being taken for a diagnosed mental health condition by 33% of participants at the time of the study. We categorized these negative experiences during COVID in to four main-themes - 'Family', 'Lifestyle', 'Personal Well-being' and 'Health Services and Shielding Populations'. The 'Personal Well-being' theme was inextricably linked to grief symptoms including 'reflection on the death', 're-exposure to feeling', 'grief', 'salience of sudden deaths in the media' and 'inability to commemorate anniversaries and rituals'. These findings were consistent for bereaved people irrespective of the recency of the death.

**Conclusion:** This study highlights the impact of the disruption caused by the pandemic on the grief-management of those bereaved by epilepsy-related death. Grief is not static and its management is connected to the psychosocial and formal support structures that were disrupted during the pandemic. The removal of these supports had an adverse effect upon the mental health and well-being of many bereaved. There is an urgent need for a system-wide transformation of epilepsy and mental health services to be inclusive of the needs and experiences of people impacted by sudden deaths in epilepsy and the contribution of the specialist service developed by families and clinicians to meet this gap.

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### 1. Introduction

Epilepsy is common globally, and in the UK alone there are over 1000 epilepsy-related deaths annually [1], most of which occur without warning and in young people [2]: up to half of epilepsy-

related deaths are due to SUDEP (Sudden Unexpected Death in Epilepsy) [3]. Before the COVID-19 pandemic struck there was an increase in the reporting of epilepsy-related deaths in the community in the UK, with particular concern for women in pregnancy, and people with epilepsy and learning disabilities [45].

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### 1.1. Traumatic grief

How people respond to the sudden death of a family member or friend with epilepsy is highly variable both between individuals and within individuals over the course of their lives. In many cases, those bereaved by epilepsy-related death experience traumatic grief that can have long-term consequences on well-being [2]. Fewer than 1% of bereaved families reported knowing someone could die from epilepsy in 2002 [6] and, two decades ago, the UK Chief Medical Officers supported the development of an action plan to tackle the findings that at least 42% of epilepsy deaths are potentially avoidable [7]. Traumatic grief increases the risk of numerous physical and mental health outcomes, including suicidal ideation, cardiac disease, [8], lower social functioning, fatigue, and well-being [9].

In many cases, those enduring complicated grief can still, a long time after death, continue to experience 'reminders' with trauma-related thoughts triggering intense psychological distress similar to those experienced directly after the death [10]. Though many bereaved people will find ways of managing their grief either formally with counseling or other support group, others can do so with a return to 'normal life' and their employment, socializing, and participation in other hobbies and activities [11]. However, while the coping mechanisms bereaved people draw upon to help manage their grief are highly individualistic, multi-faceted, and influenced by both formal and informal support structures, very little is known about the impact upon long-term grief management when these formal and informal support structures are disrupted.

### 1.2. COVID-19 impact

The COVID-19 pandemic has had an unprecedented and devastating global effect and, with nearly 18 million recorded cases and over 150,000 deaths within 28 days of a positive COVID test in the UK alone [12] there has been an abundance of media attention and research into those bereaved by COVID-related deaths during the pandemic [13,14,15]. In addition to the direct impact of the virus, societies, the UK included have had to endure prolonged periods of state-mandated isolation; lockdown measures started in the UK on 23rd March 2020. An inadvertent effect of this was to block access to people's grief-management support. We wanted to study the experiences of people bereaved by epilepsy-related death and to identify the degree of impact upon their ability to live with their grief during the COVID-19 pandemic, irrespective of when that death occurred.

Specifically, we asked: how has the COVID-19 pandemic and lockdown impacted those bereaved by epilepsy?; how are these experiences impacted by recency of death?; how can these experiences be understood in terms of contributory factors?; how have bereaved people felt supported during the COVID-19 pandemic and lockdown?

## 2. Material and methods

### 2.1. Design

We designed a self-reported qualitative and quantitative survey for people bereaved by epilepsy-related death [16]. A combination of response formats was used to both include fixed-choice responses as well as using open-ended questions (see Appendix). Fixed-choice responses were used for demographic differentiation and to categorize response data at a broad level. Open-ended response formats offered participants the opportunity to provide descriptions using their own words and with the freedom to share a more personal experience. We delivered the 33-item question-

naire via an online survey (SurveyMonkey) with hard copies also available upon request.

### 2.2. Participants

Participants had experienced an epilepsy-related death of someone close to them and responses were welcomed irrespective of when that epilepsy-related death occurred.

Participants were predominantly identified through the Epilepsy Deaths Register (EDR) (<https://www.epilepsydeathsregister.org>) within the last 5 years and had indicated in their consent that they would be happy to be contacted about future research. The EDR currently has over 950 records of epilepsy-related deaths provided by family members, friends, and professionals that relate deaths occurring since 1960 [17] and is the largest data repository of its type in the world. Emails inviting participation were sent on 31st May and 1st June 2020. Participation was also invited through social media (from 26th May 2020). Reminders of the study, including a link to the questionnaire, were also posted after the first 200 responses had been received. The data lock was on 23rd December 2021.

