

OPUS2

Scottish Covid-19 Inquiry

Day 7

November 7, 2023

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1 Tuesday, 7 November 2023
 2 (10.00 am)
 3 THE CHAIR: Good morning.
 4 Right, Mr Gale.
 5 MR GALE: Good morning, my Lord.
 6 We have three witnesses today. The first is
 7 Natasha Clare Hamilton.
 8 THE CHAIR: Very good, thank you.
 9 MR GALE: For reference, her statement is SCI-WT0370-000001.
 10 THE CHAIR: Now, I think we may have the first technical
 11 hiccup of the morning because we have a new -- I don't
 12 know what we call them -- attendee, and I am not sure if
 13 she knew to go and get the witness.
 14 MR GALE: I think she is outside.
 15 THE CHAIR: Is she outside? Perhaps I am doing the lady
 16 a disservice, for which I apologise.
 17 MS NATASHA CLARE HAMILTON (called)
 18 THE CHAIR: Good morning, Ms Hamilton. Welcome back.
 19 Questions from MR GALE
 20 MR GALE: Hello, Ms Hamilton.
 21 You have given a statement to the Inquiry. I have
 22 given the reference to that, and it will come up on the
 23 screen as you are giving your evidence.
 24 You have already given evidence to the Inquiry as
 25 part of the organisational presentation of Care Home

1

1 Relatives Scotland.
 2 Just to confirm, your full name is Natasha Clare
 3 Hamilton, I think.
 4 A. Yes, that is correct.
 5 Q. How old are you?
 6 A. 37 now.
 7 Q. Yes. You were 36 when I think you gave your statement,
 8 so we can change that.
 9 A. Yes.
 10 Q. Okay. The Inquiry has your contact information.
 11 I think you are currently a student; is that right?
 12 A. Yes.
 13 Q. Now, you are here to give evidence today about your
 14 mother, Anne Duke. I think Anne Duke is the Anne of
 15 Anne's Law.
 16 A. Yes, that is correct.
 17 Q. Later this morning, we will also hear from your father,
 18 Campbell Duke.
 19 A. Yes.
 20 Q. Could I just caution you at the moment, Ms Hamilton,
 21 that while you can obviously mention your mother's name,
 22 your father's name, please don't mention the name of the
 23 care home in which your mother was a resident.
 24 A. Yes.
 25 Q. Now, we know from your statement that your mother sadly

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1 died during the pandemic, although not of COVID per se;
 2 I think her cause of death was given as Alzheimer's and
 3 pneumonia.
 4 A. Yes, but just to add to that, she did catch COVID at the
 5 beginning of the pandemic.
 6 Q. She had had COVID?
 7 A. Yes, she had had COVID, yes.
 8 Q. And she died on 13 November 2021, so the Inquiry is
 9 conscious that the second anniversary of her death is
 10 imminent, and can we send to you from the Inquiry team,
 11 and to your father, our condolences in relation to that.
 12 You tell us that your mother was diagnosed with
 13 Alzheimer's in 2014, when she was only 56.
 14 A. Yes, and I think that is quite important. Yes, quite
 15 young.
 16 Q. At that time, she was still independent and living at
 17 home with your father.
 18 A. Yes.
 19 Q. You also say that you did not realise as a family the
 20 level of care that she would require as a dementia
 21 sufferer.
 22 A. Yes. If I can -- when I knew about dementia, I just
 23 thought people forgot stuff. I didn't realise you would
 24 become a full-time carer. Yes.
 25 Q. I think you also had guardianship --

3

1 A. Yes.
 2 Q. -- of your mother once she had been diagnosed with
 3 dementia, and that was a role you had alone, I think --
 4 is that right? -- not in conjunction with anyone else.
 5 A. No, so my dad was initially the main one, but then
 6 I stepped over, so he was secondary. Yes.
 7 Q. Okay, thank you.
 8 Now, her disease progressed so that in, I think it
 9 was, 2018 she had become non-verbal, and at paragraph 8
 10 of your statement you indicate that once she had gone
 11 into hospital, the system really took over; is that
 12 right?
 13 A. Yes. I believe so, yes.
 14 Q. She was admitted, I think, into hospital on an interim
 15 basis -- sorry, into care on an interim basis, but that
 16 became a permanent arrangement.
 17 A. Yes. We were told there wasn't enough -- there was no
 18 support for her to be cared at home, for my family.
 19 Q. I think she was 60 at the time that she went into care
 20 on a full-time basis; is that right?
 21 A. Yes, that is correct.
 22 Q. If you just look at paragraph 13 of your statement,
 23 please. I think there is a background to this, that you
 24 weren't particularly happy about your mother going into
 25 care. I think you, as a family, wanted to care for her

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1 at home or continue caring for her at home; is that
 2 right?
 3 A. Yes, we had been doing so since mum has been diagnosed
 4 and, as you stated earlier, when mum went into hospital,
 5 that is the only time I felt there was intervention, and
 6 it was against our wishes and mum's wishes. We just
 7 needed a little bit more support to keep mum at home.
 8 But I truly believe that because she was under 65, the
 9 easy option was to force us to put our mum into
 10 a care home.
 11 Q. You say you felt your hands were tied behind your back.
 12 A. Yes.
 13 Q. Can you just explain why you say that?
 14 A. Mum — if you are diagnosed with dementia under the age
 15 of 65, there is very little support in the community for
 16 you. Like, for me personally, I struggled. There was
 17 zero support for my mum.
 18 I think if she was over the age of 65, we might have
 19 been able to get a bit more care at home packages for
 20 her. But I truly believe that, because of her age, she
 21 was discriminated against, and the support she was
 22 needing at that time, it might have cost less money for
 23 localities to put her into a care home as opposed to
 24 give us more support to keep my mum at home, and we had
 25 been her main carers up until then.

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1 Q. You were willing to remain in that role as the main
 2 carers as a family, as I understand.
 3 A. Absolutely, yes.
 4 Q. Okay.
 5 Paragraph 14, you do mention, as it were, the
 6 reception into the care home that your mother went to,
 7 and I think, reading short, you say that the staff there
 8 made you, and presumably your mother, feel welcome into
 9 the care home.
 10 A. Yes, and that is partially the reason why — so it was
 11 an interim bed, and then when we realised we weren't
 12 going to be able to get mum home, we had to find
 13 a permanent care home for her, and that is part of the
 14 reason why we chose to keep her in that care home,
 15 because the length of time she was in there at the time,
 16 it just felt natural. The staff had got to know her,
 17 they got her as well for the little time she was in
 18 there, and they just made the transition a lot easier
 19 for us. So, yes, it felt the most natural thing to keep
 20 her in there.
 21 Q. There are three points you make in the following
 22 paragraphs, and can I just really summarise them.
 23 First of all, in the pre-pandemic days, your mother
 24 had many visitors in the care home, both family members
 25 and friends, and in fact your father was effectively

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1 able to — put it this way — camp out almost in the
 2 care home; he could be there to assist your mother with
 3 eating and companionship, and he was almost a
 4 semi-permanent resident in the care home. Would that be
 5 fair to say?
 6 A. Yes, yes, I would agree. And similarly, I lived in
 7 Edinburgh and mum's care home was back in East Kilbride.
 8 For the full day when I would go to visit, I would use
 9 the same term: I camped out there. I'd go to mum's in
 10 the morning and I didn't leave again until 5.00/6.00 at
 11 night, until heading home to Edinburgh.
 12 Q. I think as you say in paragraph 18:
 13 "The care home became a second home for us ..."
 14 A. Yes.
 15 Q. You could spend Christmas there and, presumably,
 16 birthdays.
 17 A. Yes. Especially — we were told this when mum went into
 18 the care home by numerous bodies that were part of that
 19 transition: treat this as your mum's home. So we took
 20 that mentality on. And especially when mum turned 60,
 21 the care home put on a massive party for mum, and that
 22 was just as mum moved into it. So, again, that helped
 23 with the whole feeling like it — it would never feel
 24 normal, but helped us feel like: this is a nice place
 25 for mum to be, this is a place for us to come, spend

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1 some quality time with mum. We know she is being looked
 2 after and we can come and go, and it felt as natural as
 3 a transition can be into a care home, in my opinion.
 4 Yes.
 5 Q. Thank you.
 6 One other point you make — and I think it is
 7 probably quite a significant one — is that it wasn't
 8 perhaps understood by some people about the grief and
 9 bereavement that your father suffered as a consequence
 10 of losing his wife to dementia and then into
 11 a care home. Can you just explain that a little?
 12 A. Yes. Living grief and bereavement is something I feel
 13 very strongly about. When someone is diagnosed with
 14 dementia, you lose them every single day. Part of their
 15 brain is dying, and you are losing that part of them
 16 every single day. Then for your loved one to have to
 17 move into a care home, you are losing that contact with
 18 them again. Some people aren't able to make phone
 19 calls, they're not able to use text messages, so for
 20 that to happen, that is a big loss in someone's life,
 21 and I remember actually asking the social work: is there
 22 support put in place for partners in those positions?
 23 I was told, "No, we are only here to look after your
 24 mum".
 25 Q. I think we are aware from your father's statement — and

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1 we will be hearing from him later this morning -- that
 2 he did suffer considerably from the grief of losing your
 3 mother into the system, and into the ravages of
 4 dementia.
 5 A. Yes, and that is why I'm now -- I took over as mum's
 6 guardianship. That is why.
 7 Q. Now, the other point I would like to just take from you
 8 is that I think you and other members of your family,
 9 particularly, became part of the team that helped the
 10 staff with your mother's care when she was in the
 11 care home pre-pandemic, and if one looks at what you say
 12 at paragraph 19 of your statement, you say that you felt
 13 you were helping ease pressure on the staff, and also
 14 you knew that they appreciated that.
 15 A. 100%. My mum's dementia got to a certain point where
 16 she needed everything done for her. So if I was in
 17 there with my mum, helping her drink and eat, even
 18 listening to music, communicating with her, that eased
 19 up pressure on staff to go and be with other residents
 20 whose families -- who maybe didn't have families to be
 21 in with them or whose families weren't able to visit at
 22 a certain time. They were able to go and help out those
 23 other residents because they knew that I was there with
 24 my mum, and they trusted me, because they knew that --
 25 we got to know each other. So for me to be there with

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1 my mum, it clearly releases pressure on the staff,
 2 because there is only so many staff within wards --
 3 units, sorry, and that is across all care homes. They
 4 are quite stretched, in my opinion. So for families to
 5 be in and helping out their loved ones, it will ease
 6 pressure on staff. I think that is just a given. Yes.
 7 Q. I think one of the points you made in that answer was
 8 quite important: that the staff could trust you for the
 9 work that you would be able to do with your mother.
 10 A. Yes. There was never -- I never felt at any point
 11 anyone was checking up on me. Yes, pre-pandemic it was,
 12 "Natasha is in her mum's room, she's fine".
 13 Q. Obviously your mother was a resident in the care home
 14 pre-pandemic, but you do note that COVID took hold in
 15 the care home, and 19 residents in that care home died;
 16 is that right?
 17 A. Yes.
 18 Q. Do you know over what period that was?
 19 A. I couldn't give a definitive answer, but I do think it
 20 was -- so my mum was diagnosed with -- she got COVID
 21 in April of that year, and I think it was around about
 22 that time a lot of the residents started passing away.
 23 So I think it was at the beginning of it, but I would
 24 need to have it clarified.
 25 Q. It's not necessary to give exact detail, but if you

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1 could -- I just wondered if you knew.
 2 I think you also surmise -- I think it is
 3 an assumption on your part -- that individuals were
 4 being sent to the care home without being tested for
 5 COVID.
 6 A. So, yes, that is my opinion, and my opinion is from what
 7 we now know, that care home residents were sent to --
 8 people were sent from hospitals to care homes untested,
 9 we know that, it has been publicised, and the reason why
 10 I think it was my mum's is because my mum's care home
 11 was an interim care home, so the local hospital was next
 12 to my mum's care home. So that is me just putting one
 13 and one together, maybe getting three, but maybe getting
 14 two.
 15 But just to quickly clarify, the 19 residents that
 16 passed away, we were never told.
 17 Q. Yes, I am --
 18 A. Sorry, okay. I just what happened to add --
 19 Q. I understand that.
 20 At that time, obviously -- and we are into the
 21 pandemic and the effective exclusion of you as a family
 22 member from your mother's care home -- you say at
 23 paragraph 22, last sentence:
 24 "However, keeping families locked out didn't prevent
 25 Covid from getting into the Care Home at this early

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1 stage."
 2 Is that another one of the reasons why you assume
 3 that it may have been caused by people being transferred
 4 from hospitals into the care home?
 5 A. It could either -- it only got in two ways: either from
 6 staff or somebody being transferred from a hospital,
 7 because they were the only people that were able to
 8 access the care home at that point.
 9 Q. Yes. I think you also say that there were interim beds
 10 in the care home, so it had available space for people.
 11 A. That's, again, from my experience of that care home.
 12 Because mum's was an interim bed, I am assuming that
 13 possibly might have been used, yes.
 14 Q. You made the point -- and I will ask you just to make it
 15 again -- you were not told by the care home that there
 16 was an outbreak, and I think you found out about that
 17 through social media.
 18 A. Yes. It's a very unfortunate situation that happened.
 19 We saw it on social media as a family, and then we
 20 assumed that it maybe just -- it was leaked. But then
 21 I knew other families that had someone in that care home
 22 and they were like, "No, we were told two or three days
 23 ago". So I got in touch with the care home. They were
 24 very apologetic.
 25 It was quite a traumatic experience again because we

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1 don't know anything about mum, we were kept away from
 2 her, and all of a sudden we find out there is COVID in
 3 her home through social media. Again, that just
 4 highlights again how stretched staff were, that somebody
 5 has forgotten to phone. If we were still able to go in,
 6 one person, (inaudible) my dad, then he would have known
 7 at that point, because that contact would have been
 8 there for my mum.

9 Q. Even within the -- let's assume there wasn't the
 10 facility for you or your dad to go into the care home,
 11 one would have thought -- well, I ask you: did you
 12 imagine that all families of residents within the
 13 care home would be informed of the outbreak within the
 14 care home?

15 A. I would like to imagine that that would be the case,
 16 yes.

17 Q. Yes.

18 Moving on, there was the possibility in April 2020
 19 that your mother might have to go into hospital; is that
 20 right?

21 A. Because she contracted COVID, yes.

22 Q. Yes. As I understand it, that in fact didn't happen
 23 initially .

24 A. No. So it did eventually. So mum contracted COVID, and
 25 the care staff were worried about her, so they phoned us

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1 and they phoned an ambulance. The ambulance came and --
 2 there is more detail in my statement, I know, but from
 3 my memories of it is that when the ambulance came, they
 4 said there was nothing they could do for my mum at that
 5 point, so that is why they wouldn't take her into
 6 hospital.

7 Q. You explain that at paragraph 25 of your statement.

8 There is something that did crop up at that time:
 9 you received a letter from your mother's GP practice on
 10 30 March 2020, and you quote from that letter in
 11 paragraph 26. Now, your father also quotes from that
 12 letter in his statement, I think a fuller quote, but
 13 I wonder if you would just read what that letter said to
 14 you.

15 A. "Many patients already have anticipatory care plans
 16 regarding their wishes for future care and avoiding
 17 hospital admission, but not all. Ideally these
 18 discussions would take place in person, in a calm,
 19 non-time-pressured way, but this is not possible. We
 20 will not abandon you or your loved ones, but I need to
 21 be frank with you regarding the realistic outcome if
 22 they were to get COVID-19. It is extremely unlikely
 23 that if they were to be bad enough to require
 24 ventilation (a machine to breathe for them) that they
 25 would survive.

14

1 "If residents become unwell, we will work together
 2 to provide the best supportive care we can within the
 3 nursing home. We have access to comfort medications for
 4 end-of-life care, known as a 'Just in case box', should
 5 things reach that stage."

6 Q. What was your reaction -- you, personally -- to seeing
 7 that letter in those terms?

8 A. It felt like my mum was just written off because of
 9 where she lived. She wasn't given a chance from the
 10 offset. That is genuinely how it feels. No one else in
 11 the community would have had that -- if mum had had
 12 dementia in the community, I don't think she would have
 13 received a letter like that.

14 Q. Your mother was subsequently admitted to hospital.
 15 I think that was something that the care home had pushed
 16 for. I think we can see that in paragraphs 27 and 28 of
 17 your statement.

18 You weren't allowed to accompany your mother to
 19 hospital, were you?

20 A. No one, not even a member of staff. It was the
 21 paramedics and my mum on her own, a non-verbal
 22 vulnerable person.

23 Q. Just to set it in context, your mother was non-verbal at
 24 this stage.

25 A. Yes, non-verbal.

15

1 Q. This may be a difficult question to answer, Ms Hamilton:
 2 did your mother have any cognitive function at that
 3 time? Do you think she understood what might be
 4 happening?

5 A. I don't think she would have understood what was
 6 happening, but I think it would be wrong to think
 7 that -- she was aware that she was being moved from her
 8 familiar surroundings with familiar people into
 9 an ambulance, loud noise, who knows what was happening
 10 in the ambulance, again into a loud environment,
 11 different visualisations that she could see. I think
 12 she would have been quite uncomfortable with that. That
 13 is definitely something I think, because if I was to
 14 walk into my mum's room, she would recognise me. She
 15 might not be able to verbalise it, but you would get
 16 some sort of recognition. So she did have that ability
 17 to recognise certain things, and noises as well.

18 So those would have definitely played an impact on
 19 her, being moved from one familiar place to something
 20 that is not.

21 Q. Perhaps taking this out -- certainly out of line in your
 22 statement, but one of the things that I picked up from
 23 your statement, and indeed from your father's, is that
 24 your visits to see your mother in the care home
 25 pre-pandemic were very important, both for your mother

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1 and, indeed, for you and your father.
 2 A. Yes.
 3 Q. Because I think what we will hear particularly from your
 4 father is that he was able to have some — well, I am
 5 sure you did as well — eye contact with your mother, he
 6 was able to touch her, he was able to — I think he
 7 would massage her hands, and there was an element of
 8 sensory connection between him and your mother and,
 9 indeed, between you and your mother, and that was
 10 important, I think, was it?
 11 A. Yes. You use the correct word there. I have always
 12 called it "sensory communication" with my mum. If I was
 13 never in the room with my mum — I would go six days
 14 a week having no contact with my mum, because that is
 15 just the way it was pre-pandemic and I understood that
 16 to be her illness. So that one day when I would always
 17 make sure I was there, that meant the world to me
 18 because I knew that she knew I was there and I hadn't
 19 abandoned her.
 20 Q. Yes. Okay.
 21 Your mother's transfer to hospital in April 2020, as
 22 you said, you weren't allowed to accompany her; were you
 23 told in advance of her transfer?
 24 A. Yes, we were — the care home were on the phone with
 25 us — pretty much someone was on the phone to us and

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1 someone was on the phone to 999, so we were aware of
 2 that at that point.
 3 Q. Once she was admitted to hospital, did you have
 4 difficulties in communications with the hospital to find
 5 out how she was?
 6 A. There was nothing from the hospital. If we weren't
 7 a family that were proactive, we would not have known
 8 anything. We took to phoning three times a day to get
 9 information on my mum. Now, who knows if they'd have
 10 maybe got in contact with us if we hadn't phoned three
 11 times a day, but there was no, "We'll phone you at this
 12 time every single day to keep you updated on your mum".
 13 So, again, she was in an environment on her own,
 14 non-verbal, and we were still sitting back, not knowing
 15 what was happening with her.
 16 Q. There was effectively the onus on you to make contact
 17 with the hospital in order to find out how your mother
 18 was.
 19 A. Yes.
 20 Q. Obviously, you weren't allowed to see your mother in
 21 hospital.
 22 A. No. No.
 23 Q. You make the point in paragraph 30 of your statement
 24 that it had been two months since you had last seen your
 25 mother —

18

1 A. Yes.
 2 Q. — because of the lockdown of the care home.
 3 A. Yes.
 4 Q. One of the difficulties, as I understand it, with that
 5 situation was one might imagine that a family member
 6 like yourself, who is constantly at your mother's
 7 care home, would be able to appreciate the perhaps
 8 subtle changes in your mother's condition.
 9 A. Yes.
 10 Q. And because you hadn't seen her for that length of time,
 11 you and your father weren't able to notice those.
 12 A. Yes. Yes. You are unaware of how she is changing day
 13 to day.
 14 Q. So, for example, you wouldn't be able to give that
 15 information to the hospital.
 16 A. No, and that is again where the whole restrictions thing
 17 is frustrating, because when mum was in the care home,
 18 we weren't really allowed to have much contact in terms
 19 of person, but as soon as she went into the hospital,
 20 the onus was on the family. It was the family that was
 21 having to tell the hospital, "My mum can do this, my mum
 22 can do that", but not the care home. But yet when she
 23 was in the care home, it's okay, it's the care home that
 24 were looking after her. So it's picking and choosing
 25 when the families can be involved and when they can't is

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1 what that felt like.
 2 Q. I think some of the examples that you give are,
 3 for example, what were features of your mother's
 4 behaviour, and also what were her food preferences. So
 5 you weren't able to — the hospital wasn't necessarily
 6 aware of those.
 7 A. Yes. We were unsure if they were just leaving food next
 8 to her thinking that she was able to eat. So we had to
 9 make sure that they were aware of that as well and aware
 10 of the types of food she was able to eat.
 11 Q. Your mother was in hospital on oxygen for about
 12 two weeks, you tell us in paragraph 30 of your
 13 statement, and she was released from hospital on 10 May.
 14 This was, I think, something that you weren't told about
 15 in advance.
 16 A. No. We were — the care home contacted us to let us
 17 know. I don't even — no, yes, we were only told when
 18 mum showed up at the care home and they phoned us to let
 19 us know that mum was home.
 20 Q. The hospital didn't tell you?
 21 A. No.
 22 Q. It was the care home, having received your mother back
 23 into care, who told you?
 24 A. Yes.
 25 Q. I think your mother had to have two negative lateral

20

1 flow tests ---
 2 A. Yes, we were aware ---
 3 Q. --- before she was re-admitted into the care home.
 4 A. Yes, we were aware of that, and we were aware we were
 5 waiting on the results coming back, so we just weren't
 6 told when the right results were there to send her back.
 7 Q. As you say in paragraph 32, your mother attended
 8 hospital again in October 2021, and we know that was
 9 immediately prior to her then being returned to the
 10 care home, and to her death in November.
 11 A. Yes.
 12 Q. You talk about your mother's care and her condition
 13 before the pandemic in paragraphs 33 and following, and
 14 we can read that.
 15 As well as the impact that dementia had on her,
 16 rendering her non-verbal, she had also lost the power to
 17 move independently, I think you say.
 18 A. My mum had --- the dementia had destroyed my mum. She
 19 was not able to do anything for herself at all. She was
 20 bed-bound/chair-bound pre-pandemic, I would put it,
 21 because we were able to help her get out of the bed
 22 and sit in the chair, and it was, like, one of these
 23 comfy chairs that she would be able to be supported in.
 24 But out of that, she really couldn't do anything else
 25 for herself.

