

**OPENING STATEMENT ON BEHALF OF
CARE HOME RELATIVES SCOTLAND/ CHRS LOST LOVED ONES**

Introduction

1. As a Core Participant to this Inquiry, with leave to appear at the hearings on the impacts of Health and Social Care, Care Home Relatives Scotland/CHRS Lost Loved Ones (“CHRS”) presents the following opening statement in accordance with the direction of Lord Brailsford dated 29th September 2023.

CHRS’s mission

2. CHRS was formed in August 2020 by five daughters and a mother, brought together by shared concerns and desperation at being separated from their loved ones. The founding members recognised the absence of a voice for the relatives of care home residents and sought to work together to provide one. CHRS Lost Loved Ones played a crucial role in supporting people who had lost a loved one in a care home during the pandemic: many had been unable to be with their loved ones for many months, or in their final moments due to the restrictions.
3. CHRS’s overarching aim is to enhance the quality of life of loved ones in care homes, by allowing essential family contact. Its objectives include:
 - introducing the concept of “Essential Care Giver Status” within guidelines for visiting care homes in Scotland;
 - encouraging a person-centred approach, enhancing and supporting well-being and avoiding further social isolation; and,
 - developing lines of communication with policy makers and representing the views of relatives and loved ones in care homes.
4. CHRS has over 2,000 members from all the regions of Scotland, and Lost Loved Ones has more than 100 members. At the height of the restrictions, CHRS had 2,300 members in its Facebook group.

CHRS’s work during the Covid-19 pandemic

5. The organisation played a leading role providing a voice for relatives with care responsibilities who had concerns for their loved ones in residential care homes during the pandemic. CHRS became their unofficial helpline and provided unmet support.

The organisation intervened on behalf of its members by contacting care home providers, Care Inspectorate, Public Health, and the Scottish Government and has played an active role in reviewing Scottish Government and Public Health Guidance. Highlights of its work include;

- In July 2020, Natasha Hamilton, daughter [Personal Data] started an online petition to formally recognise families as partners in care settings along with staff by allowing a nominated family member to enter care homes safely, and have meaningful contact at all times. CHRS continues to campaign for legislative reform due to concerns that the current proposal would not fully implement the true concept of “Anne’s Law”;
- In September 2020, CHRS advised the Scottish Human Rights Commission (“SHRC”) about concerns in care homes which were reflect in the SHRC’s statement to the Scottish Government’s Clinical and Professional Advisory Group for Care Homes¹;
- On 16 September 2020, CHRS held a demonstration outside the Scottish Parliament to raise awareness about the treatment of residents of care homes which was covered in national media;
- On 18 September 2020, CHRS met then Health Secretary Jeane Freeman for the first time. The organisation subsequently attended many meetings with Scottish Government ministers and officials;
- In February 2021, the Scottish Government issued “Open with Care” guidance². CHRS played a key role in the development and monitoring of this guidance;
- On 25 February 2021, CHRS took part in the first meeting of the Open with Care Oversight Group. The meetings are ongoing and CHRS continues to attend what has become the Open with Care/ Anne’s Law oversight group; and,

¹ Scottish Human Rights Commission letter to Clinical and Professional Advisory Group for Care Homes, 1 September, available at:

https://www.scottishhumanrights.com/media/2085/20_09_01_carehomesvisitingletter.pdf

² Scottish Government, Open with Care – supporting meaningful contact in care homes: guidance, 24 February 2021, available at: <https://www.gov.scot/publications/open-care-supporting-meaningful-contact-care-homes/>

- CHRS carried out 11 member surveys to highlight problems and concerns about guidance and implementation and contributed to the Creative Covid research on the impact of the restrictions on family of care home residents.³

The impact of the Covid-19 pandemic on people in care homes

6. CHRS members were, and are, acutely aware of the risks that COVID-19 posed to their loved ones. They did not expect life to continue as normal, particularly in the early months where there was no indication of when, or if, a treatment or vaccine could be contemplated. However, they believe that with PPE and effective infection prevention and control, at least one relative should have been able to continue their caring role, using the same safeguards as staff. The failure to allow for that care to continue meant that:

“Over the months of the pandemic, the deepest ties of love - the things that make us glad to be alive - have been treated as unimportant. Spouses, life partners, parents and children, have been treated as inessential to each other; their wishes have not been considered, their voices have not been listened to. Residents of care homes have been shut in; those who love them have been shut out.”⁴

CHRS’s position is that residents of care homes, and their families, suffered a harsher impact of lockdown than many other sectors of our society.

