Report of the Social Care Taskforce's Older People and People Affected by Dementia Advisory Group

- There have been over 50,000 deaths from COVID-19 in England & Wales
- 9 in 10 of those who died were over the age of 65
- More than 1 in 4 had dementia
- 2 in 5 were living in a care home at the time – most of whom will have died without seeing their family again[1,2].

These dismal statistics tell the story of what has happened to far too many people[1] during the pandemic to date. They are why we must take urgent action to ensure a similar tragedy does not occur this winter.

In March 2020, the Government wrote to about 1.5 million people with various respiratory conditions, certain cancers, immunodeficiency diseases and a range of other conditions, noting that they were particularly vulnerable to COVID-19 and should therefore 'shield' Dementia, multi-morbidity and frailty were not however considered to make you clinically vulnerable to COVID-19 and so those with a dementia diagnosis or in a fragile state of health were not told to shield themselves, either then or since.

Ageism and lack of understanding about dementia have together undermined efforts to support and protect people. Looking forward, to rebuild public confidence the Government should publicly commit to the notion that every older person and person living with dementia matters. An excellent way of demonstrating good intent would be to commission a rapid evidence review, to establish why these people are at so much greater risk from COVID-19 and how they may best be treated and cared for in the event of contracting the virus. Given it is abundantly clear that risk is greatest for the people who are the focus of this report, the fact that policymakers have not yet required such an analysis to be carried out is profoundly depressing.

It is imperative that the basic foundations of safe care are firmly in place

The Government must ensure that the basic foundations of a safe and secure system of social care are in place by the autumn; otherwise, nothing else we do will keep people safe:

- All care settings and providers must have sufficient PPE; given the prohibitive cost there is a compelling case for the Government to fund it, including for private sector providers and all working with self-funding clients
- There must be regular and ongoing testing of care staff and care recipients
- The testing regime must be reliable and timely in its operation and resultant data must be shared with relevant NHS bodies and professionals, as well as providers

[1] Throughout this report 'people' means 'older people and people affected by dementia' unless stated otherwise

- The flu vaccination programme must be unparalleled in its scope and ambition, and reach out to all social care staff and recipients in all settings, and informal carers too, supported by mass marketing
- The financial resilience of care providers must be kept under constant review, with plans in place and regularly updated by CQC, central and local Government, to mitigate any significant market failure
- Total and available care capacity should be published weekly
- The ongoing challenges in data sharing and data governance between health and social care settings must be resolved by September 2020

A. Restoring and sustaining contact with visitors in care homes

Conclusions: We heard that the Government's Visiting Guidance[3] is failing to enable many residents to stay in contact with loved ones.

> *"Due to lockdown and Mum isolating in a care home in West Sussex, as I live in Cornwall I haven't been able to visit her since January and I miss her and she can't understand why."*

The Guidance does not give sufficient confidence to understandably nervous care home managers to 'open up'. Plus, organising and supervising visits consumes staff time and involves senior staff in difficult negotiations with anxious families, so it is easier to 'say no'.

Yet the impact on people of being cut off is utterly catastrophic: visitors fill the gaps in care in understaffed settings, without which residents are at enhanced risk of malnutrition and dehydration; they help people living with dementia to retain their cognitive and verbal skills; they provide familiarity and reassurance as well as providing culture-specific support - especially crucial for those with dementia; for all they give a reason to hope. In the absence of visitors, older people and people with dementia are losing function and capacity and dying prematurely, their last few weeks and months lonely and sometimes frightening, despite the best efforts of staff. This cannot go on: we must change it and ensure it doesn't recur through the winter.

Most care homes have been closed to visitors for 6 months already. Without action to ensure care homes open and remain open to visitors this winter, many care home residents may have experienced a full year without contact with loved ones. This is all the more tragic when you consider that half of all care home residents die within 15 months of admission[4].

