Witness Name: Cathryn Lee
Statement No.: 1
Exhibits:
Dated:

UK COVID-19 INQUIRY – MODULE 6

WITNESS STATEMENT OF CATHRYN LEE

I, **CATHRYN LEE**, of 43-44 Crutched Friars, London EC3N 2AE will say as follows: -

1. Introduction:

1.1. I am the Chief Executive Officer of Alzheimer's Society and I have been in that position since March 2020. I therefore took on the role just as the Covid-19 pandemic was starting.

1.2. Prior to taking on the role as Chief Executive I was CEO at Young Lives Versus Cancer from 2016 to 2024 and I have also previously held a CEO role at Myton Hospice which is an adult palliative care charity based in the Midlands. Prior to that I worked for a period of 16 years at British Red Cross ultimately becoming Director of UK and International Strategy and then Deputy CEO which role I took in 2005.

2. Background matters:

2.1. Alzheimer's Society is the largest UK support service and research charity for both people with dementia and those who care for them. Our work encompasses England, Wales and Northern Ireland. We provide information and support to people with all forms of dementia, not just Alzheimer's disease, and those who care for them through information and dementia support services. We seek to be informed by the experience of people living with dementia, their carers and loved ones, using their insight to influence for improved policy and decision making at local and national level.

2.2. Our aims are contained in our Help and Hope Strategy (2022-2027) which is exhibited to this statement as Exhibit CL/01 [INQ000492898], and which sets out a five year framework of priorities which underpins all the work we do at the Society. The current strategy was created against the background of the Covid-19 pandemic and the changes that that had brought about. In terms of our aims, the strategy sets out four priorities - (i) to reach more people – our particular concern is with those people who have the least ability to support themselves and communities that are rarely receiving dementia support and experience the detrimental effects of health inequality; (ii) ensure more people get an accurate diagnosis faster – in addition to this a knock-on effect is that people will then, after a speedy and accurate diagnosis, receive a more seamless transition into effective ongoing support which will include support provided by us; (iii) make dementia the priority it should be – this can be achieved by influencing local and national decision makers and increasing public awareness of the disease; (iv) to increase our impact and strengthen our understanding – we seek to strengthen our understanding of what makes the biggest difference to people living with dementia and by virtue of that we increase our impact.

2.3. In statistical terms, in April 2024 in England there were 205,181 people recorded as living with an Alzheimer's disease diagnosis. This is 42.6% of all recorded dementia diagnoses which information has come from Primary Care Dementia Data, April 2024, NHS England Digital.

2.4. Whilst this is the statistical analysis provided by NHS England Digital it should not be taken as a wholly accurate figure. It is estimated that the total number of people living with dementia is 33% more than the recorded figure of diagnoses. In the first instance therefore this is only a percentage of recorded diagnoses, 42.6% of the estimated dementia population over 65 will be 307,465 and there is no estimate for people under 65 living with undiagnosed dementia. In addition, the percentage does not include people living with mixed dementia where Alzheimer's disease is present. There are other difficulties with diagnosis in so far as there is a significant variation in the accuracy of GPs' use of their tool to support the recording of clinical information onto national systems. There are many people who are considered to have other forms of dementia and who may have

Alzheimer's disease but have been coded as having non-specific dementia.

2.5. NICE estimate that 50-75% of dementias are caused by Alzheimer's disease and the Society estimates that, of the 982,000 people living with dementia in the UK in 2024, they would expect Alzheimer's disease prevalence to be somewhere between 491,000 to 736,500.

2.6. In summary therefore, simply on extrapolating and considering the Alzheimer's disease diagnosis data for England, there are significant factors that affect the accuracy of, and therefore one's ability to rely on, those statistics.

2.7. There is no publicly available data on dementia types in Wales or Northern Ireland but we would estimate, based on ratios one can extrapolate from the English data, that there are around 51,000 people with dementia in Wales and 25,000 people with dementia in Northern Ireland. These estimates are calculated through application of age banded prevalence rates from the MODEM project which change over time to the 2020 Office of National Statistics age banded projections by gender. The estimates do not include people under 65 due to the lack of data of this group.

2.8. Fundamentally Alzheimer's disease is the most common cause of dementia in the UK. Dementia is the name for a group of symptoms associated with an ongoing decline of brain functioning. In simple terms it can affect memory, thinking skills and other mental abilities.

2.9. The symptoms of Alzheimer's disease are divided into three main stages: early symptoms, middle stage symptoms and late stage symptoms.

2.10. In the early stages the main symptom of Alzheimer's disease is memory lapses, for example in relation to recent conversations or events, place names, repetitively asking questions, difficulty in thinking of the correct word to use, mood changes with additional symptoms including increased anxiety, agitation or periods of confusion, misplacing items and poor judgement and finding it more difficult to make decisions.

2.11. In terms of middle stage symptoms these include increasing confusion and disorientation which may include getting lost and not knowing what time of day it is, obsessive, repetitive or impulsive behaviour, delusions or a feeling of paranoia and suspicions about carers and family members, problems with speech and language, disturbed sleep, frequent mood swings, depression and increasing anxiety, frustration and agitation, difficulty with performing spatial tasks such as judging distances and seeing and hearing things that other people do not.

2.12. During the middle stage of Alzheimer's disease the person with the disease will usually need support to help them with everyday living. This may include fundamentals such as eating, washing, getting dressed and using the toilet. The later stage symptoms become increasingly severe and can include hallucinations and delusions that increasingly worsen. It may also include the person becoming violent, demanding and suspicious of those around them to an increasing degree. Other symptoms that develop include difficulty eating and swallowing, difficulty changing position or moving without assistance, weight loss, urinary and bowel incontinence, loss of speech, and problems with both short and long term memory.

2.13. In the severe later stages of the disease people may need full time care and assistance with all fundamental tasks such as eating, moving and personal care.

2.14. During the course of the Covid-19 pandemic there were a significant number of public bodies and professional organisations with whom Alzheimer's Society worked, lobbied and liaised. In so far as the UK Government was concerned these included politicians and civil servants within the Department of Health and Social Care, the Right Honourable Sajid Javid MP, who was the Secretary of State for Health and Social Care, Public Health England, and Dr Jenny Harries who was the Deputy Chief Medical Officer.

2.15. The Northern Ireland Executive and Northern Ireland Assembly Health Committee were also engaged with as was the Welsh Government.

2.16. In terms of local authorities, all local councils in England, Wales and Northern Ireland were written to and engaged with. The contacts provided information on the Society's services and also dementia related requests including for guidance relating to the National guidance.

