West Yorkshire
Health and Care Partnership

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Healthwatch Report to System Oversight and Assurance Group (SOAG) – People's experience in Care Homes

June 2021

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People's Experience in Care Homes

Introduction

Since the start of the pandemic, local Healthwatch organisations in West Yorkshire and Harrogate have been working to hear the voice of people, particularly those with hidden voices. Hearing the voice or experience of people living in care homes has been part of the work of every local Healthwatch (HW) and a priority area for several local Healthwatch. Healthwatch Wakefield has worked closely with the Wakefield Safeguarding partnership, the report is attached in the appendix. Healthwatch Kirklees had done significant pre-Covid work looking at the GP offer into Care homes. Healthwatch Leeds, working closely with Carers Leeds, has undertaken a focused piece of work since May 2020 to hear and highlight the experiences of care home residents and their families. This has been particularly focused on the ongoing significant and devastating impact of severely restricted family contact and periods of isolation.

The first report titled, "Covid might not kill them, but loneliness probably will" shone the spotlight on the essential nature of family contact as key to the quality of life and health and wellbeing of the majority of people living in care homes. The pandemic and the resulting government guidance around care home visiting and outbreak management have meant that isolation has been a key theme for many residents. Despite the roadmap out of lockdown providing a return to near normal life for the vast majority of the population, people living in care homes are still having to live under some of the most restrictive rules of any people living in the UK.

Because of the different physical environments in care homes and the differential impact of the pandemic, we know that there is a huge variance in people's experiences, with some care homes working hard to enable meaningful contact and others who appear not to adhere to parts of the guidance. We also know that monitoring of care homes in relation to meaningful visiting and the impact of restricted contact on resident and family wellbeing is not systematic or robust enough to really understand the scale of the problem.

The report below details some of the key findings and themes from this work as well as link to further information, videos and reports.

This does, of course, take place against a backdrop of the nationally identified need for a long-term solution for adult social care and many care homes experiencing, even before the pandemic, financial and operational challenges including difficulties recruiting and retaining staff and premises that require significant capital investment. During the pandemic, providers have experienced rapidly changing guidance which each has had to make sense of in the context of their own individual home. There have been significant additional demands made upon care home staff in relation to training and additional external monitoring and reporting requirements.

Staff have seen individuals pass away that they had close relationships with and have not been able to do many of the activities that normally make working in a care home a positive experience. Whilst the nation has rightly wanted to recognise and support NHS staff through discount schemes and priority access, these have rarely extended to staff working in social care and in care homes who have often felt less valued despite the difficult circumstances in which they have been working.

This is not to excuse the poor experience that individuals have had but to provide some context and to prompt discussion about the wider context for the care home sector.

Key Themes

- Deterioration in the physical and mental well-being of care home residents as a result of prolonged severely restricted contact during the pandemic.

- Impact too on the emotional well-being of family carers who have had little or no contact with loved ones for long periods of time.

- Huge variation throughout the pandemic and continuing now in terms of how different care homes have enabled contact and meaningful visiting.

- Lack of involvement of family carers in making visiting arrangements and doing person-centred individual risk assessments to take into account residents' wishes and needs regarding visiting.

- Huge variation in terms of how regular contact/communication with family members is maintained when face-to-face visiting is restricted.

- Variation over what care homes are 'allowing' in terms of visiting at the end of life despite guidance saying that end of life is the last months of

someone's life not the last days and visiting should be permitted as much as possible.

Issues in the recent past have included:

- lack of awareness amongst care homes and families and/or reluctance amongst care homes to enable an 'essential caregiver' role as outlined in the current guidance on care home visiting.

- Blanket visiting policies e.g. half an hour once a week for everyone in a designated room, irrelevant of individual needs.

- No visiting is allowed on evenings or weekends.

- Concerns are raised about the quality of care and safeguarding when family members haven't been able to play an informal 'monitoring role' by visiting regularly.

- Fear of repercussions on resident care or even eviction if concerns are raised or complaints submitted.