### 2.3. Materials

The questionnaire used for this study consisted of 26 items subdivided into three main categories: **Demographics**; about the person completing the questionnaire and the person who died; **Well-being during the COVID-19 Pandemic**; these items were drawn from indicators of prolonged and traumatic grief [2,18,19] and were contextualized for experiences of epilepsy-related death following interviews with SUDEP Action's specialist bereavement service. All responses were provided on a 5-point Likert-scale response format indicating a level of agreement; 'strongly agree', 'agree', 'neither agree nor disagree', 'disagree', and 'strongly disagree'. Participants were also asked for details and dates of any diagnoses of anxiety, depression, dissociation/dissociative disorder, panic attacks, or PTSD; **Experiences during the COVID-19 Pandemic**; a combination of Likert-scale responses, multiple-choice and open-ended questions related to participant experiences during the COVID-19 pandemic. Questions related to the impact on lifestyle (employment, leisure, social life) as well as specific questions related to anxiety, grief, and methods of coping with grief. Survey items were written in accordance with Imperial College London's guidance for writing accessible surveys.

### 2.4. Analysis

An inductive approach to analysis was undertaken following the six stages by Braun & Clarke [20]. Quantitative data were analyzed using SPSS 28 and inductive thematic analysis was undertaken independently by three researchers on the qualitative data for key themes. Ages were split into decade age bands.

### 2.5. Ethics

Respondents were anonymous and unpaid. Due to the sensitive nature of the subject matter, all participants were provided contact details for bereavement support should they feel that it would be beneficial to them. Ethics approval for this study was granted by Newcastle University 2394/2020 (21/04/20).

## 3. Results

A total of 285 responses were received, of which ten were incomplete and could not be studied as they did not include infor-

mation about the person who had died. This left 275 valid responses for further analysis, with deaths reported spanning 45 years.

### 3.1. General demographics

#### 3.1.1. Respondent demographics

The majority of respondents were aged between 40 and 69 (n = 195) and the vast majority were female (90%). Approximately half of all respondents were a parent or person with parental responsibility of the person who died (n = 130) with daughters, sons and step-children (n = 52), siblings (n = 45), partners and spouses (n = 23), and uncles and aunts (n = 8) also represented. Though the majority of participants were related to, or in a relationship with, the person who died (94%), some responses were also obtained from friends (n = 7) and 3% of respondents described their relationship to the deceased as 'other' (n = 9). Respondents were appropriately geographically distributed; 82% were from England (n = 212) with 8% from Scotland (n = 21), 7% from Wales (n = 19), and 2% from Northern Ireland (n = 6).

#### 3.1.2. Details of the deaths

Forty percent (n = 103) of deaths were seen in people aged between 20–29 when they died and 80% of deaths were between 10 and 39 years. Four percent of deaths occurred in children aged from 0–9 (n = 10). The majority of deaths were in males (64%, n = 167). Almost half of respondents were bereaved by a death that occurred since 2016 (48%, n = 123) with gradually decreasing numbers by five-year bands extending back to within the 1986–1990 year-band (Table 1).

### 3.2. Well-being during the COVID-19 pandemic

#### 3.2.1. Grief symptoms

A total of 234 participants who had experienced an epilepsy-related death prior to the first lockdown measures being implemented responded to questions asking the extent to which they agreed with ten statements associated with sudden epilepsy bereavement. Seventy-seven percent of participants agreed with the statement 'I have been thinking more about the person who died' and over half (54%) agreed with the statement 'I have had more distressing flashbacks to the time of the death'. Furthermore, nearly half of the respondents agreed that they had 'experienced more distressing memories of the person who died' and had 'experienced more feelings of guilt about the death' (Table 2). Impact on general mood was also evidenced in responses with 44% of participants agreeing with the statement that they 'felt more irritable with other people' and 41% agreeing or that they 'felt more angry' (Table 2).

**Table 1**  
Participants' responses for 'Date of Death (if known)' categorized by five-year bands.

| Year of death | N (%)     |
|---------------|-----------|
| 2021+         | 6 (2%)    |
| 2016–2020     | 117 (46%) |
| 2011–2015     | 61 (24%)  |
| 2006–2010     | 38 (15%)  |
| 2001–2005     | 17 (7%)   |
| 1996–2000     | 13 (5%)   |
| 1991–1995     | 2 (1%)    |
| 1986–1990     | 1 (<1%)   |
| TOTAL         | 255       |
| Missing       | 20        |

Sixty-one percent of participants agreed that they 'were having more difficulties getting to sleep and staying asleep' while nearly a quarter of participants agreed that their 'weekly alcohol consumption had increased'. A smaller proportion (6%) agreed or strongly agreed that their 'use of tobacco or recreational drugs had increased'.

#### 3.2.2. Comparison by year of death

Responses remained consistent irrespective of the year in relation to the number of participants who had been 'thinking more about the death' (77–79% in all cases). But the largest percentage of respondents who had experienced 'distressing flashbacks to the time of death', 'distressing memories of the person who died', and 'feelings of guilt around the death' had all experienced a death during the most recent time period (Table 3). Importantly the older deaths (over 15 years ago) were still associated with significant new concerns with participants experiencing distressing flashbacks (42%), feelings of guilt about the death (39%), and increased difficulties getting to sleep and staying asleep (52%).

#### 3.2.3. Pre-existing mental health conditions

Of the respondents who had been bereaved prior to the first UK lockdown, half of the respondents (51%, n = 128) reported that they had, in the past, been diagnosed with at least one of the following mental health conditions: anxiety, depression, dissociation/dissociative disorder, panic attacks, post-traumatic stress disorder. Where dates of diagnosis were provided, half of the respondents (50%, n = 114) who reported having had a diagnosis, reported that at least one diagnosis was given in the first year following the epilepsy-related death and 67% of these diagnoses were recorded within the first month following the death. The mental health diagnosis most frequently reported was depression (n = 99), followed by anxiety (n = 86), post-traumatic stress disorder (n = 52), and panic attacks (n = 41) (Table 4). One-third of participants were still taking prescribed medication for at least one mental health condition at the time of their participation in this study which is suggestive of enduring problems.

