OPUS₂

Scottish Covid-19 Inquiry

Day 8

November 10, 2023

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1 Friday, 10 November 2023 2. (10.00 am) THE CHAIR: Now, we have a new participant, if that is the correct word. Ms Bahrami. 4 5 MS BAHRAMI: Thank you. Good morning, my Lord. Today we 6 have four witnesses. The first witness is Lucy Holly Challoner, and for reference her statement reference is 8 SCI-WT0358-000001. 9 THE CHAIR: Very good, thank you. 10 MS LUCY HOLLY CHALLONER (called) 11 Questions from MS BAHRAMI 12 THE CHAIR: Good morning, Ms Challoner. Please come in, 13 take a seat, make yourself comfortable, and Ms Bahrami 14 will ask you some questions. 15 Thank you. 16 When you are ready, Ms Bahrami. 17 MS BAHRAMI: Thank you. 18 Good morning, Ms Challoner. Could you confirm your 19 full name, please. 20 A. Yes. Lucy Holly Challoner. 21 Q. Thank you. And how old are you? 22 23 Q. And the Inquiry has your contact information.

are working within the learning disability team of

You have recently graduated from university, and you

- 1 a local authority; is that correct?
- 2

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- 3 Q. You are here to give evidence today about your mother 4 and your grandmother, both of whom were in care homes 5 during the pandemic; is that right?
- 6
- 7 Q. You have provided a statement to the Inquiry, and we 8 have read through that, and we are grateful to you for 9 providing that.
- 10 I just want to remind you at the outset not to 11 mention any names during your evidence. There is a restriction order in place --
- 13 A. Yes.

12

- 14 $\mathsf{Q}. \ \ -- \ \mathsf{to} \ \mathsf{prevent} \ \mathsf{that}.$
- 15 A. That's fine.
- 16 Q. Now, we know from your statement that your grandmother 17 sadly died during the pandemic and the cause of death 18 was Alzheimer's disease; is that correct?
- 19 A. Yes, that's correct.
- 20 Q. Going back, I understand from your statement that your 2.1 dad sadly died by suicide when you were 10.
- 2.2 A. Yes, that's correct.
- 23 Q. And since that time, your mother struggled with her 24 mental health and alcohol use.
- A. Yes, that's right.

1 Q. You at that time tried to get help for your mother, but

- 2 she was reluctant to accept that help.
- 4 Q. And so you and your brothers essentially became unpaid 5 carers for your mother from that time, from that young 6
- 7 A. Yes
- 8 Q. In 2016, when you were 18, your mother was admitted into 9 hospital for two months, and there she was diagnosed
- 10 with alcohol-related brain damage; is that right?
- 11 A. Yes, that's correct. She was really unwell at the time.
- 12 Q. Thank you.
- 13 I understand from your statement that the prognosis 14 was that the damage shouldn't become worse if your 15 mother abstained from alcohol use.
- 16 A. Yes, so alcohol-related brain damage isn't progressive 17 if you stop drinking alcohol.
- 18 Q. With the right care and treatment, it is even possible
- 19 for individuals to have some form of recovery; is that 20 correct?
- 21 A. Yes, that's correct, if they get the right help and 22 support in place.
- 23 Q. After two months, your mum was discharged from hospital and moved to a residential rehab unit; is that right? 2.4
- 25 A. Yes

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- Q. And she stayed there for a year and a half, and during 1
- 2 that time, you applied for a court guardianship order,
- 3 as your mother had lost capacity.
- 4 A. Yes, that is correct.
- Q. And a power of attorney, of course, wasn't in place, and at that time you were studying at college and living
- with your younger brother in the family home.
- 8 A. Yes, that's right.
- 9 Q. So you had those additional responsibilities to balance 10 alongside that.
- 11 Given your mum's young age -- I don't think I've 12 covered -- could you tell us, sorry, how old your mum
- 13 was in 2016?
- 14 A. I can't remember off the top of my head. She would have
- 15 been about -- in her 50s, so relatively young, and $\,$
- alcohol-related brain damage is a condition I had never 16
- 17 heard of before. There is not much awareness of that
- 18 condition. So at the time when she was very unwell, we
- 19 knew she was drinking a lot of alcohol, but we didn't
- 20 quite know what the cause was. There was a lot of
- 21 issues with her memory, her mobility and lots of changes
- 2.2 took place. So when she was diagnosed with that
- 23 condition, it was the first time I had ever heard about
- 2.4
- Q. Given your mum's young age at that point, it was

- 1 difficult to find a care home that could meet her needs; 2 is that right?
- 3 A. Yes, that's correct, because she was quite young and
- a lot of the care homes are more catered towards elderly 4
- people, it was really difficult to find a specialist 5
- placement that would give her the right care and support 6
- that she needs.
- Q. And were you involved in the process of finding 8 9 a suitable care home?
- 10 A. Yes, I was supported by social work, and we travelled
- 11 around quite a lot of Scotland visiting several
- 12 different care homes. I think we probably visited
- 13 around ten. So visited a lot of different care homes to
- try and find the most suitable place for her, 14
- 15 considering her age and her condition, and the
- specialist kind of support that she needed. So that was 16
- 17 extremely challenging due to the lack of specialist
- 18 services in Scotland for that condition.
- 19 Q. Yes, and I think -- were you around 20 years old at that 20
- 21 A. I think I might have been slightly younger, yes.
- 2.2 I think I was 19/20, yes.
- 2.3 Q. So at that point you found a care home for your mother
- 2.4 but, after a couple of years, for certain reasons, she
- 25 had to move to another care home, and that was

- 1 in February 2020, just before the pandemic took hold; is 2
- 3 A. So, yes, we couldn't find an appropriate service in
- Edinburgh, where my mum grew up, so we had to look at
- 5 different local authorities in different areas. She
- moved to a care home there, but it wasn't really like 6
- 7 a long-term placement. She stayed there for around
- 8 two years and then moved on to another care home, which 9 she was in when COVID happened.
- 10 Q. With that experience in mind, of having to get a court
- 11 order for your mother, when it came to your grandmother,
- 12 you put in place a power of attorney to avoid that
- 13 issue: is that right?
- 14 A. Yes, it was something I never really thought about.
- 15 Like I said. I was quite young at the time. You don't
- 16 expect to be taking on those responsibilities for family
- members at that time. But when we got mum's 17
- 18 guardianship order, and we didn't have a power of
- 19 attorney in place for my gran, we thought that is
- 2.0 the best thing to do, because guardianship, it's
- 21 a lengthy legal process, and my grandma still had
- 2.2 capacity to appoint somebody at that time. So, yes,
- 2.3 that is when we got that in place.
- 2.4 Q. What were your grandmother's living arrangement at that 25 point?

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- 1 A. She was living in her own home. She was actually still
- 2 fairly independent at that time. She was fairly elderly
- 3 and frail, but, yes, she was living in her own home.
- Q. When the pandemic started? 4
- A. Yes, when the pandemic started. 5
- Q. But did she start finding it more difficult as well? 6
- 7 A. She did, yes, and she had dementia, and that progressed
- 8 over time. So she ended up getting home carers in to
- 9 give her a little bit of support. So, yes.
- 10 Q. Then I understand from your statement that she struggled
 - with the stairs in her house.
- 12 Yes, she did. Her mobility declined quite a lot. She
 - had a few falls as well. So, yes.
- 13 14 Q. And as a result of those falls had to be admitted to
- 15 hospital; is that right?
- 16 A Yes

- 17 Q. And she was there for a couple of months.
- 18 A Yes
- Q. And that was in May 2020, during the pandemic. 19
- 20 A. Yes. There was a big deterioration in her there. With
- 21 her dementia, things kind of got worse very quickly
- 22 during that time. Her mobility, her memory, things just
- 2.3 deteriorated quite quickly.
- 2.4 And you were, with your mother in a care home, the one
- 25 to take her clean clothes and visit her in hospital,

- 1 meet any needs that she had; is that right?
- 2 A. Yes. So when she was in hospital. I was allowed to
- 3 visit and take in clean clothes. We did have to wear,
- like, the masks and PPE and stuff, but I was allowed to
- 5 visit her in hospital during that time, yes.
- 6 Q. And from hospital, she was transferred to a care home;
- 7 is that right?
- 8 A. Yes.
- 9 Q. We will come on to discuss your grandmother's time in
- 10 the care home, but we will first focus on the care your
- 11 mother received in the care home.
- 12 Now, the second care home, the one you selected just
- 13 before COVID for your mother, had two buildings; is that
- 14 right?
- 15 A. Yes. that's right.
- 16 Q. And the building that your mother was in was for people
- 17 with alcohol-related memory issues.
- 18 A. Yes, that's correct, yes.
- 19 Q. Now, you mentioned in your statement, and we spoke about
- 2.0 it just briefly, that, with the right care and
- 21 treatment, there could be some form of recovery for
- 2.2 individuals. Was this care and treatment to be provided
- 23 by the care home for your mother?
- 2.4 Yes, and a lot of that kind of recovery-based work
- 25 involved her going out in the community, for example

- 1 going swimming, out to the shops, really just regaining
- 2 independence. Back when my mum first got unwell, her
- 3 mobility was extremely poor, she was very underweight,
- she was in a wheelchair. But as her recovery 4
- 5 progressed, she was able to become a bit more
- independent with mobility and stuff. So going out for 6
- 7 walks and stuff, that really was a big part of her care 8
- 9 Q. So there was a care plan in place?
- 10 A. Yes.
- 11 Q. Do you recall how many hours a week that care plan
- 12 provided for?
- 13 A. I can't remember off the top of my head, but social work
- 14 had put in hours for some one-to-one to take place for 15 that support.
- 16 Q. Did you apply for further hours?
- 17 A. So those further hours were added when she first went
- 18 there, ves, to get some one-to-one and to go out and 19 about in the community.
- 20 Q. Did you initially have concerns about the level of care 2.1 given to your mother?
- 22 A. At that care home? No, I didn't.
- 2.3 Q. Did that change as the pandemic went on?
- 2.4 A. Yes, due to the restrictions that were in place, not
- 25 being able to go out and access the community. When the

- 1 restrictions came into place, she wasn't allowed to
- 2 leave the care home, so that changed a massive part of
- 3 her routine. I wasn't able to visit. Before, I would
- visit, we would go out to the shops, go out for a walk.
- 5 She really loved nature and trees and all that kind of
- stuff. So that was a massive change to her routine and 6
- the care she was receiving, because she wasn't allowed 8 to do that because she lived in the care home.
- 9 Q. I think you mention in your statement that initially she
- 10 also went swimming.
- 11 A. Yes, she loved swimming, so ...
- 12 Q. Did you believe at the time that these activities
- 13 together could make a real difference to your mother?
- A. Oh, 100%, definitely, particularly with the mental 14
- 15 health difficulties my mum has had over the years and
- 16 with her alcohol use, exercise and going out and about,
- 17 that really does help her mental health. So, yes, that
- 18 was a big part of it.
- 19 Q. Did you have any particular fears about a decline in her 2.0 mental health?
- 21 A. Yes, definitely. I mean, particularly when it is
- 2.2 someone with alcohol-related brain damage, there is
- 23 always that risk of relapse if their mental health takes

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- 2.4 a dip, and if she was to go back to drinking alcohol,
- 25 that has significant impacts on her memory, her

- 1 mobility. So not getting that right care and support
- 2 and structure and routine in her life, that could cause
- 3 serious consequences.
- 4 Q. Thank you.
- 5 Now, when the restrictions took place, did your 6 mother understand what was going on and why?
- 7 A. She did understand about the virus, and she watched the
- 8 news and the care home spoke to her about it, so, yes, 9
 - she did understand.
- 10 Q. Before the pandemic, how often did you visit your
- 11 mother?
- 12 A. Weekly, yes, just whenever I wanted. It was none of the
- 13 booking a visit; you could just come, you could go,
- 14 I would have tea with her, have a meal with her. It was
- 15 very relaxed. So, yes, weekly.
- 16 O Okav
- 17 A. But we would mainly go out of the care home, because she
- 18 liked being out and about. So we wouldn't just be sat
- 19 in her room the whole time; we would go out and do
- 2.0 things. She got really excited for that and really
- 21 enjoyed it, so you could see the benefits from that.
- 22 Q. So you were providing quite a lot of stimulation and
- 2.3 variety for her.
- 2.4 Yes, which is really important for people with that
- 25 condition, to have stimulation, to keep their brain

- 1 growing and, you know, maintain more independence and
- 2 stuff like that. So, yes.
- 3 Q. Then, with the restrictions, the amount of times you
- 4 were able to visit your mother reduced quite a bit.
- 5 A. Yes, significantly, and she wasn't allowed to do the
- 6 things that she was able to do. Other people in society
- 7 were able to go out for their daily walks; people in
- 8 care homes weren't able to do that.
- 9 So both the quantity and quality of the visits changed 10 significantly.
- 11
- A. Yes. So it was garden visits that I was eventually
- 12 given, and that was for half an hour. At first it was 13
- only allowed to be one person that went, which caused
- tension between me and my brother because, as you can 14
- 15 imagine, you both want to see your mum. You have not
- 16 seen her in that many months and then you've got to
- 17 decide who is the nominated person going to be. So,
- 18 yes, it was -- when I eventually got to see her, it was
- 19 garden visits.
- 2.0 Q. So you were living at home with your brother. It was
- 21 iust the two of you.
- 22 Α. Yes.
- 23 So how did the tension manifest? Were you having
- 24 disagreements with your brother? Did it make your
- 2.5 living situation awkward?

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- 1 A. Yes, definitely . I mean, he wanted to see his mum. We
- 2 hadn't seen our mum in so long and we both love and care
- 3 about our mum so much, and we were seeing her -- and
- 4 obviously with my mum's health, when she was very
- 5 unwell, we have both always worried a lot about my mum.
- So, yes, it was a difficult situation. But I think, 6
- because I was the guardian, we sort of decided it would 8 be me that would be doing the visits, which probably
- 9 made him feel quite left out.
- 10 Q. But that is the choice that you had to make at that
- 11
- 12 A Yes

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- Q. You were travelling from Edinburgh to Glasgow to see 13
- 14 your mother; is that right?
- 15 A. Yes. that's right.
- 16 Q. How long did it take you to get from your home to the 17 care home?
- 18 A. Probably about an hour and a half. Quite a long time.
- 19 And then when you got there, you had a garden visit for
- 20 half an hour. So quite a bit of travelling to see your
- 2.1 mum for half an hour and then you are all the way back
- again. 2.2
- 2.3 Q. Am I right in assuming that the care home wasn't able to
- 2.4 make any exceptions and allow you longer time with your
- 25 mother at that point?

13

- 1 A. No. I mean, I think there might have been a few times
- 2 when I got slightly longer than half an hour, but
- 3 I suppose that was the rule in place. I don't know if
- that was the Scottish Government guidance or
- 5 Public Health guidance. I am not too sure what the
- 6 guidance was at that time. But, yes, it was -- we were
- 7 allowed half an hour garden visit.
- $\ensuremath{\mathsf{Q}}.$ Was your mother's stay in that care home to be permanent 8
- 9 or was there an intention for her to gradually
- 10 transition to the family home?
- 11 A. So I think with alcohol-related brain damage, because it
- 12 is not progressive, there is the ability to make some
- 13 form of recovery. So we were kind of just going to see
- how things went and monitor and review the situation. 14
- 15 So. ves.
- 16 Q. I think you mention in your statement that you had
- 17 sleepovers at one point before the pandemic.
- 18 A. So we had one sleepover before the pandemic, just to
- 19 trial how things would be, being back home. So we had 2.0 one sleepover that took place, but then COVID happened
- 21 very soon after, and that wasn't allowed to happen
- 2.2 again. But in an ideal situation, we could have had
- 2.3 more of that, because that was -- yes, that was really
- 2.4 good family time.
- 2.5 Q. When you were visiting your mother, who provided you

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- with information about visiting? Did it come from the
 - care home? Did you have to find out things yourself?
- 3 A. It would come from the care home, but then I would kind
- 4 of -- you would hear lots of things in the media or
- within groups and stuff. The guidance was changing that 5
- much back then it was hard to stay on top of what the 6 7 rules were and who was saying what. So, yes, that was
- 8 very confusing for families.
- 9 Q. So when you say it was hard to keep track of who was
- 10 saying what, are you saying that there was, at times at
- 11 least, a difference between what the care home was
- 12 telling you the guidance was and what you were perhaps
- 13 reading online --
- 14
- 15 Q. -- or hearing directly from the government?
- 16 A. Yes, definitely. It seems like different areas of
- 17 Scotland and different care homes, some people were
- 18 getting garden visits that were lasting a certain amount
- 19 of time, other people were getting different visits .
- 20 So, yes, it was confusing.
- 2.1 Q. With the distance between your home and your mother's
- 22 home, did you attempt video calls?
- 2.3 A. Yes. We bought my mum an iPad and we did FaceTime.
- 2.4 Q. How was your mum with the iPad?
- A. She was actually -- she was okay, but it's not the same

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- 1 as being in person. But, yes, we did use that quite
- 2
- 3 Q. You mentioned the care plan that was put in place for
- your mother, and with the restrictions starting, a lot
- 5 of the plans in the care plan couldn't be adhered to.
- What alternatives, if any, were put in place? How did 6
- 7 her care plan evolve?
- 8 A. I think the care homes were extremely limited at that
- 9 time because they weren't allowed to take the residents
- 10 out. I believe there was activities put on, but I did
- 11 notice a difference in my mum's mental health and
- 12 I think she was isolating herself a bit more, because
- 13 she was just down about the whole situation, not knowing
- when she was going to see her family again, feeling sort 14
- 15 of trapped and locked in. So, ves. I think that made
- 16 her feel pretty low and frustrated.
- 17 Q. Did she feel that she didn't need to be in the
- 18 care home?
- 19 A. Yes. So that was another difficult thing. The
- 2.0 situation is quite complex. My mum did not want to be
- 21 in a care home. So she didn't want to be in a care home 2.2 anyway, but being in a care home during COVID, when you
- 23 are locked in and you're not allowed to see your family,

- 2.4 you can imagine that just makes things ten times more
- 25 challenging because your routine has been changed.

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- 1 Q. Did she ever speak to you about what there was for her 2 to do in the care home?
- 3 A. Yes, we spoke pretty much every day. I think she did
- 4 quite a lot of colouring-in in her room and there was
- bingo. There were some activities. But, like I say, 5
- her mental health took a dip and I think she was staying 6
- 7 in her room quite a bit, feeling quite down about the
- situation. But the care home did have some form of 8
- 9 activities on, but because I wasn't there, I couldn't 10 say for sure what was going on.
- 11 Q. Now, you mentioned that you were allowed to have garden
- 12 visits with your mum. What form did they take?
- A. So it was a half an hour garden visit where you would go out to the garden and you had to be sat away from each 14
- 15 other in your chairs. You had to have the PPE on. You
- 16 weren't allowed to, like, touch or hug or anything. So,
- 17 as you can imagine, you have not seen your mum for
- 18 a very long time, and then the first time you do see
- 19 her, you are out in a cold garden, quite a distance
- 2.0 away, you are not allowed to do that natural thing of
- 21 giving somebody a hug. So it felt very -- kind of quite
- 22 awkward at times.
- Q. Was a member of staff with you throughout that or were 2.3
- 2.4 you given privacy?

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25 A. Luckily, we were given privacy, but the staff member

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- would take us in, take us to the seat, explain, "You've 1
- got half an hour, here's your visit". So, yes, we 2
- 3 luckily did have some form of privacy, but I suppose you
- are still out in a public garden and maybe people are
- 5 walking past, so I wouldn't say that is full privacy.
- 6 But there wasn't a carer standing next to us.
- 7 Q. Were you able to continue those visits right the way
- through during your mum's time there, or ...? 8
- 9 A. I believe they stopped for a while because there was 10 a COVID outbreak. So I can't remember the period of
- 11 time or the dates, but they did stop at some point 12 because there was COVID in the care home.
- 13 Q. You mention in your statement that, for a while at
- least, you had essential visitor status. How did that 14
- 15 come about? Did you have to ask for that? Was it 16
- offered to you?
- 17 A. Do you mean for my mum?
- 18 Q. Yes, to visit your mum.
- 19 A. I think -- no, it wasn't offered to me, no. The
- 2.0 essential visiting status, it was like this kind of --21
- 2.2 I found that out through online groups. That wasn't
- 2.3 information that was provided to me.
- 2.4 Q. When you approached the care home with that information,

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it felt to me like this hidden kind of secret. So

25 were they quite forthcoming with that or ...? 1 A. I am trying to think back the way I asked about

- essential status for my mum. I don't know if I emailed
- 3 them about it. I am just trying to have a wee look at 4 my statement just now ...
- 5 Q. I think it's at paragraph 68 and 69 of your statement
 - you talk about that -- it's paragraph 70 and 71.
- A. I don't know if that part I was maybe speaking about my 8 9 grandma when the essential visiting was given to me and
- 10 then taken away.
- 11 Q. Right, okay. It's in the section of your statement
- 12 under your mother's heading, but if that doesn't accord
 - with your recollection, it could be that there is
- 14 an error, which we can clarify with you later
- 15 A. Oh, yes, no, I see now, yes. So I had essential visits
- 16 and then I had them removed, yes. No, that's correct.
- 17
- 18 Q. You say there that, as the restrictions changed and your
- 19 status was taken away, you were worried about
- 20 challenging the care home. Can you tell us some more
- 2.1 about why you were worried?
- 22 A. Yes. Well, I think my mum had just moved into the
- 2.3 care home, so that was a big factor. You are trying to
- 2.4 build a positive relationship with the staff, and, you
- 25 know, it was a difficult situation for the care homes to

- 1 be in, I think they were under a lot of stress and
- 2 pressure, so -- also, when you've got somebody in a care
- 3 home, and particularly during COVID, you were hearing
- about the possibility of people being moved out of the
- 5 care homes if you pushed too far or rocked the boat too
- 6 much. So it's an awkward situation to be in because you
- 7 are trying to keep a good, positive relationship with
- 8 the care home, so you don't want to push things too far.
- 9 Q. Did you hear about people being pushed out through the 10 online groups?
- 11 A. Yes, through the media, yes.
- 12 Q. Right, okay.
- 13 Did you ever challenge them about the visits? You
 - had asked for essential visiting status, for example.
- 15 Were they difficult to deal with at that point or did
- 16 you find that they were quite flexible then?
- 17 A. I think it would just go back to: this is what the
- 18 guidance says or this is what Public Health have said.
- 19 So, yes, when I did challenge or ask questions, it was
- 2.0 just: these are the rules and we have to comply, so our
- 2.1 hands are tied, sort of thing,
- 2.2 Q. Before visiting, were you expected to take a COVID test?
- 23

- 24 Q. What was the procedure around that? Did you take it
- 25 before you left? Did you take it at the care home?

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- 1 A. Yes, I would take it before and then you had to, like,
- 2 register it on your phone and then you would show the
- 3 proof, and then you had to fill a form out and stuff 4 when you got there.
- 5 Q. Okay. So each time before you left Edinburgh to get to
- Glasgow, you would have to go through that? 6
- 7
- 8 Q. Every week?
- 9 A. Yes.
- 10 Q. You mention in your statement that you became aware that
- 11 the Scottish Government guidance for under-65-year-olds
- 12 in care home settings allowed walks, and you mentioned
- 13 before how important going for walks had been for your
- 14 mother's recovery. Did you try to arrange walks for
- 15 your mother while she was in the care home?
- A Yes I did and that was never allowed I believe 16
- 17 I wrote an email to the care home citing the government
- 18 guidance and my mum's age and that I thought she would
- 19 qualify for these visits . I can't remember what the
- 2.0 response is or if I have submitted that with my evidence
- 21 but, for whatever reason, that never happened, that
- 22 wasn't allowed, so we never were able to go out for
- 2.3
- 2.4 Q. And you are not sure why they weren't allowed?
- 25 A. I have a feeling it might be because Public Health said

- 1 something or the Scottish Government said something.
- 2 I think we need to remember at that time there was lots
- 3 of information coming from different people. So I don't
- know if it was maybe something about Public Health
- 5 hadn't said it was allowed, but I definitely did request
- 6 it and cited the guidance but, for whatever reason, that
- 7 never happened.
- 8 Q. Thank you.
- 9 Was there ever COVID in your mother's care home?
- 10 A. Yes. there was.
- 11 Q. Was it in her building?
- 12 A. No, it wasn't.
- 13 Q. Did visits to her building stop though?
- 14 A. Yes, and I believe that was following Public Health 15 rules
- 16 Q. Okay. How long were the visits stopped for, do you 17 recall?
- 18 A. I don't know if it was a policy in place for 28 days.
- 19 I have maybe wrote about it somewhere in my statement.
- 2.0 I can't remember off the top of my head. But I think it
- 21 was a policy if COVID was in the care home, they would 2.2 have to shut for 28 days.
- 23 Q. That is the number that you mention in your statement as 2.4 well.

