

Scottish COVID-19 Inquiry

Witness Statement

Statement taken at 1400 hours on Monday 3rd July 2023 at Thompsons Solicitors, 16-20 Castle Street, Edinburgh EH2 3AT.

Witness Number HSC0008 refers.

Witnesses were interviewed by [PD] Solicitor and [PD] Paralegal. Consent Forms signed. Also present [PD] Solicitor representing Care Home Relatives Scotland.

Organisational Witness Statement of Care Home Relatives Scotland provided by Cathie Russell, Sheila Hall, Alison Leitch and Natasha Hamilton.

Introduction

1. We are Catherine (Cathie) Russell [PD] Sheila Hall [PD], Alison Leitch [PD] and Natasha Hamilton [PD]. We are four of the core members of the group Care Home Relatives Scotland (CHRS). We can be contacted via Thompsons Solicitors who represent us.

2. We are willing to provide a statement, have our information contained within reports and are willing for our statement to be published. We agree to recording the statement.

3. We are prepared to provide evidence at the Inquiry, and we would all wish to speak to our statement. We would like to give evidence together, both to support each other and because each can speak to different parts of the statement. We do understand that this may not be possible, and it may be that only one or two of us can speak to this statement in oral evidence. We are aware that we can withdraw our consent at any time.

4. We have voluntarily provided a number of documents to the Scottish COVID-19 Inquiry which we feel may be relevant.

Our Group

5. CHRS have a set of aims and objectives written in September 2020. These are:

'To enhance the quality of life of our loved ones in care homes, by resuming essential family contact, by working to:

(i) introduce the concept of "essential care giver status" within the Scottish visiting guidelines for care homes,

- (ii) to encourage a person-centred approach, enhancing and supporting emotional well-being and avoiding further social isolation, and
- (iii) (iii) to develop lines of communication with policy makers and represent the views of relatives with loved ones in care homes.'

6. CHRS does not, and has never, received any funding.

7. CHRS has over 2,000 members.

8. CHRS was brought together out of sheer desperation. Desperation to get access to loved ones in care homes.

9. CHRS was founded on 12 August 2020. On that date, Cathie Russell, following discussion with another daughter she had seen comment on Twitter, set up a Facebook group. This lady [PD] was very involved with the work of the CHRS core group up until September 2023, when she retired due to personal commitments. Sheila Hall, whose mother [PD] was in a care home, was put in touch with Cathie via social media. Alison Leitch joined the group in August 2020 having been concerned that there were no organisations speaking out on behalf of those in care homes during the pandemic. Alison's mother [PD] was diagnosed with Alzheimer's in 2007 at the age of [PD] and was in a care home in [PD]. Natasha Hamilton joined the group in August 2020. She had been active in starting a petition in July 2020 regarding visiting rights for those in care homes. Her mother Anne was in a care home, having been diagnosed with Alzheimer's in 2014 at the age of 56. [PD]

[PD] was concerned that the plight of younger adults living in residential settings was being completely overlooked. All were concerned about visiting guidance and the lack of contact with their loved ones in care.

10. The Facebook group grew – membership numbers doubling each day at one point. In August and September, Cathie, Sheila, and others began to write on behalf of the group expressing their concerns about the restrictions and the quality of visiting involved - which all in the group found to be more like prison visiting. As well as Scottish Government and Scottish Government officials, the group corresponded with many bodies including other campaign groups representing residents, MSPs from each political party, the Scottish Human Rights Commission, the Mental Welfare Commission, Human Rights Consortium Scotland, Scottish Care, care home providers, public health, the Care Inspectorate and Alzheimer Scotland.

11. The group started to think about how they could progress matters and bring the plight of care home residents to the public's attention. Cathie has a background in PR and knew that a demonstration would generate significant attention. A long feature highlighting the plight of care home residents and their families was published in the Evening Times.