2.17. All Health and Social Care Trust Chief Executives in Northern Ireland and the Northern Ireland Health and Social Care Board were also engaged with as was Care England.

2.18. At the start of the pandemic, we engaged with colleagues at Alzheimer Scotland primarily through their temporary involvement with the One Dementia Voice coalition. Later on, we shared - on an informal basis - details of reports and publications we released as part of our policy and influencing work.

2.19. In terms of other key representative bodies not mentioned in 2.14-2.18 in the adult social care sector we engaged with: Northern Ireland Statistics and Research Agency, Northern Ireland Commission for Older People, Northern Ireland Social Care Council, Public Health Agency Northern Ireland, Northern Ireland Patient and Client Council, Northern Ireland Confederation for Health and Social Care. In England additional engagement would include the Richmond Group, Care Quality Commission; National Care Forum, local care provider associations; ADASS and the LGA. In Wales, we observed and commented on the Cross Party Group on Dementia concerns and prepared questions for Lynne Neagle MS. The key submissions made to the organisations mentioned above are listed and exhibited to this statement as Exhibit CL/02 [INQ000492899].

3. Impact of the pandemic

3.1. The Covid-19 pandemic had a very significant negative impact on the health and wellbeing of people living with dementia and those caring for them.

3.2. The most direct and fundamentally devasting impact of Covid-19 on people with dementia was the high death rate. Between 2020 and 2021 there were over 30,000 deaths due to Covid-19 among people with dementia in England and Wales and in 2020 it was the most common pre-existing condition in people who died due to Covid-19 in England and Wales.

3.3. Covid-19 appeared to cause dementia to deteriorate more quickly in a number of ways. It could cause severe inflammation in the brain leading to encephalopathy or delirium. Severe and prolonged bouts of delirium, such as those caused by Covid-19, have been shown to accelerate the downward trajectory of dementia. Delirium may also accelerate the onset of dementia in those who do not yet have it.

3.4. Post viral symptoms such as long Covid may have worsened existing problems with memory, mood or concentration. In addition, the adverse effects of hospitalisation on people with dementia was severe with intense confusion and disorientation caused by experiencing clinical staff dressed in full PPE and a lack of contact with loved ones with the exception of occasional video calls via a nurse-administered tablet.

3.5. The Society conducted a survey in July 2020 entitled "The impact of Covid-19 on people affected by dementia" which is exhibited to this statement as Exhibit CL/03 [INQ000492900]. Respondents included 134 people living with dementia and 1697 carers.

3.6. 82% of respondents reported a deterioration in symptoms. The most common reported symptoms by people with dementia were having increased difficulty concentrating (48%), memory loss (47%) and agitation and restlessness (45%).

3.7. The Survey also indicated a strong negative emotional impact on carers with their mental health (44%), added strain to their relationship with their loved one (42%) and left them struggling with caring for themselves and their loved one (22%). Other areas that were negatively impacted included exhaustion, sadness and missing loved ones.

3.8. Our July 2020 survey of informal carers supporting people affected by dementia in the community indicated further impacts on the quality of social care provided to adults living with dementia. 90% of respondents indicated the person they cared for had experienced interruptions to regular health or social care routine. The services most frequently highlighted were GPs, dentists, memory clinics and chiropodists. In terms of home care staff shortages were already prevalent but were exacerbated by the pandemic. Concerns around visiting support spreading the virus meant many families affected by dementia were left without vital support.

3.9. In residential care homes the impact of discharge from hospital without testing, lack of access to PPE and visiting restrictions all had an effect on the quality of social care provided to adults living within those homes with dementia. I will address the wider impacts of these factors later in the statement.

3.10. The introduction of new rules and guidance during the course of the Covid-19 pandemic created significant problems for people with dementia. One of the most common symptoms of dementia is problems with short term memory and therefore a person with dementia would be unlikely to be able to retain information regarding new rules and guidance for very long. Although the evidence is anecdotal there appears to be something to suggest that people with dementia forgot they needed to keep their distance and either got too close to other people or physically touched them. Similarly there are many accounts from carers about lack of understanding that people with dementia had in terms of pandemic restrictions.

3.11. In short, therefore, dementia symptoms such as memory loss or agitation posed additional barriers to infection control and people with dementia often felt confused by social distancing measures and struggled to adhere to guidance such as social distancing, handwashing and observing quarantining in a care home.

3.12. In relation to the impact of facemasks, the evidential basis of the impact is mostly anecdotal. The focus of a study entitled "Face Masks Protect from infection but may impair social cognition in Older Adults and People with Dementia" was on the impact of facemasks on social cognition when 60-70% of the face is covered when the mask is worn. This would prevent the person with dementia from being able to assess the emotional state of the other person and in addition a person with dementia wearing a mask may forget that they themselves may have more difficulty being understood than at other times. The barriers to communication caused by this could create problems ranging from misunderstandings, or delays in understanding, frustration, anger, distress or embarrassment. In addition, the impact of short term memory loss on people with dementia also impacted on those people understanding and remembering about the need to wear a mask at all causing impacts both on them and their carers.

3.13. The impact of visiting restrictions on people with dementia was disproportionate particularly in relation to the emotional wellbeing of people with dementia. The impact of them being unable to touch a visitor or having visits behind screens, on a video or at distance in circumstances where the person did not understand the restrictions had a significant effect emotionally and was also reported as causing physical distress in the person with dementia on occasions.

3.14. In so far as visits from healthcare professionals being restricted this had an impact on good physical health, wellbeing, as outlined previously, and function. The impacts included a lack or delay in diagnoses, insufficient or unsustained care plans, lack of medication or reviews of medication, dietary issues and issues relating to the management of incontinence.

3.15. Other concerns associated with visiting restrictions included issues such as concerns over nutrition in circumstances where a family may have previously helped feed a relative in care, by bringing in special food that person was more likely to eat, exercise and other activities which were also generally cancelled in the care homes due to restrictions.

3.16. The support that we were able to supply in terms of one to one and group services could not be delivered in person following Government guidance such as that of 23 March 2020. Services were reopened on a phased basis from July 2021. People with dementia as a group were particularly vulnerable to the impacts of lockdown restrictions, isolation, loneliness and struggling to cope which were among the most prevalent reported effects of lockdown for people with dementia and carers in the community. Our Covid-19 service response sought to address these as a priority.

3.17. Notwithstanding the non-delivery of in-person support services we were still able in 2020 to support 90% of the people we were supporting in 2019. This was achieved in the main by deploying remote services as a substitute. For the 10% of people who did not access these services the reasons included a preference for the previous arrangements, a lack of help and support to access the replacement services or an inability to use them.

