Witness Name: Clare Cole
Statement No.: 1
Exhibits: CC/01-CC/02
Dated: 2 July 2024

UK COVID-19 INQUIRY

WITNESS STATEMENT OF CLARE COLE

I, Clare Cole, of Personal Data will say as follows:

1. I make this statement in response to the UK COVID-19 Inquiry's request for evidence pursuant to Rule 9 of the Inquiry Rules 2006. Within this statement, I have set out my experience as a family carer during the COVID-19 pandemic. In particular, I set out the impact that visiting restrictions and infection prevention control measures had on myself and my father, when he was admitted to hospital during the pandemic.

2. I have prepared this statement in liaison with solicitors at Leigh Day who represent Core Participants John's Campaign, Care Rights UK, and the Patients Association in Module 3 of the COVID-19 Inquiry. They asked me to address questions based on the Inquiry's Rule 9 requests via email. Except where I indicate to the contrary, I make this witness statement on the basis of facts and matters within my own knowledge. Where these facts and matters are within my own knowledge, they are true. Where the facts and matters in this witness statement are not within my own knowledge, there are true to the best of my information and belief.

Background

3. My father, Bruce, was diagnosed with Parkinson's in January 2018. He was living in France as my family had moved to Paris in 1977 due to his job. My mother died in 2014, so when he was diagnosed with Parkinson's he was reliant on my brother and myself for support. My brother also lives in France and is the main earner for his family, so we all decided that the best option was for my father to move back to the UK and for me to be his primary support and carer.

4. With our help, in October 2019, my father moved to a large village in England circa 1.5 hours away from me where he still had several friends. Unfortunately, his condition progressed much more quickly than we expected so although he was still able to drive, cycle, go for walks, and enjoy a range of cultural pastimes, he found 'life administration' and settling back into life in the UK difficult. He also lost social confidence (especially as his voice weakened), and confidence to travel alone.

5. To help give my father maximum quality of life and the ability to live 'independently' I decided to give up my job in October 2019 to support and care for him. Being a carer had a huge impact on my life, and the life of my family. I was away from home one night a week at first, and by 2022 three nights a week, managing all aspects of his life. I ran my father's house (administration and cleaning); organised and attended all his medical appointments; made sure he did his Parkinson's physiotherapy and speech therapy exercises (in person or over Facetime); took him on holiday; and ensured that he saw his friends and family regularly. When I was not with him, we spoke several times a day, and had one hour Facetime calls each morning to ensure that he did his Parkinson's exercises.

Impact of the pandemic on our family and care for my father

6. The COVID pandemic had a huge impact on our lives. In mid-February 2020, my father who was following events unfolding in France decided to 'lock himself down', well ahead of the UK. This meant that I was the only person he socialised with in person, and he no longer wanted to go to places with other people, restricting himself to outdoor pursuits such as walks and cycle rides. Once the first lockdown in the UK started, I no longer entered his house, but drove the 3-hour round trip to his house in a day, staying in the garden and doing all his shopping. The disruption to medical services meant that routine care was harder to access – we ended up paying to see his neurologist and his dermatologist privately to ensure timely care.

7. I do not have any care qualifications but was registered as his carer with the NHS which meant that I received each round of COVID vaccinations sooner than my age group.

8. During the pandemic, I limited my own social contact much more severely and for much longer than we were required to do by the Government as I was terrified of contracting

COVID and infecting my father. This also limited my husband and my children who were in their late teens/early twenties. I did not want to go away on holiday if my father was not with my brother in France and sometimes my brother came to stay with him in the UK, so that I felt I could go away.

9. Prior to his fall which led to his hospitalisation and ultimately his death (as set out below), my father was managing to live ‘independently’ with my support (although from April 2022 we arranged for professional carers to call in briefly first thing in the morning and in the evening on days when I was not with him to make sure that all was well). He had just spent the summer of 2022 in France doing short walks in the Alps and visiting friends. He was participating in the local University of the 3rd Age courses including a ’short walking group’, doing his own local shopping, going to the cinema, reading, seeing friends/going on outings with me, and gardening in his garden and on a small allotment.

