

Consultation Response

Department for Health and Social Care Coronavirus: Lessons Learnt

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1. The importance of age

- 1.1 There is a rapidly growing body of evidence that older people are both at greater risk of experiencing severe symptoms and have a lower likelihood of recovery from Covid-19; with the oldest age groups, older men, those living with dementia, and those living with cardiovascular and respiratory conditions at the greatest riskⁱ. There is growing concern that older BAME people are disproportionately represented in hospital cases and fatalities; and it is clear that older people in need of care and support whether at home or in a care home have been rendered exceptionally vulnerable by virtue of their circumstances.
- 1.2 It is clear the response from Government and across public services has had, and will continue to have, a profound impact on almost all aspects of older people's lives. Therefore it's vital that older people are given appropriate consideration in current and future plans, and that we take particular care to balance the desire to safeguard the health of those at greatest risk, the impact of wider risk reduction or containment strategies on the older population and the individual rights of older people. In getting that balance right, we must guard against unwarranted age-based policy approaches and direct or indirect age discrimination.
- 1.3 This submission sets out what Age UK has heard from older people, families and loved ones about the impact the Covid-19 pandemic has had on older people's mental and physical health, access to health and social care services, and how systems must respond in preparation for further Covid-19 waves and the future.

2. The impact of lockdown on older people's physical and mental health

2.1 Older people have been disproportionately impacted by the Covid-19 pandemic. There were 1.4 million older people who were told to shield during the peak of the virus, while everyone over the age of 70 was advised to take extra precautions, including staying inside as much as possible and limiting social interactions. Even as we moved out of the first wave of Covid-19 and restrictions began to be lifted, many older people have continued to be extremely cautious and did not leave their house. Months of staying inside, with limited social interactions, reduced opportunities for physical activity, and limited access to health and social care has accelerated the ageing process for large numbers of older people and taken a huge toll on their physical and mental health.

3. Mobility

3.1 Older people have spent extended periods of time indoors with limited opportunities for movement and exercise. There has been a significant drop in activity levels amongst over 50s and only a third of people aged 75 and over have been active during the pandemicⁱⁱ. This has impacted on older people's mobility, strength, and balance, and left them at greater risk of frailty and falls. Age UK research has highlighted that one in four



older people are unable to walk as far as they could before the start of the pandemic, one in five feel less steady on their feet, and one in three have less energyⁱⁱⁱ. Levels of deconditioning vary among older people, but for some it will be essential that they are able to access rehabilitation services in order to restore loss functionality.

4. Mental health

- 4.1 Prior to the pandemic, one in four older people were already living with a mental health condition, while 1.4 million were chronically lonely^{iv}. Yet, access to mental health services has remained consistently low in recent years, with only 6% of referrals to IAPT (Improving Access to Psychological Therapies) before the pandemic coming from people aged 65 and over^v.
- 4.2 Covid-19 and the policy response to the pandemic has exacerbated this situation. Many older people have seen their mental health plummet, making it more important than ever that historic inequalities in access to services are addressed. Older people should be informed about the types of services which are available to them and encouraged and supported to seek help if they need it. They should also be offered choice in the type of therapy they receive; for some older people, online and telephone support works well, but for other face-to-face services will be needed.

5. Anxiety

- 5.1 We have heard from older people whose anxiety has increased throughout the pandemic and who, in some cases, are experiencing debilitating symptoms, including panic attacks and terror at the thought of going outside.
 - Of the older people Age UK polled, 34% told us they were more anxious now than before the start of the pandemic^{vi}.
 - According to ONS data, 44% of people aged 60 and over feel uncomfortable or very uncomfortable leaving the house because of Covid-19^{vii}.
 - 33% of adults 60 and over are reporting high levels of anxiety^{viii}
- 5.2 Older people living with long-term health conditions or who were advised to shield have been particularly impacted. Severe anxiety is twice as common among those who have been shielding than those who have not^{ix}, with older people telling us that continuous messages of increased vulnerability mean they are living in fear of contracting Covid-19.