3.18. It is difficult to assess in terms of data the impact on people with dementia relating to disruption that was caused by the pandemic and the non-pharmaceutical interventions introduced on normal routines including transfers to appointments whether medical or otherwise. Whilst it is difficult to quantify this statistically we do know that it is well established that routine and familiarity are incredibly important to people with dementia, and so any disruption will be challenging for them. As a consequence, missed appointments which were part of their routine would have an impact which would be especially true during lockdown due to the number of disruptions to routine and familiar experiences which were all happening at once. Family members also provide certain coping mechanisms such as reassurance by physical touch; being seen as a friendly face; and the removal of that contact in the same way as before would have had an impact. Whilst there is a lack of evidential data regarding the impact of disruption to normal routines, I have no doubt that a person with dementia will have been negatively affected by this disruption, albeit the specific impact may be greater or less depending on the individual involved and the type and stage of their dementia.

3.19. Virtual communications were introduced in order to try and negate the impact of lockdown and Alzheimer's Society adapted existing services from in-person to virtual formats and were assisted by delivery of new services, funded in part by an award to the Society in June 2020 of £500,000 by the Department for Digital, Culture, Media and Sport from the Loneliness Fund. These funds primarily supported delivery of two new services, welfare calls and companion calls between July and December 2020. This strategy did assist in meeting individual needs and helped service users to feel seen and cared for and provided occupation and stimulation. The sense of connectedness for people with dementia utilising virtual communications was greatly improved as a consequence. Further funding from the Department for Health and Social Care of £515,000 was used to meet demand for the national Dementia Support Line between 1 April and 31 October 2020.

3.20. In terms of the two services introduced our welfare call service involved staff in local services such as dementia advisers phoning existing service users. In the absence of face to face services, callers aimed to meet individual support needs, manage risk and promote safety, and provide useful information and signposting. Between 1 July and 31 December 2020 our staff made 11,661 welfare calls.

3.21. The companion call service involved trained volunteers phoning service users for an informal chat about a topic of the service user's choice, with the aim of helping the person feel more connected and less lonely during lockdown. Between April 2020 and June 2022 volunteers made 124,434 companion calls.

3.22. Other services were adapted from an in-person group to virtual format including as a non-exhaustive example, our carer group psychoeducation service. In terms of the services offered, many service users who attended in-person services wanted a return to that but attendees with mobility issues actually found a virtual option was more accessible than the in-person service.

3.23. As a consequence, many of the adapted or new services have been continued in some form even after the reintroduction of face to face services and we now have a blended hybrid service delivery model which is flexible according to service user needs.

3.24. There were a number of inequalities and disparities that were exacerbated by the Covid 19 pandemic. These included, (i) Inequalities between protected characteristic groups, with Black, Asian and minority ethnic communities found to be particularly Covid vulnerable, with those over 65 most vulnerable to Covid-19, and with women's caring burden increased: (ii) Geographical inequalities: many remote areas lacked good access to the internet, whether from broadband or mobile phone signal, contributing to digital exclusion. In Scotland, some remote areas had an almost complete withdrawal of public transport and home deliveries of vital supplies can be much more difficult to access and be more expensive. (iii) Socio-economic inequalities: during the entire pandemic period, the age-standardised mortality rate was highest among those living in the most deprived areas, with a clear gradient showing increasing mortality with increasing deprivation; and (iv) Common comorbidities for people living with dementia such as diabetes and heart disease raised Covid-19 risk.

4. Key decisions made by the UK Government and devolved administrations

4.1. In the course of the pandemic we raised a number of significant concerns to the UK Government and devolved administrations regarding their decisions and the Government guidance provided regarding the adult social care sector.

4.2. We felt there was a lack of acknowledgement of the scale of the impact on care homes and the pace of the virus spreading disproportionately in elderly care homes. Our report, Worst Hit: Dementia During Coronavirus, which is exhibited to this statement as Exhibit CL/04 [INQ000492901] published in September 2020 set out how the pandemic had impacted on people with dementia and their families and carers. Following the report the Government committed to (i) published the number of care home deaths due to coronavirus daily; (ii) ensured that anyone discharged from hospital to a care home was tested for the virus first; (iii) ensured that Government took a more active role in the sourcing and provision of PPE for care homes; and (iv) prioritised care home and home care workers to testing in the same way that NHS staff were.

4.3. Particular concerns included a decision to discharge residents from hospitals to care homes without testing. This had a number of impacts including infecting entire care homes which then stopped visits. It meant that care homes were forced to accept discharges of people with dementia to clear hospitals before any testing regime, PPE or vaccines were in place. There was a noted disparity with some care homes refusing admissions but others having no choice with needing the residents to obtain funding to operate. There also appeared to be an inequity between mainly local authority funded residents and homes for wholly private individuals. The former were much more adversely affected than the latter.

4.4. I wrote to the Secretary of State for Health in early April 2020, which is exhibited to this statement as Exhibit CL/05 [INQ000492902] asking for immediate steps to be undertaken as part of a dedicated national strategy to support care home residents and their families through the pandemic. This included (i) PPE equipment should be readily available to care homes; (ii) care home staff and people being discharged from hospital into care homes should be given priority testing for the virus; (iii) the Government should support care homes to put in place arrangements to ensure continued contact between residents and their loved ones. I pointed out that people living with dementia who do not use their basic communication skills frequently by talking and interacting with visiting family members could lose them; and (iv) to ensure that the impact of the virus on care homes is measured and published.

4.5. As a consequence of our action to draw attention to the unfolding crisis in care homes at the beginning of the pandemic, we were able to provide information to feed into the Government action plan "Covid-19 Our Action Plan for Adult Social Care". We still had concerns that whilst at paragraph 3.12 of the action plan, which is exhibited to this statement as Exhibit CL/06 [INQ000237459], "Do Not Attempt Resuscitation" was not permitted to be applied in a blanket fashion to any group of people, we were still hearing of cases anecdotally through our helpline. The reports on occasions indicated that the Care Quality Commission had been contacted but we were not made aware of what action, if any, they took as a consequence. We have been able to find two examples of contacts before the Government action plan was introduced relating to this issue. In the first instance a caller told us that they had been told by the home that their father was in that the Local Authority had made a decision to change care plans of all residents and that they would not be admitted to hospital if they showed signs of Covid-19 and would be treated on site and that Do Not Resuscitate would be added to their care plans. The caller had spoken to the surgery that issued these instructions and tried to contact the local authority without success. The second example related to a caller who indicated that she and her husband were given their NHS Personal Care Plan from their GP. She stated that her husband's Personal Care Plan stated Do Not Resuscitate and that he will not be taken to hospital during the pandemic if he had Covid-19. She was also listed as not having a Lasting Power of Attorney.