21

1 Q. She had also started, if she was moving independently ---
 2 if she could move independently --- to drop to the floor.
 3 A. Yes, so that was when she was first moved into the
 4 care home. That was that period.
 5 Q. I think it is also right to note that you do note that
 6 in relation to the care home, there was always a staff
 7 nurse on duty.
 8 A. Yes. So that goes back to her being admitted --- I don't
 9 know --- use the phrase --- when she moved into the care
 10 home. We were always arguing that if --- they were
 11 saying that she had to move into the care home because
 12 she needed someone with her all the time, so we were
 13 arguing: well, there's not enough staff to be with my
 14 mum at all times. So my mum could get up out of her bed
 15 at that point, and she could do that thing where --- we
 16 felt that she was just needing to sit down, but she
 17 wasn't aware where her chair was, so she would just drop
 18 to the ground. So that was our argument about: well,
 19 she is not always going to have someone with her. So
 20 eventually the social work package agreed that they
 21 would give money for another member of staff to be on
 22 shift with my mum at all times to ensure there was
 23 someone with her. So, yes.
 24 Q. I think in paragraph 38 --- and please don't name her,
 25 but I think you do mention that there was one carer in

22

1 particular, and you describe her as amazing.
 2 A. Yes. Yes. Sorry, I don't know why that has made me
 3 cry. She was amazing.
 4 Q. Well, it's your word.
 5 A. Even through the pandemic, she was the person that still
 6 let me be connected to my mum. So, yes, she was worth
 7 her weight in gold.
 8 Q. One matter I would like to pursue with you is what you
 9 say at paragraph 40 in your statement about
 10 communicating with your mother. We have touched on this
 11 a little.
 12 I don't want to go into the minutiae of your
 13 mother's condition and how she was, but I think she
 14 apparently did have some difficulty in lifting her head.
 15 A. Yes. She certainly towards --- if you want to say
 16 towards the beginning of the pandemic, if you want to
 17 put it that way, she would be, like, pretty much hunched
 18 over. She didn't really --- so that's why when she was
 19 in the chair or her bed, it was good, because the chair
 20 could be reclined so her head would be up, but then
 21 depending, she would then just start slouching down. So
 22 most of the time you would spend your time on the floor,
 23 trying to get her attention and let her know you are
 24 there.
 25 Q. But she did apparently understand, or at least manifest

23

1 that she understood, your presence, because she could
 2 smile still.
 3 A. Yes, yes. I would always (inaudible) that I didn't --- I
 4 got to a certain point where I didn't know if my mum
 5 knew I was her daughter, but she knew I was someone that
 6 made her happy in her presence, and, yes, maybe certain
 7 smiles and jokes and music, I would be able to get some
 8 smiles and acknowledgement from her, definitely.
 9 Q. And I think the point I made earlier, that your dad used
 10 to go in and massage her hands, and I think that was in
 11 the context I indicated to you earlier, the significance
 12 of sensory ---
 13 A. Yes.
 14 Q. --- contact.
 15 I think what you say at the end of paragraph 40 is
 16 probably quite important. You say:
 17 "These were precious moments as I could not
 18 communicate with my mum out with these visits."
 19 A. Yes, that was the only communication I had with my mum,
 20 was when I was in the room with her, holding her hand,
 21 singing songs with her, playing her favourite music. As
 22 soon as I left my mum's room, I knew that I would have
 23 no more contact with her until the next time I was able
 24 to visit. So you cherish those moments that you had
 25 with her.

24

1 Q. Put simply, you couldn't phone her up.
 2 A. No, no. The lines of communication with my mum
 3 disappeared. The communication with my mum is being in
 4 her room, in her presence, next to her, holding her
 5 hand, talking to her. Outwith that, I was never able to
 6 communicate with my mum because of the way the dementia
 7 has affected her.
 8 Q. Right.
 9 In paragraphs 43 through 47, you talk about the way
 10 in which you and your father could provide fruit and
 11 drink for your mother, and obviously once you were
 12 unable to visit her, all that stopped.
 13 A. Yes. Now, that is not me saying that the staff weren't
 14 doing that, but that goes back to the staff were
 15 stretched. When I would visit mum, I would be with her
 16 all the time, so she would be getting lots of fluid and
 17 lots of fruit and lots of nutrients in her, but
 18 obviously staff aren't able to spend as much quality
 19 time with every single resident in there, so that's why
 20 I feel that was a very important point to bring up.
 21 Q. Perhaps could you just read to the Inquiry paragraph 47
 22 of your statement.
 23 A. For the first two or three months of the pandemic, my
 24 mum may as well have passed away. We had no contact
 25 with her. We didn't know how she was. It was just us

25

1 phoning and asking a couple of questions. Mum just
 2 disappeared from our lives all of a sudden. My dad
 3 would phone the care home and get information. My only
 4 complaint would be that they didn't tell us enough
 5 information.
 6 Q. I don't want to pre-empt what your father is going to
 7 say, but one of the points he makes in his statement --
 8 I am sure you have seen his statement -- is that he
 9 would phone -- indeed, you, presumably, also phoned --
 10 and the response generally from the care home -- and
 11 I don't think you are being critical of them in this
 12 regard -- was that you would just be told that your mum
 13 was fine.
 14 A. Yes, and you understand they were saying that, but
 15 I would always argue that she is not fine, she's got
 16 dementia. Dementia is affecting my mum every single
 17 day. I don't know how much longer we have left with my
 18 mum. I need to know: how much has she drank today? Has
 19 she been able -- like, not to go into too much detail
 20 about my mum, but I need to know information about my
 21 mum. She's got a disease that is killing her. She is
 22 not fine.
 23 So that -- yes, that was very frustrating, and it
 24 made you sometimes feel like a nuisance, like phoning
 25 all the time. But I just needed to know how mum was.

26

1 Yes. I just -- sorry.
 2 Q. Just on that. That is your perception, or possible
 3 perception, that you were being a nuisance.
 4 A. It's --
 5 Q. Were you ever felt to be a nuisance?
 6 A. Sorry?
 7 Q. Were you ever felt like you were being a nuisance by
 8 contacting the care home?
 9 A. No, I would definitely say that. I didn't ever -- the
 10 care home never made me feel like a nuisance; I felt
 11 like I was maybe being a nuisance because I was phoning
 12 all the time, or as a family, and you just had to
 13 understanding of that, because there wasn't families in,
 14 they were being stretched to look after all the
 15 residents, so you felt like you were adding an extra
 16 pressure onto them that wouldn't be there normally if we
 17 were in the care home.
 18 Q. You then in your statement tell us about restrictions on
 19 visiting, and you tell us a little bit about the
 20 pre-pandemic situation, and I think you have told us
 21 about that already.
 22 A. Yes.
 23 Q. Several members of your family could go. You could have
 24 events, effectively, parties when it was appropriate,
 25 and you would be able to see how your mother was during

27

1 all that period.
 2 A. Yes.
 3 Q. I think one of the concerns that both you and your
 4 father had after the pandemic struck and the
 5 restrictions were put in place was that you were
 6 concerned that your mother wasn't just sitting in her
 7 room all day or sitting in a chair all day. Does that
 8 sum up, perhaps, very simply, one of your concerns?
 9 A. Yes. Yes. That's -- again, just to bring it back to
 10 the reason why she was in the care home was dementia,
 11 and there is not a cure for dementia, but keeping her
 12 stimulated, in my opinion, helps me think that I am
 13 maybe keeping my mum here a lot longer, so that
 14 stimulation that she didn't get.
 15 Q. Right.
 16 Going back slightly, your mother's care home closed
 17 down in mid-March 2020; is that right?
 18 A. Yes.
 19 Q. I think you were told that they were closing as
 20 a precaution, and this was prior to the rest of society
 21 being locked down.
 22 A. Yes.
 23 Q. I think you can date it because it was very close to
 24 Mother's Day.
 25 A. Yes.

28

- 1 Q. There was, as I understand it, a Facebook page
2 established in an attempt to maintain contact, but was
3 that of any benefit to your mother?
- 4 A. No, and that's -- I think you have hit the key point
5 there. A lot of times there is the impact about me and
6 how it affected me, but me seeing pictures of my mum,
7 okay, I can see her, but my mum still had no contact
8 with her family. Even though we were able to see that
9 she was in the day room and participating in activities
10 or whatever, my mum was still shut off from her family,
11 so it didn't matter how many pictures we would see.
- 12 Q. I think you say precisely, in paragraph 53, that this
13 just wasn't working for your mum; whether it was
14 Facebook or whether it was a video call or FaceTiming
15 her --
- 16 A. Yes.
- 17 Q. -- it didn't work for her.
- 18 A. No. No. None of it worked. Technology didn't work for
19 my mum. She needed someone to be in the room with her.
20 I will repeat that as long as I ever need to. That's
21 the only thing that would have worked for her to have
22 any sort of connection with anyone.
- 23 Q. I don't want to cause you any particular pain,
24 Ms Hamilton, but we are looking at impacts, and
25 obviously the principal impact is on your mother, but we

29

- 1 are also looking at impacts on you and your family.
2 How did you feel when you were unable to gain some
3 sort of personal contact with your mother during this
4 period?
- 5 A. You feel you've let her down. I remember, pre--mum going
6 into a care home, lying in bed with her one night, and
7 she was -- seemed scared and shouting out, and I was
8 like, "Don't worry, mum, I will always protect you".
9 So I remember when my mum went into the care home,
10 and I remember that first day, leaving to go home.
11 Absolutely horrific, thinking that I'd let my mum down
12 that we weren't able to keep her at home. And then for
13 us then to have that impact again, that she was in the
14 care home and we weren't even allowed to be in and be
15 with her. It's just horrific for someone to be
16 non-verbal and not able to communicate to not be allowed
17 to be with her family, just because of where they lived.
18 It felt like I had let her down.
- 19 Q. Did you feel guilty about it?
- 20 A. Yes, because we -- part -- yes, I feel guilty about it,
21 but I feel like also we did everything we could as
22 a family. That goes back to what I said about our hands
23 were tied behind our back. So I feel guilty, but I feel
24 like I have also -- I have fought tooth and nail for my
25 mum to try and do what I can for her.

30

- 1 Q. Now, looking at the effect on you -- the effect on your
2 mum, obviously, we can only really surmise that, but you
3 do so from an informed perspective.
- 4 A. Yes.
- 5 Q. You had been with your mum for many years suffering from
6 dementia, so you knew, probably better than anybody --
7 possibly your father may have known a bit better, but
8 you probably knew better than anybody how your mother
9 was reacting, and in this period that we are talking
10 about when you weren't able to see her, weren't able to
11 talk to her, have any physical contact with her -- and
12 I appreciate it is probably a surmise -- how did you
13 feel that your mother was reacting to it? How do you
14 think she felt about it?
- 15 A. I remember writing a blog about it from -- trying to --
16 from my mum's perspective, and the words I kept using is
17 like "I hope" -- "I feel abandoned". Those faces that
18 she knew that were visiting her all the time just
19 disappeared. We don't know if she understood why they
20 weren't there, so the only way I can think is she must
21 have felt abandoned from the familiarities that we used
22 to bring in visiting her.
- 23 Q. You first saw your mother again in August 2020, so
24 several months on from March, and this was in what you
25 term a garden visit.

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- 1 A. Yes.
- 2 Q. That was obviously arranged with the care home. Was
3 that at your behest or did the care home invite you to
4 it or --
- 5 A. That was --
- 6 Q. -- how did that occur?
- 7 A. That was just the guidance was now allowing garden
8 visits, so then it was just widely known that you could
9 be able to see someone in a garden.
- 10 Q. Paragraph 55 you say:
11 "The garden visits were horrendous."
12 And you give some explanation of that. Can you
13 explain why they were horrendous?
- 14 A. So within mum's care home, although they were calling
15 them garden visits, they weren't garden visits; they
16 were at the entrance to the care home. Part of me is
17 like: yes, okay, I get that, because they were able
18 to -- like, during the cold months, the resident was
19 able to be -- or my mum was able to be inside the
20 care home, so keeping herself warm. But there was no
21 privacy in it. Because it was at the entrance of the
22 care home as well, staff could come in and out while you
23 are trying to have -- can't even call it private, but
24 have a moment with your mum. But then it was also she
25 was still having to be 2 metres apart, like I stated

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1 earlier . She was in a wheelchair, hunched down, face on
2 the ground pretty much, and I am having to shout at her
3 like this . And she can't speak to me either, she can't
4 do anything, so you are just shouting at my mum. That's
5 all the visits entailed of. The only thing you could
6 get from it was: at least she is hearing my voice.

7 But, again, it's what I go back to with the video
8 calls . She is hearing my voice, but she's not able to
9 realise where it's coming from. When I'm next to her,
10 holding her hand, I can get her, "I am here, mum, I am
11 here". But if I'm shouting at her, she's not able to
12 really grasp where I am.

13 Q. One of the points you make is that there was a lack of
14 privacy.

15 A. Yes.

16 Q. Again, can you give some context to that.

17 A. Especially when the garden visits first started,
18 a member of staff had to be present during the full
19 visit . I don't know if that was a care home — from my
20 campaigning, I know that happened across a lot of
21 care homes as well, but it made you feel like you
22 weren't trusted. But I was trusted to be alone in my
23 mum's room pre-pandemic. So it just made you feel like
24 that, like: we need to watch you in case you do
25 something wrong to infect the care home. It made you

33

1 feel like you were just not trusted to be with your
2 mum — with my mum.

3 And just the fact that you were just out in this big
4 open space with all the windows, and people could just
5 look at you, and staff could come and go, and you maybe
6 had someone waiting for their garden visit on the bench
7 next to you. So it just wasn't private at all .
8 Especially after all those months of being kept apart,
9 for your first contact or you're first able to try and
10 reconnect within someone to be in that manner, there was
11 to privacy at all , it just — yes.

12 Q. Presumably in these visits you would want to exchange
13 personal information, even if your mother perhaps
14 couldn't understand it.

15 A. Yes.

16 Q. And you would want to disclose things to her, you would
17 want to be intimate with her.

18 A. Yes.

19 Q. And these were denied to you.

20 A. They were denied to us. We couldn't do that, but staff
21 where able to wheel her in, sit next to her, talk to
22 her, "Your husband and daughter are here", but we were
23 the ones that had to keep back.

24 Q. How did that make you feel, that you would have a member
25 of staff accompanying your mother in that situation?

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1 How did that make you feel?

2 A. I felt sorry for the member of staff as well, to have to
3 be in that awkward environment, but I also remember my
4 first visit , I wanted to walk away. My body was trying
5 to get — my feet were glued to the ground for my dad's
6 sake, but I felt humiliated that my first contact with
7 my mum was in this so-called garden visit environment,
8 with a member of staff watching over me, and it just
9 felt like: what is going on? Why all of a sudden
10 am I not allowed to be my mum's daughter? Why
11 am I being looked at in this way?

12 Q. Now, we know that your mother sadly died in
13 November 2021. You weren't with her when she died.

14 A. I was waiting my turn, to put it ...

15 Q. I think your dad was with her.

16 A. My dad and my sister. I got — I was up in my in-laws'
17 house because I wasn't able to enter the care home until
18 a certain point. I had to take a PCR test, a COVID
19 test. And I got to my mum's room and opened the door,
20 and my dad was frantic, and I looked at my sister and my
21 sister just nodded at me, and I had missed being with my
22 mum by seconds because we had to stagger who was coming
23 into the care home.

24 Q. You tell us about that at paragraph 61. I am sure it is
25 upsetting for you and I won't ask you any more questions

35

1 about it. Thank you.

2 Can we talk about essential visits , please.

3 Paragraph 62 your statement.

4 Now, can you just tell us a little bit about what
5 your understanding was in relation to what are termed
6 essential visits ?

7 A. So I was made aware of essential visits around about
8 possibly September 2020 by someone who worked in
9 Alzheimer Scotland, and she made me aware that, "No,
10 actually, you should be getting in or your mum should be
11 having essential visits because they are there for
12 distress and end of life , and your mum's dementia is
13 definitely causing her distress". But that wasn't made
14 widely, commonly known to anyone. I only happened to
15 know through all my campaigning, and this person
16 happened to get in touch with me and say, "Look, no, you
17 need to use this".

18 And when I got in touch with the care home to ask —
19 and I kick myself all the time for this, because I was
20 just trying to comply to the rules — and I emailed them
21 asking, "Are you aware of essential visits?", and they
22 said they were aware of them. I asked, "Are you doing
23 them?" They said no. I was like, "Well, how are you
24 making sure that — somebody might be — somebody might
25 be qualified for an essential visit ", and they said that

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1 they are assessing everybody every single day, and I get
 2 annoyed that at that point I didn't push for it .
 3 Q. Yes. I think you say that, that you were told that,
 4 I think, no one qualified for such visits .
 5 A. Yes.
 6 Q. And you're saying, with the benefit of hindsight, you
 7 wish you had pushed harder on that.
 8 A. Yes.
 9 Q. Was one of the reasons why you didn't push harder on it
 10 because you didn't really know about it?
 11 A. I didn't know too much about it. I didn't know --
 12 I didn't know the rules. You have got that fear -- not
 13 fear, maybe the wrong word, but you don't want to rock
 14 the boat. I can't get in to see my mum, so you don't
 15 want to upset the people -- and that's not me saying
 16 that anything bad had happened to her, but you don't
 17 want to upset the people that are looking after your mum
 18 when you are not able to get in there. So sometimes you
 19 just: okay. But then -- and you are so exhausted by
 20 fighting all time that sometimes you just accept
 21 an answer, and -- yes.
 22 Q. So on your part, was there a sort of passive acceptance
 23 of the situation, rather than arguing about it, if I can
 24 put it that way?
 25 A. Yes. Yes. As I say, I kick myself and I hate the fact

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1 I didn't push for it, but possibly at the time it was
 2 just exhaustion of everything you had to try and do to
 3 fight. You're like: okay, well, that is another door
 4 shut, I thought this might have been a way in but
 5 clearly it's not.
 6 Q. I think it is at paragraph 67 of your statement that you
 7 say that you came to understand that essential visits
 8 could be for end-of-life care, or an end-of-life
 9 situation, and/or if the resident was distressed.
 10 A. Yes.
 11 Q. Obviously it came to a point where your mother was
 12 unfortunately in both of those categories.
 13 A. Yes. So that is -- I had almost medical evidence to
 14 back up the -- despite the fact mum had dementia, that
 15 is medical evidence in itself she is distressed and she
 16 should have someone with her, but we had a doctor who
 17 had had a look at my mum's health at that point and she
 18 said, "I do think your mum is end of life", and that was
 19 an understanding that it doesn't mean it's the next
 20 couple of weeks; it could be this is her slowly starting
 21 to pass away. So that was a year before my mum passed
 22 away, actually.
 23 Q. You became obviously -- and we have heard this from you
 24 in your evidence you gave ten days ago -- part of the
 25 Care Home Relatives group, and at paragraph 68 you say

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1 that you contacted two individuals -- and, again, I ask
 2 you at this stage not to name them -- and you, as
 3 I understand it, were suggesting that the guidance
 4 should be changed and become more prominent. Can you
 5 explain the reasoning behind that.
 6 A. The video that my dad took was quite distressing, and
 7 I can't believe it took for us to have a GP say, "Your
 8 mum is end of life" for us to get essential visits. And
 9 I took a part of the responsibility, actually, that if
 10 you are part of a campaigning group and I have these
 11 contacts with these people, I felt, like, an obligation
 12 to say: look, this is somebody that wasn't getting
 13 essential visits; you think you have written a guidance,
 14 you have put it out there, you have to actually see if
 15 it is following through, you have to actually see if it
 16 is working; this isn't working, I am telling you this,
 17 and here is the evidence I can show you from a personal
 18 point of view. And I felt like they had to know that
 19 because I do think it can be quite -- I don't want to
 20 say this in a bad way, but it can be quite easy to write
 21 guidance and put it out there and think you have done
 22 your bit, but we have to make sure that that guidance is
 23 following through and actually working, and I felt by
 24 doing that I was showing them that something had to
 25 change again.