Isolation

7. The key impact that CHRS seeks to highlight to the inquiry, and the fundamental reason for its inception, was the acute and profound isolation experienced by care home residents during the pandemic. ‘Skin hunger’ was coined as a phrase to explain the need for touch and the lack of physical contact with loved ones.⁵ Residents and their families were effectively ripped out of each other’s lives, with no apparent consideration or clear thought as to how bonds would be reinstated. It is vital to acknowledge that for many relatives of individuals in care homes, young and old, they were not simply ‘visitors’ – they were vital care givers. They had intimate and life-long knowledge and experience of their loved ones and their needs, which in normal times allowed for the provision of essential care and support. In one fell swoop, with

³Creative Covid Care, available at: <https://www.creativecovidcare.com/the-cost-of-separation-the-impact-of-visiting-restrictions-on-families-of-care-home-residents-during-covid-19/>

⁴ CHRS, 5 Nations Statement

⁵ Noten, S. *et al*, (2022) “‘Precious time together was taken away’: Impact of Covid-19 restrictive measures on social needs and loneliness from the perspective of residents of nursing homes, close relatives and volunteers”, *International Journal of Environmental Research and Public Health*, 19(6)

the instigation of lock-down, care givers were relegated to mere ‘visitors’, perceived as unnecessary, inconvenient and potentially dangerous footfall.

8. Isolation was felt by so many, and in different ways. For older care home residents, with full intellectual acuity and awareness of their situation, they were left in their rooms with no social engagement, interaction or stimulation. It was little better than solitary confinement in a prison cell. Other older residents perhaps lacked the mental ability to understand, or articulate, their circumstances or emotions. It cannot be known what horrors those residents must have experienced: why they were left alone with no contact with friends or family, why people wore masks and couldn’t touch them. To be simply shown a dissociated image and hear the detached voice of a relative on an ipad must often have seemed confusing, and lacking in significant meaning. Time in later years is so very precious, and to face the bewildering and confusing situation of being left isolated must have been terrifying. For residents with dementia, every day is a day lost. Memories fade. To be kept at arms length from those we are closest to, particularly in later years, must be one of the cruellest things imaginable. Isolation from family members undoubtedly resulted in a deterioration of mental and physical health for many residents, and also lead to behavioural changes, such as aggression, which were frequently irreversible. For some, the loneliness and distress experienced contributed to their ultimate death.
9. It is also important not to forget the impact of isolation on younger residents of care homes. Many had active and vibrant social lives - they had been used to engaging in the community, attending groups and functions. All this was withdrawn, and lives that had been hitherto organised and planned were dismantled. Care packages and frameworks that had been carefully negotiated and developed were torn apart, and it would take years for them to be rebuilt – if at all.

Visiting arrangements

10. The poor handling of visiting arrangements caused a considerable impact to care home residents. As was highlighted by the campaign for what has become known as ‘Anne’s Law’, relatives are frequently essential care givers, with invaluable knowledge and skill regarding their loved ones. However, with advent of lockdown, they were not regarded as a partner in care settings; they were relegated to the status of mere visitors. Powers of attorney were often disregarded entirely. When visits were permitted, the

infection and control measures were more restrictive than for staff, who included many agency nurses and carers. Further, measures such as video calls and closed window visits, along with the requirement to wear PPE/masks, in some cases increased rather than alleviated distress.

11. CHRS would like to highlight that ‘essential visits’ were often denied even when the criteria were met, with the criteria being interpreted too strictly. This Inquiry is accordingly asked to ensure that evidence is heard from different care homes about how the criteria was assessed in different situations and areas. A further point to consider is that end of life exclusions meant that relatives were left in uncertainty and lost the last precious days and hours with their loved ones.

Impact on relationships

12. The response to the pandemic inevitably had an adverse impact on relationships; however, it is submitted this was felt more profoundly by those in a care home setting, and in many cases the damage has been irreparable. Aside from the obvious effect between family members, the relationship between relatives and care home staff were also impacted. As noted, families were often treated as potential infectants, and an inconvenience, rather than as partners working together to provide care for their relatives. A further point is that fear of reprisals meant that relatives were reluctant to raise issues with care home staff or the Care Inspectorate, and no doubt staff also felt the impact of relatives and residents experiencing isolation and becoming increasingly distressed.

Experience of residents

13. Care home residents suffered particularly significant impacts, such as receiving reduced and inadequate health care which often resulted in unnecessary worsening of pre-existing health conditions. Further, care homes were not considered or treated as residents’ homes: many homes were stripped of soft furnishings and residents had personal belongings packed away, as the home was treated as a ‘clinical setting’. A particularly insensitive impact was that in December 2020 no Christmas decorations were allowed in many homes. The thinking behind, or logic to, such measures remains unclear.