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25 Given that you were travelling between two cities, and for a while there was a tiered system with different

- 2 local authorities potentially being in different tiers
- 3 at the same time, did you ever face problems getting
- 4 from Edinburgh to Glasgow?
- A. Yes, I think I had to speak to the care home about it, 5
- and I think I had to dig deep into some guidance or 6
 - something where it said that you were allowed to travel
- 8 between the two tiers because that was considered
- 9 essential travel. So I think I had to find that
- 10 guidance and then say: look, this guidance allows me to 11 do it. So, yes.
- 12 Had they challenged you on that point?
- 13 Yes, I think it was by email or -- yes.
- 14 Q. Reading through your statement, it seems that you felt
- 15 often that it was up to you to determine or work out
- 16 what the guidance was and explain it to the care home
- 17 and others in positions of authority. Is that
- 18 a reasonable understanding?
- 19 A. Yes, I think it was very confusing because you were
- 20 seeing the guidance implemented in different ways across
 - Scotland, and because I was a part of that group, a lot
- 22 of us were speaking to each other, supporting each
- 23 other, so you thought: how come that person has got this
- 2.4 type of visit but I am not getting this visit? So, ves.
- 25 it was very frustrating and confusing to keep up with

- the guidance. And I think the guidance was changing
- 2 that much as well. It wasn't always clear what the
- 3 rules were, and because it was just guidance, it seemed
- to me anyway that they put the guidance out and it was
- 5 up to the discretion of the care home to make their own
- 6 rules from that guidance.
- 7 Q. In your statement you mention that it felt to you like
 - a postcode lottery; is that correct?
- 9 Yes, 100%, definitely. It was very confusing because,
- 10 like I said, people were getting different visits. Some
- 11 people were getting this time, other people were getting
- 12 that time. So I think it just depended on the care home
- 13 and how they chose to implement it. I am not sure what
- 14 they were getting from Public Health or the
- 15 Scottish Government at the time, but that is how it felt
- 16 to me, yes.
- Q. Then the time came in December 2020 that you decided to 17
- 18 take your mother out of the care home and move her back
- 19 into the family home; is that right? Can you tell us
- 2.0 what led you to that decision?
- 21 A. So the reason behind that was I had my grandma in
- 2.2 a care home in Edinburgh and my mum in a care home in

- 23 Glasgow. They were not allowed to see each other at
- all. There was no guidance or no consideration or 2.5 thought given for people who had somebody in one

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care home and in another. My grandma had a progressive illness, dementia. She was about 98 at the time, in a care home in Edinburgh; my mum is in a care home in Glasgow. With dementia, every minute counts, and I think once you go into a care home with dementia, the statistic is you live for around two years -- I can't remember it off the top of my head, but it is a progressive illness. Every moment counts.

If I didn't have my mum move home at that time, she would have never seen her mother alive again. So my grandma was in her late 90s, deteriorating quickly, they were unable to see each other. The only way that my mum would be able to see her mother again before she passed was if mum moved home. There was no flexibility, there was no -- that was the only option that we had at that time, so that is why the decision was made,

Q. Thank you.

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What did that move home mean for you and your

A. A massive change. It wasn't planned. That wasn't what I had planned to do. I was still studying full time at the time. We knew as well with COVID the community services were limited, so we knew and we were told by social work: if you make this decision, we can't get you a care package instantly. And they did have a chat with

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me and said: I don't know if this is the right thing to do, I understand your thinking by it, but the pressure that is going to put on you and your brother, the fact it is COVID, we can't get a care package in place, there's a lot of risks to her moving home, relapsing from alcohol, mental health dips, so on. But at that time I felt there was no alternative and there was no --I felt it had to be done due to the restrictions that were in place.

10 Q. If the restrictions hadn't been in place and your mother 11 was going to come home, I think you mentioned that that 12 would have been done on a more phased basis through 13 sleepovers and --

A. It certainly wouldn't have happened at that time anyway. Yes. It's something we did not plan to happen at that time. The timing really wasn't great, but there was no alternative. But if COVID wasn't in place, we could have done a phased return home with sleepovers, trialling it, rather than just: you've been in a care home -- and I think what we need to remember as well is: when somebody goes into a care home, it is usually a last resort. The community options have been tried. If somebody has been assessed as needing a care home, their needs are quite high, and that has

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been a decision made for a reason.

So, yes, if it wasn't for the restrictions, that wouldn't have happened in that way, and we could have done a phased return home, and I think that would have been better for my mum and better for the family because it wouldn't have been as much pressure, and the fact we had to wait so long for a care package, yes, that added extra pressures. But I was made aware of that and I knew that was a consequence I had to face.

- 9 Q. Do you recall when a care package was eventually put 10 in place?
- 11 A. About a year later.
- 12 A year. And what effect did that have on your studies?
- 13 A. Well, because of COVID, my studies went online, so I was 14 able to be in the house with my mum at all times. So, 15 in a way -- it wasn't good that I was doing the online 16 learning because of COVID, but I needed to be there with 17 my mum, and I was sort of -- ves, so it was online 18 learning, so I was with my mum at home, so I was able to 19 be with her. And she needed somebody with her at that 2.0 time, because if you imagine, you have been in 21 a care home -- in two separate care homes for years, and 22 then all of a sudden you are back home again and you've

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not got that support level that you had before, and

you've got your two children, but that is all you've

got. So it was a massive transition.

1 Q. Thank you.

If we turn to look at the care your late grandmother received.

Your grandmother, we mentioned, was admitted to hospital in April 2020 and then to a care home in Edinburgh in June 2020.

I think you told us that you had to choose a care home for your grandmother as well. With your mother's care homes, you mentioned that you visited lots of different care homes across Scotland. What was the process in finding your grandmother's care home during the pandemic?

A. It was very different . I wasn't able to go out and

visit any care home. So the first care home that my grandma went to, that was a Safe Haven placement. So she had been assessed as being medically fit for discharge, but we knew at that time going back home wasn't an option because her needs had increased so much and her dementia had really deteriorated. So we knew she needed a care home, but we weren't allowed to go and visit, go inside the care home. So it was a very different process, and you didn't have much choice or --I mean, you did have choice, because I was the power of attorney, I had to agree to it, but I wasn't able to go in, meet the staff and have a walk around like I did

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- 1 when I was visiting care homes for my mum.
- 2 Q. You mentioned a Safe Haven; what does that mean?
- 3 A. So I think it might have been a policy that came into place because of COVID, I am not 100% sure, but it was 4 to get people out of hospital if they were medically fit 5 for discharge. If they knew they couldn't return home, 6 7 it was to go to hospital, and then you would go there,
- 8 but it wasn't permanent. It was just sort of like
- 9 an interim thing.
- 10 Q. Okay. Thank you.
- 11 Since you weren't able to visit the care homes, how 12 you did have to make your decision about where your 13 grandmother would go?
- 14 A. Looking online at Care Inspectorate reports, looking at 15 the websites. Yes, that was kind of the only --
- Q. Was that simple and straightforward for you, to look 16 17 through these reports?
- 18 A. Yes, but I think sometimes you need to visit the place to get a feel for the staff and see the building. It's 19 20 a massive decision that you are making. That is
- 2.1 somebody's life and they are going to be living there 22 for a long period of time. That is your loved one that
- 2.3 is going to be living there, so you want to make sure
- 2.4 it's the right fit. But, due to COVID, you weren't
- 25 allowed to go and visit, so ...

- 1 Q. When your gran moved into the care home, were you 2 allowed to start visiting straight away?
- 3 A. No.
- 4 Q. What was the issue and when were you allowed to start 5
- A. I believe at that time when they first moved there, they 6 7 had to isolate . I don't know if you maybe go to my 8 statement, if I go into depth about that. But, yes, 9 I wasn't allowed to visit straight away, and when I was
- 10 allowed to visit, it was a garden visit.
- 11 Q. 104.
- 12 You mention -- yes -- that there was a two-week 13 isolation period and you weren't allowed to see your gran even for garden visits outside. 14
- 15 A Yes
- 16 Q. But after the two weeks, those visits were allowed. So 17 during the first two weeks, there was a risk that you
- 18 might pass on an infection, even with all the
- 19 precautions, but after the two weeks, that concern 2.0 disappeared.
- 21 A. Yes. I think it must have just been another bit of 2.2 guidance that was in place, but that must have been
- 23 extremely confusing for my grandma, because she has been 2.4 in hospital, then she is moved to a new environment with
- 25 different people, people she has not met before, in
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- a new place, and you are not allowed to see your family
 - for two weeks, and you've got dementia. That must have
- 3 been extremely confusing and frustrating and distressing
- 4 for my grandma.
 - Q. Did the garden visits remain? Did they continue?
- A. So at first it was garden visits, which were absolutely 6
 - horrendous. They were extremely distressing for me and
- 8 my grandma. My grandma was in her late 90s at the time.
- 9 She has difficulties with communication. So wearing 10
- a mask and being out in a cold garden -- when I visited, 11 there was, like, a gate in place, which sort of reminded
- 12
- me a bit of like a prison. So my gran was on one side
- 13 and I was on the other side, and the communication was
- 14 so difficult I was having to shout. She couldn't 15
- understand, she would say, "Come closer". The whole 16 thing was just really distressing and I left so many of
- 17 those visits crying, in tears, thinking: what have
- I done to my grandma? So ...
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- 19 Q. Thank you.
- 2.0 Could I ask you, please, to read paragraphs 106 and 2.1 107 of your statement.
- 2.2 A. 106, did you say?
- 2.3 Q. Yes.
- 2.4 A. Am I allowed to say the name ...
- 25 Q. You are allowed to say the name of the care home but not

- 1 any people.
- 2 A. Okay

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- 3 The visiting at North Care Home was in the middle of
 - a reception area with people coming in and out. This
- 5 was when the visiting moved from garden to inside, by
- 6 the way. At first it was garden, and then eventually it
- 7 went to you were allowed indoors. I would be seated
- 8 across the table from gran. As it was in the reception
- 9 area, delivery drivers would be coming in and out.
- 10 People were just walking here, there and everywhere.
- 11 I felt this was not an appropriate place for visits .
- 12 I would be trying to speak with my gran and she would
- 13 get so distracted with all the people going about. My
- 14 gran also thought that the people visiting were about to
- 15 tell us that our visiting time was up and ruin our
- 16 visit. We never had privacy. If my gran wished to
- 17 communicate something with me in private, she couldn't.
- 18 Having visits in a reception area like that was very
- 19 degrading.

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- 2.0 Q. Thank you, and could you read the next paragraph as
- 21 well, please?
- 2.2 I also had garden visits where both me and my gran would
- 23 be behind gates. The staff would bring my gran out in
 - a wheelchair. At the end of visits, gran would cry. It
- 25 was traumatic. She would scream. It was bad

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Q. I think that is what you were touching on before.
Are you able to expand on why your gran would cry and scream?

A. Because she was so confused. She didn't understand where her family had gone, why she couldn't go and see them, why these members of staff were wearing masks. She was extremely distressed. She didn't want to be in a care home and she didn't think she needed to be in a care home. So, as you can imagine, it must have been very distressing. And we were all very close to my gran, and usually when you would go and visit, you would hear about her life stories, take your time. You were out in a freezing cold garden with a gate there. You could barely communicate or hear each other. It just wasn't effective for either of us.

It was nice — well, it wasn't — it was nice to be able to see her, but the way the visits were set up I think caused a lot of distress for the both of us, because you weren't even allowed to give that hug and that reassurance. Every time I would see my gran, you would give her a big hug, hold her hand, give that love and affection. But you were outside in a freezing cold garden, behind a gate, shouting. So it didn't feel very dignified .

25 Q. Thank you.

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Could you read the next paragraph as well, please, 108?

- A. Yes. If the pandemic never happened, I would have been visiting gran in her room in private. I would also have photographs to look at with gran. If gran was to get distressed, I would then have the photographs to help calm her down. These were my props. I had strategies for her dementia. I was not allowed to use these. Instead, I was sitting in a busy reception. I couldn't take things in. If you did wish to take things, like a gift, then it had to be disinfected and left for 72 hours.
- 13 Q. Thank you.
- 14 A. So, yes, that was a massive part of my gran's dementia. 15 We made lots of like memory photo books, and she had 16 lots of stories she would like to tell, and you could 17 sit and talk to her for hours, and she really benefited 18 from that. And if she did get distressed with her 19 dementia, that would be a distraction technique and you 2.0 could calm her down and reassure her. When I was sat at 21 that reception. I didn't have any of that.

And she didn't understand why she was in a care home. She was asking me, "When am I going to get home? What is going on? What is happening? When am I going home?" So you didn't have these photos to

re—direct and calm her down and speak about something more positive. You were in a reception, had people coming in and out. You didn't know when your time was going to be up.

5 So, yes, I think it was extremely difficult for my grandma.

Q. Thank you.

You mentioned that she found the use of masks difficult , and you say in your statement that she was paranoid about people laughing at her behind the masks.

11 A. Yes. She didn't understand the use of the masks, and
12 I don't know if that was a part of her dementia and her
13 decline, but she felt that people were laughing at her
14 behind the mask, which must have been a very awful
15 feeling and a very scary feeling as well.

Q. You mention that, even at a distance, you weren'tallowed to lower your mask to smile at your gran.

 $18\,$ $\,$ A. Yes, so she couldn't see people's facial expressions,

and I think that is a big thing for people's

communication. You can't see if someone is smiling or
 whatever. You could barely hear people, either with the

22 masks — my gran was deaf and she didn't like wearing

23 a hearing aid, so communication was difficult without

24 the mask. Adding the mask onto that made it even more.

25 Q. Was there any discussion about the use of clear face

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1 masks?

2 A. No, that was something that never happened. I don't

3 know why that didn't happen. I think that would have

4 been really beneficial to happen, but maybe the guidance

5 didn't allow it or -- I am not too sure why that didn't

6 happen, but it was always the blue masks that we had to 7 wear.

wear.

8 Q. Your grandmother's care home was in Edinburgh. How far 9 away from you was it and how did you get there?

10 A. Probably about a 40-minute walk, and I would just walk 11 there.

12 Q. Okay. You didn't ever take public transport?

13 A. No. I don't think so.

 $14\,$ $\,$ Q. I think you say in your statement that is because you

15 were concerned about picking up --

 $16\,$ $\,$ A. Yes, yes, because I think you were just so scared at the

17 time about if you brought a virus in or whatever, so you

18 wanted to stay away from people. And my gran was in her

90s. I was terrified: if she catches COVID, what isgoing to happen? She was very vulnerable. So, yes,

going to happen: She was very vulnerable. So, ye

21 that was something you were always --

22 Q. So you took every precaution.

23 A. -- scared of as a family member: what if they catch

24 COVID?

25 THE CHAIR: Ms Bahrami, in ten minutes exactly, I am going

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1 to have two minutes. I am going to ask everyone to 2 stand up for Armistice Day. So just to warn you that 3 that is coming, so you're not taken aback.

MS BAHRAMI: Thank you, my Lord.

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Now, at paragraph 115 of your statement, you mention that you felt the restrictions were far too restrictive for a woman of 98 with dementia who was deaf. Which restrictions did you think were too restrictive, and what do you think would have been appropriate?

A. The place that the visits took place, the garden visits, I didn't think that that was appropriate, to have somebody out in the cold behind a bit of gate.

So, yes, the places of the visits, the fact they were at an open reception. You are meant to be having private family time, and you are in a busy reception where people can listen into your conversations.

And the times, the time just goes so quickly. Before you know it, that is your half an hour up. When I would first go there, my gran would be happy to see me, but also asking me lots of questions about: what is going on? What's happening? When am I getting home?

So, yes, the place that the visits took place and the timings, I thought that wasn't right.

2.4 Q. Thank you.

You say in paragraph 117 that you were concerned

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1 about whether your gran was getting enough stimulation, 2 and the length of time she was spending in her room. 3

What caused those concerns?

A. Well, I had never been in the care home, really, 5 I didn't really know the staff. I wasn't really getting 6 much feedback, actually, about what was going on in the 7 care home, really. So that was my worry: that she 8 was sat in a chair in her room on her own confused: why 9 am I here, where are my family, and what's going on?

10 Q. Did you raise those concerns with the care home? And 11 please don't mention any names.

A. I can't remember at the time. I think what you need to remember as well is we understood there was a lot of pressure on the care homes and you didn't want to rock the boat or push things too far. But I would phone up and ask how she was, but it would usually just be, "She's fine, she's settled". That was kind of the feedback you would get at that time. So it wasn't much.

Q. You mentioned in respect of your mother you were concerned that the care home might ask your mother to leave. Did that also apply in the case of your grandmother?

23 Yes, definitely , because they've got power to -- you 2.4 know, they could move your loved one out of that 25 care home, you know, they could -- anything could

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happen. So, like I said, you didn't want to push the

boat too far or offend anybody, but then also you want

3 to make sure your loved one is getting all that they

4 need. So it was a difficult situation to be in.

Q. I understand that eventually your grandmother moved on 5 from that care home. In September 2020, she moved to 6 7 a different care home in Edinburgh; is that right?

8 A. Yes

9 Q. Could you tell us about the reason for her moving.

10 A. So because the first care home she was in, that was 11 a Safe Haven placement, that was never a permanent

12 place. That was just in place to get her out of

hospital into somewhere else. So the second care home.

14 that was the one that we chose where we were like:

15 right, that is going to be the permanent one that she

16 will move to

17 Q. Okav

> You mentioned that a local authority care plan was again put in place, but you that also typed up your own care plan for your grandma; is that correct?

2.1 A. Yes, so I made, like, a wee book and a document about, 22 like, my gran's life, how she grew up, what she did for 23 a career, family photos, what music she liked. She was

2.4 a concert pianist, so she loved her music, so I wrote

25 all of that kind of stuff. How she liked to drink her

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1 tea and stuff like that, just so the carers had that to refer to and to get to know my gran, really, because we 2.

couldn't be there to do that, so ...

4 Q. Was the care home grateful for that? Did they use your 5

6 A. Yes, yes, I think that helped.

7 Q. How did the communication compare to the previous

care home?

9 It was better. The communication was much better. They Α. 10 updated me how she was settling in and stuff. So, yes,

11 that helped me and I think my gran.

12 Q. You mentioned that in the first care home you didn't see

13 much of the home at all. In the second care home,

I understand that you were able to go and help your

15 grandmother unpack and get settled in.

16 A. So we were allowed to go into her care home eventually.

17 At first it was a window visit that was allowed, and

18 that was a closed window visit. So you weren't allowed 19 to go inside and the window was actually shut. She was

2.0 on the ground floor in her bedroom, and that was another

21 reason why we chose that care home, because we had been

2.2 told if something happens, you will still be able to see

23 her at the window because she was on the ground floor.

2.4 but yes, I was then allowed to go inside and see her

25 room at a later date.

- 1 Q. You mention that you were able to set up her room. Did 2 that make a big difference to your gran?
- 3 A. A massive difference, yes. We got lots of photos on the 4 wall, personalised blankets with photos, her music, all 5 that kind of stuff, so we tried to make it as homely as possible for her, and I think that brought some comfort 6 7
- Q. When you had the closed window visits, did your gran 8 9 have trouble hearing you, given her hearing
- 10 difficulties ? 11 A. Yes, it was extremely difficult. And at that time I had 12 actually bought a device for my gran, it's called like 13 an Amazon Alexa, and it was in her room. So when I attended the window visit, I assumed a bit of the 14 15 window would be open so you could communicate, but I believe it was guidance from Public Health at the time 16 17 that the window that to be closed. So I was kind of 18 a bit shocked by that. I assumed there would be a bit 19 of the window open so you could hear each other. I was
- 2.0 trying to shout at the window and it wasn't working, so 21 I tried to connect my phone up to the Amazon device,
- 22 because I thought maybe this is a form of communication,
- 2.3 but then she was confused because I was at the window,
- 2.4 but then I am trying to speak to her through a device.
- 25 So it was just so distressing and we weren't able to

- 1 communicate at all, and I left that window visit and pretty much cried the whole way home because it was just 2 3 so distressing and ineffective.
- 4 Q. So you were trying different options but none of them 5 were really doing the job?
- 6 A. I think because my gran was in her late 90s,
 - technology she didn't understand phones. She would
- 8 call it, like, a device. She had hearing difficulties,
- 9 so although I tried to make it work with that device,
- 10 for her dementia, her age and her needs, it just wasn't 11 effective , but I was that desperate at the time, I was
- 12 just trying anything.
- 13 Q. Online visits, then, were not really an option for you?
- A. Yes. Just the communication. We did try and the staff 14 15 would try as well and set it up and encourage her. 16 Sometimes it worked better than others, but I think it 17 was certainly confusing for her, because she wasn't used
- 18 to using technology like that.
- 19 Q. And after the window visits, it then changed to garden 2.0 visits; is that right?
- 2.1

- 2.2 Q. Were the garden visits better in the second care home?
- 23 A. Yes, they were, because there was a wee kind of -- you 2.4
- weren't -- there wasn't a gate between, there wasn't

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25 bars between you as if you were in a jail , so that was

1 certainly better. But the communication, you still had 2

- to be distanced away from each other, you had to wear
- 3 a mask. It was cold. So it certainly -- it was
- 4 an improvement, but it wasn't very good.
 - Q. Sure.

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From there, you moved to indoor visits in a visiting pod: is that right?

- A. Yes. Well, they tried that. It didn't really work. So 8 9 it was like a room that the care home had added because 10 of COVID and it was, like, a bit of glass. I think they 11 were trying to do their best at the time with the 12 guidance and probably thought: right, this is a way to 13 get them indoors somewhere warm. But for my gran, it 14 just caused so much -- she was so confused by the glass, 15
 - she was trying to knock the glass down. It just -- it
- 16 didn't work. It wasn't effective for my grandma or her 17 needs.
- 18 Q. Thank you.
- 19 Did the care home manager do anything about that, 20 following your gran's reaction?
- 2.1 A. Yes, it was after that that she got essential $\,$ visits $\,$ --
- 22 we got essential visits for a period of time. The 2.3 care home recognised that it wasn't working.
- 2.4 What did those essential visits mean? Where did you 25 visit your gran?

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- 1 A. It meant I could go into her bedroom and sit next to her 2 and have her photos and stuff.
- 3 Q. Put in place the strategies that you mentioned you had 4 developed.
- 5 A. Yes
- 6 Q. How did you arrange those visits?
- 7 A. The care home had a booking system, where you had to 8 email and it was different slots.
- 9 Q. How did that compare to the previous care home and also 10 to your mother's care home? Did they use a similar 11
- 12 A. Yes, they had a booking system where you had to email 13 and confirm in advance. It wasn't just like you could 14 say, "I want to come and see my mum at 2 o'clock at this
- 15 time", you had to look at what slots were available, and
- 16 when those slots came out it was like: right, quickly, 17 quickly, get in and get what you can.
- 18 MS BAHRAMI: Thank you.
- 19 My Lord, it might be an appropriate point, or --
- 2.0 THE CHAIR: A few seconds left.
- 21 MS BAHRAMI: Thank you.

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- How many times a week were you able to visit your grandmother in the second care home?
- 2.4 A. Oh, it changed that often. Have I wrote about that in 2.5 my statement?

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- 1 Q. I think you say it eventually changed to two visits 2 a week; is that right?
- 3 A. So I believe there was, like, something in place where you were allowed one garden visit but then one indoor 4 5 visit, so I think eventually, yes, I was allowed to see her, like, once a week in her room and then I was 6 7 allowed to have a garden visit as well as that.
- MS BAHRAMI: Okay, thank you. I think ... 8
- 9 THE CHAIR: Please all rise now and observe two minutes' 10 silence
- 11 (Two minutes' silence)
- 12 THE CHAIR: Thank you all very much.
- 13 MS BAHRAMI: Thank you, my Lord.

Now, you mentioned in the second care home you were given essential visitor status again. What was that process like? Was that offered to you or did you --

A. I had to request that from -- through an email. And I think something that is important to mention is once you got, like, one essential visit, that didn't mean that that was a long-term, like, you had the essential visiting in place forever. It was kind of like you could sometimes get a one-off essential visit if you fit the criteria or whatever it was. So it wasn't just when you got essential visits, that was you able to visit whenever you want; like, things could change.

- 1 Q. Thank you.
- 2 You mention that, that initially you had a one-off 3 essential visit, then you were given essential visitor 4 status, but that that was then removed, I believe, by 5 an agency nurse; is that correct?
- 6 A. Yes.

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- Q. What happened then, and did you challenge the care home about that removal?
- 9 A. I was just told that my gran was doing better and that 10 she didn't need essential visiting anymore, which I was 11 really confused about because she was in her late 90s, 12 had dementia, a progressive illness, so I was a wee bit 13 confused as to why I wouldn't get that. But I think at 14 that time I was under a lot of pressure mentally. I had 15 my mum in a care home and I had my gran in a care home, 16 and there was lots of different guidance and confusion 17 going on. So you want to challenge things, but then 18 also you didn't want to push things too far.
- 19 Q. You mentioned that your gran's health then declined and 2.0 you were once again given essential visitor status.
- 21 In your opinion, would there have been the same 2.2 decline if your visits had continued?
- 23 A. That is a good point to make. I don't know, yes, that 2.4 could have been something to do with it, yes. I don't 25
 - think it was right that the essential visits were

- stopped then, because my gran was really quite unwell at
- 2 the time but she seemed to have, like, perked up a bit
- 3 and they thought she was doing better. But she was 4 still kind of towards the end of her life. She was 99,
 - so ...
- Q. Thank you. 6

You mentioned your mum being in a care home at that point, but there came the point where you took your mother out of the care home, and was she then able to

10 visit your gran?