6. Low mood and depression

6.1 We have heard from older people who have lost pleasure in their lives and are experiencing low mood and depression. Rates of depression among over 70s have doubled since the start of the pandemic^x and in Age UK polling 36% of older people told us they have lost motivation to do the things which they used to enjoy^{xi}. For some, low mood has now progressed to self-neglect, with older people telling us they do not want to get out of bed in the morning, get dressed, wash or eat. Sadly, a minority of older



people have also told us that they are unable to cope with the situation and are now considering suicide.

7. Loneliness

7.1 The closure of clubs, activities, and volunteering, together with restrictions on meeting up with friends and family, has also left some older people overwhelmed by loneliness. One in five older people (21%) say they either feel lonely all the time or some of the time, while 14% say they are spending too much time alone^{xii}. We have spoken to older people who have gone days without talking to anyone and feel unloved, uncared for, and forgotten. Increased loneliness has led to a surge in demand for our Silver Line helpline with a 31% increase in calls since the pandemic began^{xiii}.

8. Cognitive decline

8.1 We have heard from older people and their loved ones that reduced social contact and mental stimulation is leading to cognitive decline. One in five older people told us they are finding it harder to remember things, while friends and family have raised concerns that their loved ones are becoming confused and repetitive^{xiv}.

9. Reduced access to healthcare

- 9.1 At the start of the pandemic, NHS resources were redirected to support patients with Covid-19 and, for the most part, treatment was cancelled, postponed, or conducted remotely. As a result, some older people have been unable to access the support they desperately need.
 - A fifth of older people living with multimorbidity's say they have not had access to the community care services, social care, and support from health professionals, which they have needed during the pandemic^{xv}.
 - One in six people over the age of 50, equating to 3.6 million people, have had their treatment or surgery cancelled. For people over the age of 70 this increases to one in five^{xvi}.
 - One in ten older people have been unable to visit or speak to a GP when they have needed to^{xvii}.
 - One in three older people say that Covid-19 is affecting their access to healthcare and treatment for non-coronavirus related issues^{xviii}.
 - Nine in 10 carers of people with dementia state that the person they care for has experienced disruptions to their health and social care, including accessing GPs, dentists, and chiropodists^{xix}.
- 9.2 This has left older people in pain, with worsening symptoms, and deteriorating health. In addition to the physical side-effects, older people have told us they are feeling anxious about their health and worried there will be irreversible implications of not receiving



timely treatment. This anxiety has been compounded by a lack of communication and clarity about when appointments and treatment will be rescheduled.

9.3 As we move into the second wave of the pandemic, older people requiring healthcare face extensive waits and are at risk of being deprioritised once again. Waiting lists for NHS treatment have reached a 12-year high, with nearly two million patients waiting 18 weeks for treatment and 110,000 waiting for routine care for more than a year. It is vital that NHS England are provided with the resources they need to manage this backlog of care and that steps, such as Covid-light hubs, are introduced to ensure non-Covid related healthcare can continue as far as possible. Older people who are waiting for healthcare must also be kept informed about the progress of their treatment, to reduce anxiety and provide assurance that they have not been forgotten or removed from the system.

10. Restoring older people's confidence in the NHS

- 10.1 During the first wave, 14% of older people who needed community health and social care services did not try to access them^{xx}. Meanwhile, Age UK research has revealed that 40% of older people feel less comfortable going to a GP appointment than before the start of the pandemic, while 47% feel less confident going to a hospital^{xxi}. NHS England's Help us to Help You Campaign is important in helping older people to understand that services are still open and available, but the NHS should also proactively engage patients living with significant health needs, who are at risk of falling through the gaps.
- 10.2 In 2019 the NHS Long Term Plan set out plans for an ambitious programme to address the serious long-term deficits in provision of services for older people living with frailty and/or multiple health conditions. It recognised the combination of the lack of proactive, co-ordinated community-based services and the inability of the system to swiftly and effectively respond in the event of a crisis too often meant older people ended up in hospital for prolonged periods: both a poor outcome for individual older people and an ineffective use of healthcare resources. The Ageing Well programme was established to roll out a three-pronged approach including: anticipatory care, urgent community response and rehabilitation, and enhanced care in care homes. As well as precipitating a significant decline in older people's mental and physical health, the Covid crisis has also once again highlighted the major deficiencies in our approach to caring for older people. It is therefore clear that building better and more robust approaches to supporting older people must be an essential part of the NHS's response and recovery.