4.6. We had significant concerns as set out previously regarding the imposition of visiting restrictions and I can summarise these as being as follows.

4.7. Firstly there was a lack of clear information or consistent approach for visitors to care homes. Care home restrictions were not aligned to wider community restrictions and there appeared to be no understanding that people viewed their care home as their own home and therefore were no different in many respects to those living in their own housing. Whilst there was the potential for technology to be used within care homes to enable, for example, video contact with relatives, the use of technology was very much dependent on care home resources so replacing face to face visits could be problematic. Not all care homes have access to remote calling technology or indeed reliable internet for people's use. As I have indicated previously, this aggravated the sense of isolation and whilst better resourced care homes were able to create conditions where video contact was viable others were not thus creating inequality for those care homes with more limited funding. Furthermore, as previously set out, dementia symptoms appear to increase more rapidly due to isolation from visitors amongst people with dementia.

4.8. The impact of visiting restrictions on other visitors included concerns with delays on how deprivation of liberty safeguards assessments would be undertaken and how the essential care giver status was being used. In a document which is exhibited to this statement as Exhibit CL/07 [INQ000492904] and is entitled "Moving Forwards Stronger" we called for (i) a national two year rehabilitation strategy that ensured people who had seen significant deterioration of their long term conditions had the therapeutic support they needed; (ii) the appointment of a national clinical lead to implement the rehabilitation strategy; and (iii) local partners such as local authorities and integrated care systems should deliver their own localised rehabilitation strategy with each integrated care system to have a regional rehabilitation lead. These calls were not included within the Covid-19 Response: Living With Covid-19 Plan guidance published in February 2022 and the plan appeared to focus mostly on vaccinations albeit there were particular challenges for people living with dementia particularly those living on their own. The Society's view was that greater focus on supporting local authorities develop ways of engaging with vulnerable people would have been welcome.

4.9. The enabling of Local Authorities to invoke easements of the Care Act 2014, following the provisions of Schedule 12 Coronavirus Act 2020, had the impact that irrespective of whether a Local Authority invoked easements of the Care Act or not the evidence from both carers and social work leads within Local Authorities was that people with dementia, carer and family members that were being supported experienced significant changes in their usual care and support. According to the NIHR report on the Impact of Care Act Easements, which is exhibited to this statement as Exhibit CL/08 [INQ000492905], this "in many cases resulted in lower wellbeing and unmet need". Non-exhaustive examples reported to us included, a failure on the part of social services to undertake a care needs assessment and reductions in frequency of home care visits.

5. The management of the pandemic

5.1. We had a number of views and significant concerns regarding access to healthcare professionals, services, medication, transfers to appointments and other support services during the pandemic for adults living with dementia. We were concerned over increased use of antipsychotics during Covid-19 particularly in care homes. The rates of antipsychotic drugs being prescribed increased from 9.4% of people living with dementia to 10%. Care homes and clinicians reported to us that many residents experienced increased agitation and distress. Whilst there were non-pharmaceutical interventions that could be used to reduce these symptoms, those same people reported to us that there was a lack of access to community nursing teams during the pandemic to undertake appropriate assessments and provide adequate interventions to reduce these symptoms without the need for medication.

5.2. We further had concerns over vaccination status and infection control of all health and care staff.

5.3. The impact of the pandemic upon services was a reduction in resource and capability for the diagnosis of dementia including memory clinic closures and diversion of staff to acute or other Covid support settings resulting in what has now been identified as a drop in diagnosis rates which have only now returned to pre-pandemic levels in 2024. I should add that memory clinics not only provide a diagnosis but unlock support. This route to post diagnostic support, including adult social care support was lost as a consequence.

5.4. On a more generic level, care home residents were not getting sufficient general healthcare. It is alluded to in the report previously produced, Worst Hit: Dementia During Coronavirus report from September 2020 and 75% of care homes we surveyed in May 2020 said that GPs were reluctant to visit residents. As a consequence, there was a reliance on the voluntary sector/the community to support people with dementia.

5.5. On occasions care homes were able to refuse residents returning to the home after hospital visits which effectively amounted to refusing people with dementia the right to return to their main residence.

5.6. The lack of a face to face option in terms of healthcare meant that healthcare professionals were often only providing video care rather that in-person consultations. The diagnosis of health problems in people with dementia can be particularly complex and it is possible that more remote working by GPs and primary care teams made it harder for people with dementia to get help when they needed it.

5.7. As I have indicated previously, the impact of visiting restrictions on adults living with dementia in residential care homes was significant. As set out before, the lack of clear information or a consistent approach for visitors to care homes was challenging as was the lack of alignment between care home restrictions and those in the wider community. Technology was able to be deployed with some success in relation to ensure virtual contact between loved ones and adults living with dementia. As set out previously, this was not possible in all care homes depending on their resource and capability.

5.8. Other impacts of the visiting restrictions included restrictions on special food that a particular person with dementia liked, restrictions on the use of facilities within the room that they lived in without a visitor being present to assist, and also the cost of carers having to pay for Covid tests before visiting. These all impacted on the ability to have contact during the time of the restrictions being imposed and the quality of that contact when it was able to be undertaken.

5.9. In terms of infection prevention and control measures adopted, one concern we had was that the interpretation of guidance was being left to individual authorities and that led to differences in interpretation including confusion between Public Health Teams and Adult Social Care Teams. In addition, a lack of available PPE and a lack of a national strategy in relation to sourcing and providing it initially led to local authorities sourcing their own, borrowing from the NHS and being responsible for its distribution. In addition, residential home and domiciliary care providers also sourced their own PPE where they could and billed local authorities. It was therefore a very fragmented approach with no standard procedure until infection control funding came into force. There was also an element of care homes individually deciding on the implementation of restrictions, as they had ultimate responsibility for it, this again led to a fragmented and inconsistent rather than standard approach.

5.10. In addition to the fragmented approach to obtaining PPE, the types of PPE utilised in the pandemic, such as face masks, had an impact in terms of communication for people living with dementia. Alzheimer's Society recognises that the Government needed to balance the use of PPE and other public health restrictions for the protection of life with the impact that the use of PPE and restrictions had on other aspects of people's lives. It is important however that the impact of such measures on people living with dementia is properly weighed in the balance by the Government in future pandemics. With regards specifically to face masks it removed from them the ability to receive communication from others, at a time where many people with dementia had communication issues, including cognitive impairment as a pre-existing condition. Another concern was that some people with dementia had difficulties abiding by the requirements in relation to personal protection equipment because they would forget about the restrictions or not understand the reason for their imposition.

