

**United Nations Universal Periodic Review of the United Kingdom (4<sup>th</sup> Cycle)**

**March 2022**

**Alzheimer's Society Submission  
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## About Alzheimer's Society:

Alzheimer's Society is the UK's leading dementia charity. We campaign for change, fund research to find a cure and support people living with dementia today.

## The legal landscape:

### 1. International law

1.1. Under international law, a range of crucial safeguards are of pertinence to people living with and affected by dementia, including:

- International Covenant on Economic, Social and Cultural Rights (ICESCR)
- Convention on the Rights of Persons with Disabilities (CRPD)

**Recommendation (1):** Alzheimer's Society calls for the full implementation of both pieces of international law. We believe that the full implementation of the CRPD could lead to the equal treatment and full protection of people with dementia in society due to the broad range of community, health, and care rights that it encapsulates.

### 2. Domestic law

2.1. Alzheimer's Society, in its recent submission to the Government's consultation<sup>1</sup> on its "proposals to revise the Human Rights Act (HRA) and replace it with a Bill of Rights", voiced substantial concerns, including:

- The government's proposed restraint in positive obligations for public authorities to be held legally accountable for these rights jeopardises the protections the HRA currently provides to people with dementia and will reduce the legal responsibilities the Government currently has towards them.
- The development of a 'permission stage' to access the judiciary system will limit access to justice for those with limited resources who are genuinely subject to human rights breaches by their dementia care.

2.2. Sadly, these concerns echo many of the issues raised by member states and civil society organisations during the previous Universal Periodic Review (3<sup>rd</sup> Cycle).<sup>2</sup> In particular, some of the following key recommendations were included as part of the Matrice of Recommendations<sup>3</sup>:

- Ensure that any legislative modification, such as the enactment of the Bill of Rights, maintains the level of protection that the current Human Rights Act guarantees (Mexico)
- Take all necessary steps to prevent the new British Bill of Rights from leading to a decreased level of human rights protection (Portugal)

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<sup>1</sup> GOV.UK (2022). Human Rights Act Reform: A Modern Bill of Rights. Available at:

<sup>2</sup> United Nations (2017). Civil society and other submissions. Available at: <https://www.upr-info.org/en/review/United-Kingdom/Session-27---May-2017/Civil-society-and-other-submissions#top>

<sup>3</sup> United Nations (2017). UPR of United Kingdom of Great Britain and Northern Ireland: Thematic list of recommendations. Available at: [https://www.upr-info.org/sites/default/files/document/united\\_kingdom/session\\_27\\_-\\_may\\_2017/matricerecommendationsuk.pdf](https://www.upr-info.org/sites/default/files/document/united_kingdom/session_27_-_may_2017/matricerecommendationsuk.pdf)

**Recommendation (2):** The UK Government should retain the HRA and not make changes to the law that dilute human-rights protections in health and social care settings. The HRA is a powerful practical tool for advocacy, planning, delivering and demanding rights-respecting services, and calling for change to policy and legislation where it is found not to be human-rights compliant.

**Broader rights issues:**

3. *Access to care and support:*

- 3.1. Even before the Covid-19 pandemic, many people living with dementia could not access the requisite care. For example, the MODEM study, in 2020, estimated that about 200,000 people with moderate and severe dementia in England do not get any kind of funded or professional support.<sup>4 5</sup> This lack of support before the Covid-19 pandemic was mirrored when it comes to provisions in place for unpaid family carers. Alzheimer’s Society’s Fog of Support<sup>6</sup> report found that “respondents reported feeling that they lacked support.”
- 3.2. However, since the onset of the Covid-19 pandemic, the levels of support and care available for people with dementia have become much worse. For example, in December, the Association of Directors of Adult Social Services (Adass) commented on how “every day we are rationing care in ways that we never have before.”<sup>7</sup> Whilst, almost “400,000 people are now waiting for an assessment of their needs or service; More than 1.5 million hours of commissioned home care could not be provided between August and October because of a lack of staff, despite record growth in provision.”<sup>8</sup>
- 3.3. Similarly, during the pandemic, the levels of support available to informal carers of people with dementia have, too, deteriorated from an already poor position. For example, Alzheimer’s Society’s Worst Hit report found that “73% of carers reported that their caring responsibilities have increased during lockdown.”<sup>9</sup> More recently, the Carers Trust’s found that “91% of unpaid family carers feel ignored by the Government.”<sup>10</sup>

This reality is a particularly disappointing one given the existing safeguards, of which the UK is a signatory, under Article 12 of the ICESCR<sup>11</sup>, including:

