

Written evidence from John's Campaign (HCS0007)

Submitted by Julia Jones

Evidence in response to the question

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

Includes Introduction / Context / State of care report comments / Expectations comments / lack of consultation & poor inspection practices comments / conclusion / recommendation

Introduction

As John's Campaign we have joined with other organisations in the Power and Rights group to submit general evidence. This is a separate piece of work prepared with input from people in the Johns Campaign Care Home and Support Facebook group.

We understand that you are hoping to get a wider-than-pandemic understanding of human rights in care homes. Given that the average stay of an older person in a care or nursing home is around 2 years, it is not easy for relatives responding NOW to give you that longer view. However, at Johns Campaign we have been working with care homes since 2016. I have observed inspections as a relative in pre-pandemic times and as an organiser have engaged with the CQC (pre-pandemic) on a partnership level. As Johns Campaign is an unpaid and purely voluntary part time group, I don't want to overstate this but I hope it gives some balance to an overview of the role of the CQC in care homes. I will also add that I worked for 5 years as an OFSTED lay inspector

Context: Average length of stay in care homes

I think it's important for the committee to remember that when for instance we mourn 30,000 covid deaths in care homes (elderly care) in the first year from April 2020, the total deaths of residents in that period was 130,000. There are three points here:

1. The CQC like many other bodies has completely failed to understand the importance of proportionality: when they came in to restart inspections last autumn they focused solely on infection control – eg advocating speech through intercoms and behind screens. Covid 19 is not the main killer in care homes. It is dementia and the multi-morbidities of old age and frailty. The CQC, like other organisations has missed the point that in protecting the **right to life** against one threat, they may be inadvertently reducing protection in another area. Remembering this statistic makes it clear that the main human rights restrictions – the right to private and family life and the right to liberty - have been disproportionately curtailed.
2. Each person has only one death, each family only that bereavement. These are major individual events. IF the CQC was doing its duty inspecting in a person-centred way, they would be ensuring that this quintessentially individual happening was treated in a

way that is consistent with Human Rights. The Right to Life will always be ended by death BUT respect for the individual, their wishes and their well-being can ensure that the principles of human rights are still respected. This should surely be the prime duty of the regulator as a public body. It is not sufficient for them to say that the guidance they are being given by the DHSC or Public Health is weak. They should have clarity in their own ethical standards. This clarity of visions and understanding of purpose has been shown to be compromised.

- 3. I would like the JCHR to reflect on the overall death statistics I gave above.** IN May you made a recommendation for an amendment to the Health and Social Care act 2008 which would have enshrined care home residents' right to maintain meaningful relationships with the people who matter to them. It would have forced the CQC to inspect person centredness more proactively. It was admirable that you made this potentially transformative recommendation, but nothing has happened for almost six months. **IN that period of inaction another 250,000 people may have died having lived the last months of their lives with their wishes and liberties disproportionately curtailed.** While that recommendation continues to lie fallow and you begin this new (and important) enquiry, thousands more people will come to the end of their lives with their human rights violated. Thousands more families will be left in a state of anger and resentment as well as their natural grief. Please ask yourselves whether you have done all you could to ensure that your recommendations were worth the hours of time put into them. Currently they have made no difference to the people for whom they were intended. When the CQC spends hours of tax-payer-funded time bringing out a report such as their annual State of Care report they too should have an obligation to make meaningful change. It is ethically based implementation of individual / person centred care that is needed now. Respecting peoples right and wishes in the last period of their lives.

Group discussion of CQC

1. The State of Care Report 2020-2021

In our group we looked at the CQC State of Care report published 22.10.21 Again and again we saw the structural weakness of an organisation that has come to focus all its attention on the providers rather than the users of services. It is corporate and focused on 'professional' actions rather than looking all the time at the impact on the individual.