#### 3.2.4. Lifestyle and health

Nearly every respondent (96%) identified some negative impact in relation to their social lives, and their mental health (88%). A prevalent negative impact was also seen with regard to physical health (75%), access to support networks (72%), and financial security (55%).

Nearly three-quarters of respondents reported that the negative impact on their social life had been 'major' or 'severe' while nearly a third reported that the negative impact had been 'major' or 'severe' in relation to their 'access to support networks' and their mental health. Seventy-four percent of respondents also reported that they had experienced increased anxiety about the safety and well-being of others (Table 5).

### 3.3. Experiences during the COVID-19 pandemic

#### 3.3.1. Categorization of main-themes

Free text responses were particularly rich and informative, providing detail with regard to how participants managed their grief both prior to and during the COVID-19 pandemic. 79 participants (29%) provided free text responses. These responses independently underwent inductive, thematic analysis for main themes by three researchers with a high degree of consistency of interpretation. A high level of agreement was evidenced in independent categorization for three main themes 'Family', 'Lifestyle', and 'Personal Well-being'. A fourth distinct category of 'Health Services and Shielding Populations' was then created out of a number of sub-themes that were categorized similarly but did not fit well under any of the

**Table 2**

Participants' responses to the extent to which, compared to how they felt before the COVID-19 outbreak, agreed with a series of statements associated with well-being and grief response.

| Item Statement  | Strongly Agree | Agree       | Neither Agree nor Disagree | Disagree    | Strongly Disagree | TOTAL |
|---|----------------|-------------|----------------------------|-------------|-------------------|-------|
| I have been thinking more about the person who died                   | 99<br>(42%)    | 81<br>(35%) | 41<br>(18%)                | 11<br>(5%)  | 2<br>(1%)         | 234   |
| I have had more distressing flashbacks to the time of the death       | 66<br>(28%)    | 62<br>(26%) | 60<br>(26%)                | 36<br>(15%) | 10<br>(4%)        | 234   |
| I have experienced more distressing memories of the person who died   | 65<br>(28%)    | 50<br>(21%) | 63<br>(27%)                | 48<br>(21%) | 8<br>(3%)         | 234   |
| I have had increased difficulties getting to sleep and staying asleep | 72<br>(31%)    | 70<br>(30%) | 43<br>(18%)                | 42<br>(18%) | 7<br>(3%)         | 234   |
| I feel more angry   | 38<br>(16%)    | 58<br>(25%) | 64<br>(28%)                | 54<br>(23%) | 17<br>(7%)        | 231   |
| I feel more irritable when with other people                          | 35<br>(15%)    | 68<br>(29%) | 64<br>(27%)                | 52<br>(22%) | 14<br>(6%)        | 233   |
| I have experienced more feelings of guilt about the death             | 62<br>(26%)    | 49<br>(21%) | 52<br>(22%)                | 47<br>(20%) | 24<br>(10%)       | 234   |
| My weekly alcohol consumption has increased                           | 15<br>(6%)     | 43<br>(18%) | 41<br>(18%)                | 59<br>(25%) | 76<br>(32%)       | 234   |
| My use of tobacco or recreational drugs has increased                 | 5<br>(2%)      | 9<br>(4%)   | 30<br>(13%)                | 39<br>(17%) | 148<br>(64%)      | 231   |

**Table 3**

Split by year of death, and in comparison with how they felt prior to the COVID-19 outbreak (23/03/20), percentages of respondents 'strongly agreeing' or 'agreeing' with a series of statements associated with well-being and grief-response.

| Item Statement  | Year of Death         |                       |                       |                        |
|---|-----------------------|-----------------------|-----------------------|------------------------|
|   | 1981–2005<br>(n = 31) | 2006–2010<br>(n = 38) | 2011–2015<br>(n = 61) | 2016–2020<br>(n = 102) |
| I have been thinking more about the person who died                   | 24<br>(77%)           | 30<br>(79%)           | 47<br>(77%)           | 79<br>(77%)            |
| I have had more distressing flashbacks to the time of the death       | 13<br>(42%)           | 20<br>(53%)           | 32<br>(52%)           | 63<br>(62%)            |
| I have experienced more distressing memories of the person who died   | 12<br>(39%)           | 15<br>(39%)           | 29<br>(48%)           | 59<br>(58%)            |
| I have had increased difficulties getting to sleep and staying asleep | 16<br>(52%)           | 26<br>(68%)           | 33<br>(54%)           | 67<br>(66%)            |
| I feel more angry   | 8<br>(26%)            | 16<br>(42%)           | 24<br>(39%)           | 48<br>(47%)            |
| I feel more irritable when with other people                          | 6<br>(19%)            | 19<br>(50%)           | 27<br>(44%)           | 51<br>(50%)            |
| I have experienced more feelings of guilt about the death             | 12<br>(39%)           | 18<br>(47%)           | 29<br>(48%)           | 52<br>(51%)            |
| My weekly alcohol consumption has increased                           | 7<br>(23%)            | 7<br>(18%)            | 14<br>(23%)           | 30<br>(29%)            |
| My use of tobacco or recreational drugs has increased                 | 0<br>(0%)             | 0<br>(0%)             | 8<br>(13%)            | 6<br>(6%)              |

**Table 4**

Participants reported as having ever had a diagnosis of selected mental health disorders.

| Diagnosis                          | No. of respondents | Valid percentage |
|------------------------------------|--------------------|------------------|
| Anxiety                            | 86                 | 34%              |
| Depression                         | 99                 | 39%              |
| Dissociation/Dissociative Disorder | 4                  | 2%               |
| Panic Attacks                      | 41                 | 16%              |
| Post-Traumatic Stress Disorder     | 52                 | 21%              |

other three key headings. Sub-themes categorized under this heading included references to 'healthcare access', 'access to services', 'inability to access support groups and counseling face-to-face', and the specific impacts on 'shielding groups' or those with 'comorbidities' (Table 6).

