

Written evidence from Anonymous (HCS0024)

Context

My husband is an Indian Muslim and started his dementia journey when he was 50 years old in 2010 when he went deaf over a few months. He was a computer programmer and three years later he lost his job of 24 years when he was encouraged to take redundancy, he was devastated by this. He started looking for work and managed to find another job but did not pass his probation period and they let him go.

After this we went to his doctor to see what was happening and the doctor organised a CT scan which came out clear. As my husband was still struggling on a daily basis with tasks and understanding the meaning of words, he was referred to the memory clinic and undertook a memory test which showed he had mild cognitive impairment. He had an MRI scan in December 2015 and was diagnosed with temporal lobe Alzheimer's. His wish was to stay at home and our children left their jobs in London to help to care for him.

Unfortunately, in 2018 his behaviour changed and he became more challenging and aggressive. In February 2019 he was sectioned under the mental health act. Whilst in hospital he had another MRI scan which showed that his dementia had progressed and he now had Frontal Temporal Lobe Dementia (FTD).

Watching the person, you love struggle with this disease is heart breaking. Our children were at school and university when this started and as most couples do, we were planning for our retirement once our children were independent.

He stayed in hospital for 2 months and the consultant agreed that we could take him home to see if he would settle, this was on section 17 leave, this was with a 'full care package' of 2 half an hour visits per day, which was totally inadequate. He struggled to settle as he did not have the space to wander and got more and more agitated. As he was on section 17 leave, the hospital advised that if we could not get him to the hospital we would have to call the police. The police said this was not their job and I quite agree with this.

In addition to the above, my husband's right not to be mistreated or wrongly punished by the state was compromised through the process of being restrained by the police. This was someone who was extremely ill, and by the police being responsible for returning my husband to hospital was absurd. If my husband had been well, this would have been distressing enough. He was clearly very confused, angry and distressed and it needed six police officers to get him into the police van (with the cage). He was returned to the hospital via the police in handcuffs, extremely distressing for both him and for us to watch and really inhumane for someone who is so ill.

After looking at over 50+ care homes, he moved at an outstanding one in August 2019, just before the birth of our first grandchild. This placement initially worked and he responded to staff but during November 2019 they had a number of staff changes. This meant that he did not get the consistency he needed and he would only respond to a limited number of staff and therefore we, as a family washed him, fed him and took him to the toilet as the care home could not manage. We had various meetings with the home to sort this out and the final one was on 13 March 2020, 2 days before they locked down.

During lockdown, the care home struggled to understand his care need and support him (The care home struggled to understand ismaeel's care need / support husband with his care needs) and the home could not take him to the toilet. In order to clean him he was restrained by up to 3 members of staff and therefore lacked trust in his care home.

He was assaulted by a member of staff which was dealt with by the police and also the safeguarding team and caught covid-19 in April 2020.

His mental health was deteriorating, he was losing weight, he would not take his medication and he was sobbing on video calls. His aggression and paranoia escalated.

Prior to lockdown he could speak and could understand some instructions. Lack of contact and stimulation with his family escalated his dementia.

What human rights issues need to be addressed in care settings in England, beyond the immediate concerns arising from the Covid-19 pandemic?

Everyone with dementia is an individual and as such should be treated according to their own special requirements and needs. Blanket policies remained in place due to care home managers risk adverse attitudes, which were not aligned to the individual or how distressed they were. This was also promoted by the local Public Health Teams who advised the care homes.

Understanding dementia is the biggest factor with the human rights issues, in his case he needs actual physical contact. To hold his hand, to stroke his back and to see a smiling face. This in turn gives him the reassurance, love, stimulation and trust that he needs, which makes him feel valued, calm and listened to.

During the pandemic he was physically restrained on multiple occasions both in the care home and also in the hospital. He then went onto antipsychotic medication which chemically restrained him, this is currently being reviewed.

Facetime calls were not an adequate substitute, he did not like seeing his face on a screen and could not understand why we were not there, this escalated his behaviour.