In their section on the Fragility of Adult Social care for instance, they say "Care home providers and their representatives have told us about the operational challenges they continue to face as a result of decreased occupancy, reduced admissions, increased costs and difficulty recruiting and retaining staff. There is evidence that the pandemic may have impacted patterns of accessing adult social care. Representative bodies of adult social care providers told us that feelings of uncertainty, anxiety and fear over safety as well as restrictions on visiting, may have led to families choosing not to send relatives into care homes or take up home-care services"

A comment from our group:

(SF) The care home sector focuses on exhaustion and burn out amongst staff (rightly so) and then a huge section including graphs on bed occupancy and profit margins. One line was devoted to the restriction in visiting rights being a possible cause of people choosing not to have their loved one enter care. CQC were culpable in this tragedy and were conspicuous by their absence when vulnerable people needed their help.

There were some shocking incidents at the care home where this lady's mother lived. When the CQC was appealed to, they turned a blind ear – instead Amnesty International was involved. Personally I felt ashamed that this was necessary in the English care home system. The regulator should have felt ashamed that there was apparently nowhere else for these abuses to be aired. A serious condemnation of the CQC.

2. CLOSED CULTURE (State of Care)

In the State of Care report the CQC show they are aware of the danger of closed cultures. Our group felt that they did not seem to be aware of the extent to which their own actions during the pandemic contributed to this.

CS I thought the section on closed cultures was interesting. There has been a closed culture in most care homes during this pandemic, due to prevention of visiting from family, in residents rooms! The family are often the advocate for the resident who knows their likes/ dislikes, health concerns, memories etc etc. Just simple things like noticing mum's bedsheets hadn't been changed/ were dirty. Also personal esteem things like not been able to have a haircut for a year/ have your toe nails cut once in a year? Also access to healthcare/ dentist/ optician due to enforced 14 day quarantines (which mum did 5 times) No mention from the CQC of how the elderly have suffered.

Also how the mental health of families have suffered not being able to see relatives face to face for over a year.

It goes on to say in another section how the care homes are suffering financially due to a lack of clients. Maybe relatives are voting with their feet and exploring other options such as community care rather than the rigid restrictions in a care home??

JI I was surprised and very disappointed to see how CQC acted in the Pandemic at a time when they were really needed. Homes have become 'closed cultures' with minimal eyes on from outside. The plans to use Experts by Experience to supplement the CQC's understanding of what is actually happening needs to happen at pace. Most inspections are focused - reactive and the gaps between visits whilst 'plans to improve' are implemented are too long. I feel they have lost their independence and as much as working with homes to improve is a good methodology, the voice of the residents and relatives is not being as loud and independently sought as much as it should. Surveys, plans, processes - they all take so long and get bound up in process. There is enough evidence that the CQC need to up their game - make full use of their inspectors and employ and train others whilst expanding the use of Experts by Experience.

PS the phrase, 'closed culture' is so true. Prior to the pandemic, the 'open door' policy was THE reason many of us considered a care home might be suitable for the safety and well being of our loved ones. The scandalous overreach of human rights during the pandemic has been despicable.

JI I do believe that at the very beginning when everyone was learning on the hoof and the elderly in care homes were not the Govt priority (quite the reverse, whatever the rhetoric) closures were the knee jerk reaction. The maintaining of the closures to relatives has been and for many still is, unforgivable. Care Homes are private businesses and ultimately, most, have policies defined by their business masters. Society has to work towards a major change in the delivery of Social Care

3. EXPECTATIONS – a mismatch?

The CQC's decisions to suspend inspections last year will not easily be forgiven. I had a meeting with an inspector group in March 2020 when I was assured that even if they didn't go in, they would be in constant touch with homes offering support and advice and – above all – ensuring person-centeredness. “Fundamental Standard 9 will not be forgotten”. But it was. Even when inspections restarted, they were only focussed on infection control. This matters as, in the Human Rights Context Fundamental Standard 9 IS individual human rights. We have to ask whether forgetting this in the pandemic shows their lack of understanding of their role – at least the role that the public wants and expects.

Many of our group have received letters from the CQC saying ‘We do not investigate individual cases’ – this astounds people in a sector where there is NO obvious way to make complaints and have grievances investigated (unlike the NHS where there is a system) The CQC usually advise people to take up their problems with the care home provider. They appear not to understand that by the time people come to them, they will have exhausted every easy option. Families also know that a complaint against the care home provider (emotionally difficult anyway) also carries a high risk of the eviction of the resident.

