

Witness Name: Jean Adamson

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UK COVID-19 INQUIRY – MODULE 6

WITNESS STATEMENT OF JEAN ADAMSON ON BEHALF OF COVID-19 BEREAVED FAMILIES FOR JUSTICE UK

I, Jean Adamson, c/o Broudie Jackson Canter, 3rd Floor Walker House, Exchange Flags, Liverpool, L2 3YL will say as follows:

1. Introduction

- 1.1. On 21 June 2024, Broudie Jackson Canter received a Request for Evidence under Rule 9 of the Inquiry Rules 2006 for the attention of Covid-19 Bereaved Families for Justice UK ('CBFFJ UK'). CBFFJ UK is an organisation of approximately 7000 members, all of whom have lost a loved one to Covid-19. The campaign was founded in March 2020 with the purpose of learning lessons throughout the Pandemic in order to save lives. CBFFJ UK is a Private Limited Company by guarantee without share capital use of 'limited' exemption.
- 1.2. CBFFJ UK is a core participant in Module 6 of the Inquiry. It is represented by Broudie Jackson Canter. CBFFJ is a UK wide organisation. We have members in every nation in the UK and continue to campaign for and engage with devolved inquiries into the handling of the Pandemic.
- 1.3. This statement is structured in a way that seeks to outline the views of CBFFJ UK and its membership on each of the topics set out in the Inquiry's letter of 21 June 2024. CBFFJ UK is in the process of gathering summaries from a range of family members and will put forward a proportionate list of family witnesses who

will be able to provide evidence relating to a diverse range of issues in Module 6, which will be provided once complete.

2. Membership of CBFFJ UK

- 2.1. Module 6 is one of the most important modules for CBFFJ UK families. Many CBFFJ UK members lost loved ones who were receiving care from or working in the Adult Social Care sector ('the Care Sector'). Some were living in residential care settings; others were receiving care in their own homes. Some were infected at work and later died themselves; some were infected by their loved ones who had accidentally brought the virus home.
- 2.2. Every person who died was cherished by their family and friends. Not every person was 'older'. Not every person was white. Not every person was non-Disabled. Not every person was English. Without exception, every person was loved.
- 2.3. Covid-19 has touched every corner of our communities, and so our membership reflects a broad demographic from across the UK united by the aim to learn lessons and save lives in this and future pandemics. CBFFJ UK includes members from England, Northern Ireland, Scotland and Wales.

3. Key impacts and concerns raised by CBFFJ UK members

- 3.1. Given the large membership of CBFFJ UK, there is a wide variety of experiences of the Care Sector. It follows that the points touched on in this statement are necessarily in summary form. Many CBFFJ UK members would like to provide detailed statements to assist the inquiry in Module 6.

The non-existence of a 'Care Sector'

- 3.2. In Modules 1 and 2, the Inquiry was variously told that the Care Sector was *'fragmented'*, *'alienated'* and *'neglected'*. It was told that the Care Sector was, and still is, a Cinderella sister to the NHS. The stories of CBFFJ UK members which we have outlined below showcase just some of the services that come under the vast umbrella of 'Adult Social Care'. In our view, a unified care service is necessary to avoid the catastrophic death toll that the Care Sector experienced during the Covid-19 Pandemic in future.

- 3.3. It is shocking to our members that the UK Government and Devolved Administrations did not have sufficient plans or resources in place to help the Care Sector respond to a pandemic, given the knowledge from Exercise Cygnus. It is more shocking still that it took until April 2020 for the UK Government to publish a specific action plan for the Sector. It is breathtaking that the then Health Secretary did not know how many care homes there were in England in March 2020, and devastating that there were no data on deaths until after that point. It is incredible that there was no centralised plan or provision for Personal Protective Equipment or other Infection Prevention and Control measures.
- 3.4. If there is nothing else to be learned from the destruction caused to the lives of people receiving care from and working in the Care Sector and their families during the Pandemic, the Care Sector can no longer be ignored. The Pandemic has spotlighted the urgent need for a national care service that is anchored to the centre of Government and equal to the NHS. Guidance and contingencies alone are little use when the elements of the system are so hard to pin down.

The state of the Care Sector

- 3.5. Around 3 out of 4 of us will require social care in our lifetimes. It is deeply concerning to CBFFJ UK members that the problems that permeated through the Care Sector in March 2020 – a product of underfunding and under-resourcing – only worsened during the Pandemic and show no sign of abating. Until there is a properly resourced Care Sector in each of the four jurisdictions, people will continue to be failed in future pandemics. This must be recognized as a problem that will affect the majority of the population at some point or other, given the expected increase in frequency of pandemics and an ageing population.

Lives not numbers

- 3.6. The impact of the Pandemic on people receiving care from and working in the Care Sector is not simply reflected in the number of deaths, as horrifying as those statistics are. Each number represents a person who was dearly loved and whose life ought to have been valued by the State more than it was. One of the foremost concerns shared by CBFFJ UK members is the language that was used by politicians and policy makers, sometimes in the presence of senior scientists,

to describe recipients of care as '*bed blockers*' and people who were '*near the end regardless*'. As painful as this was for CBFFJ UK members to hear in Module 2, it validated our suspicions that our loved ones' lives mattered less to those with the power to protect them.

3.7. The paradox of this sentiment, which differentiates between the lives of recipients of social care and those people who do not receive or need it, is that the task of protecting social care was always closely linked to the task of protecting the wider population from Covid-19. As seen in Module 2, it was never going to be easy to stop all routes of ingress into care homes and a rise in the number of infections in care homes was an indication that they would soon increase more broadly in the community. That is because of the basic facts that:

- People who need care regularly require other people to provide it, whether it be medications, personal care or emotional support; and, where it is provided by professionals, they often work across settings; and
- Although loneliness is rightly recognised as an issue, older and Disabled people do not always or routinely live in isolation, but regularly mix with family and friends of different generations.

3.8. The need for care and support to continue during the Pandemic was obvious to CBFFJ UK members. It concerns many of us that it was stopped for our loved ones, in some cases without warning or mitigation, leading to isolation during times of pain and distress; but where it continued, it concerns us that there was very little in the way of precautionary measures during the first wave and that similar problems persisted during the second and subsequent waves.

3.9. The people the Pandemic killed are people with real stories and precious histories. They are people like my father, **Aldrick Cleophas Adamson**, who died on 15 April 2020 aged 98 years old. My father was a shining light; a highly influential figure in my life, whom I miss dearly. He was a Windrush pioneer; arriving from Barbados in 1956, he came to England in response to the call for help to rebuild post-war Britain and began working for London Underground. He was a diligent man, and his work ethic was second to none.

3.10. To his friends and family, my dad was affectionately known as Cleo. Indeed, he loved his family. He was quite a musician too, playing the piano and the guitar. As a child, he would regale my siblings and I with West Indian folk songs. Following a stroke in 2018, he spent his last few years in a nursing home. Even towards the end of his life, he remained robust in spirit, happy and peaceful in his demeanour; and could often be heard singing his favourite songs.