Lack of guidance/inconsistent application

14. The Scottish Government failed to issue clear guidance to care homes, and care home relatives. Further, considerable difficulties were encountered by inconsistent and contradictory application of the guidance and policies that were issued. Health boards, public health providers and care homes often applied national guidelines differently from each other, which meant that relatives frequently received conflicting advice, and this caused uncertainty and confusion. Further, the rules that were in place for care homes were different to those for hospitals, hospices and sheltered accommodation, which defies logic. The length of restrictions in combination with the tiered system meant that family members were excluded when general government guidance allowed them to visit: excluding residents from activities permitted for the general public, for example not benefiting from changes such as meeting outside, bubbles etc, resulted in justified feelings of discrimination. A further point is that the requirement to isolate on return from hospital was not in line with general public guidance, even where the admission had not been due to Covid-19. It is submitted that overall the support for care homes was an afterthought, with a lack of positive messaging and clear guidance from both Public Health and the Scottish Government.

CHRS'S EXPECTATIONS FOR THE INQUIRY

15. CHRS's hope is that the Inquiry highlights the isolation, frustration and pain felt by care home residents and their relatives, as well as the significant lengths they went to vindicate their rights despite the failings of public bodies and the care home sector.

Understanding the impact

16. For the Inquiry to fully understand the impacts of the response to the pandemic, CHRS considers that it is vital that the Inquiry hears evidence from the following groups and individuals:

- Residents of all ages and their relatives;
- Residents with a variety of health conditions;
- Care home owners and staff who provide different types of care, from care homes of differing sizes and from different geographical locations;
- Care home owners and staff from public, private and not for profit sectors;
- For care homes operating in the private sector, both operators who work across the UK and those who operate only in Scotland; and,
- A broad range of relatives including spouses and partners, parents, children, grandchildren, siblings and other carers.

Human-rights and equalities

17. CHRS fully supports the Inquiry's intention to adopt a human rights-based approach to the Inquiry. While the Inquiry is yet to publish its human rights paper, CHRS submits that its approach should comply with the following principles:

- The investigative duty under Article 2 ECHR arises when the State may be in breach of one of its positive duties to protect life. Those positive duties include the legislative and administrative framework designed to provide effective protection for the right to life, systems in place to safeguard against risks to life; the duty to provide information to individuals whose life may be at risk, and, taking operational measures to safeguard a specific individual or individuals against risks to their lives which are real and immediate and of which authorities ought to be aware⁶;
- Certain rights do not allow for any derogation, including Article 2, the right to life, (except in the context of lawful acts of war) and importantly in this context Article 3, the prohibition of torture and inhuman or degrading treatment of the ECHR⁷;
- Articles 2 and 3 may be invoked in respect of severely ill patients and people with disabilities. Their exposure to illness and extreme levels of suffering may be incompatible with the State's positive obligation to protect life and prevent ill-treatment⁸;
- Effective enjoyment of the right to family life is a benchmark of a modern democratic society. Significant restrictions to usual social and family activities may only be possible if they are established by law and proportionate to the legitimate aim pursued, including the protection of health;⁹
- The State's failure to take into account the specific needs of persons belonging to a disadvantaged group may result in a finding of discrimination in contravention of Article 14¹⁰;

⁶ *Osman v United Kingdom*, [GC] app. no. (87.1997/871/1083), 28 October 1998, at [115]

⁷ Council of Europe, *Respecting democracy, rule of law and human rights in the framework of the COVID-19 sanitary crisis: a toolkit for member states*, SG/INF(2020) 11, 7 April 2020, available at: <https://rm.coe.int/sg-inf-2020-11-respecting-democracy-rule-of-law-and-human-rights-in-th/16809e1f40>

⁸ *Ibid*

⁹ *Ibid*

¹⁰ *Horvath and Kiss v. Hungary*, app. no (11146/11), 29 January 2013

- The prohibition of discrimination may entail obligations to take positive measures to achieve substantive equality¹¹ ;
- The failure to treat different cases in a different manner may constitute unjustified discrimination¹²;
- States should take all necessary measures to ensure the safety and protection of people with disabilities in situations of risk¹³;
- Containment measures such as social distancing and self-isolation may be impossible for disabled persons who rely on the support of others to eat, dress and bathe¹⁴;
- There must be a sufficient element of public scrutiny to secure accountability in practice as well as in theory¹⁵;
- Public health emergencies must not be used a pretext for human rights infringements. Measures aimed at protecting people must be applied with strict respect for human rights obligations which include the enjoyment of fundamental rights and freedoms¹⁶;
- The victim's family or next of kin must be involved in the procedure to the extent necessary to safeguard his or her legitimate interests¹⁷;

¹¹ *Cam v. Turkey*, app. no. (51500/08), 23 February 2016

¹² *Nachova and Others v. Bulgaria*, [GC], app. no. (43577/98 and 43579/98) at [160]

¹³ United Nations Convention on the Rights of Persons with Disabilities, Article 11. The UK ratified this Convention ratified in 2009. The Scottish Government intends incorporate this treaty into Scots Law.