39

1 Q. I am not going to ask you about what you thought the
 2 terms of the guidance would be, because that is,
 3 I think, probably a fairly difficult question. Please
 4 don't take that as offensive. But I think one of
 5 the points you are making here is that the manifestation
 6 of the guidance, how that was communicated, should have
 7 been better. Have you got any suggestions how that
 8 should have been done?
 9 A. Well, I think every person that had a loved one in
 10 a care home should have known about essential visits
 11 from day one, and I don't think that was. I had to find
 12 out just because I put stuff on social media and someone
 13 I happened to know told me about it. So, yes, certainly
 14 something like that. And when guidance is put out,
 15 I think that it should be given to every -- somebody
 16 with a POA or guardianship should always be told about
 17 guidance that is there.
 18 Q. Again, looking at your feelings, at paragraph 69 you say
 19 that you feel as if you had a moral responsibility to
 20 campaign for Anne's Law -- and obviously you had started
 21 that petition by this stage -- and highlight the
 22 mistakes that were being made during the pandemic. You
 23 then went from being presumably a relatively private
 24 individual to having a public persona.
 25 A. Yes.

40

1 Q. Was that comfortable for you?
 2 A. No. No. I had to put my life out there just to try and
 3 see my mum, or for my mum to try and see someone. None
 4 of my friends were having to do that. They were able to
 5 go and visit their mums, but I feel like I was forced —
 6 yes, okay, nobody — I didn't have to do the petition,
 7 but that was just something I did one day when I was
 8 just having a really low moment about not — the
 9 situation that was happening with my mum. But it
 10 spiralled .
 11 I will continue to do it. Like, for — the other
 12 day, I walked into my daughter's playgroup, "Oh, I saw
 13 you on the TV", things like that. Like, so people
 14 I don't really share stuff with are now knowing stuff
 15 about me because I am still having to do this. I will
 16 continue to do it, but that, as you're saying, is a big
 17 impact, that I have had to really make myself more
 18 public than I would like to.
 19 Q. Yes.
 20 Paragraph 72 of your statement, I think we are
 21 talking about the arrangements for Christmas 2020.
 22 A. Yes.
 23 Q. I think this is when the then First Minister said that
 24 the country would be going into lockdown on Boxing Day,
 25 but that we could be in bubbles on Christmas Day. But,

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1 as you say, if you had somebody in a care home, then you
 2 couldn't be in that bubble.
 3 A. Yes. The First Minister stood up in Parliament and said
 4 that: "Create bubbles, but if you are visiting someone
 5 in a care home, I recommend you do not create a bubble".
 6 Didn't tell staff who were working in the care home that
 7 day, do not create a bubble, but particularly told: if
 8 you are visiting someone in a care home, do not create
 9 a bubble. Again, highlighting the impact that that was
 10 having on how families were feeling, being locked out.
 11 Why were we being treated so differently to staff?
 12 Q. Now, you probably know this, Ms Hamilton, but did the
 13 First Minister make that distinction between the general
 14 public and those in care homes when she announced this?
 15 A. The care home — sorry, the —
 16 Q. The bubbles.
 17 A. The bubbles. Yes, she stood up in Parliament and said
 18 that everybody can create bubbles, the country is more
 19 likely going to go down to lockdown on Boxing Day, make
 20 sure it is just three people — three households, if
 21 I can remember correctly. But if you were — I can
 22 visualise it: if you are visiting someone in a care
 23 home, do not create a bubble.
 24 Q. You conclude at paragraph 72 by saying:
 25 "The message about Care Homes from Nicola Sturgeon

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1 created fear."
 2 A. Yes, it just —
 3 Q. Can you just explain that.
 4 A. It just emphasised, I think, the public persona that if
 5 you visit — if you dare to think you can visit someone
 6 in a care home, you are going to put the care home under
 7 risk of putting COVID in there. That was — we had the
 8 First Minister, who was leading the country through this
 9 pandemic, standing up saying, "Do not do that", whereas
 10 we were still trying to fight to get in. But, again,
 11 I will reiterate it: she didn't tell staff to do it. So
 12 why are staff so different from the family members that
 13 are wanting to go in on Christmas Day? And that — it
 14 speaks for itself, I think. Yes.
 15 Q. Go to paragraph 75, please. Can you just read that out.
 16 I think it's a concluding comment by you on these
 17 matters of visitation .
 18 A. Many people say the guidance was there to protect
 19 care home residents. It didn't protect them. All the
 20 things that were put in place were not protecting my mum
 21 from her dementia symptoms worsening. My mum was in
 22 a care home because she had end-of-life dementia, not
 23 because of COVID. Things were not put in place for it.
 24 There is no cure for dementia. Everything was taken
 25 away from my mum. You wouldn't have taken away

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1 medication from someone — I don't know if that meant to
 2 have something else. Oh, yes, you wouldn't have taken
 3 medication away from someone who had an illness, but you
 4 took — I think what I am trying to say is you took away
 5 her family who were able to try and keep her more
 6 active, her brain, away from her.
 7 Q. Now, I am not going to ask you to go through the
 8 sections on infection control and PPE in any detail,
 9 subject to a little bit of clarification .
 10 At paragraph 79 of your statement, you talk about
 11 the first time that you got to see your mum by way of
 12 a garden visit, and you talk of humiliation. It was
 13 humiliating. Is that how you felt?
 14 A. Yes, and I think I touched on that earlier, sorry.
 15 Q. Yes.
 16 A. So that was about — actually, now I think about it,
 17 I wasn't aware that a member of staff had to sit and
 18 watch me, and I think that is why I felt humiliated,
 19 that my first time seeing my mum, I wasn't trusted to be
 20 with her, someone had to watch me, and that's again what
 21 I spoke about: I remember just wanting to leave, but
 22 because I was there with my dad, I had to support him,
 23 but I also wanted to see my mum. But it was the —
 24 I vividly remember that, feeling humiliated. I just
 25 wanted to remove myself from that situation. But

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1 I obviously wouldn't, because I wanted to see my mum and
 2 spend time with her.

3 Q. I think the final two sentences in paragraph 79, you
 4 talk about your biggest bugbear. I think I have
 5 actually counted you have got two biggest bugbears;
 6 there is another one in your statement. But your
 7 biggest bugbear, you say — well, could you read those
 8 two sentences for me.

9 A. The biggest bugbear was the difference with that member
 10 of staff who wheeled my mum out to me touching my mum.
 11 That member of staff was still able to go to their
 12 family and the shops or the pubs the next day or on
 13 holiday, but don't you dare touch your mum.

14 Q. Just to go towards concluding your evidence,
 15 Ms Hamilton.

16 Inspections, which is at paragraphs 88 through to
 17 90. You say that the Care Inspectorate should have been
 18 communicating government guidance for care homes, and
 19 you compare this to the advice for the general public.
 20 Just in relation to communication of government
 21 advice, what would you, as an affected person, suggest?
 22 How should this be done?

23 A. Maybe Care Inspectorate is not the right person, but
 24 everyone that has someone in a care home — okay, 99% of
 25 everyone that has someone in a care home will have

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1 a family member or a close relative or somebody who is
 2 an advocate. Any sort of guidance, going back, for
 3 the essential visiting that was put in place in March
 4 2020, why was that not then put — the care homes would
 5 have known about that. There should be a moral
 6 responsibility to pass that on to the care home
 7 residents as well, because there's care home residents
 8 that had their full functions on them, so they should
 9 know their rights as well, and then passing that on to
 10 the families or the people who are the closest to them
 11 to know, again, the rights for those who maybe don't
 12 have their faculties about them.

13 It felt like if you had someone in a care home, you
 14 had to fight, you had to read between the lines, you had
 15 to really go and look for it. But those working in the
 16 industry, they knew it all inside out. But it felt like
 17 it was hidden information, that: we are keeping this
 18 from you; you are not allowed to come in, but we are
 19 going to keep this information from you that might tell
 20 you how you could possibly get in.

21 Q. Just in relation to bereavement.

22 You are complimentary of the care home and the way
 23 in which they handled your mother's death.

24 A. Yes. There is obviously the run-up to it —

25 Q. Yes.

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1 A. But that is the guidance. I could speak about that all
 2 day long. But certainly when my mum passed away, they
 3 gave us all the time in the world to be there. Yes.
 4 They helped me.

5 Q. And you say they were compassionate. The staff were
 6 compassionate.

7 A. Yes. I have never once had a complaint about the
 8 care home or the care staff; it's the situation they
 9 were put in. Yes.

10 Q. Interestingly, you say in paragraph 93 that campaigning
 11 was your way of coping. Is it still your way of coping?

12 A. Yes, so that is why I am a bit of a contradiction when
 13 I say I would give this up tomorrow, but —

14 Q. I get the impression you wouldn't.

15 A. Not until I have got Anne's Law put in place. No. It
 16 has certainly been a blog since mum was diagnosed at the
 17 age of 56, and it has been some form of counselling. It
 18 is a way for me to get out how I'm coping with it.
 19 Definitely, yes.

20 Q. Now, we dealt with Anne's Law when you gave evidence,
 21 but I would just like to take a couple of points that
 22 you have made in your statement.

23 At paragraph 95, about halfway down, just below
 24 halfway in that paragraph, you felt the petitions
 25 committee did not grasp what was happening at

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1 grassroots, and:

2 "Once again it felt like everything we were saying
 3 fell on deaf ears."

4 Can you tell me why you felt that?

5 A. Because it felt like there was guidance there, so
 6 everything should be fine. But we were the ones living
 7 it. We were the ones trying to fight for it. We are
 8 telling you that, although there is guidance, it is not
 9 working.

10 I got to a point where I was like: do people think
 11 I am enjoying just going to these meetings and shouting
 12 and making noise? No. If it was working, then you
 13 wouldn't be hearing from me. There is a reason why we
 14 have had to have petitions. There is a reason why
 15 families are having to do this. But it felt like we
 16 were the ones that weren't being listened to. We were
 17 the ones that weren't allowed in. We were the ones that
 18 weren't being listened to. Everybody that works in the
 19 industry gets a say, but we don't get a say. Nobody is
 20 listening to our — the realities of what we were living
 21 through, is what that felt like.

22 Q. You make the point in paragraph 96 that the party of
 23 government committed to Anne's Law in its manifesto, but
 24 what we have at the moment in the bill that we look at
 25 last week is not Anne's Law as you understand it.

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1 A. No. Again, the former First Minister stood up and said
 2 in September 2020 — sorry, I can't remember the year,
 3 but that Anne's Law will be put in place to allow
 4 care home residents to have — care home relatives,
 5 sorry, to have access in the same way as staff do. That
 6 is not what is in place at the moment. So until that is
 7 what is in place, we will have to continue fighting for
 8 it .

9 Q. Can I take you to paragraph 98 of your statement, which
 10 is "Problems with the Pandemic Response". Would you
 11 just read that through, because I think that is, in many
 12 ways, a culmination of a lot of the things that you have
 13 said.

14 A. So the biggest thing to me during the pandemic would be
 15 if my dad would have got in. All I wanted was for dad
 16 to see his wife and vice versa. I just needed to know
 17 mum was okay. I was at home with my husband. I could
 18 see my pals, go for a walk. My mum was in that room,
 19 isolated from everyone who cared about her. Her life
 20 was torn to shreds. It hurt me more. It had a huge
 21 impact on my dad. There is a reason why I was welfare
 22 guardianship. Pre-COVID I was aware that mum was end of
 23 life . I feel like a baby wouldn't have been taken away
 24 from a parent in that context. My mum was very
 25 vulnerable and couldn't communicate her needs. People

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1 who knew my mum knew the cries, knew what made her
 2 happy. Another impact was that two grandchildren never
 3 got to see their gran. At a time in my mum's life when
 4 she was most vulnerable, she was separated from those
 5 who were most important to her. I feel she was
 6 discriminated against because of where she lived.

7 MR GALE: Ms Hamilton, thank you very much for giving
 8 evidence. We are very grateful to you.

9 THE WITNESS: Thank you.

10 MR GALE: Thank you.

11 THE CHAIR: Yes, thank you again, Ms Hamilton.
 12 Good. A break?

13 MR GALE: We have another witness in 20 minutes.

14 THE CHAIR: Yes, by all means. So that is just before
 15 the half hour.
 16 Very good. Thank you, everybody.
 17 (11.09 am)
 18 (A short break)
 19 (11.30 am)

20 THE CHAIR: Right. Thank you.
 21 Now, Mr Gale.

22 MR GALE: Thank you, my Lord.
 23 The next witness is Campbell Duke.

24 THE CHAIR: Very good.

25 MR GALE: The reference is SCI-WT0483-000001.

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1 THE CHAIR: Thank you.

2 MR CAMPBELL DUKE (called)

3 THE CHAIR: Good morning, Mr Duke. Thank you very much
 4 indeed. Please be seated.

5 Questions from MR GALE

6 THE CHAIR: Mr Gale, when you are ready.

7 MR GALE: My Lord, thank you.
 8 Good morning, Mr Duke.

9 A. Good morning.

10 Q. Your full name is Campbell Duke, I think.

11 A. It is, yes.

12 Q. And you are 68.

13 A. I am.

14 Q. And your contact details are known to the Inquiry, and
 15 you are a retired social worker —

16 A. Yes.

17 Q. — as you say in paragraph 2 of your statement, and we
 18 will come to a little more of that in due course.
 19 You are here to talk about your wife, Anne Duke, and
 20 we have heard this morning already from your daughter,
 21 Natasha Hamilton.

22 A. Yes.

23 Q. So we already have your daughter's perspective on the
 24 care of her mother and on the circumstances of her death
 25 in the care home.

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1 You have provided the Inquiry with a very detailed
 2 statement which extends over 42 pages, 255 paragraphs,
 3 and in the time that we have available, it will not be
 4 possible to read out all of that statement this morning.
 5 So what I intend to do is to ask you to concentrate on
 6 some of the matters that I think, from having read your
 7 statement, you are particularly anxious to get across to
 8 the Inquiry. But please be assured that all of what you
 9 have said in the statement has been and will continue to
 10 be considered by the Inquiry, and account will be taken
 11 of it.

12 I think also in an introduction, Mr Duke, it is
 13 right to say that your love for and devotion to your
 14 late wife is very apparent from everything you say in
 15 your statement. There is also the amount of detail that
 16 you have recorded incidents, and, as you say at, I think
 17 it is, paragraph 249 of your statement — you don't need
 18 to look at it — you have written a book in tribute to
 19 your wife; is that right?

20 A. Yes.

21 Q. At a meeting I had with you a few weeks ago, the
 22 Inquiry, through me, has indicated that we would wish to
 23 see and consider that book, and I think you are going to
 24 make that available to us.

25 A. Yes.

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1 Q. Right.
 2 I think it is important that we get a little flavour
 3 of your late wife. So could you be shown, please,
 4 paragraphs 238 and following of your statement. (Pause)
 5 It's taking a little time to come to that.
 6 A. Yes.
 7 Q. We will just wait until it is up on the screen. (Pause)
 8 Right, I think we have got there.
 9 This is perhaps a summary, on your part, of your
 10 wife. I am sure it is very difficult to convey in just
 11 a few paragraphs, but you set out some information.
 12 Would you read, please, 238, down to 242 inclusive.
 13 A. Anne was, for far too long, a mere statistic: a care
 14 home resident, an Alzheimer's sufferer, a COVID patient,
 15 a COVID survivor. On 13 November 2021, the system
 16 finally released its death grip on her beautiful soul
 17 and gave her back to her real family.
 18 Too little too late. Once more a beautiful wife,
 19 a mother to three daughters and a son, a granny to two
 20 grandsons and two granddaughters, with one more
 21 grandchild on the way.
 22 Once more the young woman who personally nursed her
 23 own grandmother through her battle with Alzheimer's, and
 24 on her death, Anne was inconsolable with grief, just as
 25 we were with Anne's passing.

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1 She was the woman who painted sunflowers and was so
 2 good with her hands that she became the go—to for
 3 wedding decorations. She ran and organised a playgroup.
 4 She led a teenage girls' group and taught little kiddies
 5 in Sunday school. She marched with thousands calling
 6 for social justice and an end to poverty. She danced
 7 stone-cold sober on tabletops, and her infectious laugh
 8 and love of life was a thing of joy.
 9 Ironically, she worked many years as a carer in
 10 care homes. Often she came home teary-eyed from
 11 a nightshift to sadly announce that, "Wee Aggie had died
 12 during the night".
 13 Q. Can you read also 242, please.
 14 A. As ill-health overtook her, and petty bureaucracy
 15 wrapped her in its arrogant duty of care, they robbed
 16 her of her unique beauty, her individuality. They stole
 17 her from us and it remains unforgivable. There was
 18 always somebody who knew best and what procedures to
 19 follow, but precious few who loved her.
 20 Q. Right. Well, thank you for that. I appreciate a very
 21 brief summary of your wife, and I am sure it can't do
 22 justice to her, but thank you for giving us that.
 23 I will give the team behind me a chance to go back
 24 to the start of the statement, but I will just take you
 25 through some matters without actually having to look at

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1 the context.
 2 She was your wife for 36 years.
 3 A. Yes.
 4 Q. You had four children —
 5 A. Yes.
 6 Q. — three daughters and a son, and until she went into
 7 care in 2018, she lived at home with you and you cared
 8 for her, together with your other family members.
 9 A. Together with family and friends, yes.
 10 Q. We know from your statement — that is paragraph 20, for
 11 the reference — and from the evidence of your daughter
 12 that we have heard, that your wife was diagnosed with
 13 early-onset dementia in 2014.
 14 A. Yes.
 15 Q. Although I think you say that she had displayed some
 16 worrying symptoms prior to that.
 17 A. Yes.
 18 Q. I think at paragraph 22 of your statement you say that,
 19 notwithstanding the effects of the disease, she was
 20 cognisant of who you were, and mostly amenable to your
 21 love and care.
 22 A. Yes.
 23 Q. I take it you were able to understand, from your
 24 knowledge of her, the reactions that she had to you.
 25 A. I think also we are going into the realm of Alzheimer's

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1 disease, which has its own peculiarities. I operated
 2 from a point of view that (a), first of all, being her
 3 husband of 36 years, that there was a lot there that the
 4 average person did not see, and I think it was too lazy
 5 an assumption by too many people that because she had
 6 Alzheimer's, then her cognitive abilities were so
 7 severely reduced that it really didn't matter what
 8 happened to her, and I think that had implications for
 9 the future in terms of the lockdown.
 10 Q. Right.
 11 Now, I think you remained in employment, at least
 12 for a while, while your wife had Alzheimer's.
 13 A. Yes.
 14 Q. In early stages, you continued to work, and you would
 15 devote your evenings and weekends to caring for her, and
 16 other members of your family would care for her at other
 17 times.
 18 A. Yes.
 19 Q. So, effectively, she was given, within her home, 24-hour
 20 care.
 21 A. She was given 24-hour care because that is what the
 22 medical world wanted, and we certainly as a family gave
 23 her that 24-hour care. We did, in fairness, receive
 24 30 hours per week from the social care system, but there
 25 are, of course, 160 hours in the week, so we did the

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1 other 138 hours, or certainly the lion's share.
 2 Q. We are aware, Mr Duke, from what you say in your
 3 statement, that your wife's move into a care home was
 4 not something that you wanted.
 5 A. No. Nobody in the family wanted it to happen, and
 6 I would remain convinced to this day that it didn't have
 7 to happen, but it did.
 8 Q. I think we can read your reasoning for that, and
 9 we understand your reasoning for that.
 10 Can we move on in your statement to paragraph 32,
 11 please, which relates to the period pre-pandemic of your
 12 wife's care.
 13 Summarising, if I may, it does appear that you and
 14 your family became an essential part of the care that
 15 was given to your wife in the home.
 16 A. Yes.
 17 Q. That is the care home, not your home.
 18 A. Yes, yes.
 19 Q. As you say at paragraph 32, you would be with her for
 20 four to five hours per day.
 21 A. Yes.
 22 Q. And you also say that her basic care needs were by and
 23 large normally well catered for.
 24 A. Yes.
 25 Q. Again, we have heard this from your daughter, but the

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1 understanding is — you say it in paragraph 34 —
 2 that — you say it in the general terms of:
 3 "A resident with a supportive family ... was of
 4 genuine value to the staff."
 5 But you clearly were.
 6 A. Yes.
 7 Q. And you appreciated that, and the staff appreciated
 8 that.
 9 A. I hope so. We did, and I think they did too, yes.
 10 Q. Okay.
 11 If we can just look at paragraph 40, please, because
 12 again, reminding ourselves that this was pre-pandemic,
 13 what you say in the final sentence of paragraph 40 is
 14 that the carers within the care home:
 15 "... never once said 'No you have to go, it's
 16 regulations!' They just said 'That's great thanks!'"
 17 So there was never any sort of, if I can put it this
 18 way, clock-watching of you in the care home; never any
 19 suggestion that you had perhaps overstayed your welcome.
 20 A. Not as such, no. There was a general give and take in
 21 that respect. Obviously, if I wanted to stay until
 22 midnight, that would probably have raised a few
 23 eyebrows, but I could be there from about 8 o'clock in
 24 the morning, if I chose, sometimes up until 9 o'clock or
 25 10 o'clock at night, and always at that point you were

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1 fulfilling some function, even if it was simply being
 2 with Anne and thereby allowing staff to do something
 3 else. So it was a good team working.
 4 Q. Yes.
 5 It may seem a blindingly obvious question to you,
 6 Mr Duke, but why did you want to spend so much time with
 7 her?
 8 A. Because I loved her. She was my wife. I can only give
 9 the blindingly obvious answer to that, but I appreciate
 10 the question.
 11 Q. I think also probably because you would know her and
 12 have an appreciation of the subtle signs that she could
 13 give to you.
 14 A. Yes. Yes. And there was plenty of evidence of that.
 15 Even if it was only me that was reading those signs, it
 16 didn't matter. She was responding to me, and I could
 17 respond to her, in a way that only couples could
 18 understand, and many of us here in this room would
 19 understand that.
 20 Q. I think you summarise this really in paragraphs 41 and
 21 42, where you say you were only too happy to help, and
 22 then in paragraph 42 you say:
 23 "We were NOT just there as visitors. We were WITH
 24 Anne. We were a vital part of Her Care Team."
 25 A. Yes.