5.11. The other aspect to consider regarding the provision of PPE is that there was simply not enough of it available. This led to insufficient infection controls, but also led to some essential care providers not coming into care homes because of the risk of infection.

5.12. The impact of the Covid-19 pandemic was not restricted to people with dementia but also their carers. This was particularly the case with carers who looked after or supported adults living with dementia who received care in their own home. A generic issue was that carers of people with dementia felt there was little to differentiate the challenges that they faced with those of other carers. There may have been some aspects to carers of people not living with dementia that were more challenging than those people living with dementia, but there was a lack of acknowledgement at times of the differentiation in the challenges faced. The experiences of people who were carers of people living with dementia, in terms of the impact of the Covid-19 pandemic and the solutions and control measures adopted in relation to it, needed, to a degree, to be viewed in isolation rather than "lumped in" with other groups.

5.13. Another challenge for visiting care workers was a fear amongst people living with dementia and families that they may spread the virus which led them to be refused entry or for the allocated support to be declined. This had an obvious impact on the quality of the care offer in place and contributed to a number of outcomes including not only a deterioration of the carer offer, but also home carer breakdown, hospital admissions and at best a significantly increased burden on home carers. This may have had other impacts such as safeguarding issues between the carers and people living with dementia and being cared for at home who are not having regular visits from external support.

5.14. A number of carers groups closed or went online only which created inequity and isolation. In our Worst Hit report we produce statistics that 92 million extra hours were spent by family and friends caring for loved ones and as set out before 95% of carers reported a negative impact on their mental or physical health. This could lead to carer burnout and a knock-on effect of that would be isolation of the person living with dementia.

5.15. There was also a feeling amongst paid care sector staff that they were not supported as well as NHS staff. NHS staff guidance, support and PPE always appeared to exceed that of social care providers we feel that social care should have been given parity with the NHS in terms of guidance, support and PPE made available. The NHS response was organised nationally but local councils were left to work with social care providers and care staff which led to the fragmentation and inconsistencies in the support and inequalities as an outcome. Furthermore, there was an impact as a consequence of day care service closures on carers. Although these services had been provided with funding when they ceased no budget was given to carers to provide any form of replacement or to receive any support when the funded services ceased.

6. Matters relating to end of life care

6.1. We had significant concerns regarding the use of Do Not Attempt Cardio-Pulmonary Resuscitation Orders and were particularly concerned that these were being imposed on some of the most vulnerable people in our society including people with dementia. Our collective view was that this should never have happened as it effectively denied individuals their right to life without appropriate discussion. Additionally, Do Not Attempt Cardio-Pulmonary Resuscitation Orders should only ever have been applied on an individual basis and people affected by dementia should have been allowed to make informed decisions about future care.

6.2. We received information to confirm that Do Not Attempt Cardio-Pulmonary Resuscitation Orders were placed on people without appropriate discussion or consent since the start of the pandemic. Our view was very much that people with dementia and their loved ones should have been enabled to make informed decisions about their future care and have those choices respected. I noted earlier in the statement that although paragraph 3.12 of Covid-19: Our Action Plan for Adult Social Care stated it was unacceptable for advanced care plans including Do Not Attempt Cardio-Pulmonary Resuscitation Orders to be applied in a blanket fashion on any group of people, the feedback we were receiving on our helpline was that this was still apparently occurring. In terms of palliative and end of life care, whilst our report From Diagnosis to End of Life: The Lived Experience of Dementia Care and Support, which is exhibited to this statement as Exhibit CL/09 [INQ000492906], was initially drafted prior to the Covid-19 pandemic the issues it highlighted were impacted even more greatly by the pandemic. One theme was for national leadership in order to build a more integrated pathway, a theme that I have referred to previously.

6.3. The report, “From Diagnosis to End of Life” highlighted how the inconsistent provision of high quality, integrated care and support access to community based palliative care can make a significant difference to both the person with dementia and their family. Key to this is ensuring specialist skills are available in care homes to ensure comfort and quality at the end of a person’s life. During the Covid-19 pandemic with family members unable to be by the person’s side this became more important than ever. Although geriatricians support people in care homes at the end of their life, during the Covid pandemic they were being deployed to acute care with care homes receiving limited support.

6.4. I should add that there were knock-on effects of these shortcomings as with care homes experiencing extremely high numbers of deaths, staff were not used to this level of mortality and it must have had an impact upon them and the efficiency of the service that they then delivered. Family contact was restricted and many families would not want to go into the care home environment and in any event this was one occasion when the facilitation of videos with families was often more distressing both to the person with dementia and the families than the alternatives.

7. Changes to the regulatory inspection regime

7.1. We had concerns regarding the CQC pausing routine inspections during the pandemic which could lead to a drop in standards, albeit against a background of a very challenging work environment, but also significantly in safeguarding concerns as abuse may have gone undetected as a consequence. This was at a time where, in some respects there was an increasing need for CQC inspections in order to ensure that everything was being done to safeguard and protect people with dementia and living in care homes at the time of the pandemic. The pausing of CQC routine inspections again meant that there was an ineffective regulatory inspection regime contemporaneous with the sector undergoing its most significant stress test.

8. Matters specific to the Alzheimer's Society

8.1. We have for some years, at least since 2010, utilised a simple support tool to enable person centred care by professionals for anyone with communication difficulties caused by dementia or delirium entitled “This is Me” which is exhibited to this statement as Exhibit CL/10 [INQ000492907]. It has been endorsed by the Royal College of Nursing since 2010.

8.2. The tool is used to record non-clinical details about a person who cannot easily share such information about themselves, for example: their culture and family background; events, people and places from their life; and their preferences and routines.

8.3. The tool can be used in any setting at home, in hospital, in respite care or in a care home. It is particularly useful when someone changes setting, for example when they are admitted to hospital, or being seen by a health and social care professional who is new to them for the first time. As a printed form this is ordered in bulk by hospitals, care homes and Society staff and in individual copies by people with dementia and carers for personal use. It can also be downloaded from our website as a PDF to complete.

8.4. In the 12 months to February 2023 an average of 6645 print copies of "This is Me" were distributed across all routes each month. In the same period there were 2143 average monthly downloads.

8.5. Using the same methodology between March 2020 and June 2022 an average of 5617 print copies of "This is Me" were distributed each month. Distribution figures were lower during the pandemic partly because our services were not operating face to face.