3.11. The people the Pandemic killed are people like **Susan Gregson** who lived with dementia and died on 8 December 2020. Her daughter, Nicola, says:

'My strong, resilient and caring mum was a loving wife, mother and grandmother and a friend to many. With dad in the army, we moved around a lot as children and wherever we were, mum created a wonderful home. She loved sport and was a keen tennis player - a hobby which has been passed on to us all. When dad left the army he moved into teaching and became a housemaster. Mum was a huge support to him in caring for the students and putting on events - her organisational skills were legendary! Family time was always prioritised and holidays together were so precious.'

3.12. They are people like **Christina Fulop**, who died on 8 January 2021 and is described by her daughter Naomi as,

'an amazing woman who broke glass ceilings before they were known to exist! Having had to leave school at 14, my mother continued her education at night school before eventually gaining a place at University (the London School of Economics). No-one else in her family had stayed on at school past the age of 14. She combined a successful professional career with raising three children, finally being appointed as a Professor at City University Business School. She and my father (a refugee from the Nazis who escaped Vienna on the Kindertransport) were married for 69 years.'

3.13. They are people like **Sheryl Dinsdale** who died on 27 April 2020 at the age of 50 and leaves behind her young son. As her mother Linda describes,

'Sheryl was a loving daughter and mother. As a child she was outgoing, singing in the church and even did a solo in Ely Cathedral at 14. She learnt to play the piano and was a skilled ballroom and Latin American dancer winning many cups and trophies throughout the country from 7 to 22 years.

She worked for various Select Committees in the House of Commons for over 20 years before she became ill with chronic pain following 2 knee

operations which led her to fibromyalgia and eventually medically retired. She was always cheerful even when she had to enter a nursing home for specialised nursing in 2018.'

- 3.14. They are people like **Amelia Vine** who died on 2 January 2021, aged just 21 years old. Her parents, Denise and Victor, say:

'We have never told anyone this story. Our daughter, Amelia, was 21 years old when she passed away from Covid-19.

Amelia was mentally ill from her early teens and spent long periods of time in hospital. Hospitalisation protected her from self-harm and suicide and provided safe surroundings for her to receive therapy and rehabilitation. Although we are shocked and grief stricken beyond all measure that Amelia has passed away, we can say that the reason she passed away was not related in any way to suicidal thoughts or self-harm. We can also say that the last 12 months were the best period of her life. This was a period when, far from being characterised by the early traumas, Amelia had triumphed to the point of recovery, hope and peace.

During the last 12 months of Amelia's life, she became an independent member of the community. She enjoyed looking after dogs, holidaying in France, Cruising, making friends with people of her own age. Amelia returned to education successfully attaining a certificate in Health and Social Care. She planned to do a full time Open University Degree in psychology and enter the world of work by first volunteering.'

Unequal impacts

- 3.15. As we have emphasised in all Modules, the impact of Covid-19 has not been felt equally, with older people, Disabled people, people with underlying health conditions, people with dementia, people living in more deprived areas, and Black people, Asian people and those from other minoritized ethnic groups facing the greatest risks.
- 3.16. Cleo's story highlights the unequal access to treatment that many older people faced. I had to fight for my dad to be taken to hospital and to receive oxygen, which only occurred 7 days after he first displayed symptoms. It is a small comfort that my dad was admitted eventually, but other people were not so lucky.

- 3.17. Susan's story illustrates the particular distress and isolation felt by many people living with dementia. With support, she had coped reasonably well in her own home during the first lockdown but had to move into a nursing home in August 2020. In October 2020, all visits were stopped. Due to her dementia, Susan was unable to use the phone or Skype without considerable support. Susan's daughter describes the '*agony of these phone calls*' which '*was compounded by the feeling of guilt at being demanding of a carer's time.*' Two weeks later, Susan contracted Covid-19 and two days before her birthday, her family was told they could enter the nursing home with restrictions for end of life visits. Nicola says,

'Over the next few days mum rallied (I am sure that this was due to us being able to be with her) to the extent that we were once again banned from visiting. This decision will haunt me forever. Although the country was in lockdown at this time the Government guidance was for restricted care home visits to continue, however although now Covid free, the ban on visits remained at mum's care home. This inequality between care home policies created further anxiety. I would have willingly self-isolated to be with her as a key worker but the government ignored advice from experts that would have both given those with dementia the basic human rights they deserved and helped support care home staff at such a difficult time. We were allowed in once again for mum's final few days. As per the rules family members were not allowed to mix and saying goodbye on my own was torture.'

Inadequate IPC, Test & Trace and Government decision-making

- 3.18. Christina's story illustrates three key deficits that created the perfect conditions for a pandemic to storm its way through the Care Sector. As outlined in our Module 2 opening submissions, Christina lived at home and was assisted by domiciliary care workers. Her daughter Naomi, a Professor of Health Care Organisation and Management, notes that the care workers were provided with no masks during March and April 2020. At the beginning of May, Christina was sent 21 masks for one week to give each carer when they visited. She had 3 carers per day. At the end of that week, Christina received a letter from the care agency saying that carers would have one mask per 8 hour shift. When Christina told her daughter this, Naomi rang the care agency to find out why the change had been made. They informed Naomi that it was due to a change in guidance from PHE.

- 3.19. Although Christina survived the first wave, she contracted Covid-19 during the winter and died during the subsequent lockdown. Naomi believes that the insufficient PPE for care workers, the late imposition of the second lockdown, and the ineffectiveness of NHS Test and Trace led to her mother's death. She further notes that she had been unable to see her mother for some months because of the lockdown, was unable to visit her in hospital when she was dying and could only have a very restricted funeral. This hugely distressing experience was greatly exacerbated as it coincided with the illegal parties at No 10.

Impact of hospital discharges to care homes without testing

- 3.20. Sheryl's story shows the impact of the hospital discharge policy in March 2020. Her mum, Linda, reports that staff shortages were already a problem prior to the first lockdown and there was inadequate PPE. Linda recalls one member of staff *'handling a drinking cup and placing the straw into this whilst carrying laundry to all other rooms which she had over her arm.'* As somebody who never left her bed due to chronic pain, Sheryl could not have caught the virus anywhere else. Given the lack of preparedness that Linda observed, discharging untested patients to Sheryl's care home was nothing short of dangerous in her view.
- 3.21. Like many other CBFFJ UK families, I had similar concerns and raised a complaint with my father's care home [JA/01 – INQ000505516]. I specifically asked about the discharge of untested patients into the home during the first wave of the Pandemic. The home eventually conceded that they could not guarantee that people coming into the home were not infected with the virus. My dad died less than a month after the hospital discharge policy was announced on 17 March 2020.