My father’s admission to hospital during the pandemic

10. I have set out a summary of my father’s experience in hospital as a blog for John’s Campaign’s website. I exhibit this blog to this statement as **[Exhibit CC/01 - INQ000489908]**.

11. On 8th October 2022, probably around 4.30pm or 5pm, my father had a bad fall at home, possibly down part of the stairs, and was lying in the hall blocking the front door. He was found at 7.40pm by a carer who was unable to go inside because of where he had fallen, but he told her that he was alright and asked her to call me. I arrived at 9.40pm with the key to the back door expecting to help him get up and go to bed. When I saw him, I called 999 immediately. I was advised that an ambulance would take at least 4 hours, and I was asked if I could take him to hospital myself. As he was lying with his head in a pool of blood, unable to move and with unknown injuries from the fall, I did not feel able to attempt this.

12. My father was admitted to A&E in the early hours of 9th October and was lucid at the time of admission but could not remember how he had fallen. He was initially given a head and chest scan, and I was told that he had a bleed on the brain and pneumonia. I was warned that the bleed on the brain would cause a loss of lucidity that would worsen before it improved. After a day in A&E and a couple more days in the Emergency Assessment Unit, he was moved to a geriatric dementia ward (I think this

was on 12th October). He was in intense pain whenever staff rolled him onto his right-hand side to change his pyjamas or bedding. X-rays of his chest and leg were prescribed although it took 3 days for them to actually be done, apparently owing to the lack of hospital porters to take his bed down. I offered to help push the bed myself but was told that I couldn't. When the X-rays were done, the images revealed four cracked ribs and a hairline fracture in his right femur.

13. During his stay on the geriatric dementia ward (12th – 19th October 2022), my brother and I were allowed to spend the whole day with him, officially from 11am to 8pm. Most days we arrived much earlier and were allowed in. My father was completely lucid about everything before his fall, being able to chat about his life at home, current affairs, follow the story of a historical novel he had been reading and that we then read to him, and look at family photo albums answering questions about people and events in the photos. However, he was very confused about the present, thinking that he had been abducted and taken overseas, or that he was staying in a hotel. He also kept trying to get out of bed as he did not believe that his leg was broken - on one occasion I spent five hours standing next to his bed holding his leg still so that he would not move it laterally.

14. In addition to keeping him company, reassuring him, and stopping him from moving his right leg, we also:
    - helped him use a urine bottle when needed so as not to become dependent on incontinence pads,
    - shaved him,
    - brushed his teeth,
    - applied cream to psoriasis on his feet which I normally helped him with at home,
    - did exercises with him 3 times a day as directed by the physiotherapists to combat muscle wastage in the legs and arms,
    - did voice exercises with him to maintain his speech,
    - chose food from the hospital menu that we knew he was most likely to eat,
    - fed him for the first days until he was able to feed himself again,
    - brought fresh fruit, yoghurts, pastries, brioche, and other food that we knew he loved from home as he didn't eat much of the hospital food (because he had Parkinson's he was put on a completely soft diet even though he ate normally at home),
    - programmed the TV set next to his bed to play Radio 4 (it is much too complicated for elderly people to do it themselves unless very tech savvy),

- facilitated video calls with grandchildren, and
- kept an unobtrusive track of the timing of his Parkinson's medication as he was at the stage of the disease where even a 10-minute delay could mean that he suddenly found small tablets hard to swallow.

15. We felt that the care we were providing was giving my father the best chance of recovering from his fall both in practical ways as well as supporting his mental well-being. It was also lightening the burden on a very overstretched and sometimes overwrought nursing team as we were the only constant visitors on the ward.

16. A couple of days after moving onto the geriatric dementia ward, the man in the next bed tested positive for COVID. We took the initiative of putting a mask on my father to try to protect him, but after three days (on 17th October) he also tested positive. It was the first time he had contracted COVID having been extremely careful since February 2020. We were told that he would be moved onto a geriatric COVID ward and that we would no longer be able to see him. I tried to argue that the care we were providing to him was very important, but we were told that we couldn't go onto the COVID ward and that the nurses there would take good care of him and that I did not need to worry.