8.6. An initiative that I instigated and to which the Society was central was the One Dementia Voice coalition. This was a coalition of eight third sector groups of which Alzheimer's Society was the largest. I did not initiate the coalition in response to the Covid 19 pandemic, it was an initiative that I had always intended to set up having run a similar coalition in my previous role. The purpose of the coalition was to facilitate informal information sharing between CEOs of similar charities. The timing of my joining Alzheimer's Society and setting up with coalition inevitably meant that many of the discussions and much external facing work of the coalition related to the Covid-19 pandemic.

8.7. Examples of external work of the coalition in relation to the Covid 19 pandemic included campaigning for (i) the creation of a social care taskforce with a specific dementia advisory group; (ii) the prioritisation of care home residents for vaccination; (iii) the expansion of PPE and testing in care homes including ensuring no hospital patients are discharged into care homes without a negative test; (iv) a road map for care home residents to be allowed regular and meaningful visits from loved ones and informal carers; and (v) the distribution of tablets to care homes to assist with virtual consultations and visits. We drafted an open letter to the Secretary of State for Health in July 2020 which is exhibited to this statement as Exhibit CL/11 [INQ000492908].

8.8. The coalition also set up an anniversary campaign a year on from the date of the lockdown called "Coronavirus Action Day". It was a one off national day marking the disproportionate impact of the pandemic on those affected by dementia. Coronavirus Action Day fell on 1 March 2021 which was roughly a year on from the anniversary of when the Coronavirus Action Plan was launched i.e. 3 March 2020 and a year approximately after coronavirus was established in the UK. In terms of One Dementia Voice campaigns from July 2020 onwards, the key issue that we campaigned upon was relating to care home visiting guidance, especially the importance of having people's family members nominated as a keyworker within care home guidance, to realise all the benefits of person to person contact with family members for people with dementia that I have alluded to previously. In summary, the purpose of One Dementia Voice was to become a vehicle by which we could bring dementia charities together to come behind single campaigns.

8.9. The Society did not award any grants or commission any research through our research funding programme looking at the effects of Covid-19 on people with dementia within the window of time specified (March 2020-June 2022).

8.10. We were already funding a project entitled Grant 433 led by Professor Kevin Brazil. Its title is "Scaling up the Family Carer Decision Support Intervention – a multi-site implementation evaluation". The only exception to the research that was undertaken during the timescale requested was that one of the researchers working with Professor Brazil authored a review publication during this time entitled "A Journalistic Review to Understand the Impact of Covid-19 on Care Home Residents Living with Dementia". The same researcher also co-authored "Aging and Mental Health and the Impact of Covid-19 on People with Dementia Particularly in Care Homes". Whilst the Alzheimer's Society did not specifically commission these pieces they were drafted during the period concerned and during the project grant and we were notified of their creation by Professor Brazil.

9. Recommendations to improve conditions for adults living with dementia in the event of a future pandemic

9.1. There are a number of ways in which adults living with dementia could live in improved conditions in the event of a future pandemic and I wish to concentrate on six themes.

9.2. Firstly, it is important that the social care system becomes more resilient. Investment now for future pandemic preparedness is essential. Social care is fundamental to people affected by dementia and provides practical support to help people with activities they need to do every day. During the pandemic social care appeared as something of an afterthought in the Government response. It was over a month after schools had closed before a Government action plan for social care was published in England. In addition, existing issues in social care were exacerbated including to quote directly from the Kings Fund " unmet need, quality of care, workforce pay and conditions, market fragility, disjointed care with a lack of health and care integration and a postcode lottery around access to care". In order for the country to be prepared for future pandemics there will need to be a sustainable and resilient social care system.

9.3. It is therefore essential that the investment is made now to ensure that systems are resilient enough to operate effectively during future pandemics or public health emergencies. That investment must ensure that high quality care is provided to people living with dementia. The minimum requirements are that a sustainable funding model that pools the risk of care costs across society is in place and a long term workforce strategy in each nation comprising the United Kingdom that reduces social care staff vacancies and turnover and achieves a resilient workforce, able to withstand challenges including public health emergencies. The workforce strategy should include mandatory dementia training for the social care workforce mapped to the dementia training standards framework or equivalent to ensure that social care staff have the skills and knowledge to provide high quality care, for example understanding the impact of social isolation on people living with dementia. The dementia training standards framework is exhibited to this statement as Exhibit CL/12 [INQ000492909]. There are equivalent frameworks in the UK, being the Social Care workforce strategy in Wales, and the Health and Social Care workforce strategy in Northern Ireland. The ultimate measure that would be required to make training mandatory would be legislation, drafted and led by DHSC.

9.4. Secondly, it was apparent from the Covid-19 pandemic that there were differences in the way healthcare and social care settings were both prioritised and resourced. The National Audit Office has produced data that confirms that 25,000 people went untested from hospitals into care homes in England between mid-March and mid-April 2020. As a consequence, in the first wave there was significantly more total deaths of care home residents compared with the five year average (26,035 and 1,046 excess deaths for England and Wales respectively). This disproportionately impacted on people living with dementia as it is estimated at least 70% of residents of older age care homes have dementia. The NAO found that, "in certain aspects the initial pandemic response reflected a greater emphasis on health than on social care. By way of example, national bodies initially provided more PPE support to hospitals than to social care. NHS Trusts received 80% of estimated PPE requirement through national schemes between 20 March 2020 and 31 July 2020 whereas social care providers received 10% of their estimated requirement". In its report assessing the Government's response to the pandemic, which is exhibited to this statement as Exhibit CL/13 [INQ000114319], the NAO recommended integrating health and social care and placing social care on an equal footing with the NHS. This is a position that Alzheimer's Society agrees with.

9.5. In summary, therefore, in so far as social care settings such as care homes are concerned, when considering public health safety measures and equipment such as PPE and testing during a future pandemic the Government should ensure that these settings are considered on an equal footing and in parallel with health settings not as a secondary consideration. Health and social care systems should operate in an integrated manner to ensure joined up care for people living with dementia, for example, to ensure hospital discharges are carefully planned.

9.6. In addition, visiting in care homes was severely restricted during the Covid-19 pandemic which led to people suffering rapid declines in their physical and mental health. As I have indicated before, this has a particular impact on people living with dementia. In our survey of 128 care home managers from May 2020, 79% reported that a lack of social contact was causing a deterioration in health and wellbeing of their residents with dementia. I have exhibited the survey to this statement as Exhibit CL/14 [INQ000492411].