Blanket use of DNACPR Notices

- 3.22. Sheryl's story also illustrates the harms of using Do Not Attempt Cardiopulmonary Resuscitation ('DNACPR') notices without consultation. Sheryl was only 50 years old, yet her mum reports that a notice was put in place without family consultation and despite Sheryl explicitly telling her doctor that she wanted to be resuscitated because she had a young son to live for. Sheryl was refused access to the Intensive Care Unit and Linda was told that Sheryl would not be

given access to mechanical ventilation because the nature of her disabilities made it difficult to turn her body. Linda also experienced obstacles in obtaining an ambulance for Sheryl, as staff at the care home initially refused to call for one.

Interaction between sectors

- 3.23. Amelia's story emphasises the overlap between the health and social care sectors. Having contracted Covid-19 in hospital, Amelia was sent home to her supported living accommodation where she died just over 2 weeks later. In her parents' view, *'had lockdowns been managed properly, and had she been granted "shielded status" Amelia might still be alive today.'* Amelia was only weeks away from being vaccinated.

4. The response of the Care Sector to the Pandemic

a. Pre-Pandemic concerns

- 4.1. Many CBFFJ UK members have concerns about pre-Pandemic staffing levels and bed capacity which affected the ability of the Care Sector to respond to the Pandemic. Many of our families witnessed the under-staffing of the sector which sometimes resulted in us having to fill gaps in care ourselves; for example, by collecting end of life medications, as Sarah Argyle did for her father, **Arthur Argyle**, who died on 3 May 2020.
- 4.2. Some families witnessed delayed transfers of care during the Pandemic, which were a known and long-standing issue before March 2020. In the context of a pandemic, delayed transfers of care routinely increased the risk of hospital-acquired infection; which sadly affected Janice Price's mum, **Ethel Price**, who died on 18 December 2020, almost two months after her 91st Birthday and is described as a *'kind, happy and friendly person always willing to help others'*.
- 4.3. It also affected Connie Mills' mum, **Mary Lenderyou**, who died on 17 April 2020. Mary had been in hospital since 3 March 2020. A home care package had been set up twice and cancelled twice. The absence of a home care package was the only thing preventing Mary's discharge but, instead of being discharged home, she was transferred to a second hospital on 27 March 2020 where she contracted Covid-19 and sadly died.

b. Discharge of untested people into residential care settings

- 4.4. In terms of early decision-making, a key area of concern for CBFFJ UK members is the decision to discharge untested patients from hospital into residential care settings. From our perspective, the decision to discharge patients without testing, isolation or proper IPC measures being in place was a disastrous move characterised by a wholesale lack of forethought and appreciation of the risk to residents and staff in residential care settings, and the wider Care Sector given the movement of staff across settings (that is, including domiciliary care).
- 4.5. Some key figures in Government during the relevant period have argued that this decision did not add substantially to infections in care homes, given the high number of ordinary visits from workers and others. Our members strongly disagree. Precisely because testing was not happening, it is impossible to say how many people were infected and died as a result of this policy, but the suggestion that only 1.6% of outbreaks were identified as potentially resulting from hospital-acquired Covid-19 infection is likely to be a gross underestimate.
- 4.6. The reality is that there were explosive outbreaks within care homes, witnessed by many of our members, and a very considerable proportion of deaths occurred in those facilities. There were equally some facilities that survived the Pandemic with no deaths from Covid-19 because of the quality of the IPC that was utilised.

Residential care settings with explosive outbreaks

- 4.7. Take, for example, the experience of Catey Sexton whose mum, **Cath Sexton**, died of Covid-19 on 26 May 2020 in her care home. Cath was the last of 24 people to die in a 3-week period. At the time, this represented one of the highest death tolls in a care home in the UK; sadly, that number has since been surpassed
- 4.8. Marie Erwood removed her mother, **Margaret Jean Smith**, from her nursing home in Hertfordshire to protect her from Covid-19, after the manager of the home told Marie that they had to take in untested patients from local hospitals. Marie describes her mum as,

'an extraordinary woman. Her heart was so large and her compassion so deep. Mum had a smile that lit up a room and the hearts of everyone who knew her. She did not know how to hate. When Alzheimer's came for her, she never lost a sense of who she was and who her family were. Her carers adored her. She thanked everyone for every little thing they did for her. She loved her nursing home and all the staff loved her.'

- 4.9. When Marie voiced her concerns to the manager about one of the care assistants returning from Italy unwell in April 2020 and providing Margaret with personal care with no mask or appropriate PPE, Marie tells us that,

'He sympathised but knew he could not protect my mother and it was his suggestion that we took her home with us even though we have a small terraced house and had to convert our dining room into a bedroom. Sadly mum must have already contracted Covid as she died two days after moving in to my house.'

- 4.10. Jillian Danson tells the story of her mum, **Gladys Shorthouse's** care home, who felt forced to admit Covid-positive residents early in 2020 because they considered that *'in law, it was their home'*. Jillian says, *'they might as well have just thrown a hand grenade in as the devastation was just as bad.'*

Residential care settings with zero Covid-19 deaths

- 4.11. In contrast, there were care homes that experienced no Covid-19 deaths. Amos Waldman's grandma, **Sheila Lamb**, died on 2 April 2020 in a care home. At the time, Amos was in training to become a trustee at a different home for adults who have learning and physical disabilities and autism in Manchester. According to Amos, no one at the care home contracted Covid-19 until November 2020 and no one required medical treatment for Covid-19. Amos says that the Chief Executive was instrumental in ensuring that there were no deaths from Covid-19 and only a few cases. The key measures adopted were:

- A preemptory lockdown one week before the lockdown in March 2020.
- Full PPE for staff.
- The use of isolation areas so there was no cross infection.
- Staff working in the same areas and not mixing.
- Stringent visiting arrangements.
- A stringent testing regime.

- The early purchase of hospital grade air filtration units at the cost of tens of thousands of pounds.
- Free taxis for staff so they did not mix on public transport.
- Full pay for staff who were isolating.
- Free staff meals.

c. IPC measures within nursing and residential care homes

- 4.12. The discharge policy was dangerous because of the unavailability of testing and lack of guidance on effective Infection Prevention and Control ('IPC') at the time.
- 4.13. **Roy Staples** died on 8 April 2020 at the age of 91. At the time of his death, Roy's family were paying over £5,650 per month towards the costs of care at his nursing home. His daughter, Pam, describes Roy as a hard-working individual who was an accomplished golf and snooker player. Inspired by Strictly, Roy took up dancing at the age of 84. In Pam's words, *'Roy was a man who always tried his best and strove to do the right thing. A man of honour and integrity. A man who was steadfast, reliable, trustworthy, decent and honest.'*
- 4.14. Roy contracted Covid-19 *'following an influx of untested new residents being placed there on discharge from hospital in the last few days of February and up until 10th March'*. Roy's family has major concerns about the adequacy of IPC at the nursing home because they think Roy was infected by a new resident who had dementia and wandered into his room. From his family's perspective, this was in part due to a lack of government guidance. As Pam says, *'the care sector was left to cope alone.'*
- 4.15. 18 days later, Ivan Pointon lost his father, **Donald 'Don' Pointon**, who was living in a BUPA care home. Don had lived through the Second World War and had two of his memories archived for the WW2 People's War. He was very much a family person and enjoyed being a grandfather to 4 and a great grandfather to 3. Ivan's views on what went wrong for Don reflect the views of many of our members:

'When care homes closed their doors to all visitors in March 2020, the managers of these homes had a unique opportunity to implement cross

infection control and protect their residents. Some managed this but some unfortunately did not.

