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A 'Hitchhiker's Guide' to Caring for an Older Person Before and During Coronavirus-19.

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Abstract

The coronavirus 19 (COVID-19) has reconfigured working lives with astonishing velocity. Older people have suffered the worst effects of the pandemic, with governments marginalising or overlooking their needs. Women perform the majority of care for older people, often compromising their working lives and health. Yet in academic articles their voices are often filtered or aggregated in quantitative studies. Based on a weave of personal experiences and secondary research, the paper traces a path through UK forms of care and shows how the inadequate response to COVID-19 stemmed from existing policies embedded in health and social care. COVID-19 has severed important informal care work, rendering the vulnerable yet more exposed and carers anxious and bereft. Longitudinal research capturing the trajectory of care from the perspective of older people and their carers would lead to improved support hence gender equality.

Key words

Care, Older people, Informal care, COVID-19, healthcarework.

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Introduction

Everyone is experiencing their own forms of loss and change with the COVID-19 pandemic. People are dying at an alarming rate and their loved ones are shocked and grieving. Many are having to wrestle with work at the same time as childcare. Others are separated from loved ones at a time of great anxiety. But what if you are a carer for an extremely vulnerable loved one whom you have had to place in a care home? You have never seen the insides of the care home because it was in lockdown. The hospital authorities wanted to free up beds for COVID-19 patients, so the transfer was speeded up. In less than a week your very frail Dad was transported by strangers from a geriatric hospital ward to this place. He is less than two miles away, confused and intermittently delirious from battling repeated infections, yet you cannot visit him. You can drive past the care home, drop items off for him and contact it by phone and get them to help you skype with him. But you cannot go in and stay for a while, comfort your Dad, do small things that you know he likes, get to know the staff and help with his care.

You wait at his house with fingers crossed as you are aware that if the virus gets in the care home your Dad will in all probability die, frightened, alone and without you. Every day you are assaulted with news reports of the virus creeping closer and closer to his care home. You are angry, because the sad toll of older people deaths is only latterly being considered worth putting in the statistics. Although in the UK one 99-year-old is rightly treasured for raising £32 million pounds for healthcare workers (BBC, 2020), all the other over 70-year olds are treated as though they are disposable. They are the ones who suffered war and rationing, voted for the National

Health Service, brought you up, yet they are not worth counting in death statistics. The people who care for them are last in the line for personal protective equipment or testing. Meanwhile, your own work goes on. Undergraduates are anxious about their final year assessments, PhD students produce drafts for reading, editors want reviews and you are aware you are behind with your writing.

The COVID-19 experience reminds me of the beginning of Douglas Adams' radio programme 'Hitch Hiker's Guide to the Galaxy' (1978). The first chapter is about a character Arthur Dent who wakes up to find there are people with bulldozers outside his house. He was not aware that his house is to be demolished to make way for a new bypass. In an instant his past life is flattened. However, a strange connection with a friend leads on to a new life of galactic travel. Arthur voyages to a series of different destinations where he meets new people and learns new things. COVID-19 has demolished much of our lives and assumptions, and we are navigating our way through a strange, unfamiliar environment.

I think my Dad has experienced this process before us, as he encounters different forms of 'care' while his health fails. From the stability of living in the same house for 50 years, he has had to cope with three different 'new normal' settings in the space of 6 months. Initially, my brother and I supported him to stay in his own home.

Progressively he ceded many tasks to us such as driving, shopping and finances. All three of us found it difficult to reconcile the ageing Dad with the Dad of his heyday.

At the core was his desire to stay at home. In October he had a serious fall and the ambulance came in the middle of the night to rescue him. Since then he has been

transported to 3 different organizational 'planets'. At a time when his cognitive faculties and memory are failing, he must cope with unwanted intrusions and systems that cannot accommodate his cherished ways of doing things.

This paper presents a kind of Douglas Adams' 'Hitch Hiker's Guide' (1978) to navigating work, COVID-19 and older people's care. I structure it like Adams' original radio series. Episodes weave vignettes of my experiences of caring for Dad as he travels through different care settings with strands of expository material about the spread of COVID-19 in the UK, its care system and work with older people. I construct the paper from qualitative materials such as text dialogues, emails, diary entries and recollections. The expository material is derived from secondary sources such as journal, government, charity and media articles.