- 14-day isolation rule after admission to a care home (from hospital or community or for respite), overnight stay or indoor visit detrimental to the wellbeing of residents. This can result in residents refusing treatment because they don't want to isolate in their room for 14 days. Issues for people with dementia or learning disabilities unable to understand the isolation and for whom it would be distressing. Parents are unable to have children home for weekend breaks. Some residents feel like they

have no choice over their own life whilst the rest of society is opening up.

We know that the NHS has also found itself facing some similar challenges in terms of families being able to visit relatives onwards or support individuals during their treatment journey.

Case Studies/Examples/Survey Findings

Impact of Covid on care home residents – June 2020 – gives a snapshot from 40 relatives of Leeds care home residents of the impact of lack of contact with family members during the first wave. https://healthwatchleeds.co.uk/reports-recommendations/2020/what-relatives-of-care-home-residents-in-leeds-are-saying/

As part of a national survey run by John's Campaign in November 2020 to get a snapshot of people's experience and the impact of visiting restrictions – 21 people from Leeds (out of a total nationally of 1049) completed the survey:

- 90% said they hadn't had any input into an individual risk assessment around visiting (90% nationally)

- 95% of relatives said they didn't think the visits made available since 5th November had met their loved one's individual needs (94% nationally).

- 71% family carers said the care home doesn't give them regular updates about their relative's mental and physical health, how they are coping and identify any additional ways they might be better

supported. 24% said the updates were variable. (Nationally, 53% said they don't get regular updates, 31% said they can be variable)

- 67% said their relative's mental and/or physical health had deteriorated as a result of visiting restrictions. 33% said it was hard to tell, mainly because they haven't been able to have enough contact to know. (80% nationally felt it had deteriorated, 17% said hard to tell nationally)

"our mum is now diagnosed with depression and acute anxiety. She lives in constant fear that something awful has happened to us. she hasn't seen her other daughter (who she day) since August because of continuous lock downs.. Her words are ' I can't cope with this life anymore'"

- 95% of family carers said that visiting restrictions had had a significant impact on their own mental health (85% nationally)

"It's been difficult for me, as we've lived together all of my life, that's 52 years. To go from being so close daily to the situation we've had since March has been very tough. I did manage to visit him during his time in hospital, but it was not ideal as he was in pain with his shoulder fracture and limited to a short stay…. I now feel very alone. There's memories of him surrounding me constantly."

“I have become increasingly upset and anxious by not being able to visit my father. I am not sleeping. Some days I find it hard to motivate myself to do even small tasks. I feel guilty that he is locked away in the care home. The home I put him in.”

“I miss my mum! I'm very thin-skinned at the moment and can be set off crying unexpectedly.”

From May 2021

“When mum was admitted to hospital last week her toothbrush was in a disgusting filthy state and obviously had not been changed for a year. There were four new packed toothbrushes in the cupboard. We as caring family members were in the home on a daily basis before the pandemic.”

Other recent callers to our enquiry line (since May 2021) have told us:

- Mother's mental and physical health has deteriorated since moving into a care home in June 2020. She has spent 8 of the last 11 weeks in isolation due to various medical appointments/moving to a new care home etc. Visiting is only allowed for half an hour once a week between 9am and 3.30pm weekdays and she hasn't seen any individual risk assessment around visiting that takes into account her mum's wishes/needs. When she has taken her mum outside, her mum has been inappropriately dressed for the weather, in other people's clothes and her dignity compromised. She hasn't been shown her mum's care plan since her mum moved in in February 2021. She didn't even know there was such a thing as a care plan. She says it is very difficult to get be able to speak to the manager about any of these issues as people hardly ever answer the phone. She leaves voicemails but then people don't pick up the messages or get back to her.

- Requests to be an essential care giver being refused verbally on the basis that it's not necessary as 'staff can meet their needs', without understanding that the families are not wanting to provide personal care but emotional and one to one support.