My father, Donald Pinton, at this time was a resident at the [redacted] I&S [redacted] in Solihull receiving respite care following hospitalisation after a fall at home a few months previous. He was of sound mind and fit until this back injury resulting from the fall. I did not have close contact with him after “lockdown”, but we continued video contact using Facebook and I had access to the [redacted] I&S [redacted] as I volunteered to collect and deliver prescriptions for the residents.

I very soon became aware that the BUPA management were not taking any action other than locking out visitors, to prevent the spread of coronavirus:

- Staff were still going to the local shops at lunchtimes*
- Staff were travelling to and from the home in workwear and not wearing aprons at work*
- Residents were still encouraged to mix in the dining room and public areas*
- There was no increased cleaning of bedrooms.*

As the front doors of the home remained locked, no one can disagree that the coronavirus was introduced into care homes by the staff. The staff cannot be blamed as they continued working heroically during lockdown. Care home management, however, failed totally by not introducing cross infection control initiatives. Simple basic nursing improvements in cross infection control would have saved many lives.

During the first week of lockdown, I wrote to BUPA Head Office in Leeds to register my concerns. I received a reply back from BUPA Quality and Compliance stating: “we have robust infection control procedures in place, and these are constantly being reviewed by the Quality team.”

Disagreeing totally with this statement, I then attempted to contact the CQC but they had “locked down”. There was a national emergency affecting care homes and the CQC had “gone home”. There was no one checking on cross infection control in homes.

A few weeks later in April, not surprisingly, my father’s health deteriorated and the GP began sedating him as she suspected coronavirus infection, as was the case for several of the other residents. My father was swab tested on Tuesday 21st April, received a positive result and died on April 26th 2020. COVID-19 did not appear on his death certificate.

I have no doubt in my mind that criticism for care home deaths should be directed at both the CQC for not monitoring cross infection control, care home management for not adopting cross infection control measures and failing in their duty of care and Public Health England for incorrect guidelines.'

d. The availability and adequacy of PPE

- 4.16. CBFFJ UK members have concerns about Personal Protective Equipment ('PPE') across settings; including the availability of PPE for residents, staff and visitors of residential care settings, and recipients and providers of domiciliary care (paid or unpaid).

PPE in residential care settings

- 4.17. Lorelei King's husband, **Vincent Marzello**, died on 31 March 2020. Lorelei and Vince had been married for 32 years. Lorelei describes Vince as,

'sociable, irascible, adorable, intense. He loved running and physical fitness, he loved a debate, he loved history, he loved music and had an extensive collection of vinyl. He was a fantastic cook – especially when it came to Italian food. He was incredibly kind, especially to the elderly. He seemed to know everyone in the neighbourhood and considered it his duty to look after our more vulnerable neighbours.'

Despite advancing Alzheimer's, his personality still shone through. I treasure a video taken a few weeks before his death where he made me giggle helplessly as he relayed a story of something that had happened to him. Words were harder for him to find, but his knack for physical comedy never left him. Until the end, he was absolutely Vince.'

- 4.18. At the time of his death, Vince was living in residential care in London. By early March, more than one staff member had told Lorelei of their concern that the home had not locked down. In relation to PPE, Lorelei recalls that, *'Around that same time, the manager of the care home was nearly in tears when she told me she simply couldn't get any PPE for her staff. Everywhere she tried said it was all seconded to the NHS.'*
- 4.19. Kim Nottage's mum, **Maureen Nottage**, died on 7 April 2020 at the age of 86. Kim describes Maureen as *'a true mum, always there for all of us. Family really did mean everything to her. She loved each and every one of us dearly.'* Maureen

loved shopping, Arsenal and eating out. She worked until she was 72 years old. Kim was not told her mum was ill until after she had died. When she visited the care home on the day of Maureen's death, Kim noted that staff, including the GP and care home manager, were walking about without PPE and the one nurse who was on duty on the nursing floor where Maureen had been staying was walking between rooms without changing PPE.

- 4.20. Many of our members have spoken about care and nursing homes having to obtain PPE for themselves. Sarah Argyle recalls having to collect end of life medication for her father, **Arthur Argyle**, due to the lack of staff and resource: *'When I dropped it off the nurse had a plastic apron on and a make shift mask. The PPE looked all homemade and taped together.'*
- 4.21. The availability and adequacy of PPE remained a problem throughout the Pandemic. Charles Persinger tragically lost his mother and wife to Covid-19. His wife, **Kathleen Persinger**, was a care home manager who died on 28 February 2021 after she contracted Covid-19 at work. Charles is sure she died because of inadequate national policy and inadequate PPE. She was just 51 years old.
- 4.22. On 7 February 2021, Margaret Allan lost her husband, **Steven Allan**, who was only 57 years old when he died. Margaret describes how she worked in a care home and contracted Covid-19. She blames herself for her husband's death after he caught the virus from her. According to Margaret, there were a number of things that were not being done properly in the care home; for example, staff were testing at work instead of testing at home, and there was no proper training on how to use PPE. 11 residents died from Covid-19 in the care home where Margaret worked.
- 4.23. Just under a year later, **Rex Webb**, died; 2 days before his 77th birthday. Rex's partner, Valerie Baker, describes how he had only been living in the care home for a matter of weeks before his death. She describes not knowing whether the staff were trained to use PPE properly, or even whether they were routinely using it. According to Valerie, Rex and the other residents were like *'sitting ducks'* when the virus broke out at the care home.

PPE in domiciliary care settings

- 4.24. Richard Brown lost his mother, **Naomi Brown**, on 5 April 2020. Following Naomi's diagnosis of dementia in 2016, Richard gave up his job to look after his mother 24 hours a day. They were provided with a home carer for around 30 hours a week, which was an essential help. According to Richard,

'My mother caught Covid-19 in late March 2020 from one of the carers who brought it into the house. There was no plan in relation to ensuring that my mother's risk was assessed. I complained to the care company about my concerns and no PPE. The carer and her husband were ill at the same time as my mother. She was also travelling to other clients and care homes as she told me she had 2 jobs. This also happened to my friend. He was carer for his mother. The carer came to his home with his mother present. The carer stated that she had a temperature and felt unwell, sweating, etc. My friend's mother passed away 2 weeks later.'

Once it was confirmed by medical staff that my mother had Covid-19, I had to isolate with her at home for 14 days. The care agency stopped the support and left with immediate effect. Myself and my mother were left at home with no consideration of the outcome. It was a terrible 2 weeks as I was awake 20 hours a day. It was the worst 2 weeks of my life.'

