

Covid-19: the impact on the rights of older care home residents



Brief overview of care home residents

- There are an estimated 400,000 care home residents aged 65+ in the UK
- The majority of residents in both residential and nursing care are over the age of 85
- An estimated 75% of care home residents are living with dementia
- Nearly 50% of care home residents require residential and nursing care specific to their dementia
- 45% of care home residents are self-funders, meaning they pay fully for their social care without state support



Key issues faced by the social care sector before the pandemic

- High workforce vacancies
- Severely underfunded
- Fragile market
- Increasingly complex need of care home residents



Covid-19 has had a devastating impact on older people living in care homes

- In the last 15 months many care home residents have died
- Care home residents have experienced a significant and likely irreversible deterioration in their physical and mental health
- People's dementia has progressed rapidly and many care home residents have lost the ability to recognise their loved ones or communicate verbally
- Many people have not seen their loved ones for 15 months
- Most care home residents have been unable to leave their care home



Protection of care home residents

- Covid-19 presents a very serious risk to older people
- Care home settings rendered residents and staff more vulnerable to the virus
- Care homes were waiting a long time to receive tailored support and guidance
- Care workers were faced with a significant shortage of PPE
- There was limited community healthcare support coming in to the home
- CQC paused routine inspections

“The challenges I face to provide care during the pandemic are a lack of PPE. You had to make face masks last for days and make your own PPE.”

“The strain of trying to keep residents and staff safe with constantly changing guidelines, staff worried about giving the virus to their families. There have been lots of breakdowns with staff in tears.”



The use of blanket DNACPR policies

- Some older people, including care home residents were not involved in conversations about a decision to invoke a DNACPR
- In some cases GPs, CCGs and other health systems approached care home managers to apply DNACPR notices to all residents
- We were pleased that the Government and NHSE made clear such approaches are unacceptable

Age UK was contacted by the husband of an older lady living in a care home at the start of the pandemic. He received a letter from the care home explaining that the GP had told the manager that all residents in the care home must have DNACPR in their care plan – which included his wife and that was official Government policy and not up for discussion.



Access to health care

- Prior to the pandemic care home residents faced barriers to access health care services
- At the height of the pandemic we heard examples of residents being denied access to urgent and emergency care
- Residents and care workers also told us they faced issues around accessing health care for everyday treatment of slips/trips, falls and pain management
- This was an extremely challenging for residential care staff in particular

“Age UK was contacted by a care worker who told us that they felt like their residents were being left to die. They were unable to get the GP to visit the home and they were being asked to insert DNACPR notices into people’s care plans. When they phoned 999 the paramedics were refusing to take their residents to hospital.”



The impact of 14 day isolation period

- Until very recently residents who required medical care outside of the home faced a 14 day isolation period on return
- Some residents are unable to cope, understand or are fearful of complete isolation
- Their physical and mental health has suffered as a consequence of this
- And people have been living in acute pain and severe distress

“My husband has to go to the hospital for treatment every few weeks. After each appointment he has to isolate in his room for 14 days. In this time he is not allowed to see anyone, and this is very difficult for him.”



Access to loved ones

- People have not seen or spoken to their loved ones since the start of the pandemic
- When visits are enabled they are not fulfilling and loved ones feel unable to support someone in the way they feel is necessary
- People have told us about the severe distress people have faced and the irreversible deterioration their loved ones have experienced in this time
- For most care home residents and their loved ones maintaining a connection has been impossible

“My mother is bed bound and totally dependent on others for all needs. The staff are busy so don't have time for anything other than basic needs. My mother had daily visits from me and my father prior to lockdown.”

“I had a mother in residential care, but sadly she died on 9th September. She had mild dementia, and I think she just gave up. She stopped eating and drinking. From March until she died we only saw her the final 2 weeks.”

Ability to leave the care home

- Care home residents have faced more restrictive guidance than the general population
- This has meant that many care home residents have not left the care home since early last year
- We know that some care home residents have wanted to leave the home for a walk or change of scenery, but have been stopped

“I hope we will be able to sit in the garden with mum when the weather is warmer, be able to take her sister to visit her even if its outside and be able to take her a walk in her wheelchair out to the park for an ice cream or cup of tea.”

“I would wish to take my dear sister for a drive and say visit a pond and wild life and let her experience the outside world as before.”



Deprivation of liberty

- Prior to the pandemic there was already long waits for DoLs applications to be processed
- And there continues to be confusion and misunderstanding about how to use DoLs by providers
- There was a sharp fall in the number of notifications CQC received about the outcome of DoLs between March to May 2020. In adult social care services there has been a 31% decline and in hospitals a 65% decline.
- It has been extremely challenging for providers to balance DoLs with Covid-19 guidance



Is there an overuse of anti-psychotic medications?

- We are concerned about whether there has been an increase in the use of prescribed antipsychotic medication to people living with dementia during this time
- We have heard from pharmacists and prescribers anecdotally that there has been an increased in antipsychotic medications
- The pandemic has been extremely distressing for older people experiencing cognitive decline and lacking mental capacity
- We know that care providers have faced significant workforce shortages and in some cases struggled to meet people's needs



Learnings

- Understanding how people living in care homes are supported to assert their rights
- Encourage individuals and systems to consider their assumptions about care home residents
- Think about how we move forward
- Reopening of closed cultures - relatives and loved ones are key
- How to prioritise holistic and fair access to care in unprecedented times