11 Yes. So my mum was actually out of the care home a wee

12 bit before then, but at first it was only allowed to be 13 one person visiting, so it took a while until my mum was

allowed to be visited -- to visit my gran. That was

14 15 another thing I had to look into the guidance about,

16 because my mum wouldn't have been able to visit my gran

17 without me being there, a carer to facilitate that. She

18 wouldn't have managed to independently travel there. So

19 my mum was able to see her eventually, yes, with myself.

20 Q. With you as well. Where did the visits take place at 2.1 that point?

2.2 A. In my gran's bedroom.

Once your gran was nearer the end of her life, were you 2.3

2.4 all able to visit her: you, your mother, your brothers?

2.5 A. Yes, we were. Things became more flexible towards the

1 end of her life . She was in her bed a lot, so a garden

2 visit just wouldn't have been able to happen. So, yes,

3 we were all allowed to see her together at the same

4

5 Q. You mention that you were able to also, by presumably

6 doing further research about the guidance, get a visit

7 for your gran with her Jack Russell terrier before she

8 passed away.

9 A. Yes, she was able to see her wee dog that meant an awful 10 lot to her. So I think that had to be risk assessed and

11 stuff, but I had a discussion with the care home and she

12 was allowed to see her dog, so that was nice.

13 Q. What was the impact of that on your gran, seeing all the 14 family and her dog?

A. I think it was probably quite overwhelming for her, but 15

I think -- and I hope -- it brought some comfort to her 16

17 during a really difficult time.

18 Q. Thank you.

19 Towards the end of your gran's life, did you still 20 have to use the booking system or was there more

21 flexibility ?

2.4

2.2 A. I think towards the very end there was more flexibility .

23 I didn't have to book. It was more just speaking over

the phone and getting updates, how was she doing, that

25 sort of thing.

- 1 Q. Thank you.
- 2 In the second care home, there came a point where
- 3 your gran caught COVID; is that correct?
- 4
- 5 Q. And that was either in January or early February of 6
- 7
- Q. And you asked for essential visits in February, but you 8 9 were refused. Were you given a reason as to why?
- 10 A. I had asked for essential visits multiple times.
- 11 I can't remember the reason I would have —— the response
- 12 I would have got at that time. Yes, I don't know if
- 13 I have wrote in the statement why I was refused.
- 14 Q. I don't think you have mentioned it here.
- 15 A. Yes.

2.4

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- 16 Q. So you weren't clear on --
- A. What the reason would be, no. 17
- Q. Thank you. 18
- 19 You say that, following that refusal, you contacted 20 Alzheimer Scotland and they were a big help you to.
- 2.1 A. Yes. So they had a helpline in place where you could
- 22 contact them and speak about the situation, and they
- 2.3 short of helped you understand the guidance a bit.
- I think the guidance was very confusing and people 25 weren't sure what they were entitled to, what was

- 1 allowed to happen, what wasn't allowed to happen, what
- 2 the Scottish Government were saying, what Public Health
- 3 were saying, what the care home were saying, it was very
- confusing. So, yes, I had support from them, and then
 - I asked for essential visiting again.
- 6 Q. And that was in May 2021 --
- 7 A. Yes.
- $\mathsf{Q}.\ --$ where you say you provided evidence about why you 8
- 9 should receive the visiting rights.
- 10 A. Yes, it was a very long email about me justifying and
- 11 evidencing my gran's needs, her situation, why she 12 needed the visits due to her health, mental well-being
- 13 and stuff like that. 14 Q. Does that mean, then, that you hadn't visited your gran
- 15 between January and May of 2021?
- 16 A. I can't remember the dates and stuff off the top of my 17
- 18 Q. Because in your statement at paragraph 175 you mention
- 19 that you had sent an email asking the home for an update
- 2.0 on COVID cases — this was after your grandmother had
- 21 contracted COVID -- and in February you had asked for 2.2 essential visitor status. That had been rejected. Then
- 23 in May you emailed them again explaining why you should
- 2.4 have visiting rights. So does that mean in that
- 25 intervening period, you didn't visit your gran?

- 1 A. I think I was asking for the essential visits on top of 2 the original visit -
- 3 Q. Ah, okay.
- 4 A. -- where I think at that time you were allowed one visit
 - a week, half an hour.
- Q. So you were able to have indoor or garden visits, but 6 7 not the additional visits?
- 8 A. Yes

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- 9 Q. Okay, thank you.
- 10 A. Because with the essential visits, I think they weren't to be as timed and restrictive as the other ones. 11
- 12 Q. Thank you.
 - You say in your statement that, while you weren't able to see your gran, you asked that she be provided with physio, other exercise and access to a doctor.
- 16 What was the response to that?
- 17 If you want to refer to your statement, it's at 18 paragraph 179
- A. Yes, so I have said that I have asked by email for her 19
- to receive physiotherapy and access to a doctor and 20 21 exercise, which I received a reply informing me that the
- 22 home was encouraging gentle daily exercises, and that
- a lot of professionals were not visiting the care home 23
- 2.4 at that time. All dental and optician appointments were
- 25 stopped.

- 1 Q. Did that cause any concern for you?
- 2. A. Yes, it did, because to provide some context, when my
- 3 grandma was at home, she was like -- her mobility was
- poor, but she was able to walk around, and when she
- 5 first went into the care home, she was able to walk
- 6 around, and there was a massive decline in her mobility.
- 7 She went from being able to walk around -- she did use
- 8 a stick, and her mobility still wasn't perfect, but to
- 9 being more in her chair a lot of the time and struggling
- 10 to move. So I was really concerned about her mobility
- 11 at that time and how much it had declined, yes.
- 12 Q. Thank you.

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2.0

2.4

- 13 Then you go on to say that just a few weeks before
- your grandmother passed away, you were able to take her 15 out for the day. Are you able to tell us where you went
- 16 and the difference that that made to your gran, to you,
- 17 to the rest of your family?
- 18 A. Yes. So eventually I think the guidance must have
- 19 changed again and this was a new thing that was now
 - allowed, so I had asked the care home if I could take my
- 21 gran out for the day, which they had to do risk
- 2.2 assessments and we had to do tests and all those
- 23 precautions were in place, and then we went out to the
 - botanic gardens and had a really nice day together with
- 2.5 family there.

I think it must have been quite overwhelming for my 2 gran to actually finally get out of the care home, 3 considering she had been locked in a place for so long, 4 but, yes, it was a brilliant day, she enjoyed it, we 5 were able to be together as a family, and, yes, it was a really special memory. 6

Q. Thank you.

You then go on to mention that your gran had a do not attempt cardiopulmonary resuscitation order in place

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12 Q. You say that you weren't aware of this, so you weren't 13 involved in that being put in place, despite having 14 power of attorney for your gran; is that right?

15 A. Yes. I don't know when that was put in place. No discussion took place with myself. The only reason 16 17 I actually found out about that was because I found it 18 ripped up in her house. So, yes, I am not sure when 19 that was put in place.

2.0 Q. Okay. So you are not sure why it was ripped up and you 2.1 didn't speak to your gran about that afterwards?

2.2 A No

2.3 MS BAHRAMI: Okav.

2.4 THE CHAIR: We should really take a break for the stenographer's sake. I sense you are very close to the

1 end

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MS BAHRAMI: Yes, I think maybe another five minutes. 2. THE CHAIR: I think, in fairness to Ms Challoner, we will just sit for the extra five minutes until you finish. 5 MS BAHRAMI: Thank you.

I want to move on to the impact on you, and I think it is captured here quite well, so \boldsymbol{I} wonder if you could read from paragraph 182 of your statement, please.

9 A. Yes.

> The stress and pressure of having two different relatives in two different care homes had an impact on my mental health. The added stress of being a power of attorney and a welfare guardian would be stressful just in normal times. However, you add in the pandemic and different people telling you different things, this also had an impact on me.

Q. I think you told us that the different things you were being told were by care homes, by the government, by people in online groups, and that was all adding to the confusion.

21 A. Yes, it was extremely stressful and confusing, and 2.2 because you had two different people in different 2.3 care homes, you would hear one thing from this side and 2.4 then kind of assume it would be the same, but that 25 wasn't always the case.

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1 Q. Thank you.

Could you continue reading from there, please.

A. Yes.

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There was a lot of pressure on me. I would cry all the time. I used to snap over small things because of the pressure of what was going on in the background.

I also had to deal with the tensions within the family and the arguments. There was conflict going on within family relationships.

10 There was an impact on my education. I was meant to 11 be studying for my degree at university. How was 12 I meant to focus on my studies with that much pressure? 13 I managed to gain my degree as a lot of the work was

14 online. My attitude was that I had started the degree 15 so I must finish it.

16 Q. If you continue, please.

17 A. I graduated with everyone else on my course. I received 18 support from the university. I could speak to the 19 carers person they have there. The university put 2.0 a carers plan in place for me. This meant I could have 21 extensions if I needed them and extra help. To be fair, 22 I got good support from the university.

2.3 Q. Thank you, and the next one, please.

2.4 I had no time for friendship groups as I felt I was 2.5 chasing up care homes and speaking to all the different

1 people I had to speak with. I also had to visit homes 2 in Edinburgh and Glasgow. I had no time. I couldn't be 3 bothered socialising, to be honest. A lot of people my age do not have the unique family situation that I have. 5 None of my friends are power of attorney for a parent or 6 grandparent. It means you can't really relate to your 7 friends

> I did have the Care Home Relatives Scotland group and they were a good support. I would speak with members online. That was good as I could speak to people who were going through a similar situation. We could compare notes and give each other advice.

13 Q. Thank you.

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When you say that you had no time for friendship groups because you were chasing up care homes, do you mean by that what you have said: that you had to find guidance and contact the care homes about this, or do you mean the initial finding the care homes?

A. Around the guidance and stuff, I was really worried

about my mum and my gran and when I was going to next see them and what was going to happen. So the last thing on my mind was going out and socialising with friends and acting like things are normal and happy, because they certainly didn't feel normal and happy to

25 me at the time.

statement reference SCI-WT0378-000002. 1 Q. Thank you. 1 2 Then you make a few points in your statement where 2 MRS ALINA ELIZABETH DUNCAN (called) 3 you -- and I think you have touched on this already, 3 Questions from MR GALE THE CHAIR: Ms Duncan, good morning still. Make yourself 4 that in future you believe there should be rules for 4 comfortable and then Mr Gale has some questions for you. 5 people who have loved ones in more than one care home 5 and to facilitate visits between care homes. Mr Gale, when you are ready. 6 6 You also mention in your statement that you believe 7 MR GALE: Thank you, my Lord. 8 there should be more accountability with organisations; 8 Good morning, Mrs Duncan. Your full name is 9 is that correct? They should take more responsibility. 9 Alina Elizabeth Duncan; is that right? 10 10 A. Yes. It felt like it always just came back to: this is A Yes 11 the guidance, but we can interpret into it our own 11 Q. And you are 56; is that right? 12 12 different way. So I felt there wasn't accountability. A. Yes 13 When things were challenged, it would say: oh, it's 13 Q. The Inquiry has your contact details. 14 You are employed, I think, at the moment; is that 14 Public Health that says this, it is the Scottish 15 Government that says this, it's the care home that says 15 16 16 this. So it was very confusing to know who was making A. Yes, on a part—time basis. 17 17 the decisions that was having a really negative impact Q. I don't want to ask the identity of your employer. 18 on your family members. 18 Obviously the Inquiry knows that. But for the purposes 19 19 Q. You say that there should be better guidance for family of your evidence, it is I think useful that we know that members so that they are regarded as carers, rather than 20 2.0 you are a carer working in the provision of care at home 2.1 iust visitors . 21 2.2 Finally, could you please read paragraph 197 for us. 22 A. Yes 2.3 A. My hopes for the Inquiry would be to do some things 2.3 Q. How long have you been doing that? 2.4 2.4 A. Since the start of COVID, so about three years. better the next time, to ensure that the country is 25 better prepared. Also to think about family members not 2.5 Q. Thank you. 59 1 as visitors but carers. I looked after my mum for 1 You provided the Inquiry with a written statement, 2 years, since I was 12 years of age -- probably a bit 2 I think, which you confirm is your evidence, and that 3 earlier than that, actually. I also looked after my 3 it's the truth and that you are agreeable to having your gran for a long time. So from being a carer to 4 evidence recorded and published. 5 5 a visitor did not feel right. I felt there was no A. Yes empathy towards carers. I felt like the care homes were 6 Q. Thank you. 6 7 acting as if it was us against them. It should not have You are here to tell us about your husband, 8 8 felt like I was fighting against care homes, James Duncan. 9 Public Health and the Scottish Government. I think 9 A. Yes. 10 care homes and families should have been working 10 Q. Who I think is known as Jim. 11 together. I also don't think it should be a blame game. 11 12 There are lessons to be learned on all sides. 12 And that is how you refer to him in your statement. MS BAHRAMI: Thank you. 13 13 A. Yes Q. Is it all right if I call him by "Jim"? 14 Those are all the questions that I have for you. 14 THE CHAIR: Thank you very much indeed, Ms Challoner. That 15 A. Yes. 15 16 was very helpful. I am very grateful for your 16 Q. Now, we know from your statement that he died on 17 17 25 August 2022. 18 Very good. We'll take -- let's try and make it just 18 A. Yes 19 shy of 15 minutes, so 11.30. 19 Q. And he would have been 70. 2.0 2.0 (11.19 am) A. Yes 21 21 Q. And that in 2008, when he was only 55, he was diagnosed (A short break) 22 (11.30 am) 2.2 with a rare form of dementia called posterior cortical 23 THE CHAIR: Mr Gale. 23 atrophy; is that right? 24 MR GALE: Thank you, my Lord. 24 A. Yes $\ensuremath{\mathsf{Q}}.$ You tell us in paragraphs 5 and 6 how this affected him. 25 The next witness is Alina Elizabeth Duncan. Her 25

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- 1 I know it is probably distressing, and I don't want
- 2 to go through the detail of that. We obviously know it
- 3 from your statement. But taking it briefly, if I may,
- 4 he was left with problems with his eyesight, insofar as
- 5 it appeared that messages from his eyes were not getting 6 to his brain.
- 7 A. From the brain to the eyes.
- Q. Brain to the eyes, sorry, obviously the other way round, 8 9
- 10 Also, he struggled with communication.
- 11 A. Yes
- 12 Q. And his communication became somewhat inappropriate.
- 13 A. He was non-verbal, yes.

Q. Yes, before it.

- Q. Can you tell us a little bit about Jim before his 14
- 15 diagnosis.
- A Before? 16

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- 18 A. Before his diagnosis, he was very active in the local
- community. He received an MBE from the Queen in the 19
- 20 millennium honours list for raising over £150,000 to set
- 2.1 up a hyperbaric unit for people with multiple sclerosis .
- 22 Through his business, he worked with his father and his
- 2.3 brother in a retail environment, and he was very
- 2.4 well known in the local community, very active, and very
- 25 well loved.

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- 1 Q. He was also a fit and active man, I understand.
- A. Very fit and very active, yes.
- 3 Q. You also say elsewhere in your statement -- it is
- paragraph 23, I don't think you need to look at it
- 5 because it is just a very brief reference -- you say he
- was someone who was never ill. 6
- 7 A. No, he had never really been to the doctor's for
- 8 anything before his diagnosis.
- 9 Q. You have three children, two sons and a daughter.
- 10
- 11 Q. I think you are agreeable that you can name your
- 12 daughter. I don't want to single her out particularly,
- 13 but your daughter is Louise, I think is her Christian
- 14 name.
- 15 A. Yes.
- 16 Q. The reason I will just ask you about this is that you
- 17 give some information later on in your statement about
- 18 Jim's condition, and it relates to something that your
- 19 daughter was involved in.
- 2.0 A. Yes.
- 21 Q. We will come to that in due course, but I think, just
- 2.2 for present context, your daughter is a very skilled
- 23 professional golfer.
- 24 A. Yes.
- 2.5 Q. I think she was in contention, whilst still an amateur,

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- 1 in the British Open in 2021.
- 2 A. Yes, she finished tied 10th.
- 3 Q. We will come to that in just a little when we come to 4 vour statement.
- 5 Am I right in thinking that when Jim was diagnosed
- with dementia, he was still living at home with you and 6 7
- the family, back in 2008?
- 9 Q. And you were working at that time, not as a carer --
- 10 A. No.

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- 11 Q. -- but you were working at that time, but as you say at
- 12 paragraph 9, you gave up your job, I presume in 2012, to
- 13

A. He was, yes.

- A. Yes. My mother had passed away. My mother stayed next 14
- 15 door to me, and she was very much my main support, and
- 16 she had passed away very suddenly, I had found her one
- 17 morning, and Liust felt —— Liust couldn't do
- 18 everything. I couldn't look after Jim, I couldn't look
- 19 after the kids, if I was working as well.
- 20 Q. The children would have been relatively young --
- A. Yes 21
- 2.2 Q. -- when your husband was diagnosed.
- 2.3 A. My daughter was 8, my middle son was 11 and the eldest
- 2.4 one was 14
- 25 Q. I take it you became, effectively, his full -time carer?

- 1 A Yes
- 2. Q. How much care did he need in those early days?
- 3 A. In those early days, it was mainly supervision. He was
- still $\,--\,$ because it was a family business, he was still
- 5 able to go to work. Sometimes he would get the bus up
- 6 and the girls that he worked with would make sure he got
- 7 the bus home, the correct bus, and latterly, when we
- 8 stopped doing that, I would take the kids to school and
- 9 I would drop them all at the same time. And he was --
- 10 when I say work, it was very loosely speaking, he was
- 11 mainly supervised there, so -- by the other staff, who
- 12 were fantastic. But then the business was sold in 2015,
- 13 I think it was
- 14 Q. And it would have provided him with an environment with
- 15 which he was familiar.
- 16 A. Yes
- THE CHAIR: Work as therapy. 17
- 18 A. Absolutely.
- 19 MR GALE: You made the decision in 2016 to move Jim into
- 2.0 full -time care at the Arran View Care Home in Saltcoats:
- 21 is that right?
- 2.2 A. Yes
- 23 Q. And you explain why you made that decision in
- 2.4 paragraphs 11 and 12, and I don't want to go through
- 2.5 them in any detail, but one of the reasons that you

- 1 chose that home was that Jim had had some respite care 2
- 3 A. Yes.
- 4 Q. — and the experience that you had had there was a good 5 experience.
- A. Yes 6

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- 7 Q. You tell us about the layout of the home at
- paragraphs 13 and following, and we can read that, and 8
 - I don't want to take any of that in detail. But you say
- 10 at paragraph 14 that you were not sure if Jim understood
- 11 why and where he was getting moved to. Can you just
- 12 explain that, what his position was when he was being 13
- 14 A. His speech wasn't great by that point, and it was
- 15 difficult to know what he was thinking, what he was
- understanding. I think he maybe did understand a little 16
 - bit when he went in. It was very difficult to know
- 18 what
- 19 Q. Yes. Obviously the situation had become that you had to
- 20 accept the need for him to move into care.
- 21 A. Uh-huh.
- 2.2 Q. Yes. You tried to visit him, I think you say, every
- 2.3 day.
- 2.4 A. I did, yes. 25 Q. Sometimes more than once a day.

- 1 A. Sometimes, if he wasn't very well, I would maybe go down
- 2 three or four times a day. It was only four miles from 3 the house.
- Q. Initially you have a lot of praise for the care home,
- 5 its staff and the care that Jim was given pre-pandemic.
- A. Yes. The staff were fantastic. They just loved him. 6
- 7 They would -- I couldn't have praised them any more at
- 8 that time. But things did change throughout the 9 pandemic.
- 10 Q. I think things changed during the pandemic obviously
- 11 because of the restrictions
- 12
- ${\sf Q}.\ --$ that were then placed upon visiting and your access 13 14 to .Jim.
- A. Yes. 15
- Q. But also because the care home changed hands. 16
- 17 A. It did change hands, yes, and things started to go
- 18 downhill. 19 I was in regular contact with a number of staff from 2.0

the unit Jim was in, and I could tell that there were

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- 21 staff shortages, things were starting to go downhill. 2.2 Although there was other things that improved. You
- 23 know, at some point the lounge area was done up. I did
- 2.4 buy a television for them because they didn't have a
- 25 remote control for their television. But things like

- that, some things improved. Other things didn't.
- 2 Q. I think you set this out at paragraphs 20 and 21 of your
- 3 statement, but even in the period after the change of 4 ownership of the care home, you continued to identify
- particularly individual carers who were very close to 5
- Jim and very good with Jim; is that right? 6
- 7 A. I did, and I always made sure, if I was sending any
- emails, that that was always my first paragraph, was 8
 - that -- the lady who was the manager in Jim's unit had
- 10 been there for 25 years. She is near retirement age 11 now, and still employed by them, although I believe she
- 12 is off sick. But ves, she was fantastic and just loved
- 13

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- 14 Q. There was a care plan in place for Jim and, as we have
- 15 said, paragraph 24 of your statement, you reiterate what
- 16 you have just said: that you never faulted the treatment
- 17 at any time before the pandemic.
- 18 A Uh-huh
- 19 Q. May I just ask you about visiting pre-pandemic.
- 20 Obviously you visited regularly --
- 2.1 A I visited
- Q. Other family members? Your children? 22
- 2.3 The children visited, and also his brother and
- 2.4 sister -in-law visited every Wednesday afternoon, and
- 2.5 when he was able to, they were able -- they took him

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- 1 out. But we -- I had had an experience where I had
- 2 taken him out, I think it was maybe three months before
- 3 the pandemic, and he had been very, very sick in the
- car, and I think I put it down to his eyesight problems
- 5 and the movement in the car. So we made then the
- 6 decision that we wouldn't take him out, maybe a walk
- 7 around the gardens. But even in that time, his brother
- 8 and sister - in-law came to visit him in his room, they
- 9 put the music on, just had some fun time. But that all 10 changed.
- 11 Just in relation to your children, how had they adjusted
- 12 to the dementia that your husband and their father was 13 suffering?
- A. They have been fantastic. They -- it was very much day 14
- 15 to day. The eldest, he probably knew his dad a wee bit
- 16 more because his dad did an awful lot with him.
- 17 In fact, when I was at work on a Wednesday and it was
- 18 Jim's day off, he would, you know, if it was school
- 19 holidays, take them out or do something with them and
- 2.0 make the dinner and -- but obviously then they found
- 21 it -- they have found it very hard. But throughout the
- 2.2 whole thing, they have been fantastic, and they have
- 23 grown into very well adjusted people. 2.4
- When you were visiting your husband in the care home 25 pre-pandemic, did you assist with his care while he was

- 1
- 2 A. Occasionally I would maybe feed him or get him a drink
- 3 or ... I didn't do any personal care with him.
- 4 Q. Yes.
- A. But then when I -- yes, I did do some -- there was one 5
- time when he was in there, just near the beginning, he 6
- 7 had stopped eating and we couldn't understand why, and
- we thought he maybe doesn't like the food, and that is 8
- 9 understandable. So I would make soup at home and
- 10 I would go and say, "This is soup that I have made, you
- 11 need to eat it", so he would eat it. And he would eat 12 anything I took in, but he wouldn't eat what the staff
- 13 would give him. And I am not sure quite how we worked
- 14 it out, but we think he actually thought he was in 15
- a restaurant and he didn't have any money to pay for it,
- 16 so we put some money in his room, explained to him,
- 17 "That is the money for your meal", you know, just so 18
- that he knew he had something there, and that seemed to 19 work out, until he forgot about that.
- 20 Q. You tell us about that in your statement.
- 2.1 A. Yes.
- 2.2 Q. Probably a very insightful way of dealing with the
- 2.3
- 2.4 A. You just have to work it out day by day, try and work
- 25 out what is going on.

- 1 Q. Can we go to restrictions, please, paragraph 26 of your
- 2 statement and following. 3 19 March 2020, you were made aware by a member of
- the care home staff who told you that they had been at
- 5 a managers' meeting and been told they were going into
- lockdown, and you would not be allowed to see Jim 6
- 7 anvmore.
- 8 A. Yes. To this --
- 9 Q. Was it in those simple terms?
- 10 A. Yes. Well, I remember saying: "Well, what does that
- 11 mean?" "You won't be able to come in here." But
- 12 I don't see how -- to this day, I can't understand how
- 13 I can't see my husband. Just ... yes, I just couldn't
- 14 understand how anybody can then decide whether I can see
- 15 my husband or not. It was just beyond thinking. 16 Q. I think you tell us subsequently in your statement it
- 17 was a total of 17 weeks before you were able to see him 18
- again. 19 A. Yes, I think so. I am not sure exact dates, but ...
- 2.0 Q. You have given that figure of 17 weeks. I am sure you 2.1 are right.
- 2.2 A. Yes. We kind of worked it out, I think, from 23
- 2.4 Q. Also at this time, you had taken up your job as a carer.
- 2.5 A. I did, yes.