> *"I feel extreme guilt that I can't visit my mother properly, she can't understand why I won't enter her care home. I feel distraught watching her cry or refuse to come to the window to see me."*

However, we heard that visits can happen safely and in a way consistent with infection control -

individual risk assessments are crucial to this. When visitors are treated as key workers and 'part of the team', which they essentially often are, it is perfectly possible for them to continue to be in a setting safely, equipped with the requisite PPE and given access to regular testing. New technology may be helpful, such as pop-up pods that can be erected in the garden, or even self-cleaning door knobs, but it is family and friends who make the biggest difference.

Recommendations:

1. The Visiting Guidance should be amended by DHSC: i) to enable and encourage at least one visitor per resident to be classified as a key worker, with the training, testing and PPE they need to be 'part of the team'; **ii)** to require any care home that imposes or reinstates a 'no visitor policy' to inform the CQC, along with the mitigating actions they will take to facilitate ongoing contact in indirect ways (e.g. via video link); **iii)** Performance in enabling safe visiting and meeting cultural needs should also form part of the CQC's inspection framework during the pandemic.

2. DHSC should rapidly co-produce with a small group of care providers and others a highly practical toolkit for care homes on how to implement the Visiting Guidance safely, drawing on best practice.

3. Government funding must be made available to care homes to facilitate safe visiting; this could be through the Infection Control Fund, which should be in place until at least April 2021, or a new fund. Providers should be able to spend the money on extra staff to organise and supervise visits, technology and kit, and PPE for visitors, among other things.

> *"I work full time and this has continued but my caring duties have increased three-fold. I am exhausted, mum is so unsettled and often violent too now."*

B. Restoring care services and assessments

Conclusions: Evidence from Carers UK shows that 70% of unpaid carers are providing more care due to the pandemic and 55% of unpaid carers feel overwhelmed and are worried they are going to burn out in the next few weeks[5].

We heard that during the pandemic home care provision became much patchier for some older people and people living with dementia, with packages sometimes reduced or even removed altogether. A bigger problem still seemed to be people who normally receive home care turning it away, for fear of the infection entering their home via an unsuspecting, asymptomatic domiciliary carer. CQC told us that 6% of commissioned home care is still not being delivered for this reason at present. In addition, a UKHCA survey indicated that about 1.2 million domiciliary care visits had been cancelled over a two week period in April[6].

For people not to receive a care service when they are in need is a recipe for them to deteriorate fast in terms of their health and wellbeing, and also places extra stress on informal carers. An Alzheimer's Society survey found that nearly half of all people with dementia who received a care and support package have had this reduced or stopped since lockdown began[7]. In addition, we were told of long delays and other problems in accessing an assessment for people whose needs had increased during the pandemic, or for those who had developed needs for the first time in recent months. As a result they were going without the care they need.

> *"…her brother, in his 70s, who has a fracture, dementia, and difficulty with walking. He is usually looked after by his son and daughter-in-law but they're self-isolating due to symptoms. He's been trying to cope alone for three weeks without carers and hasn't been able to shower. His sister also worries that he's had some falls and whether he's taking his medication*."

Recommendations:

4. Steps are urgently needed to rebuild the confidence of people who need care at home but who are still too afraid to have services back by: **i)** DHSC and CQC encouraging and supporting providers to roster staff so there are as few different home carers visiting as possible; **ii)** using the Infection Control Fund or another fund to incentivise this; **iii)** co-producing a good practice guide with home care providers, including encouragement to work sensitively and flexibly with informal carers. E.g. one care visit a day from the same paid carer may be better than none at all, if that's all that's achievable within existing staff resources.

5. LAs must reach out proactively to people who withdrew from services and encourage them to reconnect; i) they should work closely with people with personal budgets to try to identify alternative services if the ones they usually rely on remain closed; **ii)** they must ensure that care and carer needs assessments are revised for those with progressive conditions like dementia as quickly as possible, and take urgent steps to clear the backlog of assessments for those with new needs **iii)** Government should recognise the extra costs for LAs in undertaking these tasks and provide additional funding.

