**Our right to spend time with loved ones is being cruelly violated by the government**

*[Nicci Gerrard](https://www.theguardian.com/profile/niccigerrard) The Guardian Sun 13 Sept 2020*

Just as I sat down to write this piece, my phone rang. The woman’s voice was thick with distress. She didn’t want her name to be public, didn’t want practical help; she just wanted to tell her story to someone and she didn’t know who would listen and who would care.

Her husband, to whom she has been married for 57 years, has dementia and is in a home. Before lockdown, she visited twice a day, spending hours with him, kissing him, hugging and holding him. He is at a stage of his dementia where it can be hard to have a conversation, but, she says, “he understands affective language” – the language of touch, of physical presence and affection. People with dementia lose so much, but they usually do not lose their deep feelings, their love and need.

In March, the doors shut. When at last she was allowed to see him – at a window, at a distance, wearing a mask – he was blank and confused. On the second visit, he was more responsive. He stood with his arms held out for a hug and beckoned her to come closer. “I kept saying, ‘Darling, I can’t, my darling.’ It was torture, for him and for me. And he might forget, he has dementia, but I – I don’t forget.”

She hasn’t been back to that window since. It would be too cruel. She hasn’t seen her husband for three and a half months, nor held and comforted him for six. She goes to the care home every day with fresh fruit, because he loves fruit and because it is something – the only thing – she can do.

This is one woman’s story; it is the story of thousands who are separated from those they love. [John’s Campaign](https://www.theguardian.com/society/series/johns-campaign), which speaks for people with dementia and for their family carers, has heard such tales of grief and guilt, damage, bewilderment and despair that it could break your heart in pieces.

In the name of infection control, great harm is being inflicted. [Seventy per cent of people in care homes have dementia](https://www.alzheimers.org.uk/about-us/news-and-media/facts-media), which is a neuro-degenerative condition that can attack a person’s deepest sense of their self. Family carers are crucial to keep them connected to the world and for their survival. ONS figures show that deaths from dementia have risen by more than 50% in the past six months. People can die of heartbreak.

These stories are why John’s Campaign, after months of campaigning for change, has asked the government [for a judicial review](https://johnscampaign.org.uk/" \l "/post/a-judicial-review-of-the-governments-care-home-visiting-guidance).

Only the government can provide the context in which residential settings can follow sensible precautions while behaving humanely towards those in their care. Only the government can enable care homes to follow fundamental principles of individual rights. Only the government can end this avoidable suffering, which is happening on a mass scale and that should make us sick with shame and pity.

It’s as simple, as obvious, as that. We trust paid (often grossly underpaid, usually kind and honourable) carers to take precautions and avoid risk; surely we should trust family carers who are the most invested in the safety of the person in the home, to do the same. And this includes young people, who have become a target for blame and naff soundbites (“don’t kill granny”) but who often bring great joy, hope and renewed energy to their grandparents.

John’s Campaign fully understands the need for safety and caution, but Covid-19 is not the only risk and people with dementia are not a faceless category: they are individuals whose needs should be taken into account and who should be given agency and allowed choice.