Caring for older people is a gendered topic (Ravenswood and Harris, 2016). The vast majority of carers are women. If they are paid at all they are working for the minimum wage or not much better. There is a considerable literature on older people and caring for older people. Like women and work, older people are seen as problems to be solved rather than treated respectfully. Some articles mention the care of the elderly, but they are bracketed after others (see for example Emslie and Hunt, 2009). There is comparatively little research that charts the experiences of relatives caring for older people through a variety of care experiences. I argue that there are strong feminist concerns about the undervaluing of older people's lives, the low pay of carers, and unpaid gendered labour that has resulted from the monetarist policies for social care. It has disproportionately affected women. For me, the

COVID-2019 pandemic in the UK has brought caring work for the elderly into sharp focus.

Planet COVID- 19

In late December 2019, a strain of respiratory illness emerged, a new form of coronavirus. The first cases were formally identified on the 31st of December 2019 and within a month the World Health Organization labelled 'COVID-19' a problem disease for all nations. Then on March the 12th the official classification changed to a global pandemic, as the disease had spread so rapidly. People who catch COVID-19 can suffer a range of effects from no or mild symptoms ranging to serious breathing difficulties and organ failure leading to death. Older people and those with an underlying health condition are more likely to experience severe effects. The virus has spread extremely quickly. Every government has put in place their own processes to address the healthcare crisis.

The UK government advised people aged 70 to shield for 12 weeks. They are supposed to 'self-isolate', meaning keep away from other humans and stay at home. However, older people are dying in their thousands, they have not been shielded enough. Hans Kluge the Regional Director of the World Health Organization for Europe delivered a statement on the 23rd of April, 2020: 'According to estimates from countries in the European Region, up to half of those who have died from COVID-19 [55,000] were resident in long-term care facilities. This is an unimaginable human tragedy.... Even among very old people who are frail and live with multiple chronic

conditions – many have a good chance of recovery if they are well-cared for. This pandemic has shone a spotlight on the overlooked and undervalued corners of our society. Across the European Region, long-term care has often been notoriously neglected’ (Kluge, 2020).

April 22nd, 2020

I have spent the morning drafting the introduction of this article and decide to break for lunch. I find it difficult to return to the article afterwards. I watch the 12.30 briefing on television from the First Minister of Scotland, Nicola Sturgeon. Wednesday is the day they present the real death statistics from the National Records of Scotland. The ones on other days are about testing, hospital cases of the disease, Intensive Care Wards and Ventilation. The death statistics are horrendous. Nicola admits reading them out is the worst task she has ever had to perform. In the last week, 637 people have died of COVID-19 in a country of 5.4 million people, bringing the total to 1,616. Of the COVID-19 deaths, 910 occurred in hospital, 537 in care homes, 168 at home or a ‘non-institutional setting’ and one person has died in an ‘other institutional setting’, a prison. Over 600 of these deaths are people over 85, and the majority are male (National Records of Scotland, 2020). I flood with a mix of emotions at the news of all these deaths and start crying. All of these families are dealing with their grief in such awful circumstances. I text my brother and he phones immediately. He has been watching the same briefing and it triggered him too. We discuss our responses to the news. We are both angry at the death rates, especially in care homes and how the people in them seem to be left to rot with the virus.

Accepted Article

At the prompting of hospital staff, we took a joint decision to shield our father in a care home. We thought it less likely he would be exposed to the virus in a smaller care home than in the hospital. However, for weeks the government did not even report deaths in care homes. The Scottish government started reporting care home deaths weekly from April the 15th, the UK from April the 28th although the lockdown began on March the 23rd. There is a constant flow of items on television news about care home deaths and problems with sourcing personal protection equipment (PPE). Some carers have left their families and moved into their workplace to help shield residents. There is a deathly silence about whether a COVID-19 sick person in a care home would be transferred to hospital, although the first minister of Scotland is reporting that hospitals are not at full capacity. I am finding it difficult to concentrate on work. I need to read and comment on drafts of two PhD students' thesis today and finish a review for a journal article. What is going on in Dad's care home? Is he ok? My only insight is via a laptop camera lens.