Not just his human rights were breached during the pandemic but also his right to his religion. He was in an environment where he was the only Muslim resident, contact with his family was crucial to maintaining this connection. Understanding the importance of an individual's religion and how they practice this is limited in care settings, especially if the staff are not the same religion.

He has a Deprivation of Liberty (DoL) in place, due to requiring covert medication and part of this is to have 'face to face' contact with his representative. This was denied during the pandemic and without the Essential Carer status, which I now have with his new care home, this would still continue to be denied during any outbreaks.

His teeth were neglected, he hadn't seen a dentist since he was sectioned in February 2019 and he needed to see a chiropodist every 6 weeks to help him to walk pain free. By stopping these services, this contributed to the escalation in his behaviour.

How effective are providers at respecting the human rights of people under their care?

All decisions should be about what is best for the person and not the easiest option. The covid pandemic seems to have become the default option and it is certainly easier for care homes to continue to deny access and limit visits and access to our loved ones in care. This is not fulfilling the rights of the individual.

No matter how distressed my husband became we were powerless to help what was going on in the home due to being denied access to him. He was in severe distress, was unable to communicate, stopped eating, was rapidly losing weight, would not take his medication and was constantly being physically restrained.

Providers need to understand that the person has a family, they have not abandoned the individual. Working together ensures the provider respects and protects the resident's wellbeing, autonomy and choices. This did not happen throughout the pandemic and is still going on now in quite a few care homes. Some homes even remained open during the pandemic as they recognised the individuals under their care needed to have the support of their families. Providers also need to understand that care plans are in place for a reason, so they need staff trained on these, in order to understand the needs of individuals. The individual then has the consistency they need whether it is an agency person or a permanent member of staff.

His first care provider did not take my husband's individual needs into account. They were risk averse and extremely slow to put anything in place. They had an outside space but my husband did not feel safe outside of his unit on the first floor therefore even though visits were arranged he only came out on a small number of occasions. So as society opened, care homes were still locked down.

Guidance changed in July 2020 and from that point on, care homes were meant to introduce individual risk assessments. My husband's assessment took place in early September 2020 and I was told that my husband would be one of the few to have an inside visit. This did not materialise as the home did not allow this to happen until all the other residents' risk assessments had taken place. This was going on for some time and felt like a delay tactic, especially when his behaviour was reaching crisis point. The home went into lockdown on the advice of the local Public Health stopped all visits, without any thought to the individuals. Every opportunity to delay putting these risk assessments in place seemed to be occurring. My husband was so distressed that he was sectioned for a second time under the mental health act at the end of October 2020.

As he was in hospital, their visiting was slightly different and we were able to see and hold his hand in November 2020, after 8 months. The escalation of his dementia and his level of distress were awful to see. In the hospital, my husband was again restrained on numerous occasions, and was also very heavily medicated because the staff could not deal with him. He had very limited communication after the 8 month period without us and had lost lots of the abilities that we were helping him to retain. He exhibited behaviours of feeling abandoned, and staff did not have the time to sit with him, even though this was in his care plan.

How effective are regulators in protecting residents from human rights breaches and in supporting patients and residents who make complaints about their care provider?

The Government Guidance, interpreted by local Public Health and Care Homes took away the regulators ability to protect residents as far as I can see. Blanket visiting bans applied to all, not just families. Effectively the guidance gave care providers carte blanc to do what they wanted without looking at the individual under their care. The individual risk assessment process was another long winded tick box exercise.

I have made a formal complaint about his first care home to the care home itself and social services but not the regulator. As safeguarding incidents are automatically uploaded to the CQC why are complaints not treated in the same way?

The regulator does need to ensure that care providers are following the guidance but it appears that they have no powers to make sure this is happening. They were very quiet during this period of time and let the individuals in care and also their families down. Equally the regulator does not appear to be independent as detailed on the Gov.uk website it is sponsored by the Department of Health and Social Care. Where does responsibility of the failure of care home residents lie?