Next Steps

12. A demonstration was planned outside the Scottish Parliament for 16 September 2020, marking six months from the start of lockdown restrictions and the last meaningful contact with their relatives in care homes. The group's aim for the demonstration was to highlight the issue and get into conversation with the Scottish Government team who were issuing the guidance.

13. The police at the Scottish Parliament were notified in advance by CHRS of the planned demonstration. The group asked those attending to follow social distancing guidance and to wear face masks.

14. The media became aware of the planned demonstration, and the group were invited to speak on the Kaye Adams BBC Radio show on the morning of 16 September 2020. Members of the group also appeared on Politics Scotland that evening to put forward their position and also featured on Reporting Scotland. Sheila and Alison were interviewed on BBC Radio Scotland DriveTime and the demo was covered on many local radio stations.

15. At the demonstration, the group used posters and placards to try and bring attention to the forgotten community of those in care homes.

16. There was a very good media turnout. Members of the CHRS core group have featured in the press and media on numerous occasions.

17. The pressure of the demonstration and media coverage resulted in Jeane Freeman (Cabinet Secretary for Health) inviting the group to meet with her.

18. Members of CHRS met with Jeane Freeman (online) on 18 September 2020. Cathie, Sheila and Natasha were present. Jeane Freeman listened carefully to all the group had to say and explained that they would look at the situation and would call another meeting the following week.

19. The next meeting was delayed until 2 October but at that meeting, attended by all the core group members, all were delighted when Jeanne Freeman told them new guidance would be published shortly and that one relative would be able to see their loved one more often, in the residents own room and touch would be allowed. When the guidance was published on 12 October, it said there could be one meeting a week for up to four hours

however it soon became apparent that very few relatives would benefit from these changes. Jeane Freeman continued to meet the group regularly and was sent surveys which showed the situation with visiting was deteriorating despite the improved guidance.

20. The combination of local area restrictions, reluctance by care homes to adopt guidance, the care sector's fear of litigation as they had not been given the indemnity offered to the NHS, confusion on how guidance was to be interpreted, different attitudes to risk from local public health teams, all acted as barriers to relatives being reunited with their loved ones and thousands of residents died during these months without ever having any meaningful contact with their loved ones.

21. Nicola Sturgeon did not meet with the group despite many requests. CHRS always believed if she had used a daily briefing to explain clearly what was expected of care homes, many residents would have got more contact than they did.

22. CHRS viewed their role, in part, in meeting with Jeane Freeman as explaining what was going on at grass roots level in care homes. For people who did not have a loved one in a care home they simply did not know what it was like 'on the ground'.

23. CHRS saw themselves as essential care givers – active participants in their loved ones care, and not simply just visitors.

24. CHRS were not campaigning for 'open door' access for everyone, but for access to those who were carers prior to their loved ones moving to reside in a care home.

25. CHRS put forward their objective that a family member should have 'essential caregiver' status regarding a loved one in a care home, thus having access to the home in times of restriction.

26. CHRS were concerned that Scottish Government and their Public Health Advisers saw COVID-19 as the only harm. They did not consider the trauma and the effect on mental health that enforced separation from loved ones would cause.

27. Since the start of the COVID-19 pandemic, CHRS have had in excess of 130 meetings with Scottish Government and decision makers. Following the initial meeting with Jeane Freeman these then took place at regular intervals via "Teams". After the Scottish Parliament elections in 2021 contact continued through Kevin Stewart (Minister for Mental Wellbeing and Social

Care) and still continues with Marie Todd (Minister for Social Care, Mental Wellbeing and Sport). Meetings have also been held with The Care Inspectorate and Scottish Care as well as other organisations. (Detailed on the spread sheet that has been provided to the Inquiry by our solicitors)

28. The group's campaign work has been recognised in a series of National Awards. We were finalists in the following –

Scottish Charity Awards – Campaign of the Year

Scotland's Champion - "Making a Difference" Awards

The Herald's Political Awards – "Campaign of the Year"

29. Members of CHRS core group have been invited to give presentations at events, conferences and webinars organised by many different bodies including NHS Lothian, Scottish Care, Trade Union Organisations, Infection Prevention Society, TIDE (Together in Dementia Everyday)

Inconsistencies

30. Following the improved guidance in October 2020, Alison Leitch was asked to take part in a trial involving visits with touch. Three of these visits took place prior to them being halted by the care home provider. The reason given was that the provider felt these visits were too risky and that the Government had made the wrong decision.