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<sup>4</sup> Health and Social Care Committee (2021). Oral evidence: Supporting those with dementia and their carers, HC96. Available at: <https://committees.parliament.uk/oralevidence/2189/pdf/>

<sup>5</sup> Alzheimer’s Society (2021). A Future for Personalised Care. Available at: [https://www.alzheimers.org.uk/sites/default/files/2021-03/A\\_Future\\_for\\_Personalised\\_Care.pdf](https://www.alzheimers.org.uk/sites/default/files/2021-03/A_Future_for_Personalised_Care.pdf)

<sup>6</sup> Alzheimer’s Society (2020). The Fog of Support. Available at: [https://www.alzheimers.org.uk/sites/default/files/2020-09/as\\_new\\_the-fog-of-support\\_carers-report\\_final-compressed.pdf](https://www.alzheimers.org.uk/sites/default/files/2020-09/as_new_the-fog-of-support_carers-report_final-compressed.pdf)

<sup>7</sup> Adass (2021). A national emergency for social care – ADASS’s plea to the public. Available at: <https://www.adass.org.uk/adass-press-release-a-national-emergency-for-social-care>

<sup>8</sup> Adass (2021). ADASS Press Release: Snap Survey reveals a rapidly deteriorating picture of Social Care Services. Available at: <https://www.adass.org.uk/snap-survey-nov21-rapidly-deteriorating-social-services>

<sup>9</sup> Alzheimer’s Society (2020). Worst hit: Dementia during Coronavirus. Available at: <https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf>

<sup>10</sup> Carers Trust (2022). Pushed to the Edge: over 90% of unpaid carers feel ignored by the Government. Available at: <https://carers.org/our-social-care-campaign/carers-trust-social-care-survey-findings-2022>

<sup>11</sup> UN General Assembly (1966). International Covenant on Economic, Social and Cultural Rights. Available at: [https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg\\_no=IV-3&chapter=4](https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-3&chapter=4)

*“the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”*

Similarly, CRPD<sup>12</sup> contains elements relating to the provision of sufficient levels of care and support, including:

*“a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”*

The CRPD also contains rights relating to the support available for people with disabilities and their families through Article 28, which states:

*“the right of persons with disabilities to an adequate standard of living for themselves and their families” (...)* *“and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realisation of this right without discrimination on the basis of disability.”*

Whilst informal carers are indirectly covered by a plethora of human rights conventions. For example, the Northern Ireland Human Rights Commission has noted<sup>13</sup> that “the experiences of carers may however engage a number of human rights standards”, including:

- The right to health
- The right to family life
- The right to an adequate standard of living
- The right to work
- The right to participation

**Recommendation (3):** The UK Government should ensure the full implementation of the Care Act provisions to ensure the requisite levels of support are provided for unpaid family carers and those who draw on support and care.

**Recommendation (4):** The UK Government and local authorities need a more effective complaint and resolution process. Our joint project<sup>14</sup> conducted with together in dementia everyday (tide) noted the fundamental dysfunctionalities in the current system, leaving individuals unable to challenge the current system and unaware of their rights.

#### 4. Quality of social care:

- 4.1. The Wellbeing Principle of the Care Act<sup>15</sup> sets out the need for personalised care. Whilst internationally similar provisions are made under the CRPD<sup>16</sup>, including:

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<sup>12</sup> UN General Assembly (2007). Convention on the Rights of Persons with Disabilities. Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

<sup>13</sup> Northern Ireland Human Rights Commission (2014). The Human Rights of Carers. Available at: [https://nihrc.org/uploads/publications/The\\_Human\\_Rights\\_of\\_Carers.pdf](https://nihrc.org/uploads/publications/The_Human_Rights_of_Carers.pdf)

<sup>14</sup> tide (2021). tide members respond to Inquiry into challenging decisions about adult social care. Available at: <https://www.tide.uk.net/tide-members-respond-to-inquiry-into-challenging-decisions-about-adult-social-care/>

<sup>15</sup> UK Government (2014). Care Act. Available at: <https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

<sup>16</sup> UN General Assembly (2007). Convention on the Rights of Persons with Disabilities. Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

*Article 19 – “b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;”*

- 4.2. However, all too often, these standards are not reflected in reality when people are drawing on care. Currently, an individual’s experience of social care is that it often solely focuses on receiving help with things essential to daily functioning, also described as ‘personal care.’ For example, the Care and Quality Commission (CQC) describes a lack of high-quality, person-centred homecare and suitable residential care provisions for people with high support needs, including those with dementia.<sup>17</sup> Whilst we are frequently made aware at Alzheimer’s Society that people often receive basic personal care such as washing and feeding; however, they remain unable to access their community, engage with valued activities that give their life meaning, and remain socially isolated and inactive at home.
- 4.3. Whilst the Covid-19 pandemic, again, has made this issue more acute; for example, Adass’ Winter Contingency Survey<sup>18</sup> found that “49 Councils are, for at least some of the time, taking at least one of the measures needed to prioritise care and assess risk that Directors regard as least acceptable – e.g. prioritising life-sustaining care such as supporting someone to eat, and remain hydrated over supporting some to get out of bed or complete other activities.”

