COVID INQUIRY MODULE 6

WRITTEN OPENING SUBMISSIONS FOR
HEARING COMMENCING 30 JUNE 2025
JOHN'S CAMPAIGN, THE PATIENTS ASSOCIATION
AND CARE RIGHTS UK

Introduction

1. These Opening Submissions address some of the key concerns of John's Campaign, Care Rights UK, and the Patients Association (together the "**CPs**") on the topics falling within the scope of Module 6.

2. The CPs have extensive experience of the adult social care sector – before, during, and after the pandemic. They listened to and supported people drawing on care as well as their chosen supporters and representatives and the people providing care. In Module 6 the CPs will seek to ensure that the experiences and full range of voices of those drawing on and giving care are central to the Inquiry's investigation.

3. It is essential that the humanity and equal worth of people who draw on care underpins the recommendations that the Inquiry ultimately makes. Every person deserves care that is high quality, dignified, and tailored to their individual needs, and that involves their chosen supporters and representatives. The CPs have provided a number of real-life accounts about people drawing on care, including in "The Holding Pen" (INQ0002723453) and in a selection of case-studies (INQ000273460). The Chair is respectfully invited to read those accounts in full, so that she has a clear understanding of the actual impact the response to the pandemic had on these people.

4. In these submissions when we refer to a person's "chosen supporters and representatives" or to "family carers", we refer (as we did during our participation in Module 3) to a person close to the person drawing on care who helps support and provide care to them, who knows them intimately and is trusted to be their eyes, ears and voice where necessary. Many family carers will be related to the person receiving care, by consanguinity or partnership ties; but some are not. A particular special friend, and even in some cases a paid companion, may fulfil this role. Some will hold formal authority, for example a power of attorney for health and welfare, whilst others may advocate for the person on a more informal basis. Although their precise relationships may vary, they will normally be easily identifiable because of their importance to the person receiving care and their expert knowledge of the person's needs and wishes. In every case, the care and support they provide is vital and they should always be treated as part of a person's core care team.

5. The CPs respectfully invite the Inquiry to explore how and why individualised care, which involves family carers and meeting people's needs, was not provided during the pandemic,

and what steps are necessary to ensure that it is provided now and in any future emergency. In performing this task, it is essential to recall that all of the settings making up the adult social care sector, including care homes, are not just service providers: they are people's homes. Decisions about residential care settings during the pandemic should have been made with the same care and caution as would be expected in relation to decisions affecting private homes, affording people living in care settings the same dignity and concern. Instead, there was "*general neglect and misunderstanding shown towards social care before and during the pandemic by the core political and administrative decision-makers*" (Rayner, Chair of the National Care Forum, INQ000475131, §3.3), and the care sector was repeatedly overlooked and treated as an expendable after-thought.

6. In the week ending 17 April 2020, deaths in care homes in England and Wales were 252% higher than average – a far higher increase than in hospitals or elsewhere (INQ000185073, p30). Yet despite this, and the clear evidence that people needing care and living in care settings were among the most severely affected by the pandemic and its response, the care sector was neglected by decision-makers. As the Older People's Commissioner for Wales, Helena Herklots CBE, said in her 18 August 2020 report, "*Many of [the deaths in care homes] could have been prevented had there been a better understanding of the risks faced by care home residents and the action required to ensure they had the protection and support they needed*": INQ000184908, p11.

7. These submissions cover 13 issues of particular (but not exclusive) interest to the CPs, which the CPs hope are helpful for setting the scene for Module 6. There are also four preliminary issues which cut across all of them which are important for the Inquiry to bear in mind:

   7.1. <u>Diversity within the care sector</u>. There is wide variation in: (i) the settings in which people receive care (for example there are individual homes, mental health units, rehabilitation centres, supported living and residential care homes with some providing specialised care and others more general care); (ii) the people receiving care (e.g. by reference to age, disability, independence and level of support needed); and (iii) the way in which care is provided (e.g. from employed staff in residential settings or paid or unpaid carers at home). This diversity gave rise to very different needs and different risks during the pandemic. One of the major problems with the pandemic response was the Government's failure to recognise these differences, instead taking a sector-wide approach (see, e.g. Rayner §3.2 INQ000475131). For example, it imposed blanket rules for all residential settings, at times based on an incorrect assumption that the whole care population was a homogeneous group. The pandemic – and the Government's response to it – had a distinct impact on people with different care needs and in different care settings. The CPs urge the Inquiry not to repeat the error of treating the adult social care sector as a homogenous entity. The Inquiry's recommendations will need to be tailored to address the variability of the sector and the people it is intended to serve. The CPs' primary focus during the pandemic was on residential and nursing homes, but they were aware of issues arising in other settings and invite the

Inquiry to conduct a thorough examination of all settings where care is provided.

7.2. People needing care were treated very differently from the rest of the population. They were subjected to far more stringent restrictions for far longer than the rest of the population which led to enforced and prolonged isolation. Even when comparable groups outside the care sector were allowed to spend time outdoors and meeting others, those living in care settings remained confined and isolated. The CPs urge the Inquiry to properly investigate the reasons for, and decision-making process which resulted in, the significant (and numerous) differences in treatment between people needing care (in particular, those living in residential care settings) and the general population. For example, drawing on her own experience, Diane Mayhew from Rights for Residents explained to the CPs: "*When society regained their freedoms, 'Eat Out To Help Out' was launched, people could go to parties, weddings, take holidays abroad (including [care workers] who were looking after and providing personal care to our loved ones), but we were still forcibly separated from Mum. During one such window visit, Mum (Jean, whose nickname was 'Smiler') was crying so much we had to call a carer to come and calm her down*."

7.3. Care at home. A huge proportion of care is provided at home (including by family or other unpaid carers). More than 1 in 10 (12%) of people aged over 65 in the UK received some form of formal help or care in their homes pre-pandemic (Ms Abrahams, Caroline Abrahams, Director of Age UK, §12 INQ000509808). There were particular and unique challenges faced by those needing and providing care at home. It was provided by professionals as well as by families or other supporters. Each faced distinct challenges, but each was overlooked[1] (INQ000587830). They received even less support and guidance than residential care homes, for example in respect of access to resources, testing and PPE. Furthermore, pre-pandemic, people receiving and giving care at home relied heavily on third sector organisations, as well as local authority provision. Many of them drastically curtailed on-the-ground operations during parts of the pandemic, which meant that people receiving care at home lost vital support. The CPs urge the Inquiry to take account of the cumulative impact that the loss of such support had on those needing and providing care at home.