3.3.2. Main theme 1 - Family

A common theme emerged in relation to lockdown preventing people from spending time with family. Sub-themes within this are 'loss of practical support with day-to-day living', 'distance and separation', 'loss of emotional support', and 'anxiety and con-

cern for the well-being of others'. The first two sub-themes referred to the disruption of COVID-19 and lockdown to daily life and, generally speaking, these comments did not directly refer to the impact of bereavement and were referred to as more of a practical, interfamilial problem. The sub-theme of 'loss of emotional support', however, though not something exclusive to bereaved communities, was frequently contextualized in relation to the participant's bereavement and in relation to the absence of emotional support from family members that had been valued.

*"Not being able to see members of our family (other children & Grandchildren) to help each other though this difficult time. The death of our youngest son was a shock and unexpected. He was on one of his many respite weekends and never came home."* (Parent of male, 26)

Anxiety was highly prevalent in society as a whole but this concern for family members during COVID-19 was often contextualized as something that could heighten fears.

*"The pandemic has increased my anxiety and makes me fear losing my family. I'm not sure if this is exaggerated after losing my son but*

**Table 5**

Based on self-assessment of severity, participant responses to the degree to which the coronavirus/COVID-19 outbreak and government response measures had negatively impacted their health and aspects of daily life.

| Question Item                   | Severe      | Major        | Moderate    | Minor       | None at all  | TOTAL |
|---------------------------------|-------------|--------------|-------------|-------------|--------------|-------|
| Your financial security?        | 13<br>(6%)  | 15<br>(7%)   | 58<br>(25%) | 40<br>(17%) | 103<br>(45%) | 229   |
| Your employment status?         | 11<br>(5%)  | 17<br>(7%)   | 28<br>(12%) | 15<br>(7%)  | 156<br>(69%) | 227   |
| Any voluntary work that you do? | 11<br>(5%)  | 18<br>(8%)   | 19<br>(9%)  | 14<br>(6%)  | 157<br>(72%) | 219   |
| Your physical health?           | 7<br>(3%)   | 31<br>(14%)  | 81<br>(36%) | 51<br>(22%) | 58<br>(25%)  | 228   |
| Your mental health?             | 19<br>(8%)  | 50<br>(22%)  | 80<br>(35%) | 54<br>(23%) | 28<br>(12%)  | 231   |
| Your social life?               | 59<br>(26%) | 102<br>(45%) | 45<br>(20%) | 12<br>(5%)  | 10<br>(4%)   | 228   |
| Access to support networks?     | 28<br>(12%) | 43<br>(19%)  | 52<br>(23%) | 40<br>(18%) | 63<br>(28%)  | 226   |

**Table 6**

Main themes and sub-themes elicited from open-ended responses provided by bereaved people in relation to their experiences during the COVID-19 pandemic.

| Main theme                                | Sub-theme  |
|---|--|
| Family                                    | Loss of practical support with day-to-day living<br>Loss of emotional support<br>Anxiety and concern for well-being of others  |
| Lifestyle                                 | Distance and separation<br>Adverse impact on ability to socialize with friends<br>Adverse impact on participation in activities and groups   |
| Personal well-being                       | Disruption to routines and 'ways of living'<br>Reflection and rumination<br>Re-exposure to feeling<br>Grief<br>Salience of sudden deaths in the media<br>Anniversaries and rituals |
| Health services and shielding populations | Impact on experience of services<br>Impact on support groups attended<br>Impact on experiences of counseling   |

*it's something I do worry about anyway. When we went into lockdown I would cry on my way to work.* (Parent of male, 14)

3.3.3. Main theme 2 - Lifestyle

The COVID-19 pandemic and lockdowns have had a predictable adverse impact both on 'socializing with friends' and 'participating in activities and groups' were often referenced together. Employment and volunteering, as categorized by 'disruption to routines and 'ways of living' also featured in many responses.

*"The only way you can talk to anyone either doctors or friends is over the phone, so I can't meet up with friends and my doctor's appointments are either cancelled or over the phone. I volunteer to help drunk and homeless at the weekends but as all the pubs/clubs are closed I can't do that. It makes you lose your sense of purpose."* (Friend of female, 26)

*"As a self-employed person, my work has ceased and I have not qualified for any government support. My volunteering took me out to meet people and was a large part of my social life."* (Parent of female, 22)

3.3.4. Main theme 3 - Personal well-being

The categorization of 'Personal Well-being' encapsulates five sub-themes that are inherently tied to bereavement, along with the emotional state and mental health of the bereaved person. 'Reflection and Rumination' as a sub-theme, cropped up time and

time again in reference to the experience of lockdown leaving people with more time left to their own thoughts about the person who died.