> *"I still feel that COVID-19 has robbed me of some of my remaining years living with dementia rather than the years when I will be reliant on other people totally."*

C. Reinstating and sustaining community-based services and support

Conclusions: As a result of local services reducing or closing, over a third of unpaid carers are providing more care[8]. We heard that during the pandemic almost all community support, like group activities and lunch clubs, which keep some fragile care arrangements together, stopped functioning and are yet to start up again. An

Alzheimer's Society survey found that between 34-40% of people with dementia had lost confidence in going out and carrying out daily tasks since lockdown began[9]. This lack of support is creating a real risk of carer breakdown, especially where older carers or carers for people with dementia are concerned. Some of this provision has gone forever because the local charities that ran them have gone bust, or they've survived so far but have had to fold these specific services in the absence of self-funder income and demand, or because local authority funding has been pulled. In some areas new models are being developed to factor in social distancing rules, including 'community hub' models that provide a mix of small group activities and home-based services.

Recommendations:

6. To avert an imminent crisis in community support the Government should encourage LAs to make transition funding available to their providers, usually from the VCS, to adjust or change services to deliver COVID-19 secure services that address the deterioration and change in need over the course of the pandemic.

D. Restoring and sustaining access to health care

Conclusions: We heard of some good practice (e.g. technology used to give care home staff 24/7 access to consultant geriatric advice across a locality) but more often of problems in providing care homes with the ongoing health support they needed during the pandemic, when hospital admissions were discouraged and clinicians physically withdrew. NHS bodies were sometimes naive about how much unqualified and under-trained care workers could do, including providing end of life care to residents dying painfully of COVID-19. Even when palliative drugs were available care staff did not always have the confidence to use them. Other essential supplies, such as oxygen, have remained hard to access. Despite the increased use in virtual consultations, a survey by carehome.co.uk found a fifth of care workers said their care homes have no WiFi. Of those care homes that do have WiFi, access to the service is mixed, with 18% saying WiFi is only available in communal areas[10].

> *"The donepezil began not to work so they put her on something else and she started hallucinating. 3 weeks ago she had to be admitted to our local dementia hospital under a section 2. I found it very hard to take."*

We also heard that many older people and people living with dementia have experienced significant deterioration to their physical and mental health in recent months, at home and in care homes, and that local health services have not yet returned, including visiting services such as podiatry and dentistry. 33% of all calls to

> *"Loss of muscle mass, strength and stability leading to being more wobbly, more risk of falling, and this is due to not being able to leave the property."*

Alzheimer's Society's Dementia Connect support line in July 2020 were related to concerns around an increase in dementia symptoms[11]. We know too that many older people at home are struggling to engage with their GPs, especially if they are not online and find it hard to hear on the phone. We cannot expect these older people and people living with dementia always to ask for the help they need; services need to engage them proactively.

There has been a significant decrease in dementia diagnosis rates from 67.6% in February 2020 to 63.5% in June 2020. This means that more people with dementia are living without a diagnosis, unable to access emotional, practical, legal and financial advice, as well as vital support services and pharmacological and non-pharmacological interventions. These things are even more important at a time when symptoms may be worsened by social distancing and closure of community services.

Recommendations:

7. i) There should be regular monitoring and data collection on the implementation of The Enhanced Health in Care Homes programme by NHSE. **ii)** DHSC should pay for every care home to have Wifi installed and fund tablets and staff training in how to use it, to facilitate ongoing remote consultations with clinicians (this would also support indirect visiting at recommendation 1. above); **iii)** At least for the period of the pandemic, NHSE should ensure that every residential care setting has nursing staff allocated to work in the setting at all times. Nursing returners could be prioritised to fill these roles. **v)** The Anticipatory Care element of the NHSE Long Term Plan's Ageing Well programme should be implemented as quickly as possible, alongside Rehab, following a rapid review of what needs to change because of the pandemic. In addition to people with 'clinically vulnerable shielding status' and those in receipt of formal care services at home, the roll out of these services must capture people living with significant health needs, co-morbidities, dementia and frailty – all of whom we now know are vulnerable to Covid-19. **vi)** National clinical guidance must be issued by NHSE on preventing and reversing deterioration of people's physical and mental health following prolonged periods of lockdown and isolation.