7.4. Social care was neglected. The NHS was prioritised to the detriment of social care (CPs INQ00514104 §32-34, 96; Mr Macaskill INQ000509530, §52-57 and 139-184). This was harmful for all involved, not only for those needing care. In evidence received in Module 3, the CEO of NHS England Amanda Pritchard warned "*don't forget social care*" – because that was too often what happened during the pandemic, and "*we can only do what we can do in the NHS if we've got an equally… strong partnership with social care*" **[29/149/16-23]**.

7.5. Examples of how social care was overlooked include that family carers were not

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[1] See John's Campaign blog: < https://johnscampaign.org.uk/post/the-right-thing-to-do>

treated as key workers until 13 October 2020, and even then, initially only on a 'pilot' basis (INQ000499396). Essential unpaid carers never received this important designation. The care sector was allocated less funding and resources and had less political value and support than the NHS. Priority was given to the NHS in terms of testing and PPE (Hancock INQ000587746, §103). The 2020 discharge decisions prioritised hospitals over social care. Consistent messages to "protect the NHS" were a constant reminder that the Government's approach to the pandemic was to protect institutions over the people they exist to serve; and to protect the NHS over other crucial institutions and sectors including the care sector. The CPs are concerned to ensure that those mistakes are not repeated and, in particular, that the focus is on people, not institutions. It is vital that lessons are learnt so that in any future pandemic the response focuses on the people most at risk, ensuring the services they rely on (across health *and* care) have the resources they need and are equally valued. Steps to ensure cohesion between health and social care, for example in ensuring discharge care packages were in place and involving family carers in the development of those packages, were not taken during the pandemic but are essential to ensuring good, joined-up care for those who need it.

8. The CPs note with disappointment that many witnesses who represent people needing care and their supporters have not been called to give oral evidence during the Module 6 hearings. In order to ensure that those people have a voice, and the evidence the Inquiry receives is not biased towards those with power over policy and practice, it is important the Chair takes full account of the written evidence from the excluded witnesses. The Inquiry should not just be a place for powerful people who failed the care sector to defend themselves, but for the people affected by those failings to explain the impact and the change needed to ensure those mistakes are not repeated.

(1) People living with dementia

9. The CPs welcome the Inquiry's decision to focus on people living with dementia who were particularly adversely affected by the pandemic. Considering the perspective of and impact of the pandemic on people with dementia is a helpful illustrative lens through which to consider and understand specific issues faced by the wider care sector. In many instances, people with dementia were acutely and disproportionately affected, so their experiences provide a stark example of how poorly thought through and harmful many of the Government's pandemic responses in the adult social care sector were.

10. The experiences recounted in "The Holding Pen" (INQ0002723453) demonstrate just how harmful the effect of Government restrictions were on people with dementia, as well as others subject to the draconian isolation rules. To pick three examples: "*Jane said: Dad thought he'd done something wrong and was no longer loved*"; "*From Laura: my mum called me relentlessly, sometimes in excess of 50 times a day, day and night, sobbing and begging me to go to her and let her out*"; "*From Christine on her mum with dementia: she would stare blankly at the screen, was very monosyllabic and all she would say is 'I'm a prisoner, I have to stay in my room'*".

11. It has been estimated that nearly 1 million people were living with dementia in the UK in 2024 (INQ000498137, §2.5). In England and Wales, dementia (including Alzheimer's disease) was the leading cause of death of care home residents across all waves, with one exception[2] (INQ000587832). Dementia was the most common co-existing condition for those who died of Covid-19 across all four nations of the UK and over 25% of all deaths from Covid-19 in 2020 were of people with dementia, even though they made up only 2% of the total adult population (Banerjee, INQ000546956, §§12-22).

12. Access to family carers is particularly important for people with dementia. They rely (often heavily) on their carers to meet their critical needs. Effective care or treatment requires a "*holistic and person-centred approach which considers the person as a whole and the family and social context in which they live*". However, "*almost all of these modalities of care and support were stopped or curtailed in the pandemic*" (Banerjee, §§43-44), due to restrictions on contact with carers or otherwise.

13. The denial of appropriate person-centred care from family carers led to profound harm for people with dementia. It rapidly exacerbated their conditions. Pandemic response measures that restricted access to family carers not only denied person-centred care (which is the only treatment known to improve dementia), they also resulted in the rapid mental and physical health deterioration (*ibid*). Surveys found that lockdown caused a deterioration in symptoms in 82% of people with dementia; a deterioration in health and wellbeing in 79%; exacerbated agitation and depression in 54%; difficulty concentrating in 48%; and memory loss in 47%: e.g. Alzheimer's Society July 2020 INQ000492900; INQ000498137, §8.8; and Equality Impact Assessment on 27 August 2020 INQ000087134.

14. Professor Banerjee et al considered that the inaccessibility of non-Covid-19 treatment and care, the effects of social isolation, and potentially unconscious discrimination were among the causes of the very high death rate among people with dementia. There was a major increase in both Covid-19 and non-Covid-19 deaths during the pandemic (Banerjee §17-22). Further evidence of the "*shocking*" adverse impact of restrictions on those with dementia is INQ000492911 (Alzheimer's Society report 5 June 2020, e.g. p2), INQ000499382 (Alzheimer's Society open letter, 30 July 2020), and INQ000520994 (Alzheimer Scotland) §18 and 49.

15. Despite the severe and well-known impact on people with dementia, little or no specific consideration was given to them in the early stages of the pandemic by the Government. As Professor Banerjee explains, "*Dementia, despite being very common and the group most vulnerable to Covid-19 and death, did not get explicitly mentioned in key policy documents*

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[2] Office for National Statistics Webpage, 'Deaths involving COVID-19 in the care sector, England and Wales: deaths registered between week ending 20 March 2020 and week ending 21 January 2022'<www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglandandwales/deathsregisteredbetweenweekending20march2020andweekending21january2022>

in the first nine months of the pandemic” (§72, INQ000546956). There appears to be no national database about, or central oversight of, dementia mental health units.

