Lives and Deaths with Dementia During Covid-19: Our Shameful (But Hopefully Transformative) Post-Pandemic Legacy

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“How do I escape from here?” The question took me by complete surprise. “This is a care home, Muriel. Your daughter brought you here because it’s safe for you.” Little did I know at that time, only about two months ago, that this will change so dramatically in a matter of weeks.

Muriel is a cheerful lady in her nineties, living with dementia of the Alzheimer’s type at Golden Age Care Home. Her round face, curly hair and light blue eyes make her look like one of those grannies in children’s book illustrations. When I met her, she broke the chocolate bar she received with her tea and handed me half. She loves having a chit-chat about clothing. She always compliments me, even though I don’t have such a great sense for fashion. For two months, between January and mid-March before care homes closed to external visitors due to the Covid-19 pandemic, I’d been visiting Golden Age twice a week for my research. Through my PhD project, I try to learn how people living with dementia in Scottish care facilities bond with animals during Animal-Assisted Therapy activities. What, in our most advanced forgetfulness, still makes us human, still makes us alive?

Muriel was diagnosed with advanced Alzheimer’s disease about two years ago, after being hospitalised following a fall in her own home. The City Council evaluated her situation and declared it not safe for her to live anymore in her own home. In her own home, the report concluded, there was too much hazard, too many risks, too many needs unmet. Moving to a care home was the mandatory course of action. The care home was deemed a haven, a safe place to live and to eventually die a good, dignified death.

In Muriel’s care file, the words Alzheimer’s disease flicker everywhere, like Christmas lights in the dark on an invisible tree. They’re meant to explain why Muriel behaves like such and such, to create a guiding care map for her supposed needs. Her name is mentioned everywhere, followed by Alzheimer’s disease, as if they can’t exist anymore without each other. It might just as well be called Muriel’s disease. The whole person that is Muriel seems to have shrunk under a label stuck to her progressively shrinking brain.

Many people think that Alzheimer’s replaces a person’s individuality with the disease’s symptoms until the person disappears completely and finally dies physically. Like some sort of a death seed that grows into a bigger and bigger weed, feeding on the person until there’s nothing left. In the absence of a cure or treatment, those with dementia who die from something else before reaching the end stage are considered lucky. Funny thing, to think that someone got lucky with terminal cancer. But when dementia becomes too advanced, it’s extremely easy, indeed, not to distinguish anymore between the person and the disease. “She never used to be like this. Now it’s only this left”, Mary, a sister of one of the residents, tells me. When people arrive at the point of needing permanent help and supervision, as happened to Muriel, a care home usually becomes the safest place to be. The world itself – life as it happens in all our entanglements – would otherwise have to be permanently risk-assessed.
Curiously, but not surprisingly, of all those living in a care home in the UK (approximately 400,000), statistics tell us an overwhelming majority lives with dementia. Being isolated in the name of safety becomes the new normal once moving to a care home. For someone with dementia living in a care home, lockdown is a permanent way of living. Life reduced to the essential. Of course, what essential means may include all sorts of activities, designed to ‘stimulate’ and ‘enrich’ within this confinement of safety. But the things that make life ever so charming and frightening, so ‘alive’, have been risk-assessed and, as much as our mortal condition allows, eliminated. Indeed, life has become bare life.

Before the general population went into lockdown, most Scottish care homes had already decided to close their doors to all external visitors as of the 12th of March, to keep their residents safe. Once again, a care home seemed a safe place to be. When I found out about this, I felt such a huge relief. Horrific memories of a local outbreak of stomach bug infections in the New Zealand care home where I used to work years ago had been haunting me since Italy unveiled its gruesome Covid-19 death statistics. But the global governments, and we along with them, got the magic formula to keep the virus at bay: #Stay home. Our emails, sent from the safety of our homes, were for care home admissions during the pandemic, a total disregard for PPE supply for care home workers, and the initial hidden, uncounted deaths of care home residents and workers due to Covid-19, revealed a tragic story of a long-practised necropolitics: when a government decides, in what Agamben calls a state of exception, whose bodies are disposable, whose lives and deaths matter. Once the virus gets inside, a care home becomes the opposite of a safe place to be: a death trap, without any escape. As per last week (ending on the 17th May, week 20 of the pandemic), 55% of all people who had died from Covid-19 in Scotland were care home residents. We clapped for our NHS heroes saving lives, but turned our heads away from care workers attending to those slowly dying. These lives, we thought, would end anyway, sooner or later. There’s no national mourning for these people because it’s a shameful story we don’t want to tell our children about ourselves as humanity: that we may all be in this, but not in the same way, that we think some lives and deaths matter more than others. Because it is a story of failed humanity.

Lost for words – probably forever – Grace, another resident living with very advanced dementia at Golden Age, used to stroke my hair in a gesture of tender care when I talked to her. It’s what she had left after losing her memory, her judgment, her words. But her gesture saves us as humanity. Our humanity is all condensed into this tiny lady, stroking tenderly a stranger with her thin, transparent fingers. We are not all lost, as individuals and species if, in our most advanced forgetfulness, kindness, love and care still make us human, still make us alive. But I wish I could go back in time about two months, and work out an escape plan with Muriel instead of saying that she was safe. She might still be safe from the virus. For now. But the government and we as a society have lamentably failed to keep safe those who couldn’t – and can’t – #Stay safe by themselves. Because care, as any carer will tell you, is a long process, not a one-time, or emergency-infused action. So, now it may be the right time to work together on an escape plan from a care system that facilitated such a huge number of lives to be
transformed into horrific Covid-19 death tolls. The right time to think what and when #Save lives should mean. Now that restrictions are slowly lifting for us, we should think and act for those who live in permanent lockdown, for whom social isolation is the new normal until their death.

Most people think dementia tells a hideous story about our loss of humanity. A story about an invisible something that insidiously creeps into people’s brains, and ends up locking down their whole life. The huge number of deaths of those living in care homes caused by the Covid-19 pandemic, most of them living with dementia, tells us a different story. A story of our failed humanity that needs to change. Because lives and deaths with dementia teach us a fundamental lesson about what it means to be human. Because when everything breaks to pieces around us, we can still show kindness, love and care. It’s the lesson I’ve learned from those who lost the most, long before a pandemic brought us all into this, together.

*All names have been anonymised.

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ABOUT THE AUTHOR

Cristina is a medical anthropologist working towards her PhD at the University of Aberdeen. Her PhD research project explores the relationships between people living with dementia in Scottish care facilities and therapy-animals (dogs and owls). Currently, she is working with Dr Andrew Whitehouse as editors of a collective volume about the entanglements between ageing and more-than-human companionship (to be published at Rutgers University Press). Her research has been funded by Parkes Foundation and Elphinstone Scholarship (University of Aberdeen).

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