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- 1 Q. So you, as a carer, were visiting people in need of 2 at-home care.
- 3 A. Yes
- 4 Q. You would be going into people's houses.
- 5 A. I was going into people's houses. I felt I would be bored throughout lockdown, so I thought: what can I do? 6
- 7 So I got a wee job. Sometimes I was going into 20
- 8 people's houses per day, obviously with full PPE on and 9
- taking the necessary precautions, but, yes.
- 10 Q. Yes.
- 11 You make an interesting observation at paragraph 29
- 12 of your statement, towards the end. You say that you
- 13 once asked some of the service users -- I assume that
- 14 means the people you were caring for.
- 15 A. Yes
- 16 Q. That if they only had a year to live, would they want to
- 17 see their families, even if it shortened their lives?
- 18 A. Yes, every one of them said, "Oh, yes".
- 19 Q. Yes, thank you.
- Right. As I say, you said that you didn't see ${\sf Jim}$ 2.0
- 21 for 17 weeks, but there were facilities offered for you 22
- to contact him: phone calls, iPads. Were they any use? A. No, absolutely not. Jim had never even seen an iPad, 2.3
- 2.4 never mind -- we tried -- first of all we tried the
- 2.5 phone. Well, he is non-verbal, so that is not going to

- 1 work. IPads, no. For people with dementia, not any
- good. He couldn't see it anyway, so what was the point 2.
 - in that? No.

3

- Q. Did that not seem to be appreciated by the care home,
- that that would not be a sensible way of communicating? 5
- 6 A. Yes, they did say this is just stupid. But at the start
- 7 of the pandemic, there actually wasn't even broadband in 8
- the unit Jim was in, in the care home. So I think they 9 were tethering it up to their own phones, the staff.
- 10 But it just wasn't of any use.
- 11 Q. You also, I think, as we can see from paragraph 32,
- 12 phoned regularly to find out how Jim was.
- 13 A. Yes, every day.
- 14 Q. Understandably. You indicate -- I think it's something
- 15 we have heard before -- that you got the reply usually
- 16 that he was fine.
- A. Yes. What does "fine" mean? It would depend very much 17
- 18 what member of staff answered the phone, but you would
- 19 usually get, "Oh, he's fine, he's sitting listening to
- 2.0 his music, he's fine". But that really didn't tell
- 21 me -- Jim didn't have good skin, whether his skin was 2.2 infected, whether he had eaten his dinner. It didn't
- 23
- 2.4 Q. We have heard from a number of witnesses, and I just ask
- 25
- you in this context: did you feel a bit of a nuisance

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phoning all the time?

2 A. Very much so, and I was told in on a few occasions,

3 "We're really busy, we have not got enough staff, we're 4 really busy, we can't just be answering the phone all 5 dav".

6 Q. Okay.

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You did see your husband, I think, for a couple of minutes because his father was also in the care home, and I think his father died.

A. His dad did, yes. His father was admitted to the same care home but a different unit because of mobility issues, and I had got a phone call to say —— well, the care home were in lockdown at that point —— that his father was very ill. So I immediately said, "Well, I want to be there for him". So they said, "Do a test, just come down".

So when I went down and I was sitting with him, I was told, "Well, you can't just sit here all day". This man is dying, you know? So I said, well —— his dad was mentally fine. I said his dad —— he wants to see Jim. It's one of the things we kind of said when he went in, "Oh, you will be able to see Jim, it will be great, you will be able to see your son", and he hadn't seen his son because that would mean taking one person from one unit over to the other, and infection control

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1 and all, whatever.

So I went on and on and on about it: his dad needs to see his son, he needs to see him. So eventually they said, "Okay, we will bring him over". Well, it was 8 o'clock at night. It was — the weather was horrendous. It was wet. He was in a wheelchair. He was — Jim didn't understand what was going on. He was — and it wasn't for Jim's benefit, it was for his dad's benefit, and he wasn't happy when he came in and he started shouting and whatever, you know, to express that he wasn't happy, and his dad just couldn't understand it, "What is wrong with Jim? Why is he like that?" And basically I just said, "Look, just take him away". His dad had seen him. But it was awful. And just the whole — we weren't allowed — you know, "Your time is very limited here, you can't sit with him".

17 Q. In brutal terms, it was probably of little benefit to either Jim or his father.

19 A. Probably, but at least his dad saw him.

20 Q. He did, yes.

At paragraph 35 you mention that you found out that care home residents were not allowed to be out of their rooms and, in particular, weren't allowed to go into the lounge area.

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25 A. Yes.

1 Q. How did you find that out?

A. I had got a phone call one Friday afternoon to say that

3 the local council had instructed that all residents were

4 to remain in their rooms, and I went -- I just said,

 5 $\,\,^{''}\text{Absolutely not, that is not happening to Jim", and}$

I was very firm. And the reply I got, "Well, that's

fine, we will just put it in his care plan, Jim is to go

8 through to the lounge".

9 The lounge area was bigger than this room. He 10 wasn't anywhere near anybody. It was easy to isolate

people in the room. And he had his music and his comfy

 $12\,$ chair, and he wasn't anywhere near anybody, so I said:

13 absolutely not. If he had been stuck in his room, he

14 would have been stuck in his bed at that point.

15 Q. Was that pleading on his behalf --

16 A. Yes, absolutely.

17 Q. -- any use?

18 A. Yes, it was. I just put my foot down and said: that is

19 not happening.

20 THE CHAIR: Does that mean that he wasn't -- I appreciate

21 that he would have been in his bed if he was in his

22 room, whereas in the lounge he could sit in a comfy

23 chair.

24 A. Yes.

3

25 THE CHAIR: As I understand what you are saying is the case,

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1 there would be no other residents in the room, so he

2 would be sitting in a lounge room all on his own, albeit

in a comfy chair.

4 A. But at least he was getting a walk from his room to --

5 you know, he was still using his legs. If you are stuck

6 in your bed, your mobility goes very quickly.

7 THE CHAIR: But am I right that, as far as you're aware --

8 $\,$ A. As far as I was aware because I wasn't in -- I don't

9 know --

 $10~\,$ THE CHAIR: $\,--$ the other residents remained in their rooms?

 $11\,$ A. Yes. I know certainly, once visiting did resume,

12 I asked where a few of the residents were, and it was

ones that kind of generally walked about a lot, and

14 I was told, "Oh, they got put to their bed and they

15 died". Not of COVID, but of something else.

16 THE CHAIR: Sorry, Mr Gale.

17 MR GALE: Thank you, my Lord.

Paragraph 36 you mention your 30th wedding

anniversary on 18 September 2021.

20 A. Yes

18

 $21\,$ $\,$ Q. Obviously that was a date you wanted to share with Jim

22 in some way.

23 A. Yes

24~ Q. I think you were, as you put it, sneaked in --

25 A. I was, yes.

- 1 ${\sf Q}.\ \ --$ to the unit by somebody.
- 2 A. Yes.
- 3 Q. I think you were very grateful for that.
- 4 A. I was extremely grateful, yes, that I was able to spend some time with him. I didn't stay long, but I was still 5 able to -- not that Jim understood, I don't think, for 6 7 a minute, but I did.
- Q. You also talk about visits in a corridor. 8
- 9 A. Uh-huh.
- 10 Q. And you indicate that during these visits, Jim became 11 very distressed.
- 12 A. He did. The corridor was -- it was an outside 13 corridor -- well, it was a corridor through to the 14 offices, and where the care home sits, it sits up very 15 high. It has fantastic views towards Arran. You know, 16 you were making an appointment -- you had to make 17 an appointment, and you don't know what the weather is 18 going to be like. So he was wrapped up in a wheelchair. 19 not understanding why he was taken out his comfort zone, 2.0 and the wind was howling in around about him. There was 21 another staff member there, I was outside, and it was
- 22 just -- he just kicked off. He just started shouting 2.3 and screaming. And what can you do? I just have to
- 2.4 walk away. I'm not watching anybody being distressed.
- 25
- Q. Just to be clear, that was part of his condition?

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- 1 A. Well, it was his way of communicating. It wasn't $--\ \mbox{Jim}$
- 2 was the most docile person you could ever meet, but it
- 3 was the only way he could communicate and tell people he
- wasn't happy was -- somehow he managed to find swear
- 5 words, I don't know how he managed that but -- he never
- 6 swore in his life, but he did then. And, you know, he
- 7 would try to get up and, you know, get very distressed,
- 8 and I wasn't going to watch that.
- 9 Q. I think also in paragraph 38 you mention that trying to 10 see him through a window wasn't particularly useful
- 11 12 A. Yes. Well, his room, although it was ground floor,
- 13 there was actually metal fencing right round. So you 14 would have had to go and get in through the gate and it 15 was all double locked and whatever. So you couldn't 16 actually have seen in the window unless you had a set of 17 step ladders anyway. So we tried -- in the lounge area 18 there was patio windows which opened up, and you could 19 see the whole view. The unit manager, she actually --2.0 she would open it a wee bit. But, again, it was windy, 21 it was cold, he didn't like that either. But if the 2.2 overall manager was anywhere near, that would get shut.
 - So how can you communicate with anybody? He couldn't hear my voice through a double-glazed window and the wind and -- so I had to give that up as well,

- because it really just didn't work.
- 2 Q. I think you make the comment at paragraph 37 in the last 3 sentence, you say:
- 4 "I didn't understand why they weren't more prepared 5 for these visits when it had been announced that they could happen." 6
- 7 A. Yes. When visiting did open up -- and the guidance 8 always came out on a Friday at lunchtime. The office
 - staff are not there. They disappear early on a Friday.
- 10 And any time -- it was usually me telling the care home
- 11 that there was new guidance out, and the answer would
- 12 always be. "Oh, we've not got it vet", or, "We need to
- 13 read it thoroughly and then get agreement for anything
- with Public Health". And that -- I just couldn't 14
- 15 understand why we had been closed for all these weeks,
- 16 and they knew visiting was going to open up at some
- 17 point, so why was that not all prepared? Why did it
- 18
- then take two weeks for Public Health, who had every 19
- care home, to agree their visiting and all that? Why 2.0 did it take that two weeks when, again, we couldn't see
- 2.1 our loved ones?
- 22 Q. There was a degree of recognition -- well, perhaps
- 2.3 a degree of recognition -- and you mention it in
- 2.4 paragraph 39, that if he was told you were coming to
- 25 visit, he would smile.

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- 1 A. He would, yes. Or, you know, it used to be -- it was --
- 2 when I walked along the corridor, and I would usually be
- 3 chatting to staff or some of the other residents, and if
- you turned the corner and you could see his face, you
- 5 could see that he heard my voice and he had a wee smile 6 on his face.
- 7 Q. You became a designated visitor, I think.
- 8 A. Yes
- 9 And that was introduced, and after you had -- well, you 10 had access to COVID tests.
- 11
- 12 Q. And that enabled you to see him inside.
- 13 A. Yes. I had spent my time phoning Public Health, phoning
- 14 the care commission, phoning anybody that would even
- 15 listen to me, and both Public Health and the care
- 16 commission, when I described Jim's condition, they all 17
- said, "Absolutely, you should be the designated visitor,
- 18 you should be getting in, his condition allows it". But 19
- the care home very much were: "Well, no", you know. It 2.0
- was only after a lot of pleading, a lot of shouting, 2.1
- that they actually listened to me and they did let me 2.2

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But through my work, I had COVID tests. We were testing at least twice weekly for my work, and I also ordered some online. So I would be testing every day.

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- We had to test as well before we went into the care
- 2 home, so -- or when we were there, depending on what
- 3 member of -- staff member was on, whether she trusted
- 4 you or not to do it before you went in. Some insisted
- 5 you did one and then waited half an hour out in the car. and others let me do it before I came down.
- 7 Q. How did you find out about designated visitors? Did you
- 8 find that out from the care home?
- 9 A. No. They weren't letting anything like that away to
- 10 anybody, because if I found out about that, then -- you
- 11 know, I was frequently told, "Well, everybody will want 12 that, and we can't cope with that". I think -- I am
- 13 pretty sure I found out about it through the Care Home
- 14 Relatives Scotland Facebook page.
- 15 Q. There seems to have been not a consistency in the
- 16 meetings that you had with Jim within the care home.
- 17 Sometimes it would work, sometimes it wouldn't.
- 18 A. Yes. You just never knew which -- that is his condition 19 that caused that.
- 20 Q. You do mention at paragraph 42 -- and I would just like 2.1 to ask you about this -- Jim was frequently in
- 22 a wheelchair, as I understand it.
- 2.3 A. At that point, ves.
- 2.4 Q. And you say that you were aware that his posture wasn't

good.

6

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- 1 A Yes
- Q. Could you explain how you became aware of that and what 2. 3 the problem was.
- A. Yes. By that time, I had been allowed -- we had,
- 5 I think, about five different managers throughout the
- 6 pandemic at the care home, and every time there was
- 7 a change of manager, I had to explain Jim's condition.
- 8 So one of the managers had agreed with me that I could
- 9 go into the lounge area and sit with Jim, and that
- 10 worked really well because he wasn't needing to be
- 11 moved, he wasn't distressed, he still had his music, and
- 12 then an area manager was down, and when I got there,
- they were like, "Alina, you can't come through to the 13 14
- lounge today", and I am like "Why?", and, "You need to 15 go into the visitors' room because this area manager is
- 16
- saying". 17

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- So Jim was put in a wheelchair, taken through to the visitors ' room. He was -- I tried speaking to this area
- 19 manager, but she just wasn't for listening . He was
- 2.0 leaning out the wheelchair, he was screaming and bawling 21 and shouting. She actually phoned me while we were in
- 2.2 the midst of this, and I actually was really annoyed.
- 2.3 I was like, "My husband is about to fall out of this
- 24 wheelchair because of what you have done to him", and
- 25 her reply was, "Oh, I'd better get off the phone then",
 - 82

- and I never spoke to her again.
- 2 Q. Do you attribute the change in his posture to anything
- 3 in particular?
- 4 A. Yes. I think it was probably -- a decline in his
 - illness, a decline in -- when people are walking, if
- they are getting plenty of exercise, they are standing 6 7 up straight, your muscles in your back are getting used.
- 8 If you are just sitting in a chair, you are slouching.
- 9 I think it was probably fatigue within his muscles and
- 10 a lack —-
- 12 A. With assistance. The corridors in the care home were
 - quite long, it was quite a -- I mean, not a massive walk
- 14 to you and I, but to him it was quite a walk, and we
- 15 kind of felt that his legs would maybe give way, so that
- 16 is why he was then put in a wheelchair.

Q. Was he mobile at that time at all?

- 17 $\ensuremath{\mathsf{Q}}.\ \ \ensuremath{\mathsf{I}}$ think we can see from paragraph 42 that it was not
- 18 long after this that it was agreed that Jim should
 - remain in bed for his own safety, as his mobility had
- 20 become very poor.
- 2.1 A. Yes. If he was getting distressed, he was trying to get
- up, and we felt that if he did do that, he was at risk 22
- 23 of a fall, and the last place I wanted him was in
- 2.4 hospital with a broken hip or whatever.
- 25 So I had always said from the very, very beginning

- that I do not want Jim in a hoist. I use hoists for my
- 2 work: I know they are not nice to be in. So I always
- 3 said Jim with his eyesight, his dementia, he wouldn't
- understand about the whole hoisting thing. So if it got
- 5 to that stage, he would be in his bed, and actually he
- 6 was happier in his bed, and when we look back, we think
 - that was the right decision to do.
- 8 Q. You make an interesting comment in paragraph 43 of your 9 statement, and perhaps you can explain what you mean by 10 that. You sav:

11 "The care home made me feel like a criminal for 12 wanting to see Jim. Every time I tried to visit, it

13 failed as Jim got distressed, swearing and shouting and 14

15 a bad fall."

Why did you feel like a criminal?

- 17 A. Some of the comments that were made to me. Especially
 - if you had to make an appointment, sometimes -- I think

he tried to walk. He was in severe danger of having

- 19 I was just constantly on their backs, and I think
- 2.0 because I was a wee bit younger, I was more able to do
- 21 that, whereas some of the other residents, maybe their
- 2.2 wives, husbands, whatever, were elderly and kind of
- 23 accepted it. Particularly the office staff and the 2.4
- overall manager, it was, "Alina, we can't let you do 25 that because everybody will want to do that, everybody

- 1 will want to feed their family member, you just can't be 2 doing that", and it was just -- some of the comments 3 were really not nice.
- 4 Q. Did you feel they were personally directed at you?
- A. Yes. Yes. I think because I was asking probably for 5 more, just to get inside, to be able to give him his 6 dinner, to be able to -- "No, you just can't be doing 7 8 that".
- 9 Q. Were you a bit bolshie?
- A. Yes, I was. But hey—ho, you know, it's your husband. 10
- 11 Q. Lunderstand.
- 12 Now, you do mention a visit from Jim's doctor -- and 13 I'd be grateful if you don't name the doctor --
- 14
- 15 $Q. \ --$ but you arranged for a visit from his doctor, and 16 I think his doctor lived quite close to you.
- A. His GP he had moved medical practice when he went 17 18 into the care home, but his GP stays three doors down 19 from me. So he has a dog, I have a dog, so if we were
- 2.0 out walking the dogs, he would often say, "Have you seen
- 21 Jim yet?", and I would say no, and he would shake his
- 22 head and say, "That is ridiculous". So when there was
- 2.3 a period I hadn't seen him for quite a while, and he
- 2.4 knew Jim's condition, he said, "Look, I will go in", and
- 25 he said, "I think Jim must be needing a review of his

- 1 medication anyway". He said, "I will go in".
- 2 So I got a phone call from the care home manager,
- 3 absolutely not happy at all, "You've asked someone to go
- in here and that is someone who doesn't need to be in this care home". I said, "I am very sorry, but 5
- I haven't seen my husband for weeks, I want someone 6
- 7
- checking up on him". But they were so unhappy that 8 I had done that. But I had informed them that he was
- 9 going in, and by email.
- 10 Q. Yes, and Jim's doctor did go in.
- 11
- 12 Q. He was able to see him, although not particularly
- 13 close --
- A. Yes. 14
- 15 Q. -- contact, wasn't it?
- 16 A. No, he was able to see him, and he said he did look
- 17 a bit thinner, but it's difficult to know when you are 18 only seeing somebody just for a very brief period.
- 19 Q. How did you feel about the difficulty that you
- 2.0 experienced in getting a GP visit to Jim?
- 21 A. It was terrible. Because his GP was my neighbour
- 2.2 then -- I have got two GPs that are neighbours and, you
- 2.3 know, so I was fortunate that I could -- if I was 2.4
- worried about anything, I could speak to them. But 25 I really don't think there was GPs going into the

- care home much at all.
- 2 Q. Can we just look at -- I don't want you to read through
- 3 them, but paragraphs 47 and 48, you mention guidance, 4
- and I think it's picking up something -- and I think you have already referred to this -- that where changes in 5
- guidance came about, and in particular where those 6
- 7 changes in guidance led to lifting of restrictions, how
- 8 did you find out about that?
- 9 A. Usually through the Care Home Relatives Scotland
- 10 Facebook page. I would immediately phone up the
- 11 care home and I would be told. "But we haven't received 12 them yet", or if they had received them, "We haven't had
- 13 time to read them and process what is in them".
- 14 One minute they were saying to me, "But it's only 15 guidance, we don't need to go by them", and then the next minute they were saying, "Oh, but we need to follow 16 17 that". So it kind of depended which -- you know, what
- 18 it was you were wanting.
- Sometimes -- I just felt as if I was always telling 19
- 2.0 them what they should be doing, instead of -- I had to
- 21 ask them, "Do you think you could send an email out to
- 22 the families?", and I remember in particular having
- 23 a really strong argument with one of the managers, who 2.4 said to me, "We have sent an email out", and I said,
- 25 "Well, I haven't received it, and if I haven't received

- it, then probably nobody else has received it.'
 - "I can assure you it has been sent out."
- I said, "Well, I definitely haven't received it."
- And she did come back later that day and apologise
- 5 and say, "No, I believe it hasn't been sent out", and 6 they then sent it out.
- 7 But there was not really any communication, very,
- 8 very little, from the care home regarding visiting or 9 anything that was happening.
- 10 Did you feel sympathy for the care home and the position
- 11 that they were placed in, in trying to accommodate
- 12 constant changes in guidance and get that guidance out
- 13 to people?

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- A. No, because -- well, I felt sorry for the actual staff 14
- 15 that did the caring, but not for the management and not
- 16 for the office staff. I never felt any sympathy at all 17 because I felt it could have been all -- there could
- 18 have been far better communication and it could have
- 19 been handled so much better.
- 2.0 Q. You mention, and you have mentioned, the habit, as it
- 21 appears — and we have heard more about this from other
- 2.2 witnesses -- of issuing guidance on a Friday afternoon.
- 23 Yes. Nobody is there on a Friday afternoon. The carers 2.4 can't do anything, so it has to be the office -- the
- 2.5 manager, and often they would finish early on a Friday,

- 1 or wouldn't be in on a Friday sometimes, or working from 2
- 3 Q. Could you just go to paragraph 52, please, and just read 4 that out so that we have it in your voice.
- A. I don't feel that the isolation that came about because 5 of the restrictions was appropriate or proportionate. 6 7 I wouldn't have allowed it.
- 8 Q. In making that observation, are you bringing to bear 9 your experience as a carer?
- 10 A. Yes. I mean, if I was able to go into people's houses 11 with the correct infection control mechanisms, then why 12 couldn't I go and visit my husband? His room was near 13 the door. I was going straight there. I had my full 14 PPE on. I had tested.

15 The staff were going out. Once things had opened up a bit, the staff were going out and meeting their 16 17 families. Why couldn't I do that? Why couldn't I visit 18 mv husband?

- 19 Q. I suppose the contrary argument might be that they were 20 taking a precautionary approach to matters, and 2.1 attempting to protect other residents from the 22 possibility of somebody coming in and carrying the 2.3 virus.
- 2.4 A Yes
- 25 Q. Do you have any sympathy or appreciation of that?

- 1 A. Yes. I was -- there was lots of times when I -- as 2 I drove into the car park, the office manager's office 3 and window looked right onto the car park, so she would see me coming in, and sometimes I would walk around to 5 the unit and they would be like, "Alina, we've got an outbreak, you can't come in". So -- well, who is 6 7 telling me this? Nobody is telling me this. I have 8 turned up. So I would go round to the office and say, 9 "Look, you know, my husband has got a right to a family 10 life, he has got a right to see me", and always the 11 reply would be, "Yes, but the other residents have got 12 a right to be safe". Can't argue with that. But, yes, 13 it was very, very difficult .
- $\mathsf{Q}.\;\;\mathsf{Do}\;\mathsf{you}\;\mathsf{think}\;\mathsf{it}\;\mathsf{was}\;\mathsf{possible}\;\mathsf{that}\;\mathsf{your}\;\mathsf{own}\;\mathsf{job}\;\mathsf{might}\;$ 14 15 have had some influence on this?
- 16 A. Yes

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Q. I think you perhaps allude to this at paragraph 67 of 17 18 your statement. You say:

> "One of reasons they thought I was a risk was because of my job as I was going in and out of other people's houses, but my work were very good and if they knew that somebody on my rota had Covid then they were happy to tell me not to go as they knew my circumstances."

25 Presumably you were also -- and I think you have 1 told us this -- you were also wearing full PPE?

- 2 A. I was
- 3 Q. And you were testing regularly?
- 4 A. Yes. My work were extremely good. We were told at the 5 beginning we can't refuse to go into someone with COVID.
- However, they were sympathetic -- very sympathetic to my 6
- 7 situation and, if I found out anyone -- my service users
- had COVID, I would just phone up the office and they 8
- 9 would say "Right, it's okay, we'll get that changed for
- 10 you", and they would put me into someone else rather
- than the person with the COVID. 11
- 12 You became aware I think that Jim was declining in
- 13 health. I think you say that at paragraph 54. I think
- 14 you were throughout this period, as you put, constantly
- 15 complaining, begging and threatening lawyers. Did you
- 16 actually ever do anything about engaging lawyers?
- 17 A. No. because I didn't know who to phone.
- 18 Q. How were you aware that Jim was declining in health?
- 19 A. Sometimes the unit manager would send me a photograph of
- 20 Jim and I could see he was getting thinner. I could see
- 21 his posture was not good. By the time he was in his bed
- 22 I was getting in to his room to see him and I could
- 23 tell, just his whole look, he's sleeping more, he was
- eating less, swallowing became difficult.
- 2.5 Q. I think you tell us at paragraph 56 and following that

1 your eldest son was particularly upset during this

2. period?

3 A. Yes.

- 4 Q. Did he get to see his father during this period?
- 5 A. Yes, he did. It was -- I think because he was the
- eldest and he had done so much with his dad that he knew 6
- 7 his dad the best, better than the other two. He has
- certainly taken it worse. When he was able to go and 8
- 9 see him, it took me five attempts for him to get out of
- 10 the car in the car park because, as soon as you would
- 11 drive in, he would just be in floods of tears
- 12 Eventually his girlfriend persuaded him and she came
- 13 with us to see him, but -- and certainly prior to Jim's
- 14 death he was there every day.
- 15 Q. I mentioned earlier your daughter. At paragraph 57 you
- 16 mention this incident. Just tell us about it, please;
- 17 what you say at 57.
- 18 A. Yes. My daughter, when she was at school, she -- she
- 19 was playing for the Scotland team. She was offered 2.0 plenty of scholarships to go to America and do her
- 21 studying and play golf there, but she wouldn't go
- 2.2 because she was worried that her dad would forget her.
- 23 She actually -- she went to Edinburgh University and
- 2.4 then on to Stirling . But she just -- she just couldn't
- 25 bear being that distance away from her dad and we --

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1 before COVID we had had an incident where we were in 2 Wales and she was competing and we had got a phone call 3 to say that Jim had ten minutes to live, and they had 4 called -- actually we got the phone call to say they had 5 called the doctor because his observations -- his oxygen levels weren't good and the doctor phoned me and said he 6 7 had ten minutes to live. In hindsight, you would think, 8 well, why would you even think of moving somebody that's 9 got ten minutes to live out -- you know. So I'd had 10 a glass of wine, which I never did, but that time I did, 11 so Louise was -- she must have been 17, she was driving. 12 We left, we were bombing it up the road, and I couldn't 13 argue with the doctor because it was all in his care 14 plan that he wasn't to go to the hospital, what was to 15 happen, but she wasn't for listening, and, because 16 Louise was driving, I didn't want to have any arguments. So eventually I said "Okay, take him to hospital". His 17 18 brother went down and basically took him out the 19 hospital because he was kicking off, he wouldn't keep 2.0 the oxygen on. When I arrived at 3 o'clock in the 2.1 morning he was sound asleep in his bed. He lived 22 three years after that. So ... 2.3 Q. A little premature?