*"During lockdown and during isolation periods x 3 I have become very low thinking about my daughter all the time."* (Parent of female, 21)

Under the 'Re-exposure to feeling' sub-theme, respondents also reported experiencing a 're-awakening' of the trauma that they experienced at the time of the death or an 'amplification' of those feelings of loss they are learning to live with.

*"You never get over a son dying but this has bought all of it back, feelings of guilt and why."* (Parent of male, 19)  
*"Since my son's death I am a shell of what I was, but this year has just magnified everything."* (Parent of male, 22)

COVID-19 lockdowns have exacerbated grief reactions. By disrupting the already isolating and unpredictable grieving process, respondents reported an adverse effect on their well-being.

*"Now I have no option but just to go home every evening, which I find lonely and depressing. It compounds my grief. Losing a partner suddenly to SUDEP is so traumatic and it was so unexpected."* (Spouse/Partner of male, 52)

Furthermore, at the very same time that those bereaved by an often-sudden epilepsy-related death are finding more time to reflect on their loss, they have been simultaneously assailed by a constant stream of news of sudden death and 'death-counts' in the media that evoke painful reminders for people who have themselves experienced the sudden death of a family member or friend in the past.

*"I am always distressed when hearing of sudden death. When it's unexpected for families it always has a greater effect on me. This has obviously increased at the moment."* (Parent of male, 30)

Many bereaved people recognize and commemorate anniversaries and birthdays of those who died - often in supportive groups but also in traveling to and visiting graves. In this way, the lockdown prevented many bereaved people from marking key dates, and being unable to commemorate these occasions caused considerable distress to many respondents.

*"We had arranged several family and friend gathering to honour him and his memory on what would have been his 20th birthday. All this was stopped due to covid 19."* (Parent of male, 19)

3.3.5. Main theme 4 - Health services and shielding populations

This theme reflects the views of so many respondents in relation to the disruption to more formal grief-management struc-

tures. Typically, this would refer to counseling sessions and bereavement support groups but there were additional comments in relation to, for example, housing support services and CBT sessions.

*"I have struggled with not being able to attend a local Child bereavement group that I had been going to. While it is now happening via Zoom online, I struggle to participate in this way, although I am grateful for the amount of effort they put into making this happen, it doesn't work for me, and I find I am dwelling more on my negative thoughts since our son passed away."*

(Parent of male, 10)

*"As a result of the pandemic and an increase level of stress at work I was diagnosed with anxiety which I chose to support through counselling. It was agreed that the current anxiety may stem from my experience of my bereavement. Unfortunately, the counselling had to be postponed due to restrictions."* (Parent of male, 17)

#### 4. Discussion

The COVID-19 pandemic unlike any phenomenon since the World Wars has inflicted multifaceted global repercussions upon the way people live their lives. As life has returned to some sense of perceived 'normal', the legacy from the pandemic has persisted both in terms of economic impact as well as on the way people live, such as the commonality of remote and hybrid working [21]. The NHS still has a growing backlog of people on waiting lists for services [22] and the significant deterioration in mental health during the pandemic has not returned to pre-pandemic levels [23]. It is important to recognize the long-term impacts of bereavement and vulnerability on mental health and well-being, not only for those bereaved by COVID or those bereaved during the pandemic.

We demonstrate the prevalence of increased intensity of grief symptoms associated with epilepsy-related deaths and the degree of impact that the COVID-19 pandemic has had on people bereaved by epilepsy-related death. There is a lack of comparative data from the literature in relation to the long-term impacts of epilepsy-related bereavement but the responses here are indicative of large numbers of people bereaved by epilepsy-related death experiencing an increase in symptoms consistent with indicators of prolonged and traumatic grief [21819]. Notably, these findings conflict with other research where no difference in grief severity was found prior to, and during, COVID in people bereaved by deaths that were classified as being either 'natural' or 'unnatural' (e.g., suicide or accident) [24]. Contrarily, during a lockdown, large numbers of participants in this research, bereaved specifically by epilepsy-related death, experienced an increase in grief symptoms including distressing flashbacks to the time of death, distressing memories of the person who died, and more feelings of guilt around the death. Participants reported the distress experienced with the time to reflect and ruminate on their loss accompanied, in many cases, by re-exposure to the experience of feelings felt at the time of the death. The salience of 'sudden deaths' running through the media alongside the inability to commemorate and recognize key dates of their loved ones has also caused much anguish.

##### 4.1. Lockdown harms

Critically when participants needed increased support, their ability to access this from traditional networks was removed from them. Restrictions imposed by the lockdown and the consequent changes to the delivery of bereavement services and counseling sessions have isolated people, making it harder for them to manage their grief while amplifying issues and feelings associated with a

death they had experienced. It is noteworthy that these findings with people bereaved by epilepsy-related death are not replicated in research with bereaved people generally [24] which may point to the increased likelihood of traumatic grief accompanying the often sudden and unexpected nature of many epilepsy-related deaths [2] and the differences in grief-expression when this is the case [9]. Importantly, all of these negative 'grief-symptoms' experienced during the COVID-19 pandemic occurred irrespective of the date of death. Comparable experiences were reported by people who experienced a death over a decade prior to COVID restrictions as well as those who experienced a death more recently.