**Recommendation (5):** The UK Government should mandate a minimum set of data relating to quality-of-life measures for people with dementia drawing on care.

**Recommendation (6):** The UK Government should implement mandated minimum levels of evidence-based skills development and training in personalised dementia care for health and social care workers.

## 5. Deprivation of Liberty Safeguards (DoLS):

- 5.1. Article 5 of the HRA guarantees the right to personal liberty and provides that no one should be deprived of their liberty unless it is prescribed in law.<sup>19</sup> Similarly, in international law, these rights are conferred through Article 12 of the CRPD, which states:

*“States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.”*

*“States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”*

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<sup>17</sup> Care Quality Commission (CQC). The state of health care and adult social care in England 2019/20. 2020. Available at: [https://www.cqc.org.uk/sites/default/files/20201016\\_stateofcare1920\\_fullreport.pdf](https://www.cqc.org.uk/sites/default/files/20201016_stateofcare1920_fullreport.pdf)

<sup>18</sup> Adass (2022). Adass Winter Contingencies Survey. Available at <https://www.adass.org.uk/adass-winter-contingencies-survey>

<sup>19</sup> UK Government (1998). The Human Rights Act. Available at: <https://www.legislation.gov.uk/ukpga/1998/42/schedule/1>

5.2. The DoLS were introduced into the Mental Capacity Act (MCA) to provide a legal process for authorising a deprivation of liberty for those who need to be in a care home or hospital for care or treatment but lack the mental capacity to consent to be there, for example as a result of cognitive symptoms of dementia. However, the implementation and application of the DoLS have been widely criticised, including:

- The Care and Quality Commission’s 2020 *State of Care* report found that “despite years of the legislation being in place, there is still huge variation in understanding and practice, and in the quality of training.”<sup>20</sup>
- The latest data shows a significant backlog of applications, with 120,000 outstanding applications, and over 46,000 of these have been outstanding for a year and over.<sup>21</sup>
- Through our Dementia Connect helpline and our Dementia Talking Point online community, people affected by dementia have told us that they encounter many issues with DoLS, including a lack of information about the process and their rights.<sup>22</sup>

In turn, we welcome the forthcoming introduction of the new Liberty Protection Safeguards (LPS) system, which will see the DoLS replaced with the LPS.

**Recommendation (7):** The UK Government must commit to implementing the new LPS system in a timely but effective manner after the public consultation of its Code of Practice.

**Recommendation (8):** A thorough review of the LPS should be carried out after implementation to ensure that it has addressed the issues that exist under the DoLS system. Including whether it is still an adequate safeguard.

## 6. Mental Health Act (MHA):

6.1. Dementia falls within the definition of ‘mental disorder’ used within the MHA, and therefore in certain cases, people with dementia are detained, assessed, and receive treatment under the MHA. Worryingly, people affected by dementia are facing several issues when they encounter the MHA, including:

- The MHA should only be used as a last resort; however, it is unclear in some cases whether the MHA is being used to respond to people’s behaviour rather than to assess and treat them.
- We also know that a lack of mental health services in the community contributes to the number of people with dementia being detained under the Act.<sup>23</sup>
- People often find the process of being detained frightening and confusing, and they are not always meaningfully involved in their care and treatment or provided with information.

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<sup>20</sup> CQC (2020). The State of health care and adult social care in England. Available at:

[https://www.cqc.org.uk/sites/default/files/20201016\\_stateofcare1920\\_fullreport.pdf](https://www.cqc.org.uk/sites/default/files/20201016_stateofcare1920_fullreport.pdf)

<sup>21</sup> NHS Digital (2021). Mental Capacity Act 2005, Deprivation of Liberty Safeguards - 2020-21. Available at:

<https://digital.nhs.uk/data-and-information/publications/statistical/mental-capacity-act-2005-deprivation-of-liberty-safeguards-assessments/2020-21>

<sup>22</sup> Alzheimer’s Society. Your support services. Available at: <https://www.alzheimers.org.uk/get-support/your-support-services>

<sup>23</sup> Alzheimer’s Society (2016). Fix Dementia Care: NHS and care homes. Available at:

[https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/fix\\_dementia\\_care\\_nhs\\_and\\_care\\_homes\\_report.pdf](https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/fix_dementia_care_nhs_and_care_homes_report.pdf)

- Due to a lack of appropriate settings, we are increasingly finding that people are detained under the act in hospitals and institutions far away from their families and thus depriving them of their Right to Family Life under the HRA.