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A. Yes. But, yes, she wouldn't — she was just absolutely

devastated that ...

Q. Tell us about the occasion when I suppose some clarity
 so far as Jim was concerned reigned and he realised what
 was going on on the television.

A. Yes, when Louise was playing in the British amateur, and it was during COVID, I wasn't allowed to go, it was on a local course, and I was only allowed there for the final, along with 25 others. But it was all recorded on Sky Sports and I had —— after it, she had won it, she had won by the greatest margin that there had ever been, and when I went back into the care home I put it on my phone and let Jim listen to the commentary and at one point they were talking —— the commentator had said "Can she do it?", and Jim went "Oh yeah!"

That was something that -- he hadn't managed to speak but he managed to get that out. So I am kind of aware. Then when she was playing at the British Open I did the same. I just always put it on my phone and let him listen. They mentioned her name a lot and I think he was kind of aware.

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20 Q. Thank you. I would just like to ask you a little bit 21 about paragraphs 61 and 62 of your statement. You were 22 obviously a regular --

23 A. Nuisance.

24 Q. That's your word --

25 A. Yes.

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Q. — Mrs Duncan, but you were obviously a regular
 communicator with various organisations. I think you
 said you:

"... phoned the Care Commission and Public Health who both stated that due to Jim's condition, particularly him being blind and unable to communicate, I should get access to him but the management of the care home continually stated that I was not essential to his well—being ..."

10 And you say:

" ... but the evidence proves otherwise."

A. Yes. At one point I was told "Well, why do you want to 12 13 go and see him, because you don't do anything anyway?' 14 I thought: well, nobody is ever going to say that to me 15 again. So I started giving him his meals. So I would 16 finish work -- I did split shifts -- finish work at 17 12 o'clock or 12.30, go straight down, give him his 18 lunch, go back at 4 o'clock, give him his dinner. By 19 this time they weren't restricting me, much. But I was 2.0 under the impression that I was helping out the 21 care home, because they didn't need to feed him. I was 22 making sure he was eating and what he was eating, and 2.3 I was getting contact. 2.4 I think there was an incident you refer to in

paragraph 63 of your statement, where you had to go and

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get a bib for him, and this was observed and there was some kickback about that?

3 A. Yes. I had gone in one lunchtime and by that time I was -- often when I was in, I was in Jim's room and 5 then they would bring his lunch or his dinner through to 6 me and they would maybe just bring one course and would 7 I have to say "Is Jim not getting any pudding today?" 8 "Oh, sorry, we forgot", so they would go and get it and 9 bring it back. So I started going through to the 10 trolley in the lounge area, which was all covered by 11 CCTV by that time, I went back, got his meal. I asked 12 one of the staff members "Is it okay if I make Jim 13 a drink?", and they said "Yeah, go ahead". I was always handed the food, I never went into any -- I wouldn't --14 15 and also I would never have eaten the food myself 16 because I didn't like it, but that was besides the 17 point. So I went back to his room, put his food in and 18 I went to get a kind of bib thing that they used and 19 they were in a locked cupboard and, just at that, in the 2.0 front door came an assistant manager, someone else and 21 a wee old dog that followed the assistant manager about. 2.2 and she just laid straight in -- I said "Oh, can you get

 25 $\,^{\prime\prime}\text{Right},$ we have seen you taking food from that food

get me a bib for Jim?", and she just laid right into me

into that cupboard?", because it was numbered codes "and

trolley. You can't be doing that. You're an infection risk?" and I'm thinking "Well, wait a minute, your dog who's wandering about here's not an infection risk", but I thought I'd better not say anything. So of course I got really, really upset and I just left.

The following day somebody had said to me they had been at a management meeting and I had been -- and this person had said I had taken food from the food trolley, and I said "Well, I can assure you I certainly didn't. Anything I was handed and I asked if I could make a drink, and it was fine."

So I put an email in asking — explaining what had happened, asking for a meeting with the overall manager. Not once did they ever reply to any of my emails by email. It was always when I pulled into the car park somebody would come out the office to come and get you "Oh, the manager wants to speak to you" or whatever. So I was — the secretary came running out "Oh, I've to make an appointment for you to come in". So I said "Well, I'm bringing my brother", "That's fine".

So when I went in, fair do's, they had looked at the CCTV. I had done absolutely nothing wrong and I got an apology and told -- I had actually phoned up the Care Commission thinking I was wrong and the

25 Care Commission said "You're joking? You're helping

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- them out and they're saying this to you? Don't be daft." So we did get an apology.
- 3 Q. You provide us with some information on infection
- control and prevention and we can obviously read through that. Just one point to take from that section of your
- 6 statement. At paragraph 71 you say you think that
- 7 overall the care home lost about 20 residents to COVID?
- 8 A. Uh-huh.

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- 9 Q. Where do you get that information from?
- but it has disappeared. So, yes, I am sure it was one of the managers.
- 16 Q. I think you say Jim didn't get COVID but you don't17 really know how.
- 18 A. I don't know how. Unless he was non—symptomatic.
 19 Because he wasn't very happy when he had to get tested
- so I eventually said: no, don't put him through that.

 He is not anywhere near anyone else. He just didn't
- understand why they were putting things down his throatand up his nose. So eventually I just said no.

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- $24\,$ Q. Was testing difficult for him?
- 25 A. Yes, very much so.

1 Q. You have a passage about do not resuscitate notices?

2 A. Yes

3 Q. That was something that Jim had put in place?

4 A. Yes, he had. When he was diagnosed he actually said
5 himself that he wished he had had a brain tumour because

6 it would have been quicker, and he also told his social

worker that he wished he could have just taken a blue

8 pill and ended it all . But he went to the doctor on his

9 own when he was still at home and he completed his full

10 DNACPR, and that was just -- I updated it every

11 whatever.

12 Q. So you were aware of that?

13 A. Yes

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m Q}.~{
m And}$ it was a decision that he had taken --

15 A. Yes.

16 Q. — presumably in consultation with you?

17 A. Absolutely.

 $18\,$ $\,$ Q. You tell us about the period immediately before Jim's

 $19\,$ death, and I realise this will be distressing for you to

 $20\,$ $\,$ read over it and I don't want to take you through it in

any detail. But I think from your own experience as

 $22\,$ a carer, you knew that Jim was dying?

 $23\,$ $\,$ A. Yes. I could see he was struggling to swallow. He was

 $24\,$ starting to choke. As a carer, I know what foods you

25 can give to people in that situation. So he lived off

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1 of puddings and Caramac bars, which are no longer going

2 to be made so ... I am glad he's not here ... but, yes,

3 it was just things like that. And I could see it

4 getting worse and worse.

 $5\,$ $\,$ Q. I think on the last day of his life you had phoned in

6 the morning and were told that he was washed and fine.

7 A. Yes.

 $8\,$ $\,$ Q. And you walked in just after 11 am I think, this is

9 paragraph 82, and here you saw that his mouth was dry 10 and that he had what you term the "death rattle"?

11 A. Yes. That week, because he was on no fluids by that

time, every single time I walked in he was distressed.

13 I care for people in the community that are dying.

1 care for people in the community that are dying.

14 I know — we have fantastic district nurses in our area
 who worked right throughout COVID and were basically the

only ones, apart from ourselves, going into people's

17 only ones, apart from ourselves, going into people s

17 house, I know how settled people should be with the

18 right medication. So I was constantly on their backs

saying "Jim needs more medication, Jim needs something

 $2\,0\,$ to settle him." I totally felt every time I asked for

21 a nurse that I was being a nuisance.

So on the day, myself and my son had been there all week and Louise was in Sweden competing, I had kind of wanted her away from the situation because I knew what

25 was going to happen. Her boyfriend was going with her,

1 so I thought, well, at least she's got someone with her. 2 My son had phoned and I said "Look, don't come down, this is not nice." I had walked past a management 3 4 meeting — I had phoned at 2 o'clock in the morning, 5 I had phoned at 8 o'clock in the morning, I was told he was absolutely fine, he had been washed, he was fine. 6 7 So I didn't rush down. So I was walked in just after 11 8 I walked past a management meeting and I walked into his 9 room and what I saw, I was horrified, absolutely 10 horrified. He was in a terrible state. He was really 11 distressed, his mouth was all dry, it was brown and his 12 chest was rattling, and I knew myself this is not going 13 to be long. But he needed more medication. So -14 Q. I think you say in paragraphs 84 and following that 15 there was a problem trying to get that medication? 16 A It was terrible Q. I think you were annoyed about that. 17 18 A. I was very annoyed, yes. I was told -- I went through 19 to the lounge and said to one of the young staff 2.0 members, "Can you get a nurse here?" 21 "Oh, I am sorry, they are all at a meeting at the 22 moment.' 2.3 I said, "I don't really care, I want a nurse here

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now". And to be fair on the girl, she did go over and

get them and a nurse came over and gave him

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an injection. He was already on a syringe driver by that time, which the district nurses are the ones that attend to that and increase medication for that, and they come in every 24 hours and top it up, and it's all locked away in a wee kind of box.

Anyway, the nurse told me, "Well, Jim's only got one more of these injections that I can give him today", and I said, "I don't really care, you will need to get on to the GP and the district nurse". So, "Okay, that's fine, we have left a message for the district nurse". And I said -- I know that -- I have the phone numbers for the district nurses in my village where I stay, the mobile numbers, because I know that they are only in the GP's surgery before they go out on their rounds and at lunchtime and after to pick up any messages. So they said, "We have left a message for the district nurse", but they are not going to be there until lunchtime. "Well, we can't do anything more". So I said, "Well, you need to phone the GP". So they did, and the GP phoned back and said, "Yes, I have agreed an increase in the medication". But then the care home said the district nurse has got to come in, pick up some card thing, take it down to the doctor's surgery, get it signed and then come back and administer it. I'm like, "How long is this going to take?"

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So anyway, by that time my son had texted my brother 2 and my brother had come in and was sitting with me, and 3 I knew it wasn't going to be long, but the last half 4 hour he just settled and passed. But under normal circumstances, I would have stayed with him until the GP 5 had come out to certify his death, but I was so angry 6 7 that I just had to leave. When I went through to the 8 office and said, "Jim's passed" and they just looked at 9 me, and they said "Jim's passed?" I said yes, and they 10 just: "Oh, we'd better get a nurse then". Could you not 11 see what was happening here, you know? I just -- I am 12 angry to this day. 13 You tell us about that in paragraph 87 --14 A. Uh-huh. 15 -- of your statement. I suppose one can say you were at 16 least with him when he died. A Yes

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18 Q. You tell us about the impact at paragraph 88 and 19 following. I'm particularly, as I was earlier, 20 interested in the impact on your children.

2.1 A. Yes.

 $\ensuremath{\mathsf{Q}}.$ You said they struggled to visit after COVID due to the 2.2 2.3 severe decline in their dad, and you say it took five 2.4 visits to the car park before your eldest would see his 25 dad because he was so upset.

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1 A Yes

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2 Q. The continuing restriction and lockdown and inability to 3 see their father, how would you say that has had any long-term effects on your children?

A. Probably, yes. When the care home opened up for visiting , we -- well, myself, my daughter and my middle child were always staying in the same house, and I kept asking: can the kids come and see him? And, "No, it's only one person allowed". But I can't — Jim had deteriorated so much through that period. I said the kids are really, really upset. I can't ask them to go in on their own and see their dad in that situation I didn't know how his behaviour would be. He might be shouting, screaming, whatever. I have always protected them against seeing that, because I don't think it is nice for anybody to see their father as distressed as that, and I just didn't want that. So basically they couldn't go until I was allowed to go with them.

And I think when you are seeing somebody day in, day out, you are not noticing the changes quite so much, but I think because there had been such a long period, they did notice it. And, yes, I mean, they talk of their dad very fondly, but there are lots of times that they just don't know about their dad, about what he did, what his $\,--\,$ you know. And they will maybe say to me, "What

1 happened then?", you know, or "What was dad doing?" 1 rather than as it is now currently proposed in the bill . 2 Every day they did ask about their dad, "How's dad 2 A. Yes 3 today?" I would say, "Yes, he's fine". I wasn't going 3 Q. I think you also say, Mrs Duncan, that you have a number 4 to tell them he was distressed, he wasn't --4 of emails and other documents that you can provide to the Inquiry, and can I just say that the Inquiry team 5 Q. Repeating what you were told by the care home: "Yes, 5 fine". 6 will be in touch with you to get those documents --6 7 A. Exactly, I know. But I wasn't going to tell them that 7 8 he maybe wasn't eating or he was distressed, you know. 8 Q. -- if they haven't already been sent. 9 You try and protect your kids as much as you can. 9 A. Yes. Some of them I have not been able to get. I put 10 Q. Of course. 10 in a subject access request, but I haven't received any 11 Would you go to paragraph 90 in your statement, and 11 documents from that. 12 12 I would like you to read, so we have it in your own Q. Yes, you haven't had the response. 13 words, from 90 through to 93 of your statement. 13 A. But I have other ones I will pass on. A. ""In my opinion, the Scottish Government and the 14 14 Q. Yes. We will be grateful to receive those 15 care home management should have considered quality of 15 Mrs Duncan, thank you very much. Is there anything life , not quantity. Management used government else that we haven't covered in this statement that you 16 16 17 legislation and public health rules to hide behind and 17 would like to briefly say? 18 keep relatives out. Many times I quoted the Human 18 A. No, I don't think so. MR GALE: Well, thank you very much for your time. 19 Rights Act; however, I was always told that the other 19 2.0 residents had a right to be kept safe. 20 THE CHAIR: Thank you, Mrs Duncan. 21 Through the whole period, the staff in the unit had 21 THE WITNESS: Thank you. THE CHAIR: Right. 2 o'clock. 22 had been fantastic. However, management have not taken 22 2.3 2.3 MR GALE: 2 o'clock, my Lord, yes. individual circumstances into account, and not taken 2.4 into account the fact that my husband was in the last 2.4 THE CHAIR: Thank you. 25 stage of his illness." 25 (12.41 pm) 105 107 1 I kept having to say -- I am not reading this now --1 (The short adjournment) that Jim could potentially -- we didn't know when it was 2 2. (2.00 pm)3 going to happen, but it was going to happen, and nobody 3 THE CHAIR: Another new face. Mr Caskie. MR CASKIE: Good afternoon, my Lord. I appear this afternoon and will be leading two witnesses. 5 Do you want me to read on? 5 Q. If you would. 6 My Lord has already granted a restriction order in 6 7 7 A. "During his illness , when I couldn't see him, I was relation to the identity of the first witness and her 8 8 unable to tell him what his children were doing and how father, who will be the subject of much of the evidence. 9 proud of them he should be. After a while, it became 9 But at this stage I would simply ask the first 10 10 witness to be brought in. My husband passed away not of COVID, but of his 11 11 THE CHAIR: Very good. Thank you. 12 illness, and I regret every day not being with him in 12 WITNESS HSC0049 (called) the last two years of his life ." Questions from MR CASKIE 13 13 THE CHAIR: Good afternoon. Please come in and take a seat. 14 Q. Would you just read on 94 and 95, please. 14 15 15 A. "I want to be included in the Inquiry as care home Mr Caskie, when you are ready, 16 residents have been treated, in my opinion, worst of all 16 MR CASKIE: Thank you. 17 by the Scottish Government and the managers of the 17 I have already identified to Lord Brailsford that 18 homes. 18 you have obtained a restriction order in relation to 19 Nobody should have to do without their families by 19 your own name and that of your father, but it is 2.0 2.0 their side to be their voices and just be there for them predominantly your father we will be talking about. 21 21 when they are suffering enough with horrendous illnesses What I would like to do to begin is to ask you to

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the Inquiry supports Anne's Law as it was proposed,

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You set out a couple of paragraphs of your hopes for the

and possibly at the last stages of their life."

Inquiry, and principal of those hopes are that

person. He didn't get a great education, but he was 108

Okay. My dad was a strong, energetic and dynamic

identify or to give us some information about your dad

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- 1 a clever man who was ambitious and wasn't afraid of hard
- 2 work. He had his own business for most of his working
- 3 life . He was creative. He could turn his hand to any
- 4 kind of DIY task. He loved nature, being outdoors, and
- 5 he loved his garden. He was a charming, sociable man 6 who loved outings, tea dances, choirs, and he was
- 7 respected and very much loved by his family.
- 8 Q. Thank you very much.
- 9 Your father was born on 28 September 1933 --
- 10 A. That's right.
- 11 Q. — and sadly passed away on 6 September 2021.
- 12 A. Yes.
- 13 Q. And his cause of death was recorded as COVID
- 14
- 15 Q. I understand that 12 years before his death, he was
- 16 diagnosed with dementia.
- A. Yes 17
- 18 Q. But that was initially managed at home.
- 19 A. His dementia progressed very slowly and, with the
- 20 medication that he was prescribed and support at home,
- 2.1 we managed perfectly fine.
- 2.2 Q. In the initial stages, who provided the support at home?
- 2.3 A. His family.
- 2.4 Q. And was your mother in a position to do that then?
- A. She was, yes, although my mum had physical problems, but

- 1 mentally she was fine, so they both worked well
- 2
- 3 Q. And I think it's correct that sadly your mother passed 4 away in March 2018.
- 5
- Q. At that point, did you take a power of attorney in 6
- 7 relation to your father?
- 8 A. Yes. I did.
- 9 Q. Did he continue to live in what had been the family
- 10
- 11 A. Yes. We were able to, with the help of a band of
- 12 carers, look after my dad after my mum passed away,
- 13 myself and my siblings and the carers. Someone always
- 14 slept over and was with him all the time. So we managed
- 15 to do that for 15 months or so, until we were kind of
- 16 forced to change.
- Q. Did that happen around June 2019? 17
- 18 A. (Witness nods).
- 19 Q. What was the change?
- 2.0 A. There was an incident where my dad had shown some
- 21 aggression towards one of the lady carers who was on her
- 2.2 own with my dad in the house, and that -- we were
- 23 concerned that we had a duty of care to the carers for
- 2.4 their well-being, and it was at that point we felt it
- 25 was time to look at a care home for my dad.

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- 2 Now, I understand that between then and your
- 3 father's death, he had been in three care homes or
- 4 institutions: is that correct?
- 5 A. That is right.
- Q. I will refer to each of the care homes by the sequence 6
 - in which he was in them, so care home 1, care home 2,
- 8
- 9 A. Okay.

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- 10 Q. Okav?
- 11 I think it's correct that he went into care home 1
- 12 in June 2019
- 13
- Q. Tell me about the selection process for the care home. 14
- 15 A. As my mum and dad both started to need more help, a care
- 16 manager became involved with the family in 2017, and
- 17 a care package was put in place for both my mum and my
- 18 dad. Through discussions with the care worker, we
- 19 realised that it was more than likely that my mum would
- 2.0 predecease my dad because of her health, and that there
- 21 would be a point in the future that my dad would
- 22 probably need to go into a care home. So, in advance of
- 23 that, the care worker recommended that we start looking
- 2.4 around, go visit a few care homes, which my brother.
- 2.5 sister and I did, and we went to many care homes, and

- 1 the ones that we liked the best were the local authority
- care homes, and the one in particular that my dad ended 2
 - up in was the one we liked best.
- Q. And we are going to refer to that as care home 1.
- 5 A. Yes, care home 1.
- 6 Q. Now, whilst your father was in care home 1, can you tell
- 7 me about visits that you and other family members would
- 8

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- 9 Yes. We were allowed pretty much unrestricted access to
- 10 the care home, other than trying to avoid mealtimes, but
- 11 we could pop in just about any time, and that included
- 12 evenings. Often I would finish work and pop up at
- 13 8 o'clock, have an hour with him, a cup of tea or go in
- his room and watch TV, and that was always welcomed. 14
- 15 I was able to go in and help my dad with personal care.
- 16 shower him if he needed it, shave him. So it really was
- 17 like his home, inasmuch as our family and friends could
- 18 come and go as we wished.
- 19 Q. How frequently would you go in? 2.0 Four or five times a week.
- 21 Q. Were there other family members visiting at that time as
- 2.2

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- My brother. My sister. My dad had three sisters. 23
- 2.4 Friends. He went out to a tea dance a couple of times
- 2.5 a week, and other activities . So he had a very busy

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- 2 Q. In terms of his what one might call ordinary medical
- 3 needs, the things that everyone needs -- access to
- 4 a dentist, podiatrist and so on, and I understand he
- also had diabetes, so diabetes screening -- how was that $% \left(1\right) =\left(1\right) \left(1\right) \left$ 5
- dealt with? 6
- 7 A. I took him to all the appointments he needed to go to,
- 8 whether it was the dentist or the screenings or
- 9 podiatrist.
- 10 Q. During the period that he was in care home 1, what
- 11 developments were there in his dementia?
- 12 A. Again, he settled quickly into the care home, and it
- 13 progressed slowly. He started to show a little bit more
- 14 aggressive behaviours, a bit more challenging
- 15 behaviours, over the period of time he was in there.
- 16 But in the main, it wasn't progressing hugely, I didn't 17
- 18
- Q. Was a decision made during the period that he was in
- 19 that care home that it would be appropriate to carry out
- 20 further work with him, an assessment or --2.1 A. Well, the care home approached us in March 2020 to say
- 2.2 that they felt that they could no longer meet his needs.
- 2.3 This is the phrase that they use when they have -- well,
- 2.4 they found his behaviours too challenging for them.
- They were a residential care home, not an EMI unit.

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- 1 Q What is FMI?
- 2 A. Elderly and mentally infirm. That means that the staff have additional training to cope with more challenging 3
- dementia behaviours.
- So they didn't have the staff trained in that way 5
- 6 and therefore felt they couldn't meet his needs, and so
- 7 they asked that we agree to him going to the next 8
- facility to be assessed, with a view to his medications 9 being tweaked to help better manage his behaviours, and
- 10 they assured us that, if that happened and things
- 11
- settled, they could look at him coming back to
- 12 care home 1.
- 13 Q. Okav
- Now, we are going to talk about care home 3 in a few 14
- 15 moments, but was there a distinct difference between
- 16 care home 1 and care home 3 and care home 2. Was
- 17 care home 2 different?
- 18 A. Very, very different .
- 19 Q. In what way?
- 2.0 A. Not homely. I thought very stark, bleak, unstimulating.
- 21 I didn't like it at all.
- 2.2 Q. Who ran care home 2?
- 23 A. That was an NHS facility.
- 2.4 Q. Was the function of that facility to take people in in

114

25 the long term? A. I don't think long term. As I understand it, typically

- 2 people like my dad would have gone in there for six to
- 3 eight weeks to be assessed, their medication to be
- 4 tweaked, amended, with a view to things settling down
- 5 and then him moving on.
- Q. To either the first care home or a third care home? 6
- 7
- 8 Q. I understand that he moved to a third care home. Why 9
 - didn't he move back to care home 1?
- 10 A. Care home 1 weren't prepared to take him back. After the eight or nine weeks that he had spent in
- 12 care home 2, once they decided things were more settled
- 13 and he could leave there, care home 1 said they didn't
- 14 feel they could best meet his needs so weren't prepared
- 15 to take him back, so we were left in the position of
- 16 having to find somewhere else for my dad.
- 17 $\mathsf{Q}.\;\;\mathsf{Okay}.\;\;\mathsf{I}\;\;\mathsf{will}\;\;\mathsf{ask}\;\mathsf{you}\;\mathsf{about}\;\mathsf{finding}\;\mathsf{care}\;\mathsf{home}\;\mathsf{3}\;\mathsf{in}$
- 18 a moment, but before I do that, can I ask you how these
- 19 events -- your dad going into care home 2 -- coincided
- 20 with COVID lockdowns?
- 2.1 A. I believe it was March 11 that -- or was it March 8? It
- 2.2 was three days before the NHS lockdown, and that was
- 23 before the general lockdown. So I had taken him up to
- 2.4 care home 2, we had to agree to him being sectioned
- 25 under the Mental Health Act, and I left him there that

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- day. I saw him the next day, and when I had gone back,
- 2 I think, on day four, it was at that point that I was
- 3 told I couldn't come in, the ward was locked, and that
- the NHS had decided to lock down all their facilities at
- 5

1

- 6 Q. How did you find out that the ward had gone into
- 7 lockdown?
- 8 A. Just when I arrived. I had come up with some of my
- 9 dad's clothes and was told: can't come in.
- 10 How long was your dad in care home 2?
- 11 Eight or nine weeks.
- 12 I think you said earlier in general people would be in
- 13 for about six or slightly more.
- 14 A. That is what we were told at the outset.
- 15 Q. But for your dad, it took eight or nine weeks?
- 16 A. Yes
- 17 Q. Did you see your dad during the eight or nine weeks that
- 18 he was in care home 2?
- 19 A. No.
- 2.0 Q. So you had been visiting four or five times a week, you
- 2.1 had had other visitors -- did anyone else get into
- 2.2 care home 2 to visit him?
- 23 A. No.
- 2.4 Q. No.
- 25 At the end of that eight or nine-week period, you

2

- 1 said that you had to find another place for him to go.
- 2 Can you tell me about the selection process
- 3 A. So I contacted one or two care homes that we had
- 4 previously seen and that we thought were okay, but they
- weren't prepared to take him. After discussing my dad 5
- with the medical people at care home 2, they came back 7
- to me and said they didn't feel they could meet his needs. So the social carer -- the social worker, she 8
- 9 was able to find a place in another care home, one that
- 10 we hadn't seen and that we weren't familiar with, but we
- 11 didn't have many options at that point.
- 12 Q. Okav.