- 4.25. As with many unpaid carers, Richard received no guidance on effective IPC. There were no risk assessments and the care agency was unable to provide any policies. In relation to PPE, *'I called the care agency and asked for this and they told me that there is nothing. I was shocked. Not even a glove. No discussions. They never called me. I called them.'*

e. Restrictions on visiting

- 4.26. Some of our members are unable to verify staffing levels or PPE in residential care settings, or the number of untested patients who were discharged to their loved one's home, due to the restrictions on visiting. For example, Larry Byrne's father, **Laurence Byrne Snr**, died on 20 April 2020. Laurence was born in Ireland and worked for 43 years as a railway guard and later as a timekeeper. He was *'so truly loved'* by his family and is greatly missed. Larry is concerned that his father had been in a bad way for longer than suggested by his care home. Throughout the week Laurence was ill, the care home staff would not let Larry speak to him and made excuses as to why his dad was unavailable. Even though

Larry had two phones and was easily contactable, he was told his father had been admitted to hospital by email [JA/02 – INQ000505517].

- 4.27. In some cases, families were not offered a suitable alternative to in-person visits. For example, Amos Waldman and his family were unable to visit his grandma, **Sheila Lamb**, and there were no video call facilities at the care home either.
- 4.28. Restrictions on visiting had a particular impact on residents with dementia. CBFFJ UK members describe a *'postcode lottery'* between areas and the private/public provision of social care, which resulted in anomalies, inconsistencies and a hesitance to facilitate essential visits from family carers.
- 4.29. Jane Wier-Wierzbowska lost her mum, **Patricia Smalley**, on 27 January 2021. Patricia is described as *'a strong and resilient woman and a devoted wife, mother and grandmother'*:

'For most of her life she loved sport and in her early years was a swimmer, fencer and archer and later on she enjoyed tennis, badminton and yoga. Her energy and passion drove her life. She was also a home maker and very house proud. Our homes and gardens were always lovingly tended and immaculate. All of this was on top of a number of full time jobs. She began her working life training as a hairdresser and ended it working in the NHS as a clerk in a children's ward. The key to her success in all she did was her love of people, especially her family, but she also loved animals too and for most of her life kept pets.'

- 4.30. Patricia moved into sheltered accommodation in 2012 and soon after received an Alzheimer's diagnosis. In December 2019, she suffered a devastating stroke which immobilised her. The only option for her was to go into a care home. Jane last had the opportunity to visit her mum on 17 March 2020. Jane says, *'For the last ten months of her life, when she needed me the most; as her eyes, ears, memory and advocate; I was not able to be with her.'* The account Jane gives of her experience chimes with many, many others:

'The ten and a half months between lockdown and her death brought extreme anguish for us both. I saw her every day in any way I could: Skype calls, window visits, pod visits, whatever the situation would allow. I also spoke to her each evening on the phone. But, as every dementia expert will testify, not having that close personal contact with a loved one was

detrimental, and like so many others in care homes, her mental and consequently physical health began to deteriorate. It was very hard for her to understand why I wasn't there with her; the escalating loss of memory together with her recent loss of mobility was made even more traumatic by what must have appeared to be the loss of her family. It was heart wrenching for me to have to explain every day why I couldn't be there; to seemingly shrug it off and to try to be bright, cheerful and positive when inside my heart was breaking.'

- 4.31. Jane recalls that, in July 2020, dementia charities formed a group called One Dementia Voice. They wrote to the Government imploring them to give nominated relatives key worker status to enable visits. Jane expressed her support for key worker status on TV and radio, but nothing changed for her or her mum. Jane wrote to the then Prime Minister, Boris Johnson MP, on 7 October 2020 [JA/03 – INQ000502217] and to her MP, Sir Geoffrey Clifton-Brown, on 29 October 2020 [JA/04 – INQ000502218] to alert them to this issue. Jane believes that if she had been able to visit her mum, she would not have seen such a mental and physical decline. Patricia had been able, with support, to live independently for over 7 years after her Alzheimer's diagnosis until her stroke.

f. Restrictions on access to healthcare professionals

- 4.32. Many CBFFJ UK members describe a lack of access to healthcare for residents of care and nursing homes. **Margaret Smith's** daughter, Marie Erwood, says,

'There was no input from primary care services in care homes - such as from GPs - once Lockdown begun. Elderly vulnerable residents were abandoned. However, once we removed my mother to my house, we did have wonderful care for three hours from two paramedics who responded to my 999 call on Easter Saturday - and they were able to give us the option of either taking mum away in an ambulance to die on her own in a corridor of a hospital or letting her die with her daughter in familiar surroundings. We chose the latter option. The best decision of my life.'

g. The use of and communication about DNACPR notices

- 4.33. Restrictions on access to healthcare go hand in hand in many cases with the use of DNACPR notices without consultation. Many CBFFJ UK members are concerned about the blanket use of DNACPR notices for their loved ones.

- 4.34. Victoria Opalka describes a *'ceiling of care'* for her mother, **Judith Platt**, who lived in a care home and died on 7 May 2020. Judith was 76 years old and, although she was diagnosed with dementia, she was otherwise physically well and happy. Victoria and her sisters had to press for their mum's GP to see her when she became unwell and to have her oxygen levels taken. Victoria believes that the care home staff underestimated the extent of her mum's illness, who was eventually taken to hospital by ambulance. Like so many CBFFJ UK families, a DNACPR notice was put in place without the family's knowledge, consultation or consent; and in this case, despite Victoria having Lasting Power of Attorney. That there was a *'ceiling of care'* is not just Victoria's perception; it is something she was consistently reminded of by healthcare staff. *'Frailty'* was recorded on Judith's death certificate alongside Covid-19.
- 4.35. Likewise, Benita Finch reports there being a DNACPR notice in place for her mum, **Rita Hall**, without her knowledge and against her mum's wishes. Benita describes being *'haunted by the fact that [her mum] will have struggled to breathe without any oxygen or intervention and she passed away in the most undignified, lonely and horrendous way.'*

h. End of life care and medications

- 4.36. Many CBFFJ UK members have concerns about the use of drugs known to cause respiratory depression, such as morphine and midazolam, for older and Disabled people. In some cases, families were not able to obtain end of life medications for their loved ones who died in the community; in others, end of life medications were administered without their knowledge or consent.
- 4.37. This is part a wider concern about access to hospital treatment for older and Disabled people. For example, Emma Covell lost her dad, **Alan Covell**, on 25 April 2020. Alan was a temporary resident in a care home, where he had been admitted for rehabilitation following a hip injury. Emma describes her dad as,
- 'a wonderful man, everyone liked him. He never complained and always tried to be upbeat and positive, and would often make people laugh with a cheeky joke. People often described him as a gentle giant as he was so placid. He was an avid Crystal Palace fan, and watched every game that he could.'*

- 4.38. Alan was only 73 when he died and, apart from his need to recover from his hip injury, was otherwise able to live independently at home. After a 2-day delay in testing him, Emma received a call to say her dad was Covid-positive and would be given end of life care at home. As Emma recalls,

'I was so confused. I asked at what point he would go hospital and the response was "he wasn't a suitable candidate" for hospital admission because of his age, he wouldn't even be given oxygen. Simply left to die... a dog is treated better. And die he did Saturday Morning. The home, the Government all failed my father.'