16. People with dementia are “*not a homogenous group, their experiences of living through the pandemic were varied and resulted in differing outcomes in their well-being and life quality*” (Banerjee, §§79 and 85). The experiences of people with dementia provide a compelling illustration of the need for all decisions relating to care, and possible restrictions on care, being predicated on individualised assessments of the person in question – a necessary practice, and legal requirement, which fell significantly by the wayside during the pandemic period and which in many cases is still not satisfactorily embedded now.

(2) The failure to provide person-centred care or individualised assessments

17. The critical principle of person-centred care was lost in the pandemic. This principle was recognised as long ago as ancient Greece, when the physician Hippocrates declared that “*it is more important to know what sort of person has a disease than to know what sort of disease a person has*”. During the pandemic the person needing care was very often ignored. Blanket policies and decisions were imposed when there should have been individual assessments of the circumstances of each person’s case. For important decisions there was a failure to seek the views of those needing care and their chosen representatives. Even if their views were heard, they were too often ignored. This deficit existed in respect of decisions about individuals as well as higher-level policy decisions.

18. As the CPs explained in their Module 6 Witness Statement, “*it is impossible to understand how to provide good quality care until you listen to those who need and receive care, and their chosen representatives, as well as those who provide it*” (§37, INQ000514104). But systems were not in place that ensured this would occur during the pandemic, and nor was the importance of creating such systems or listening recognised.

19. Guidance often imposed – or appeared to impose – blanket restrictions (e.g. a general suspension of visits to care homes). This was wrong in both practical and legal terms (overlooking legislative requirements e.g. under the Human Rights Act 1998 to make individualised assessments and decisions about care). There should have been person-specific decisions, based on an assessment of risk against benefit for individuals. This would have provided a properly tailored response and avoided much of the unnecessary harm. It also would have complied with the statutory obligations under the Human Rights Act 1998, Equality Act 2010 and mental capacity legislation which require individualised assessments (see further, below).

20. In contrast to this (providing just one example of unlawful guidance which harmed people in the adult social care sector), the guidance on visits into care homes, until November 2020, failed to articulate the importance of considering the rights and needs of individual residents when assessing whether visits should be allowed (CPs, INQ000514104, §107). It remained lacking thereafter and set the tone for a restrictive and often blanket approach taken by care homes even when the guidance was (to some extent) improved. The

continuing failure by the Government to properly enunciate and clarify the relevant legal duties in its guidance formed the basis of the repeat judicial review actions which John's Campaign brought in respect of care home guidance. It was also a feature of other decisions made in response to the pandemic. If there had been, as there should have been, a focus on the enduring importance of person-centred care then this failure to account for individuals and require individualised assessments would not have occurred. Another example, as Ms Kilbee of Scottish Covid Bereaved explains was that the Highlands was low risk for most of the pandemic but visiting was still stopped in all care homes: §47, INQ000520272.

21. There were failures to implement established processes for ensuring the particular views, needs and circumstances of the person needing care were taken into account. For example, there were failures to carry out proper needs assessments, to agree and share care plans, and to use 'this is me' forms. DNACPR decisions were made on the basis of certain characteristics without consultation with the individuals concerned. Communication with families in many cases stopped or was inadequate. This is all linked to the failure to apply existing legal duties, including human rights duties, considered below.

(3) <u>Failure to ensure respect for equality and human rights</u>

22. There was a widespread failure to recognise and take into account legal obligations. For example, key duties under s.6 of the Human Rights Act 1998 read with Articles 5 and 8 of the European Convention on Human Rights ('ECHR'); s.4 of the Mental Capacity Act 2005; s.21 and/or s.149 of the Equality Act 2010; and regs 9 and 10 of the H&SCA 2008 (RA) Regs 2014 were frequently overlooked. Those duties were seen as '*distractions,'* whereas they were even more important in the pandemic than normal (Hancock, INQ000587746, §11). This is a primary concern of the CPs: a great deal of harm would have been prevented if existing legal protections and obligations were respected. For example:

    22.1. Kamran Mallick from Disability Rights UK described how "*as well as a general lack of Equality Impact Assessments there was often no provision for reasonable adjustments for disabled people*" (§117, INQ000520998).

    22.2. The British Institute of Human Rights found a worrying reduction in the protection of rights in the care sector including, in particular, the right to be consulted in relation to decisions that affect an individual's right to care services as protected by Article 8 ECHR (§93, INQ00052099). It conducted surveys which found that: 23% of care recipients, their family members and unpaid carers said that since Covid-19 they were no longer involved in decision making about their care and support; 60% were not told under what legal basis the change to their care and support was made; over 45% of advocates and campaigners did not think that the specific characteristics or needs of the people they supported were considered when decisions were made; and 76% of people working in health and care said that they had not been provided with legal training or clear information about upholding human rights law (INQ000518423/2; INQ000518424/2; INQ000518425/2).

22.3. Government guidance and regulations not only failed to make specific reference to statutory duties to protect rights but in some cases had the effect of encouraging rights to be ignored or breached, including the Article 8 ECHR right to be involved in decision-making and Articles 5 and 8 ECHR in relation to the prolonged and disproportionate isolation of people needing care.

(4) Failure to obtain and take into account views of stakeholders

23. There was a general lack of knowledge within Government about how social care operated. This meant there was a pressing need to take account of the views of stakeholders (who include those needing care, their chosen representatives and supporters, representative organisations, and other experts). But that was not done: there was a failure by the Government to properly engage with people on the ground and to really listen to and learn from their views and experiences. The problems are explained in more detail, for example, in the CPs' statement (§§73-78, INQ000514104); by Ms Rayner (§§1.8-1.15 and 3.17 INQ000475131); Ms Weatherley MBE (§§3.4, 4.11, 4.14 INQ000504053); and Ms Abrahams, (§§40, 100-110 INQ000509808).

24. The failure to properly engage meant that the Government did not understand: the real-world impact of its decisions on those needing care, their chosen representatives and supporters, and care staff; the diversity within the care sector; or the individual circumstances of those its decisions would affect. The CPs were forced to go to extreme lengths to have their voices heard, including by bringing legal action, only to be told they would be excluded from conversations with Government because they had brought legal action. The very limited engagement that took place was belated and chaotic, undermining the ability for meaningful engagement. Any input that stakeholders gave was often disregarded. Cathryn Lee, CEO of Alzheimer's Society, explained that the care sector was "*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*" (INQ000498137, §11.1). That corresponds to the CPs' experience (see the CPs' Witness Statement, INQ000514104, §70).

