

Written evidence from Anonymous (HCS0003)

██████████ – my late, younger sister, ██████████ was a care home resident from May 2017 until her death on 4th December 2020 – she did not die from Covid.

I was my sister's Legal Power of Attorney for both Finances and Health & Welfare as well as being her DOLs Representative – I have grave concerns over the ongoing care home visiting restrictions – any future blanket ban on visiting – the need for a change in the law to protect Essential Family Caregiver status.

Background Information:

My late sister's stroke in May 2010, left her severely physically disabled together with never regaining meaningful speech. Sandra was divorced at a young age and had no children - I was her staunch support - the only family member who stood by her throughout her adversity. Prior to Covid there had never been a time in the ten years following her stroke when she was left longer than longer than three days without my support.

In 2017 due to worsening dementia problems I had to make the hard decision to place ██████████ into residential care – hardly ideal at the still young age of just 64 and with dementia exacerbating her communication difficulties - However, prior to lockdown, I would visit 4/5 times per week, monitor her changing care needs, help with personal care, difficult mealtimes, help staff get to know her likes and dislikes through my input, help her be involved in social activities when possible, her young age often put her off the normal care home type entertainment, so I would provide stimulation more in keeping with her interests. Following lockdown – from 12th March 2020 - I was not 'allowed to spend any meaningful time with my sister.

There was an exception during this period – though that was time I would have preferred not to spend: Due to being isolated in their rooms for long periods of time, there was an occasion when my sister (by this point not independently mobile) trying to attract attention to her toileting needs but going unnoticed / ignored, fell from her chair – my concerns about this were dealt with through the proper channels at the time CQC etc – however, also due to lockdown ANPs / GPs were not going into the care homes either, but diagnosing via video link – disgraceful!! This situation resulted in my sister suffering an undiagnosed fracture of the fibula until, 10 days on from the fall, I paid a 'random window visit'. Witnessing her obviously swollen leg and distressed state I contacted GP surgery and insisted she be physically checked X-rayed etc. Had I been going into care home to visit as 'normal' there is no way her pain and distress would have passed unnoticed for this length of time.

Despite the blanket visiting ban - the Xray / Fracture clinic appts resulted in my twice having to accompany my sister to hospital in a wheelchair taxi, be with her throughout the examination process etc – two periods of approx 3 hour close contact each time – both times returning her to care home in a distressed state, but having to hand her over to care staff at the door – was this not farcical?

What these two occasions did highlight however was the much deteriorated state of my sister's mental health / wellbeing. It should be noted that her general state of decline by March 2020 was such that anyone with any wit should have appreciated

the fact her remaining life span was limited – however even stating that, her further decline into Dementia had progressed at a frightening speed. I am convinced this was due to lack of my visits / support / keeping her connected. Over the Summer of 2020 I was ‘allowed’ a pre-booked, once per week, 20 minute garden visit, hardly ideal when my sister had to be transferred to a wheelchair (not without difficulty), wheeled out of doors into a drafty gazebo – that is unless the visit was cancelled due to bad weather / gazebo blowing down.

From 12th October 2020 onwards I was being advised by the care home that my sister’s condition was deteriorating further, she was lethargic, not eating /drinking, refusing long term medication – my pleas to both the Care Home Manager / Directors and the Local Director of Public Health to be allowed ‘Exceptional Circumstance’ access were constantly refused.

On 20th October my sister was admitted to hospital. Due to her Dementia and lack of speech I was allowed to be with her for the admissions process and one further short visit in the following days to help the SALT nurse determine if my sister would accept thickened food / establish level of thickness required to prevent choking.

Had there not been this 7 month blanket ban on care home visiting - had each resident been assessed for individual needs with respect to a family member being treated as 'essential to their care' - my sister's condition would not have deteriorated to a stage requiring hospital intervention.

On 27th October my sister was discharged back to care home – it was felt she would fare better in familiar surroundings! She didn’t – she continued to refuse to eat / drink and the hospital had changed her prescription so she was no longer receiving her long term (post stroke medications) - in short they had discharged her as end of life – though at that point no one had used those words.

From that point onwards I continued my battle, with the aid of an exceptional Social Worker, to try and gain ‘exceptional circumstance’ admittance to the home – despite our determined efforts this was never granted. Throughout November my once weekly 20 minute visits consisted of standing outside of my sister’s closed bedroom window – watching as she was slowly dying in front of me – oblivious to me being there.

I was finally allowed inside the care home, on end of life basis, from late afternoon Monday 30th November, my sister died at 11.20pm on Friday 4th December – I will never know if she knew I was with her. I am haunted by her ‘voice’ hoarse, with constant calling? Just because she was unable to say my name does not mean she was not calling for me. Did she feel I had abandoned her too as the rest of her family previously had? These are the nightmares that I have to live with.

My reasons for supplying evidence:

During all of the period / happenings described above – the points that kept returning to my mind were - that quite apart from the obvious emotional aspect - the close sibling bond which was being totally ignored and disregarded – was the fact that alongside this, the legal obligations I had undertaken to support my sister in every way suddenly counted for nothing. This alone must be a breach of Human rights.

When my sister suffered her stroke I had quite willingly undertaken / signed a legal document to act as her Legal Power of Attorney – when she unfortunately had to move into residential care setting I had also willingly signed/ taken on the role as her DOLS Representative (another legal power as far as I am aware).

Over the 10+ years following her stroke I had never once let her attend a medical appointment / rehab therapy without my presence / support – there was no one person who understood her needs / knew more about her medical background than I did. The fact that this blanket ban on visitors prevented me from monitoring my sister's changing care needs – making it impossible for me to discuss any concerns about same with medical staff, in any sensible manner, ought be considered as a cause for concern alone - I mentioned this point on many occasions to various people – Care Home Management - CQC – Social Services – GP – my MP - local Director of Public Health – all to no avail.

Given my experience of the care home system prior to the pandemic visiting catastrophe, I would also add that in my opinion visiting a care home 'by appointment' should not be allowed to become the new normal – bodies such as Social Services and CQC – do not serve as a satisfactory ongoing day regular monitoring of 'the system' – there were many times over the years of my sister's residency when I needed to raise concerns relating to her day to day care with Senior Care staff / Manager / Company Quality Director – the fracture described above was not the only occasion when I needed to override staff / ANP opinion and take my sister to A&E - Family being allowed to come and go at will are the only certain monitors to provision of quality of care.

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