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1 Q. That was your perception.
 2 A. That was my perception, obviously based historically on
 3 the fact that, until the point when she came into the
 4 care home, we were the care team, and therefore we felt
 5 it was very important that our contribution be
 6 recognised as being vital. And in many ways, we saw the
 7 care home as an adjunct to the care we had already been
 8 providing. It wasn't something we had wanted as such,
 9 but given that it was there, we were prepared to enter
 10 into a new negotiation with them and work as a team to
 11 continue to care for Anne in the same way as we had been
 12 caring for her.
 13 Q. You call it an adjunct; perhaps another way of
 14 describing it, so far as you were attempting to do,
 15 would be to see it as a continuum of the level of care
 16 that she was receiving at home.
 17 A. Yes. Yes.
 18 Q. Right.
 19 Could you go back to paragraph 36, please, within
 20 the statement. Again, we touched on this slightly with
 21 your daughter earlier this morning, but you tell us
 22 there some of the things that you could do with and for
 23 Anne, and I think we see she required, as you put it,
 24 direct personal intimate experience.
 25 A. Yes.

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1 Q. And she also needed to be touched, cuddled, embraced,
2 whispered to, and to be engaged in eye contact.
3 A. Yes.
4 Q. And you say she responded to that and, as you put it:
5 "We had a continuing meaningful relationship given
6 that she had such a significant illness."
7 A. Yes.
8 Q. We have heard already in the Inquiry, Mr Duke, the
9 importance of sensory contact for dementia sufferers.
10 A. Yes.
11 Q. So you can take it for granted that we are aware of
12 that. It's not something that comes as a surprise or
13 seems slightly unusual. We are aware of that.
14 Could you go to paragraph 48, please. You put it
15 there -- and this is just pre-pandemic --
16 A. Yes.
17 Q. -- December 2019:
18 "... apart from the dreadful scourge of the
19 Alzheimer's that continued to exact its dreadful toll,
20 we had reached an accommodation with Anne's reality and
21 were working in tandem with the care staff."
22 Can you just explain to us what you mean by
23 "an accommodation with Anne's reality"?
24 A. I think I would go back to the word you used: continuum.
25 Anne was still the same Anne that was living with me

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1 before she entered into the care home, but she had
2 changed because of the Alzheimer's. If circumstances
3 for whatever reason dictated that she ended up in
4 a care home, it was still the same Anne and, therefore,
5 we continued to work, and as a family we were looking at
6 how the care home was an extension of the things we had
7 been doing.
8 There was nothing, with all due respect to the
9 care home, that they were doing for Anne that we had not
10 been doing a whole range of her life: incontinence care,
11 feeding, washing, recreational. We were doing that
12 before she went into the care home. There was nothing
13 exceptionally different that the care home were doing
14 for Anne that we had not been capable of doing. It is
15 just a different location.
16 Q. Okay, thank you.
17 Can we move on to the event of and after March 2020.
18 Can we go to paragraph 52, please. I think you say
19 there what confronted you on 13 March 2020, when you
20 found the door to the care home locked, and -- well,
21 both doors to the care home locked, and eventually
22 somebody came out to see you, and that person said to
23 you, "You can't come in, we're in quarantine, no one's
24 allowed in".
25 A. Yes.

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1 Q. Obviously there had been some widespread awareness of
2 the impact of the virus prior to that. Was that
3 situation that confronted you on 13 March a surprise to
4 you?
5 A. It was. Not in the sense of there was a virus stalking
6 the land, but finding the door locked was my first
7 understanding that matters had got serious within the
8 care home.
9 Q. You weren't alerted to that in advance?
10 A. Not to that particular issue, no. I went in the full
11 expectation of being able to visit that night.
12 Q. Paragraph 54, you say that you were informed that they
13 were in lockdown.
14 A. Yes.
15 Q. "... and that if they let me in, [you] would spread the
16 virus and they would be sued."
17 Is that what you were actually told?
18 A. Yes.
19 Q. That is not an impression that you got from --
20 A. No, it's not an impression. That is a fairly accurate
21 rendition of what I was told. I remember it distinctly.
22 And it wasn't the last time that something of that
23 nature would be said.
24 Q. I think you go on to say that this was not untypical of
25 the superficial though certainly stigmatising attitudes

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1 towards relatives that almost immediately took root.
2 A. Yes.
3 Q. So that was something that continued, in your
4 experience?
5 A. I think it did throughout the duration of the lockdown
6 from the top down. There was a simple message that
7 seemed to be given that: we have a serious situation
8 here; we will fix it by banning the relatives, sorted.
9 Q. At paragraph 55, you indicate that it was seven months,
10 from 13 March to 29 October 2020, that you were not
11 allowed back into the care home.
12 A. Yes.
13 Q. As I understand it -- and, again, it is something that
14 your daughter has also spoken to -- in that period, the
15 onus was on you to contact the home to obtain
16 information about your wife.
17 A. Yes.
18 Q. If you go to paragraph 58, please, you give the
19 impression there that there was an almost stereotypical
20 conversation between you and the care home, which would
21 begin with you making an enquiry as to your wife's
22 condition and health and general well-being, and you
23 would simply be told that she was fine.
24 A. "Fine" was the operative word. Yes.
25 Q. What would you have liked to have been told? What

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1 amount of detail would you have liked to be told about
 2 your wife during that period?
 3 A. I mean, we were aware that the care home staff were
 4 under a great deal of pressure, but the word "fine"
 5 seemed insufficient. I wasn't necessarily expecting
 6 a full bulletin, but perhaps some description of what
 7 she had done with her day, how was her health in
 8 general, because she wasn't simply being secluded from
 9 Coronavirus; she was a woman who was in a care home
 10 because she had Alzheimer's disease, and that continued
 11 to work its way through her, notwithstanding the virus,
 12 and therefore we were still keen to know how she was
 13 coping with Alzheimer's. Was she generally okay? Was
 14 she being given one-to-one time, or was she spending the
 15 bulk of her time -- which was our fear -- on her own,
 16 which was just a dreadful thought.
 17 Q. That would presumably be a fear for you as well.
 18 A. A huge fear. The guidelines from -- the Scot Gov
 19 guidelines at the time from March and May were making it
 20 quite clear that they were encouraging the care homes to
 21 seclude care home residents in their rooms, and I could
 22 kind of understand the reason for that. But for
 23 somebody who was really needing intimate contact and
 24 touch, the concept of her being stuck in her room, with
 25 maybe the Alexa turned on loud perhaps, was unthinkable,

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1 but was quite probably happening. And I am not meaning
 2 that as a criticism of the care home staff. They were
 3 not -- there were not enough of them to give Anne the
 4 four to five hours a day that I had been giving her, and
 5 other relatives and friends as well. So it was a worry.
 6 Q. I think you say in paragraph 59 that this situation was,
 7 in your view, highly unsatisfactory.
 8 A. I think it was absolutely unsatisfactory. Yes.
 9 Q. During this time, obviously, you were not aware of what
 10 was happening within the care home, so far as your wife
 11 was concerned, but you knew, as you say in paragraph 61,
 12 how this would impact on her cognitive activities and
 13 overall health.
 14 A. Yes.
 15 Q. Now, you told us at the beginning of your evidence that
 16 you are a retired social worker. Were you able to bring
 17 to bear any of your knowledge and experience as a social
 18 worker to the situation that you knew your wife was
 19 likely in?
 20 A. I tried not to because it wasn't a speciality of mine,
 21 but yes, I mean, I was aware of it from some of my
 22 training, some of my work. I was anxious to explain to
 23 the care home that I was the anxious husband. That was
 24 my speciality. But we were aware.
 25 And even if we had not been aware, I think the other

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1 thing that the care industry -- the care home industry
 2 needed to start understanding much quicker was that the
 3 relatives as a group, around the country, were a good
 4 cross-section of society with a lot of professional
 5 experience and, if not, access to the internet, and we
 6 were fast becoming a group of people who were cluing up
 7 on Coronavirus and how it might affect and impact on
 8 people's mental health. So we knew that there were
 9 serious risks, and everybody knew that there were
 10 serious risks.
 11 Again, I go back to the Scot Gov guidelines that
 12 were issued in March and May in particular were saying
 13 to the care homes: there will be a risk to your
 14 residents' mental health, and you should be looking at
 15 individual needs-led assessments to perhaps even at that
 16 the early stage determine the need for essential
 17 visitors, but it never happened.
 18 Q. As I said to your daughter a little while ago, we are
 19 obviously looking at the impacts that the pandemic had
 20 on your wife, but we are also looking at the impact it
 21 had on you as a wider family --
 22 A. Yes.
 23 Q. -- and some of the reactions that you had.
 24 If you go to paragraph 68, you indicate there that
 25 you could have insisted that you stayed, and you say

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1 that you were pretty certain that if you had done that,
 2 the police would have been called. Sorry, that is in
 3 67.
 4 You go on to 68, and you say that you did not wish
 5 to offend the staff. If you had caused a scene:
 6 "... I am sure the Care Home manager would have
 7 decided that, even in these extreme circumstances,
 8 I would not be allowed back to see Anne, and it would
 9 have been counter productive."
 10 You say:
 11 "Yet I still feel The Guilt and it will never [go]."
 12 A. Yes.
 13 Q. Just tell me about the guilt you feel.
 14 A. I suppose a natural instinct, if I just talk about, you
 15 know, a couple, a man and a woman, who love each other
 16 deeply. If I had been out somewhere and a speeding
 17 truck was to come towards my wife, I might be inclined
 18 to jump in its path to protect her. I don't want to
 19 sound overly dramatic. The urge to care for and protect
 20 somebody you love is so powerful that I am sure
 21 everybody in this room and elsewhere will understand,
 22 and yet you found yourself having to be very wary of
 23 stepping in because there was this power imbalance
 24 between the family and the care home. What had hitherto
 25 been a reasonably good working relationship suddenly

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1 became one that was fraught with difficulties .
 2 I couldn't be sure if I was to second—guess the staff
 3 and perhaps make a nuisance of myself by every second
 4 day phoning the manager to say, "Blah, blah, blah", then
 5 the staff would inevitably, I think, in all fairness to
 6 them, become a bit weary of me, and indeed if I had been
 7 forcing the issue and said, "I am not leaving",
 8 I understand that probably officers of the law may have
 9 been required to come and remove me from the building,
 10 and it wouldn't have gone down well.

11 In other words, I was learning quickly that we had
 12 to learn to be compliant. That didn't help me, and it
 13 certainly didn't help Anne, but it made sure that the
 14 regulations, as dictated from on high, were able to
 15 operate easily because we all obeyed them.

16 Q. At paragraph 69 of your statement, you set out a long
 17 quotation from a letter that was sent from your wife's
 18 GP —

19 A. Yes.

20 Q. — which you received, and we have heard about that from
 21 your daughter and she quoted part of that, so we have
 22 got that quotation.

23 But you take the matter on a little more, in that
 24 you go on to talk about DNR. As I understand what you
 25 say in your statement, you saw that letter as almost

1 an implied requirement that you should, in relation to
 2 your wife, agree to DNR.

3 A. I think it was very subtly put, but the implication was
 4 there. And I think if you weren't totally aware of
 5 the situation or, indeed, what DNR really was, or if we
 6 hadn't been aware of the fact that — we as a family had
 7 had a meeting with staff previously and had made it
 8 quite clear in framing an anticipatory care plan that we
 9 did not and would not consent to signing DNRs.

10 Therefore, it being requested again in a letter, which
 11 I think is the one that uses various other comments such
 12 as — yes, "it will result in a number of deaths", that
 13 was quite a heavy emotional statement to come from the
 14 GP.

15 Now, I understand it may have been telling it like
 16 it was, but there was nevertheless a lot of weight
 17 behind that and saying: bad things are going to happen,
 18 here's the best way to handle it. And we were saying:
 19 but we've already decided we don't want to do it that
 20 way. So we had to ignore that subtle — I think it
 21 might be subtle, but maybe not so subtle — pressure to
 22 sign a DNR.

23 Q. That is certainly what you implied from it.

24 A. Yes, that's certainly what we took from it, yes.

25 Q. Interestingly, you have told us that there had

1 previously been discussions about DNR in relation to
 2 your wife.

3 A. Yes. As I was saying, when we framed an anticipatory
 4 care plan, looking to future needs for my wife, it
 5 included such matters as: would you be prepared to sign
 6 a DNR? We discussed that with the nurse, and Natasha,
 7 my daughter, was there too, myself, and we said: no, we
 8 don't.

9 Q. So you resisted and that remained your position in
 10 relation to your wife.

11 A. It did, yes. We sent a letter back saying that we will
 12 not consent to signing a DNR. If we have to have some
 13 decision taken that my wife can no longer be treated, we
 14 would prefer it to be from a doctor or any hospital
 15 setting when all else had been tried, rather than — my
 16 fear was it was going to become a default position,
 17 meaning that, amongst many other people in the care
 18 home, you then had a care home which was full of people
 19 who had signed DNRs and almost de facto would no longer
 20 be considered necessary for them to go to hospital, even
 21 if medically it might have been a good idea.

22 Q. You go on to tell us that on 10 April — this is
 23 paragraph 74 — you discovered through social media that
 24 there was a COVID outbreak in Anne's care home, and
 25 I think you were told that that was COVID downstairs.

1 I think your wife was upstairs —

2 A. Yes.

3 Q. — in the care home. I think you were told that nobody
 4 in her unit had COVID.

5 A. Yes.

6 Q. However, thereafter, there was some concern about your
 7 wife's condition, and due to her blood sats, which were
 8 at 92%, there was a proposal that she be admitted to
 9 hospital as a precautionary measure. That, in fact,
 10 didn't happen, I don't think.

11 A. No.

12 Q. I think she was — was that the occasion on which she
 13 did get into an ambulance and the paramedics took the
 14 view that it wasn't necessary?

15 A. It was the care home on 13 April that had called for
 16 an ambulance to attend at the care home because of the
 17 blood sats being low. Our difficulty was that we were
 18 of course behind the curve, on the wrong side of the
 19 telephone, after the event, so to speak, and we were
 20 only hearing about whatever discussions took place
 21 between care home staff and the attending ambulance
 22 crew, who no doubt were also speaking to some doctors at
 23 the hospital. The end product was they decided that my
 24 wife would not be admitted to hospital that day.

25 We are never sure to this day yet whether that was

1 because she was no longer medically needing to be taken
 2 into hospital. That can happen, even though somebody
 3 had called for the ambulance. Or ... well, I mean, our
 4 fear — we were talking about this is my lived
 5 experience, so our fear was there was some kind of
 6 subtle decision that: well, it's somebody who is frail
 7 and living in a care home, and maybe didn't merit — if
 8 they were triaging for some other reason at the
 9 hospital, didn't come up high on the list of priorities
 10 for hospitalisation, therefore she stayed in the
 11 care home. And, you know, we could not be sure. We
 12 don't think the care home could properly answer that
 13 question. We never did quite get to know exactly why
 14 she wasn't taken to hospital.

15 Q. I think at paragraph 78 you quote from an email that you
 16 sent to the care home about this matter. Perhaps you
 17 would just read the terms of that email, please.

18 A. I emailed the care home saying:
 19 "[Regarding] Anne Duke you will be aware we have
 20 been advised today that Anne has been refused hospital
 21 admission despite there being concerns re her oxygen
 22 sats. We greatly appreciate the nurse who has updated
 23 us. However, we feel it is unfair on her to have to
 24 deal with patient care AND liaise with families at such
 25 a difficult time. We have not been approached by any

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1 medical doctor and this decision seems to have been
 2 taken without the courtesy of consulting with Ms Duke's
 3 family. Is there a member of your team who can give us
 4 a more detailed feedback today? Thank you ..."

5 There was one final sentence: I did not receive any
 6 feedback from management, although I think it was the
 7 weekend. Bizarrely, they did not work at the weekends.

8 Q. Did you ever get a satisfactory explanation of that, or
 9 response to that?

10 A. No. Now, in fairness to the care home, we probably
 11 didn't pursue it. Now we come back to the guilt thing
 12 again, because we didn't want to keep pushing that
 13 issue. But we had made it clear to them: if she falls
 14 ill again, we really do expect her to be taken to
 15 hospital, unless somebody can speak to us directly and
 16 give us a medical reason why it was not indicated.

17 Q. You do make a suggestion in relation to this and in
 18 relation to communication in paragraph 80 of your
 19 statement. You say:
 20 "... I feel they [the care home] should have had
 21 an additional seconded member of staff, to co-ordinate
 22 such matters. They could be in the room noting the
 23 circumstances and they could feed back to the family.
 24 I appreciated that if there was a nurse on the floor
 25 dealing with a crisis and then someone buzzes because

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1 they need to go to the toilet then that cannot be
 2 helpful. Staff must have been under constant pressure."

3 A. Yes.

4 Q. I think you appreciate the pressure that staff were
 5 under.

6 A. We knew the pressure that staff would be under because
 7 we had been living with and working with them for two
 8 and a half to three years before the pandemic struck,
 9 and to the best of my understanding, there had been no
 10 change in their staff numbers. So they lost all the
 11 input — the valuable input — from families, they were
 12 dealing with all the extra precautions and risks
 13 associated with COVID, and they simply would not have
 14 had the time to do that, and I wondered why perhaps the
 15 government — there seemed to be a lot of money for
 16 furloughing, etc — why the government could not perhaps
 17 have given some money to care homes to employ some extra
 18 staff. My understanding was none of that happened in
 19 care homes.

20 Q. Going on to paragraph 88, on 17 April, your wife tested
 21 positive for COVID.

22 A. Yes.

23 Q. You were subsequently informed that she had been
 24 admitted to hospital on, I think, the 24th.

25 A. Yes.

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1 Q. Again, perhaps I am an expert on the blindingly obvious
 2 questions, Mr Duke — I apologise for that — that must
 3 have been a very worrying period for you?

4 A. I mean, it was. We were aware that it was a global
 5 pandemic and, in that sense, we were not unique, and yet
 6 my relationship with my wife is unique. Therefore,
 7 I felt quite entitled to be terribly worried about it,
 8 as I should have been. It was very, very hard. It was
 9 that same instinct that I mentioned earlier, where under
 10 normal circumstances your wife is taken seriously ill
 11 and rushed to hospital, what do we do? We rush to
 12 hospital. Instead, we are told: stay where you are.
 13 And I appreciate that was happening to everybody, but it
 14 doesn't lessen the fact that it was a dreadful
 15 experience have to undergo, and we had to consult over
 16 the telephone, and usually, again, after the fact. We
 17 were just catching up, and always just worrying that she
 18 could be dead before we make the next phone call.

