

Written evidence from Anonymous (HCS0023)

Introduction about myself:

I am a family carer to my husband who has young onset Alzheimer's Disease. He lived in three different care homes between 2015 and 2020 and now lives at home with me.

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

Care home residents should have the right to:

- see a GP
- see family and friends
- have opportunities to go out of the home
- get sunshine and fresh air
- have their incontinence needs met according to need and not according to a timetable
- have a bath or shower and not just strip washes
- be assisted to brush their teeth or have someone brush them

Most people would assume that the above are a given, but sadly many of the above are not at all a given in many care homes.

One particular issue which concerns me a lot is the right of family members to read the care notes about their relative. My husband lived in three care homes. The [REDACTED] home allowed me to read his care notes. The notes were done on paper and I requested the lever arch file and read the notes every Sunday. However, when he lived in an [REDACTED] home, the notes were done on computer and I was not allowed to read his notes. They cited GDPR reasons and when I eventually got some notes (they printed off some notes once), they had made a big deal about redacting names. This issue needs to be resolved as family members have a right and indeed a duty to stay informed about developments in their relative's care.

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

The quality of care provided by different providers appears to be extremely variable. My husband lived in three different care homes ([REDACTED]) and there were problems at all three homes. Maybe we were unlucky. I brought him home at the beginning of the first lockdown and we have live-in care now and the quality of his care is vastly superior now compared to when he lived in care homes.

In the third care home ([REDACTED]), my husband was physically abused - see safeguarding letter below. One of the reasons this occurred was a culture in the home which did not encourage whistleblowing. The member of staff concerned was not even suspended, she was simply moved to another floor - what kind of message does this give out? I imagine the home was struggling with staffing levels and didn't think it could afford to suspend her. If pay were better and it were easier to recruit staff, standards could be improved by not keeping members of staff who are temperamentally not suited to the job.

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

CQC is pretty ineffective at protecting residents, in my humble opinion. I worked as an Expert by Experience for CQC for about a year in 2016/17 so I had some insight.

Neglect is a human rights breach but much neglect occurs in care homes because of low staffing levels.

There are legal requirements for staffing levels in children's nurseries, there needs to be the same legal requirement for care homes and nursing homes!

As for supporting patients and residents, the CQC says on its website:

“Although we are not able to take forward complaints on your behalf, information given to us helps protect others from going through the same experience.”

So it doesn't claim to support patients or residents who make complaints, so I don't really understand the question ...

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

The concept of Essential Caregiver needs to be enshrined in law so that it isn't down to individual providers as to whether or not they allow family members to spend time with relatives in care homes and nursing homes.

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01/11/2021