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Forget me not: dementia in the time of Covid-19

When countries rushed to lock down, they forgot about the needs of the most vulnerable

By Jordan Kelly-Linden

14 July 2020 • 4:59pm



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When the UK went into lockdown in March, Vera paid little attention. Not even a global pandemic could stop her visiting her 91-year-old mother.

Nada was diagnosed with vascular dementia and Alzheimer’s disease seven years ago. While she still lives alone in her home in south Manchester, simple tasks such as going to the toilet or doing her own grocery shopping are now difficult – if not near-impossible – for her to do alone.

Each day, before and after work, Vera pops around to help. Even at the height of lockdown, when the threat of Covid-19 was at its most severe, she didn’t stop visiting her mother.

“It was automatic. I didn't give it a second thought,” says Vera. “If I had abandoned her and left her, she would have gone hungry. She wouldn't be able to cope.

“You have to make a judgement call on the risk of taking in Covid. Only for a split second you think, well which is going to be worse? And I know which is going to be worse: leaving the woman is going to be worse. Getting Covid is minimal really.”

What are the early signs of dementia?

According to the Alzheimer's Society, 850,000 people in the UK have dementia, with one in six aged over 80. There is no cure, but early diagnosis can help ease the symptoms, which include behavioral changes and memory loss.

The symptoms of Alzheimer's can be divided into three main stages. It can take years to progress from mild to serious, and each person will develop them at a different rate.

According to the NHS, the most common early symptom is memory lapses, which may include:

Forgetting recent conversations, events or whereabouts of household items

Forgetting place or object names

Regular repetition or asking the same question several times

Poor judgement and finding it tough to make decisions

Becoming less flexible or resistant to trying new things

There may also be mood changes, increased anxiety or confusion. As the disease develops from the early stage, memory deteriorates further, with names of loved ones harder to recall. Even recognising friends and family can become difficult.

For more details, go to [alzheimers.org.uk](https://www.alzheimers.org.uk)

Nada doesn't know much about what's going on beyond her front door, but that's fine with Vera, she doesn't want her mother to worry. Having a conversation about the coronavirus crisis wouldn't make much sense anyway.

Last month Nada fell and broke her wrist. In a bad week, convincing her mother to keep her brace on can be a bit of a battle. At times being her sole carer has left Vera in tears: "It's just quite a difficult disease to deal with," Vera says.

"Everyone says it, because it's still her but without the lovely fuzzy warm bits of your mum. That just makes it tough."

Vera and her mother aren't alone. Globally more than 50 million people have dementia and one new case is diagnosed every three seconds. While it is those with the disease that arguably suffer the most, families and carers do not emerge unscathed, and the [pandemic has only made life more complicated](#).

When Spain declared a state of emergency in mid-March more than 300 dementia associations were forced to cease their specialised services and support. As partial lockdown hit Australia, Dementia Australia soon found that social isolation brought on by coronavirus restrictions only exacerbated feelings of anxiety and loneliness among sufferers.

While in India, where an estimated 90 per cent of dementia cases already go undiagnosed, one of the world's strictest lockdowns coupled with inadequate healthcare saw many older people left hung out to dry.

'We're powerless': Care home staff open up about coronavirus deaths



[Global shutdowns](#) have made it much more difficult for the elderly to access help and social care across the board, but, in some countries, policies designed to keep others safe have put older people in more danger.

“There are stories of people with dementia who live alone and therefore without support who were found wandering the streets in France,” says Paola Barbarino, chief executive of Alzheimer’s Disease International (ADI).

“Other stories from the Caribbean have come about people feeling scared by their carers wearing masks.”

When countries rushed to lock down they forgot about the needs of these vulnerable people, says Ms Barbarino.

“Right from the start, it was pretty clear that there were going to be issues with people caring and living with dementia,” she says, citing examples from the Philippines where dementia sufferers infected with Covid-19 were denied hospital treatment.

“There are people in our society whose memory is not strong enough to remember, not strong enough to understand that this is the change of situation,” she says.

“Governments rightly have to use very blunt instruments sometimes. But a number of these broad brush decisions have been very shocking,” she says.



A resident of St Cecilia's Nursing Home in Scarborough having a socially distanced reunion with her son | CREDIT: Simon Townsley

Stark statistics show that in countries with community transmission of Covid-19, more than 40 per cent of the total confirmed coronavirus deaths occurred in [long-term care facilities](#).

In some cases, it is closer to 60 per cent, according to the WHO. In the UK alone, more than 11,000 people diagnosed with a form of dementia died from Covid-19 between March and

May. That's equal to more than 25 per cent of all Covid related deaths.

Sandra's 88-year-old mother, Mary, was one of them. Her care home in Drumchapel, Scotland went into lockdown the week before Boris Johnson enforced a UK-wide shutdown on 23 March, but that wasn't enough to stop her mother contracting the virus. Mary suffered from vascular dementia and had lived at the Almond Court nursing home for three years.