19 Q. What was the level of communication you received about
 20 her condition during that period?

21 A. From the hospital?

22 Q. Yes.

23 A. Not much better than was given by the care home, but the
 24 hospital appeared to have more time for us when we
 25 phoned them. So we quickly — she was in hospital for

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1 14 days, and we quickly developed a routine of phoning
2 three times a day. We divvied it up between children
3 and me and phoned morning, afternoon and evening, and we
4 usually got just a bit more information. She was on
5 oxygen, antibiotics and IV fluids, and they would
6 explain to us how she had been during the day, and
7 certainly we got more information from the hospital than
8 we often did from the care home. But it remained the
9 case, understandably, we weren't allowed to go see her.

10 So, you know, as -- in a situation where she nearly
11 died -- on the evening she was taken into the hospital,
12 the doctor had told me, "Be prepared for bad news",
13 which I took to mean, "Your wife is going to die",
14 because they had said to me, "We will not intubate, we
15 will not take her into intensive care, she is too
16 frail". So I certainly expected her -- all the evidence
17 that I had before me was saying: Anne is going to die
18 tonight. And so you find yourself sitting at home with
19 your mobile phone, praying that it doesn't ring, and
20 fearful that it would.

21 Q. Yes, I understand that.

22 Eventually, you did receive some heartening news.

23 A. Yes.

24 Q. And after two weeks, your wife was well enough to return
25 to the care home.

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1 A. Yes.

2 Q. When she got back to the care home, as you say in
3 paragraph 95, she had to be isolated and barrier nursed
4 for a further 14 days.

5 A. Yes.

6 Q. You weren't given an indication that she was in advance
7 going to be returned to the care home.

8 A. No.

9 Q. In fact, it was the care home that got in touch with you
10 to tell you that.

11 A. I think it was generally the case that we only found out
12 about things afterwards. So we weren't sure when she
13 was going to be returned to the home.

14 I should mention -- I think it is worth mentioning,
15 if it is all right with yourself -- it seems like a slip
16 of the tongue, it doesn't seem too important -- for me,
17 it was a terribly important thing -- the care home
18 manager said that once she had been able to announce to
19 me that Anne was back, she said, "It is so good to have
20 her home", which rather stung, because we -- it was this
21 taking over the concept of family that permeated
22 throughout, again, I think, the social care industry.
23 I think it was used as a fig leaf for what other things
24 may have been going on by simply trying to persuade us
25 that the care home was an adequate substitute for

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1 her lifelong family and kinship. So they quickly fell
2 into using that kind of language.

3 So it may seem a slight matter. I think to us as
4 family we were saying: we are the family, and you need
5 to recognise our role in this woman's life.

6 Q. It is probably fair to say that that probably wasn't
7 meant as an insult to you --

8 A. No.

9 Q. -- or a slight on you, it was just the way it was put.

10 A. No, no, but -- well, yes, but it became an unconscious
11 belief within the care home system that we are the
12 family. And I think the average care worker meant well
13 by that. I think I maybe said elsewhere, and we may
14 come to it, my wife was a carer in care homes.

15 Q. Yes.

16 A. I feel well qualified to speak about that in that sense.

17 But they were not her family. We were her family.

18 Therefore, even unconscious use of that kind of
19 language -- yes, I guess we were a bit sensitive, but
20 that is how it felt.

21 Q. Thank you.

22 At paragraph 100, you mention that there was no
23 allowance for "creative management". Can I just
24 understand what you are saying there?

25 A. To the best of my knowledge, all that happened

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1 on March 13 in terms of what was going on in care homes
2 to minimise the risk -- I know there were some other
3 issues for the care staff in terms of using PPE, etc,
4 but it certainly weighed heavily on our minds that the
5 notion of banning the relatives seemed to have fixed
6 everything, but not much else had been attempted beyond
7 that.

8 I was reading in newspaper reports about the English
9 Cricket Board had a big international test match going
10 on, and they had invented all sorts of systems using
11 flexiglass, creative use of rooms, and they were
12 cohorting, different players would move in different
13 directions, and I wasn't aware of any such imaginative
14 thinking going on into what was going on inside a care
15 home, and certainly nobody in the care home ever gave us
16 the understanding that that was case. They simply had
17 made sure that we were not allowed in, because we
18 would -- and I need to stress that again; it wasn't
19 about "you might"; "you will bring in the virus and you
20 will be the cause of death". And yet the virus did get
21 into the care homes, and it wasn't the relatives that
22 did that.

23 So we wondered why there couldn't have been more
24 imaginative use of cohorting. The pressure on people to
25 sign DNRs -- perhaps those who wanted to live with DNRs

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1 could have been sectioned off. It was a big
2 care home — some smaller ones couldn't do that — and
3 they could run that risk, and those wanting to have
4 their relatives come in could have been in a different
5 part of the building, and some kind of imaginative
6 system to allow some people in, bearing in mind that not
7 every care home resident sadly receives visitors anyway,
8 so it's not as if the care home was going to be
9 inundated with visitors.

10 Q. Thank you.

11 Can we take you on to the section in your statement
12 on treatment and care of residents. Again, a lot of the
13 factual background to this we have from your statement
14 and also from your daughter's statement and the
15 background in that statement, so we are aware of the
16 situation.

17 A. Yes.

18 Q. I would like to pick up a couple of points, if I may.

19 Paragraph 105. This is you talking about the fact
20 that you were aware that your wife had lost weight,
21 although, again, that was something you found out
22 ex post facto —

23 A. Yes.

24 Q. — in conversation, as you say. You were never given
25 much information, there were no doctor's letters, and

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1 you go on to say:

2 "I do not believe people realise how far out of the
3 loop we were as Family."

4 A. Yes.

5 Q. Again, can you explain that a little bit, in a little
6 bit more detail.

7 A. I think the general population did not really understand
8 that simply by saying that we were not allowed into the
9 building, it meant so much more than that. It was
10 almost like if the government diktat from on high had
11 said: we will ban the relatives, then it allowed the
12 care home industry to adopt a whole set of other
13 measures which, in a sense, were punitive towards the
14 families, so that if we weren't allowed in the building,
15 it wasn't so tellingly necessary for us to know about
16 how my wife's health was doing because those who were in
17 situ were the ones who were dealing with her, and as
18 long as they knew how she was coping and managing, then
19 there wasn't an overwhelming need for them to keep
20 telling the family and keep them up to date. We were
21 simply erased from the picture.

22 And I think it was probably unintentional, but it
23 was nevertheless a direct and what I call an unintended
24 consequence of that whole ethos that went through the
25 whole system.

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1 Q. Just on unintended consequences, because that is
2 something you mention in paragraph 106, but I think you
3 mention it in a rather more general way, because you
4 preface what you say by saying:

5 "I cannot believe that the officials who instituted
6 the bans on care home relatives ever seriously
7 contemplated the unintended consequences."

8 A. Yes.

9 Q. Just stopping there, firstly, how have you formed that
10 belief? And perhaps you can give some more indications
11 of what you see as the unintended consequences.

12 A. I think the unintended consequences came — it's also
13 through the entirety of my witness statement, and also
14 through the entirety of our experience. It may be all
15 right under any circumstances for any system to plan at
16 a high level, governmental level, HQ, that this should
17 be the case, but as it works its way down the system,
18 what happened was that in the care home, care home
19 staff, care home manager, the families, albeit excluded
20 from being inside the building, had to try and make
21 sense of that. This probably became more apparent once
22 we were finally allowed back in, but it became the case
23 that: well, why do we need to tell the families?

24 Where did that doctor's letter go from the hospital?
25 Well, obviously it goes to the place where the person is

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1 going to, and she wasn't going back to my house or our
2 house, she was going back to the care home. Therefore,
3 the doctor's letter with all the attendant information
4 went to the care home, which may have included
5 references to weight loss, etc. It wasn't something
6 that we needed to know directly because we weren't
7 dealing with her on a day-by-day basis. Therefore,
8 these are some of the examples that became even more
9 bizarre and complex when they were finally letting us
10 into the building.

11 But I think that was part of it, just this notion
12 that: ban the relatives and that fixes everything. You
13 couldn't un-ban the relatives, in the sense that you
14 could stop us getting into the building, but you
15 couldn't stop us caring and loving our relatives. It is
16 a powerful urge that we all understand, I am sure.

17 Q. I think you reflect in that paragraph one of
18 the competing issues that the Inquiry is aware of in our
19 work so far and we will continue to be aware of, where
20 you say:

21 "The system gave the Care Homes carte blanche. If
22 they could ban the relatives they could by implication
23 ignore them."

24 You go on to say:

25 "Powers of Attorney and Guardianship rights were

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1 overturned by the Covid legislation .”

2 A. That is my understanding. I wasn't aware of it at the

3 time, but obviously people more expert in these matters

4 would know, but I believe the Parliament passed the

5 Coronavirus Act, which most of us only heard about in

6 passing, but a powerful set of laws or powers that were

7 then given to the care home to be able to protect us,

8 and I think as my daughter once said, they knew what

9 they were trying to protect and from, but they never

10 seemed to understand what they were protecting her for.

11 Q. Okay.

12 Again, that paragraph is, if I may say, quite

13 a significant paragraph in your statement, Mr Duke. You

14 conclude by saying:

15 "The Care Home Residents were one of the few sectors

16 of society whose obedience to the laws was seriously

17 policed. Anne was literally under Lock and Key."

18 A. Yes. I think that is an important point, that she

19 was — I can't stress this enough — she was under lock

20 and key. I know that the majority of us in the

21 population were expected to obey COVID regulations, but

22 much of it was taken as given. We were trusted to

23 behave ourselves, and if your elderly relative was

24 shielding in their flat somewhere in town, you shouldn't

25 be going to see them. But we know from the trouble they

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1 had with the R number in the general population that

2 many people in society were bending the rules. I don't

3 need to have much evidence to suggest that may have been

4 the case.

5 Q. I guess disobeying them.

6 A. Disobeying them, because you could go and see your

7 granny if she was living in her own house, even though

8 the regulations said don't go see her. We simply could

9 not do that. We were one of the few — well, not we; my

10 wife was one of the few sectors of society who literally

11 had somebody standing at their front door with the key

12 saying, "You will not pass".

13 Q. Can we go on to paragraph 110 of your statement, please.

14 I just want to get the context of this right, because it

15 may give a slightly false impression, and I just want to

16 understand what you are actually saying.

17 You refer to, as it were, the projection of care

18 staff as a band of angels who are risking their lives

19 for the benefit of residents. But as I read what you

20 say, and particularly what you say in paragraph 111,

21 I don't think you are being critical of the staff; what

22 you are criticising is, as I understand it, the image

23 projected by the industry and government; is that right?

24 A. Yes. If I was a PR representative for the government,

25 one of the best wizard ideas I could have come up with

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1 was presenting care home staff as a group of angels.

2 And I stress this again: as the husband of a carer,

3 I feel well enough qualified. I lived with a carer,

4 with an angel. She was not necessarily always an angel;

5 she was just a human being. The government I think were

6 using it as a fig leaf and saying: these are people who

7 are going above and beyond the call of duty, and it was

8 very much then inclined to make us, as the relatives,

9 back off from being too critical. And yet it was the

10 interface between us and these carers where we had to

11 live, and it was very difficult because if we looked as

12 if we were being critical, then it could look bad. But

13 I think it was that the carers were being played by the

14 government as much as the families were.

15 Q. I think you set that out in paragraph 111, where you say

16 that put unfair and unrealistic pressure on staff and

17 families.

18 A. Yes.

19 Q. It wasn't just the families that were adversely impacted

20 by that.

21 A. No.

22 If it's fair to say, could I — and we alluded to

23 the fact that we quickly became very attuned — with the

24 wonders of the modern internet, etc, we, as a group of

25 families, became very, very knowledgeable about what was

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1 going on, and I certainly was coming across comments and

2 statements made by other agencies — one national agency

3 was often talking about the pressure on care home staff,

4 talking about them leaving the job or being — phoning

5 in sick, not just because of COVID; talking about staff

6 having suicidal ideation. These poor people were put

7 under tremendous pressure. And also, by implication, if

8 that was the case that these people were feeling that

9 way, then by that same measure they were incapable of

10 providing adequate care for our families. Not because

11 there was anything intrinsically wrong with them, but

12 because they were caught up in a situation that was

13 always doomed to have more problems than it was worth.

14 Q. Right, can we go on to visitation, please. You deal

15 with this over several paragraphs, and there are just

16 one or two points I would like to extract from what you

17 say in relation to visitation.

18 First of all, at paragraph 119, you have talked

19 about window visits and garden visits. If one has the

20 perception of a garden visit as sitting in a nice lawned

21 area with rosebuds over the arches and a gazebo at the

22 end of it, that wasn't really what it was like, was it?

23 A. Well, obviously I can only speak to my experience, but

24 I am sure it was probably replicated throughout the

25 country. No, our garden visits were taking place in

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1 a car park with potholes in it, 15 feet away from the
2 pavement, where people were passing by, and my wife was
3 brought out to be paraded and sat 2 to 3 metres away
4 from me, with a member of staff sitting, watching,
5 listening to everything.

6 It was cold. Scottish summer, August/September, so
7 it was cold anyway. And Anne had not been outside.
8 Therefore, she was wrapped up: woollen hat, scarf,
9 gloves, big jacket, a tartan rug over her. It was hard
10 to see her sometimes, and you could just about see her
11 face. And in any case, I was having to shout at her
12 from 3 metres away, "I love you". Try doing that in
13 public. Not a terribly satisfactory experience.

14 Q. I think you make the point, and your daughter made the
15 point, of lack of privacy in these situations.

16 A. Absolutely. Seriously, people were walking by
17 10/15 feet away. They could see us. They could hear
18 us. They knew what was going on: there is that guy
19 visiting his wife. It wasn't private at all.

20 Q. I think you also indicate that on a number of occasions
21 visits were cancelled, because obviously you had to
22 arrange these visits in advance, and they would often be
23 cancelled, sometimes probably for weather reasons, and
24 also on occasions because of your wife's condition.

25 I think on a number of occasions you say that she was

1 sleepy or you were told she was sleepy.

2 A. Yes. Now, one always has to take these things at face
3 value, but the longer you are kept out of loop, you
4 cannot help -- we are all human; you cannot help but
5 start to be a bit suspicious and, in fact, I think we
6 had grounds for that being justifiable suspicion at some
7 point, which we may discuss.

8 Q. Paragraph 123 -- and this may be leading on to that,
9 Mr Duke -- the last sentence, you reiterated
10 a request -- this is in June -- that had been previously
11 made for some form of comprehensive assessment of Anne's
12 mental and emotional health. Why did you ask for that
13 and did you ever get it?

14 A. Okay. We asked for it because we just were concerned in
15 general about her state of health, and we weren't sure
16 what her state of health was.

17 I have to apologise to the Inquiry. That has been
18 omitted from my witness statement. We did eventually
19 get some form of a response from the care home, which
20 was essentially that the care home manager had decided
21 that Anne's mental health was fine. So this wasn't
22 an assessment by a mental health practitioner; it seemed
23 that the care home were judge, jury and executioner on
24 these matters.

25 Again, we could have probably taken it further, but

1 one again was always trying to be amenable,
2 understanding, and not push too far for fear of souring
3 the relationship.

4 So we didn't get a proper response or an adequate
5 response.

6 Q. Can I take you to paragraphs 129 and 130 of your
7 statement, please. You mention there in August 2020 the
8 Government published:

9 "Care home residents will be able to receive more
10 outdoor visits from Monday 10 August ..."

11 This was a quote attributed to Jeane Freeman, the
12 Health Secretary. And:

13 "It also stated that indoor visits would be
14 introduced as of 24 August ... providing necessary
15 criteria were met."

16 You then received after the issuing of that advice
17 an email from the home saying:

18 "We have discussed this with Public Health this
19 morning, who advised that they were unaware that these
20 changes were occurring. As it stands, garden visits
21 remain the same."

22 What was your reaction to that? Well, I think you
23 tell us in the next sentence.

24 A. Very frustrated, yes. This was not untypical and,
25 again, this is what I referred to as an "unintended

1 consequences". Somebody at a high level was saying "let
2 it be this way". It works its way through the system
3 and it started to become quite apparent that Public
4 Health were often flying under the radar and were like
5 the powers behind the throne, as it were. The
6 Government could say one thing but, if Public Health
7 said something else, then it often seemed to us that
8 the care home would use that as their yardstick for
9 deciding what to do. I can understand to a certain
10 extent where that was coming from. Public Health were
11 keeping a close eye on the R number and obviously, if
12 that was changing and going in the wrong direction, then
13 Public Health would err on the side of caution and say:
14 well, it's all very well for the government -- I am
15 paraphrasing here -- all very well for the government to
16 say we will open up to more visits, but we say
17 otherwise.

18 Q. Thank you. At paragraph 134 you describe a garden visit
19 which occurred on 21 August 2020, and we can read what
20 you say there. But as you saw it, and one can
21 understand it, there were lots of unsatisfactory aspects
22 to that visit --

23 A. Yes.

24 Q. -- some of which I think involved the fact that there
25 was a staff member who was able to be close to Anne, you

1 obviously couldn't be, and there were other people who
 2 were able to walk past. I think you made a complaint
 3 about that and you got a response from the care home on
 4 15 September —

5 A. Yes.

6 Q. — of that year saying it wouldn't happen again and that
 7 staff had been better trained.

8 A. Yes.

9 Q. So did you feel you had actually made some progress on
 10 that matter?

11 A. Temporarily. It happened again one year later.

12 Q. You describe window visits, as you put it, as "a comedy
 13 of errors". A comedy of errors. Again, I think we can
 14 see there, I think you give one example of that, that on
 15 a particular occasion the sun was shining so you
 16 couldn't see your wife?

17 A. No.

18 Q. There were also occasions when she was moved to
 19 a different room but, because of the slope in the grass,
 20 the window was more than five feet above ground level
 21 meaning all Anne could see was your head?

22 A. Yes.

23 Q. If we move on to paragraph 140 and 141, please. Again,
 24 here you are indicating that you had received an email
 25 from the care home stating that they had received

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1 a letter from Public Health that internal visits will
 2 not proceed due to "cases and clusters and local
 3 prevalence". You sent an email to Public Health seeking
 4 clarification. However, you did not receive a reply?

5 A. No.

6 Q. You go on to say in 141:
 7 "Care home residents were not obtaining new freedoms
 8 yet, because the R number had spiked, as the general
 9 population could not seemingly behave themselves."
 10 Is that how you felt?

11 A. It may be a bit pejorative, but I am not really sure
 12 what other connotation I could put on that. But it
 13 certainly seemed the case. As we knew, there were all
 14 sorts of issues but it seemed that, if the R number
 15 wasn't coming in the right direction, Public Health
 16 were, you know, really desperately trying to figure out
 17 what to do about that. But the one thing they knew they
 18 could do was continue to maintain the ban on relatives
 19 getting into care homes, and it never seemed to make
 20 much sense to us as families and nobody ever really
 21 tried to explain the science behind that. They just
 22 banned us.

23 Q. You conclude that paragraph by saying:
 24 "They effectively sanctioned the care home residents
 25 for others' misbehaviour. It felt harsh and punitive."

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1 A. Yes. The care home residents were not misbehaving.
 2 They were not bending the rules. If the R number wasn't
 3 behaving itself, it must have been because the general
 4 population wasn't doing the right thing or listening to
 5 the instructions properly. But the one group of people
 6 that were clearly impacted by that were the care home
 7 residents, whose situation was maintained by this strict
 8 ban, and that seemed terribly unfair.

9 Q. Can we move on to paragraphs 147 and 148, please. You
 10 talk about a visit that you had on 4 October on the
 11 outside looking in, as you put it, and you then indicate
 12 that on your side of the divide it was cold and wet and
 13 dark, and you still struggle with how the world seems so
 14 easily disposed to dismiss the intense instinctual urge
 15 to touch or hug.

16 A. Yes.

17 Q. That was clearly obviously something you found
 18 difficult?

19 A. It was terribly difficult. You know, again the common
 20 perception was that these window — euphemistically
 21 styled window and garden visits, were beautiful moments
 22 and they were not. They were dreadfully difficult and
 23 really just underscored the fact that you were separated
 24 from your loved one. It could have been anybody else.
 25 I am talking about myself and my wife, and the

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1 nonsensical way these things were operating. It sounded
 2 lovely but it was dreadfully difficult to organise, for
 3 the care home staff and for the families, and not least
 4 for the residents. So my wife was brought to a window
 5 inside and she is feeling a bit tired or sleepy and I am
 6 shouting at her or trying to get her to listen on the
 7 phone, and it's pouring down of rain and she is inside
 8 and not able to focus properly. Whereas I could rest
 9 assured, had I been inside and with her, she would have
 10 derived much more benefit from my visit simply by my
 11 being able to hold her hand, even if it was with a latex
 12 glove at that point, and talk quietly to her and share
 13 some of her favourite music; a great benefit to her.
 14 And it wouldn't have required a member of staff standing
 15 watching, because I could have been on my own with my
 16 wife in the room. But it wasn't allowed.

