Shining a light on care homes during the COVID 19 pandemic in the UK 2020

Annie Stevenson

Abstract

Purpose – *The purpose of this paper is to explore the link between age discrimination and the injustices that have taken place in our care homes during the COVID-19 pandemic in this country. It seeks to show how destructive age discrimination is to those who live in our care homes and attempts to shake up our attitudes to older people, as the pandemic continues. It is hoped that shifts in attitude would lead to a societal revolution in care and support for older people as the pandemic shows us how the current system is breaking down.*

Design/methodology/approach – *This is a personal insight into the plight of the care home sector during the COVID-19 pandemic in the UK. The writer has worked in the field of social care and older people's services for many years and felt compelled to share her learning and observations. This led to venturing more deeply into understanding why those who live, work and visit care homes have been so neglected and "cast into the shadows" in the face of such desperate danger. Whilst tracking the media narrative during the first wave, she attempts to apply her knowledge, in particular gained from working for Help the Aged (now Age UK) as a policy manager for Quality Care, but also draws on experiences as a social worker, commissioner and care provider from the 1980's to the present. By "shining a light" on care homes, revealing that the darker practices that have taken place contravene the Human Rights Act 1998, it is hoped that the recognition of age discrimination will happen at every level and become better known in its application. The paper observes how deeply rooted it is in us all.*

Findings – *Having highlighted some shocking examples of bad practice from the authorities relating to care homes, the article concludes that Government policy on care homes from March to July 2020 was discriminatory and questions how far lessons have been learned. The legislation is in place in the form of the Human Rights Act 1998 to protect older people in care homes but is not being widely implemented at regional policy level. Government rhetoric remains far from reality Instead of redressing the gap and admitting mistakes, there is evidence at a high level of continued denial and the projection of blame on to the care homes themselves.*

Originality/value – *The author's professional background includes meeting the founder of the Gray Panthers, Maggie Kuhn, in the United States in the 1988. This was a defining moment that gave her an original insight into age discrimination and influenced her entire career. It eventually led to her working in national policy for one of the most influential charities for older people at the turn of the millennium, Help the Aged. Here, she co-founded the My Home Life Programme (promoting quality of life in care homes). The paper offers a unique insight into why it is so challenging to achieve quality of life for older people needing care and should be of interest to policymakers, clinical commissioning groups, local authorities, older people's care providers and carer and user organisations.*

Keywords *Attitudes, Quality of life, Ageism, Institutionalised, Care homes, Residents, Human rights, Neglect, Age discrimination, Injustice, Care workers, COVID 19 pandemic*

Paper type *Opinion piece*

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> "I don't understand why I've been left alone". (Quote from My Home Life database: 'Caring Conversations Spring 2020): A care home resident living with dementia confined to their own room, to be safeguarded from COVID-19 risks.

This quote represents the perspective of many older people, wherever they live around the world, during the first half of 2020, as we were engulfed by the pandemic's effects:

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> "My staff and I feel very second class." (Quote from My Home Life: A care home manager, talking during the COVID 19 pandemic).

> "Between March and June 2020 there were 66,112 deaths of care home residents (wherever the death occurred); of these, 19,394 involved Covid-19 which is 29.3 per cent of all deaths of care home residents" ONS 3.7.20.

The above statistic shows that there was a huge increase in the number of excess deaths in care homes during the lockdown phase of the pandemic in the UK. In addition, around half of all deaths at this time in the UK (approximately 40,000) were in care homes.

Care home managers in the UK struggled from the start of the pandemic, as the spotlight was entirely on preventing the National Health Service (NHS) from being overwhelmed. Care homes have always existed in the shadow of the NHS, "second class" to the "World class NHS", and never more so than during this first phase of the pandemic. As a collective panic overtook the nation in March 2020, after an initial period of inertia and denial and despite events seen in China, Italy and Spain, there was feverish activity to eject patients from hospitals and to build extra capacity within the NHS. It was as if the care home sector was engulfed in darkness. Once older patients were out of sight and away from the care of the NHS, they were set out of mind. They no longer mattered.

This paper explores the link between age discrimination and what happened to and within care homes during the first phase of the COVID-19 pandemic in the UK. It highlights stark injustices, especially neglect, and seeks to deepen understanding of why things went so badly wrong for many of those living, working and, until then, visiting care homes. It attempts to illuminate what we can all learn from what happened and how to ensure care homes are brought out of the shadows to be recognized as amazing places of compassion, inspiration and care. Finally, it calls for considered reflection of what "We're all in this together" really means as the reality of the pandemic has challenged us to face the consequences for older people of a deeply divided and disconnected society.