17. When we returned the following day (18th October) my father was still on the geriatric dementia ward behind drawn curtains as there was no space on the COVID ward. We were given PPE and encouraged to spend the day next to him as he was very ill. The following day (19th October) we found that he had been moved onto the COVID ward but had been placed in a side room, so we were still allowed to see him. He had perked up, was sitting in a chair, and seemed very lucid. He was able to read the Economist magazine, walk short distances with a frame, eat normal food, and chat to us. However, at the end of that day an oncologist came to see him to deliver a very hard piece of news: an investigation of an X-ray had led them to discover that he had prostate cancer. He was devastated as there is a family history of prostate cancer and he had feared it all his life.

18. I had spoken to the oncologist just before he entered the room to deliver the news to my father. I asked him whether he could delay telling my father about the prostate cancer until after he was out of the COVID ward as he would be incredibly stressed. The oncologist said that he couldn't wait as they wanted to start giving him a drug to treat the cancer and it was unethical to medicate someone without their knowledge.

19. On 20th October my brother tested positive with COVID too, but I didn't as I had had COVID myself in late July and had just received the autumn booster. When I arrived at the hospital, I was told that my father had been moved from the side room onto the main COVID ward and I was therefore not allowed to see him. I could not understand this as the previous two days we had been allowed to see him despite him being infectious, and I was concerned that he would wonder where we were. I was concerned that all the additional Parkinsons-specific care/physio exercises that I had been providing would suddenly stop as the nursing staff would not have time, or be in a position to continue them. I was also worried that he would be stressed about the prostate cancer news he had received the day before. I would have been happy to wear PPE and follow the same infection control procedures as the paid nursing staff – they were wearing FFP2 NR masks and normal uniforms.

20. We were allowed to phone him whilst he was on the COVID ward and the staff were good at giving him the phone, but since his voice had become very quiet because of the Parkinsons and no one was doing the speech therapy exercises with him, it was very hard to have a conversation. I also found it extremely difficult to get information about how he was doing more generally from the staff (as set out below).

21. A week later, on Wednesday 26th October, my father tested negative for COVID, but I was told that we were not allowed to see him as he was still on the COVID ward. This was because the hospital did not have any space on the normal geriatric dementia ward for him and some other people in his bay were still testing positive. I was very distressed and kept pointing out that I had had COVID myself recently and had not caught it from him, but to no avail. I was also worried as I had overheard a conversation my father had with the oncologist. We had been speaking on the phone and my father did not hang up when the oncologist arrived. I heard my father ask whether they would operate and was told that they wouldn't, and would treat the cancer with drugs. I was desperate to be with him to support him.

22. I was finally given permission to visit on Friday 28th October, but when I arrived at the hospital the staff were not the same staff that had said I could come, and I was told I couldn't visit after all. I pushed back and pleaded with the staff to let me see my father. In the end I was allowed to see him for 5 minutes – he was very drowsy so not very aware of my flying visit – and also soaked in urine. I raised this with staff as my father was lying with his eyes shut but waving the wet sheet as if he was trying to dry it. The staff I raised this with, said they would change his sheets, pyjamas, and pad.

23. I was not allowed to see my father again until Monday, 31st October when they grouped all those who were testing negative in one bay (a Step Down Geriatric COVID Ward) so that they could have visits. By then I had not seen him for 11 days. I was completely shocked by the state I found him in: dehydrated, unresponsive, and a terrible colour. I was then told that he had stopped swallowing and speaking a couple of days earlier. He was never able to talk to us again. He was not on a drip. He looked very thin and weak – desiccated really. He looked completely different from how he had looked when he was still in the side room of the COVID ward. The physios who came round later that day told me that they had got him out of bed a few times over the past 11 days to practise walking with a frame, but it felt like he had deteriorated significantly. Despite our daily phone calls with staff during which we asked about his progress, we had not been made aware of the fact that he was deteriorating.