- 4.39. Many members remain affected by the acute isolation their loved ones experienced before their deaths. Clare Welch's dad, **Roy Prisk**, was 85 years old when he died in a care home in Wales on 12 April 2020. Roy had semantic dementia but no memory loss and Clare is sure Roy was well aware of what was happening to him. Jane Wier-Wierzbowska recalls standing by her mum's window for days in the *'rain and then snow'* but not being able to hold her hand. Some members describe their loved ones experiencing hunger and thirst before their deaths.

- 4.40. Sarah Argyle lost her father, **Arthur Argyle**, on 3 May 2020. Arthur had dementia and was *'visibly scared'* when using FaceTime. Once it was confirmed that Arthur had Covid-19, Sarah recounts that, *'He was isolated upstairs in the care home. He died alone even though we asked someone to sit with him and leave him music playing.'* Sarah describes the experience for her father as *'barbaric'*. She says it has taken a long time to grieve because of the guilt that she and her family should have done more to help him. According to Sarah, 11 residents died in Arthur's care home.

- 4.41. Amos Waldman's grandma, **Sheila Lamb**, died on 2 April 2020 in a care home. Amos describes the special relationship he had with his grandma:

'She was an incredibly loving, caring and charismatic woman. She was very stoical and fiercely independent. She was Mensa certified, a talented pianist (grade 8) and a dancer. She was awarded a scholarship at Trinity College, for ballet, but didn't take up the offer, partly due to the war. She was a prolific knitter and crocheter. She made my mum's wedding dress,

which she copied from the front of Harper's Bazaar. She worked in the civil service in primarily clerical roles and eventually in my Grandpa David's wine wholesaler business. She and my Grandpa were devoted to each other.'

- 4.42. Amos recalls 'haunting' telephone calls with his grandma in the days before her death when she had become delirious. Their family was given inconsistent information by the care home about Sheila's state of health. At first, they were told she had a water infection, then a chest infection. When they later received the medical notes, the doctor recorded textbook Covid-19 symptoms. Sheila did not receive effective pain relief until the night before she died. She was given morphine, which her family thinks precipitated her death.

- 4.43. Pam Staples writes this about her dad, **Roy Staples**, who died on 8 April 2020:

'They didn't have anticipatory drugs available at the time, there was a 'shortage' in the community and they were not given the authorisation to use other resident's anticipatory drugs until after my Dad had died. I believe my Dad suffered more than he should have done because of mismanagement. We were not able to follow the funeral process that we would and should have been able to. It still haunts me. We were not able to visit my Dad in the chapel of rest, say our goodbyes etc. I asked for photos of my Dad in his coffin and when I received them you could tell he had just been dumped and left in a body bag. He was all contorted, his mouth was wide open and the only way I could tell that the corpse was my Dad was to look at his hands. I can't get that image out of my mind. There were only 4 of us at his funeral. There was no point in getting an order or service printed. There was only 1 florist open, 20 miles away. When I ordered flowers I was rushed and there was limited availability. I had to wait outside on the pavement and write the card to go with the flowers. We could not have a church service as well as cremation like we had with our Mum. We could not sit together, comfort each other, there were no Hymns. There was no wake. Dad always loved a knees up and he'd be so upset that we didn't give him a good send off with money behind the bar to buy people drinks.'

- 4.44. The story of body bags and hazmat suits is one that is told by countless CBFFJ UK members, and which haunts them to this day. Lindsay Jackson lost her mum, **Sylvia Jackson**, on 17 April 2020. Lindsay describes her experience in this way:

'We were utterly unable to follow funeral procedures which was extremely distressing. Mum was treated like medical waste. Sealed in a body bag. I was unable to see her, to say goodbye to her - it was all a complete nightmare - one from which I'm yet to awake.'

- 4.45. The situation was no better during the third lockdown almost a year later. As Naomi Fulop puts it,

'I believe my experience of bereavement was significantly different from my experience following my father's death in 2017. I did not see my mother for three months before her death as I was trying to protect her from covid. I was then unable to be with her in hospital when she was dying which was extremely painful. We had to have a very limited funeral and I was unable to be with my siblings to grieve with them, as I would have, due to the lockdown. This in addition to being part of a collective trauma particularly in January 2021 when she died at a time when 1000 people were dying of covid every day made this a very traumatic experience.'

i. Regulatory oversight

- 4.46. Many CBFFJ UK members have raised concerns about the impact of a lack of regulatory oversight during the relevant period and a lack of candour from care providers. Some CBFFJ UK members have said they only learned of outbreaks through media outlets. Many members were not told of their loved one's death until it was too late.
- 4.47. Fiona Crawford, from Glasgow, tells the story of her mum who died on 18 December 2020. **Margaret Crawford** had Alzheimer's and had been living in a care home since 2018. Fiona had numerous concerns regarding her mum's care before the Pandemic; such as, being confined to her room for long periods and there being evidence of missed meals and clothing soaked in urine. When Fiona phoned the home, she was regularly spoken to by unfamiliar staff who would tell her that her mum *'had had a great day and had been really chatty with staff and other residents'*. Margaret was latterly unable to communicate verbally. Fiona also reports being told that her mum had eaten all her meals, yet at the time of her death, Margaret weighed less than 4 stone.
- 4.48. When Fiona was told her mum's health had taken a turn for the worst, she was not told that there had been a Covid-19 outbreak in the home. After her mum

tested positive for Covid-19, Fiona and was told she was on oxygen and *'when it ran out she wasn't expected to live for long after'*. Fiona says, *'I asked if I could stay with her until then and was told no'*. Fiona writes,

'My Mum died at 1am on Friday December 18th alone. I received a black bin bag with what I was told were my Mums possessions, I returned about 60% as they didn't belong to her, what items that were my Mums were broken and filthy. I complained and was told they had no idea where my Mums belongings were. I wasn't allowed to supply a change of clothes for her to be buried in. It was a very stressful and distressing time for both my Mum and myself. And I felt the staff had no idea how to deal with the situation. When you asked a question they couldn't answer, I'd need to speak with a supervisor, but there was never one available. The PPE was just sitting on a table, outside the toilet in reception, no guidance on how to handle it. And a sign in book. There seemed to be a lot of agency workers, and staff I had never seen before. The whole building had a disgusting smell.'