25. This had serious consequences. Many of the problems identified in this submission could have been avoided had there been proper engagement. In Module 3, there was widespread agreement among witnesses that decisions made without proper consultation with directly affected people were not good decisions. Mr Hancock acknowledged that "*there's a vital need to consult people on the ground, both through organisations and directly*" [36/199/8-10]. But that belated recognition was not put into practice during the pandemic.

26. The lesson from all of this is that mechanisms for listening to and including those with lived experience must be improved. Professors Sleeman and Barclay, Experts on Palliative and End of Life Care, recommend that it is essential to "*Ensure patients and families are at the centre of pandemic planning for care, innovation and research*" (INQ000587295, §214).

(5) Restrictions on movement in and out of care settings

27. Some of the harshest measures imposed on the adult social care sector, with some of the most enduring negative consequences, were the restrictions on movement in and out of all residential care settings. These include not only care and nursing homes but also (too often) supported living units, rehabilitation centres and specialist mental health units (e.g. for people with advanced dementia). These caused severe and disproportionate harm.

28. A chronology of the key restrictions and their adverse impact is identified in the CPs' statement at §§48, 66-67, 73, 94 and 104 onwards. The harms they caused are widely documented, including in 'The Holding Pen,' which contains numerous accounts by individuals who experienced imposed isolation in care settings INQ000273453. See also Midsummer Milestones (July 2021) INQ000176369; John Shaw: INQ000499309; Amnesty (Oct 2020) p39-43 INQ000499381; Sleeman §182 INQ000587295; Ms Nolan §34 INQ000520202; and Abrahams §§53-55, 68 INQ000509808, who noted the Government "*disastrously underestimated the crucial importance to health and wellbeing of contact with loved ones*". Care Rights UK has also documented and published personal accounts of people directly and indirectly affected by enforced isolation.[3]

29. The harms included the withdrawal of hands-on care, which for many was essential to their physical and mental health as well as their well-being. They also included inability to access health assessments and treatment leading to illness, deterioration of pre-existing conditions and many deaths. For example, care home mortality in Wales from non-Covid-19 causes more than doubled in April 2020: (INQ000350133/5). Just one example of the accounts in 'The Holding Pen', among many, is Rosemary (p12-13). An old friend she was caring for was placed in a care home on what was meant to be a short-term respite basis. At the time of admission "*she was fit and well in spite of being 83 years old… suffering from the early stages of atypical dementia but was enjoying life*." She was required to isolate and was denied visitors, and Rosemary was given no information about her friend's health. "*18 days later she was dead. The deterioration in her health was catastrophic…*". A further stark example is the following account provided to Care Rights UK by a concerned daughter: "*it was only a few days into lockdown but already mum was unable to speak. Her glow and warmth had all but disappeared. She went from being chatty and writing in her diary daily to being unable to talk and write, within days. Her deterioration was so rapid and all consuming"* (INQ000273456).

30. The Government knew or ought to have been aware of the impact that the restrictions would cause from the earliest stages. The importance of meaningful interaction with family carers was well-documented before the pandemic (e.g. INQ000499300). It was evident to anyone who was involved in the care sector and was repeatedly pointed out to Government after Covid-19 appeared. To pick a few examples:
    30.1. On 2 July 2020 a coalition of dementia specialist stakeholders ('One Dementia Voice'), including the CPs, wrote to Mr Hancock, identifying the severe adverse

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[3] See Care Rights UK blog: <https://www.carerightsuk.org/care-rights-blog>

impact of the restrictions that preventing visits into care settings by family and essential carers caused. They noted the 52% increase in non-coronavirus related deaths for people with dementia (INQ000492343).

30.2. Similar concerns were raised in a letter to the Secretary of State dated 1 Nov 2020 from the CPs and other stakeholders, who called on the Government to change "*the effective blanket bans on visiting in care homes*"; noting "*the extreme anguish that this is causing*"; and explaining that visitors can "*play a fundamental role in the everyday care of residents*" (INQ000532365).

30.3. Amnesty International's 2020 Report "As if Expendable" detailed the enormous harm being caused by the access restrictions: "*Every single one of the family members and care home staff interviewed by Amnesty International expressed concern that the prolonged isolation of care home residents… had devastating consequences*" (INQ000509643 §39).

30.4. Further evidence of the severe harms, and what should be done to avoid them, was set out in a submission to the Select Committee on 10 Jan 2021 by John's Campaign and others (INQ000273450) and in a submission to the APPG on Coronavirus by Care Rights UK (then called the Relatives and Residents Association) in August 2020 (INQ000231911). On 9 Feb 2021 another letter from John's Campaign, the Relatives and Residents Association ("R&RA") and others drew attention to the same issues and explained that individual assessments could be used to enable visiting by essential family caregivers and others (INQ000532368).

30.5. Yet disproportionate restrictions remained in place. John's Campaign and R&RA wrote to the Prime Minister on 15 Oct 2021 highlighting that "*Whilst restrictions for the rest of the population have been removed, people living in care homes are still subject to stringent restrictions on their contact with family/ friends*"; the "*disparity between care home residents and the general population is now vast, making people in care homes feel abandoned and left behind in isolation*"; and the "*devastating impact on the mental and physical health of individuals in care homes*" (INQ000273486).

31. Little, if any, notice was taken of all of this. Excessive restrictions remained in place, long after many people living in care homes were fully vaccinated and well beyond the lifting of restrictions on the wider population. The CPs have a number of specific complaints about this.

32. <u>First</u>, essential family care givers should never have been excluded from care. In the understandable attempt to reduce the number of people coming in and out of care settings, there was a crucial failure to differentiate between 'family carers' (essential to individual well-being) and visitors (arriving for purely social reasons.) The exclusion of family carers had a serious adverse impact on the quality of care available, people's quality of life and quality of death during the pandemic period. This is illustrated by the significant impact on people living with dementia which has been touched on above.