The regulator needs to ensure care homes statutory responsibilities as far as their websites are met. Do care homes even have any statutory responsibilities? I had to ask for the complaints policy which was not available on the homes web site.

What lessons need to be learned from the pandemic to prevent breaches of human rights legislation in future?

The whole concept of all of the acts and rights is to protect the individual. This did not happen during the pandemic. Their individual needs and rights were ignored, even when it was clear that their wellbeing and mental health were deteriorating.

The treatment of people with dementia for all services needs to be joined up, clear and timely. Care homes taking months to implement 'Government Guidance' is simply not acceptable. Denying the individuals access to their immediate family when they do not have capacity is totally inhumane. As care providers do not seem to be able to put guidance in place voluntary and families are still being denied access to their loved ones, something needs to be put into law to state that individuals in care settings have a few nominated people (the number needs to be clearly stated so there is no ambiguity) whether these are called Essential Caregivers or not is not the issue but recognition that some individuals require more contact from their family than others.

All those who give advice, including the Government and local Public Health are responsible for the interpretation and therefore should put clear specific measures in place quickly with the regulator to ensure the individual and their wishes are at the centre of all decisions being made. This failed to happen. Contradictory advice meant that in some areas, especially where we live, were disproportionately affected by constant local downs and restrictions, which in turn affected our loved one in the care home and led to him being re-sectioned.

Families of loved ones in care are not 'visitors' most are essential to their continued wellbeing. It is extremely frustrating and disappointing that a system that is there to care for vulnerable people instead was used to put measures in place that ultimately harmed them both physically and mentally. Unless you have a family member with dementia you will never understand the harm and stress this pandemic has caused using the 'protective' measures that were put in place.

Having a dementia friendly flower on your car or on your window, as in the police and also hospitals does not show that your organisation is empathic to dementia, this should be followed through via action within the service. Mental health patients should not be left to the police, they need a doctor to see them as well to reduce their stress.

In the hospital it was felt that his teeth were causing him pain, a dentist came to see him and said that he would have to go under aesthetic for treatment, which I felt would be the best option for him but that they would take out all his teeth that were damaged rather than fix them. Human rights is not just about care homes or the regular it is about every service.

I find it staggering that I am being asked about a Do Not Resuscitate (DNR) order as according to the doctor my husband does not have any quality of life and would not be able to cope with resuscitation. I have ignored this advice, my husband has dementia and is now 61, which other otherwise healthy 61 year old would have a DNR order in place? Why is this different for people with dementia?

Treating people with dementia with dignity is key and joining up the services properly not on paper. People with dementia are not criminals, they are confused and are the vulnerable one.

The energy it takes to keep on fighting for the rights of a person in care is draining. This process is overly bureaucratic, confusing and you need a law degree to understand the systems. Ultimately at the core of this is a very vulnerable individual who is struggling at home. Moving them into care is not to 'make it easy' for the family, in fact it is more stressful, it is about looking at whether their needs can be met at home, this is not available at this time. This is a massive issue for people with working age dementia, who are physically fit, extremely strong and very active. The services simply do not exist.

The one guaranteed aspect of dementia is when they unlearn a skill it is extremely difficult for them to relearn it. Social isolation and lack of contact has done this. The care sector needs to not just be about ticking boxes but also about following through in it's actions and the individuals care plan. This would be solved by someone who is standing up for the rights of these individuals not as a title but actually talks to people accessing the system.

A clear priority is the training of the staff and the financial acknowledgement that care work is an extremely hard job. Staff who have the empathy for this job will then have the empathy for the individuals they care for, which in turn should allow the individual in the care home to flourish.

People in care homes have no less value than anyone else and should not be made to feel that they are an afterthought, they have a family that love them very much.

This is the most traumatic and degrading experience I have ever had the misfortune to be part of and this needs to be changed for others who do not have a voice or someone to advocate on their behalf.

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