April 21st, 2020

'Are you seeing me Lynne?' asks the cheery carer. She is smiling, unmasked into the laptop camera while taking it along a corridor to our Dad in his room. The room is decorated like a nice country house hotel. She puts the laptop on a table facing my Dad and says 'It's your daughter, Bob! Lynne!' I say hello to Dad and smile. My 96-year-old Dad looks quizzically at the laptop, examining the keyboard. He has not used a laptop before the last three weeks. The carer asks him if he can see me. I wave and he registers it is me. I join my nephew into the call. Dad is pleased to see his grandson. My nephew pans out his camera and shows Dad his wife and small

baby. The baby is waving, and he bears a strong resemblance to my brother at that age. Dad is smiling and happy. He talks as if he has not talked much that day. He forms the words with difficulty at the start though after a while he gets better. My nephew wants to show his grandad some decorating he has been doing in his flat. He takes his laptop through to the room and shows with pride the precise decoration for his new son. I am pleased. Dad decorated his home with precision and care – I should know, I am sitting in it. Dad then has a 'one of his wee turns' which means he seems conscious, but he does not respond to us. We are anxious and ask him if he is ok. After a time, he rouses and answers. My nephew returns to his wife and son and we have another short chat with Dad happy looking at the baby. Then it is obvious Dad is getting tired and we gently end the chat by wishing him well and telling him we will see him again soon. I feel guilty I am not there to be an advocate for Dad or check that he is being cared for thoroughly.

The video call happens after 6 pm. I have been working today with colleagues on a progress meeting for a PhD student then researching the care sector for this paper. The communications work intermittently – I have no Wi-Fi. I have fibre broadband at my own home, but the company will not transfer it to Dad's. I manage with 2 phone data packages, one of them has a poor signal but limitless data. Work is the main reason I consume gigabytes of data, yet they would not consider paying the bill now we are 'working from home'. I am not alone in subsidising university work.

Apparently, we can claim a tax deduction. My printer is beside the Wi-Fi router- not here. I like to read text on paper- you comprehend more (Akerman and Lauterman, 2012). I have also been told to protect my hands by switching from screen to paper regularly. Work will not ship a printer to me.

On the upside, Dad's house is incredibly peaceful, with birdsong and Spring flowers in the garden. I am living a life remarkably like the one I lived as a child in the 70's, static and home-centred. When I am not doing Management School work, I am spending my time much as I did at school: short bursts of knitting, playing the piano and drawing. There are beautiful parks nearby for my once a day outside exercise. Preparation of food takes longer, and I think of my Mum and how she lived in the house. As Dad's not physically living here anymore, there is time for music and memories. My parents' more vibrant younger selves are very present, and I am conscious of their influence. It is difficult to take in Dad's sharp decline in health.

In the UK, there are 5.4 million people over the age of 75 (AgeUK, 2019). 500,000 of them over 90. Most people over 75 live at home, with 410,000 living in care homes (Competition and Markets' Authority, 2017). The Care home sector in the UK is worth an estimated 15.9 billion a year, with about 5,500 different organizations running 11,300 homes for older people. All except for 5% are run by independent organizations, a mix of profit, non-profit and charity providers. Local government commissions care homes to provide nursing or residential care. Most people must fund on average £44,000 a year (2016 rates) to pay for the cost until their wealth falls below a certain level and the local government pays (Competition and Markets Authority, 2017). In contrast, front line care workers receive the minimum wage or even below and are more likely than other workers to be on zero-hours contracts. 83% are women, of whom 18% are Black and Minority Ethnic people (Resolution Foundation, 2020). Where does the money go? A report by the independent

thinktank 'Centre for Health and the Public Interest' (Kotecha, 2019) showed that the private companies with the biggest number of care homes structured their businesses in a complex way. They secured a higher proportion of the income than they otherwise might through a series of linked companies. £120 of the weekly cost of being in care goes on rent for things like beds and the buildings. However, 45% of this sum was the company in effect paying another part of the company. The large care companies were registered in tax havens, not the UK. As with rail and the public financing of construction projects, the public ends up paying more for the service when it is privatised.

Two Horrible Narrow Escapes

17th April 2020

A news article reports that 20 people have now died in a care home we visited to see if it would be suitable for Dad. They were full at the time of our visit. We were recommended it by a friend who gave healthcare to several homes. She said that the care home staff really cared about their residents. When we visited, we saw that the carers and residents had a very good relationship. So many people will be heartbroken. 43% of all Scottish care homes have at least one incidence of COVID-19 amongst their residents on this date (National Records of Scotland, 2020).

13th April 2020

4 people die in a care home less than a block away from the one where Dad is a resident. It had been on our list of ones to view because of positive recommendations from people whose loved ones had been well looked after there.

We investigated possible care homes because Dad's time on planet 'Rehabilitation Hospital' was coming to an end.

Planet Rehabilitation Hospital.