33. <u>Second</u>, there was an inappropriate use of blanket restrictions, as addressed above. Such

restrictions should never have been imposed. Policy and guidance should have made clear that statutory duties continued to require individualised assessments, so that individualised responses would be both permitted and necessary whenever that assessment determined so. This should have applied not only to whether family carers should be permitted access but also to other restrictions, for example whether to apply the requirement that care home residents isolate for 14 days after any "visit out" of the care home (which included attendance at any medical appointment off the care home premises). The CPs know of people living in care settings with cognitive impairments who could not understand or comply with requirements to "self-isolate", and who were therefore made subject to physical restraint and deprivation of liberty (strapped to chairs in their room, locked inside their room, or sedated) to ensure the isolation requirement was met: The Holding Pen, INQ0002723453. Such practices were flagrant violations of people's human rights and should never have happened. As the JCHR recorded in its report of 22 July 2022, "*Protecting Human Rights in Care Settings*", restrictive practices of this sort "*could amount to a breach of the prohibition of torture and inhuman or degrading treatment (Article 3 ECHR) and the right to liberty and safety (Article 5 ECHR)*" (INQ000499428). The CPs are disturbed to read in Mary Cridge's evidence that "*the Inquiry has confirmed that CQC's role in examining the use of restraint, seclusion and segregation is not within the scope of Module 6*": INQ000584245, §15.2. These practices were used in the care sector to enforce the onerous blanket restrictions introduced during the pandemic to the significant harm of the individuals subjected to them. The Inquiry should look at why this happened instead of appropriate, person-centred and proportionate restrictions tailored to the risks and needs of the person affected. Instead, unnecessarily harsh restrictions remained in place and were applied across the board even when Covid-19 rates were low, the harm caused to individuals of enforcing the restrictions was high, and there was no scientific basis for them.

34. <u>Third</u>, the approach to restrictions failed to have regard to indirect harm and focussed too narrowly on infection control. While that may have been *understandable* at the start of the pandemic, given the challenge Covid-19 posed, that does not make it *right*, and it became ever more inappropriate as time went on. It meant that one risk (Covid-19) was privileged over all others, no matter how severe those other risks were. From early 2020 there was readily available, increasing (and ultimately, overwhelming) evidence of the profound indirect harm that was being caused to people needing care. Rather than taking a narrow focus on the reduction of Covid-19 as the primary (often, as the sole) aim, guidance should have been context-specific to strike an appropriate balance between IPC restrictions and individual human needs (see the consideration by the CPs of how to strike the balance: INQ000499303, and *Care Home Voices: A snapshot of life in care homes in Wales during Covid-19*, INQ000181725. See also Care Rights UK's suggested rewrite of visiting guidance, as sent to the DHSC: INQ000499364.

35. <u>Fourth</u>, visiting restrictions were inconsistently applied by individual care providers and also by local authorities. There were discrepancies in the approach advised and taken at national, local, and individual care home level. This led to confusion and lack of clarity. The "*persistent lack of formal guidance on visiting meant that care home staff were often*

left to manage the accessibility of visits themselves leading to an inequality of approach even within individual care homes" (Mr Mallick, Disability Rights UK, §108, INQ000520998). The unpredictability of approach contributed to the distress caused when family carers and loved ones were excluded. There was uncertainty about whether the Government guidance was mandatory (with legal backing) or whether it was optional 'guidance' which could be ignored. Constantly changing versions did not help.

36. <u>Fifth</u>, it is hard to justify the restrictions on access to family carers when staff were allowed to move liberally, including between care settings (Abrahams INQ000509808, §68). This carried a much higher risk of transmission than allowing a family carer in, since staff would have contact with many more people (see Hancock, §129, INQ000587746 "*We learned in the summer of 2020 that staff movement between care homes was the main source of transmission*.").

37. <u>Sixth</u>, concerns about insurance had an undue impact on restrictive approaches towards visiting in care homes. In the CPs' experience, care homes often cited issues with their insurers as a basis for taking a risk-averse approach (see also Donald Macaskill, CEO of Scottish Care, who described the "*culture of fear*" from concerns about losing indemnity from insurance: §§90-92, INQ000509530, and Rayner who described "*insurers refusing to renew policies or placing constrictions on cover that left providers unfairly exposed and risking regulatory non-compliance*": §1.10, INQ000475131). The Coronavirus Act 2020 provided for an indemnity in England Wales and Scotland to health service activity (s.11-12) but there was no equivalent for social care.

<u>(6) End of life care</u>

38. One of the most upsetting aspects of the deterioration of care and exclusion of family carers during the pandemic was the impact those developments had on people at the end of their life and on their loved ones. There were widespread failures to provide people with dignified deaths with the presence and support of their loved ones. It was not until late in 2020 that visiting guidance in care homes and hospitals was adapted to provide for in-person visits for people at the end of life, leaving thousands of people dying without the presence and support of their loved ones (Caroline Abrahams, INQ000319639, §48). This was an indignity that can never be recompensed. Excluded family members still feel profound guilt and heightened grief at their loved one having died alone without the comfort and care they would have provided at the end. As the CPs observed in their oral evidence in Module 3: "*the legacy of grief, guilt, anger, and mistrust that's left behind it is massive and so if one could do just one single thing, it would be to say, if you are dying you have the right to have somebody with you and we will facilitate that and that is our legal duty*" **[21/42/17-22]**.

39. Even when guidance indicated that in-person "end of life" visits should be facilitated, no definition was provided of "end of life." There was wide variability in how it was interpreted in different settings, ranging from the last days, to the last hours, to the last minutes of life. This increased the distress caused to dying people and their excluded loved

ones by the unpredictability of approach. Too often, as in the case of Judith Kilbee, access was eventually permitted too late with their loved one having died before they arrived: INQ000614380. In other cases, like Jane Wier-Wierzbowska's, she was able to be present when her mother died but told she could not have any physical contact, so could not hold her hand as she died: INQ000614372. The approach taken lacked humanity without any clear infection control justification, and the distress caused to the bereaved is still acutely felt today.

40. As well as the exclusion of loved ones, end-of-life care also suffered because there was inadequate access to specialised end-of-life and palliative care to manage people's symptoms and distress as they died. Age UK describes how "*older people in care homes were left to die of Covid-19 and other illnesses without sufficient clinical support or sometimes access to palliative care teams or palliative care medicines… care staff [were] told that their job was to provide end of life care for residents"*, but *"prescribing and treatment expectations were beyond residential care staff training and experience… and in some places supplies of end-of-life medication ran out*" (INQ000319639, §47).