We have become familiar with identifying vulnerable people and promoting the need to shield to prevent contact with the virus, but people bereaved by epilepsy already form a vulnerable group [7]; this research shows the harm of COVID-19 lockdowns on them. Many participants in this study had a historic diagnosis of a mental condition such as anxiety, depression, and post-traumatic stress disorder. Furthermore, a third of participants were taking regular medication for this condition at the time of data collection. Disruption to regular, formalized, face-to-face counseling sessions and/or attendance of bereavement support groups stripped bereaved people of a support structure they had relied upon. While these findings came from research with people in the UK, they could likely be generalizable to other countries and health systems as well.

##### 4.2. Limitations

We recognize a number of limitations in this study. This is not an epidemiological sample and there will be a recruitment bias favoring families who have had contact with SUDEP Action. Inevitably, this makes it less likely that participation was obtained from 'hard-to-reach' groups or the technologically averse. Views of fathers have also been under-reported and low participation of males generally will impact upon findings and may influence relative theme-applicability. A greater proportion of men are likely to exhibit instrumental, rather than intuitive, grief patterns [25] which are less well aligned with research into grief emotions and reflection. Low participation of males in bereavement research is, however, not unusual, and male participation at around 10–20% has not been uncommon with other research into bereavement during COVID [2426].

Though overall response rates to fixed response questions were high, since responses to questions were optional, there was missing, non-response data in the set. Those people who chose to give us qualitative data may not be representative of the whole. When asking participants to draw a comparison between their experiences pre-COVID and post-COVID, there are issues with recall bias and, with something as complex as grief (which is continuous and can change for better and worse over time), there is subjectivity in how participants framed their comparisons. Finally, the study also lacks a control group so it is not possible to compare the reported experiences of those bereaved by epilepsy-related death with those bereaved by any other death or, indeed, the impact of the lockdown on those not bereaved at all. However the intensity and level of measurable distress in this group may highlight issues appropriate for study in other sectors of the population.

##### 4.3. Conclusion

The COVID-19 pandemic and subsequent lockdown measures had a significant detrimental impact on the well-being of people bereaved by epilepsy-related death. Isolated from activities, psychosocial support structures, and formalized support provision, along with the salience of sudden COVID-deaths in the media, have intensified people's feelings of grief by removing or adversely

impacting their grief management supports. Those suddenly bereaved by epilepsy will carry their grief with them for the rest of their lives and the ability to manage that grief is not static. Against a backdrop of over 6 million people waiting for access to services in the UK [27], it is imperative that plans for recovery include epilepsy and sudden bereavement in epilepsy in tackling systemic inequalities for the most vulnerable.

In the UK coroners, health professionals and patient organizations can also contribute to putting NHS RightCare (a national program in the UK using evidence to support healthcare systems) into practice by including signposting to SUDEP Action and the Epilepsy Deaths Register which has been shown to be partially cathartic. In times of significant disruption, health professionals and patient organizations must learn from this pandemic to react quickly in the future, in order to be prepared to take a significant role in assisting them to access the support and help they need. Ignoring the impact of COVID-19 and response measures on the mental health of those bereaved by epilepsy now will have long-term consequences and the implications of these findings stretch beyond epilepsy-related bereavement, as those bereaved by a sudden COVID-related death may find themselves in a similar position in the future.

### Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Rhys H Thomas has received honoraria from Arvelle/Angelini, Bial, Eisai, GW Pharma/Jazz, Sanofi, UCB Pharma, UNEEG, Zogenix, and unrestricted research funding from Arvelle and UNEEG. Mike P Kerr has received honoraria from Zogenix and Angellina Pharma.

### Appendix – Full Questionnaire

#### **The impact of the Coronavirus/COVID-19 pandemic on people who have been bereaved by epilepsy-related death**

### Invitation to Participate

#### *Involvement*

This project is a collaboration between SUDEP Action, the Epilepsy Deaths Register (EDR) team and the appointed research team at Newcastle University working together to research and raise awareness of the impact of COVID-19/Coronavirus on people who are bereaved from epilepsy-related death. The project will be managed by the EDR team who have experience of supporting and working with the bereaved in research projects.

#### *Purpose of this Project*

The recent COVID-19/Coronavirus outbreak continues to have a significant impact on the way in which we all live our lives as well as on personal well-being. However, as the progress of this pandemic dominates the media and as the government and health and other services available to the public respond with unprecedented response-measures in relation to it, there is a risk that other aspects of well-being, related even indirectly to the outbreak itself or because of lockdown measures, find themselves relegated to the shadows. There is a risk that their impact, though keenly felt at an individual level at this time may only truly manifest in significance further down the line unless efforts are undertaken to understand them now.

The purpose of this research is to gain a deeper understanding into how those who are bereaved by epilepsy-related death are adjusting and coping with the implications of the virus, the knock-on effect on prioritization of health and other services and the isolation measures that have been implemented. Findings from this research will give an indication both of the scale of impact as well as provide a knowledge-base that can be used to support people affected both now and in the future.

#### *Procedure*

Participating in this research involves completion of a questionnaire that is split into three main sections:

1. General/Demographics
2. Well-being
3. Experiences during the COVID-19/Coronavirus pandemic

The questionnaire includes both multiple-choice and free-text response formats and completion of the questionnaire, in full, should take no more than 15-20 minutes. If you need any additional assistance to participate in this research for any reason, please contact the EDR Team at [team@epilepsydeathsregister.org](mailto:team@epilepsydeathsregister.org).

#### *Benefits and Risks*

Benefits of participation include the knowledge that your anonymised data will be used to further understanding into the impact of COVID-19/coronavirus on people affected by epilepsy-related death in order that findings can guide action to provide support and help where needed.