24. On the same day, 31st October, I was taken to a side room by the Consultant in charge of the ward and told that he would almost certainly not recover, that he had entered a downward spiral that was virtually impossible to reverse. We agreed that they would try inserting a nasal feeding tube which did happen, but once in place, no food was put into it for a day and a half as the staff said they were waiting for a dietician to visit and give instructions. When the dietician came on the second day, she said to me that she could not understand why feeding had not started as there are starter bottles of food on the ward to use whilst awaiting her visit.

25. The feeding was halted soon after it started. My father had pulled the tube out twice and we were told by staff that because he had pulled it out twice and it was distressing to put the tube in, it was not worth trying again because they did not believe feeding would work by then. We were therefore told that feeding would be abandoned, and he would be given palliative care. I don't know whether this was explained to him.

26. After my father was put on the Step Down COVID ward, a senior oncologist came on 3rd November to tell him that the drugs were working well but that the cancer had spread to his spine. I was present when the oncologist came to speak to my father. They told him that they would see him after he was discharged in the oncology outpatient clinic. Confusingly shortly afterwards, a palliative care nurse arrived and told him that he was now on palliative care. If one team had decided he was dying, I don't know why the oncologists came and told him they would see him in the outpatient

clinic. I felt that the communication around his cancer diagnosis and treatment was confusing and like we didn't get a proper opportunity to discuss and digest it as a family.

27. During his last days, we were concerned about the environment that he was in because although he was now lucid, the other 5 patients on the Step Down ward all had dementia and were setting alarms off, shouting and swearing all day and all night. It was an extremely stressful place for everyone. We asked whether my father could be moved as it did not feel like a dignified place to die but we were told that there was nowhere else to move him. We tried to put earphones in so that he could listen to music and to drown out the noise of the ward. The staff told us on Friday 4th November that they would explore options of moving my father to a hospice on 7th November, but he died in the early hours of the 7th.

28. We stayed by his side looking after him as he gradually got weaker and on 6th November, he developed a temperature. We were told that he had got pneumonia again but that it would only be treated with paracetamol in line with the palliative care protocol. The decision to move to palliative care was discussed with us and we had discussed with my father a couple of years before this that he did not wish to live in a completely diminished state, so we felt we were respecting what he had requested.

29. My father died in the early hours of 7th November, relatively quickly compared to the timeframe we had been given (we were told it could take several days or even a week but in fact he died within 24 hours of getting pneumonia again). We were not present. The causes of death listed on the Death Certificate which I exhibit as **[Exhibit CC/02 - INQ000489909]** are:

    a) Aspiration Pneumonia,
    b) Oropharyngeal Dysphagia,
    c) Parkinson's Disease II, and
    d) Hypertension, traumatic brain injury, COVID-19 Infection, metastatic prostate cancer.

30. I found the phone call I received to inform me of my father's passing very upsetting and later raised with the hospital that I didn't feel it was handled as it should have been. I was woken by the call and told very matter of factly that my father had just died and was then asked about whether someone was coming in to view the body. I did not feel that the conversation was handled sensitively or compassionately. I was also upset that we were not with my father when he passed away and that I didn't realise how quickly we were going to lose him.

31. Although my father, brother and I were able to be together on the Step Down COVID geriatric ward for the last few days of my father's life, the man who came out of the COVID isolation ward was unrecognisable compared to the man who was placed on the isolation ward 11 days earlier. After being cared for by us so intensively on the geriatric dementia ward during his first 12 days in hospital we were then totally excluded from his care, except for phone calls which were unsatisfactory as his Parkinson's made speaking on the phone difficult. I fear that the sudden and dramatic separation from us caused my father distress and despair, and potentially resulted in him giving up hope of recovering from the fall. This was exacerbated by being given news about prostate cancer when no one was there to support him. In addition to the negative effects that the enforced separation had on his well-being, it has also caused great ongoing distress to me as his primary carer and daughter because I felt unable to provide the essential care that I knew he needed.