(7) Restrictions on access to healthcare and other services

41. Access to physical and mental healthcare and support services was wrongly restricted during the pandemic. This was in part due to excessive 'visiting' restrictions; including the deterrent effect of isolation requirements before or after trips to medical appointments; and in part because medical professionals themselves decided to stop attending those in care.

42. There is ample evidence of this. For example, the "Worst Hit" Report by the Alzheimer's Society noted 75% of care homes surveyed in May 2020 said that GPs were reluctant to visit residents (Lee §§5.4 and 3.14, INQ000498137). A survey by Care Rights UK noted 88% of respondents said that the healthcare their loved ones received was made worse by restricted access to healthcare professionals during the pandemic (p5, INQ000273449). A Patient's Association survey in Sept 2020 identified serious adverse impacts on disabled people of services being cancelled (INQ000273484).

43. Physical health care and screening appointments were cancelled. Community care and support services and learning disability social care packages were withdrawn. Therapists, mental health professionals, occupational therapists and community nurses stopped providing services. Ambulances refused to take people from care settings to hospital. Home-based support for disabled people was withdrawn. "*This sudden cessation in care led to some respondents reporting being forced to sleep in their wheelchair, and being unable to get out of bed to wash and dress themselves*" (Ms Nolan, §30-31 INQ000520202). These points, and the serious harm that resulted, are also explained by the CPs at §47 INQ000514104; Weatherley §5.7 INQ000504053; Abrahams §37-51 INQ000509808; Simmons §44 INQ000520994; Amnesty p21-24, INQ000499381; Mr Hodgkinson §22.2 INQ000474414; and Professor Hatton §§100-108, 118-122 INQ000587296).

(8) Discharge from hospitals without testing

44. The policy to discharge from hospitals into both care homes and family homes without prior testing was wrong. There were extremely high rates of Covid-19 in hospitals at the time. The care home population was highly vulnerable to Covid-19, and family homes might also contain people vulnerable to Covid-19 including older people or clinically vulnerable people.

45. The risk of asymptomatic transmission, and the consequent importance of testing, were well-known by the time of the 17 March 2020 discharge decision, and of subsequent decisions to maintain the policy. The evidence for this is summarised in detail in the CPs' M2B closing submissions at §§13-16. The evidence was of asymptomatic transmission, not merely asymptomatic illness. Applying the precautionary principle, given people living in care homes were in highly vulnerable situations, the extensive mounting evidence meant prior testing should have occurred. There were failures to consult care homes in advance which meant that patients were discharged to places without isolation facilities which were unable to prevent the spread of Covid-19. There was also a failure to consult the patients or their families, again leading to bad decisions (CPs §§251-258 INQ000514104; and Weatherley §3.6 and 4.2 INQ000504053).

46. The impact of the discharge policy was catastrophic. Not only did it cause people in vulnerable situations to be infected with Covid-19 leading to illness and in some cases death, the belated recognition of its negative impact then served as the justification for the onerous restrictions that were placed on care homes. The restrictions imposed in the name of protecting residents who had been left so vulnerable by the discharge decision then caused further untold harm in the very same settings.

(9) Structural and resourcing issues

47. Many of the issues experienced by the adult social care sector during the pandemic were products of or exacerbated by the significant structural and resourcing issues that the sector faces. Prior to the pandemic, social care was already in crisis after years of neglect by the government (Ms McHugh §47 INQ000475047; and Rayner §2.1 INQ000475131). Some of the myriad problems falling under this heading include that:

    47.1. Social care was chronically under-funded by central government, as recognised by the Health and Social Affairs Committee (CPs §33-34 INQ000514104; and INQ000471095) and the Economic Affairs Committee (Rayner §2.2). Immediately before the pandemic there was a shortfall of £8bn per year for adult social care. This created a "*perfect storm*" (McHugh §49-50) and a "*human catastrophe*" in social care (Chair of the United Nations Committee on the Rights of Persons with Disabilities: Ms Sansome §20 INQ000520343) and made it much harder for the sector to cope in the pandemic.

    47.2. The under-resourcing caused serious staff shortages. For example, there were at least 122,000 vacancies in the workforce of adult social care: Rayner §2.3 and Bottery §53, INQ000502030. There were shortages in 45% of care homes during the pandemic

(Sleeman, §174 INQ000587295), with an inevitable impact on the quality of care and the wellbeing of people living and working in care homes alike.

47.3. Other staffing issues were significant and undermined the sector's resilience to the pandemic. There was a high incidence of zero hours contracts and use of agency workers who did not receive sick pay, and low rates of pay generally offered to care workers. This created impossible pressures for these workers, including e.g. to continue to work instead of self-isolating. It contributed to the high level of movement between care settings and between different people needing care. It also undermined the continuity of care which was important for many.

47.4. The level of protection for the rights of those needing care is variable depending on how the care has been arranged/funded: see e.g. s.73 Care Act 2014 and the judgment in *Sammut v Next Steps Healthcare* [2024] EWHC 2265 (KB). This created a two-tier system where people whose care is arranged and funded privately apparently cannot rely on the direct duty on providers to respect rights under the Human Rights Act. This creates confusion and is a barrier for people to access their rights. It is a significant structural problem which must be put right. All regulated health and care providers must have a direct legal duty under the Human Rights Act.

47.5. The complicated structure of social care means that the sector overall lacks clear lines of accountability and oversight, which creates particular problems at moments of crisis and stress such as those caused by the pandemic. In Module 1, Mr Hancock accepted that there was "*a structural problem*" in social care which made it harder to protect those in care homes. This arose from the fact that formal legal responsibility for care homes lay with local authorities, not with the DHSC. This also made gathering data "*extremely difficult*" **[10/48/24-25]**.

47.6. The system for resolving complaints against professional care provision, was inadequate. There was no single, clear, and confidential process which anyone needing care, or their supporter could use. The CQC did not deal with individual complaints. Redress through the Ombudsman or legal proceedings would take too long and come too late for people nearing the end of life. The lack of an independent, fully confidential process leads to victimisation of complainants, including instances of people being evicted, or family members being excluded, after making a complaint (see INQ000499316 and INQ000587829). The lack of a proper complaints mechanism was a serious concern during the pandemic, since other mechanisms for challenging problems, including the presence of family carers, and in-person inspections by the CQC, were largely absent. An independent and confidential complaints process would help to redress the power imbalance in care where people are too afraid to raise concerns due to fear of reprisals, given the vulnerable position of people in care.