We know that your committee is aware of the lack of ‘tenancy’ rights for very many people who pay their own care home fees The reality of evictions for people who complain has been made clear over the past year. It's not a rumour it's a fact. The CQC's failure to provide a proper channel for dispute investigation and resolution plays a part in this. It's a longstanding ‘structural’ problem.

Perhaps there is a mismatch between what the CQC think they are doing and what the public expect. Even in good times their inspection procedures are not felt to be properly consultative and now they have seriously lost the trust of families.

Here are some comments:

LJ I do not think the CQC is fit for purpose, my experience of the care facilities are only from pandemic times so my lack of knowledge caused me so much distress. I witnessed my husband neglect and miss treatment, there was no rights afforded to my husband or myself and trying to get him moved was a challenge that nearly beat us, my story is one I would not wish on any one. How are the government going to put this right is anyone's guess, but I have no faith in anything the CQC has to say.

CSI have no faith in the CQC either. I spoke to mum's previous homes CQC inspector regarding all my concerns and all she could say was to put a complaint to the home! Which I

did, it went to the second stage. It ended up affecting my mental health so mum and I decided to move her to a better care home. Best thing I ever did

LJ I have evidence of my husband mistreatment and the CQC have come close to saying I am a liar! the stress has cost me my health and mental health:(there is no redress for us or our loved ones)

CS A social worker tried to see mum without my knowledge (the home didn't tell me, but mum said a man from the council was going to see her!) The social worker was allowed to see mum face to face in her room, but I wasn't allowed in! I insisted on being on FaceTime for the meeting, and although mum has mild dementia, she was able to tell him why she wanted to move care homes! I advise everyone to get POA for health and welfare, as we now have. Questions need to be answered by the CQC and I think we all sincerely hope they will have to in an inquiry... I won't hold my breath though.

4. Lack of consultation with relatives / poor inspection practices

There is a strong anger among families that their rights and responsibilities such as POA have been ignored and very often the regulator, who they had expected to take this seriously, has not done so. People who have responded to the CQC invitation 'Tell us about your care' have often felt let down

ED The company where my husband last lived had 7 homes in the London area and most were Requires Improvement before the pandemic. Now - miraculously - following ONLINE (?!) inspections, they are all rated Good. Sorry to be blunt but I think it's all BS ...

DD As a general point, having had many dealings with CQC about a failing care home, I think that they often give the home the benefit of the doubt. They will take their word when they say they will improve and rely on the documentation provided by the home to prove their point. Documentation is often incomplete or inaccurate. In terms of the value or weighting of information, the value given to information from relatives and residents is given a lower value than that gathered from the home.

I think my main point is that not enough weight is given to the views/opinions/observations from relatives. It takes a lot for people to speak out and raise concerns. If families get to the point where they raise a concern with CQC they are usually very worried and concerned and feel that they have tried everything else and nothing has worked. That has certainly been true in my case when trying to sort out my mum's care, I would try informal chats with carers, informal chats with the manager, formal discussions or emails to the manager, discussions with social workers (this has included raising safeguardings, asking for best interests meetings or care reviews) and when all that failed I would contact CQC. Yet often the concerns expressed by family members are trivialised or diminished. (She then gives a specific example involving an eviction notice)

In desperation I contacted CQC to express my concerns about how the notice had been served. One of the assistant inspectors rang me after she received my online form. I explained to her what had happened, how anxious and upset I was and how badly I felt the care home had behaved and continued to behave. I should point out at this point that the care home had been rated as Inadequate by CQC in March 2020 and was in special measures. Her response to me was "well they are very busy and they can't always get things right". She said they would hold the details on the record. I was left feeling that CQC did not care what the care

home had done or how unprofessionally and callously they had acted. I totally lost faith in CQC at that point to be an effective regulator and to protect the most vulnerable people in our society.

SP yes - so much of what CQC do is about checking documentation, but you can have all the 'i's dotted and the 't's crossed in the paperwork but still be missing the point

GJ I as many have put on here their failings. Big one for me is that they will not support the ECG role and not listening to the many that have it and how different it can be in so many homes. No Consistency has led to heart break .