17 Q. There was a point I was looking for and I have found it.
 18 At 152, you are talking about privacy being non-existent
 19 and, it may be apocryphal, but you seem to have made an
 20 excuse that you needed to go shopping to get away.

21 A. Yes. These are the things that induce guilt in me,
 22 because I had learned to come up with excuses to absent
 23 myself from the visit if it wasn't going well. So
 24 I would simply say to Anne "I need to go shopping now",
 25 which was a lie. I never felt good about doing it, but

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1 it was one of those situations where you couldn't
 2 linger, you couldn't keep saying "I'm going now", step
 3 back five paces, "I'm almost gone". You simply had to
 4 say "I'm going to the shops, goodbye", and I would turn
 5 my back on her and walk away, just to try and make the
 6 thing more manageable. Certainly that left a lot of
 7 guilt on my part. It's not one of my proudest moments
 8 but it was the only way I could deal with a situation
 9 like that.

10 Q. I think you put it quite forcefully at the bottom of
 11 paragraph 153 where you say:
 12 "Dear god, I hated this. I wondered if there was
 13 any point in coming back. But I knew I would."

14 A. Yes. I think — I think the general public should
 15 probably understand — because we all live in family, we
 16 all have love in our lives, and quite how general
 17 society failed to understand how this was happening that
 18 it wasn't seriously detrimental to the residents' health
 19 and, indeed, to the relatives' health, I really don't
 20 know, and I do sometimes fear that underlying this was
 21 a double jeopardy in the sense that many of the people
 22 in care homes already had an illness or a situation that
 23 was already terribly misunderstood. Anne had
 24 Alzheimer's, therefore what did it matter what was
 25 happening to her? And one feels this was some form of

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1 discrimination, apart from simply the harsh application
 2 of lockdown rules.

3 Q. One of the concerns you had I think at the time was your
 4 wife's intake of fluids and the possible concern about
 5 her kidney function, is that right?

6 A. Pardon?

7 Q. You had a concern about your wife's intake of fluids.
 8 I think that was something in the past that you had been
 9 able to aid with?

10 A. Yes. If we were in — it's recognised in care homes
 11 that one of the great advantages of having a relative in
 12 is that they can do the kind of hour-by-hour,
 13 minute-by-minute care that often carers don't have the
 14 time to do. An attentive relative can make sure, as
 15 best they can, that their loved one is drinking
 16 properly, etc. So it transpired there may have been
 17 an issue for Anne being sleepy. There may have been
 18 a reason behind that. Which I was observing through the
 19 windows, but the care home were again telling me she's
 20 fine, and that is the operative word that was often
 21 used; she's "fine". "But she looks awful sleepy to me".
 22 "No, she's fine". Until she wasn't.

23 Q. Can I just take a few more points. You organised what
 24 is termed an "essential visit" with your wife. I think
 25 again your daughter has explained the background to

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1 that. You make a comment at 166 of your statement about
 2 the position after that essential visit. You say that
 3 the relationship with the care home:
 4 "... was now more passive/aggressive. We as
 5 a family did not want to be seen as troublemakers and
 6 the home struck me as being overly burdened with rules
 7 and regulations. An uneasy truce developed."

8 A. Yes.

9 Q. I think you heralded this previously in your evidence,
 10 but you had obviously — using a word that you used
 11 before — reached some sort of accommodation with the
 12 care home.

13 A. Yes. I'm appreciative of the time.

14 We had arranged our review because I had been
 15 worried about the sleepiness. As part of that review,
 16 I asked that her health be checked. They checked on her
 17 health, took blood tests. Transpires there were serious
 18 problems with her bloods, and the Hospital at Home team
 19 had to visit two or three days later. Matters were
 20 resolved and, as a result of that, we managed to finally
 21 "negotiate" — I put that in inverted commas —
 22 an essential visit, because we as a family had pushed
 23 the button to say: we want a social work review, and if
 24 we hadn't done that, then there remains the possibility
 25 that she may have deteriorated further. But we were

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1 being told she was fine when the blood test clearly said
 2 she wasn't fine.

3 Q. I am also conscious of the time, Mr Duke, so forgive me
 4 if I do take things relatively quickly.

5 A. Sure.

6 Q. You make the point in 168 and then further on about the
 7 visiting rules during Lockdown were not proportionate.
 8 I think that remains your view now —

9 A. Yes.

10 Q. — two years on.

11 A. Yes.

12 Q. You also say at 173 to 177, you record that 23 people
 13 died of COVID in your wife's care home, and your wife
 14 nearly died, and you set that out.

15 You also say at 175 that:
 16 "... WE never took the virus in because WE were not
 17 allowed inside."

18 That seemed to be your perception.

19 A. Yes. It goes back to 13 March, when we were told —
 20 I was told: you will bring the virus in. Rather an
 21 uneducated viewpoint, frankly, I think, because it
 22 wasn't us. Inevitably, it came in through the care
 23 staff, and that is not because I am blaming them, but
 24 there had to be some vector for it, and therefore it
 25 seems very unfair that we were simply sanctioned,

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1 whereas other people, care staff, were always coming in
 2 and out. And nobody was checking what they were doing
 3 at the weekend. Nobody was standing outside their house
 4 with a key, only outside my wife's house.

5 Q. Again, I want to just take these points briefly, and
 6 perhaps I can just make the reference to it.

7 Paragraph 185, you talk about the arrangement that
 8 you had with your wife to assist her with eating, and
 9 you had to apply for effectively permission to do that.
 10 Even that itself proved problematic.

11 A. Yes. Unforeseen consequences. The fact of the matter
 12 was that on the day, at that moment, the care home
 13 industry, from the First Minister down, was represented
 14 by whichever carer was standing outside Anne's room and
 15 their interpretation or whatever interpretation -- or
 16 somebody else's interpretation of guidelines that they
 17 had on the day, and that would often change from one
 18 carer to the next. So even though I got permission from
 19 the manager to feed Anne, that carer was uncertain if
 20 that was the case, and the manager wasn't available and
 21 the carer erred on the side of caution -- "You cannot
 22 feed her" -- and I erred on the side of caution by not
 23 making a fuss about it. More guilt.

24 Q. Yes.

25 Just, again, you make reference to a garden visit --

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1 this is in paragraph 196 -- and you explain some of the
 2 movements around that garden visit. This was on
 3 26 May 2021, which included:

4 "... the postman, 2 members of staff,
 5 1 tradesperson, and ... other relatives entered the
 6 building and then exited past Anne, our daughter, and
 7 me."

8 You said this was an outrageous repeat of an earlier
 9 incident.

10 A. That was the incident which resulted in the uphill
 11 complaint, and yet it happened again.

12 Q. Yes.

13 Can we just go on to paragraph -- I think it is fair
 14 to put this to you. This had quite an impact on you,
 15 and paragraphs 207 and 208, I think you reflect the toll
 16 that it did have on you. You were ill.

17 A. Yes. I mean, again, conscious of the time, very
 18 briefly, I have a pre-existing heart condition. The
 19 constant stress of dealing with all of these issues
 20 seemed to accumulate into one rather tetchy phone call,
 21 well-mannered but tetchy phone call, between myself and
 22 the care home manager. It wasn't going terribly well,
 23 and I ended up taking unwell. I ended up in hospital
 24 with a heart event, as they are known.

25 I am certainly quite clear, and I am not saying --

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1 and I want to stress -- that the care home manager
 2 caused that heart attack.

3 Q. No, no.

4 A. But the stress of that particular incident I am clear in
 5 my mind was the accumulation of all that stress. Many
 6 people had psychological stress, emotional stress. My
 7 heart registered my stress, and it could have been
 8 fatal. But I am here.

9 Q. You are indeed.

10 Just one point from paragraph 213 on infection
 11 control. Perhaps the significant point -- perhaps one
 12 that can be overlooked -- you say in the middle of that
 13 your wife would never have seen a human face with
 14 a smile on it in that time because you were always
 15 having to wear PPE and masks.

16 A. Yes. Sorry, I am -- yes, so little is understood about
 17 what was going on. I imagine the fact of the matter was
 18 quite probably, if everybody was obeying the rules, my
 19 wife never saw a smiling human face for the last
 20 20 months of her life. It's as simple as that.

21 Q. Briefly -- and I do this deliberately, Mr Duke, and
 22 I would have done it notwithstanding the time
 23 pressure -- I don't want to take you through the passing
 24 of your wife, but you were able to be with her when she
 25 passed.

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1 A. Yes.

2 Q. Fortunately, one of the things that was done, as she had
 3 been in hospital and been returned to hospital, the
 4 planned quarantining of your wife was reduced in terms
 5 of the time, I think to five days, and I think you are
 6 very grateful for that.

7 A. I am very grateful, but I had to plead for it.

8 Q. Yes.

9 A. The rules at that point said although she was coming
 10 back from hospital for end-of-life care and she had
 11 received two negative COVID tests, the rules said that
 12 she should have been placed in 14-day quarantine, and
 13 she had a barrier nursing sign hastily taped onto her
 14 door. I managed to renegotiate that with the care home
 15 manager, and I am grateful for that.

16 Q. You have told us that your wife passed away at 2.06 on
 17 the afternoon of 13 November. You were able to be with
 18 her; your daughter Natasha wasn't, and we have heard
 19 that earlier.

20 Can you just finally read what you have set out in
 21 your statement at paragraph 245 and 246.

22 A. Okay.

23 And in her last hours, we finally held hands.
 24 I stroked her precious, hot-flushed cheeks, cuddled, and
 25 yes, I took off the damned mask and kissed her, but what

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1 a God—awful price she had to pay for such warmth and
 2 intimacy. In those last few hours, we sang and kissed
 3 and cried, and we reminded her that she was truly loved.
 4 It should not have been so.
 5 246 is a poem. I don't want to necessarily indulge
 6 myself.
 7 Q. Okay, no, that is fine. But you penned a poem about the
 8 situation.
 9 A. Yes. It's in the book.
 10 Q. We are appreciative of that and we will get it in
 11 literary form in due course. Thank you.
 12 You make the point in 247 that:
 13 "Government must NEVER again be allowed to imprison
 14 our most frail and vulnerable in such an inhumane way.
 15 It has been despicable, heartless, and relentless."
 16 A. Yes.
 17 Q. Again, you adhere to that view.
 18 A. It's an easy thing for an emotionally distraught husband
 19 to say, but sometimes genuine change only comes about
 20 when people will stretch themselves, will blow whistles,
 21 will make a noise, and I pay full credit to everybody
 22 working in Care Home Relatives Scotland. We stood up
 23 and said: this is wrong, and if anything is to change,
 24 it will be because some people have said that was wrong.
 25 Q. You make certain suggestions of lessons to be learned

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1 and hopes for the Inquiry, and we can read those,
 2 Mr Duke. I don't ask for you to read them out, but
 3 I think one of the points is that you hope that the
 4 Inquiry will make a recommendation that Anne's Law, as
 5 petitioned for by your daughter, is enacted, and we know
 6 the deficiencies that your daughter sees in Anne's Law.
 7 We are aware of that.
 8 You also say it's important to allow people to
 9 speak. It is cathartic. Have you found this cathartic?
 10 A. It has been very valuable. I deeply appreciate the
 11 opportunity. I wish I had more time, but there we go.
 12 But it has been very worthwhile, and I do — I am
 13 grateful for the opportunity.
 14 MR GALE: We are very grateful to you, Mr Duke. Thank you
 15 very much. We have just made the time.
 16 THE CHAIR: Thank you very much, Mr Duke.
 17 THE WITNESS: Thank you.
 18 THE CHAIR: Thank you. We will rise until 2 o'clock.
 19 (1.00 pm)
 20 (The short adjournment)
 21 (2.00 pm)
 22 THE CHAIR: Good afternoon, everybody.
 23 Right, Mr Gale.
 24 MR GALE: Yes, my Lord. The next witness is Alison Leitch.
 25 The reference to her statement is SCI—WT0370—000001.

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1 MS ALISON LEITCH (called)
 2 THE CHAIR: Good afternoon. Welcome back, Ms Leitch.
 3 Mr Gale.
 4 Questions from MR GALE
 5 MR GALE: Thank you, my Lord.
 6 Ms Leitch, your full name is Alison Leitch, I think.
 7 A. Yes.
 8 Q. How old are you?
 9 A. 46.
 10 Q. You are currently employed and the Inquiry is aware of
 11 that, the nature of that employment and also of your
 12 contact details. We have that information.
 13 You gave evidence ten days ago as part of the
 14 Care Home Relatives Scotland core group speaking to
 15 an organisational statement, and now you are providing
 16 a personal impact statement, and this is in relation to
 17 your mother, and we are not naming your mother, nor are
 18 we naming the care home where she was and is a resident.
 19 You are agreeable and have been agreeable to
 20 providing a statement to the Inquiry, and you are
 21 agreeable to that statement being published.
 22 A. Yes.
 23 Q. Your mother was a resident in a care home during the
 24 pandemic, and you provide us with some information about
 25 your mother prior to her going into care at paragraphs 5

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1 to 12 of your statement.
 2 Just taking that relatively briefly, if I may, your
 3 mother was diagnosed with Alzheimer's when she was 60;
 4 is that right?
 5 A. Yes.
 6 Q. At that time, you were living and working abroad, and
 7 I think your mother and father were living together.
 8 A. Yes.
 9 Q. I think, sadly, your father died, and it was then that
 10 you returned to live in Scotland to assist with the care
 11 of your mother.
 12 A. Yes.
 13 Q. When you did return to live in Scotland, I think as you
 14 state at paragraph 6 of your statement, it was then,
 15 really, that you realised just how much care and support
 16 your mother needed. You also tell us that you and your
 17 brother had a power of attorney in relation to your
 18 mother's affairs and that, effectively, you became her
 19 full-time carer.
 20 A. Yes.
 21 Q. Your mother's condition declined and she was moved into
 22 supported living about ten years ago.
 23 A. Yes, that's right.
 24 Q. She didn't settle there and, indeed, it was only a day
 25 later that she was moved to hospital. And then, with

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1 assistance from your mother's psychiatrist, she was
 2 moved into a care home.
 3 A. That's right.
 4 Q. As you say at paragraphs 14 and 15 of your statement,
 5 your mother settled relatively quickly into the
 6 care home.
 7 A. She did. My mum is a very quiet, unassuming lady that
 8 just needs kindness and chocolate.
 9 Q. I can share that desire, yes.
 10 A. And because she was so young in comparison to the rest
 11 of the residents, it was like she kind of became
 12 a favourite, so she settled in very well, and we were
 13 made to feel very welcome. As Natasha mentioned this
 14 morning, you were made to feel that that is your mum's
 15 home.
 16 Q. Her mobility at that stage was fine, as you say in
 17 paragraph 15 of your statement. She could walk a fair
 18 distance unaided. But dementia had pretty much
 19 destroyed her speech.
 20 A. Yes. Just as it was mentioned by Natasha, early-onset
 21 dementia can be quite aggressive in different parts, and
 22 my mum slowly lost her speech. But we used to say from
 23 the head down, she was physically well. So we always --
 24 well, certainly for me, anyway, any time I went, we
 25 always left the building, because she was able to, so

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1 why not?
 2 Q. From the head down, it might have been business as usual
 3 for her and she was mobile. You make the point in 15
 4 that her personality never changed.
 5 A. No. If you can be lucky with dementia, you are lucky in
 6 that the personality doesn't change. No violence, no
 7 swearing, no --
 8 Q. She had an active social life and was able to enjoy
 9 life, generally.
 10 A. Very much so.
 11 Q. That active social life, how was that organised?
 12 A. Well, as I mentioned, my uncle took my mum out once
 13 a week, I think. They used to work their way around all
 14 the cafés. I was there twice a week, my brother was
 15 there twice a week, and we had a befriender. I would
 16 take my mum to see her friends. We would go to cafés.
 17 So she was fairly active and out and about.
 18 And also the activities in the care home. They
 19 would have bus trips. In the local park, there is
 20 Cycling Without Age, where there are motorised bikes
 21 which cater for two people on the back. So there was
 22 lots of activities. So my mum was always out and about.
 23 Q. As you say, she was out of the home regularly, with you
 24 and other family members.
 25 A. Yes.

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1 Q. You describe the onset of pandemic and the effect it had
 2 on your mother in paragraph 17 and following of your
 3 statement. I would like to examine with you some
 4 aspects of that, if I may.
 5 Firstly, the closure of your mother's care home.
 6 You say in paragraph 17 that you went to see your mother
 7 on 12 March. You weren't allowed in -- you weren't
 8 allowed, sorry, to take her out. I think you were told
 9 it wasn't recommended. Is that right?
 10 A. Yes. The member of staff actually walked past me and
 11 said I wasn't allowed to take my mum out as she walked
 12 into the garden to have a cigarette, so I queried it,
 13 and the assistant manager at the time, that was what
 14 I was told, it was not recommended. But I couldn't
 15 quite understand why going out for some fresh air wasn't
 16 going to be recommended. But they did allow that to
 17 happen.
 18 Q. Then as you say in paragraph 18, the following Monday,
 19 the care home phoned to say that they were closing, but
 20 that they had a tablet so you could book a FaceTime call
 21 with your mother, and you said at that time to your
 22 brother that, "Mum would fall off a cliff if we couldn't
 23 have any contact".
 24 It may be really self-evident, but I don't suppose
 25 a FaceTime call via a tablet is going to be terribly

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1 much use to your mother.
 2 A. No. I remember it took over a week for me to see my mum
 3 smile on a FaceTime call.
 4 Q. At paragraph 19 of your statement -- and, again, this is
 5 reflecting some of the other evidence that we have
 6 heard -- your mother was practically non-verbal, and you
 7 say she "needs me to be beside her". She keeps her head
 8 down, isn't good with eye contact unless you are beside
 9 her, and:
 10 "As with many people with dementia, body language
 11 and touch are essential."
 12 A. Absolutely. And because we had never used any form of
 13 technology before, this would have all been new to her.
 14 I can only presume it was confusing. She could hear my
 15 voice, but she didn't know where I was. She didn't know
 16 where the voice was coming from. Depending on which
 17 member of staff was beside my mum, the ones that I knew,
 18 they would facilitate a conversation, they would engage
 19 with my mum, but there was occasions where there was
 20 a carer sat next to my mum that I didn't know and she
 21 didn't know me, so she would sit in silence. So I was
 22 having a conversation with nobody.
 23 Q. Just looking at that, could you be aware as to whether
 24 your mother was coping with that situation, being
 25 communicated to through a tablet or something of that

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1 nature?
 2 A. In a sense, yes, if it was a carer that was familiar
 3 with us, she was -- it was kind of almost like
 4 a three-way conversation with only two people speaking,
 5 but a familiar carer would be able to tell me what they
 6 had been doing or how -- what my mum had eaten that day
 7 or she had had her music on or something. But if it was
 8 somebody that wasn't interacting with my mum or if my
 9 mum wasn't doing so well, you could see -- like, my mum
 10 does try to speak, but it can be repetitive noises or
 11 words. It is like she is trying to speak. And you can
 12 also tell a lot by her face. You know, my mum can still
 13 laugh, she can still smile, but when her face was -- it
 14 was almost contorted, I would try to calm things or that
 15 is when I really needed the carer to engage to reassure
 16 my mum and calm her down because, you know, I am stuck
 17 behind a screen.
 18 Q. You let us know some details of that in paragraph 20 of
 19 your statement. In particular, you say on occasions you
 20 thought that your mum was clawing her face, and you say
 21 it was very hard to watch her doing that and being so
 22 distressed and not being able to do anything. You say:
 23 "She knew we weren't there and something was
 24 different."
 25 A. That was the twice -- there was twice I remember seeing

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1 that, and that was when she was isolated in her room.
 2 Q. I think you say that you had never seen her that
 3 distressed --
 4 A. Never.
 5 Q. -- since the lockdown period started.
 6 A. Never, and her dementia has deteriorated quite a lot
 7 since then.
 8 Q. As with other witnesses, obviously we are focusing
 9 largely on the impact on your mother, but obviously this
 10 had an impact on you. Can you just describe that sort
 11 of situation where you were unable to communicate or be
 12 physically with your mother. What was the impact on
 13 you?
 14 A. I think I have gone through every single emotion in the
 15 last three years. But that initial period ... video
 16 calls were better than nothing, and I was still going
 17 over every Sunday to drop stuff off, so I was seeing my
 18 mum at a window, which was much better than a video
 19 call. So anything was better than nothing at those
 20 times. So I suppose by seeing her, I was reassured that
 21 she -- I could physically see her for myself. But it
 22 was -- as things progressed, and things started opening
 23 up for society, that's I suppose when it hit, because
 24 there was nobody standing up for my mum. I used to
 25 think I was losing my mind at times, that my friends

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1 could go for dinner, go for coffee, they could go on
 2 holiday, but these restrictions were still enforced on
 3 my mum and nobody seemed to be concerned about it.
 4 Q. I suppose you were having to surmise how your mother was
 5 coping with this, and obviously she couldn't communicate
 6 that to you. So what sort of things were going through
 7 your mind as to how you thought your mother was coping
 8 with the situation she found herself in?
 9 A. My mum is a tough cookie. You know, I have never really
 10 seen her -- she seemed -- growing up, she used to take
 11 things in her stride. So I was confident initially she
 12 would be okay because there was good staff, they knew
 13 her well, didn't think this would go on for too long.
 14 But then as it did go on and I was seeing how distressed
 15 she was on video calls, you then start to think: where
 16 does she think we have gone? Does she think we have
 17 just abandoned her? So you are haunted by: what is your
 18 mum thinking? And why could I not keep her at home?
 19 You start thinking: can I get her out? Can I move home?
 20 Can I give up work? Can I go back to being a full-time
 21 carer? How can you resolve this situation, because
 22 everything is out of your control.
 23 Q. We have heard from a number of witnesses about feelings
 24 of guilt. Did you have them?
 25 A. I had guilt from the day my mum went into a care home.