11. Remote consultations

11.1 Prior to the pandemic it was estimated that 95% of GP appointments were conducted face-to-face, whereas since Covid-19, 85% of appointments have been delivered remotely^{xxii}. While virtual appointments have worked well for some older people, we have heard from many who feel uncomfortable discussing their feelings over the phone and



are worried that doctors will be unable to accurately diagnose them. Some older people face additional challenges, such as hearing problems or communication difficulties, which makes virtual consultations near on impossible, while others do not have the technology, or the skills needed for remote consultations. To avoid additional barriers for older people, it is essential that GPs continue to offer face-to-face appointments for those who need them.

12. The impact of health inequalities

- 12.1 The COVID-19 pandemic has exacerbated pre-existing health inequalities and there are differences among older people in how the pandemic has been experienced. Older people told us that their personal circumstances, such as not having a garden or space or experiencing financial worries on top of the pandemic, were making their experience of lockdown much more challenging. Older people from more disadvantaged socioeconomic grades have been more severely affected, both mentally and physically.
 - 41% of people from more disadvantaged social grades say they feel less motivated to do the things they used to enjoy compared to 30% of those from the most advantaged
 - 39% of people from more disadvantaged social grades say they have less energy compared to 26% of those from the most advantaged
 - 39% of people from more disadvantaged social grades say they have less energy compared to 26% of those from the most advantaged

13. The impact of the pandemic on older BAME people

- 13.1 Since the beginning of the coronavirus pandemic in the UK there have been indications that our BAME population have been more at risk of the worst consequences of coronavirus than the white population. The Intensive Care National Audit and Research Centre (ICNARC) collects information on people in hospitals across England, Wales and Northern Ireland who are seriously ill with coronavirus. They have found that 34% of people who have been admitted to critical care in the UK with coronavirus were BAME. The chances were much higher for BAME people than expected: if BAME and white people had the same chances of being admitted to critical care, only 22% of those admitted would have been BAME. They also found that BAME people were more likely to die in critical care: 39% of white people died compared to 45% of Asian people and 42% of black people^{xxiii}.
- 13.2 This has also been shown to be true in care homes, where BAME people are more likely to have died from Covid-19: the Care Quality Commission found that Covid-19 was responsible for 54% of deaths among black people and 49% of deaths among Asian people in April and May, compared to 44% of deaths among white people^{xxiv}.
- 13.3 The reasons behind this increased risk are complex and multi-faceted. Some evidence has suggested that there may be a greater chance of BAME older people catching coronavirus because of their living situation or family circumstances. For example, evidence suggests that BAME pensioners are more likely than white people to have family who are in key worker roles^{xxv}.