Dad arrived in the geriatric long-stay hospital in mid-November 2019. We were told he might transfer from Planet Acute Hospital, but the specific day it happened I was at work. My brother ended up visiting both the hospital Dad left and the new one because nobody informed us he was moving. Planet Rehabilitation Hospital is a sprawling structure that consists of large wards connected with long corridors. Inside each ward, there are a series of rooms with 6 patients alternating between male and female occupancy. Most patients are over 70 with a range of frailties. The end walls of the rooms have glass windows and staff sit at a desk outside in the corridor looking through to check on patients while they fill in documents in paper files or type in laptops. There are a small number of individual rooms. Dad's ward had a large 'day room' with many tables and chairs and a smaller physiotherapy room with some equipment.

In the four months Dad stayed in that hospital I saw three male healthcare professionals in total – a nurse and two medical practitioners, the rest were women. Most staff were care assistants, cheerily handing out teas and scones, doing the necessary toilet and washing support and making sure the patients did not fall. They were led by a small team of nurses, again women. Nurses in the UK are paid between £26,000 and £31,000; Care Assistants about £18,000. Doctors arrived once a week on a Monday and did their rounds. The staff had long shifts. Each day they

were assigned to work in a different area of the ward. There were two physiotherapists for the entire hospital as far as I could see, who worked from Monday to Friday. They had a constant flow of patients.

The rehabilitation hospital ward seemed both well organized and caring. My brother and I divided the week into weekends and midweek with an overlap day to update each other. I covered the four days over weekends, visiting twice a day, taking laundry home and buying additional clothes and blankets for Dad. It meant that for two working days I had fragmented time and had to catch up over the weekend. I also travelled in the evenings – the round trip from work to Dad's was 584 miles each week. It was exhausting, with little time for recovery. Two periods of strike action were a relief – apart from the feelings of guilt about not appearing enough on the picket line.

Initially, Dad was put in a single room beside the nurses' station for assessment. He was very weak when he arrived, and it was with some trepidation we visited. We worked out from his records that in the 6 weeks he was in the previous hospital he had lost over 2 stones in weight (13kg). He was not overweight before being admitted to hospital. We were a mixture of anxious about the move and pleased he had got out of the acute hospital. The rehabilitation hospital staff were very good at getting him to eat and his weight loss stopped. Adequate nutrition has been shown to improve older people health outcomes (Pilgrim et al., 2016). The staff would also initiate discussions with me about him and we would collaborate in trying to help him. On my first visit, they had him in physiotherapy and working a floor pedal exerciser. I

was hopeful – maybe this would help him walk? However, it soon became apparent that Dad would be in bed or seated all day. The physiotherapists had a tiny amount of time with each patient and the ward staff did not help patients walk. Instead, their focus was on preventing falls. He moved into a space in the ward, placed next to the door so they could watch him.

The systems in place to manage patients seemed to counteract each other. He was supposed to be relearning how to walk, but in the ward there was huge anxiety about him standing or walking outside of these times. If they were short-staffed at the weekend the patients did not get out of bed at all. They monitored his vital signs several times a day, watching for signs of infection or blood pressure issues. But the work system imposed a sedentary or recumbent lifestyle that generated further health problems in patients. While at the rehabilitation hospital Dad suffered intermittent infections, including norovirus. They were swift to remedy any problem, however, he seemed to be a 'sitting duck', as did the other patients. My brother and I had an advocate role for Dad with the staff. We had to explain Dad's history and how he behaved multiple times because shift work and rotations meant constantly changing staff. Dad did not seem to recognise any of the carers, just us.

It is not surprising Dad and I found the staff rotation quite confusing. The National Health Service (NHS) in Scotland has a whole-time equivalent workforce of over 141,000. Just over 77% of healthcare staff are women. Over the last 12 years the average age of healthcare staff has increased from 43 to 46. The proportion of people over 55 has increased from 14.6% to 22.2%. Women are a slight majority of

just over 50% in the medical and dental professional group but form 89% of nursing and support staff (Information Services Division, 2019: 31). 73% of nurses are regulated professionals and just over 26% unqualified care assistants. Later the report notes that over the last decade there is an increasing number of women over the age of 40 transferring from full time to part-time contracts (ibid: 61). In addition to part-time and whole-time equivalent workers, there are 'bank' and agency staff. Bank staff are NHS employees who are called on either to cover vacant posts, or a temporary shortfall in staffing such as sickness or paid leave or provide additional capacity. Agency staff perform similar roles as bank staff. There has been a steady increase in bank and to a lesser extent agency staff over the last decade. The government reports on the cost of bank and agency staff, not their proportion of the total. The variety of employment contracts combined with the 12-hour shifts in patterns of two or three days followed by two or three days off produce a rotating population of workers in wards. Engaging with a series of staff creates its difficulties for carers. If you tell one person some information you cannot guarantee that the next person who is caring for your relative will know what you said. If you are older, unwell and out your normal environment it is bewildering.