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1 Q. Can we go to paragraph 21, please, of your statement.
 2 At one point you make the point that it was very
 3 difficult not to be able to reach out and touch your
 4 mother, and I think perhaps one of the examples of
 5 humanity was that a carer once slipped your mother's
 6 hand out so you could touch it.
 7 A. I remember coming home that night and speaking to my
 8 neighbour, and he kind of said, "What is wrong with
 9 you?", and I said, "I feel like somebody has charged me
 10 up". And then reading the Alzheimer Scotland literature
 11 review that talks about skin hunger, that makes sense
 12 now.
 13 Q. Can I just take you on to paragraphs 24 and following.
 14 This was an incident in May 2020, where your mother
 15 had some unexplained bruising on her arm. I don't think
 16 you are making any criticism, this just happened.
 17 A. Uh-huh.
 18 Q. And it can obviously happen in care homes where other
 19 residents can do it, so it's not a criticism.
 20 A. Yes.
 21 Q. You I think wanted to see it.
 22 A. (Witness nods).
 23 Q. Initially you were told no, and then you were told you
 24 could do so if you had a mask on and washed your hands.
 25 A. Yes.

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1 Q. But in the course of this, you touched your mother's
2 arm, and one of the care home staff reported you for
3 that.
4 A. The assistant manager had let me stand at the door, and
5 then said, "Wash your hands and put a mask on and you
6 can come in, come in past the door", so there wasn't
7 cold air coming in. So I did that, and then a carer
8 brought my mum out and they rolled up her sleeve, and
9 there was this hand-shaped bruise, and it upset me. My
10 mum was — she was still mobile fine then, but her
11 spatial awareness is rubbish, so my mum was walking
12 around, and because I was so upset, I just reached out
13 and touched her with my fingertips, and a nurse came
14 downstairs and shouted, "What is she doing in here? Get
15 her out."
16 So I was ushered out and my mum was taken away, and
17 I came back to Edinburgh, and I phoned — I think the
18 assistant manager phoned me to say the nurse had
19 reported me to the head office, and their words were,
20 "Your mum has been taken away, stripped, showered and
21 isolated for 14 days."
22 Q. I think you subsequently took a test, which was
23 negative, and you let the care home know that that was
24 the case and the isolation was restricted to five days,
25 I understand.

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1 A. Yes, that's right.
2 Q. How did you feel about that?
3 A. I was devastated. I was devastated I had caused this,
4 I was devastated that my mum was now being treated like
5 this, I was devastated that I had caused the care home
6 extra work. I didn't leave my house until the results
7 came back, because I had it in my head that if my mum
8 wasn't allowed out, then why should I be.
9 Q. I think you say in paragraph 30 that you felt awful for
10 what had happened, presumably because you blamed
11 yourself.
12 A. (Witness nods).
13 Q. Nobody is blaming you, Ms Leitch —
14 A. No, no, I did, absolutely.
15 Q. — but presumably you felt that way.
16 A. I did. But then, you know, after — when the result
17 came back negative and everything could go back to
18 normal, then you start thinking about it, and what did
19 I do differently? I washed my hands, I had a mask on.
20 That is all that staff were doing at the time. I just
21 reacted in a way that any human being would react. But
22 I didn't say anything because I had a sense that I had
23 caused this trouble. I got a row from my brother for
24 doing it. He said he understood why I did it, but he
25 said: it had to be you that did it.

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1 Q. That's a brother for you. Yes.
2 Can I ask you a little bit about window visits and
3 garden visits, which you go on to in paragraphs 31 and
4 following of your statement.
5 Is there a distinction between window visits and
6 garden visits or are they used as the same concept?
7 A. We did have different ones. My mum's unit is on the
8 ground floor, and the lounge is at the far — the dining
9 room, sorry, is at the far end of the building, so it is
10 floor-to-ceiling windows, so you could have a window
11 visit standing up there. Then when they moved to garden
12 visits, those were in the garden or the car park.
13 Q. Just on window visits, you say in paragraph 31 that the
14 window was closed to you and not open as before, and you
15 were told this was government guidance.
16 A. Yes.
17 Q. Who told you that? I don't want the name, but who told
18 you that?
19 A. The manager.
20 Q. Did you check whether that was the case?
21 A. No. I wasn't aware of any government guidance at this
22 time. I was just being told what the care company — we
23 were getting regular updates from them, and obviously
24 what had happened with me touching my mum, I wasn't
25 going to question too many things.

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1 Q. Yes.
2 Now, you set out, at paragraphs 32 and following,
3 some points about garden visits, and I think in some
4 ways these could more accurately be described as car
5 park visits.
6 Just tell us a little bit about how you would
7 criticise — if you would — these sorts of visits.
8 What was wrong with them, so far as you were concerned?
9 A. Well, the care home is in a cul-de-sac, a housing
10 cul-de-sac, so there would be people in their gardens,
11 people cutting their grass, all sorts of noise going
12 around. I was the only person that I knew that was
13 getting a car park visit. I had to stay in my car, and
14 there is a part of me that thinks that is because of the
15 incident of me touching my mum, that I couldn't be
16 trusted to be out of my car.
17 Q. We have heard criticism of these types of visits on the
18 basis that they weren't very private. Is that something
19 you experienced?
20 A. Yes. I mean, you are sitting in an open space. Staff
21 would be coming and going. There was — as I say, there
22 was noise from gardens around. I was shouting at my
23 mum. There was a carer next to her, but that was needed
24 because of my mum's poor spatial awareness. So, for her
25 safety, there needed to be somebody there. But you had

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1 to watch somebody hug your mum, hold her hand, reassure
 2 her, whilst I am shouting. It wasn't very dignified .
 3 Q. No. I am not wanting to suggest anything to you,
 4 Ms Leitch, but was there an understandable degree of
 5 envy on your part when you saw other people being able
 6 to interact with your mother when you couldn't?
 7 A. I think the initial feeling was that somebody was able
 8 to comfort her, and that — she was my main concern, so
 9 as long — yes. Of course, I would rather I comforted
 10 her, but if somebody else was able to do it — because
 11 we've since heard in other government meetings when we
 12 have spoke about this that we have been shot down to say
 13 carers shouldn't have been comforting our loved ones.
 14 So if some carers weren't comforting residents, then
 15 I feel quite lucky that somebody was.
 16 Q. At paragraph 38 of your statement, you talk about
 17 an inside visit in the café room in presumably your
 18 mother's care home in August 2020. While it may seem
 19 like, I suppose, a slightly insignificant matter,
 20 presumably — and you mention it specifically — your
 21 mother's hair had got long and was beyond — so was
 22 that, again, one of the areas that, as a consequence of
 23 lockdown and restrictions, tended to just be ignored,
 24 personal appearance and these sorts of matters?
 25 A. Yes, hairdressers weren't allowed back in the home for

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1 quite some time, so it would be left to some carers, if
 2 you asked them, to cut hair. And my mum's hair is
 3 short, so it very quickly can go out of control almost.
 4 And we brought this up in government meetings about
 5 care home residents' dignity. You know, when the rest
 6 of us could go back to having hair done and different
 7 things, they just weren't allowed, and at that point
 8 there was no scope for hairdressers to come back, and
 9 even when things did improve, the hairdresser was going
 10 between various homes, so I asked if I could take my mum
 11 to my hairdresser, who had their own shop and had
 12 offered to open it up just for my mum, and I was told,
 13 "I would rather you didn't because I don't know what
 14 your hairdresser does".
 15 Q. The other point you make in 38 is about your mother
 16 getting up and walking towards you and, as a consequence
 17 of that, in order to preserve the distance between you,
 18 you yourself had to keep moving, and you say that having
 19 to do that, particularly under the supervision of
 20 care home staff, you put it was heartbreaking.
 21 A. I can relive it in my mind. The carer was actually
 22 sitting on this side of the room, so wasn't next to my
 23 mum, and there was a round table between us. And again,
 24 it was slightly better than being in the car park, but
 25 I am shouting at my mum, she is keeping her head down,

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1 and then she just got up and started walking towards me.
 2 So it took the carer just — it wouldn't have taken too
 3 long, but she had to get up and cross the room, and all
 4 I could do was keep pushing my chair back trying to keep
 5 this distance, and really — that is my mum.
 6 Q. And obviously your mum wouldn't be able to understand
 7 why you were doing it.
 8 A. No.
 9 Q. Okay, can we move on to essential visits.
 10 Paragraph 39 and following, you tell us about
 11 a conversation you had with Natasha Hamilton, who gave
 12 evidence this morning, and then a conversation with a
 13 representative of Alzheimer Scotland. It was then that
 14 you became aware of essential visits .
 15 A. That's right.
 16 Q. This is not a criticism , Ms Leitch, but you hadn't been
 17 aware of that before then.
 18 A. No. No, very similar to what Natasha described earlier.
 19 No, I didn't know anything about that. The befriender
 20 that my mum had prior to the pandemic was
 21 an Alzheimer Scotland befriender, and I had no contact
 22 from them.
 23 Q. If one is looking at perhaps a position of a care home,
 24 one might have expected a care home to be proactive in
 25 informing the families of residents as to the existence

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1 of the concept of essential visits , but that didn't
 2 happen, as I understand it.
 3 A. No, although now you have mentioned, I do remember the
 4 sign on the door said, "Closed, no entry", and then in
 5 very small, "Apart from essential visits ". And I think
 6 at the time I had asked what was an essential visit , and
 7 I was told it was end of life . So that was very, very
 8 early on.
 9 Q. I think we understand, particularly from Ms Hamilton's
 10 evidence, that an essential visit could also include
 11 a situation where the person being visited suffered
 12 dementia or was distressed; is that right?
 13 A. Yes.
 14 Q. But that wasn't brought home to you —
 15 A. No.
 16 Q. — by anybody within the care home industry?
 17 A. No.
 18 Q. You also tell us at paragraph 43 that your mother
 19 trapped her hand and needed stitches. You tell us that
 20 an arrangement had been made for your mother to be taken
 21 to hospital following that, but she was taken to
 22 hospital in a taxi, obviously with a driver who was
 23 a stranger to her. There was never any question of you
 24 taking her to hospital?
 25 A. I asked if I could take my mum, and it was on a weekend,

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1 so there was no manager in, and the nurse just said to
 2 me, "Please don't ask me that".
 3 Q. It may be, again, fairly evident, Ms Leitch, but how did
 4 you feel about a situation where your mother was being
 5 taken to hospital in a taxi by a stranger?
 6 A. Absolutely helpless. I could have — my mum was hurt.
 7 I didn't know how badly she was hurt. I knew there was
 8 a risk if she stayed in hospital for any length of time
 9 she would have to be isolated, because I had met the
 10 others in Care Home Relatives and I knew there was
 11 experience of this. I was terrified she was going to be
 12 shut in a room. And I knew when the nurse said, "Don't
 13 ask me if you can take her in the car", that just
 14 don't — don't push this anymore. But then again
 15 because you are always grateful for what you get, you
 16 don't want to push your luck. But then of course it was
 17 just like: well, I don't want to delay my mum getting to
 18 hospital, so just take her in the taxi. But then
 19 afterwards, it is like: how can that make sense? How
 20 can a taxi that could have had multiple people in the
 21 car that day be deemed safer than me?
 22 Q. I think, fortunately, it wasn't a particularly bad
 23 injury and it was something that could be dealt with
 24 relatively quickly.
 25 A. It was, and she wasn't isolated afterwards.

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1 Q. At paragraph 45, you tell us about — well, before I go
 2 to that, by this time you had become involved with
 3 Care Home Relatives Scotland.
 4 A. That's right.
 5 Q. And did that increase your awareness of matters of
 6 guidance and, as it were, rights that you might have or
 7 your mother might have in relation to visiting?
 8 A. Oh, definitely. Definitely. And it was such a relief
 9 to find out about this group because you — if you don't
 10 know other people that have loved ones in a care home,
 11 it is very isolating. Certainly none of my peers have
 12 a parent in a care home. And you are just living this
 13 life very isolated. So to find this group was just
 14 a godsend, and you had people feeling exactly the same
 15 about you. So you very quickly became aware of all this
 16 paperwork and guidance that existed that just — it
 17 wasn't anything like what life used to be like. So
 18 collectively, there was this agreement that we had to do
 19 something about it. So very quickly, got up to speed
 20 with what was out there.
 21 Q. I suppose as a consequence of becoming involved with
 22 Care Home Relatives Scotland and various meetings that
 23 you had with government representatives, you became
 24 aware of guidance that had been published in October
 25 2020, which stated that residents were to receive

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1 four hours' worth of visits per week with touch.
 2 A. That was after the protests and the first meeting with
 3 Jeane Freeman. I was invited to join the second
 4 meeting, and that is when Jeane Freeman said that she
 5 would change the guidance to the four hours a week with
 6 touch.
 7 Q. You say that when the guidance came out, the care home
 8 management said that they would try it, and you spoke to
 9 a representative of the care home — again, please don't
 10 name him — and there was a suggestion, at least, that
 11 you would trial a visit with your mum based on that
 12 guidance.
 13 A. That person used to be in government meetings, so ...
 14 Q. Yes.
 15 In paragraph 46 you tell us about that trial visit.
 16 Perhaps you could just read 46 out for us.
 17 A. I got to go in to visit my mum in the relatives' room,
 18 sit next to her, and hold her hand for an hour.
 19 I didn't go near anyone for days before this visit.
 20 During this visit I was still covered from head to toe
 21 in plastic, but the care staff told me that my mum was
 22 so settled that night. I had three visits where I could
 23 sit next to my mum and hold her hand. I was only
 24 allowed inside by myself and for my brother to see my
 25 mum, we had to be outside so we tried to have visits

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1 outside as much as possible. I had three touch visits
 2 in total.
 3 Q. I think you go on to mention ... yes, you mention in 47,
 4 I think it's your mother's birthday, was it?
 5 A. (Witness nods).
 6 Q. And that something as simple as blowing out a candle
 7 wasn't allowed. Presumably —
 8 A. No.
 9 Q. — you could expel air and droplets from your mouth by
 10 doing it, and you weren't allowed to take off your masks
 11 to eat birthday cake.
 12 A. No.
 13 Q. That didn't last very long, these touch visits.
 14 A. No.
 15 Q. And the decision to withdraw those touch visits — and,
 16 again, please don't name anybody — that was a decision
 17 taken by the care home, was it?
 18 A. It was the care provider.
 19 Q. The care provider. And what was, as far as you were
 20 aware — were you aware of the rationale for the
 21 withdrawal of those visits?
 22 A. Initially there was a lot of confusion. Another
 23 relative had contacted me to say that she had tried to
 24 book one of these visits and had been told no. Then
 25 I phoned and the carers had said they had just been told

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1 they were back to distanced visits . I then had to
 2 escalate it , and I was eventually told that the provider
 3 thought that Jeane Freeman was wrong and that these
 4 types of visits were too risky , and they thought we
 5 would have to wait until the vaccinations were in place.
 6 Q. Was the government guidance changed or was that a matter
 7 of interpretation by the care home?
 8 A. The government guidance was for four hours with touch.
 9 That is what the guidance said.
 10 Q. That remained the government guidance?
 11 A. (Witness nods).
 12 Q. But, in essence, it was not followed by the care home?
 13 A. No, we were —
 14 Q. The care home, at its discretion , took the view that it
 15 should not be followed?
 16 A. That's right. That is when we started to hear: guidance
 17 is only guidance.
 18 Q. Paragraph 50, you talk about the longer visits that you
 19 had with your mother, and that you noticed that her
 20 mobility had declined a lot.
 21 Just explain how you noticed that? What was it
 22 about her that brought that home to you?
 23 A. Well, the distance visits , quite often my mum would
 24 already be in the car park or she would be in the room
 25 or she would be in the garden already, because you had

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1 to be escorted in and out, and so I would just see my
 2 mum sitting in a chair . But those longer visits I had
 3 with her, because I was allowed to touch her, especially
 4 if we were inside, my mum would get up or — if there
 5 was music on — we would just do — I didn't want her
 6 just sat still . But because I got to spend that time
 7 with her on our own — and that is not a criticism,
 8 because I knew she had to be supervised — so I could
 9 look after my mum, and if she got up I would help her,
 10 that I noticed she was kind of more shuffling, and
 11 certainly much slower.
 12 Now, I hadn't said anything about that initially
 13 because we were getting these four hours with touch, so
 14 I thought: well, I can work on this with my mum. But
 15 when the provider chose not to follow that guidance,
 16 that is then when I asked for essential visits because
 17 of what I — the deterioration I was seeing.
 18 Q. Now, you would be applying your assessment of that
 19 against your mother's situation really pre—pandemic and
 20 her ability to mobilise at that stage. So in that
 21 period of time, how would you describe the extent of the
 22 deterioration in her mobility?
 23 A. Prior to the pandemic, there was a couple of times my
 24 mum just had unexplained bruising, which again, as we
 25 have mentioned, it is not a criticism of anybody.

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1 Because of her spatial awareness, sometimes she would
 2 have bruises on her face because she would literally
 3 just walk into things, or she bends down quite a lot as
 4 if she sees something to pick up, so she could maybe
 5 bang her head off something. So they put her on hourly
 6 checks, which were almost just to find out where she
 7 was, because she was just always on her feet. So then
 8 when you suddenly see somebody who is shuffling, that is
 9 quite a deterioration .
 10 Q. Once you noticed that restriction or change in her
 11 mobility , you requested, as you say in paragraph 50,
 12 essential visits , and you say at first you didn't
 13 receive a response. You pursued it, and were told by
 14 the manager that your mum didn't meet the criteria.
 15 A. Yes.
 16 Q. I think you escalated that further after that, and you
 17 were told at some point that essential visits were for
 18 end of life only, and that she was — this is the
 19 care home manager — keeping residents safe.
 20 You did escalate that further. What was the outcome
 21 of escalating it further?
 22 A. I escalated it to the CEO, who I knew through the
 23 government meetings and who had asked me to trial the
 24 visits . I had a very lengthy conversation with him.
 25 I made it very clear I didn't want to be in the

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1 building, that I wanted to walk with my mum in the
 2 garden. I didn't want to put anybody else at risk,
 3 I wanted to keep my mum as safe as possible being
 4 outside, and I also wanted to keep her — I didn't know
 5 how often she was getting out, so fresh air would be
 6 good for her. And he said to me he would do what he
 7 could to get me essential visits and to leave it with
 8 him.
 9 He then contacted me — he sent me an email about
 10 a week later, and I think I was about at Haymarket when
 11 I read it, and I think I was hysterical the whole
 12 ten—minute walk I had to do before I could get a hold of
 13 him on the phone, and he just told me that the manager
 14 had spoken to the Care Inspectorate and social work, and
 15 they were all in agreement that my mum didn't meet the
 16 criteria .
 17 Q. They were in agreement with that?
 18 A. They were in agreement. Nobody asked me for any
 19 opinion. Social work hadn't been near my mum for years.
 20 We never had any need for the Care Inspectorate.
 21 I couldn't — I could not get my head around how
 22 a decision had been made with nobody actually seeing my
 23 mum, knowing my mum, asking my opinion of anything.
 24 So I then phoned the Care Inspectorate — I spent
 25 the rest of that day on the phone to the Care

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1 Inspectorate and social work explaining what had
2 happened and questioning things. The Care Inspectorate
3 actually turned around and said that they were wrong,
4 but there had been no recording of the conversation, so
5 my only option would be to make a formal complaint. And
6 when I spoke to social work, it was the duty social
7 worker who had made this decision and it would be
8 recorded on my mum's file.