9.7. New regulations, set out in regulation 9A Health and Social Care Act 2008 (Regulated Activities) Regulations 2014, making visiting a fundamental standard of care that can be expected by the CQC are welcome, however, they still permit visiting to be restricted in exceptional circumstances. It is vital Governments do not repeat the mistakes of the Covid-19 pandemic, with restrictions on visiting that were unclear, meaning that visit restrictions went on longer than necessary and some care homes did not give sufficient thought to how visits could be facilitated safely. In short, therefore, Governments should give proper weight to the vital importance of visits from family and friends to the health and wellbeing of people living with dementia in the event of a future pandemic.

9.8. The pandemic put an enormous strain on health and care providers, including care homes, with end of life and palliative care decisions having to be made quickly. There were numerous reports of DNACPR notices being added to the files of people living in care homes on mass without consultation with their families. As a consequence, health and care systems must ensure that staff receive sufficient end of life training and receive the support they need to deliver compassionate, personalised end of life care. Health and care systems must ensure that DNACPRs are never applied in a blanket manner, and that people living with dementia, whether in a care home or a hospital and their families are supported to have meaningful conversations about DNACPR decisions as part of a holistic approach to advanced care pressure. Further, health and care systems must require staff working with people living with dementia to have sufficient understanding of the Mental Capacity Act or in Northern Ireland the Mental Capacity Act (Northern Ireland) 2016). This will help to ensure staff understand that people without capacity should still be consulted on their wishes and preferences for future care and their past wishes should be taken into consideration.

9.9. Thirdly, in terms of domiciliary care and unpaid carers there are further improvements that can be made.

9.10. In respect of domiciliary care in our July 2020 survey, that I previously referred to of informal carers supporting people affected by dementia in the community, 90% of the 795 respondents to one of the questions generated a response that stated that the person they cared for had experienced interruptions to their regular health or social care. In home care, existing issues such as staffing shortages, were exacerbated by the pandemic. Concerns around visiting staff spreading the virus meant many families affected by dementia were left without vital support. The Government needs to ensure in the future that the provision of domiciliary social care, which is a vital lifeline for people living with dementia and unpaid carers, continues uninterrupted during any future pandemic.

9.11. Likewise, the impact on unpaid carers and the care they provide was significant. The National Institute for Health and Care produced evidence in a report which is exhibited to this statement **(CL/08 - INQ000492905)** entitled, "The impact of Care Act easements under the Coronavirus Act 2020 on older carers supporting family members living with dementia at home" which included evidence from carers of people living with dementia and local authority social work leads. It revealed that carers and the family members they were supporting experienced significant changes during the pandemic to their usual care and support, which in many cases resulted in low wellbeing and unmet need. The Society is aware from our own research that many unpaid carers experienced a negative impact on their health and wellbeing during the pandemic and had to make drastic changes to their own lives to support people living with dementia. As I mentioned previously, concerns were raised with the Society at the time and were vocalised through our Dementia Voices Group, from carers of people living with dementia feeling "lumped in" with other groups on the basis that there was a belief from Government that there was little differentiation of the challenges faced by generic "carers". It is vital that Governments learn lessons of the crisis that unpaid carers faced during the pandemic. As a consequence, the Society's view is that local systems must proactively offer carers of people living with dementia the statutory needs assessment to which they are entitled and ensure carers receive the personalised support they need. It is particularly important that, ahead of future pandemics, local systems ensure that they can identify carers of people living with dementia in need of support, including those who have not yet had a statutory needs assessment. One way of achieving this could be to ask people to self-identify as a carer when registering with their local GP. Governments should ensure local systems have the funds necessary to achieve this. In addition, local systems must also ensure that dementia specific respite care can continue during pandemics. Governments should ensure local systems have the funds necessary to achieve this.

9.12. My next concern relates to dementia specific planning for future pandemics as the Covid-19 pandemic had a disproportionate impact on people living with dementia both in terms of deterioration of symptoms due to isolation and excess deaths. Taking into account the lessons learned from this pandemic, Governments must ensure that this impact is mitigated in future pandemics through dementia specific planning which would include that firstly, public health announcements and guidance must be made in such a way that people living with dementia who are cognitively impaired, can understand them. We recommend that easy read versions of all announcements and guidance are published simultaneously, as secondly the Covid-19 pandemic has shown that social isolation required as part of public health measures can significantly contribute to deterioration in symptoms of people living with dementia. Local systems must therefore make advanced provision for social care support to continue during pandemics (both in care homes and in domiciliary care) to not only provide essential personal care but also to support activities such as social interaction and exercise that can slow cognitive decline. Governments must provide sufficient funds to enable this and Governments should ensure that health and social care staff are trained in dementia so they understand the impact of a pandemic and associated isolation on people living with dementia. In terms of inequalities the pandemic laid bare and exacerbated existing inequalities for people living with dementia and their carers. As previously indicated this included inequalities between protected characteristic groups with BAME communities found to be particularly Covid vulnerable, with those over 65 most vulnerable to Covid-19 and women's caring burden increased. As set out before there are also geographical, social and economic inequalities and inequalities of people with comorbidities such as diabetes and heart disease in addition to dementia and as a consequence having a raised Covid-19 risk. When balancing public health restrictions necessary for the protection of life (such as PPE or social isolation) with people's right to private and family lives, Governments must ensure that the impact of such restrictions on people living with dementia (such as deteriorations in symptoms from lack of social contact) is given proper weight.

9.13. It is vital that care for people living with dementia who have a protected characteristic is individualised to meet any needs arising from their protected characteristic. Governments should consult with people living with dementia, researchers and health and care practitioners to develop policy responses to any future pandemic that are evidence informed and that embrace the lived experience of diverse people living with dementia and their care partners. Governments should also address existing societal inequalities that meant certain groups of people living with dementia were more vulnerable to Covid-19. Governments should also ensure that social care systems are sufficiently resourced so that staff can provide quality care that is personalised and individualised to meet each person's needs, including those arising from protected characteristics. This is particularly important in pandemics where, for example, families may have less contact with loved ones in care homes, making people more reliant on professional carers' understanding of their needs. Finally, Governments and public bodies should ensure that more comprehensive data is collected and published in the context of dementia inequalities. For example, data should always be disaggregated by a protected characteristic group.

9.14. A final set of recommendations relate to dementia diagnosis as the national diagnosis rate of people aged 65 or over who are estimated to have dementia (in England) declined steadily during the pandemic dropping to 63.2% of those people having a recorded diagnosis in July 2020, substantially below the national target rate of 66.7%. As set out before, in our survey of informal carers supporting people affected by dementia in the community, 90% (795 respondents to the question) stated that the person they care for had experienced interruptions to their regular health or social care. Memory clinics are a vital part of the diagnostic pathway, one of the most frequently mentioned services that people said had been interrupted. The impact of the pandemic on dementia diagnosis is ongoing: as of April 2024 the dementia diagnosis rate in England remained below its pre-pandemic level at 64.6%. Delays to diagnosis mean that people cannot access symptomatic treatment, or the right social care support, which can lead to a more rapid deterioration of symptoms. It also means they cannot plan for the future.