When I spoke to the nurses about the impending COVID-19 pandemic, they were very philosophical. They were used to wearing very basic PPE to help with bodily function nursing, and the recent norovirus outbreak showed they could manage these kinds of things. We were surprised they did not lock down the hospital before the government advice for March the 23rd. The care homes nearby had been in lockdown for a week before that date. An isolation room was created at the hospital after the series of discharges to care homes freed up space and there has been a

steady flow of deaths reported in the newspapers. The staff I encountered seemed good with older people and those with dementia and I can imagine the pandemic has had a serious effect on their mental and physical wellbeing.

Planet Acute Hospital

Before transferring to Planet Rehabilitation Hospital, Dad spent 6 weeks on Planet Acute Hospital from early October 2019 because of the effects of his fall and a chest infection. He had to cope with a radical change in his daily life. From living alone, he was placed in a room with 6 other men within a larger ward. He hated it there and we hated how it affected him. He had to get used to having no privacy and it was very noisy. Shortly after being admitted he fell again after trying to get up to go to the toilet. I got the feeling that the staff were not geared for older patients – although 4 of the 6 in Dad's room were indeed over 70. Another older patient who had been told he was fit enough to go home fell going to the toilet and died the next day. The nurses responded to call buttons but did not monitor the wards in the same way as the Rehabilitation Hospital. Dad received physiotherapy sometimes, but mostly he was in bed or sedentary. They stabilised his chest infection and he recovered from the injuries caused by his falls. However, he caught two other infections while he was there. Despite very curable conditions, he seemed to be shrinking in front of our eyes. As we would later find out – he did lose 2 stones in weight in 6 weeks. They did not check he was eating sufficiently.

We were hypervigilant about his welfare and covered as many visiting times as possible. I shoe-horned as much as possible into visits to the office and worked

remotely from Dad's house near the hospital when I could. In some senses the COVID-2019 lockdown is a more extreme version of what I experienced those 6 weeks. I was anxious, had difficulty concentrating, and had a sense of foreboding although I still had to get my work tasks done. The nurses were pleasant enough but seemed busy round the desk filling in forms. It was quite difficult to get updates on Dad's condition. They would speak to me if Dad needed anything, not my brother, which annoyed both of us. There was a mismatch between the stability of his vital signs and how we thought he was. They thought he was fine and we did not. The only time I spoke to a physician was when one came up to him and asked if a group of students could question him about a topic Dad would have no interest in at all. I discussed it with him and we explained to the physician that it would be another intrusion Dad would rather not accommodate. Latterly, it was clear that Dad was only there because there was no space yet for him at the geriatric rehabilitation hospital. He was in a sense a 'bed blocker'.

According to official statistics, one in three people over the age of 75 in Scotland experienced a hospital admission in 2017 and 2018 (Information Services Division, 2018: 15). The average length of stay in acute hospitals is just under 7 days. There were people who arrived and left within a week in Dad's ward. However, two patients had been in for over 15 weeks, with problems associated with their onward care causing them to remain. The nurses were not geriatric specialists despite having many older people to care for. Acute hospitals have been at the forefront of COVID-19 responses and many health practitioners have lost their lives. A study of 119 health practitioner deaths in the NHS found that Black and Minority Ethnic people were more than 60% of deaths yet there are 17% of the overall population. The

study also found that deaths occurred less often in Intensive Care Units (ICUs), health practitioners were more likely to catch the virus in other settings. Cook et al. (2020) argued that PPE use was stricter in ICU settings. The UK government announced on the 27th of April that the families of NHS staff who died would get a payment of £60,000 for the death in service of their loved one.

Planet Home Care

Before Dad went into the Acute Hospital in early October 2019, he experienced had less than a week of professional care at home. He had started falling in the house due to two medical problems. He had not sought help himself but had taken to his bed. When I had paid a routine visit, I had found him unwell and rung the GP. Dad did not want to go to hospital Accident and Emergency. His last visit to the GP a few months before had resulted in me driving him immediately to the acute hospital. He was given a thorough set of checks that took 7 hours and we returned home that night. He hated the experience. My brother and I tried to care for him for 3 weeks before the home care visits started. We organized our lives into shifts so that we could stay over with him. It did not work because it needs two people to help Dad – he is a tall man with a wide chest. It was not sustainable in the long term. Dad disliked the role reversal.