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3

- 13 The eight or nine-week period that he was in 14 care home 2, what impact did that have firstly on him, 15
- so far as you are aware?
- A. Well, when I did eventually see him, when the window 16 17 visiting began, I was quite shocked at his decline. He
- 18 had gone in a fairly -- well, a very physically fit man,
- 19 who was still quite animated and lively, and when I saw
- 2.0 him, he had changed hugely. Physically much slower, and
- 2.1 mentally much poorer.
- 2.2 Q. But you had managed to find care home 3.
- A. With the help of the care manager. She had let us know 2.3
- 2.4 about the care homes that did have spaces. We had
- 25 a video tour of the care home prior to agreeing that he

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- 1 would go and live there, and it looked okay. I looked
- 2 at some of the Care Commission reports on the home and
 - it looked okay, so we had to go with it.
- 4 Q. Did you consider the possibility of him coming to live
- 5 with you at that time?
- 6 A. I did. I did. And that is something that I -- over the
- 7 years, as I knew my dad's dementia was progressing,
- 8 I always felt that that would be where he would end up:
- 9 with me. However, my husband was diagnosed with cancer
- 10 at the end of 2019, so he was undergoing treatment
- 11 in March of 2020, when all this was going on,
- 12 and I didn't feel that I could cope with all of that
- 13 that was going on. Plus the care managers, everybody was saying to me: it's too difficult, it's too much, you 14
- 15 don't know what you are taking on. 16 So it was something I wrestled with and still feel
- 17 somewhat guilty about now.
- 18 Q. I am sure there is no reason to feel guilt.
- 19 When your dad was moving to care home 3, did you 20 consider that that was likely to be a place that he
- 21 would be in the long term?
- 2.2 A. I thought it would be, yes.
- 23 Q. As a result of that, did you take the normal personal
- 2.4 items that one retains to the care home?
- 25 A. We took, yes, his clothes and, yes, his personal things,

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- pictures and so on, we took them up, and had to leave
 - them at the care home door, obviously
- 3 Q. When he initially arrived in care home 3, how was his
- 4 physical health?
- 5 A. They told me that he was settled, and that is how he was
- able to leave care home 2, but within a few days of him 6
- 7 arriving in care home 3, he seemed -- he had a fall, and
- 8 there was a query over whether it was COVID that he had
- 9 or they suspected possibly a chest infection, so his GP 10
- saw him and recommended that he go to hospital. 11 Q. Were there any other health issues at that time that
- 12 resulted in him being referred to the hospital?
- 13 Not that I am aware of.
- 14 Q. Did he have a chest infection?
- 15 A. That was -- well, he had fallen and the query was: was
- 16 it COVID or was it a chest infection?
- 17 Q. In terms of the transfer to the hospital, can you tell
- 18 me about the communication you got from care home 3 to
- 19 say he was going to hospital?
- 20 A. I think they reported to me that the GP had seen him and
- 21 that they recommend he go into hospital. I believe
- 22 an ambulance took him to hospital. But the hospital
- 2.3 felt that they couldn't treat him and that it was
- 2.4 best -- it would be better for him to be returned to the
- 25 care home.

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- 1 Q. In terms of -- how long was he in the hospital?
- A. I believe it was two days. 2.
- 3 Q. When he went back to the care home, did he require
- ongoing high-level medical treatment or not?
- 5 A. No. I think he might have had antibiotics, but it was
- 6 a requirement that he be isolated. Despite having
- 7 a negative COVID test in the hospital, when he came back
- 8 to the care home, it was a requirement that he be
- 9 isolated in his room for another 14 days.
- 10 Q. How was your dad, do you think, in relation to
- 11
- 12 A. Well, the dad that I had known would have found that
- 13 very difficult because physically he was very fit and
- 14 liked to walk about, so I think they would find that
- 15 difficult, to keep him in his room.
- 16 Q. Were any attempts made to facilitate communication? Did
- 17 he have a telephone in his room?
- 18 A. No.

2.2

- 19 Q. Were you able to phone the care home?
- 2.0 A. I was able to phone the care home and got updates any
- 21 time that I wanted them. One -- after he arrived in the
 - care home, one of the carers got her iPad and made
- 23 a Zoom call with us, so I was able to see him for the
- 2.4 first time in many weeks on the Zoom call, but he seemed
- 25 a bit confused about where my voice was coming from and

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- 1 it wasn't really satisfactory.
- 2 Q. Did you have any more Zoom calls --
- 3 A. No
- 4 Q. —— after that?
- A. No. 5
- Q. So one attempt and it didn't work? 6
- 7
- 8 Q. Okay
- 9 You had mentioned that when he was in care home 1, 10 in terms of his ordinary care -- dentist, podiatrist, 11 dietician, screening and so on -- that you would be the 12 one that would take him to have those things carried 13 out. Did that continue when he was in care home 3?
- 14 A. None of that could continue because I wasn't able to see 15 him, to get in -- to get into him. I was aware at one 16 point that his toenails had needed some attention. So 17 I think all that seemed to fall away during the 18 confusion of lockdown and all that was going on at the
- 20 Q. I think in the statement at paragraph 48 you make 2.1 reference to your father having dentures.
- 2.2 A. Yes.

19

- 2.3 Q. Were there problems with that?
- 2.4 A. They appeared to be mislaid. So for a number of weeks -- it was partial dentures, so he had missing --

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- 1 he was missing his dentures for a few weeks, and it took
- a few weeks before the community dental team were able 2
- 3 to come into the care home to fit him for a new denture.
- THE CHAIR: For the record, that was paragraph 50, not 48.
- MR CASKIE: Thank you. Thank you, my Lord.
- THE CHAIR: Sorry, just for the record. 6
- 7 MR CASKIE: You said you were able to phone and get updates
- from the staff at the care home. Did you feel they had 8 9 time to do that?
- 10 A. Yes, I never had any problem in speaking to -- it was 11 usually the nurse that was on duty that I would talk to, 12 the nurse on his wing, and she wasn't always available 13 when I phoned, but she always called me back at some 14 point.
- 15 Q. I think the next significant event that happened in 16 terms of contact between yourself and your father was 17 the introduction of window visits.
- 18 Can you tell me about your experience of window 19
- 2.0 A. Well, it was great to actually see him in the flesh, 21 that is the first thing to say, after so many weeks 2.2 apart. He was in a lounge behind a closed window, and 2.3 I, and I think my brother and sister had gone along, 2.4 were outside with masks on, just able to shout through
- 25 the window, make some hand gestures. But my dad's
 - 122

- hearing wasn't great, so whilst it was great to see him, 2
 - there wasn't a lot of communication.
- 3 Q. How often would window visits happen?
- 4 A. We were restricted because there were so many residents
 - in the care home. I want to say maybe once a fortnight.
- I honestly can't remember. 6
- 7 Q. Did you attempt to get the frequency of contact
- 8 increased?
- 9 A. Always. Always. Because, as I said, I am one of three
- 10 children. We all wanted to see our dad. His sisters
- 11 wanted to see him, his friends. So we had to share out
- 12 the visits so that everyone got a chance to see him.
- 13 But you weren't allowed to see him en masse or -
- 14 No, no. I think two was the limit.
- 15 Q. Were the care home providing you with information about
- visits and what limits there were and what the 16
- 17 conditions and criteria were?
- 18 A. The management -- the manager of the care home was the
- 19 one who was updating us as things changed, but I was
- 20 quite proactive and it was usually me that was emailing
- 21 her or calling her to ask when the next stage in
- 22 visiting would start, as things slowly started to
- 23 change. I was pushing for those changes quicker than
- 2.4 they happened.
- 25 Was there anyone outside the care home who was providing

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- 1 you with advice or information?
- 2 A. Well, I joined the Care Home Relatives Scotland group
- 3 and they were a great resource for me of information and
- support. I knew of other people who had relatives in
- 5 care homes, and so anecdotally I was getting information
- 6 from them too about what was happening in their
- 7 relatives ' care home.
- 8 $\ensuremath{\mathsf{Q}}.$ Were you able to use that information in your discussion
- 9 with care home 3?
- 10 Yes, I was. I was pushing them all the time to go
- 11 faster, to implement the changes quicker.
- 12 Q. Now, I understand that care home 3 was part of a larger
- group of care homes. 13
- A. Yes 14

2.0

- 15 Q. Again, don't mention the name. But did that have
- 16 a management structure which extended outside the
- 17 care home, went up?
- 18 A. Yes. So it seemed that all the changes were cascaded
- 19 down from their head office. So the manager would often
 - say to me she couldn't do anything until she had had
- 21 instruction and guidance from her head office.
- 2.2 When instruction or guidance was issued, was that always
- 23 followed by the care home?
- 2.4 I am not aware of it not being followed. I think it was
- 25 followed. Although I became aware that garden visits

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- 1 had started in other care homes in the area, and
- 2 care home 3 hadn't yet started it there. So I wanted to
- 3 know why and was pushing for it to begin.
- 4 Q. What were you being told? Were you being told that was
- 5 an internal decision --
- 6 A. Yes.
- 7 Q. $\,--$ within the care home $\,--$
- 8 A. Yes.
- 9 Q. -- or within the organisation?
- 10 A. Yes, that they hadn't yet had permission from their head 11 office to go ahead with that.
- 12 Q. Right.
- 13 Did you think that the communication between
- 14 care home 3 and their management outside the care home 15
- A. I can't say if it was or not. I don't know, Mr Caskie. 16
- Q. The next thing which they started, I think, was window 17 18 visits at care home 3.
- 19 A. Garden visits
- 20 Q. Sorry, garden visits, yes. Tell me about the garden 2.1 visits
- 22 A. Yes. So they took place in the extensive gardens at the
- 2.3 care home, with a -- they put up one of these sort of
- 2.4 pergola things. Chairs were put around, maybe 3 metres 25 apart, and initially a carer would bring my dad down,

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- 1 sit beside him, and we would see him and shout across to
- 2 him, and it was good to see him in the flesh.
- 3 Q. Was there any privacy?
- A. No, no privacy, and I became aware that there had been
- 5 a complaint about: why was it necessary for a carer to
- sit beside our loved one, and that subsequently changed. 6
- 7 Q. How long did the visits last?
- 8 A. They lasted half an hour.
- 9 Q. In a garden?
- 10
- 11 Q. Was he always appropriately dressed to sit in the garden
- 12 for half an hour?
- A. No. There was one occasion when I arrived for my 4 pm 13
- 14 visit, was waiting in the garden, and dad wasn't brought
- 15 down until 4.10, which I was unhappy about because that
- 16 was taking away ten valuable minutes of my time with
- 17 him. But when he was brought down, he didn't have
- 18 a coat on, and so within a very few minutes of him 19
- sitting outside, it was clear he wasn't comfortable, it
- 2.0 was chilly, he was cold. So I raised that with the 21
- 2.2 (b) it wasn't acceptable that there was no consideration

management, about (a) why was he brought down late and

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- 2.3 given to his clothing and making sure that he was
- 2.4 comfortable.
- 25 Q. When you were giving your earlier answer, I think you

- said, "He was brought down ten minutes late and I was
 - happy about that".
- 3 A. Unhappy.
- 4 Q. Unhappy, sorry, my fault.
 - How important were those visits for you?
- A. Very, very important. 6
- 7 Q. Was there anyone else in the family visiting at the same
- 8
- 9 A. My brother, my sister, as I say, my dad's sisters, who 10
- would usually bring along someone. 11 Q. How important to them were the visits?
- 12 Α Very. Very important.
- 13 How important do you think they were to your dad?
- 14 A. Well, I think — they must have been very important to
- 15 him because, having not seen us for so many weeks,
- 16 I can't -- I can only contemplate what he must have felt
- 17 when all contact with his family, his activities, his
- 18 social life, all abruptly stopped. He ended up in
- 19 an unfamiliar, unstimulating place, care home 2. He
- 2.0 wouldn't have understood what was going on. All he
- 21 would know is: where was his family? Why had he
- 22 apparently been abandoned? So to see us again must have
- 23 been great for him too. Because he still knew us. He
- 2.4 still knew us all.
- 2.5 Q. After a period of garden visits, there were indoor

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- 1 visits . How frequently did they happen, once they
- 2 started?
- 3 A. I think, again, they were maybe once a fortnight.
- Again, for half an hour. They made a lounge available
- 5 on the ground floor that could be accessed from the
- 6 outside. It had an external door. And again, dad was
- brought down and left in the room, with me appropriately
- 8 dressed in PPE.
- 9 Q. You?
- 10 A. Yes
- 11 Q. Not your dad?
- 12 A. No. me
- 13 Q. Right.
- 14 At those visits, were you able to give him gifts or
- 15 things that he enjoyed?
- 16 A. I would bring him some fruit, which he always likes, but
- 17 nothing else because it was -- they made clear that
- 18 anything, for example a birthday present, would have to
- 19 be given a few days early so they could quarantine it
- 2.0 for I think 48 hours to make sure it wasn't infectious.
- 21 Q. You mentioned fruit. Was there a particular fruit that
- 2.2 was your dad's favourite?
- 23 A. He liked bananas a lot
- 2.4 Q. Did anyone think of peeling the banana in front of him
- 2.5 and giving him the banana?

- 1 A. Well, we tried to give him a banana on one occasion on 2 a garden visit and the carer took it from us and said we 3 couldn't give it to him. They were worried about 4 passing COVID on to him, so ...
- 5 Q. That was at the time of garden visits?
- A. That was when they were supervised, yes. 6
- 7 Q. Right.
- Were some of the rules just petty, in your view? 8
- 9 A. They seemed to be, to me.
- 10 Q. In terms of your interaction with the care home, did you 11 contact anyone outside the care home about what the 12 situation was there?
- 13 A. I was speaking to the care manager to try to get 14 guidance and help from her. At times, I think I was 15 referred to the Public Health team at one point, when 16 there was word of -- that I would be able to take my dad 17 out in the car, and I was advised that there had to be 18 a risk assessment done and the care home said I needed 19 to speak to Public Health about that, about this risk 2.0 assessment, and when I spoke to them, they said, no, it 21 was nothing to do with them and I should go back to the 22 care home because it was their responsibility to do a risk assessment. So it was all rather confused. 2.3
- 2.4 No one seemed to know.

Q. Was that your impression generally?

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1 A Yes

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- Q. Not just about that aspect, but just in general? 2.
- 3 A. Conflicting messages, confusion, yes.
- Q. Why do you think that the care homes were reticent to 5 let you do the things that you believed, from reading the guidance, that you were entitled to do?
- 7 A. Everyone -- there was this great drive to protect people 8 in care homes. We, families, I think were seen as the 9 route by which the virus would be brought into the 10 care home, so we were to be kept out at all costs 11 because we were the risk. I don't agree with that, but 12 that was the overriding feeling at the time.
- 13 Q. You say you don't agree with the family being the risk. 14 Tell me why you have reached that conclusion.
- 15 A. Well, I was living a very, very sheltered, quiet life 16 during all of lockdown because my husband was undergoing 17 treatment for cancer, so he was compromised. I am sure 18 that there were -- many of the care home staff were 19 living more "risky" lives, if you want to call it that, 2.0 in terms of picking up the virus than I was. So I felt 21 strongly that I wasn't a risk and that I should be
- 2.2 allowed to come in and continue to care for my dad in 23
- 2.4 Q. And the restrictions that were imposed upon you by the 25 care home and by the government, do you regard those as

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proportionate?

2 A. No.

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- Q. Tell me why.
- 4 A. Just as I said, because I felt it was unfair, I felt it 5 was cruel, that the value that people like me and other families brought to our loved ones and to the care homes 6 7 wasn't appreciated. As I said, we were seen as the enemy. We had a lot of -- we could have helped in 8 9 a huge way to look after our loved ones and to help 10 protect their health, both physically and mentally, and 11 I just felt it was cruel to take away the contacts, the 12 family members, from our loved ones, who are in the last 13 vears of their lives. And I feel bitter that the last

18 months of my dad's life was impacted because

we weren't able to spend time with him in the way that

17 Q. Take a breath.

we should have

18 I understand that your father's health then started 19

20 A. Yes. As I say, there was a big change in him after he 21 moved to care home 3, I think in part due to the fact 22 that all of his stimulation had ceased, all of the 23 activities that he was taking part in, the outings that 2.4 would have helped his physical health, the stimulation 25 to help his mental health. When that all stopped, I am

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- 1 sure that contributed to the dementia progressing more 2 quickly, and he had changed markedly.
- 3 Q. Now, I just want to clear one thing up.

Towards the very end of your father's life, what happened to the visits then?

- 6 A. When the care home told me -- I think we became aware 7 that COVID was circulating again in his care home and 8 they were doing tests, and they told me that my father 9 had tested positive for COVID, and within a day or two 10 it was clear that it was serious, and he was confined to 11 his bed and he was poorly. And at that point my sister 12 and brother and I were told we could come and see him at 13 any time, for as long as we wanted. We were able to get 14 into his room via a fire escape because his room was at 15 the end of a corridor, so there was no need for us to go 16 through the care home. So we were able to come up 17 a back stair and go directly into his room.
- 18 Q. You mentioned earlier that you had received information 19 and support from Care Home Relatives Scotland, and you 20 will know that one of the things that that they have 21 spoken about is Anne's Law.
- 2.2 Α.
- 23 Tell me what difference you think Anne's Law would make.

- 24 I think it would make a huge difference. I know if
- 2.5 I had been that designated individual that could

THE CHAIR: On you go.

MR CASKIE: The next witness is Tracey Anne McMillan.

3 felt abandoned. We could have continued our contact. 3 MS TRACEY ANNE MCMILLAN (called) I would have been able to carry on the oversight that Questions from MR CASKIE 4 4 THE CHAIR: Ms McMillan, good afternoon. In you come and I had had with my dad to make sure that he was well and 5 5 being looked after, that everything was being done for sit down, make yourself comfortable. 6 6 him. And for me too. The pain of that separation, 7 7 When you are ready, Mr Caskie. 8 I wouldn't have had that. MR CASKIE: Ms McMillan, you have provided a witness 8 9 Q. Okay. 9 statement for the assistance of the Inquiry. Is the 10 I understand from the witness statement that the 10 content of that true? family, including your dad, had put in place 11 11 A. Yes 12 12 Q. And you want Lord Brailsford to take that into account an anticipatory care plan. 13 13 when you are giving evidence? Q. And that came to its conclusion on 6 September 2021, 14 14 A. Yes, please 15 when your father passed away. 15 Q. There is a restriction order in place in relation to A Yes 16 16 mentioning other members of your family, including your 17 mother, so you shouldn't mention their names in relation 17 Q. Were there any restrictions on the funeral? 18 A No 18 to any of this, and I also see from the witness $\mathsf{Q}.\ \mathsf{I}$ think those are all the questions I have for you, 19 19 statement that you have a professional role in health 20 apart from one: do you feel as though you have had the 20 and social care. 2.1 opportunity to say the things you need to? 2.1 A. That's right. 2.2 A. I do, other than to say that if my dad had been able 2.2 Q. I understand you want to say something about the to -- had he been asked the question and been able to 2.3 2.3 evidence that you are about to give. 2.4 answer it about what he would have wanted, would he have 2.4 Yes. I think the evidence that I will be giving today 25 wanted to be sequestrated away, protected at all costs 25 will be from the perspective of a daughter, of having 133 135 1 if that meant no family contact, I know he would have 1 a loved one in a care home at that time, not referring 2 said no. He would have wanted to continue to see his 2 to my -- not as a professional. I want to be very clear 3 family, even if that meant there was a risk to him of 3 about that. picking up the virus. I know that for sure. THE CHAIR: That's very fair. MR CASKIE: Okay. Thank you very much. MR CASKIE: From the statement, I see that your mother was 5 6 THE WITNESS: Thank you. born on 3 March 1948, and sadly passed away on 6 7 THE CHAIR: Thank you. I am very grateful for your 7 25 April 2021; is that correct? 8 8 A. That's correct. attendance. 9 THE WITNESS: Thank you, my Lord. 9 Q. Where did she live her life? 10 THE CHAIR: Good. 10 A. In East Ayrshire, in a small village, Ochiltree. My mum was very much part of the community there. She was 11 Now, Mr Caskie it's 2.40. Is it possible to have 11 12 your next witness earlier than anticipated? Is she 12 a very community person, a real people person. She 13 13 here? would welcome any new people to the village, make sure MR CASKIE: Yes, she is here and I think ready to go, if we they knew what was happening. My mum was connected with 14 14 15 the Girls' Brigade and the Old Folks Committee. So 15 iust have ten minutes. 16 THE CHAIR: I was going to say, shall we give the 16 I suppose she really was preferring to be part of the 17 village, and she really just moved from the village into stenographer ten minutes now and that would mean coming 17 18 back at 2.50. 18 a smaller town in East Ayrshire really after my dad died 19 MR CASKIE: Yes 19 and her diabetes worsened and her eyesight worsened. 2.0 THE CHAIR: Very good. Thank you. 2.0 Q. Before she moved into the other village --21 21 (2.41 pm) A. Yes. 2.2 (A short break) 2.2 -- would you describe her as a stalwart of the 23 23 (2.50 pm)2.4 THE CHAIR: Now, good afternoon, Mr Caskie. 2.4 Yes, and I think really when she died, the community MR CASKIE: Good afternoon again, sir. 25 were keen to recognise that, and there is now a bench in 134 136

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continue to support my dad in the care home, I believe

it would have made a huge difference. He wouldn't have

1 the village with her name on it so people can -- are amputation. With that, from hospital she moved to 2 aware of, I suppose, the impact that she had within the 2 receive rehab, and then a local community hospital. village 3 3 With the combination with the difficulty with her 4 Q. Okay. 4 evesight and then with that below-knee amputation which 5 You said that when her husband died, she decided to 5 impacted on her mobility, that is when we, as a family, 6 downsize; is that correct? and my mum and my brother, we felt that: how safe would 6 7 A. That's right. 7 she really be at home, and I suppose the really 8 Q. That would be in 2012 --8 difficult decision about her moving into a care home 9 A. Yes. 9 setting. 10 10 Q. -- is that right? So it was with great reluctance she moved in, in 11 A. My dad died in 1997, and I suppose she had kind of 11 the December of 2017. She moved into a local care home 12 12 struggled on in the house, and at the point when my dad in Cumnock then. That initially was really difficult 13 died, I suppose that is when her diabetes began to 13 for my mum because prior to then she had her own house, 14 14 worsen and her eyesight worsened and her mobility. So her own independence, she could come and go as she 15 I suppose that combination, that is when she then moved 15 pleased. But I think over time, and over the initial 16 16 on to Cumnock months she was there, they got to know my mum and got to 17 Q. Tell me about her eyesight worsening. 17 know what was important to her, and that community was 18 A. So my mum had -- was diagnosed with diabetes, I think, 18 really important to her, being part of a community. 19 in about 1976, and that was managed by diet. But then 19 being known in that community and maintaining really when my dad died, my mum was widowed, she really 20 2.0 friendships and relationships in that community. Also, 21 struggled with that, and she really quite low in mood 21 I suppose, fresh air was really important to her, and 22 and I think her eating was impacted, and then from there 22 getting out and about, actually socialising . 2.3 23 her diabetes management was really quite poor and she So I think when they realised in terms of for 2.4 2.4 maintaining my mum's mood, it was really important that had to move on to that being managed by medication and. 25 latterly, insulin. I suppose her eyesight worsening was 2.5 she can maintain those things, so with a wheelchair taxi 137 139 1 really a part of her diabetes. So my mum latterly, when 1 she could get out and about have a cup of tea with she lived in Cumnock, was registered blind. 2 2 friends, she could get out and about and go to the local 3 But in spite of her blindness, my mum -- she was 3 shopping centre, and then come back with that quite feisty, quite resourceful, but still very much wrap-around care of an evening, because she would 5 a member of the community. So when she was in Cumnock, 5 require two carers to transfer her and to kind of meet 6 she was a member of the Cumnock Blind Club, and she 6 her needs and keep her safe. 7 7 actually used to go and road test their activities --So really the initial part of being in a care home 8 8 was about that wrap—around care, whilst allowing her to Q. What do you mean road test, for the Blind Club? 9 9 A. So in terms of -- I suppose almost using her disability be part of a community. 10 to an advantage. So when they were planning ahead for 10 You spoke about her having a below-knee amputation. Did 11 activities, her and her friend would go in advance, 11 she get a prosthetic? 12 months in advance, and go out and find out how 12 A. Not initially . She was not initially deemed to be 13 disability and blind-friendly a café or a local 13 worthy of it. So once she was in the care home -14 community place was. Was it somewhere in terms of 14 I think when she tried the rehab initially, I think her 15 15 adequate space, was there a distinction in terms of -mood had been really low, and I think losing her leg. 16 so would it be a safe place for other people who are 16 for somebody that had been really quite independent and 17 17 blind to go and visit, so ... used to being on the go, was really difficult for her, 18 Q. She was road testing it. 18 and I think she found it really painful and hadn't 19 A. Yes. 19 engaged well with rehab. But once she was within the 2.0 2.0 care home, the care home had embraced something called Q. Okay. I understand that better now. 21 21 I understand that the diabetes also had another CAPA, which was a Care Inspectorate initiative about

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Q. What was it called?