9.15. Governments should therefore ensure that in future pandemics diagnostic pathways for dementia continue to function and be resourced so that people can continue to access an early and accurate dementia diagnosis.

9.16. In terms of the general Government response, I am very much of the view that the voluntary sector was a resource that the Government could have utilised better both in terms of providing guidance and information about the impact of control measures and how to implement control measures to better balance their impact in a way that would affect people living with dementia and their carers the least. Too often it was the case that guidance or restrictions were introduced and the voluntary sector then responded, for example through the Richmond Group. We could have been seen and utilised as part of the solution which may have been an opportunity missed. In future pandemics proactive consultation with the voluntary sector in considering the impact of measures on care homes would lead to a more targeted and focused response.

10. Aspects in response to the pandemic that went well or were a success in how the adult social care sector responded

10.1. Alzheimer's Society recognises the dedication and resilience of staff working in the adult care sector. There were numerous incidences of staff going above and beyond the call of duty for people in their care. For example, care home managers and staff living in-house 24/7 to safely care for residents, and domiciliary care staff working beyond their hours to cover for absent colleagues.

10.2. On behalf of the Society I also wish to commend the local community and voluntary sector responses to the pandemic which anecdotally included much needed practical help and support for people living with dementia in their own homes. As I set out in some detail previously, public health restrictions during the pandemic meant that Alzheimer's Society had to move from face to face to virtual services. Our strong working relationships with health and care commissioners meant that contracts based on in-person services were interpreted flexibly and in some cases extended on that basis, such that services and contract income were both protected. In addition, pivoting to a virtual offering of some services created better collaborative working with digital support organisations. By way of example, in North Wales the local service team connected with Digital Communities Wales to help people affected by dementia use digital technology so they could use digital technology so they could access virtual services. The majority of the anecdotal feedback we received from our bid and tender team was that although not all health and care commissioners, most health and care commissioners worked with us in this pragmatic way.

10.3. There were examples of local systems' engagement with voluntary services, including Alzheimer's Society, to put a recovery plan together. A specific example is that in early 2021, commissioning managers from Birmingham City Council and Solihull Metropolitan Borough Council, as well as from Birmingham and Solihull Clinical Commissioning Group proactively contacted Alzheimer's Society to ascertain what our priorities were for a recovery plan. As a consequence the engagement was positive and the upshot was a recovery plan that included targeted support for dementia patients and their carers which set out clear plans to be delivered over 12 months to address key issues dementia patients and their carers faced during the pandemic.

10.4. Undeniably more could have been done by central Government during the pandemic specifically to engage with social care and the voluntary sector, however, I appreciated the personal calls and updates from junior Ministers particularly the then Minister of State for Care, Helen Whately, making herself available to charities and care home advisers to explain decisions taken and receive feedback. Whilst the engagements I refer to were often empathetic and positive, this did not often lead to actions by more senior Ministers. I accept however that this was an example of attempted collaborative decision making which I welcome.

10.5. In Northern Ireland the Patient and Client Council, an arm's length body within the Department of Health that provides a patient voice into the health and social care system, convened weekly meetings for Departmental officials, family members and organisations such as Alzheimer's Society to shape a 'care partner' model to allow family members access to visit loved ones in Care Homes. These meetings allowed for barriers such as extra testing or access to PPE to be thought through and planned for and demonstrated the value and importance of the 'care partner' to the resident. It also allowed Care Homes that were implementing the new 'care partner' model to demonstrate to other Care Homes that it was workable and share best practice on how barriers could be overcome.

10.6. The inclusion of people living with dementia within initial vaccination priority groups was a welcome and significant step towards tackling the health inequalities and loss of life experienced since March 2020 by people with dementia. The Society was encouraged that in surveying people affected by dementia between November 2020 and December 2020 regarding the subject of vaccines we found that 92% said they would be vaccinated if they were given the opportunity with only 8% refusing. The main reason cited for having the vaccine was protection against the virus. People also felt that having the vaccine would help prevent the spread of the virus to loved ones. In addition, carers wanted to ensure that they remained well so they could continue caring for loved ones with dementia, and therefore welcomed the vaccine to protect against serious illness. The inclusion of frontline health and social care workers within initial and subsequent vaccination priority groups was another welcome step towards protecting people with dementia living within, or accessing, health and social care throughout the pandemic.

10.7. Research funding was made available during the coronavirus pandemic which meant that some research was funded to generate real world evidence on the experiences of people living with and affected by dementia during the coronavirus pandemic. For example, our Alzheimer's Society research Centre of Excellence 'Improving the Experience of Dementia and Enhancing Active Life 2' (IDEAL-2) was awarded funding by the National Institute of Health Research through the Older People and Frailty Policy Research Unit to complete a sub-study called 'IDEAL-2 COVID-19 Dementia Initiative' (IDEAL-CDI). The sub study was rapidly established to identify concerns and issues faced by people living with dementia and their carers during the coronavirus epidemic. The aim of IDEAL-CDI was to provide timely evidence to inform policy and practice to better address the needs of people living with dementia during lockdown and as we emerged from it.

11. Conclusion

11.1. Insofar as Alzheimer's Society was concerned, particularly at the start of the COVID-19 emergency we, in common with so many others in the third sector and more widely across the economy, were faced with a deeply uncertain situation in terms of our income. We were required to make difficult decisions around redundancies and the furloughing of large numbers of our people. The voluntary sector played a significant role in supporting millions of people during the pandemic while having to make some profound organisational changes. At the same time, however, there were occasions during which the sector was not an equal partner with government. We were too often engaged on matters of policy or decisions at a late stage, rather than being consulted meaningfully and more effectively at an earlier point. Better collaboration and a greater understanding from government of the voluntary sector as key to finding a way through the pandemic could and should have led to better quality policymaking, particularly during the first few months.

11.2. That said, my own experience of dealing with specific Ministers within the UK Government in particular was a positive one. I very much appreciated the direct approach in dealing with me as a voluntary sector leader by the Minister of State for Care, Helen Whately. She understood and empathised with the challenges in the care home sector and people affected by dementia more generally. However, too often junior ministerial engagement and understanding did not necessarily translate into formal government policy.

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: 15/10/2024