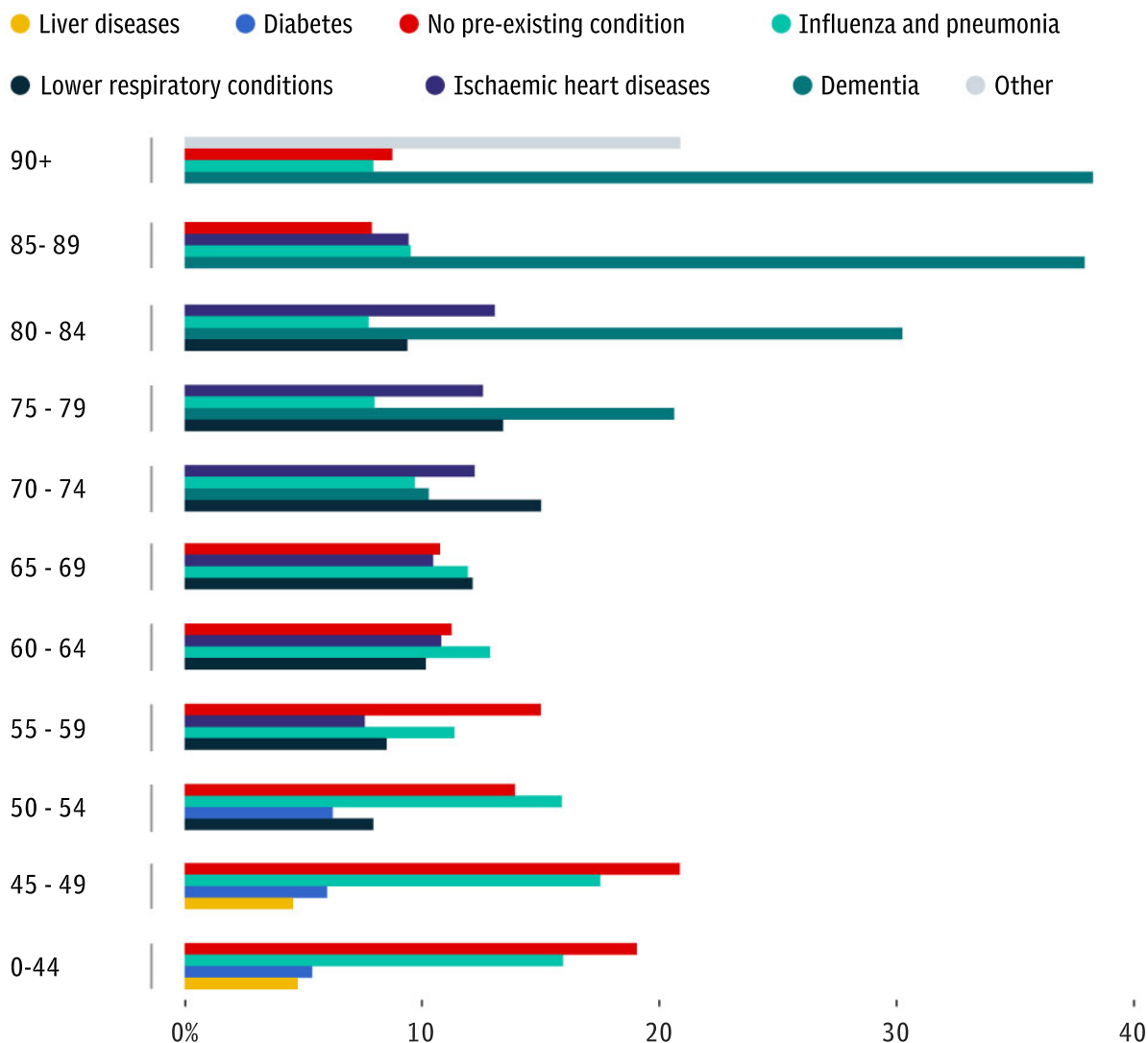
Sixteen days before she died, a fellow resident returned from hospital with suspected Covid-19 symptoms.

"She was abandoned. That's how I see it," says Sandra, who believes her mother was deprioritised and denied hospital treatment due to her age and underlying health conditions.

"Even though she had vascular dementia, she was actually quite robust," she says. "She'd had a Do Not Resuscitate order since the very beginning of her stay. But twice she had been hospitalized and treated; once for something that was a bacterial infection. On this occasion she was never given the opportunity to get oxygen or anything."

A quarter of all Covid-19 deaths between March and May were linked to dementia or Alzheimer's

Main underlying conditions of coronavirus victims in England and Wales between March and May



SOURCE: ONS

The GP did administer morphine, but only in the few hours before her mother's death, says Sandra. "It just seems horrific," she says. "She was struggling. If she had got oxygen or pain relief, it would have been a much better death."

Sandra's case has since been raised in Holyrood and a public inquiry into the Scottish government's decision to [discharge older people from hospitals to residential homes without being tested for Covid-19](#) is underway.

And it's not just in Scotland where these decisions are being questioned. In the UK as a whole [16,000 care home residents have died from coronavirus to date](#). Many commentators believe

the coronavirus crisis has exposed the neglect of care homes as a sector - in its rush to shield hospitals the government forgot about the most vulnerable in society.

“To be frank, I was just flabbergasted that in the UK, nobody was thinking about Covid-19 being a threat to care homes,” says Paola Barbarino from ADI. “In Italy and in Spain, the evidence was very strong that care homes were really the foci of the disease.”

“We could have had a two weeks advance notice on this and started taking some measures but nothing happened and therefore we are where we are,” Ms Barbarino says.

As parts of the world begin to emerge from lockdown we may actually see rates of dementia begin to increase as evidence emerges that one of the [long-term complications of Covid-19 is cognitive impairment](#). So, the need for better dementia care will be more urgent than ever.

**Paola Barbarino spoke at a webinar organised by Qatar Foundation’s Education City Speaker Series, in partnership with the World Innovation Summit for Health.*

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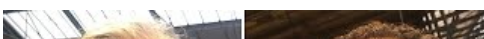
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