- 13.4 Other evidence from the Office for National Statistics (ONS) suggests that people living in households with fewer other people may have been less likely to catch coronavirus than people living in larger households^{xxvi}. While the majority of older people in the UK either live alone or with a partner, older people from most BAME groups are more likely than white older people to live in larger, multigenerational households. For instance, less than 2% of white people aged 70+ live in multigenerational households, while 56% of Bangladeshi, 35% of Pakistani, 13% of Indian, 11% of Black African and 6% of Black Caribbean people aged 70+ do^{xxvii}. Living in a multigenerational household means older people are more likely to be living with someone who is going out to work, and so at higher risk of catching coronavirus.
- 13.5 Differences in risk after catching Covid-19 must partly be due to the inequalities in health we see across the population. BAME people are more likely to have some of the underlying conditions, including obesity, diabetes, and heart disease, which increase the chances of the worst outcomes from coronavirus. These health inequalities, which are exacerbated by coronavirus, are due to experiences of social and economic inequalities, and racism, across BAME people's life courses.
- 13.6 Despite not telling the full story, the evidence available so far shows clearly that BAME older people are at higher risk of catching coronavirus than white older people, and suggests that they are at greater risk of dying from it once they have caught it. It is essential that we learn from the experiences of older BAME people during the first wave and take proactive steps to ensure that older BAME people do not experience the same disproportionate impact again.

14. The impact of the pandemic on the social care system

- 14.1 The challenges faced by the social care sector before the coronavirus pandemic were deep rooted and systemic. The system had struggled for many years with a lack of investment from central government while older people's social care needs continued to become more complex, and demand increased.
- 14.2 Over the last decade, a series of deep financial cuts and only short-term cash injections aimed at easing pressure rather than restoring the system, led to significant market instability, poor workforce retention and insufficient capacity in the system. The impact of this has been felt by millions of older people who have had to manage without the support they need, relying on a system unable to meet their needs.
- 14.3 As a result, prior to the pandemic we were witnessing levels of unmet need rising steeply for all older people, irrespective of their access to formal or informal care or their ability to fund care. We estimated that 1.6 million people over age of 65 nearly one in seven are struggling without all the help they need to carry out activities of daily living (ADL) essential everyday tasks, such as getting out of bed, going to the toilet or getting dressed^{xxviii}.
- 14.4 Since the pandemic in March, older people's needs have changed, and many have



reported a deterioration in their physical and mental health. Age UK research suggests that older people who previously did not need support to maintain their independence, are now requiring care and support for the first time, and much earlier than would have otherwise been the case. It has also told us that those who were already struggling to carry out Activities of Daily Living, such as walking, eating, showering, and getting dresses are now finding things harder. In fact, two in five (39%) older people who were already finding it hard to walk short distances told us this is more difficult for them; one in three (33%) older people who struggled to get up and down the stairs say this is now harder; and two in five (41%) older people who already found it hard to clean their house say this is now more challenging^{xxix}.

- 14.5 Our research and insight also suggest that people living with dementia have suffered greatly during the pandemic as regular routines have been turned upside down and there have been restrictions on spending time outside of the home. Families have told us that they have seen a significant decline in their loved one's cognitive function, which has led to memory loss and changes to behaviour. The Alzheimer's Society recently reported that 46% of people with dementia that they surveyed reported that lockdown had a negative impact on their mental health^{xxx}.
- 14.6 It is also the case that informal carers have taken on a significant caring responsibility since the start of the pandemic, with many stepping up to provide care to a loved one. This has meant that the number of people providing care has grown significantly Carers UK recently estimated the number of carers had grown by 4.5 million people since March. Carers are now providing more care than ever before, with 81% of carers reporting an increase in the care they provide and 78% reporting that the needs of the person they care for have increased since the start of the pandemic^{xxxi}. Family and friends caring for loved ones with dementia report spending 92 million extra hours caring^{xxxii}.
- 14.7 As well as higher levels of caring, carers themselves are seeing a worsening in their health and wellbeing, with Carers UK reporting that two thirds of carers have seen their mental health worsen as a result of the pandemic and only 50% feeling as though they are able to manage their caring role^{xxxiii}. For family and friends caring for loved ones with dementia, The Alzheimer's Society report that 95% of carers in their survey told them their mental or physical health have been negatively impacted because of additional caring pressures.
- 14.8 Changes to the physical and mental health of older people and their carers paints a particularly concerning picture of the impact that the pandemic will have had on the levels of unmet need. The system was already unable to meet significant levels of unmet need, and it is difficult to see how it will manage an increasing demand in the coming months and years.
- 14.9 The long term precarious financial position of the sector has been well documented, and with rising levels of unmet need, alongside decreasing nursing care capacity and an unsustainable burden on informal carers, there was already an urgent case for reform.



