

## PE1841/PP

Alison Leitch submission dated 15 March 2021

I fully support this petition as my relative who has Alzheimer's disease, lives in a care home and has been cut off from the outside world for almost a year. Prior to the pandemic, my relative was out with family members 5 days per week, participating in society and life as much as possible. With a degenerative brain condition, every day matters; familiarity and routine are critical, and family members play an essential part of any care package.

It was fully understandable when care homes went into lockdown in March last year, we have all experienced this with norovirus, but no one expected this enforced separation to continue as long as it has. Right away I was offered video calls to my relative, but when someone has never used these and is non-verbal, the only thing these offered was the chance for my relative to hear my voice - when it didn't cause distress as this was just a voice coming out of nowhere.

As things began to open up for the general public in the summer, I was continually told 'the guidelines say no' but yet when the guidelines changed in October to allow touch, suddenly the guidelines were 'only guidelines'. Can you imagine what it feels like to be told that you can't hold your loved one's hand or to watch your loved being restrained from walking towards you as they don't understand what is going on. When you rely on body language, touch and eye contact to communicate, sitting two metres away or standing at a closed window is only marginally better than nothing at all, it is certainly not meaningful or representative of a person's right to a family life (Article 8 of The Human Rights Act 1998). The lives of care home residents are in the hands of private care companies because the guidelines are not enforceable, and families are completely powerless despite holding Power of Attorney.

This country has done a huge amount of work over the last few years in protecting the rights of people with dementia [Charter of Rights for People with Dementia and their Carers in Scotland \(alzscot.org\)](#) however these have been completely disregarded for a year. People with dementia have been disproportionately affected by this pandemic; the use of antipsychotics and sedatives have increased and people have declined at a faster rate because of the lack of contact with families and the loss of routine.

Breaches of human rights must be proportionate; how can it be deemed to be proportionate for one section of society to be completely stripped of their rights and their voice for almost a full year? All of us will grow old and a pandemic will happen again, we have to ensure that lessons are learnt from the last 12 months. It is absolutely essential that legislation is passed. The Government must protect those in fulltime care to ensure that this human rights catastrophe is never, ever allowed to happen again.