The impact of visiting restrictions

32. As set out above, on Thursday 20th October my father was put on the main COVID ward, and I was refused permission to see him. I was told that absolutely no visitors were allowed, and this was for my own safety. I disputed this as I had had COVID for the first time recently (end of July 2022), had just had my autumn booster, was 55 years old and very fit, had been with him when he was at his most infectious, and was prepared to wear/buy any PPE that was deemed necessary. Despite all of this, I was not allowed to see him.

33. I did not see my father again until 31st October (except for 5 mins on 28th October) at which point I was told that he would die. The lack of access to him meant that he was alone for 11 days with very occasional phone calls from my brother and myself which were extremely hard. It was difficult to get through to the ward at all (even going through the switchboard), and when we did manage and the nurses handed him the phone, it was hard for us to hear him as his voice was weak because of having Parkinson's Disease. By the time of his last weekend in isolation my father could hardly whisper 'yes' or 'no' and by Monday 31st October he was no longer able to use his voice at all.

34. When I asked the nursing staff how he was, I was always told that he was taking his pills, so I was expecting him to be fully recovered from the COVID when I saw him next. All the care that I had been giving him up until that point – love, moral support,

attending to his immediate physical needs/personal care, bringing food and entertainment from home, facilitating calls with grandchildren, doing the physiotherapy exercises, monitoring the timing of his Parkinson's medication – stopped from one moment to the next. To make matters worse, the oncologist visit I overheard regarding treatment of his prostate cancer using drugs would have made him feel completely terrified and I had no way of being with him to provide what I felt was essential emotional support. Ironically, we later discovered that the drugs that he was given for his prostate cancer worked incredibly well, but by then it was too late because he had deteriorated so much overall.

35. My brother and I found the 11 days of separation from our father extremely difficult – although we did not realise that he was deteriorating so much. I spent all my time worrying about him, but felt that I should not phone the hospital more than once a day as I did not want to be a nuisance to the staff.

36. When the hospital told me that patients on the COVID ward were not allowed visitors I found it very surprising given the attitude to COVID in the UK by October 2022. To my shame and regret, I did not seek out more senior hospital staff to question them about their policy and whether it followed any remaining national guidance. I assumed it did.

37. I did have COVID-19 tests available to me at the time (they were tests we had kept from when they were available free of charge during the pandemic) and as set out above, I would have been willing to wear PPE and take other precautions, but this did not make any difference to whether I was able to visit my father. As outlined above, I tried to set out all the infection control steps I could take to ensure safe visiting, but this did not change the staff's approach to refusing access to my father.

Communication over the phone

38. As I explain above, we were offered the opportunity of communicating with my father by phone. We were given a direct number for the COVID ward and when we managed to get through, a nurse would take him the handset if it was a good time to speak to him. We did manage to get through on several occasions, but it was quite difficult to get through and we sometimes had to go through the main switchboard. Having a conversation was really hard as my father's voice was very weak because of the Parkinson's and because he wasn't doing his speech therapy exercises. By the final couple of days of his isolation he was unable to say anything. I had enquired about

leaving his iPad with him to have Facetime calls, but the staff were not keen to have high value items on the ward, and I did not know whether it would stay charged and be within reach if I left it, so in the end we relied on the phone.

39. Although the nursing staff were very kind when we got through, I did not have any idea of the condition my father was in and how much he was deteriorating. The staff did not give details or assessments of my father's condition at all – all the information I was given was very basic and high level – it was limited to telling me he had taken his pills. As my dad became less and less communicative, I was under the mistaken impression that I was calling at bad times and that perhaps this was affecting my dad's ability to speak to me (rather than a general decline in his condition) so I did not realise how much my father was deteriorating.