47.7. The CPs have also raised concerns about the narrow focus of PHE/UKHSA and public health teams on infection control, leading to restrictions which were to the detriment of the wider health and wellbeing of people needing care. PHE's Senior Reporting Officer on Covid-19 response in Adult Social Care was Dr Eamonn O'Moore, a prisons specialist who lacked expertise of the care sector and was simultaneously the adviser on Covid-19 response in prisons. The CPs are concerned that the elision of two strikingly different kinds of settings may well have contributed to the excessively restrictive measures imposed on adult social care and led to an increase in institutionalised care and closed cultures which persist in some care settings today. Care homes are homes, not ‘secure settings’.

(10) The form of legislation and guidance

48. The *substance* of guidance and legislation is dealt with elsewhere but there were also real problems with its *form*. Firstly, there were long delays in guidance being produced for residential care providers as well as home care providers. Indeed, until 13 March guidance advised it was “*very unlikely that anyone receiving care in a care home or the community will become infected*”: INQ000609933, p1. The guidance that was produced from 13 March 2020, and the adult social care action plan dated 15 April 2020, was vague and inadequate A specific care home support package was not implemented until 15 May 2020 (Mallick, §66, INQ000520998). There was no guidance on visits out of care homes until December 2020 and there were substantial delays in updating guidance on visiting, particularly during summer of 2020 (CPs §101 INQ000514104). There was delay in Government guidance on re-opening day centres for disabled people, which meant they stayed closed for longer than necessary. There was also limited guidance dealing specifically with supported living settings, which varied by nature from other residential care settings and led to providers relying on inappropriate care home guidance.

49. When legislation or guidance for those in care did come it lacked clarity, was confusing, contradictory, rapidly changing and poorly communicated (CPs §124-138; Mallick §108 INQ000520998; and Rayner §§3.21-3.23, 4.13-4.15 INQ000475131). There was a “*dizzying array of national and local instructions*” (Weatherley, §4.4 INQ000504053). This caused chaos and confusion which contributed to care homes taking the most restrictive approach possible and closing their doors. They did so based on fear that without clear guidance requiring access they would be criticised for providing access, fear of the spread of infection and of the implications on their insurance. Clear and consistent guidance was particularly important to many of those needing care, for obvious reasons.

50. The perception of the status of Government guidance by providers swung between it being seen as advisory and mandatory. When the guidance was restrictive, many providers interpreted this as something they must follow or risk repercussions with the regulator or their insurers. This was despite the fact that the non-statutory guidance was at odds with long-standing legal rights protected by primary legislation. When the guidance finally indicated that access should be provided many care homes persisted with the earlier restrictive approach. They continued to exclude family carers and dismissed requests from family carers to be nominated as an essential care giver. For some providers a restrictive, risk-averse approach had firmly embedded, resulting in a closed culture. The fear of doing wrong was apparent, and was exacerbated by comments from the top of Government attributing the high death toll in care settings to providers not following the guidance.

51. A practical example of the lack of clarity in the guidance is provided by the guidance on visits at the end of life. There was no definition provided of ‘end of life’ or the ‘exceptional

circumstances' in which visits were said to be allowed. This led to inconsistent and often highly restrictive interpretations, with family members in some settings being refused visits until the very last minutes of life, if at all. At times the CQC's guidance contradicted Government guidance. For example, CQC guidance updated on 20 May 2022 indicated that people returning from hospital should be isolated, whereas Government guidance from 3 May 2022 stated that people should not be required to isolate upon discharge if they had a negative test. Juggling this guidance was a minefield for care providers and their response was often to default to the most restrictive option.

52. At times legislation and guidance treated the care sector as a homogeneous whole, disregarding some settings which required a specific approach (such as supported living) or that had facilities that would have allowed a less restrictive approach. The myriad problems set out above are probably linked to the fact that the views and experience of stakeholders, such as the CPs, were not listened to or taken into account.

(11) Inadequate monitoring, oversight, and regulation

53. The CPs consider that "*monitoring and oversight are key components of safe and high quality care*" and the restrictions in place during the pandemic meant this was even more important for protecting rights (§236, INQ000514104). But, in direct conflict with this, the CQC abandoned its responsibilities (*ibid* §236-250; Professor Green §82, INQ000505008). The CQC ceased inspections and it had an extremely limited role, focusing on compliance with infection control measures. The suspension of inspections led the Minister for Social Care to be "*extremely concerned*" about cases of neglect or abuse arising: INQ000609960. The CQC did not properly monitor and enforce the duty to provide person-centred care.

54. Many stakeholders agree with the CPs that the pandemic was a time when oversight and monitoring was needed more than ever. As Cathryn Lee, CEO of Alzheimer's Society explained, the need for oversight was increased while the sector was undergoing its most significant stress test (§7.1, INQ000498137). This was a time when routine visits from other professionals, including safeguarding teams, social workers and health practitioners, as well as loved ones whose presence provided additional oversight, were seriously restricted. As Ruth Allen explains, life-altering decisions were being made so it was important for independent professionals to have access to the person needing care: INQ000572015, §71.

55. Members of the Covid 19 Bereaved Families for Justice raise concerns "*about the impact of a lack of regulatory oversight during the relevant period and a lack of candour from care providers*" (§4.46, INQ000474426). The harrowing experiences shared by families of what they noticed was missing in their loved ones' care when they were eventually permitted access highlight the significant deficiencies in monitoring and oversight. These failures caused untold damage to the wellbeing and mental health of people drawing on care with many refusing to eat and drink and simply giving up the will to live. To highlight just a couple of examples:

55.1. Diane Mayhew (Rights for Residents) described her mum's experience: "*There were no curtains on the window, no duvet on the bed and no things of mum's put out to make it feel less strange. The room was eerily silent. No one had thought to set mum's TV up to stream a film or turn on her radio or DVD player to create some background sound that would distract her from confusion and fear. Mum was in her wheelchair facing the closed door with tears streaming down her face when she looked up and said clear as day "has someone moved me?" That mum was treated so callously, at a time when we had access to tests and PPE was hard to comprehend*."