- 4.49. Anne Elliott's brother was living in a care home in Northern Ireland when he died on 7 December 2020. The care home was split into two floors, with the first floor reserved for dementia patients. At the start of the Pandemic, the ground floor was empty. As soon as Anne heard about the plan to discharge untested hospital patients to care homes, she raised her concerns with the care home manager but within a week of the announcement, the ground floor was full of new residents. Although the manager tried to tell Anne her brother was safe, Anne was not confident they could protect him. Anne contacted the Regulation and Quality Improvement Authority in Northern Ireland to raise safety concerns but her calls went unanswered; she left messages, but her calls were not returned. In Anne's view, *'The RQIA failed miserably in their duty to protect our elderly.'*

- 4.50. Jan Bladen believes that her beloved partner, **John Leslie McEwan**, and his beloved son, **John David**, both died as a result of lack of appropriate care in their care home in Harrogate. John David was registered blind and severely Disabled. After John Leslie had had to be admitted to a care home following a fall, Jan's family decided it would be best for John David and John Leslie to live together in the care home because of the close relationship between father and son and John David's natural anxiety about being separated from his dad. Tragically, Jan describes her partner as *'skeletal and unrecognisable'* at the time of his death on Easter Sunday in 2020. When her step son died three weeks

later, the attending paramedics raised concerns about his care to adult safeguarding and the CQC.

j. Vaccination

- 4.51. Many of our members are concerned that their loved ones were vaccinated too late or not at all. Sally Anne Goffin-Adams describes the death of her father, **Norman Adams**, who was 94 years old when he died on 8 February 2021. Sally believes that he contracted Covid-19 from an agency carer. Norman received the vaccination on 8 January 2021 but sadly developed Covid-19 symptoms two days later. By 13 January 2021, Norman's oxygen saturation levels had dropped dramatically and he was admitted to hospital. Following a visit a week later, Sally contracted Covid-19 herself and was also hospitalised. Sally listened to patients dying each night, knowing her father was two floors up and dying too. Her sister feared she would lose them both. A week after Sally was discharged, Norman died. They said goodbye by video link.
- 4.52. Sue de Beauvoir lost her father, **Anthony 'Barrie' Grantham**, on 28 January 2021. Sue describes the love between her parents and her father's decision to move into the care home with her mum, Ann, because she was his *'wife and bedrock of 60 years'*. Although Ann lived in a secure dementia wing, Barrie would go to her every day and sit with her to keep her company. Sue sold the family home to fund the care for both her parents. She describes how the care home struggled with under-staffing; with some staff members having to work 24/7 to ensure there was enough cover for residents. Although the home was extremely diligent, the staff were forced to admit a patient from hospital who had not been tested. Covid-19 spread through the home as a result. Sue's parents, despite being clinically vulnerable and living in a care home, did not receive vaccinations before her father died. Sue reports being told that the home was not considered a high priority because there were fewer than 65 residents. Sue is sure that, had he been vaccinated, Barrie would not have died from Covid-19. Ann was not allowed to see Barrie during his last days for fear of her contracting Covid-19, which was distressing and confusing for her, and Sue was not able to give her a hug after he passed due to restrictions.

5. The impact of the Pandemic on CBFFJ UK members

- 5.1. The impact of the Pandemic on CBFFJ UK members whose loved ones were receiving care from or working in the Care Sector, or were doing so themselves, is untold. Some bear the unimaginable burden of having infected their loved ones through their work, and a number carry the weight of losing multiple family members. Most CBFFJ UK members have been traumatised by the manner in which their loved ones died – many of whom died alone or at a distance from their families – and their own experiences of bereavement.
- 5.2. We have been told countless stories of bereaved families not being able to see their loved ones before their deaths and of stark variations in post-death processes. Janet Berry lost her mother, **Marjorie Berry**, on 10 April 2020. Janet describes having *‘ten minutes to say goodbye to her mother before she was put in a plastic bag and carried out to an unmarked vehicle’*. Another member describes their loved one’s funeral taking place in a car park.
- 5.3. Many families describe the devastation of not being able to see their loved one for weeks, months and even the year before their death. Some bereaved family members had to choose which of them would visit their dying parent because only one of them was allowed.

First wave

- 5.4. Lorelei King describes the situation as it affected her and her husband, **Vince Marzello**, before his death on 31 March 2020:

‘As the numbers of infections increased, we were in constant discussion about balancing the emotional benefits of visits with the physical realities of the disease, which were becoming more and more apparent. We could not understand why the PM was refusing to implement a lockdown. The carer I hired to visit my husband was expressing grave concerns about the disease. I was desperate to protect my husband and the other residents, and on Sunday the 22nd we decided to stop visits ourselves. The next morning the CEO of the care home sent a letter saying he was limiting visits. This was on the morning of the day the Prime Minister finally announced that too-late lockdown.

I started to visit my husband by iPad; something difficult to arrange after lockdown, as the staff were kept very busy with some staff out sick and without family visitors to help.

I started to notice a gradual decline in my husband. His breathing became shallower, and he seemed more out of it. I pointed this out to staff and the doctor, but there were no tests available as a first port of call. They tried other things, changing his medication and so on, but he continued to decline.

On 31st March 2020 a nurse phoned from the home to say my husband had died very early that morning. I said I was coming to be with him. At that point, having been deprived of visiting him for the last ten days or so of his life, I was not going to stay away.

I feel lucky to have been able to sit with my husband's cooling, stiffening corpse for few hours. I know many who would give everything that they have to have had that opportunity.

My husband was Roman Catholic, but I couldn't get a priest to give him last rites, as was his wish. The priests wouldn't or couldn't come. The doctor declared him dead over iPad.

After a few hours men came in hazmat suits to take his body away, as though he were radioactive waste. I accompanied his temporary coffin to the van. As they opened the door to put him in, I saw it was already full of coffins, stacked on shelves like loaves on baker racks.'

- 5.5. Almost one month later, Robert Holmes lost his fiancé, **Jemma Gates**, who was only 36 years old when she died. Robert was working in the community as a Care Sector support worker. He was unable to obtain tests for weeks prior to his fiancé's infection. When Robert became ill in March 2020, which was not an unusual thing to happen, he was told '*multiple times*' that the risk of him contracting Covid-19 in the community was '*negligible*'. Jemma became ill later that month. Unbeknown to Robert and Jemma's family, a DNACPR notice was put in place, apparently with their consent (which had not been provided). Robert was not told of Jemma's death until 7 hours after she had died.

Second wave

- 5.6. Cilla Merryweather lost her parents, **Rosemary and Ronald Brown**, on 22 November 2020 and 22 January 2021 respectively. Both Ronald and Rosemary

were diagnosed with dementia. In March 2020, Rosemary was admitted to hospital after she injured her head during a fall, and later to a care home. When the first lockdown was announced, Cilla recalls that all the additional support that her parents had begun to rely on started to disappear; including a chiropody service and visits from the dementia nurses. Cilla describes an overworked and under inexperienced domiciliary care service which resulted in Ronald rarely being seen by the same care worker:

'It was obvious that during the pandemic the agency had such a high turnover of staff and sickness they were desperately trying to fill vacancies and gaps with anyone who was willing to take on the job.'