9 Q. So did you get an essential visit at any stage
10 thereafter?

11 A. I did, about a month later. The manager was off sick,
12 so the assistant manager was acting up, and this was
13 when the lateral flow tests were just being introduced,
14 and I think Jeane Freeman had pushed for the lateral
15 flow tests, all the training to be done, so that
16 relatives could have a Christmas Day visit, because we
17 were going back into lockdown on Boxing Day. So by the
18 time the training was done, it only really left about
19 a week's window, and for some reason the assistant
20 manager gave out the four or five Christmas Day visits
21 without telling all the relatives. It seemed that
22 whoever had asked got a visit, and by the time I asked,
23 there were no visits left, and he had given five
24 one-hour visits. It's a 40-bed home.

25 So I had complained about this and ended up speaking

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1 to an area director about this, and went through the
2 whole scenario over essential visits, and he promised me
3 he would do what he could. And somehow he phoned me
4 back on Christmas Eve to tell me that I had essential
5 visits and a Christmas Day visit.

6 Q. We will come to that in a moment.

7 Outside visits did continue during this time, as
8 I understand it?

9 A. No, the assistant manager stopped outside visits --

10 Q. Oh, that had been stopped, had it?

11 A. -- because it was too cold.

12 Q. Right.

13 Just probably taking this slightly out of order, but
14 at paragraph 61 of your statement, you say there that:

15 "The duty nurse stated that this didn't sound like
16 something this member of staff would do. They stated
17 that if my mum was my priority, I wouldn't have her
18 sitting out in the cold."

19 And you told the nurse that:

20 "... I wasn't a liar and that I was doing my best so
21 that my mum could see her children."

22 Just explain the context of that, please.

23 A. So for my mum to see my brother and I, it had to be
24 an outside visit, and I knew -- I wanted my brother to
25 be able to see his mum, because you couldn't alternate

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1 a visit inside, so we would arrange to go on a weekend
2 and we -- there was a gazebo, a very flimsy gazebo,
3 in the garden, and we would play it by ear every week as
4 to how cold it was, whether we should go ahead with it,
5 we would take advice from the care home, and we decided
6 this day to go ahead with it.

7 The care home provided blankets. We had bought
8 a little hot water bottle to go inside my mum's jacket
9 to keep her warm. So we were sitting in the garden with
10 her, and my mum has a little twitch where she bounces
11 her knee, and the carer kept putting her hand on her
12 knee, and I asked her not to do it and she said, "Your
13 mum's cold", and I said, "She's not cold, that is her
14 little twitch". She had only been out for five or
15 ten minutes, and I said, "We are not staying because it
16 is getting cold". And other comments were made that
17 just played on my mind.

18 So later that day I phoned back just to ask had my
19 mum been cold, what was she like when she went back in,
20 and that is when I was told that if my mum was my
21 priority, I wouldn't have her sitting out in that cold.

22 Q. What was your reaction to that?

23 A. I was devastated.

24 Q. I think you have taken us on -- it is my fault entirely,
25 Ms Leitch, but you had taken us on to Christmas

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1 essential visits. I think you talk about that at
2 paragraph 65 and following.

3 You were able to secure, as I think you have
4 indicated, a Christmas visit, but I think you surmise
5 that that may well have been due to your involvement in
6 Care Home Relatives. Why do you do that?

7 A. Sorry?

8 Q. Why do you do that? Why do you make that assumption?

9 A. I think because I knew the guidance inside out by this
10 point. I probably knew more than some of the staff in
11 the care homes, and because of the people from that
12 provider that were in the government meetings, they knew
13 who I was.

14 Just to go back to your previous point about that
15 nurse's comment, that comment devastated me that much
16 that I was signed off my work the next day, because
17 I couldn't do any more than I was doing for my mum, and
18 to be told, "Your mum isn't your priority", when I was
19 doing every single thing in my power that I could do,
20 that broke me, and that is when my work kindly said
21 I could have carer's leave to continue my involvement in
22 Care Home Relatives, as opposed to having to make back
23 the time, because I still do have a full-time job.

24 Q. Can you go on to paragraph 69, to March of 2021. This
25 was the first time you were able to take your mother out

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1 in a car, and this, as you say, still only allowed
 2 30-minute visits within the home.
 3 How was that escalated up to you being able to take
 4 your mum in a car?
 5 A. I asked.
 6 Q. Simple as that?
 7 A. Yes. I think because, as I said to you, I always took
 8 my mum out. You know, I know there will be a time when
 9 I can't take her out, and I think she spends far too
 10 much time in that home. So that was always my
 11 driver: get her out, she has been in there for a year.
 12 So I asked if we could go to the cemetery and explained
 13 the length of time it would take. But I do think the
 14 driver behind that was the work that Sheila within her
 15 group had done with the IPC consultants, that I had a
 16 leaflet of how to take somebody out safely in the car.
 17 Q. Is this the work that had begun with, going back several
 18 months, the letter to the Nursing Times that we talked
 19 about —
 20 A. Yes.
 21 Q. — and that higher level of infection control?
 22 A. Yes.
 23 Q. What was your mother's reaction to being taken out in
 24 the car?
 25 A. I think I go on to mention in that that I was a bit

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1 anxious: would she know how to get in the car? Would
 2 she get car sickness? Because it had been over a year
 3 since she had been in a car. How would she respond?
 4 But she did okay. She still could get in and out the
 5 car.
 6 But I think that was the first time I really
 7 realised how distant she seemed, because whenever we
 8 were in the car, we would always have music on. Music
 9 is probably the best medicine you can use with somebody
 10 with dementia, and she would either hum or tap her foot
 11 or tap her hands or try to sing along with the music.
 12 We always had a bit of a laugh in the car with music.
 13 And she sat next to me and there was no reaction at all.
 14 Q. Did I pick up that you were able to take your mother and
 15 give her access to relatives that she had not seen for
 16 a long time?
 17 A. Yes. I took longer than 40 minutes that day.
 18 Q. You stretched it.
 19 A. (Witness nods).
 20 Q. Okay.
 21 You do say at the end of paragraph 70 that you
 22 became aware, at least, that your mother seemed to be
 23 more like her old self.
 24 A. It was like rebuilding a relationship or reconnecting.
 25 Maybe she had to get used to me being there again, but

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1 that — it was a blessing, I guess, that she did. Her
 2 old self came back a little bit with the music. We
 3 would always have a laugh. Neither of us can sing, but
 4 we try, and you would get the odd little smile, the odd
 5 little giggle, so ...
 6 Q. Okay.
 7 As you said, and as you have just said, you say it
 8 seemed odd having to build a relationship with your
 9 mother.
 10 A. (Witness nods).
 11 Q. Again, can I just ask you, what was your feeling about
 12 having to do that?
 13 A. Well, as Natasha explained earlier, every day you lose
 14 a bit of your mum when there is dementia, every day her
 15 brain is deteriorating, and you don't know if you can
 16 rebuild anything, you don't know if you can get anything
 17 back. So it's always a little bit of apprehension as to
 18 what is still there. I mean, I was delighted she could
 19 still get in a car. She can still get in my car today.
 20 But that whole thing about: does my mum remember how to
 21 kiss anybody? And, I mean, I absolutely — other than
 22 pushing my 40 minutes, I stuck by all the rules.
 23 I always kept my mask on in the car. The windows were
 24 open. I wasn't going to do anything that put my mum at
 25 risk. So by the time you were able to give her a little

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1 kiss or ask her for a kiss, you are very apprehensive
 2 because, if that has gone, then how do you deal with
 3 that? Because with dementia, you are constantly waiting
 4 on the next thing to go.
 5 Q. Can we go to paragraph 76, please. This is about
 6 a revision of the guidance to say that testing was only
 7 necessary if the resident had been somewhere mixing with
 8 others. You say on one occasion a carer insisted that
 9 your mum was to be tested before you went out, and you
 10 refused to allow that to happen because, as you said, it
 11 wasn't in the guidance. Again, from what you have said
 12 earlier, you were probably more of an expert on the
 13 guidance than anyone else in this scenario.
 14 A. It was, because I think we had come up against this in
 15 guidance, when they introduced that a resident had to be
 16 tested before they went out and when they came back, and
 17 I asked: what if the resident isn't going anywhere?
 18 What if they are just going out for a walk outside of
 19 the care home or they're just going for a run in the
 20 car? Because I would have still been testing at that
 21 time. And that was when the government guidance then
 22 reflected that.
 23 But I remember sitting that night with the guidance
 24 on my phone showing the carers: my mum doesn't have to
 25 be tested. And it was a carer that had been there for

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1 a long time and we have a really good relationship with
 2 her, and she was in tears saying, "Don't make me fall
 3 out with you because we have to test her". I stood my
 4 ground and I said, "I am not consenting to you testing
 5 her because the guidance says ..." and they said, "We
 6 don't have to follow government guidance".
 7 Q. I think you indicate at the end of paragraph 76 that
 8 this highlighted the lack of understanding and confusion
 9 of guidance.
 10 A. The last thing -- I mean, as I say, I have a lovely
 11 relationship with the carers that are still at my mum's
 12 because they have been a huge part of our family for so
 13 long. The last thing I want to do is get into
 14 a stand-off or have them in tears. But it was so
 15 frustrating. And as I say, I know more about care homes
 16 than I ever, ever wanted to know, but I knew that
 17 guidance inside out, and my mum just wasn't being
 18 tested.
 19 Q. This was a put your foot down moment, was it?
 20 A. Absolutely.
 21 Q. You tell us at paragraph 78 that, in August 2021, you
 22 tested positive for COVID. What were the consequences
 23 of that?
 24 A. I got another row from my brother.
 25 My mum was classed as a close contact and isolated

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1 in her room. Again, that is the guilt that you have
 2 done this. So I thought the only way I could try and
 3 help my mum was to see if I could get her tested to see
 4 if she had COVID, because things were so -- opening
 5 up -- well, they had opened up for everybody else, and
 6 there was different -- sorry, the restrictions had
 7 loosened, so that if you were deemed as a close contact,
 8 you could take a lateral flow test and go about your
 9 daily business. So I thought the least I can do is get
 10 somebody to treat my mum in this way.
 11 I contacted Public Health and they just flatly
 12 refused to test my mum. I pushed and I pushed, and then
 13 they eventually agreed, but then said it wouldn't matter
 14 what the result was; she wasn't coming out of her
 15 isolation. And at this very point, Nicola Sturgeon was
 16 a close contact, but was able to take a lateral flow
 17 test and attend Edinburgh Book Festival.
 18 Q. You say that generally this was an issue that you raised
 19 with government, and your belief is that the guidance
 20 was revised in October/November.
 21 How was it revised, do you remember?
 22 A. Because of our group raising it. It was ... I don't
 23 know. I work in health and social care now. Previously
 24 to me looking after my mum, I worked in corporate
 25 banking. I did a little bit of project management where

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1 you would trial every possibility, you would trial every
 2 outcome, you would look at every possibility that could
 3 come up, and when things were so open for the general
 4 public, it seemed as if nobody was thinking through this
 5 guidance and what the implications would be. Because it
 6 seemed to be people within our group that hit these
 7 blocks, which then meant we had to go back to the
 8 government and say: this doesn't make any sense. This
 9 happened on a couple of occasions with my mum.
 10 But why was that left to a group of relatives? Why
 11 did nobody else think this through? Because we made
 12 enough noise about it, but it wasn't about making noise;
 13 it was just about pointing out the obvious. If
 14 a care home resident is only going out the front door
 15 for a walk or going for a run in the car, or going to
 16 one person's house that there is nobody else in there,
 17 why do they have to be tested? And you would present it
 18 and they would go: yes, you are right, we had better
 19 change that guidance.
 20 Q. Was it a surprise to you that that rationale had not
 21 been thought about?
 22 A. Knowing what I know now, no. But I was at the time.
 23 Q. I am not quite sure I follow that.
 24 A. At the time I would think: well, why haven't you thought
 25 about this? But then having gone through all this for

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1 three years, you can understand now why nobody did.
 2 Q. And why do you think nobody did?
 3 A. I think it's like we touched on through our group
 4 evidence, there was no one person in charge that
 5 understood care homes or understood how care homes
 6 worked. We have heard repeatedly about Public Health.
 7 They had people drafted in from Public Health -- from
 8 all different areas of Public Health, areas I don't even
 9 know. But some of these people had never set foot in
 10 a care home. Did they think the residents didn't go
 11 out? There was just this lack of awareness of what life
 12 is like in a care home.
 13 Q. Just on the point of, I suppose obliquely, the concern
 14 that you had that one person wasn't in charge, you do
 15 say in paragraph 79 -- and this is under reference to
 16 the Christmas 2021 bubbles that we all heard about --
 17 that that was one of the very few times Nicola Sturgeon
 18 mentioned care homes in the same breath as the public,
 19 and I think we have heard that from your colleague,
 20 Natasha Hamilton, this morning.
 21 You say in paragraph 80:
 22 "Our relatives were rarely spoken about in the
 23 public briefings. This made me feel as though my mum
 24 didn't matter."
 25 I suppose it is really, again, asking you the

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1 obvious, but reflecting a disappointment that there was
 2 not, within the public briefings, mention of care home
 3 residents.
 4 A. Yes. I think the way everything was dealt with in
 5 Scotland, you know, it seemed to me like most of the
 6 population would join these briefings to find out what
 7 was going to happen, what was going to be the next step.
 8 So you kind of joined with baited breath waiting to hear
 9 and then care home residents just never appeared in
 10 that. So that feeling, yes, my mum just didn't matter;
 11 she wasn't on anybody's radar.
 12 Q. I think you have mentioned this in the course of your
 13 group evidence last week, but you did ask to meet the
 14 former First Minister, and you raise that in
 15 paragraph 81 of your statement, but that didn't happen.
 16 A. No, and I think it was more than twice that we asked to
 17 meet her, and certainly in meetings we would bring it
 18 up — I think there were three times we wrote officially
 19 asking for a meeting and then in various meetings we
 20 would ask for a meeting, but it never happened. I think
 21 one of the harshest points was when Monica Lennon MSP,
 22 who has always been a great supporter of Care Home
 23 Relatives, raised it in Parliament and — well, she said
 24 in Parliament that Natasha's mum had passed away and
 25 Nicola Sturgeon never acknowledged that.

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1 Q. Can I just take you forward a little to paragraph 84 and
 2 the events running up to Christmas 2022. Because
 3 I think what happened then was that there was
 4 a statement put out on Christmas Eve in relation to your
 5 mother's care home that Public Health had stated that no
 6 visits were to be allowed. Again, probably obvious but
 7 what was your reaction to that, given that that was the
 8 third Christmas?
 9 A. I knew that that Christmas wasn't going to be as we had
 10 planned because there was norovirus, suspected flu and
 11 suspected COVID within the home. So it had gone to the
 12 three named visitors, which is kind of the foundation of
 13 Anne's Law. It had been agreed that I would go in and
 14 see my mum and, if she wasn't impacted by any illness,
 15 I would take her out and she would see my brother on
 16 Christmas Day at his house. However, it was about
 17 8 o'clock on Christmas Eve I got the phone call. It was
 18 absolute sheer disbelief that I was being told this, and
 19 even the poor nurse that had to make those phone calls,
 20 she said to me "I've been nursing 30 years and I have
 21 never heard of a care home being closed for flu", and
 22 that was a resident had tested positive for flu. I said
 23 to her on the phone that I had essential visits on the
 24 care plan and that I would be coming in to see my mum,
 25 unless my mum was poorly in any way, but that I would be

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1 coming in to see her. She knew that essential visits
 2 were on the care plan, so she didn't have a problem with
 3 that.
 4 Q. I think you mention in paragraph 84 that Public Health
 5 reversed that decision on Boxing Day night without any
 6 explanation.
 7 A. Yes. I have still — I still — words fail me about
 8 this; after everything that we have been through,
 9 somebody made a decision to ruin Christmas again. I saw
 10 families shouting through windows on Christmas Day last
 11 year. The place was so empty. We had — there was —
 12 quite a lot of new people have moved into my mum's, so
 13 you don't really see families, but I knew there was
 14 a lady who had moved in, her and her husband must be in
 15 their late 70s, married for forever, he really struggles
 16 with his wife being in that care home. He had been
 17 planning to have his Christmas lunch with her and that
 18 was ruined on a locum's decision.
 19 Q. Yes, I think you mentioned that it was a locum's
 20 decision.
 21 A. Yes. I know there were people that were preparing for
 22 that to be their last Christmas because their relatives
 23 were really poorly, and I just think what they did was
 24 unforgivable. I wrote to Kevin Stewart and the
 25 government team. I don't think it was Christmas night

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1 but probably the next day. I have no doubt that
 2 somebody went through Public Health and that, as I say,
 3 the decision was reversed within 48 hours. But that
 4 highlights the risk and the threat that we all live with
 5 that somebody can make that decision. I also know that
 6 quite a lot of the families impacted, they haven't lived
 7 through the pandemic. They don't know the guidance.
 8 They will just take what they are being told, and
 9 I think Natasha touched on it earlier, there has to be
 10 some commitment to making people aware of the guidance
 11 or the rules or whatever they need to do, so that nobody
 12 can make that decision. You know, Kevin Stewart said it
 13 was a blip. I don't think it was a blip. I think it
 14 was luck that it happened to my mum's home, because it
 15 was me that flagged — I got in to see my mum. I didn't
 16 have to contact the government, but because it happened
 17 to my mum, or to the home — but how many care homes up
 18 and down this country has that happened to, that people
 19 don't know and are just taking everything on face value?
 20 Q. Finally, Ms Leitch, can I ask you just a little bit
 21 about Anne's Law, because you have talked about this in
 22 your organisational statement. Could you go to
 23 paragraph 93, please in your statement. I think
 24 you make the point that it was the party of government's
 25 election manifesto to deliver Anne's Law and that you

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1 still don't have it, and you have made the point about
 2 that in your organisational evidence. Perhaps one thing
 3 taking on from that, do you have any optimism as to
 4 whether Anne's Law will be enacted?
 5 A. I have to.
 6 Q. Is that realistic ?
 7 A. I have to hope it is, because we have been doing this
 8 for three years. It has been helpful that since the
 9 start of the Inquiry that there has been a lot of focus
 10 on Anne's Law. Other MSPs have picked up on it.
 11 Alzheimer Scotland raised about it being watered down.
 12 I would like to think that they have to change it. And
 13 I think, as Natasha said as well, I don't think any of
 14 us will stop until it is changed. Because no one should
 15 have the right to cut my mum off from the ones that mean
 16 most to her, and I think every one of us in this room is
 17 an accident or illness away from needing care, and we
 18 need to be thinking about how would we want to be
 19 treated if we were to end up in full-time care.
 20 Q. Another point in that same section of your statement,
 21 94, paragraph 94, you mention I think a recurring
 22 criticism of the government was that it would roll out
 23 advice or guidance late on a Friday afternoon, and you
 24 say that they continue to do this. Has that changed in
 25 any way, do you know?

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1 A. There is certainly not the volume of guidance coming out
 2 anymore. I know it has been raised many, many times by
 3 various different sectors — or partners within the care
 4 sector about the Friday afternoon guidance, but what it
 5 would mean is, because we had seen — we had seen what
 6 the proposed change is in advance, we would have fed
 7 back on it, we knew what was coming and then we would
 8 probably very quickly do a bullet point summary and get
 9 that up on our group so that, by the time the managers
 10 were even in on the Monday to pick up the guidance, our
 11 members knew exactly what was expected. Because it was
 12 always a huge lengthy document, so what we would — or
 13 Sheila, Sheila was the expert at it, Sheila would
 14 condense it into bullet points to say: this is what you
 15 need to know. I don't know when the last guidance came
 16 out, but it certainly — it was something we continually
 17 fed back, but it didn't really change.
 18 Q. Could I take you on to what is one of your concluding
 19 points, paragraph 105 in your statement, please.
 20 Perhaps you would just read that, because I think it
 21 does encapsulate a lot of what you have already said.
 22 A. People with dementia were disproportionately affected by
 23 the pandemic. The removal of routines and familiarity
 24 has a significant impact on an individual with dementia.
 25 My mum would have declined cognitively anyway due to her

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1 condition, but I feel that she declined faster,
 2 especially in terms of her mobility, due to the
 3 restrictions on her and in the home.
 4 Q. You go on to talk about your inability to enforce any of
 5 the powers under your power of attorney.
 6 A. Yes.
 7 MR GALE: Ms Leitch, that is all I have to ask you. Thank
 8 you very much indeed.
 9 THE WITNESS: Thank you.
 10 THE CHAIR: Yes, thank you, Ms Leitch.
 11 Very good, ladies and gentlemen.
 12 MR GALE: That's the end today.
 13 THE CHAIR: Friday, I'm afraid, at 10 o'clock. Thank you.
 14 (3.15 pm)
 15 (The Inquiry adjourned until 10.00 am on Friday,
 16 10 November 2023)
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