31. One major concern of CHRS was that when guidance was published, it was the responsibility of individual care home managers to interpret and implement it.

32. Guidance was not clear and individual care home managers would often err on the side of caution.

33. CHRS heard reports of some Scottish care homes applying English guidance.

34. The group was concerned that care home managers and Public Health Scotland were giving insufficient reasons as to why relatives were being excluded from care homes, often simply citing 'infection control measures' as a reason for refusing visits. Relatives had no right of appeal to these decisions.

35. The group was often asked for their views on the guidance. They played an extensive role, including commenting on and suggesting edits for all versions of the Open with Care Documents. The group has also reviewed guidance produced by public health. In order to clarify the confusing guidance, the group produced their own summary documents to provide clarification for their members.

36. Having seen an open letter in the Nursing Times in October 2020 from IPC Consultant Jules Storr and signed by many prominent members of the IPC community, CHRS contacted the author and they collaborated together to produce the "Enable Safe Care" website and guidance. This received very positive feedback but was never formally recognised or adopted in Scotland.

Anne's Law

37. Prior to joining CHRS, Natasha Hamilton started a petition on change.org in July 2020. (PE1841 refers) She publicised this on social media and was directed to CHRS in August 2020 by Rights for Residents, a campaign for care home residents in England.

38. This petition sought to ensure that people who live in adult care homes have the right to see and spend time with people who are important to them.

39. Natasha had been unable to see her mother Anne for prolonged periods and the petition called for a designated visitor to be allowed into care homes to support loved ones.

40. The petition has more than 97,000 signatures

41. It was placed before the Scottish Parliament Petition Committee in November 2020.

42. It received a lot of media coverage, particularly from the Sunday Mail, which coined the name 'Anne's Law' after Natasha's mother.

43. Anne's Law was added to the SNP manifesto during their election campaign in 2021. It was also included by Labour, Liberal Democrats, and the Green party in their manifestos.

44. Anne's Law has not yet been enacted in legislation. It is being taken forward as part of the National Care Service Bill, however CHRS believes the Bill does not go far enough.

45. Section 40 of the National Care Service Bill still does not give residents the right to have a designated carer/visitor, but gives Ministers (in consultation with Public Health) the power to make directions to allow people into care homes, or indeed to keep people out of care homes.

46. CHRS believes a stronger statement is needed to ensure that at least one essential care giver/visitor will always be allowed into care homes if there are any visiting restrictions imposed.

47. In the meantime, two new Health and Social Care Standards were introduced in March 2022, reinforcing the rights of people in care homes to see and get support from people close to them. All registered adult care homes are expected to meet these standards and they are used by the Care Inspectorate during inspections.

48. The group are concerned, however that because Anne's Law is not yet enacted in legislation, there are no guarantees that another prolonged lockdown that would imprison care home residents and deny them any access to their loved ones could not happen again. For example in December last year, Public Health Fife took a decision on Christmas Eve to stop all visits to a care home, this decision was reversed after 48 hours and later admitted the decision was wrong - but families live with the constant fear that they can be locked out.

Interactions with families

49. During the pandemic, CHRS would assist members of the public. They became a helpline for support, provided moral support as well as giving advice based on their own experiences about how to interact with care home providers, public health, and the Care Inspectorate.

50. CHRS report that throughout the pandemic there was a clear gap in support for those who had loved ones in care homes. There continues to be a gap for support and this is regularly highlighted to Scottish Government.

51. CHRS report families contacting them whose loved ones were receiving end of life care. Those loved ones who were allowed access were afraid to leave the care home at any point in case they were not allowed back in. CHRS intervened for a number of families.