A shift in culture in care homes from task-centred to relationship-centred care is now critical, as evidenced and promoted by the My Home Life Programme. (My Home Life, 2020a) (MHL) Social care at its best can resist institutional practices, otherwise absorbed from the NHS, to help ensure that the individual's personhood and humanity is not lost. My Home Life, a charity working for quality of life for people living, dying and working in care homes was initiated by Help the Aged in partnership with the National Care Forum and City University, London. It was supported by BUPA Giving and co-created by a reference group with key stakeholders including a care home resident. It is now an international organisation with My Home Life England based at City University providing leadership programmes for care home managers. Insights in this report have been informed by its work and the stakeholder quotes in this report are drawn from the database "Caring Conversations Spring 2020", collected by the My Home Life Programme from care home managers during the pandemic:

> "Staff at the beginning were anxious. We were on our own. But we pulled together as a family to prevent relatives worrying. We have a positive morale which has strengthened us and the team are willing to change and adapt with a lot of policy changes every day. We have regular 'huddle' meetings, appreciation awards, 2 newsletters a week for relatives so they can be reassured. Care Homes don't stop and do nothing. We are doing more!!" (Quote from My Home Life: A care home manager talking during the COVID 19 pandemic).

> "My wife cries at me on the phone now I can't see her every other day, begging me to get her out. If she gets coronavirus I'll never see her again." (Quote from My Home Life: Husband of resident, who praises the care home but now wants his wife to return home).

Introduction

In 2005, the author was policy lead for Quality Care in care homes for Help the Aged (HTA, now Age UK). I had many years of experience as a community and hospital social worker in London with older people, a residential care worker and commissioner as well as Head of Care and House Management at the Abbeyfield society. From the millennium onwards, HTA was pioneering age discrimination. My manager, Tessa Harding, was instrumental in convincing the formative Equality and Human Rights Commission to include Age alongside the other strands of discrimination. This led to the Equality Act 2010 outlawing discrimination on the grounds of age.

In May 2005, I was interviewed on national television about the consequences of not implementing the recommendations of a Care Home Market Study, published by the then Office for Fair Trading and supported by the Social Policy Age Information Network. The report highlighted the lack of power and rights of older people as consumers in the care home market. My rhetorical answer simply stated "Older people in this country will become more and more isolated and neglected. What does this say about us as a "civilised" society?"

It was difficult then to see how the country could literally abandon older people and those caring for them even though before 2020 we saw instances of covert and overt ageism. Yet, since the spring of 2020, despite the Government claim to have thrown a "protective ring round care homes at the start of the pandemic" (quote by Matt Hancock on 15.5.20 during the Downing Street briefing), we have now seen neglect happening before our eyes in real time. We have seen how this is playing out supported by continuing ageist prejudice, and how hard it is to call out.

It was weeks into lockdown before the Government noticed they were not counting the excess deaths of people in care homes. This was the ultimate in isolation for older people: to be living there, and be so insignificant as not to be counted within the country's daily death toll. We need to see how this comes from neglect and discrimination.

What is neglect?

The meaning of neglect is not just about failing to care, it is essentially to disregard and look away, which underpins our "civilised" society failing older people so badly. What has happened throughout the pandemic, and still is happening, to our care homes, gives the clearest examples of this. This is not to detract from the equal disregard for all the other services for older people who need social care, but this paper concerns the neglect of the care home sector as the stated "institutional partner" to the NHS which, by contrast, has been at the forefront of the Government rhetoric to save lives at all costs. We need to understand why this stark contrast is at best not obvious to most people and at worst, denied by those responsible for the wellbeing of every citizen from "cradle to grave".

Providing this understanding offers the path to an enlightened approach to the care of older people that values, includes and connects with those who need care near the end of their lives and those who provide this care. I draw here by learning from my own privileged experience of working with some of the most enlightened people in the health, housing and care sectors. Those who stand out most are older people themselves with their experience and wisdom.