- 5.7. Before Rosemary's death, Ronald had not been able to see her for 9 months, which affected him deeply. Cilla and her brother were given the unenviable task of deciding who would go to the hospital to be with their mother during her last hours as, like so many families, only one of them was allowed in. When Ronald was told that Rosemary had died, he was *'beside himself with grief'*.
- 5.8. Due to a decline in Ronald's health and increase in his need for care and support which could not be met by the domiciliary care package that was in place, the decision was made that Ronald would also move into a care home. At the time, Ronald was in hospital following a fall. His discharge was delayed due to problems persuading Adult Social Care to complete an assessment and agree that Ronald's need for 24/7 support could only be met in a care home. Cilla reports that her father *'languished'* in hospital for about a week before being discharged. When eventually discharged, Ronald was admitted to a care home where staff were regularly absent with Covid-19. Cilla wonders whether they were pressured to work while infected because of their pay and conditions. It was here that Ronald contracted the virus.

Third wave

- 5.9. Valerie Baker describes feeling *'numb'* for a time after her partner, **Rex Webb's** death on 3 January 2022. Rex had a diagnosis of Bipolar Disorder and had been admitted to a care home for convalescence following a fractured femur. He had begun to have frequent falls due to Parkinson's disease. Valerie has a number of concerns about the care Rex received, including whether he was discharged

from hospital with an adequate needs assessment, and whether the care and support he received during isolation was appropriate. By the time Valerie felt able to find answers for Rex and his care in the home, she felt it was *'too late'*.

6. Unequal impacts of the Pandemic

- 6.1. As outlined in Section 3, the impact of the Pandemic has not been felt equally, with older people, Disabled people, people with underlying health conditions, people with dementia, people living in more deprived areas, and Black people, Asian people and those from other minoritized ethnic groups facing the greatest risks.

7. Summary of CBFFJ UK engagement with the UK Government and CQC

- 7.1. CBFFJ UK members engaged with the UK Government, including the Department for Health and Social Care, and the CQC a number of times during the Pandemic. Key meetings and letters relating to the Care Sector include:

- 7.1.1. **17 March 2021:** 1st meeting with the CQC to request the publication of death data across care homes in England.
- 7.1.2. **7 May 2021:** 2nd meeting with the CQC to request the publication of death data across care homes in England.
- 7.1.3. **8 June 2021:** 3rd meeting with the CQC to request the publication of death data across care homes in England.
- 7.1.4. **20 July 2021:** 4th meeting with the CQC to request the publication of death data across care homes in England.
- 7.1.5. **10 August 2021:** 5th meeting with the CQC to request the publication of death data across care homes in England.
- 7.1.6. **28 September 2021:** meeting with the then Prime Minister Boris Johnson MP to encourage consistency of messaging, mask use in Parliament and to urge the UK Government to undertake an inquiry into the handling of the Pandemic as soon as possible.
- 7.1.7. **22 November 2021:** a meeting with the then Minister of State for Care and Mental Health, Gillian Keegan MP, to discuss bereavement support.

- 7.1.8. **23 February 2022:** letter to the then Prime Minister, Boris Johnson MP, asking him to reverse the decision to end free Covid-19 testing [JA/05 – INQ000502219].

8. Summary of CBFFJ UK evidence and engagement regarding the way the Care Sector operated during the Pandemic

- 8.1. CBFFJ UK members engaged with parliamentarians and provided evidence to Parliamentary Select Committees throughout the Pandemic as part of the campaign to encourage the UK Government to learn lessons and save lives. Key contributions as they relate to Module 6 include:

- 8.1.1. **w/c 28 September 2020:** meeting with Jeremy Hunt MP and Greg Clarke MP regarding the Health and Social Care Committee and the Science and Technology Committee's joint inquiry into the handling of Covid-19.
- 8.1.2. **28 September 2020:** letter to Stephen Timms MP, Chair of the Work and Pensions Select Committee, to provide a briefing ahead of the Select Committee's questioning of the then Secretary of State for Work and Pensions [JA/06 – INQ000502220].
- 8.1.3. **26 October 2020:** letter to Harriet Harman MP, Chair of the Joint Committee on Human Rights, to call for an inquiry and for urgent review and action [JA/07 – INQ000502221].
- 8.1.4. **29 October 2020:** letter to Virendra Sharma MP, Chair of the APPG on Vulnerable Groups to Pandemics, requesting urgent action to address the great loss of life among Black people, Asian people and other minoritized ethnic groups [JA/08 – INQ000502222].
- 8.1.5. **22 February 2021:** appearance at the APPG on Adult Social Care's event with Amnesty International UK and the Equality and Human Rights Commission on 'Valuing the lives of people who receive care and support during COVID-19: A Human Rights approach'.
- 8.1.6. **22 November 2021:** submission to the APPG on Hospice and End of Life Care Review into the Lasting Impact of Covid 19 on Death, Dying and Bereavement [JA/09 – INQ000502223].

9. Recommendations

- 9.1. Although we have not yet seen all the evidence in Module 6, there are some recommendations that are clear to us from the evidence the Inquiry has heard in Modules 1 and 2 (including 2A, 2B and 2C). They are:
- 9.1.1. The need to establish a national care service that is anchored to the centre of Government and equal to the NHS.
 - 9.1.2. The need to ensure sufficient resource in the health and social care sectors to deliver high quality care on a routine basis and to respond to infectious disease outbreaks with pandemic potential.
 - 9.1.3. The need to ensure adequate, centralised and free access to PPE for the Care Sector.
 - 9.1.4. The need to establish the posts of Commissioners for Older People and Ageing in England and Scotland.
- 9.2. The Inquiry received a substantial amount of evidence in Modules 1 and 2 calling for parity between the NHS and Adult Social Care and stressing the need for a Care Sector which is adequately funded, resourced and valued for it to withstand a future pandemic. It also heard evidence of structural ageism and discrimination, which underlies the recommendation for Commissioners for Older People and Ageing in England and Scotland. These Commissioners would act as independent champions for older people and ensure that their long-term needs are considered in policy and practice across all government departments, and specifically in pandemic planning and response.
- 9.3. Just last May, Caroline Nokes MP (then Chair of the Women and Equalities Committee) wrote to the then Minister for Women and Equalities highlighting the *'insufficient focus on ageing and older people in the machinery of government and wider governance framework'* and the *'overwhelming'* case for a Commissioner for Older People's Rights in England [JA/10 – INQ000505518]. As the Inquiry heard in Modules 2B and 2C, these roles have been established in Wales and Northern Ireland for over a decade. For CBFFJ UK families, there is a pressing need for there to be someone in government in England and Scotland who is specifically tasked with promoting the interests of older people and reviewing the adequacy and effectiveness of the law as it affects them.

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: 11th October 2024