55.2. Ms Adamson (INQ000474426, §4.48) refers in her statement to the following example: "*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*."

56. Particularly concerning was the CPs' experience that people who complained about the treatment of their loved ones were banned from visiting (April 2019 Article INQ000499316) or were given an eviction notice. The CPs' concerns about the inadequacies of the CQC have been substantiated by the findings of an interim independent review of the regulator. On 26 July 2024, the review into the operational effectiveness of the CQC found that it was not fit for purpose (INQ000499438). The regulatory oversight failings were also compounded by a lack of oversight of the care sector at a national level. Simon Bottery, from the King's Fund, explained that "*oversight from central government was weak and adult social care not apparently seen as a priority*" (§82, INQ000502030).

<u>(12) Data relating to the care sector</u>

57. Many of the aforementioned issues with the Government's handling of the care sector were apparently linked to a lack of data relating to the care sector.

58. There was (and still is) a lack of data and/or research on the care sector, including information elucidating who and what constitutes the care sector (CPs §259-264 INQ000514104; Ms Adamson §3.6 INQ000474426; Rayner §2.6 INQ000475131; and Sleeman §169 INQ000587295). There was, and remains, no way for the Government to readily access data on the care workforce (including unpaid carers), people needing care, quality of care, care funding, infection surges in residential settings and mortality rates. There is no national centralised accessible database to consolidate data from local authorities, care settings and carers, and no consistency in the nature of data recorded.

59. Perhaps the most important deficiency was an almost complete lack of data on indirect harms. While enormous efforts were made to gather data about Covid-19 itself (in particular, Covid-19 deaths and infection rates), there was little evidence of any

consideration being given to measuring and/or quantifying the impact of indirect harms. That had an obvious impact on Government decision-making and the factors that were prioritised, it led to measures causing significant indirect harm being introduced and maintained over a considerable period of time.

60. The difficulties in obtaining meaningful data about the care sector arose in part from the structural problem highlighted above, namely the fragmented nature of the sector: see Ian Diamond, from the UK Statistics Authority, who considered statistical comparisons are "*not currently possible*" (§213, INQ000553814; Albert Heaney, the Welsh Government's Chief Social Care Officer, §157, INQ000532383; and Cathryn Williams, on behalf of the Association of Directors of Adult Social Services §13.22 INQ000571608).

61. Without appropriate data, decisions were made which did not properly reflect the composition and needs of the sector and the people within it. The absence of data reflecting the diversity of the care sector, for example, will have contributed to the Government's unfortunate tendency during the pandemic to treat it as a homogenous whole despite the wide range of needs, risks, and circumstances reflected within it.

62. Ms Abrahams for example raised concerns about the Government's failure to collect any routine, real time data from the care sector and the Government's resistance to engaging with data collected by other bodies (§§65, 108, INQ000509808). She supports the development of a national register of all care workers and social care providers to address urgent data deficiencies (§122 INQ000509808).

63. Alongside significant lacunae in the available data the CPs are concerned that where there *was* data, it was not always properly considered. A particular example in this respect is that, despite the ONS data showing that deaths caused by Covid-19 were low (particularly as compared to deaths from other causes in residential care settings), restrictions on the people living in those settings and their representatives and loved ones remained harsh. Better systems for processing and responding to relevant data are obviously necessary to avoid the promulgation of harmful policies at odds with what the data shows to be required.

(13) Unpaid carers

64. A fundamental contribution to the adult social care system is made by unpaid carers, but their value is rarely recognised. The pressures of the pandemic impacted on them enormously and caused a swelling in their ranks: Carers UK estimated in June 2020 that an additional 4.5 million people had become unpaid carers since the pandemic began (bringing the total to 13.6 million) and the CQC's 2020/21 edition of its State of Care report outlined the increased strain on carers (INQ000398569). Some of this additional need was created by the closure of professional homecare services, anxiety about the infection risks of permitting professional carers into the home, and the closure of day services which may previously have met care needs[4]. In some cases, as described by Susan Lyons in respect of

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[4] see John's Campaign, <https://johnscampaign.org.uk/post/the-right-thing-to-do>

her care for her daughter Sarah, people who lived in care homes were sometimes not permitted to return to their home once lockdown was announced, and remained therefore at the family home. Susan had to stop her paid employment as an accountant to meet Sarah's care needs in the time she was at home (INQ000587637 §21). The value of the care provided by unpaid carers was already equivalent to the total annual cost of health spending in the UK: about £162 billion. (See Bottery §37 INQ000502030; McHugh, §38-40, INQ000475047; Mallick §26 INQ000520998; and Carers UK report, p4, INQ000239459).

65. Unpaid carers stepped up to relieve the pressure on health and social care systems or because there was simply no other option for them, and they did so without adequate support and without, in most cases, the benefit of key worker designation. The reduction in on-the-ground operations of many charities and third-sector support organisations meant that the burden on unpaid carers was even more than normal. 6 out of 10 carers (61%) said their physical health worsened as a result of caring, while 7 out of 10 (72%) said they have experienced mental ill health[5] (INQ000587831).

66. Yet the importance of unpaid carers was not recognised in decision-making during the pandemic. They received inadequate respite care, financial support (e.g. Carer's Allowance), and access to equipment including PPE. Visiting restrictions often prevented unpaid carers from accessing those they were supposed to be supporting, and there was no right for the unpaid carer to be recognised as part of the care team (CPs §28-29 INQ000514104). Care supporters did not get priority access to vaccines. More generally they were often not listened to or given respect by healthcare professionals. "The Holding Pen" contains real-life examples of the serious adverse impact all of this had. The Alzheimer's Society 'Worst Hit' report explains that "*95% of carers reported a negative impact on their mental and physical health*" (INQ000492901).

Conclusion

67. The CPs look forward to exploring these important issues with the witnesses to this Module, identifying further issues on the basis of that oral evidence, and supplementing what is set out here in the closing submissions. They are grateful for the Chair's careful consideration of the points they raise.

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13 June 2025

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[5] See Carers UK webpage: <https://www.carersuk.org/policy-and-research/our-areas-of-policy-work/health/>