JR absolutely. Lack of consistency, even day to day within the same care home it can vary. Having to challenge refusals in visiting requests is stressful, at a time when family members are already suffering because of the health of their loved one. It really is rubbing salt into exposed wounds and harming both parties. It's such a cruel situation that no-one ever imagined would happen. One of the many during the pandemic that's been poorly handled with incalculable harm done.

GJ The CQC give a "Tick" to show the "Care Homes supporting Visiting ", but they don't explain just what "Type" of "Visits" a given "Home" is actually offering, are they satisfied the "Homes" are offering Skype calls? Window visits? because as we know these homes are saying they're "Complying with guidelines " when in reality they are not supporting proper visits or allowing every Resident an Essential Family Carer. Added to the CQC "Homes Inspection" the real picture of "Care", and some of the real picture of "Safeguarding" issues would be best represented by sending every Residents family a questionnaire about the Care Home rather than just relying on the "Homes Self Assessment online"

GS The CQC is not fit for purpose. I have recently moved my man from a good care home to a needs improvement care home. He has been there 4 weeks. He is calmer & not on any other meds than at the prev care home. They have cut his hair, not a brilliant cut but they are slowly getting his trust. He still flinches when he's not expecting you to touch him. Not been in shower yet but they have done wonders in 4 weeks. It is not a fancy place but the care he gets is focused on HIS needs not the staff's needs. Nowhere is going to be perfect but I can live with a bit of shabby. It is clean. He does not have the tormented look he had before. And to top it all I can go into his world & be with him for hours at a time. Won't trust CQC again. They need to get out of their offices & do spot checks, no warning only then will they see what's happening behind closed doors.

AC Ask the questions to the families. Spot checks are the only way they will see how homes are run. Question staffing levels and the various needs of residents, bearing in mind there are various reasons why residents are there not only dementia.

JD Instead of waiting for people to log complaints about visiting they should be out there collecting data and information. They have allowed care homes to develop closed cultures. What is their plan to ensure the damage is reversed?

NW Mums home had an unexpected visit from the cqc and went down from good to requires improvement on well led and safe. The cqc were assured of several things including that the care home were following current guidelines for visits. However there were no essential care giver visits. I now have that status along with my sister but it feels wrong that relatives have

not been informed of what residents are entitled to. Not everyone is able to keep up with the guidelines so they miss out. I went in to see my Mum for the first time today and as I arrived there was a lady who was visiting at the window. How is that right?

HW There is no robust process to consistently hear from relatives prior to inspections. The cqc apparently tell the care home manager to let all families know they are going to be inspected and ask them to give feedback. In 16 years of my mum being in a care home, I was never once told or given an opportunity to give my feedback to cqc prior to an inspection, yet in the reports it's clear that they do speak to a handful of relatives. Are these the ones that are cherry picked by the manager who is gatekeeper of the whole process? Cqc also say they contact local Healthwatch for any feedback prior to an inspection, but the reality is that local Healthwatch hears very little feedback about care homes because again they are in the main reliant on families being proactive to contact them. It is evident from this tokenistic process that families are not taken seriously as partners in care by cqc. I would like to see meaningful, consistent and proactive engagement with families, not just being continually signposted to an online form....

MC I'd like them to acknowledge their complicity in allowing care homes to breach article 5 and 8 of The Human Rights Act. And the mental capacity act, without challenge.

CONCLUSION

The feeling of this group is that the CQC's withdrawal from meaningful involvement and assertion of individual needs and rights, at the time these were most at risk, showed that they don't see themselves as having a primary responsibility in this area. This allowed closed cultures to develop. They have not supported relatives and residents wishes to resume a version of 'normal' family life and they do not seem to take seriously relatives' wish to advocate for their loved ones. Inspection practices are not what families deem effective. They focus on providers and policies rather than consulting service users. This is serious at all times as there is no effective system of complaint and redress in residential care – unlike the NHS. The CQC could redress the power imbalance but does not.

RECOMMENDATION FOR ACTION

At the very least we would like to see the JCHR recommendation from May 2021 implemented into to the Health and Social care Act so that the maintenance of essential life-relationships was accorded the same priority as choice of food and access to medical care – and the CQC had to implement it.

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