**Recommendation (9):** The UK Government must invest in the workforce to ensure that the Mental Health Act is being utilised and implemented appropriately.

**Recommendation (10):** The UK Government must develop sufficient regulation and data to ensure that there are the appropriate levels of oversight of the Mental Health Act's implementation.

7. *Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders:*

- 7.1. During the first wave of the pandemic, we heard a number of concerns from people affected by dementia in relation to DNACPR orders. People told us they received letters from their GP surgery informing them that they were now under a DNACPR order due to their dementia diagnosis, and in other cases, people in hospital for minor conditions were being asked about their feelings about DNACPR or having DNACPR orders placed on them solely due to their dementia diagnosis and not an individual clinical decision. This is reflected in the review<sup>24</sup> conducted by the CQC into how DNACPR decisions were made during the pandemic. Their research found that professionals felt conversations were often taking place at a much faster pace during the pandemic, and carers often felt these conversations came 'out of the blue'. Some people had even been discharged from hospital with a DNACPR order of which they or their families were unaware. Some families stated that they had been pressured into agreeing to these decisions. There was also blanket application of DNACPRs orders applied to groups of people, including people with dementia.<sup>25</sup>

**Recommendation (11):** We would echo the sentiment contained within the MCA Annual Forum Chair's Report<sup>2627</sup> that conversations about DNACPR must be approached sensitively as part of wider discussions around advance care planning, be appropriately monitored and clinically appropriate to the individual, rather than guided by economic expedience

**Recommendation (12):** The UK Government should support and resource professional training on advance decisions for those staff involved in such processes.

**Recommendation (13):** Government, health, and social care stakeholders should all be supporting advance planning within systems on advance decisions and more end of life discussions taking place at an earlier stage.

8. *Visiting restrictions in care homes:*

<sup>24</sup> CQC (2021). Protect, respect, connect – decisions about living and dying well during COVID-19. Available at: [Protect, respect, connect – decisions about living and dying well during COVID-19 | Care Quality Commission \(cqc.org.uk\)](https://www.cqc.org.uk/publications/protect-respect-connect-decisions-about-living-and-dying-well-during-covid-19)

<sup>25</sup> British Medical Journal (2020). Some care home residents may have died because of blanket DNR orders, says regulator. Available at: <https://www.bmj.com/content/371/bmj.m4733>

<sup>26</sup> National Mental Capacity Forum (2022). Chair's annual reports 2020 – 2021. Available at: <https://www.gov.uk/government/publications/national-mental-capacity-forum-chairs-annual-report-2016?msclkid=9f25972baabd11ecb22a2bacc66f8d43>

<sup>27</sup> Human Rights Joint Committee (2022) Protecting human rights in care settings. Available at: <https://www.parliamentlive.tv/Event/Index/dd9f7454-4672-4ac7-b070-0ed9d2b26f14>

- 8.1. Article 8 of the HRA protects an individual’s right to “enjoy family relationships without interference from government.”<sup>28</sup> Similarly, rights are conferred under Article 23 of the International Covenant on Civil and Political Rights.<sup>29</sup>
- 8.2. However, during the pandemic, visiting restrictions in care homes meant many people with dementia went without face-to-face contact with loved ones for many months. The impact of this lack of meaningful contact has been linked to worsening symptoms, deterioration in the condition, and possibly even deaths. Our inquiry found that 79% of 128 care home managers surveyed reported a lack of social contact was causing deterioration in the health and wellbeing of their residents with dementia.<sup>30</sup> We recognise that the pandemic led to an unprecedented impact on all citizens’ human rights to enable public health protection. However, people with dementia have been slower to regain the same rights as wider society. Thanks to Alzheimer’s Society campaigning, essential caregivers have been enabled to maintain visits to care homes even during outbreaks of Covid-19. This is vital as often; family are the only people who can support someone with dementia to eat and drink, maintain their hygiene or engage with the world around them.

