Dear Secretary of State,

The hidden catastrophe that is taking place in care homes because of Covid-19 needs to be addressed urgently by the government. Alongside the extraordinary number of deaths in homes, vastly higher for people with dementia than any other group, there has also been much suffering and a deterioration in mental and physical health among many of the residents because of the ban on all visitors.

This enforced separation has had particularly damaging consequences for those living with dementia (who make up over seventy per cent of the population of care homes) and their carers. Family carers have reported that the Covid-19 guidance on visiting care homes is not uniform across the UK nations, and providers interpret it differently leaving many feeling exasperated by this lack of consistency. This is particularly acute where they are distant carers, with their relative in another one of the nations. The inconsistency of the guidance and policies across the UK is causing additional confusion and stress.

However heroic a job staff have been doing, family carers remain key, essential members of the residents’ care and support network, as the biggest workforce in dementia care providing 44% of the total cost of care, saving the economy £13.9bn a year. They not only provide practical services that contribute directly to their family member’s well-being, but also act as their advocates, voice and memory, keeping them connected to the world. We have heard countless stories of the anguish that both the residents (who may feel bewildered and abandoned) and their anxious family carers have experienced.

What’s more, without these essential family carers, the cognitive abilities of a person with dementia can deteriorate rapidly, and this enforced isolation from family and friends can be fatal. The sharp spike in excess deaths in care homes since the pandemic began is not just caused by the virus; there has also been a significant rise, 52%, in non-coronavirus-related deaths for people with dementia. It is vital that the contribution of family carers is respected and that, in the context of Covid-19 policy guidance, they are recognised as ‘Key Workers’ alongside professional staff - so we are calling for safe, regular and repeated testing of all staff & residents, to ensure safety of visits.

On 23 June, the Prime Minister announced that, on 4 July, pubs, hairdressers, cinemas, museums and galleries in England could all begin to open their doors. But he made no mention of care homes - not even an explanation of why they are exempt from the relaxation. So now, if someone with dementia is in hospital, they can be visited: hospitals changed their visiting guidelines at the end of April to take account of the danger that isolation poses to people who have mental health difficulties such as dementia, though not all ward managers are welcoming this. If someone with dementia lives in their own home, they can be visited. But if they live in a care home, they often cannot. This is not just cruel and unnecessary, it is a violation of their fundamental rights under the Human Rights Act 1998 (Article 2: Right to life; Article 8: Respect for your private and family life, home and correspondence) and the United Nations Convention on the Rights of Persons with Disabilities (Article 19: Living independently and being included in the community). All public bodies, including government, local authorities and care home providers, have a legal duty not only to uphold people’s human rights but also to promote them - which in this particular case they are failing to do.
Family carers, whose own mental health has been put at risk by the separation, should, and must be able to, see, nurture and touch those they support, while of course following exactly the same infection-control protocols as the paid carer. For this to happen, care homes urgently need informed guidance from a government that has been strangely silent. The care-provider organisations have done their best, but they do not have the authority to instruct their members, and many managers of care homes will refuse to open up until they receive specific instruction to do so from the Government. Meanwhile, every day counts: many of the residents are in the last stage of their life. Families have reported immeasurable feelings of living grief and bereavement as a result of not being able to see their relatives, and not being able to spend quality time with them at this end stage of life. Covid-19 has been a tragedy in those very places which should be refuges; the consequences of preventing people who are frail and precarious from seeing those they know, love and need may in the long term be even more damaging, both to them and to all those who care for them.

We are therefore calling – with one united voice - for the Government to grant designated family and friend carers the same status as a ‘Key Worker’ care home member of staff, allowing them the same access to care homes with the same provision of testing so they can meet the essential needs of residents. This is in recognition of the damage that separation can have on those with dementia and the legal obligations to ensure that people's human rights are recognised, respected and upheld in all care settings.

Yours sincerely,

Nicci Gerrard and Julia Jones,
Co-Founders, John's Campaign

Hilda Hayo,
Chief Admiral Nurse/Chief Executive,
Dementia UK

Tessa Gutteridge,
Director, YoungDementia UK

Ian Wilson,
Chief Executive, Alzheimer’s Research UK

Philly Hare,
Co-Director, Innovations in Dementia

Anna Gaughan
Chief Executive, TIDE (Together in Dementia Everyday)

Kate Lee,
Chief Executive, Alzheimer's Society

Hilda Hayo,
Chief Admiral Nurse/Chief Executive,
Dementia UK

Anna Gaughan
Chief Executive, TIDE (Together in Dementia Everyday)

Kate Lee,
Chief Executive, Alzheimer’s Society

Yours sincerely,

Nicci Gerrard and Julia Jones,
Co-Founders, John's Campaign

Hilda Hayo,
Chief Admiral Nurse/Chief Executive,
Dementia UK

Tessa Gutteridge,
Director, YoungDementia UK

Ian Wilson,
Chief Executive, Alzheimer’s Research UK

Philly Hare,
Co-Director, Innovations in Dementia

Anna Gaughan
Chief Executive, TIDE (Together in Dementia Everyday)

Kate Lee,
Chief Executive, Alzheimer’s Society