As Dad was not getting better I called the GP out a second time. The GP triggered a care needs assessment. The team leader arrived that day and brought some physical equipment. Later that week four visits a day were scheduled to help with Dad's care and further technology installed. The entire goal was to keep him at home

as he wanted. However, being an intensely private man, being cared for at all was a trial for him. At that point we had the impression things could be fixed and Dad could carry on in his home.

Time is of the essence (Rubery et al., 2015; McDonald et al., 2019). Private contractors schedule care at home workers many visits a day to frail people. The carers have to do their tasks speedily and getting round everyone, creating tensions. If the older person needs more care than usual, it takes more time. They are running at full capacity. In Dad's local authority, home care workers have to visit 10 people a shift, often three or four times for each patient. They are constantly jumping in and out of cars and travelling between patients. The private care companies expect workers to have their own transport, although they pay the minimum wage. Many are on zero-hours contracts effectively below the minimum legal rates (Rubery et al., 2015). The carers' work often seeps into unpaid labour (Aronson and Neysmyth, 1996). The UK government was slow to address PPE stocks for home care workers in the COVID-19 pandemic. In Scotland, 128 people had died at home due to the virus before mid-April. Their carers were short of PPE.

Planet 'Informal' Care

Before the short spell of care work at home, there was a long spell of our amateur care. Care by relatives is known as 'informal' in publications (see for example Arksey and Glendinning, 2007; Henz, 2004; Van Houtven et al., 2013). In our case, it began 15 years ago as my mother's dementia got worse and Dad struggled to cope. We have experienced this sad trajectory of years of increasing frailty then loss before. It

evolves in quite a surreptitious way. For the last 10 years, I have spent a day a week visiting and caring. I have not reflected upon the time it has taken up until this enforced hiatus, I have just done it and juggled with the consequences for my work and health. At crisis points, I have stayed over for weeks. Dad concludes conversations even today when we are skyping during the COVID-19 lockdown with 'Are you coming on Sunday?'. His tone is slightly anxious because he wants to see me, but he does not want to impose on me. Presence is very important for him and his adult children. Phone calls have always been very transactional with Dad because he sees them as expensive and gets off the line very quickly. If you want to see how he is, you have to visit. On planet 'informal care' we established a routine of separately visiting Dad, taking him for meals, walks and shopping. Over time we organized additional care for the house and latterly his medicines and a meal delivery service. We took him for healthcare appointments and stayed with him when they were debilitating, such as cataract operations. Staying overnight involved broken sleep and some tensions.

Caring for older people is a role reversal that does not sit entirely comfortably with either party. It is carefully negotiated on a minute to minute basis. Dad sees us both very much as his children even though increasingly we have become guardians to his 'child'. There is a gender dynamic to this too. When I got the job in York Dad's first comment was 'who will take me for my colonoscopy'? I replied: 'you have another child'. Dad thought I meant he had a third child. It did not enter his head that my brother could be disturbed for that kind of task. My brother has performed such tasks repeatedly over the years since then. Neither our parents had to care for their

parents in the same way we have had to care for ours, as there was a functioning social care system when my grandparents were ageing.

A recent academic study for Carers UK (2019) found that people have a 65% chance of having to provide informal care. The report found that over 46% of carers are middle-aged. Women begin caring at the age of 46, men at 57. It has a gendered depressive effect on careers and work (Van Houtven et al., 2013) and participation in the workforce (Henz, 2004). Middle-aged women who are carers are significantly less likely to remain in employment than women with no caring responsibilities (King and Pickard, 2013). Spending less time in work affected their pension and future financial security. Caring has been found to undermine the health of carers, extending to after the period of care has finished (Larkin, 2009). Depression, anxiety and stress are most commonly reported, and physiological health deterioration is associated with intensities of caring episodes (Brimblecombe et al., 2018).

Discussion

Initially, the government and their advisors in the UK pursued a policy of 'herd immunity' and treated vulnerable and older people as disposable. Their policy did not emerge out of thin air, it was in line with their previous policies institutionalised in care work. Eventually, they realised the likely death rates of this policy were unacceptable – between 117,000- 390,000 (Horton, 2020) and belatedly started to manage the problem. In the UK, there is a strange divide between 'health' and 'social' care. Health is the responsibility of the central government, social care local government. There have been decades of reducing funding for social care and a

refusal to address problems with the system. Vulnerable people such as the elderly are very far down the political agenda, as evidenced by the lack of care home death reporting or lack of prioritisation of adequate PPE for care workers.