40. On the evening of Wednesday, 26th October, I was getting increasingly worried and asked to speak to a different member of staff in the hope of getting a more detailed update – I wanted to know how my father was beyond whether he had taken his pills or not. I spoke to the nurse in charge of the ward that day. It was only then that I discovered my father was not doing well. It was that staff member who suggested I visit my father on Friday, 28th October. She said she would seek permission for me to visit and confirmed that I had been granted it on Thursday, 27th October. She said that she would make sure staff knew I was coming the following morning, but when I arrived different people were on shift, and it was only after being very insistent and saying how far I had come that I was allowed in for 5 minutes. My father did not look well, was soaked in urine, and did not open his eyes. When I saw him a few days later, on Monday, 31st October, I was incredibly shocked – there had been an even more dramatic deterioration over the 3 days between the 28th and 31st.

Raising my concerns with the hospital

41. In late January 2023 I had a Zoom meeting with a Consultant, the Head of Nursing and the Chaplain at the hospital and received an apology. This followed a complaint I made to the Patient Advice and Liaison Service (PALS) because I had not been allowed to visit / be with my father on the COVID ward and because I didn't know what had happened when he died, and whether he had been comfortable as no one was able to tell me this on the day he died. I also wanted to let them know how I was told that he had died, and about communication problems we had with the nursing staff, including about the limited information we had been given about my father's condition. The staff

member I spoke to said that with hindsight they felt that I should not have been prevented from seeing my father and that they were going to allow visits going forward. My comments about communication were also noted and I was told they would be taken into account in relation to training for staff. I had not raised my concerns at the time my father was still in hospital because I was concerned about jeopardising his level of care if I was perceived as pushy and difficult.

The impact of other Infection Prevention Control measures/other aspects of the pandemic on healthcare

42. By October 2022, it seemed that all government policies and guidance regarding COVID in everyday life had been dropped. There were no testing requirements – even to visit a hospital. The hospital in question did provide masks at the entrance and ask people to wear them but this was not observed by most people on the ground floor (café and shops).

43. As explained above, the main Infection Prevention Control measure that impacted my father, my brother and I was the hospital's decision to completely restrict access to the COVID ward.

44. As a result of the pandemic and the pressure on the hospital, some of the services that my father needed were either delayed (the follow up X-rays that determined that he had broken his ribs and cracked his femur) or much more infrequent than staff admitted were necessary (the physios came twice a week and not daily). The physios asked me to do the exercises with my father regularly as they did not have time to come each day, but this stopped when I was deprived of access to him. I do not know whether the late arrival of the dietician to oversee the nasal tube feeding was also due to staff shortages exacerbated by the pandemic, but it is possible.

Conclusion

45. I feel that the last two weeks of my father's life were filled with loneliness, despair, and fear after he was isolated on the COVID ward. I also feel that all facets of his personal care and well-being were reduced dramatically once I was no longer allowed access to provide them to him. I also feel the opportunity of precious final conversations with him was taken away from us as he could no longer speak (and was too weak to write) when we were allowed to see him again. We were left wondering what he was thinking,

whether he was afraid, whether he knew and accepted what was happening, whether there were things we could do or bring for him in his last days, whether he was at peace.

46. I feel that my father should have had a right to our loving presence and care throughout the last weeks of his life. If I had been given permission to wear PPE and care for him on the COVID ward, I feel the risk to myself would have been minimal and greatly outweighed by the benefit to my father, my brother and myself.

47. Indeed, the events surrounding my father's death had, and still have a huge negative impact on my own mental well-being. I feel that I failed him, having promised when he moved back to the UK to always be there for him. I also feel that I did not keep the same promise that I made to my mother on her last day to always be there for my father. I feel a huge sense of guilt alongside the feelings of grief and loss wondering whether I could have done more to pressure the hospital authorities into giving me greater access. I also feel that if I had been kept fully informed about how much my father deteriorated whilst in isolation, I would have pushed harder to be with him.

48. I would like all UK hospitals to modify their visiting policies so that measures are put in place to ensure that vulnerable people are never forcibly separated from their carers and loved ones. I also believe that the right of access to one's primary carer should be enshrined in our national legislation so that it is clear and there is no disparity of application across the UK.

Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Signed: **Personal Data**

Dated: 2 July 2024