**Recommendation (14):** In light of the above, we are deeply concerned about the Government’s decision to end free Covid-19 tests to care home visitors. Alzheimer’s Society recommends that lateral flow tests should continue to be provided for those visiting care homes for free to ensure that people can see their relatives while managing the risk of Covid-19.

## 9. Access to healthcare

- 9.1. Under the CRPD, Article 25<sup>31</sup>, “States Parties shall”:

*“b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons.”*

- 9.2. However, during the pandemic, people in care homes struggled to access healthcare – 75% of the care homes we surveyed in May 2020 said that GPs were reluctant to visit residents.<sup>32</sup> Being unable to access healthcare early on means that the person’s condition is likely to deteriorate further, and they are more likely to present to acute services when they reach crisis point.

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<sup>28</sup> Equality and Human Rights Commission. Article 8: Respect for your private and family life. Available at: <https://www.equalityhumanrights.com/en/human-rights-act/article-8-respect-your-private-and-family-life>

<sup>29</sup> UN General Assembly (2007). Convention on the Rights of Persons with Disabilities. Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

<sup>30</sup> Alzheimer’s Society. (2020) Thousands of people with dementia dying or deteriorating – not just from coronavirus as isolation takes its toll. 2020. Available at: <https://www.alzheimers.org.uk/news/2020-06-05/thousands-people-dementia-dying-ordeterioratingnot-just-coronavirus-isolation>

<sup>31</sup> UN General Assembly (2007). Article 25 – Health. Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-25-health.html>

<sup>32</sup> Alzheimer’s Society (2020). Worst Hit: Dementia during Coronavirus. Available at: <https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf>



**Recommendation (15):** The British Geriatrics Society has been campaigning to improve residents’ access to healthcare and is calling on the NHS to work with care homes to roll out and fund programmes to enable enhanced healthcare services to be provided in all care homes<sup>33</sup> – Alzheimer’s Society is supportive of this call.

10. *Discharge of patients with Covid-19 to care homes*

10.1. Article 12 of the ICESCR<sup>34</sup> states the following positive obligation:

*“(c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases”*

10.2. Despite this, during the Covid-19 pandemic, between the 17<sup>th</sup> March and the 15<sup>th</sup> April 2020, around 25,000 people were discharged from hospitals into care homes.<sup>35</sup> It is unknown how many of these people had COVID-19 at the point of discharge, as testing of people being discharged was not required until 16th April.<sup>36</sup> The House of Commons Public Accounts Committee concluded that ‘discharging patients from hospital into social care without first testing them for COVID-19 was an appalling error’.<sup>37</sup> This may well have placed residents and staff within the care homes at greater risk of COVID-19 and may have contributed to the number of care homes that experienced an outbreak. It is also worth noting that, in broader terms, “Of the 73,766 people who died from COVID-19 in 2020, almost 25% (18,420) also had Alzheimer’s disease or another disease that causes dementia.”<sup>38</sup>

**Recommendation (16):** There is a need for policymakers to learn from the motives and beliefs that led to such decisions being taken and ensure that these actions are never repeated.

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<sup>33</sup> British Geriatric Society (2021). Ambitions for change: Improving healthcare in care homes. Available at: <https://www.bgs.org.uk/resources/ambitions-for-change-improving-healthcare-in-care-homes>

<sup>34</sup> UN General Assembly (1966). International Covenant on Economic, Social and Cultural Rights. Available at: [https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtmsg\\_no=IV-3&chapter=4](https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtmsg_no=IV-3&chapter=4)

<sup>35</sup> House of Commons Public Accounts Committee (2020). Readying the NHS and social care for the COVID-19 peak. Available at: <https://publications.parliament.uk/pa/cm5801/cmselect/cmpubacc/405/405.pdf>

<sup>36</sup> NHS England and NHS Improvement (2020). Letter: New requirement to test patients being discharged from hospital to a care home. Available at: <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0324-Newrequirement-to-test-patients-being-discharged-from-hospital-to-a-care-home.pdf>

<sup>37</sup> House of Commons Public Accounts Committee (2020). Readying the NHS and social care for the COVID-19 peak. Available at: <https://publications.parliament.uk/pa/cm5801/cmselect/cmpubacc/405/405.pdf>

<sup>38</sup> Alzheimer’s Society (2021). Biggest killer in the UK is now COVID-19, but deaths from dementia remain high. Available at: <https://www.alzheimers.org.uk/blog/research-UK-biggest-killer-high-dementia-deaths#:~:text=Of%20the%2073%2C766%20people%20who,another%20disease%20that%20causes%20dementia.>