I tracked the media narrative on care homes as it unfolded in 2020 throughout the months of lockdown. In late July 2020, Parliament, through the Public Accounts Committee, finally recognized the failures. The voices from the sector had been crying out week after week about the injustices and suffering ongoing in care homes. My observations have been sharpened by the lens of age discrimination in a wider context where all aspects of discrimination have been strongly playing out during the pandemic. Black Lives Matter, in particular, illustrates the deep historical wounding from long term social injustice. It is no

coincidence that much of the social care workforce is affected by many strands covered by the Equality Act 2010, in particular sex and race. Finally, a report by Amnesty International entitled 'As If Expendable' has now been released offering evidence that Covid care home policies as 'violating human rights' (p. 48). This calls for a 'full independent public inquiry without further delay, grounded in a human rights framework'.

As the pandemic has catalysed the inequalities and injustices in our society, so, to stop more suffering, we must dig deep to enable a paradigm shift in attitudes to each other and re-envision our society as less self-obsessed and more connected.

Thanks to advances in medical care, we now live twice as long as we did 150 years ago. Our increased longevity should be a cause for celebration, yet despite science overcoming many challenges to achieve this, ensuring quality of life during our extended years eludes us. We need to place priority on a life that is worth living.

COVID-19 is simultaneously "discriminatory," in affecting black and minority ethnic people, older and people with underlying health issues more, yet also a "great leveller" as anyone can get it. Neither is true. COVID-19 is a virus; it does not have a mind for formulating beliefs which lead to individual and societal attitudes. It is people who can be both discriminatory and equalisers. It is up to us how we respond to the challenges posed by the virus. A virus cannot be held accountable!

Part one: Care homes in the shadow of the pandemic

> "Everything that we see is a shadow cast by that which we do not see" Martin Luther King Jr, 2013. From *The Measure of a Man 1959*.

Ageism leads to age discrimination. In 1988, I met the Founder of the Gray Panthers (The New York Times, 1995), Maggie Kuhn, at her home in Philadelphia, USA. She was a friend of Robert Butler, a gerontologist whose greatest impact on the lives of older people in the USA may have been his use of the term "ageism". He used it to describe prejudice and abuses committed against the elderly in a 1969 article (Butler, 1969) for a medical journal. He was one of the first to perceive the denigration and systematic exclusion of older people as equal to other kinds of discrimination related to race, ethnicity or gender. He saw that the widespread dismissal of older people as "geezers" or "codgers" harms not just them, but society as a whole. The UK caught up with its Equality Act 2010.

Ageism is an attitude of mind that leads to discrimination. However, despite this being legally enshrined since 2010, most people in the UK have yet to wake up to the damage of ageism on us all. The 2020 report by the Centre for Ageing Better, *Doddery but Dear?*, has brought us up to date with current age-related stereotypes, but the link between these attitudes and the end result of neglect of older people, as the COVID-19 pandemic is highlighting, is still not understood.

Age discrimination can be *individual, institutional, overt or covert* as highlighted in five reviews on *Ageism and Age Discrimination in Health and Social Care* (Clark, 2009) commissioned by the Centre for Policy in Ageing 2009 commissioned by the UK's Department of Health. *Individual* discrimination results from ageist attitudes which lead to older people not being valued or treated as equals, which permeates to those caring for them. *Institutional* ageism is when these attitudes are reflected in written policy and organization cultures. *Overt* age discrimination is when it is open, explicit and visible, while *covert* is when it pervades hidden conventions and subconscious attitudes, as in the earlier examples given here.

Why do we discriminate? Death remains one of our society's largest taboos and fear and denial of death, may well underlie ageism. Although we all face death, few of us have seen anyone die as most people die in an institution, typically hospital. Therefore we are not in control of our natural journey nor are our wishes always heard and respected. The end of life

care in hospices, where institutional practice is minimized, offers an excellent model of integrated health and social care, but sadly usually only available for those with cancer.

One of the darker clinician practices alongside the nownotorious practice of knowingly discharging patients with possible COVID to care homes was the way a do-not-resuscitate order (DNR) was applied in some cases during the pandemic. A DNR is a legal order indicating that a person does not want invasive intervention to prevent them dying. This requires sensitive discussions with a person about their wishes towards the end of their life and can be designed to empower frail older and disabled people. However, instructions were given to some care home managers to apply DNRs to *all* residents. Ignoring the individual's wishes and medical condition is to blatantly contravene the Human Rights Act 1998, Article 2: the right to life:

> "Did anyone else get given a huge set of blanket DNRs for the entire Home? What kind of message is that? I did not do it. I purposely did not follow it. Thankfully they all stayed well". (My Home Life, quote from a care home manager).

This is an example of a home manager resisting extreme overt discrimination exerted through a most powerful institution, the NHS. Such resistance would have taken great courage on this and other managers' part, and largely go unrecognized and unsupported.