¹⁴ United Nations, Office of the High Commissioner on Human Rights, *Covid-19: Who is protecting the people with disabilities? – UN rights expert*, 17 March 2020 which refers to the declaration of the UN Special Rapporteur on the rights of persons with disabilities, available at:

<https://www.ohchr.org/en/press-releases/2020/03/covid-19-who-protecting-people-disabilities-un-rights-expert?LangID=E&NewsID=25725>

¹⁵ *Guiliania and Gaggio v. Italy*, [GC], app. no. (23458/02), 24 march 2011 at [304]

¹⁶ Consultative Council of European Judges, Statement of the President of the CCJE, *The role of judges during and in the aftermath of the Covid-19 pandemic: lessons and challenges*, 24 June 2020, available at: <https://rm.coe.int/ccje-2020-2-statement-of-the-ccje-president-3-lessons-and-challenges-c/16809edo60>

¹⁷ *Al-Skeini and Others v. United Kingdom*, [GC], app. no. (55721/07) 7 July 2011 at [167])

- The pandemic highlighted human rights gaps in society and demonstrated that stronger protection of human rights is an essential ingredient for pandemic prevention, preparedness and response; and,
- Non-discrimination and equality should be fundamental principles of all strategies for pandemic prevention, preparedness, and response, with special attention given to the protection of vulnerable groups, including older persons and persons with disabilities¹⁸.

18. Similarly, the Inquiry should have regard to the provisions of the Equality Act 2010. Many residents in care homes have the protected characteristic of disability¹⁹ and age²⁰ among others.

19. As a result, CHRS submits that the Inquiry must examine whether the Scottish Government, health boards and local authorities complied with their public sector equality duty (“PSED”) during the pandemic. The Inquiry must consider whether their policies, practices and decisions had due regard to the need to eliminate discrimination, advance equality and foster good relations between care residents and others who do not share that protected characteristics.²¹ In doing so, the Inquiry should ask whether Scottish Government, health boards and local authorities complied with their PSED in substance, with rigour, and an open mind.²²

The duty of candour

20. CHRS recognises and supports the commitment of both the Chair and the Inquiry Team to carry out an exhaustive investigation into Covid-19 in Scotland in accordance with the terms of reference. CHRS is committed to assisting the Inquiry in an open, constructive, and collaborative manner.

¹⁸ United Nations, Office of the High Commissioner on Human Rights, *Human Rights in the new pandemics instrument*, 14 July 2022, available at: <https://rm.coe.int/ccje-2020-2-statement-of-the-ccje-president-3-lessons-and-challenges-c/16809edo60>
<https://www.ohchr.org/sites/default/files/documents/issues/health/activities/2022-07-15/Human-rights-in-the-new-pandemics-instrument.pdf>

¹⁹ Section 6, Equality Act 2010

²⁰ Section 5, Equality Act 2010

²¹ Section 149, Equality Act 2010.

²² *Hotak v. Southwark LBC*, [2015] 2 WLR 134 at [75]

21. CHRS believes that it is vital that all core participants, and especially public bodies, commit to doing the same. Many individuals, families and organisations have been failed in the past by public bodies not cooperating or acting with absolute candour. This Inquiry cannot allow the same to happen.
22. Accordingly, all core participants must to commit and adhere to the principles contained in The Right Reverend James Jones's *Charter for Families Bereaved through Public Tragedy*, namely to:
- Place the public interest above their own reputation;
 - Approach the Inquiry with candour, in an honest, open and transparent way, making full disclosure of relevant documents, materials and facts. The objective should be to assist the search for truth. They should be willing to learn from the findings of external scrutiny and from past mistakes;
 - Avoid defending the indefensible or to dismiss or disparage those who may have suffered; and,
 - Recognise that they are accountable and open to challenge.²³

CONCLUSION

23. CHRS welcomes the beginning of the public hearings for the Scottish Covid-19 Public Inquiry and commends the Chair's and the Inquiry Team's commitment to ascertaining the truth. CHRS believes that this Inquiry can play a key role in assuring that care home residents' and their families' rights are respected at all times, but including in future pandemics and public health emergencies. The failures of the Covid-19 pandemic must not be repeated.
24. CHRS was formed as a collective to give voice to the many residents in care homes without a voice during the pandemic. It stands ready to lend its voice, experience, and expertise to the Inquiry's assessment of the impacts of the pandemic on residents of care homes and their families.

²³ The Right Reverend James Jones KBE, *The patronising disposition of unaccountable power'. A report to ensure the pain and suffering of the Hillsborough families is not repeated'*, 1 November 2017, available at:

https://assets.publishing.service.gov.uk/media/5a82c1cce5274a2e8ab5931d/6_3860_HO_Hillsborough_Report_2017_FINAL_updated.pdf