A. Her name's leg

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A. Yes. So that is when my mum initially had a sore on her

toe which led to hospital admission, but the sore just

really spread and then that led to a below-knee

major impact on her in around 2017.

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being active. So they had a bit of a campaign in her

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2.4

- 1 Q. Well done.
- 2 A. So with that, it almost became a bit of a campaign
- 3 within the care home to get her back to physio, to get
- $4 \qquad \qquad \mathsf{her} \,\, \mathsf{mood} \,\, \mathsf{--} \,\, \mathsf{and} \,\, \mathsf{realising} \,\, \mathsf{being} \,\, \mathsf{part} \,\, \mathsf{of} \,\, \mathsf{the} \,\, \mathsf{community}$
- 5 was actually enhancing her mood. So with that, she got
- 6 back to physio, was engaging with that, and she then was
- 7 given a false leg, which really helped her mood and her
- 8 sense of self, because it gave her a complete two set of
- 9 legs again, so that kind of filled a gap in her
- 10 trousers. So when she was going out socialising, she
- 11 was part of that.
- But just to note, I suppose, with my mum dying, that leg has a new life in Africa, and I am sure my mum would
- $14 \qquad \text{ approve of that in terms of } -- \text{ yes.}$
- Q. You said that the prosthetic helped not just in terms of mobility, but when she was going out with friends and so
- 17 on. Tell me about that.
- 18 A. Yes, just to give her that sense of self. Because
- I think in terms of like -- just gave her that kind of
- 20 complete look in terms of having her two legs. And
- $21\,$ I think it was still really important for her to be part
- of that community, and still going out for her cups of tea and on the quest for the perfect strawberry tart.
- 24 THE CHAIR: Did she find it?
- A. Well, I could give you some recommendations of bakers.

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- $1\,$ $\,$ MR CASKIE: Tell me about visiting her in the care home
- 2 prior to the pandemic.
- 3 A. Prior to the pandemic, it was very open and relaxed.
- 4 There wasn't really any set timescales or restrictions
- 5 set on that. How that would generally work -- because
- 6 I suppose I had my social work career in Aberdeen and
- 7 have a life in Aberdeen, which is like a 400-mile round
- 8 trip to go. So the way it would work best is I would go
- 9 down on a Saturday once a month and then Easter
- 10 holidays, summer holidays, Christmas holidays and have
- 11 longer then. But generally on a Saturday, that is when
- we would go shopping, out for lunch and have a whole day of it. Alongside that, her friends would visit as they
- 13 Of it. Alongside that, fier friends would visit as they
- wanted to. My uncle would visit generally twice a week, go in with the local paper, read the local paper with
- her, so that they could keep up to date with what was
- happening community—wise. So there was no restrictions
- 18 that impacted.
- 19 Q. Lockdown happened in March 2020.
- 20 A. That's right.
- Q. Can I ask you, when did you last see your mum before lockdown?
- 23 A. So literally about the week before, because she had
- 24 a hospital admission -- that had been quite unusual for
- her, but her diabetes had been impacted, she had low
 - 142

- blood sugar and she had been in hospital overnight. So
 - I had gone down to visit, just to make sure things were
- 3 back on an even keel. So I spent the day with her in
- 4 the care home, had food with her, but I suppose then --
- 5 obviously, I didn't know what was going to happen next
- 6 and was just planning to be back down for my next
- 7 monthly visit, not knowing I wasn't going to see her 8 again for months.
- $9\,$ $\,$ Q. You explained about the distance between where she lived
- and where you lived. Was there a close relative who
- 11 lived close by?
- $12\,$ $\,$ A. Yes, I had an uncle who lived about a mile away from the
- 13 care home, and he is the one who would go in with the
- 14 Cumnock Chronicle and read the highlights of that to
- 15 her.
- 16 Q. That wouldn't take long.
- 17 A. That wouldn't take long, but the births, deaths and
- marriages are very important for keeping up to date.
- And also he would then go in generally on a Sunday as
- $20\,$ well . So he would be a regular visitor , and he would
- $21\,$ just kind of go in quite informally, and if there was
- anything responsible needing to be done, he would have
- $23 \qquad \quad \text{been able to go in to rectify that}.$
- $24\,$ $\,$ Q. You also spoke in the statement about that relative, $\,$ if
- 25 $\,$ she became diabetic -- diabetically challenged, if I can

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- $1 \hspace{1cm} \hbox{put it that way $--$ he had a particular mechanism for} \\$
- 2 dealing with that.
- $3\,$ A. Oh, yes, we had -- so that was her fish supper. Yes, so
- $4 \qquad \quad \text{what we found out $--$ sorry, it's a bit food-related,} \\$
- 5 this. So what we found -- obviously, a fish supper,
- 6 because they are quite all—consuming in terms of not
- 7 just the taste, the whole smell and everything. So
- 8 sometimes, if my mum wasn't eating well or needed 9 prompting to eat, we actually found a fish supper
- delivery, and prompting with that was often a thing that
- 11 would actually almost get her eating again and restore
- that balance and help maintain her diabetes.
- 13 Q. You spoke about that as the emergency fish supper.
- 14 A. Yes.

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- 15 Q. I am going to jump ahead now towards the end of your
- mum's life, although I will come back to the emergency fish supper in a second.
 - Did the emergency fish supper play a role towards the end of her life?
 - A. It did. I hoped that would have rekindled something.
- So in the -- I think it was January 2021, when I had
- been afforded the essential visits , my mum by that time hadn't really been eating. Her diabetes wasn't
- 24 really -- they were really struggling to manage it, in
- spite of the diabetic nursing support, and they had

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1 requested an essential visit . I had started that --2 initially I had started with one essential visit in 3 the January, and that is -- I felt, given her new 4 location in the care home and where it was, we would try out the fish suppers and see if that rekindled her 5 appetite again or her engagement with food, and it did 6 7 initially work, it did initially give that engagement, but what was observed, because I was only afforded 8 9 initially the one essential visit for that to be 10 face-to-face, they would see the difference on that 11 night and when that was happening, they would see the 12 engagement, they would see her actually eating on that 13 occasion. But it was only afforded on that one night. 14 And then by the February, it then went to two nights. Q. From your perspective, was it the low fat diet of that

- Q. From your perspective, was it the low fat diet of that night or the fact that her daughter was there that made a difference?
- 18 A. I think it was a -- certainly because I was having the 19 time alongside her, because there had been encouragement 20 along with -- because my mum by that point had really 21 kind of given up. So it required lots of prompting, to 22 be efficient judges of the best fish and chips in 2.3 Aberdeen, to say, "You need another bit of that batter, 2.4 you need another bit of that fish. Oh, you need to try 25 a combination with a chip to work out so we can score

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- this properly". So staff wouldn't have had the time.

 But I think actually just having that whole conversation

 and engagement is actually what made the difference, and

 staff could see that because they would see a lift in

 her spirits when I had been, and they would see

 a different engagement. They would almost see

 a different side to my mum from that.
- 8 Q. I am now going to go back to the first experience of
 9 emergency fish suppers, the point at which she is in the
 10 care home in the south—east of Scotland, and at that
 11 point, you went to see her just before lockdown
 12 happened.

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How did you find out lockdown was happening, apart from your professional experience?

A. I think because I was living it every day, and then the care home phoned to say what was happening. Yes, they just advised that the care home was closed. And then thereafter trying to gain communication with the care home was really quite difficult, because the lines were just frequently busy or engaged.

Initially , the care home set up a Facebook page, which was new for them, and it would show, I suppose at that time, some resident activity . But what you would do is each day you almost log in just hoping you would see your relative 's face on Facebook, hoping I would see

 $1 \qquad \quad \text{my mum, and trying to work out if that meant } -- \text{ does she}$

look happy? What does she look like? Or, you know,

- trying to take a lot from that picture, because that wasreally the only interaction I was then gaining.
- 5 Q. Was there ever anything set up by way of iPads or
- anything like that?A. Yes, that came a bit later on, but that wasn't the best
- A. Yes, that came a bit later on, but that wasn't the best in terms of because it wasn't you didn't know when they were going to call. So it wasn't as if you would go: oh, every Sunday at 2 o'clock, this is happening.

 So it was quite sporadic, and often relying on we had a very good key worker, and I think a lot of the good communication relied on her availability. But

 I appreciate they were really busy, so it would be quite

When I gained that contact, it was amazing, in terms — like it was so important just to have caught that glimpse of mum. Because on the iPad, I could see her, but perhaps she couldn't see me, I'd be pretty much that voice, but she knew who I was and my daughter could engage with that conversation as well when it was by an iPad, my four—year—old daughter at that time.

23 Q. Four-year-old at that time?

sporadic.

- 24 A Yes
- 25 Q. So was that the only contact at that time that she had

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- 1 with her gran?
- A. Yes. Latterly, in July, she was afforded the being
 on her dad's shoulders to look over a fence to see her
- $5\,$ $\,$ Q. Was that to do with garden visits?
- 6 A. Yes, that is when it went on to garden visits, but she 7 wasn't allowed to be in the garden at that time.
- 8 Q. At paragraph 37 of your witness statement, you make 9 reference to a call that you received in May 2020. What 10 was that call about?
- A. That was advising on the Sunday night that a member of
 staff had COVID, and then that followed on the Tuesday
 to say that my mum had now tested positive. But I was
- aware from other relatives that other residents too had tested positive. And that is really, I suppose, when my
- tested positive. And that is really, I suppose, when my mum really, I suppose, was placed in her room, and then
- didn't really come out of her room until we were
- 18 afforded the 20-minute visits in July, and then until we
- 19 moved up the road to Aberdeen, she was in her room and
- $20\,$ $\,$ in a shielding position, which I think -- my
- 21 interpretation of that is really almost like a solitary
 - confinement, the way it was actually exercised by the
- 23 care home's interpretation.

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- $24\,$ $\,$ Q. You said care homes; was that your general experience,
- $25 \hspace{1cm} \hbox{although you are not speaking in a professional} \\$

1 capacity?

- 2 A. Yes, I think in terms of that was that particular
- 3 care home's interpretation of it . There is -- across
- 4 guidance, from speaking to colleagues and from friends,
- 5 there has been many interpretations of the whole range of guidance that was issued throughout the whole 6
- 7
- Q. In terms of the isolation caused by lockdown, how did 8 9 you cope?
- 10 A. How I did cope? So in terms of when mum was isolated,
- 11 I really struggled just wondering how she actually was, 12 because having my mum with COVID in a care home, but my
- 13
- daily living experience of contact in care homes and
- 14 finding out people were dying, I was thinking: how is my
- 15 mum really? And just having -- struggling to get
- 16 through to the care home and being told that she is
- 17 okay, but you are thinking: what does that "okay" really
- 18 mean? Is she dying, not quite dying, or -- it was very
- 19
- 2.0 And then I think in terms of knowing that my mum was 21 isolated and just having sporadic contact, and
- 22 when I was seeing her, I just felt that she was getting
- 2.3 lost within herself.
- 2.4 Q. You said when you were seeing her. Was that because the
- 25 good key worker --

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1 A Yes

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- Q. What was she doing, Facebooking?
- A. She was -- yes, she was either -- well, Facebooking or
- she would send a photograph, because at that time they
- 5 were still accepting parcels, so sometimes I would send
- down a parcel of, like, flowers or biscuits for the 6
- 7
- staff or whatever, and they would -- or a picture of $\boldsymbol{m}\boldsymbol{y}$ daughter's arms outstretched giving her granny a cuddle, 8
- 9 because that was the only way she could do that, we
- 10 would take a photograph of that and mum received it, and 11
- they would -- I would have a picture of my mum to know 12 that she had got the gift, and having that image of my
- 13 mum. But I could see the deterioration in her.
- Q. Okay. 14
 - The next thing which was introduced were window visits, and I want to ask you some detailed questions
- 17 about window visits
- 18 Before I do that, can I just ask, how many window
- 19 visits did you have with your mum?
- 2.0 A. In Cumnock? Zero. And for any relative, zero, within 21
- 2.2 said it was company policy. Even though my uncle was
- 23 a mile away and would pass regularly, he wouldn't be
- 2.4 allowed to visit -- a window visit. They didn't
- 25 approve. They said it would be distressing for people,
 - 150

that particular care home. They weren't allowed. They

- 1 even though I felt that my mum would have benefited from 2
 - the comfort of knowing that my uncle was there
- 3 Q. So you were getting occasional -- or sometimes
- 4 getting --A. Sporadic.
- -- sporadic Facebook communication with her. What 6
 - communication did she have with her brother?
- 8 A. None.

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- 9 Q. None?
- 10 A. No. The only time he saw her was in July 2020,
- when I was eventually afforded the $20-minute\ visits$, and 11
- 12 he could see over the fence, because he was behind the
- 13 same fence when my daughter was on her dad's shoulders
- 14 And then, when I moved my mum, he then saw her that day.
- 15 Q. Now, I said I would ask you some questions about those 16 visits. What I want to know is whether there was any
- 17 flexibility in terms of who was doing the garden visits
- 18 or —-
- 19 A. Oh, no, no. So I think when we move on from the window
- 20 visits to the garden visits, which I think come in in
- 2.1 the July, initially the care home announced them, but
- 22 then stated that I wouldn't be allowed to have a garden
- 23 visit because my mum was shielding and she would be 2.4
- remaining in her room. And I was like: no, I will be
- 25 seeing my mum.

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So that kind of prompted me to write to

Jeane Freeman -- who was my mum's MSP, and also the

3 Health Secretary at that time -- to my own MSP, to the

Care Inspectorate, and literally anybody I felt that

5 would listen, because I really felt that my mum couldn't

6 be further discriminated and further isolated from her

7 family.

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8 I wrote to Jeane Freeman in July, just saying: is

9 this not a human rights issue in terms of my mum's

10 ability to have that contact? Because I felt the way

11 that the shielding was being utilised by the care home,

12 where she literally was in her room, she wasn't out in

13 the communal areas, her social contact was really

14 limited, it felt very much like a solitary confinement,

15 and I could see her mental health being really damaged

16 by that, and I felt there had to be kind of a balance

17 and a risk assessed approach to this. It didn't make

18 any sense to me. It just seemed absurd.

19 So after my series of complaints, to where I spoke,

2.0 I suppose, with Public Health that covered East Avrshire 21 as well, because I couldn't understand the

2.2 interpretation of that compared to my Aberdeen

23 experience, the care home manager relented. She was

2.4 very clear to say she wasn't doing that -- she felt as

if I had made trouble by doing that, whereas I was

1 saying: I really just want to see my mum. This is not 2 about -- it's important that mum has this connection.

3 It's important to maintain my mum's health that she has 4 this connection

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- Q. When you started to have contact, how did that happen? What was it?
 - A. So in the July -- because the agreement at that time, it was interpreted it was a 20-minute garden visit, and I identified to the care home how impractical it was for me to travel a 400-mile round trip for 20 minutes, and they were like: well, that is the guidance. So with that. I did ask if I could alternate it with my uncle. who was nearby. I was told that I wasn't allowed to alternate it

So after the complaint, they then allowed me to have three consecutive 20-minute visits when I was down visiting Avrshire. So it allowed me not to go back and forward

- 19 Q. 20 minutes back—to—back or 20 minutes ——
- 20 A. 20 minutes one day, 20 minutes the next, but in the 2.1 garden.

So it was a bit of an absurd situation in terms of my mum was inside, there was a table between us, about a six-foot table, patio doors, and my mum was wheeled to the end of it . I had on a mask and an apron, and I just

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1 had to shout across the table at her. My family weren't allowed in the garden. They were behind the garden 2 3 fence and having to peak over. And that is how I had the first contact since March, in the July.

When I saw my mum, I couldn't believe the deterioration in her. She just looked as if her spark had gone. She looked like a shell of a person, in terms of there wasn't that interaction , there wasn't that $\, \dots \,$

- 9 Q. Do you associate that with a physical deterioration in 10 your mum or something else?
- 11 A. Very much a mental deterioration, as if she had kind of 12 given up and not really understanding what was 13 happening. Because for my mum, being a very social 14 being and that need for socialising , that need for 15 conversation, that need for actually knowing what is 16 going on in her community, her world had really been 17 lost and disconnected.
- 18 Q. So you have described particular features of your mum, 19 and you have also described particular features of 2.0 yourself, particularly in relation to the distance that 21 you were away from your mum. Ultimately, that resulted 2.2 in a change, where they gave you the three visits 2.3 back-to-back, as it were. But how difficult was that to 2.4 negotiate?
- 25 A. Very difficult . It was after the series of complaints

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to the two MSPs, the Care Inspectorate, Public Health,

- to actually say this -- to say why can't you -- I know
- 3 there is guidance; can't you apply some human rights to
- 4 this? Can't you apply some —— not looking for special 5
- treatment, but just some common sense as well in terms of the importance and balance of my mum's health and 6
- 7 well-being to how you are trying to apply the guidance.
- 8 Q. In terms of that humans right approach, which we are 9 doing, one of the things about human rights is that
- 10 equal treatment doesn't mean the same treatment; if
- 11 different people are in different situations, then there
- 12 might be a different response. Did you see any of that?
- 13 Not within the care home in Ayrshire, no.
- 14 Q. What was the reaction of the care home when you started 15 to push back?
- A. They weren't happy. So I think after the three days of 16
- 17 having seen my mum, and each time having seen how
- 18 visibly changed she was, how withdrawn she was, I felt
- 19 I just couldn't allow this to continue. I just couldn't
- 2.0 allow my mum to be subject to these conditions. So,
- 21 through discussion with my uncle, my mum's brother,
- 22 I was like: I feel that I really do need to move her to 23 Aberdeen.
- 2.4 When I mentioned this to the care home, in spite of 25 me having power of attorney and my mum agreeing to this

- plan, they were like, "You can't move her". 1
- $\ensuremath{\mathsf{Q}}.$ Okay. We will come back to that. Let's try to unpack 2. 3 what you said a little bit.
- 4 You said you had a power of attorney.
- 5 A. That's right.

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- 6 Q. When did you get that?
- 7 A. So when mum moved into the care home, we -- she signed
 - her power of attorney then, and she also arranged her funeral plan then.
- 10 Q. In terms of the power of attorney, who was the attorney?
- 11 Myself, with my uncle as well.
- 12 Q. And I'm not talking about right at the end of your mum's
- 13 residence there, but during the period she was there,
- 14 what impact did the fact that you had a power of
- 15 attorney in relation to your mum have on the care at the
- 16 care home?
- 17 A. Generally, they were aware the power of attorney
- 18 existed, it was within their file, they had a copy of
- 19 it, so it wasn't like news sprung on them when I was
- 2.0 mentioning it in July. But generally that would have
- 2.1 meant they would have consulted with me. I felt like 2.2 a bit of a partner in her care, and decisions would be
- 23 made together. So that is generally how it had
- 2.4 previously operated.
- 2.5 Q. How did it operate now?

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- 1 A. So in the July, it was very much trying to state that
- 2 I wasn't allowed to do those things. It felt as if
- 3 there had been a power shift, as if I wasn't allowed to
- 4 move my mum, and I was like: but I can. That was --5 Q. Once you met pushback against the idea of you moving
- your mum to Aberdeen, what was their reaction? 6
- 7 A. They were saying that I couldn't. So I then felt that
- I needed to speak with the local social work department 8
- 9 to say, "Can you please help me engage with the 10 care home to explain my rights and the rights of a power
- 11 of attorney"
- 12 Q. So that is the social work department in the area that 13 vou live in. not --
- 14 A. No, the area that my mum was in, sorry.
- 15 Q. So that was down in the south—east?
- A Yes —— west 16
- 17 Q. Sorry. Sorry. My geography is upside down.
- 18 What reaction did you get from them?
- 19 A. They were helpful and they explained to the care home
- 2.0 I had power of attorney, and if that was my mum's wish 21 and my wish as power of attorney, they should support
- 22
- 2.3 However, the care home manager, when I was on my
- 2.4 third and final of the 20-minute visits, told me not to
- 25 mention it in front of staff, which is pretty difficult

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- 1 because the garden visit was being supervised, staff
- were there, so of course -- I wasn't going to silence 2
- 3 it. It was important for mum's preparation that the
- staff were aware of it. But I was being advised not to
- 6 Q. Have you any idea why they advised you not to mention 7 that?
- 8 A. I have no idea.
- 9 Q. No?

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- 10 A. No.
- 11 Q. That's fine
- 12 So you had spoken to the social work department, the
- 13 social work department spoke to the care home. Was 14
- there then agreement reached that you could move your
- 15 mum to Aberdeen?
- 16 A. Sorry, could you repeat that?
- 17 Q. So stage 1 is -- well, it's not stage 1, but the first
- 18 of the three stages is you speak to the social work
- 19 department. The social work department then speak to
- 2.0 the care home, and the care home then understand that 21

you have the power to take your mum to Aberdeen.

- 2.2 A. Uh-huh.
- 23 Q. Physically, how did you do it?
- 24 A. By a wheelchair taxi, and then with my husband in the
- 25 car alongside with my mum's luggage.

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- 1 Q. Overall, what do you think the reaction of the care home 2 was to you doing that?
- 3 A. They weren't happy. They didn't really feel as if it
- 4 was something I could do. They felt that my mum
- belonged to them, and the carers were like, "You can't 5
- do that to her". But it's my mum. Do you know? It did 6
 - really feel as if, like, whilst they were being
- 8 protective of her, it was almost as if, like, their
 - sense of -- that had shifted and they weren't really
- 10 understanding or respecting, I suppose, I was her
- 11 family, and the importance and value of that in terms of
- 12 how that was important to my mum and how that was
- 13 important to her mental health.
- 14 Q. I think you described that a moment ago as being a shift
- 15 in power. A Uh-huh
- 17 Q. Was that "We have the power" attitude something that was
- 18 typical of your experience of the care home down there?
- 19 A. I suppose that is the only experience I had, was of that
- 20 one particular care home, yes. But that hadn't been my
- 2.1 experience until, I suppose, the pandemic. Up until
- 22 then we had worked together. But that was really how
- 23 they were operating at that time and how they were
- 2.4 really using the guidance as a kind of tool for that.
- 2.5 Q. A tool. What kind of tool?

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- 1 A. A tool that kind of felt as if -- to exclude and their
- 2 interpretation of how to use it -- how to use the
- 3 guidance.
- 4 Q. Would it be fair to say they didn't like another
- 5 interpretation?
- 6 A. Yes
- 7 Q. We know that you decided and in fact did take your mum
- 8 to Aberdeen. What contact did your mum have while she
- 9 was in the care home with medical staff, doctors, CPNs?
- 10
- 11 So when she was in the care home in Cumnock?
- 12 Q. Uh-huh.
- 13 A. So it would have been just quite regular contact as and
- 14 when she required it. Like, she would get her
- 15 prescription. There wasn't anything particular. At
- 16 times we had tried to involve the CPN when my mum had
- 17 periods of confusion, but that had never really
- 18 proceeded. She didn't really have an open relationship
- 19 with the CPN, so it was just standard GP support she
- 2.0 had.
- 2.1 Q. So what was the problem with engaging with the CPN?
- 2.2 A. They would often say that her infection was much more
- 23 physical health—based rather than mental health—based.
- 2.4 But she was on anti-depressants when she moved to
- 25 Aberdeen.