Low status. The terminology used for workers in social care is unclear to most people. "Healthcare" and "key workers" are not widely understood as being in the category of social care. Many supermarkets and retail outlets therefore offered generous discounts to those in the NHS but denied to social care workers who do not possess an NHS card. This makes the label of a "Cinderella service" resonate more strongly as care workers are excluded from special treatment by a retail outlet. One care worker even described people tutting at her for wearing her carer uniform in the street between home visits.

Institutional and overt inequality: Government attitude to social care compared with the NHS written into policy

Social care wages

At least half of frontline staff in social care are paid less than the living wage. Most are women. According to the Resolution Foundation, care workers are four times more likely to be on a zero-hours contract than the average worker. These contracts bring all the disadvantages of "no work, no pay" which compromises those who need to self-isolate, perhaps having picked up the virus from working in a care home. The Home Office view that care workers are "unskilled" shows a lack of understanding of the nature of care work.

I have witnessed the extraordinary skills that all care workers, at all levels, need as they are now increasingly required to perform tasks previously deemed "nursing" tasks. To label as "unskilled" someone who is able to calm down a distressed person in the last stages of dementia in order to wash, dress or feed them, is insulting. Why do we punish our "angels" in social care while eulogising those in the NHS? There appears to be a false and devaluing divide between personal and nursing care, depending less on skill or merit than on who their employer is.

Inequalities between health and social care

The NHS is centrally-run and funded. Social care is delivered by local government authorities (LAs) and most of the care is contracted out by them. Both are our "giant pillars" of care, yet underpinned by different legislation. LAs are responsible for social care delivered under the Care Act 2014. They struggle in practice due to underfunding, as they assess only those with high care needs and deliver mostly through contracts. Around 80% of beds are in "for profit" private sector, 13% in not for profit independent sector and 4% in LAs. Around 53% of people pay for their own care, 43% are paid for by local authority.

"Looking away" has played out since the 1990s social care underfunding has been ignored by successive governments and placed in the "too difficult" pile. Despite holding five independent commissions and publishing twelve government papers, none have been implemented. The underlying problem has been setting an inadequate LA fee rate at the time of the Community Care Act 1990 setting up a constant source of friction between providers and LA commissioners when setting annual fee rates. The funding of care home placements were based on the supplementary benefit level set by the then Department of Health and Social Security to cover the "hotel" cost of the accommodation and care. So the cost of care was greatly underestimated. Those who needed "nursing care" were entitled to NHS Continuing Care funding for long-term care. The LA fee rate was based on the supplementary benefit level allowing older people to be housed and fed, but with no extra amount to meet their physical, psychological and emotional needs. Care providers therefore struggled to offer an environment to enhance their quality of life, or to place meaningful engagement and activity at the heart of the culture of care. The average LA rate is £650 per week while the average cost of an NHS hospital bed is around £2,500.

The inequality between the NHS and social care sectors widened with the amount of funding the Government allocated each to manage COVID-19 at the start of the pandemic. The NHS had £6.6 billion whilst social care had £1.6 bn. This was compounded by the NHS receiving the money directly and social care providers depending on their LAs to distribute the funds and personal protective equipment (PPE) they needed, and where a proportion of the money did not reach the frontline. Care providers are widely seen to have been forced to source and self-fund their own PPE throughout the pandemic, passing on part or full costs to the residents. This continues with July 2020 Government announcement of injecting another £3 bn into the NHS to "prepare for a possible second wave" yet failing to balance this with extra funding for social care.

Fixing their focus on protecting the NHS, the Government was slow to attend to care homes. As the virus started to spread globally, the Government's scientific advisors (SAGE), met regularly to advise the ministers. Not one adviser has specific expertise on old age or social care. In February much SAGE time was spent planning how the NHS would cope. While 400,000 people live in care homes in England, official minutes show that care homes did not appear on the agenda for the first eleven meetings.

Care homes received a "blizzard" of confusing guidance from the DHSC not clearly written for busy care home managers. Many made their own decisions about protecting residents and staff and locked down, with no support, before the Government picked up the mandate. Some care workers made the ultimate sacrifice of leaving their families for months and moving into their care home to protect the residents.