Questions in this questionnaire are, necessarily, quite sensitive in nature as they relate to your experiences of bereavement following someone's death. If you do not wish to provide a response to any question, you always have the option to leave it blank and move on to the next question. For more information about support services or to speak to someone, you can email us at [team@epilepsydeathsregister.org](mailto:team@epilepsydeathsregister.org) or call our support line on 0330 088 1220 (UK local rate call).

#### *Confidentiality*

All information collected through this questionnaire is anonymised and no identifiable information will be used in any reports produced. Data is stored on a secure server that is managed and maintained in accordance with GDPR and the EDR's own data-protection protocols. Only those parties directly working with data and listed in the 'Involvement' section (above) will have access to the data and you may withdraw your data at any time whether partially-completed or at any time after completing the questionnaire in full. Any of your data which has already been analysed and used in study publications cannot be removed but will not be included in any future publications. Please contact the EDR team at [team@epilepsydeathsregister.org](mailto:team@epilepsydeathsregister.org) if you wish to have your data withdrawn and this will be actioned without question.

#### *Consent*

By ticking the following check-box, you are indicating that you are over 18 years of age, that you understand the above information and that you are volunteering for your data to be used for research aimed at understanding the impact of COVID-19/Coronavirus on people who are bereaved from epilepsy.

Please note that if you do NOT tick this box, we be unable to use your data.



The Epilepsy Deaths Register

If you have submitted your data to the Epilepsy Deaths Register already, please note that there may be some duplicate questions within this project as it is an independent project and all participant data is anonymous. If you have not submitted data about an epilepsy-related death to the Epilepsy Deaths Register, please consider doing so as well. The Epilepsy Deaths Register is the largest and most powerful collection of information on epilepsy deaths in the world aimed at reducing epilepsy deaths and improving outcomes for people with epilepsy and their families in the future. It can be accessed at the following address: [www.epilepsydeathsregister.org](http://www.epilepsydeathsregister.org)

Section 1: General/Demographics

About you

1. What is your age?

- [Open-text box]

2. How would you describe your gender?

- [Male]
- [Female]
- [Prefer not to say]
- [Other... please specify] → [open-text box]

3. What are the first three characters of your postcode?

- [Open-text box]

4. What is your occupation?

(Why are we asking this question? Because we know that coronavirus/COVID-19 and government response-measures have varying impact on people depending on the work that they do)

- [Employee – please specify job-title] → [open-text box]
- [Self-employed]
- [Parent/carer (for child or adult)]
- [Voluntary work]
- [Retired]
- [Unemployed]
- [other – please specify] → [open-text box]

5. What was your relationship to the person who died? Were you the:

- [Spouse /partner]
- [Parent or person with parental responsibility]
- [Daughter / son or step-child]
- [Sibling]
- [Grandparent]
- [Uncle /Aunt]
- [Cousin]
- [Flatmate or living together]
- [Good friend]
- [Neighbour]
- [Acquaintance]
- [Other – please specify]→ [open-text box]

About the deceased

6. What was their age at death?

- [Open-text box]

7. How would you describe their gender?

- [Male]
- [Female]
- [Prefer not to say]
- [Other... please specify] → [open-text box]

8. What was the date of death?

- [Fixed format DD/MM/YY]

9. Was there an inquest or any public enquiry or hearing into the death?

(Why are we asking this question? Because we want to understand if and how experiences of this process might differ both prior and during the coronavirus/COVID-19 pandemic)

- [Yes]
- [No]
- [Unsure]

If no, are you aware if there will be an inquest, public enquiry or hearing?

- [Yes]
- [No]

Please comment further if you wish (date of inquest, public enquiry or hearing / what you have been told about the inquest, public enquiry or hearing)

- [Open-text box]

Section 2: Well-being

1. Based on how you have felt over the last 7 days, please indicate the extent to which you would agree with the following statements:

|  | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
|--|-------------------|----------|----------------------------|-------|----------------|
|--|-------------------|----------|----------------------------|-------|----------------|

I keep thinking about the person who died  
Flashbacks to the time of death have been distressing to me  
Memories of the person who died have been distressing to me  
I have difficulties getting to

**Section 2: Well-being** (continued)

|   | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
|---|-------------------|----------|----------------------------|-------|----------------|
| sleep and staying asleep                              |                   |          |                            |       |                |
| I feel angry  |                   |          |                            |       |                |
| I feel irritable when with other people               |                   |          |                            |       |                |
| I experience feelings of guilt about the death        |                   |          |                            |       |                |
| I feel isolated                                       |                   |          |                            |       |                |
| My weekly alcohol-consumption has increased           |                   |          |                            |       |                |
| My use of tobacco or recreational drugs has increased |                   |          |                            |       |                |

**2. Have you ever been diagnosed with any of the following?**

| Condition                          | Yes/No | Approx. date of diagnosis (MM/YY) |
|------------------------------------|--------|-----------------------------------|
| Anxiety                            |        |                                   |
| Depression                         |        |                                   |
| Dissociation/dissociative disorder |        |                                   |
| Panic Attacks                      |        |                                   |
| Post-Traumatic Stress Disorder     |        |                                   |
| Other (please specify)             |        |                                   |

**3. Are you currently prescribed medication to help with any of the above?**

- [Yes]
- [No]