I have tried to show throughout the paper that care work is configured by a deliberate reification of care services into matters of timing, physical symptoms, and cost.

Ironically, it has had the effect of extending the time Dad has spent in healthcare, added to his physical symptoms and increased the costs of his care. Healthcare is driven by political decision-making to focus on the easily fixable and short term.

Many healthcare conditions are not fixable at all and/or are long term. During COVID-19 pandemic 'preparation', central policymakers told hospitals to shed existing patients or not admit older people to make space for people more likely to survive the pandemic. It replicated pre-existing institutionalised ageism, and generated additional early deaths.

The lack of attention given to caring for older people is a gendered issue for women's economic freedom and wellbeing. Women become unwaged carers at 46 on average, men at 57 (Graham, 2019). Charlesworth et al. (2015) showed that caring disproportionately affects women's ability to work and subsequent finances. The typical age of health and social care workers overlaps with unwaged carers. These people are currently applauded as 'key workers' in the fight against COVID-19 but mostly they are ignored. Whereas some other life processes are part of an entitlement system such as child-rearing and sickness, caring for older people is individualised at work. There are no formal entitlements in the UK for time off, it is all discretionary. Good employers enable 'flexible working' however that has been

shown to have no positive effect on women's jobs (Henz, 2004). Lockdown has caused distress by isolating many carers from the people they care for. Reducing restrictions will lead to additional pressures on informal carers who will worry about transmitting the disease.

When researching this paper, I have been struck by the lack of studies tracing the care journey from the perspective of the older person. It has made me want to ask more about how they cope with the dramatic transitions they have experienced. I think many older people have repeatedly endured the dramatic reconfigurations COVID-19 is imposing on the rest of us now. The time of writing coincides with the 75th anniversary of the ending of the second world war in western Europe. We are hearing the voices of older people who experienced that war. I think they are worth listening to on other days about other matters. Their trajectory through different care settings deserves more attention because it could be much better, and by doing so it would improve gender equality.

References

Adams, D. (1978). Hitchhiker's Guide to the Galaxy, BBC. Retrieved from <https://www.bbc.co.uk/programmes/b03v379k>

Ackerman, R., & Lauterman, T. (2012). Taking reading comprehension exams on screen or on paper? A metacognitive analysis of learning texts under time pressure. *Computers in Human Behavior*, 28(5), 1816–1828.
doi.org/10.1016/j.chb.2012.04.023

AgeUK, (2019). Annual Report, Retrieved April 30th, 2020. Retrieved from www.ageuk.org.uk/about-us/what-we-do/annual-reports/

Arksey, H., & Glendinning, C. (2007). Choice in the context of informal care-giving. *Health & Social Care in the Community*, 15(2), 165–175. doi.org/10.1111/j.1365-2524.2006.00671.x

Aronson, J., & Neysmith, S. M. (1996). “YOU’RE NOT JUST IN THERE TO DO THE WORK”: Depersonalizing Policies and the Exploitation of Home Care Workers’ Labor. *Gender & Society: Official Publication of Sociologists for Women in Society*, 10(1), 59–77. doi.org/10.1177/089124396010001005

BBC (2020). Captain Tom Moore’s NHS Appeal Tops £32 million on 100th Birthday. Retrieved from www.bbc.co.uk/news/uk-england-beds-bucks-herts-52472132

Brimblecombe, N., Fernández, J.-L., Knapp, M., Rehill, A., & Wittenberg, R. (2018). Review of the international evidence on support for unpaid carers. *The Annals of Long-Term Care: The Official Journal of the American Medical Directors Association*, September, 25–40. doi.org/10.21953/lse.ffq4txr2nftf

Charlesworth, S., Baines, D., & Cunningham, I. (2015). “If I Had a Family, There Is No Way That I Could Afford to Work Here”: Juggling Paid and Unpaid Care Work in Social Services. *Gender, Work, and Organization*, 22(6), 596–613. doi.org/10.1111/gwao.12111

Competition, & Markets Authority. (2017). Care homes market study: summary of final report. Retrieved from www.gov.uk/government/publications/care-homes-

market-study-summary-of-final-report/care-homes-market-study-summary-of-final-report