- 14.10 The coronavirus pandemic has only put more pressure onto the social care system and revealed the true extent to which the issues outlined above have had on the system's ability to respond and protect older people at a time of crisis.
- 14.11 The financial challenges to the sector have only been exacerbated during the pandemic. Despite funding to the sum of £3.7billbeing made available for local authorities to help them support the social care sector to respond to COVID19 pressures and the £1.1billion Infection Control Fund to support care homes with infection control measures to March 2020 and £588 million for hospital discharge^{xxxiv}, providers are still reporting significant concerns to the financial viability of their service.
- 14.12 It is likely that these financial pressures are being caused by a wide range of unplanned costs that care providers were in no place to manage. Many have faced significant increases to the amount of PPE they have needed to purchase and inflated purchase prices. Some reports have suggested that PPE costs have increased twelve-fold since the start of the pandemic^{xxxv}.
- 14.13 Others have faced a significant reduction in the demand for their services as older people particularly self-funders chose to cancel their care packages due to concerns about transmission of the virus. A UKHCA survey indicated that about 1.2 million domiciliary care visits had been cancelled over a two-week period in April^{xxxvi} and recent reports suggest the capacity of care homes has now fallen below 75% of usual capacity since March 2020^{xxxvii}. Further, recent polling suggests that around 40% of people over the age of 65 are less likely to seek residential care services following the coronavirus pandemic^{xxxviii}. This is extremely concerning for the financial viability of care providers now and in the longer term.

15. The impact of the pandemic on older people in receipt of social care

- 15.1 From the outset of the pandemic it was clear that care providers would face an uphill battle to protect services users and contain the virus. The vast majority of older people in need of care and support will be living with multiple long-term conditions and frailty and are among the most vulnerable to the effects of this virus. They are also rendered more vulnerable by virtue of their circumstances. Nearly all will be receiving intimate personal care with no possibility of social distancing; and in the case of care homes, residents are living in group settings where the virus can easily spread.
- 15.2 Yet despite early indications from the sector that swift action was needed, Government did not publish a strategy until April 16th, by which time the virus had already taken hold and fatalities were rising^{xxxix}. Many in the sector have also criticised the timeliness, clarity and adequacy of the guidance that has been issued along the way. Fundamentally though, the shortage of PPE and slow and halting progress in organising testing were major contributing factors to the tragedy played out in care homes across the country. While the government's commitment to provide free PPE to the social care sector will help to ensure providers are able to meet infection control measures, it is concerning to hear that providers still report



significant delays in turning around test results for staff and the impact this has on their ability to maintain safe staffing levels.

- 15.3 At the start of the pandemic, many older people in receipt of social care, as well as those living independently in the community, were approached for advanced care planning discussions. Unfortunately, in some cases individuals told us they felt under pressure to agree to do not attempt cardiopulmonary resuscitation (DNACPR) notices and/or to declining the option of being admitted to hospital in an emergency. We have also seen examples of blanket policies being put in place around DNACPR, escalation, admission, and treatment criteria. While we were pleased that the Government and NHS England made clear that such approaches are unacceptable, we are aware that certain policies and practices persist locally. Advanced care planning is an important tool to support people to discuss and record decisions about their care, however this crisis has revealed a deeply concerning lack of systematic training and awareness of how these tools should be appropriately used.
- 15.4 Despite tremendous efforts on the part of those working in the care sector, the tragic result of so many outbreaks of the virus across care homes has meant that 18,986 care home residents over the age of 65 died due to Covid-19 in the space of 14 weeks, from 2nd March to 12th June 2020^{xl}. On top of this, between the 10th April and 19th June, there were 819 deaths of recipients of domiciliary care attributable to Covid-19, although it is possible this figure could be higher given domiciliary care recipients have been much less likely to have their death attributed to Covid-19 than care home residents^{xli}.
- 15.5 Data has also begun to show us that throughout the course of the pandemic, there has been a significant increase in loss of life more broadly for those receiving social care. In fact, between 7th March and 22nd May, the number of people who died in care homes was more than double (110%) the usual number of deaths in care homes^{xlii} and between 2nd March and 12th June, there were 6,523 deaths of recipients of domiciliary care; this was 3,628 deaths higher than the three-year average, so double the number of deaths than would usually be expected^{xliii}.
- 15.6 Weekly data published at the time of writing this submission suggests that the number of care home residents dying from Covid-19 has been increasingly continuously since the week ending 4th September when 17 people died in their care home due to Covid-19. In the most recent week, this had risen to 389 ^{xliv}.