Approaching the peak of the pandemic when NHS beds were desperately needed, there were two stark examples of overt age discrimination. One was when hospitals were told on 19 March 2020 (DHSC Coronavirus [COVID-19], 2020) to discharge vulnerable people into care homes without proper testing and when a system for testing and tracing was still being worked out as "You have the facilities". Around 25,000 patients were discharged from hospitals to care homes to free beds. The cross-party Public Accounts Committee has recognized this as a "slow, inconsistent and at times negligent" approach to social care (Commons Report Public Accounts Committee, 28.7.20).

When care homes then found themselves with residents infected with COVID-19, some could not access clinical support from the NHS. In "The ones they couldn'*t* save", the BBC's *Panorama* television programme reported Alison Holt following two care homes during the pandemic, with a nurse working alone overnight looking after a dying resident, graphically describing his anguish at facing such a challenge as the prescribed drugs were not working:

> "In a hospital I would have turned to senior doctors for advice. Instead I was going on YouTube, on NICE guidelines, trying to find better ways to help. It didn't. I've failed Bryan".

Another example of overt discrimination has been the struggle for care providers to source PPE constantly placed second after the NHS. BBC *Panorama* investigators, broadcasting on BBC1 on 31st July 2020 reported questionnaire responses from 124 care-home providers, 71 of whom felt pressured by councils and hospitals take hospital discharges who had not been COVID-tested 73 felt pressured not to send their residents to hospital and 92 saw GPS and other medical staff as reluctant to visit in March and April. They also found managers claiming their supplies were diverted to the NHS, leading prices to skyrocket.

Tagging onto a consultant-headed medical team, my experience as a social worker in the 1980s was being blamed on the ward round for not getting the older patient out of hospital quickly enough. We put the argument that premature discharge home without having time to set up services would lead to readmission, but the alternative, was being prematurely admitted, against their choice, to a care home for the rest of their life. Their frustration that I was employed by the LA and could not be overruled was palpable. Seeing bullying of care home managers this year to take patients without being tested has not been surprising.

From this experience, differing values could be seen to be translated into practice. Hospitals are the domain of science-based medicine, designed to deliver excellent acute care free for all at the point of delivery. When sick, a doctor will prescribe treatment to target the ailing part of the body. Social care is mostly about care for those with chronic health conditions, needing to focus on the whole person and their need to be in control of how their care is delivered.

Whilst I have seen many NHS workers transcend the top-down pressures from March 2020 to focus more narrowly, many succumb in desperation to move the hugely increasing numbers of patients with complex conditions through the system. These pressures contribute to the transfer of patients without testing for the virus, with catastrophic results for so many.

On April 9, 2020, Richard Horton, editor of *The Lancet*, wrote an opinion piece in the Guardian about our knowing the pandemic was coming but not being prepared. He quoted Goethe, referenced by the US Institute of Medicine in 2004, evaluating the lessons of the 2003 SARS outbreak: “Knowing is not enough; we must apply. Willing is not enough; we must do.” He concluded that SARS had been a warning, and that continued vigilance was vital.

A new coronavirus strategy for adult social care was published in early April after the outcries from care homes and other providers about their struggles with PPE shortages and access to testing.

Testing before discharge from hospital to care homes was finally required on 16th April.

Part two: Care homes moving out of the shadows into the light

> “Sunlight is said to be the best of disinfectants” Justice Louis Brandeis on the need for openness and transparency.

The pandemic may have finally pushed social care to the buffers. The care providers that have managed to deliver a different approach to care from the traditional institutional practices have been swimming against the tide. Housing with Care organisations such as the Extracare Charitable Trust offer a space with “your own front door” with a focus on involving tenants and with a choice of activities. Residents where care homes embrace initiatives such as National Activity Providers Association, the MHL, Ladder to the Moon, among many espouse, may experience better emotional connection with others in the home as they increasingly emphasise reflective practice and relationships. This combination of developments has created a watershed moment for reform so that these organisations with their focus on the person being central to the delivery of care can become mainstream.

Furthermore, the proclamation "we're all in it together" sounds hollow to all those in need of and who provide social care. The multiple disconnects in our society need to be joined. Starting with connecting the generations, we must not see the younger generation turn against older people as they bear the brunt of years of government mismanagement. Family relationships need to be strengthened and fractured relationships healed. Communities need to reconnect. As a higher level of unemployment looms there is never a more important time than now to reconsider our own assumptions and prejudices about others. The only way this can happen is for our country's leaders and policy makers to embrace the understanding of why we have neglected older people and those closest to them during the most desperate time of danger to our population, and shift their focus to considering what they have previously overlooked. Black Lives Matter has spurred the nation to do this for our black and minority ethnic citizens. We must do the same for older people. This is the way out of the darkness, and it starts with taking a long hard look at ourselves.