52. CHRS drew up a 'pro forma' letter which could be sent by families to care homes and gave advice on how guidance should be applied.

53. CHRS were concerned that when members contacted the Care Inspectorate for help in getting to see distressed or dying loved ones, care homes often reacted very badly and the relative's relationship with them was adversely affected.

54. Members of the core group made numerous interventions on behalf of members of the wider group. They contacted care home providers, public health and the Scottish Government. These interventions were by Messenger, telephone and by e-mail. The core group often heard of distressing situations late on Friday afternoons when no statutory services were available.

55. When Open with Care was launched in February 2021 and more determined efforts were made to get visiting started, the Action for Rights Service provided by Alzheimers Scotland (funded by Scottish Government) took on this support role very successfully for a short time but no funding was made available to continue this.

56. At the height of the pandemic, CHRS had 2,300 members in their Facebook group. They carried out 11 surveys in total to demonstrate the problems and issues that their members were experiencing with the guidance and its implementation. The group provided survey results to Scottish Government.

57. The CHRS Lost Loved Ones group was set up to provide a place where members who had lost a loved one in a care home during the pandemic could provide support to each other. Many had been unable to be with their loved ones in their last months, days and hours due to restrictions and have found it very difficult to come to terms with their grief.

58. Members of the core group contributed to a range of research on the Impact of Covid 19 restrictions on families of Care Home residents. Members of the wider CHRS group carried out in depth research relating to Care Inspections and Scot Gov statistics, which can be provided to the Inquiry.

Concerns

59. The Government failed to recognise the need for at least one key relative such as a husband, wife, mother or daughter to be given essential caregiver status. We believe that essential caregivers, using all the same mitigations as staff including PPE and infection control protocols, could have ensured their loved one was supported and kept in touch with their wider families throughout the pandemic. Close relatives desperate to see their loved ones were made to feel like the enemy when they should have been welcomed as part of the care team.
60. The Scottish Government failed to provide clear direction to care homes and failed to insist that guidance was adopted and followed. This was despite the fact they laid down the rules in every other sector of society. They claimed they had no 'levers' to do this in care homes but this could have been achieved by amending the Care Standards much earlier or explaining that payment of fees or personal care allowances which go direct to homes would depend on them implementing the Scottish guidance.
61. The Government failed to ensure care home residents benefited from the route out of lockdown. Instead they had no access to services such as opticians, podiatry, hairdressing for more than a year and they were unable to get out in the fresh air. It was seven months after the Chancellor's Eat Out to Help Out before care home residents were even able to go for a walk or a run in the car.
62. As a group, we felt we had no way to challenge these decisions even though we were sure they were unlawful. When your rights are being challenged to this extent, there should be some way to access justice.
63. We felt many others paid by the public purse to protect the interests of vulnerable people failed to speak out on behalf of those in care homes – such as Directors of Social Work and the Office of the Public Guardian. Imprisoning people for a year and isolating people in small rooms for weeks on end should have been challenged.
64. The Scottish Government and their Public Health Advisers failed to recognise the huge impact their policies were having on older people who were approaching the end of life even without Covid, and the impact that such long periods of isolation and confinement were having on the entire care home population which includes a substantial number of young people.
65. The Scottish Government was able to create an impression in the press and media that indoor visiting had restarted, but in huge areas of Scotland, it continued to be heavily restricted with only closed window visits or outdoor visits available. Many people in Greater Glasgow and Lanarkshire had no direct contact with loved ones for a full year.
66. The Scottish Government has never said sorry for what relatives of those in care homes have been through.
67. The needs of young adults in care homes were ignored.
68. When Public Health Scotland produced a final set of Covid guidance in January 23, care home guidance had been amalgamated with the guidance for prisoners. This was only changed after complaints from CHRS.

69. Any one of us could end up in care – lessons must be learned so that this never, ever happens again.

[statement concluded]

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:

18th March 2025.