8. DHSC/NHSE must develop and implement a clear recovery plan to ensure the freefall in dementia diagnosis rates does not continue and memory assessment services are enabled to re-open and urgently catch up on waiting lists, particularly among those of BAME heritage who are historically under-diagnosed.

E. Ensuring effective safeguarding

Conclusions: Since the start of lockdown CQC has reported seeing notifications for the application of 'Deprivation of Liberty Safeguards' from adult social care services drop by almost a third (31%) and in hospitals by almost two-thirds (65%)[12]. 18% of all calls to Alzheimer's Society's Dementia Connect support line in July 2020 were related to concerns around care homes[13]. We heard a number of serious concerns

about poor care, neglect and abuse going undetected in care homes and in people's homes, in the absence of the CQC or other services, or visitors going in through the pandemic. Restoring visiting to care homes and services into people's homes will help mitigate these risks.

Poor understanding of DoLS has remained a fundamental issue. This together with the delays and uncertainty over the progress of LPS may mean there is an increasing risk of people being deprived of their liberty without the proper authorisation[14]. Any approach must consider and seek to address the disproportionate use of DoLS on those who are BAME

Recommendations:

9. i) CQC should urgently investigate the reduction of DOLs applications. CQC should use the information gained under recommendation 1 (above) **ii)** to prioritise scrutiny of care homes and other settings that are 'closed' to visitors **iii)** CQC must urgently organise a cross sector meeting to brain-storm ways of sustaining effective safeguarding in care during the pandemic, with a focus on how to sustain open cultures in residential settings at this time.

F. Planning for and managing outbreaks

Conclusions: We were told that collaborative planning across health and social care providers in every LA area will be key to managing a response to a local outbreak, a second wave and/or increased winter pressures. This should include prioritising local capacity for step up and down care and understanding how to best meet the treatment and care needs of people living in residential care. Escalation and contingency plans need to be shared with care recipients, their informal carers and loved ones, and local agencies.

Recommendations:

10. i) PHE should ensure that every social care provider has an escalation plan in place which states clearly what they will do in the event of an outbreak, local lockdown or second wave and detail how this will be shared as proposed above. **ii)** CCGs and Trusts should be required to demonstrate contingency plans are in place to secure appropriate step-down facilities to support people moving safely from hospital or home into a residential setting. **iii)** In the event of a local lockdown or second wave, Every care home should have a designated link officer appointed for them at their CCG and Local Authority and the named above should be charged with co-ordinating and overseeing rapid access to PPE and testing supplies, and support with implementing effective infection control **iii)** NHSE must rapidly publish clinical guidance on best practice treatment and care to people who contract Covid-19 while living in a residential care setting.

Submitted by Age UK and Alzheimer's Society

Acknowledgements

As part of this project we have spoken to and consulted with experts from a range of sectors, including care providers, clinicians, regulators, local government, the third sector, policy professionals and others. We are indebted to all who have shared their time and insights with us these last few weeks. They have told us that there are many lessons from the pandemic and we are confident that if we learn them we can do more to ensure people are better protected and better served between now and April 2021.

This piece of work has also been substantially informed by extensive consultation Alzheimer's Society and Age UK have undertaken throughout the course of the pandemic with people affected by dementia and with older people more generally, including with older carers, and with colleagues who provide services to them.

However, the contents of the report are the responsibility of its authors and involvement in the consultation process should not be interpreted as endorsement or otherwise of the report's contents or recommendations.

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