Going deeper: facing ageing, tackling fear and ignorance, sticking to our beliefs and connecting with each other

Where and how do we want to live in our old age? A positive attitude to ageing is a major element to improve quality of life. We should look forward to older life by being proactive and managing what we need, along with the transitions of physical change and nurturing our relationships. Connecting to a local community and age-proofing housing could make all the difference to maintaining independence and postponing the need for care, if required at all.

Death. We all need to face our fears and deal with them. We need to break the taboo about death and bring it out of the shadows. Death is part of life and the lessons that help us die well, also help us to live our lives better. The help and information is available to plan for a good death, with guides published by charities. This empowers us all and protects us from not being in control at the end of life.

Values. What we believe determines what we think, which leads to how we behave. The greatest antidote to ageism is a shift in attitude and beliefs. In my experience the best care settings which provide quality of life to those who live, work and visit are those that are led by their values. Witnessing dignity and respect being embedded in a culture that underpins relationship-centred care is seeing the light shine on care of older people.

Our communities. Humans are social animals and we need each other. However, as families have dispersed, communities have fragmented and older people have become increasingly excluded. The pandemic has hit these communities hard with lockdown literally isolating people from each other and social distancing becoming the new normal. Sarah Wren, CEO of the Hertfordshire Independent Living Service, delivering vital services to people living in their own homes, spoke to me as the pandemic entered its fourth month:

> "Never before have I seen such unprecedented levels of loneliness and isolation amongst older people than I'm seeing now. It's heartbreaking. I'm truly shocked and appalled at their lack of voice at this point and how few people seem to understand this".

Collective, collaborative and creative thinking within a calm environment offers a way forward. This requires courageous leadership to promote shared values such as mutual respect and fairness.

What is the light?

The My home life programme

The My Home Life Programme (My Home Life, 2020b) is a movement for change in care homes across the UK and internationally. In 2006, it was co-created by the author at HTA with Tom Owen, the then Research Manager. We saw the need to eradicate blame

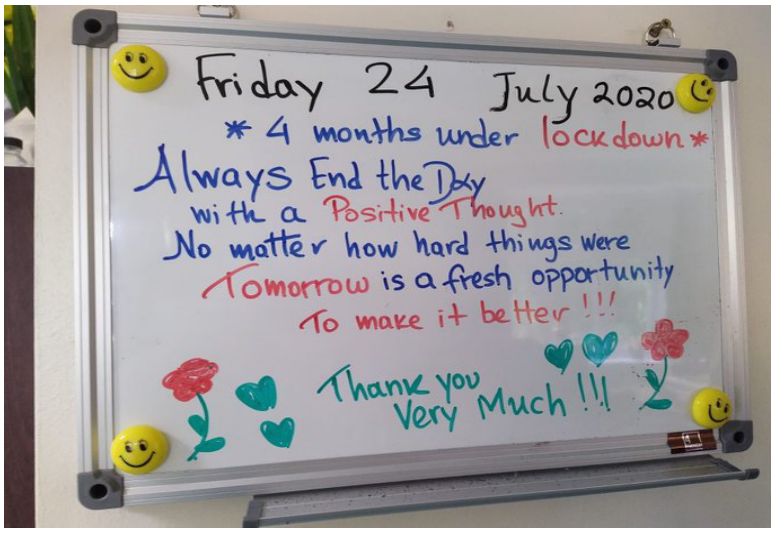
in the care sector and replace it with respect and responsibility in order to improve quality care. Every stakeholder was brought in to co-produce the programme envisioned to grow with everyone buying into the essential principles. It has since built a network of individuals working in care homes across borders, after completing the MHL Leadership and Support Programme to connect with each other to support and exchange ideas on best practice. These ideas are embedded in relationship-centered care, to improve relationships between professionals and help close gaps between health, housing and care workers and easily conveyed by social media, across the world. Healthy, caring and re-energising relationships can be sustained despite the hardship, by staying positive, adopting guiding principles of developing best practice based on evidence from care home residents' perspective, being appreciative and having caring conversations (Figure 1).