Cook, T., Kursumovic, E., & Lennane, S. (2020). Exclusive: deaths of NHS staff from covid-19 analysed. Health Service Journal. Retrieved April 30, 2020, Retrieved from www.hsj.co.uk/exclusive-deaths-of-nhs-staff-from-covid-19-analysed/7027471.article

Emslie, C., & Hunt, K. (2009). "Live to Work" or "Work to Live"? A Qualitative Study of Gender and Work-life Balance among Men and Women in Mid-life. *Gender, Work, and Organization*, 16(1), 151–172. doi.org/10.1111/j.1468-0432.2008.00434.x

Graham, R. (2019). Will I Care? The likelihood of being a carer in adult life - Carers UK. Retrieved from www.carersuk.org/for-professionals/policy/policy-library/will-i-care-the-likelihood-of-being-a-carer-in-adult-life

Henz, U. (2004). The effects of informal care on paid-work participation in Great Britain: a lifecourse perspective. *Ageing & Society*, 24(6), 851–880. doi.org/10.1017/S0144686X04002351

Horton, R. (2020). Offline: COVID-19-a reckoning, *The Lancet*, 395(10228), 935. doi.org/10.1016/S0140-6736(20)30669-3.

Information Services Division (2018). Acute Hospital Activity and NHS Beds Information in Scotland. Retrieved from www.isdscotland.org/Health-Topics/Hospital-Care/Publications/2018-09-25/2018-09-25-Annual-QuarterlyAcuteActivity-Report.pdf

Information Services Division (2019). Acute Hospital Activity and NHS Beds Information for Scotland. Retrieved from www.isdscotland.org/Health-

Topics/Hospital-Care/Publications/2019-09-10/2019-09-10-Annual-AcuteActivity-Report.pdf

King, D., & Pickard, L. (2013). When is a carer's employment at risk? Longitudinal analysis of unpaid care and employment in midlife in England. *Health & Social Care in the Community*, 21(3), 303–314. doi.org/10.1111/hsc.12018

Kluge, H. (2020). Statement – Invest in the overlooked and unsung: build sustainable people-centred long-term care in the wake of COVID-19. Retrieved from <http://www.euro.who.int/en/health-topics/health-emergencies/coronavirus-covid-19/statements/statement-invest-in-the-overlooked-and-unsung-build-sustainable-people-centred-long-term-care-in-the-wake-of-covid-19>

Kotecha, V. (2019). Plugging the Leaks in the UK Care Home Sector, Centre for Health and Public Interest. Retrieved from chpi.org.uk/papers/reports/plugging-the-leaks-in-the-uk-care-home-industry/

Larkin, M. (2009). Life after Caring: The Post-Caring Experiences of Former Carers. *British Journal of Social Work*, 39(6), 1026–1042. doi.org/10.1093/bjsw/bcn030

McDonald, A., Lolich, L., & Timonen, V. (2019). "Time is more important than anything else": tensions of time in the home care of older adults in Ireland. *International Journal of Care and Caring*. Volume 3, Number 4, November 2019, pp. 501-515(15). doi.org/10.1332/239788219X15622468259858

National Records of Scotland (2020) COVID Deaths Report week-16. Retrieved from www.nrscotland.gov.uk/files//statistics/covid19/covid-deaths-report-week-16.pdf

Pilgrim, A. L., Baylis, D., Jameson, K. A., Cooper, C., Sayer, A. A., Robinson, S. M., & Roberts, H. C. (2016). Measuring appetite with the simplified nutritional appetite

questionnaire identifies hospitalised older people at risk of worse health outcomes. *The Journal of Nutrition, Health & Aging*, 20(1), 3–7. doi.org/10.1007/s12603-016-0668-3.

Ravenswood, K., & Harris, C. (2016). Doing Gender, Paying Low: Gender, Class and Work-Life Balance in Aged Care. *Gender, Work, and Organization*, 23(6), 614–628. doi.org/10.1111/gwao.12149

Resolution Foundation, (2020). What happens after the clapping finishes? Retrieved from www.resolutionfoundation.org/publications/what-happens-after-the-clapping-finishes/

Rubery, J., Grimshaw, D., Hebson, G., & Ugarte, S. M. (2015). “It’s All About Time”: Time as Contested Terrain in the Management and Experience of Domiciliary Care Work in England. *Human Resource Management*, 54(5), 753–772. doi.org/10.1002/hrm.21685

Van Houtven, C. H., Coe, N. B., & Skira, M. M. (2013). The effect of informal care on work and wages. *Journal of Health Economics*, 32(1), 240–252. doi.org/10.1016/j.jhealeco.2012.10.006