- Families have seen no evidence of an individualised risk assessment that involves the family in the decision about request for essential care giver (as stated in the government guidance). One of the family's relatives is recently bereaved, registered blind and has a hearing impairment and the family have continually requested that these needs are considered in the decisions around visiting for many months without a satisfactory response.

- Family members reporting that relatives' mental health has really deteriorated through limited contact and that they need more contact.

- Family member having to make a 200-mile round trip every time they visit and despite requests were still only permitted the standard half hour visit in line with care home blanket policy for indoor visits.

- All indoor visits are in a main reception area where there is no privacy as the receptionist is always there. Feels like the visits are intentionally supervised.

- Person calling to say that they had just found out that their relative had been in isolation for 6 weeks (due to 14 day isolation rule) because of series of appointments to get new dentures that the care home had lost. This was resulting in deterioration of resident's mental health. Family had not been informed up to this point and no risk assessment had been done to assess actual risk of going to a one-to-one appointment at the dentist. When they were linked up with the infection control team, the outcome was that the woman had not needed to isolate because the visit was deemed very low.

- Person recently took relative home for a week against care home wishes as so desperate that she didn't spend birthday under restrictions but then had to isolate for 14 days and says resident feels like they're "picking on me" or "punishing me for coming home for my birthday." Lack of mental stimulation and activities in resident's room whilst in

isolation. The only walking that they could do was from her bed to the bathroom and back which made resident's walking deteriorate.

- Relative says there is no communication or regular updates at all by email or post between the care home and relatives and she had no information about the what the care home was doing or how her mum was doing in the whole 18 month her mum has been in care apart from a couple of phone calls about things to do with her mum's health.

Impact or conclusions

Despite changing government guidelines advocating increased visiting in care homes, there is still huge variance across the sector as it is down to each care home how they interpret and implement the guidance. There is also the question of whether or not visiting is person-centred and meaningful. Just because a care home is enabling visiting doesn't mean it is always meaningful and meets the needs of all residents. Guidance is clear that individual needs and wishes should be taken into consideration, and family members involved when making decisions about visits, but we know from feedback that this isn't always happening. Despite the rest of society opening up and 'getting back to normal', care homes are way behind the rest of society in this respect, with visiting still restricted to half an hour a week for many and 14-day isolations imposed if residents leave the home for an overnight stay or hospital admission.

Each of the places in West Yorkshire has been working to support care homes and to enable visiting in a meaningful way and progress is being made, but it is clear that there is still further work to do and, in particular, whilst many care homes have sought to do a good job in very trying circumstances, there are families who have had poor experiences.

Recommendations to SOAG:

- That consideration is given by the Health and Care Partnership about how it will work to ensure that care home staff feel valued and supported in the work that they do

- That workforce strategies for the Health and Care Partnership fully consider the social care workforce

- That, in rolling out additional training and support for the care home sector to take on tasks often previously undertaken by other professionals and organisations, consideration is given to the impact this has on staff time in care homes. Additional tasks will need to be accompanied by resourcing to enable staff to have time to spend with people rather than be task focused.

- That the Health and Care Partnership establishes a multi-agency task and finish group, including with family carers, to consider the longer term conditions needed for residents and their families to have a high quality experience in a care home.

Appendix

Results of a survey run by Johns campaign in November 2020 gave a snapshot of the impact of visiting restrictions at the time. https://johnscampaign.org.uk/post/the-grim-truth-behind-the-governments-fine-words

Healthwatch Leeds report on the impact of Covid 19 on Care Home residents June 2020:

https://healthwatchleeds.co.uk/reports-recommendations/2020/what-relatives-of-care-home-residents-in-leeds-are-saying/

Care Home staff feedback report: https://healthwatchleeds.co.uk/reports-recommendations/2021/care-home-staff-feedback-report/

Care Home Show reel video (short clips of care home issues) 3:02 minutes
https://www.youtube.com/watch?v=wKiEt0GwDeA&feature=youtu.be

Care Home video (compilation of issues relating to care homes) 14:50

https://www.youtube.com/watch?v=Me47pR_LSHw&feature=youtu.be