The Care Act 2014 superseded the Community Care Act but does not apply to the NHS. Local authorities now have a duty to maximise the wellbeing of those needing care and support through personalised care and support plans. Anyone receiving care and support from a regulated provider and arranged by the council will be covered by the Human Rights Act 1998. Older people living in their own homes should have more choice than previously and receive care in their own homes, if they wish. They may have a personal budget in order to choose their own carers and will be responsible for employing them. Once more the lack of funding has undermined its laudable principles. It was hoped that new ideas for care provision would come to the fore, but they remain on the margins and are not mainstream.

Different models of care

The traditional options for care other than families caring, are living in your own home with carers visiting, sheltered housing or a care home. However, there are others that are not so widely known. The most promising models are those that allow for the generations to interconnect, for example, increasing numbers of care homes inviting day nurseries to bring in small children to engage with residents.

Figure 1 Photo is from Frithwood Nursing Home, Northwood, London in a tweet



Source: https://twitter.com/MyHomeLifeUK/status/1286619801469812743

Other examples of new models include the following:

Shared Lives Plus is a membership charity for a "kinder, stronger society" built on families sharing their lives and homes with people who need support.

Homeshare, now within Shared Lives Plus, is a concept founded by Maggie Kuhn. An older homeowner who needs support will house a younger person who needs accommodation. A careful matching process is used to set up a unique partnership that can enrich the lives of both parties.

Assisted living, housing with care, extra care housing and care villages all provide dwellings for living on your own but with care provided when you need it. Information on care options can be found on the Care Choices website which provides a comprehensive guide to care provision. (www.carechoices.co.uk)

The Abbeyfield Society, founded in 1953 by Richard Carr-Gomm, is a non-institutional option, reflecting a widely-shared vision to tackle loneliness and isolation by offering communal living in the heart of the community.

Conclusion

COVID-19 is here to stay. Care homes experience has been very far from being better protected and "having arms wrapped around them"; they were actually silenced, put out of sight and out of mind. The UK already has the legal framework to stop age discrimination, with the *Human Rights Act* and the *Equality Act*. The gaping hole between the legislation, policy and practice must be closed. Reports such as that by Amnesty International may encourage many more older people's organizations to ensure the voice and rights of older residents are heard and recognized. There is a critical role to close the hole for the politicians, Clinical Commissioning Groups, family physicians, local government and, nationally, the Care Quality Commission. This must be done without delay.

This requires a transformational style of leadership in organisations, which can create relationships and motivation among staff members. Fear and blame must be eradicated. Instead we must recognize that open and transparent organisations and governance at national and local levels, are vital.

The future of social care is again being considered by Government. However, still deep-rooted ageism heightens the risk of new policy continuing as tainted. There is a space for a radical counter-movement such as the Gray Panthers founded by Maggie Kuhn, to run with Black Lives Matter, seeing all issues of injustice as inevitably linked. In the 1970s, Grey Panthers, focused on peace, presidential elections, poverty and civil liberties alongside the Black Panthers.

The Royal Society of Arts recent report recommending a "People'*s* Health and Social Care Commission' to ensure that any large-scale change is people-led is exciting. This would create change in the Health and Social Care systems that supports all citizens and should build in safeguards to deter discrimination. However, without the voice of older people being heard, such a report will gather dust.

Are the lessons being learned by those who need to learn them?

I am not optimistic. The blame game continues. On 6th July 2020, the UK Prime Minister, Boris Johnson told journalists that "too many care homes didn't really follow procedures" during the pandemic, implying that this increased the virus' spread and it was their fault. Public reaction against this was strong.

The rhetoric remains distanced from reality. The ongoing struggle of care homes to fight the virus is constantly in the news. The Government's "looking away" from care homes has helped the virus become endemic in the UK, so everyone remains at risk. Despite the

Department of Health and Social Care (DHSC) announcing on 3rd July 2020 that staff would be tested weekly and residents every 28 days to prevent the spread of the virus, staff in English care homes were still not being tested weekly for COVID-19 after that date (Nursing in Practice, 28.7.20).

The PAC Chair, Meg Hillier MP, has summed up the position of the national care home sector:

> "The failure to provide adequate PPE or testing to the millions of staff and volunteers who risked their lives to help us through the first peak of the crisis is a sad, low moment in our national response. Our care homes were effectively thrown to the wolves, and the virus has ravaged some of them. The deaths of people in care homes devastated many, many families. They and we don't have time for promises and slogans, or exercises in blame. We weren't prepared for the first wave. Putting all else aside, government must use the narrow window we have now to plan for a second wave. Lives depend upon getting our response right".