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- 1 Q. You have your statement there; yes? You have your 2 witness statement there?
- 3

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- $\mathsf{Q}.\;\;\mathsf{Can}\;\mathsf{I}\;\mathsf{take}\;\mathsf{you}\;\mathsf{to}\;\mathsf{paragraph}\;\mathsf{74}.\;\;\mathsf{You}\;\mathsf{express}\;\mathsf{an}\;\mathsf{opinion}$ 4 in paragraph 74. Can you just read that. 5
- A. Mum had gone into her room mid-May because that is when 6 7 they started enforcing the shielding thing. It was 8 really bizarre in a care home, where most people would
- be shielders. You'd think they would safe together, 10 given that nobody else was allowed in.
- 11 Q. Then carry on, next paragraph.
- A. I was physically shocked when I saw my mum at the July 12 13 visits, her physical appearance and her mental health
- appearance. She was just so inside herself. She had 14
- 15 checked out. I couldn't believe how frail and
- 16 disengaged my mum was. She was a shell. Her face had
- 17 caved in. Her clothes were hanging off her. She was
- 18 like a shell with sunken cheeks.
- 19 Q. How long had it been since you had previously seen her?
- A. Face-to-face, since the March, and then at other times 20 2.1 it had just really been through the occasional iPad, but
- 2.2 I suppose I hadn't really $\,--\,$
- 2.3 Q. How long since iPads?
- 2.4 A. Probably about a month or so. But I think when you actually see it much more face-to-face and gather it and

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- 1 get, I suppose, the whole picture in terms of her
- 2 clothes, and just seeing her mental health engagement
- 3 back -- because I think sometimes when you are perhaps
- engaging somebody in conversation and not getting
- 5 a bit $\,--\,$ she was so just wheeled to the end of the
- table, and just -- and she was so enclosed within 6
- 7 herself
- 8 Q. Then at 84 you describe something else. Can you go to 9
- 10 A. I wrote a letter to Jeane Freeman on 6 July 2020 to 11 express my fear and frustration about recent guidance in
- 12 regard to care home visits lacking compassion and having
- little regard for the quality of life of residents. She 13
- did respond, but it was so bland. I think it must have 14
- 15 been a standard letter. It didn't address my letter at
- 16 all. It didn't take it point by point. It just said to
- refer to most of the policies at the time. It just
- 17
- 18 directed me back to the guidance.
- 19 Q. Then paragraph 86.
- 2.0 A. My local MSP, Alex Burnett, gave a much more
- 21 personalised response. He did identify the Care Home
- 2.2 Relatives Scotland group and directed me to them. The
- 23 group has been useful. It helped me feel that you are 2.4
- not isolated, that other people have had equally poor 25 experiences, and you realise that you are not alone.
 - 162

- 1 Q. Have you found Care Home Relatives Scotland something 2 positive?
- 3 A. Yes. I think it was a safe place for expressing,
- 4 I suppose, your sense of despair.
- 5 Q. Were they also able to provide you with practical
- advice? 6
- 7 A. I think together we would share: who could we write to,
- who could we lobby, who could we make aware of what is 8
- 9 going on, because surely if people know, they would want
- 10 to do something different.
- 11 Q. Paragraph 91 through to 97. Can you just read those.
- 12 A. Yes
- 13 I think, because my profession, I knew the
- 14 connections to go to the local social work department.
- 15 If I hadn't known, I would probably just have accepted
- 16 what the care home were saying. I would have thought:
- 17 well, they must know better, they must be right. But
- 18 they weren't. It wasn't true. I could use my power of
- 19 attorney -- sorry, that is not the statement, but it is
- 2.0 the context of it.
- 21 When I spoke to social work about the power of
- 22 attorney and being able to make decisions regarding
- 23 moving mum's care homes, I did think mum had capacity,
- 2.4 but alongside it, it was meeting her previous wishes.
- 25 You took your mum to Aberdeen.

- 1 A Yes
- Q. And she went into a care home up there. 2.
- 3 A. That's right.
- Q. Tell me about the selection process.
- 5 A. Of how I chose it?
- 6 Q. Yes.
- 7 A. Well, at that time I was employed within the social work
- 8 department, and one of my responsibilities was due to
- 9 oversight, and Scottish Government had asked for
- 10 an overview of all the care homes functioning within
- 11 Aberdeen city. So between a colleague and I, we had to
- 12 go and visit all 30-plus care homes within a two-week
- 13 period. So that gave a bit of an overview of -- as much
- 14 as I knew the care homes, it was a bit of a whistlestop
- 15 tour of what was happening, how they were functioning.
- 16 And then, from there, I suppose I selected a care home
- 17 in Torry, which is an area of the city, because for me,
- 18 when I had visited, it was the banter between the staff
- 19 and the residents was really key. I actually felt in
- 20 some ways it was a friendly environment where I felt my
- 2.1 mum would be safe.
- 2.2 And you had the opportunity, fortunately, because of
- 23 your professional experience, to make that judgement.
- 24 A. Yes.
- 2.5 Q. That comparison.

1 A. Yes.

2

Q. Okay.

3 I understand that when your mum moved to Aberdeen 4 into a care home, she continued to have window visits.

- 5 A. That's right. The window visits, bizarrely, seemed like a bonus in terms of moving to Aberdeen. So when she 6 7 moved to Aberdeen, she had to isolate for a two-week period, but there wasn't any limits to the window 8 9 visits . They were -- in terms -- and staff would 10 actually enable them. So they would open the window and 11 allow that -- so it wasn't as if you could only appear
- 12 whenever —— fortunately, my mum had a ground—floor room. 13 so when you'd appear, they'd open the window. And
- 14 visually I could see that my mum appeared more content. 15 She would recognise me at the window, and my daughter 16
- could come along and shout in the window too. 17 Q. Was that in contrast to what had happened in the 18 south—east?
- 19 A. Yes, yes. It was a different experience.
- 20 Q. West, sorry.

21 Did you get the impression that the care staff in 22 Aberdeen had a greater interest in your mum's 2.3 well-being?

2.4 A. I don't know if I could really — they were — they had a care plan in place and we planned for a visit, and

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- 1 I suppose I had hoped that the opportunity of moving to 2 Aberdeen, that my mum could become much more re-engaged
- 3 and could perhaps get more of my mum back, because
- I really felt I had lost a lot of her.
- 5 Q. Did you still require to attend at a fixed time?
- A. Yes, the window visits were unlimited, but there were 6 7 garden visits which took place in an area of the garden 8 that was covered, but they were at a fixed time. 9 I would be in PPE, and if my daughter was attending.
- 10 she -- you had to stand a certain distance apart and 11 they were supervised.
- 12 Q. Can I ask you to read paragraph 118.
- A. My mum really liked the outdoor visits. They were 13 short-lived, given she would be brought out during your 14 15 allotted time, but they were under a canopy, and you sat 16 so many feet away. But my mum could see, and we could 17 have a conversation, and it worked really well.
- 18 Q. At paragraph 120 you talk about phone calls being 19 answered in Aberdeen and being able to get through. 2.0 That is a contrast with what had been the situation 21 previously: is that correct?
- 2.2 A. It was. It felt much more effective in terms of I could 23 find out what was happening with my mum, and I really 2.4 hoped with the move as well there would be that greater 25 connection with her, if there were any health needs that

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- needed to be addressed as well.
- 2 ${\sf Q}.$ At one stage in Aberdeen -- and ${\sf I}$ am now looking at
- 3 paragraph 121 — you talk about your mum developing 4 pressure sores --
- 5 A. That's right.
- $Q. \ --$ and that being very upsetting for her. 6
- 7 A. So I think when we were outside on a visit, she would
- 8 start crying and she would start trying to tell me how 9
- sore her bottom was, and she would start crying, but 10 I wasn't allowed to touch her. I wasn't allowed to
- 11 comfort her, and I found that really distressing,
- 12 because I think the most natural thing to do when
- 13 somebody is crying is to go in, to touch and to
- 14 reassure, but that wasn't allowed. I can remember
- 15
- a member of staff saying, "You are not allowed to go near", and I was like, "Okay, can you speak to my mum 16
- 17 and can you reassure her, because you are beside her,
- 18 you are allowed to do that".
- 19 I did actually write a complaint to the care home 2.0 manager because there were two instances where my mum 21 was in tears. I wasn't allowed to comfort her, but 22 equally, the members of staff that were with her, they
- didn't comfort her either, and I found that really 23 2.4 distressing
- 25 Q. At any point did you see, in Aberdeen, any of the

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- 1 care home staff comforting your mother in the way that
- 2. you describe?
- 3 A. Yes, it was in those two occasions they didn't do it,
- and I felt that needed to be addressed, in terms of it
- 5 was really important that if somebody is upset, you deal
- 6 with it.
- 7 Q. So --
- 8 A. So sometimes I would be observing when I was on a window 9 visit. I would see some really compassionate care, and
- 10 them begin to understand a bit more who my mum was and
- 11 what her needs were.
- 12 Q. In your private life, as it were, you weren't able to
- 13 give your mum a cuddle, but in your professional life,
- 14 you were able to visit 30 care homes.
- 15 A. Which is really difficult, because I could see so many
- 16 other people's mums and chat to them, see them, sit
- 17 alongside them, but I wasn't allowed to do that with my
- 18 own mum, which really kind of plays a lot in your head.
- 19 It doesn't seem right or just. 2.0
- $\ensuremath{\mathsf{Q}}.$ Paragraph 125, you talk about breaking the rules. Tell 21
- me about that.

2.4

- 2.2 That was having an illegal cuddle, because I think --
- 23 which sounds really absurd. But I think maybe at that
 - time you were maybe allowed to touch a hand but not to
- 25 have a cuddle, which is just $\ \dots \$ but I was aware that in

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into the care home.

terms of the member of staff, if she probably had reported it, she would have got into trouble as well.

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Q. You then, in the next section of your witness statement, describe in some detail the difficulties of not being able to have physical contact. I am looking down towards 130. So from where we were to 130.

Is there anything you want to add or expand on in that section?

A. So it was really $\mbox{ difficult }$, so -- because my mum had been sore -- was in pain with the bed sores, I was allowed two room visits in December, and that was amazing. I wasn't allowed to touch anything and they were supervised, and I could just sit in the chair and only allowed to hold hands, and that is when I had a cuddle then. So I felt as if I had like -- oh my goodness, I have been allowed to see her. But then because she improved, that then stopped and I was back to having it more restricted.

But then it was December, and with Christmastime. they said they couldn't allow face-to-face visits at Christmastime. And my mum's an early January birthday, that wasn't allowed to be a face-to-face, because I think, trying to give staff a break and manage the rotas, they felt it would be unfair because they felt that all families would want Christmas Day. So then

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- 1 again it went back to a window visit and taking my daughter along with a stepladder to open presents and be 2 3 at a window with her.
- 4 Q. A stepladder? Tell me about that.
- 5 A. Yes. She is only small. So because she was four, in terms of trying to -- so she could have eye contact with 6 7 my mum, we would take a stepladder in the car, so she 8 could actually see my mum and shout in and speak to her.

So Christmas Day that year was really my daughter on a stepladder, and inside the staff helping my mum opening her presents so we could have some sort of family Christmas. But it makes for the most bizarre, strange pictures which you can't cuddle and touch the person that you really care about.

- 15 Q. You spoke about Christmas. There had been an earlier 16 party -- looking at paragraph 138 -- in the care home. 17 Tell me about that.
- 18 A. Yes. That was -- so in this care home as well, they 19 equally had a Facebook page where you would look out for 2.0 your loved one or find out what was happening. But 21 I suppose at Halloween and October, I noticed there had 2.2 been a Halloween party, but it seemed to be the staff 2.3 were there, but they weren't wearing masks. And I was 2.4 like: this is wild, given I am not allowed to see my 25

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mum, I am only allowed 20 minutes, and it's -- so

- supervised, but yet there are staff going around without 2 masks dressed for Halloween. I again raised that with 3 the manager and the pictures were removed from the 4 Facebook page.
- 5 Q. I am jumping ahead now to paragraph 157, and at this point your mum's health is deteriorating. Again, tell 6 7 me a bit about that.
 - A. So that is when I get the essential visits, but I suppose the build—up to that was my mum had —— her diabetes was getting more and more difficult to manage, and I suppose I was increasingly going on window visits. I had been called by staff to have telephone calls with my mum to prompt her to eat, because they would see the difference that actually made because I could prompt and encourage her through having the relationship with her and get her to eat, which would actually help manage her blood sugar, help manage her health.

So I suppose there was a whole kind of lead up in terms of -- I suppose in the November, there was the whole obscure -- where the staff wanted me there. My mum had -- I went and purchased food for her. She then had a plate of -- I would be standing on one side of the window, just begging and encouraging my mum to eat and thinking: how can this be right? How can this be okay?

So as my mum's health deteriorated -- and I suppose

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I identified in some ways, like, feeling the Christmas that had passed, that would be my mum's last Christmas. That was potentially her last birthday. But not being allowed that contact, not being allowed to touch her, just to see her through glass, see her through a window. So I asked if I could be afforded an essential visit, because I think, by definition, at that time there was essential visits in place which would afford you to go

So initially I was allowed in on a Sunday night to help, really, with the teatime routine for helping my mum to eat and to be prompting her medication, and that seemed to have real benefits

- O. You spoke earlier about the emergency fish supper, but 14 15 that was part of the care that you were providing. 16 Other people were involved in that. She was diabetic, 17 so presumably her GP was involved. Was there 18 a dietician?
- 19 A. Yes. That is a bit of another story. So there should 2.0 have been a dietician because my mum was really reduced 2.1 in weight, and I think what really came out at her care 2.2 review was from the time of admission until her death, 23 she had lost over 3 stone, so gone from 9 stone to just

2.4 over 6 stone, and you could really see that visually and 25 the impact on her. So, yes, a referral had been made to

1 the dietician, but it got lost, and then the second one 2 took some time to proceed, once they had worked out the 3 first one was lost.

But what I really felt was happening was the dietician was giving advice, but equally the diabetes nurse was giving advice, and sometimes that would be counter-advice. I didn't really feel her healthcare needs were very joined up.

Q. What about the GP? Were they involved in that? A. Yes, the GP didn't really have any face-to-face contact until -- I suppose until she was admitted to hospital in the April. There was also a CPN involved, but she didn't have any visual contact with mum until months after my mum had been in Aberdeen. I think I had said my mum had moved up to Aberdeen on a prescription of anti-depressants. That continued in Aberdeen and, when her mood —— I suppose really dipped really from November, 2020, there were changes to her medication and that was really done with the CPN and the care home staff and them advising what the changes were. So there would be tweaks and changes and additions made but not really with the CPN reviewing the impact or

2.3 asking my mum "How do you feel?", which is a bit key;

2.4 that you might ask your patient --

25 Q. I have a couple of questions arising from that. At this

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- 1 point you still have a power of attorney?
- 2. A. Yes

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- 3 Q. Can I take you to paragraph 166.
- A. Nobody was looking holistically, nobody was looking at 5 the whole picture. Everybody had a strand and each time 6 they would respond reactively. I felt we needed to sit

7 down as a group and actually make a plan together.

- 8 Q. Did that ever happen?
- 9 A. Yes, eventually, by the April. But my mum died 10 late April.
- Q. Do you think it might have made a difference if it had 11 12 happened earlier?
- A. I think if it had happened earlier, I think it could 13 have been much more co-ordinated. It could have --14 15 particularly in regard to her mood. I think her mood 16 was so key on her eating and her eating was so key on 17 her well-being, I think it was all interlinked and 18 I think to look at them separately was not beneficial to 19 my mum's health.
- 2.0 Q. At paragraph 173 you refer to a medical mishap.
- 2.1 A. Yes.
- 2.2 Q. Do you want to tell us about that.
- 23 A. Yes. That was in January. One of the nurses gave my 2.4 mum a double dose of insulin, which obviously could have
- 25 been fatal. So with that, that resulted in an adult

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- protection investigation. What we learned is the nurse 2 hadn't looked at the MAR chart when she came on shift $-\cdot$
- 3 Q. MAR?
- 4 A. The medication ... I don't know what it's ... medication 5 administration record.
- 6 Q. Yes.
- 7 A. So when she went on shift she hadn't read that, she
- 8 just -- automatic pilot, knows my mum is at a certain 9 time for insulin and she gave it to her without looking
- 10 and it had already been given. So then that led to
- 11 linking in with the NHS out of hours service to monitor
- 12 my mum's reaction. But the only benefit to come out of
- 13 it was it allowed me to get into the care home to
- 14 actually be with my mum and actually to work out what
- 15 happened around the clock and to just --
- 16 Q. You tried to remember about your mum's weight loss.
- 17 Can I take you to the end of paragraph 179.
- 18 A Yes
- 19 Q. You give numbers there?
- 20 A. That is right, and that is from her care plan review,
- 2.1 which happened on 9 April. So in terms of on admission
- 22 she was 9.8 stone to then be weighing 6.7 stone
- 2.3 in March, so a loss of 3.1 stone.
- 2.4 O
- 2.5 A. So that was really noticeable visibly in terms of her

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- 1 clothes, in terms of her face, in terms of her -- I was
- 2 just watching my mum visually shrink and disappear.
- 3 Q. Paragraph 184 in the witness statement. Do you want
- moment? Have some water. It is not up to me to make 5
 - any decisions, but you've done really well.
- 6 A. Okay.
- 7 Q. Paragraph 184. I will read that.
- 8 A. Okay.

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2.2

- 9 "On the Sunday before my mum died (19 April 2021) I was
 - visiting my mum in the home, and she seemed really
- 11 confused. She had an infection. I think it was
- 12 a urinary tract infection (UTI). I did advise staff at
- 13 the time that I thought my mum had a further infection
- 14 and asked would they keep me informed if they got the GP
- 15 and what the GP said.
- 16 "They phoned me the following day to say that they
- 17 had phoned the GP and they were waiting for feedback.
- 18 They asked me to come in. It seemed that my mum was
- 19 getting worse, was more confused, and she wasn't
- 2.0 responding, she wasn't speaking anymore.'
- 21 Your mum then died?
 - Yes. She then went to the hospital and then died
- 23 a couple of days after that.
- 24 Is there anything to say about the transfer to the
- 25 hospital?

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- 1 A. It was a farce.
- 2 Q. Tell me about the farce.
- 3 A. Sorry. So in terms of giving this as a kind of -- my
- 4 mum is by this time now unresponsive. The GP phoned for
- 5 an ambulance because she was unresponsive. So the GP
- then left and said, "If the ambulance isn't here in 6
- 7 an hour, get the care home to follow up and prompt it."
- So when an hour had passed, the ambulance wasn't there 8
- 9 and I said to the care home and they were like "Oh, no,
- we don't do that." And I was like, "Oh, yes, we do. 10
- The GP said to do that." So whilst we are debating who 12 is going to phone the ambulance turns up. However, the
- 13 care home in their wisdom felt that was a good time to 14 show a student nurse what to do when somebody goes to
- 15 hospital. So, with that, they felt that the student
- 16 nurse should then take my mum's stats, her vital
- 17 statistics, take blood, but I was really concerned that
- 18 was delaying the time of her getting to the hospital,
- 19 and that is not something -- that is not really when you
- 2.0 should be doing that. It was a crisis. It was a 999
- 21 ambulance. It is not really the time for doing that.
- 22 I later wrote a letter of complaint to the care home
- 2.3 about the management of that.
- 2.4 Q. But she was taken to hospital.
- 25

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- 1 Q. Did the hospital maintain contact with you?
- 2 A. Yes. They phoned about 10 o'clock that night, because
 - I wasn't allowed in. My mum was unresponsive and I was
- saying, "Can I be there? Can I speak for my mum? Can
- I give you her medical history? Can I explain who she 5
- 6 is?" They were like, "No, we will phone you later."
- 7 She had gone in about kind of 4 o'clock, kind of
- 8 before teatime, and they phoned at 10 o'clock and they said they were processing her and they had a few
- 10 questions about her diabetes. I explained what she had
- 11 been like on the Sunday, because she had been speaking
- 12 then, but I felt she was now quite unresponsive and that
- wasn't like my mum. The registrar, when they phoned, 13
- 14 they said they weren't sure she would make it through
- 15 the night, so I staved awake just waiting to hear
- 16 anything. They didn't phone. I phoned to find out that
- 17 they were actually going to be transferring $\,--\,$
- 18 Q. Sorry, who phoned who?
- 19 A. Sorry, I phoned the hospital.
- 2.0 Q. You phoned the hospital.
- 2.1 A. Because they hadn't phoned me, because I was waiting
- 2.2 thinking I was going to get a call saying my mum had now
- 2.3 passed. That didn't transpire, so I wanted to know how

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- 2.4 my mum was and I wanted to know if I could see her. So
- 25 there were many calls back and forth. They were going

- to then transfer her to a ward and I asked if I could
- get a pass to come in. The nurse said she would ask if
- 3 I could but then didn't phone back, so it took several
- 4 calls through the day to then establish that I could get
- a pass to get into the ward. And with that they put my 5
- 6 mum on an end-of-life management plan.
 - Q. Did vou see her?
- A. Yes. I moved into the ward. So I think, using the 8
- 9 opportunity of now having a pass to the ward, I managed
- 10 to get a mattress and just slept alongside her.
- 11 Q. How long were you in?
- 12 A. It was the Wednesday and my mum passed on the Sunday
 - night, so a good few days in hospital. But I felt that
- 14 afforded me the opportunity to give her all those
- 15 cuddles that I hadn't been able to give before. Sorry.
- Q. Did you make up for it? 16
- 17 A. Sorry?
- 18 Q. When you were in the room, did you make up for it?
- 19 A. Yes. Completely. I made up for that time, by just
- 20 being allowed to cuddle my mum, being allowed to speak
- 21 to her freely, play the music she would have enjoyed and
- 22 just give that little bit of comfort that she hadn't
- 23 been allowed for the last few months of her life.
- 2.4 Q. Did you get comfort from that as well?
- 25 A. I did. I did.

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- 1 Q. In your statement at paragraph 206 you say you feel
- guilty about moving your mum up to Aberdeen. 2 3
- A. I had really hoped it would be an improved situation.
- I really hoped that I would have got improved access and 5
- maybe have got much more of my mum back. I suppose 6 I am not naive enough to think that my mum was going to
- 7 live forever, but I had really hoped that in the time in
- 8 Aberdeen we could have maybe repaired some of that
- 9 damage from the shielding experience in Avrshire.
- 10 Because I really think that really damaged her mental
- 11
- 12 Q. So you are saying there you feel guilt about moving her
- 13 to Aberdeen. What did she want?
- 14 A. She wanted to be with her family, she wanted to be in
- 15 her community and I suppose she -- ves, she wanted to be
- 16 able to cuddle her granddaughter, and that was something
- 17 we never, ever got. Whilst I got all the cuddles in the
- 18 hospital, it still was very much one visitor in the
- 19 hospital.
- 2.0 Q. In the witness statement, I will take you back to the
- 21 witness statement just now, you talk about getting her
- 2.2 belongings back and buttons to sew on her clothes and so
- 23 on. All of that will be read. We don't need to talk 2.4 about that, unless there is anything you particularly
- 25 want to say?

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1	Α.	No, I think in some ways that was almost like a final	1	listened to. I felt as if I was just kind of forced	
2		straw for me. What had happened, when I got my mum's	2	back into referring back to guidance, whereas I think	
3		belongings back I found them to be soiled or vandalised	3	today has allowed me to tell my mum's story.	
4		by having her room number written on her clothes. So	4	MR CASKIE: We have listened to you. Thank you very m	uch.
5		I couldn't then pass them on to anybody. They were just	5	THE CHAIR: Very good. Thank you very much indeed,	
6		destroyed, in my eyes. When she had moved into the care	6	Ms McMillan. I am very grateful. Tuesday morning,	
7		home they had asked that I buy buttons with her name on	7	10 o'clock. Thank you.	
8		them, which I had done, and that is something that could	8	(4.00 pm)	
9		have been done and made it less institutional and would	9	(The Inquiry adjourned until 10.00 am on Tuesday,	
10		have allowed me, I suppose, to have those final memories	10	14 November 2023)	
11		of my mum and her clothes, but I just felt in some ways	11		
12		during this time the way people in care homes have been	12		
13		treated, it was quite institutional and quite regimented	13		
14		and I just felt that was like a further thing that could	14		
15		have been avoided, in terms of just putting her down $$	15		
16		depersonalised her further.	16		
17	Q.	Unlike her prosthetic leg.	17		
18	A.	Yes.	18		
19	Q.	What did it say on your mum's death certificate?	19		
20	A.	It was about her diabetes.	20		
21	Q.	Sorry?	21		
22	Α.	It was diabetes. She died due to her diabetes, and it	22		
23		also mentioned her amputation as well. However, I felt	23		
24		in some ways what had hastened her death was really her	24		
25		treatment and the impact, I suppose, of not being able	25		
		181		183	
1		As an annual transfer of the state of the st	1	INDEX	
1 2		to manage her diabetes, not being able to manage her well—being, not being able to manage her mental health,	1 2	MS LUCY HOLLY CHALLONER1	
3		that loss of contact with her family. Because	3	(called)	
4		a 20 minute visit through glass or a 20 minute visit in	4	Questions from MS BAHRAMI1	
5		a garden or a 20 minute visit inside is not enough to	5	MRS ALINA ELIZABETH59	
6		sustain a relationship.	6	DUNCAN (called)	
7	0	You move on to suggest lessons to be learned, and they	7	Questions from MR GALE59	
8	۷.	seem to focus on communication between the professionals	8	WITNESS HSC0049 (called)108	
9		involved and the important role that family play in the	9	Questions from MR CASKIE	
10		care of people in care homes.	10	MS TRACEY ANNE MCMILLAN	
11	Α.	Yes.	11	(called)	
12		Is that correct?	12	Questions from MR CASKIE135	
13	•	I think family are key. For many individuals, that is	13	,	
14		really a key part of their network and they can't be	14		
15		shut up, they need —— they need their family around them	15		
16		to support them, to be their voice, to advocate on their	16		
17		behalf, to be there to cuddle them.	17		
18	Q.	You also say something about your hopes for the Inquiry.	18		
19	Α.	Yes.	19		
20	Q.	How has today been for you?	20		
21	Α.	Sorry?	21		
22	Q.	How has today been for you?	22		
23	A.	I feel as if I have had my voice heard. I have been	23		
24		able to tell my mum's story. I suppose I tried doing	24		
25		that during the pandemic but I didn't really feel	25		

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