**Section 3: Experiences during the Coronavirus/COVID-19 pandemic**

**1. To what degree have the COVID-19/coronavirus outbreak and consequent government response-measures impacted upon the following:**

|                             | None at all | Minor | Moderate | Major | Severe |
|-----------------------------|-------------|-------|----------|-------|--------|
| Your financial security?    |             |       |          |       |        |
| Your employment status?     |             |       |          |       |        |
| Any voluntary work you do?  |             |       |          |       |        |
| Your physical health?       |             |       |          |       |        |
| Your mental health?         |             |       |          |       |        |
| Your social life?           |             |       |          |       |        |
| Access to support networks? |             |       |          |       |        |

**If you are happy to do so, please provide further details:**

- [Open-text box]

**2. Has the recent coronavirus/COVID-19 outbreak impacted upon your anxiety?**

- [Yes]
- [No]

**If yes, how?**

- [Open-text box]

**3. Have you experienced an increase in anxiety about the safety and well-being of others?**

- [Yes]
- [No]

**If yes, how?**

- [Open-text box]

**4. Has the recent coronavirus/COVID-19 outbreak impacted upon your grief?**

- [Yes]
- [No]

**If yes, how?**

- [Open-text box]

**5. What personal ways of coping have helped you manage your grief in the past?**

- [Open-text box]

**6. Can you please describe the extent to which you are able to use these personal ways of coping now?**

- [Open-text box]

7. At this time, do you feel you have people you are able to talk with about your grief and the person who died?

- [Yes]
- [No]

8. Have you used virtual communications with family and friends during the outbreak?

- [Yes]
- [No]

If yes, please describe your experience of this.

- [Open-text box]

9. At this time, how do you find communicating with family and friends about your grief?

- [Open-text box]

10. If you found it difficult to ask for help before the COVID-19/Coronavirus pandemic, is it more difficult now?

- [Yes]
- [No]
- [n/a]

If yes, please provide details.

- [Open-text box]

11. Have you been in communication with any of the following during the time of the COVID-19/Coronavirus pandemic with questions or complaints about an epilepsy death?

| Yes/No | If yes, did you get a satisfactory response? (please give details) | If applicable, how did you feel about doing this during the coronavirus/COVID-19 outbreak? |
|--------|--|--|
|--------|--|--|

|  |
|--|
| <p><b>Health Services</b><br/>(eg. In UK - National Health Service (NHS))</p> <p><b>Social Services</b></p> <p><b>Schools</b></p> <p><b>Residential Services</b></p> <p><b>State investigation</b><br/>(e.g. in UK Coroner or Procurator Fiscal)</p> |
|--|

12. Have you been in communication with any of the following during the time of the COVID-19/Coronavirus pandemic in relation to your own or a member of your family's health and well-being?

| Yes/No | If yes, did you get a satisfactory response? (please give details) | If applicable, how did you feel about doing this during the |
|--------|--|---|
|--------|--|---|

Section 3: Experiences during the Coronavirus/COVID-19 pandemic (continued)

| Yes/No | If yes, did you get a satisfactory response? (please give details) | If applicable, how did you feel about doing this during the coronavirus/COVID-19 outbreak? |
|--------|--|--|
|--------|--|--|

|  |
|--|
| <p><b>Health Services</b><br/>(eg. In UK - National Health Service (NHS))</p> <p><b>Social Services</b></p> <p><b>Schools</b></p> <p><b>Residential Services</b></p> |
|--|

|  |
|--|
| <p><b>coronavirus/COVID-19 outbreak?</b></p> |
|--|

13. As this project progresses, we may wish to conduct phone interviews with people who would be willing to consider discussing their experiences further. If you would be willing to talk about the possibility of participating in further research in relation to this, please tick the following box and provide contact details where indicated. [ ]

Phone number: [open text box]

Or Email address: [open text box]

14. If there is anything else you would like to add that has not been covered by this questionnaire, please tell us here:

- [Open-text box]

Thank you so much for taking the time to complete this questionnaire to help us better understand the experiences during the coronavirus/Covid-19 pandemic of the bereaved who have lost people to epilepsy-related deaths.

If you have not already done so, please consider registering the death at the EDR website [www.epilepsydeathsregister.org](http://www.epilepsydeathsregister.org). By doing so, you will be adding your data to the largest and most powerful collection of information on epilepsy deaths in the world aimed at reducing epilepsy deaths and improving outcomes for people with epilepsy and their families in the future. The EDR team is particularly keen to hear views and experiences of services before and after death. Whether or not the death was before or after the coronavirus/Covid-19 pandemic, you will be contributing to research that can help save lives and improve services.

We appreciate that completing a questionnaire of this nature can bring up a number of questions both about the research itself and managing your feelings related to your grief.

If you wish to speak with someone who has many years' experience in supporting those bereaved by epilepsy-related death, you can email us at [team@epilepsydeathsregister.org](mailto:team@epilepsydeathsregister.org) or call our support line on 0330 088 1220 (UK local rate call). This support line is staffed by qualified counsellors, who have a special interest in sudden death and the coping strategies that bereaved people can use in their day-to-day lives.

If you wish to contact someone about this research project and its objectives, please email [ben.donovan@sudep.org](mailto:ben.donovan@sudep.org).

If you'd like to consider and/or discuss ways in which you can be involved further in supporting SUDEP Action with its goal of raising awareness of epilepsy risks and tackling epilepsy deaths including Sudden Unexpected Death in Epilepsy, please visit the SUDEP Action website at [www.sudep.org](http://www.sudep.org) or phone 01235 772850.

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