The irony seems lost on a Government which rightly recognized Sir Captain Tom's heroism for raising millions for the NHS. Yet many of his generation who live in care homes also fought in World War 2 to secure our freedom and are also heroes. They should be cherished alongside all at most risk from COVID-19 within a genuine "protective ring" of empathy, respect and dignity. None of us want to live in the shadows in our old age, as victims of age discrimination: shut away in a care home, invisible in sheltered housing or lonely and isolated in our own homes, too scared to move. We all want to live in the light wherever we live: within our local communities, choosing to participate or not, but always connected to our friends and relatives. We want our spirits to soar: to enjoy the arts, laugh, dream, follow our passions, as the older we get the more we know that this is how we connect with others and ourselves. Above all we want to die when it is our time, not when others determine it because they do not value older people. Whatever their age, no one should be denied this.

Is the "narrow window" to which Meg Hillier refers, now open enough to let in the light for the care home sector in the UK?

References

Butler, R. (1969), "Age-Ism: another form of bigotry", *The Gerontologist*, Vol. 9 No. 4 Part 1, pp. 243-246, doi: 10.1093/geront/9.4_Part_1.243.

Clark, A. (2009), "Ageism and age discrimination in social care in the United Kingdom, a review from the literature", *Centre for Policy on Ageing*, available at: www.cpa.org.uk/information/reviews/CPA-20ageism_and_age_discrimination_in_social_care-report.pdf (accessed 10 November 2020).

Department of Health and Social Care (2020), "Coronavirus (Covid-19) guidance and support press release: regular retesting rolled out for care home staff and residents", available at: www.gov.uk (accessed 3 July 2020).

DHSC Coronavirus (COVID-19) (2020), "Hospital discharge service requirements 19.3.20", available at www.gov.uk/government/publications/coronavirus-covid-19-hospital-discharge-service-requirements Institute for Health Metrics at the University of Washington. www.bbc.co.uk (accessed 15 July 2020).

Martin Luther King JR (2013), "(Reprint of 1959 edition) *The measure of the man* Martino fine books".

My Home Life (2020a), "Caring conversations spring 2020", available at: www.myhomelife.org.uk (accessed 24 July 2020).

My Home Life (2020b), "About us", available at: https://myhomelife.org.uk/about-us/ (accessed 10 November 2020).

The New York Times (1995), "Maggie Kuhn, 89, the founder of the Gray Panthers, is dead", Section 1, p. 47.

Vollset, S.E., Goren, E., Yuan, C.-W., Cao, J., Smith, A.E., Hsiao, T., Bisignano, C., Azhar, G.S., Castro, E., Chalek, J., Dolgart, A.J., Frank, T., Fukutaki, K., Hay, S.I., Lozano, R., Mokdad, A.H., Nandakumar, V.,

Nandakumar, V., Pierce, M., Pletcher, M., Robalik, T., Steuben, K.M., Wunrow, H.Y., Zlavog, B.S. and Murray, C.J.L. (2020), "Fertility, mortality, migration, and population scenarios for 195 countries and territories from 2017 to 2100: a forecasting analysis for the Global Burden of Disease Study", *The Lancet*, doi: 10.1016/S0140-6736(20)30677-2.

Further reading

Amnesty International (2020), "As if expendable: the UK government's failure to protect older people in care homes during the Covid-19 pandemic", available at: www.amnesty.org

British Broadcasting Corporation (2020), "Panorama 'the forgotten frontline' (accessed 31 July 2020)".

Horton, R. (2020), "Opinion: coronavirus is the greatest global science policy failure in a generation", available at: www.theguardian.com/uk (accessed 9 April 2020).

Kuhn, M., Long, C. and Quinn, L. (1991), *No Stone Unturned: The Life and Times of Maggie Kuhn*, Ballantine Books.

Mimi Launder (2020), "Care home staff not tested because of delivery lag. Nursing in practice", available at: www.nursinginpractice.com (accessed 28 July 2020).

Office for National Statistics (2020), "(last updated 3 July 2020 by Sophie John) Deaths involving Covid-19 in the care sector, England and Wales: deaths occurring up to 12 June 2020 and registered up to 20 June 2020 (provisional) ons.gov.uk".

Office of Fair Trading (2005), *Care Homes for Older People in the UK. A Market Study*, London, Office of Fair Trading.

UK Parliamentary House of Commons Report (2020), "Public accounts committee (29.7.20) readying the NHS and social care for the COVID 19 peak", available at: https://publications.parliament.uk/pa/cm5801/cmselect/cmpubacc/405/40502.htm

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