16. Restrictions on visiting in care homes

- 16.1 As the pandemic has continued to hold its grip on the nation, residents of care homes and their loved ones across the country have largely been unable to spend time together and essential informal carers have been unable to provide vital care. For many it has now been more than nine months over 200 days since they have seen their loved one in person.
- 16.2 We have closely observed the effect of this, with relatives witnessing the rapid deterioration of those they love and for many witnessing a loved one ultimately dying



sooner than would have otherwise been the case. In a recent Age UK survey, extremely concerned relatives shared with us the devastating impact that separation had had on their loved ones physical and mental health, with most telling us that the deterioration experienced by their loved one was now irreversible^{xIv}. The Alzheimer's Society have also reported that 82% of people with dementia have seen an increase in symptoms since the start of lockdown, including memory loss, difficulty concentrating and an increase in restlessness and agitation^{xIvi}.

- 16.3 While some families were able to benefit from the easing of restrictions over the summer months, spending time with their loved ones in a garden, or through a window, many have not. A recent Age UK survey suggested that 70% of residents and relatives who responded had not been able to visit since the start of the pandemic^{xtvii}. This has meant that hundreds of thousands of older people and their immediate family and friends are unable to see their loved ones, effectively split apart, powerless to provide essential physical and emotional support to the person they care for.
- 16.4 While there must be a rigorous approach to balancing the risk of a coronavirus outbreak in a care home, especially given the catastrophic suffering and loss of life in the first wave of the pandemic, so must the approach to enabling in person contact between loved ones. Everything must be done to ensure that care homes and their residents are able to make individual assessments about risk, including the ability for providers to carefully manage 'visits' to reduce the risk of the virus spreading, while prioritising the emotional well-being of residents.
- 16.5 We welcome the Prime Minister's recent commitment that every care home resident will be able to have two continuous visitors, who are tested twice weekly and will be able to visit someone in person. There are still a number of fundamental steps that can be taken by government to enable visiting and contact between loved ones, acknowledging coronavirus is not going away quickly. These include:
- Public liability indemnity for care providers, particularly given care home providers are under very real pressure from the tightening insurance markets.
- Investment into built environments to minimise the risk of visiting. There are hundreds of creative schemes being enacted across the country – let's 'ramp' this up with, if necessary, some targeted capital investment, so every home has a space they can use to keep people safely connected.

17. Looking to the future for social care

17.1 Alongside working closely with the sector in preparation and during further waves of the pandemic, it is vital that the Government accelerates plans for system-wide reform. It must support the sector to recover from the effects of the pandemic, equip it to protect the health and wellbeing of older people in the longer term and establish a new and higher standard for what older people and their families can expect from their social care. The interdependency of the NHS and social care has been manifest during the pandemic so this emphasises the need for reform. In addition, the moral case for Government, on behalf of us all, to act to make good the deficits that have been laid bare is even stronger than it was before. Older people in receipt of care, in



care homes especially, have been catastrophically let down and many have died before their time as a result. The fact that similar tragedies have unfolded in other countries too is no consolation and no excuse.

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