Unseen, Unheard, Untouched A View from the Interior

Ailbhe Smyth, 12 June 2020

Isolation is a continuing experience for me, so this is personal and raw.

Isolating

It's 93 days and counting since I've felt a hand in mine, at my back or on my shoulder. All that time without feeling warm breath, the smell of a small child's hot, damp skin, the embrace of someone I love, linking arms with a friend, the generous contiguity of the pre-pandemic world.

During the first weeks of confinement, I found myself wondering if for those of us who live alone, and we are many, (at least a quarter of over-65s live alone, rising sharply for those in their 80s and 90s) the absence of human touch is not the hardest deprivation of all. We are such tactile creatures. My friends said, isn't it great we have Zoom, what a difference the internet makes, we can meet for a chat. And we do.

But it's not the same.

Virtual touch is the ultimate oxymoron, leaving me with an ineffable longing, an ache, a need.

Sometimes, like a child, I pinch myself to prove I still feel something.

Mind you, it's better than the silent void to which 'the over-70s' in Ireland have been condemned. We are incommunicado. Over half of older adults in Ireland have never been online, a shocking lockout.

We are unseen, unheard, untouched. Untouchable?

Beneath the numbers lies an unfathomable depth of loneliness. Calls of distress to organisations for older people shoot up. Visits to nursing and care homes are forbidden. Grandparents are denied the joy and solace of their grandchildren. In hospitals, deathbed farewells are made via Facebook or Zoom. For a time, attendance at funeral services is prohibited and relatives stand in graveyards two metres apart as they bury their dead. The cruellest cut of all.

The full 'collateral' impact of Covid 19 on older people has not yet been measured, but the effects of isolation and the deprivation of touch have already been exposed starkly in the 'excess' rate of deaths of dementia sufferers in nursing and care homes. Loss of familiar routines, the stimuli of visits and activities, and above all the absence of physical tenderness are noted as contributory factors to these 'excess' deaths. Hugs it seems are necessary for life. There is a great weight of sadness at the losses we have sustained which we haven't even begun to allow ourselves to acknowledge and experience.

'Children should be seen and not heard'. The admonition echoed throughout my childhood. I resented it, thought it was stupid (I was right), did everything I could to ignore it. Now here I am, officially old, silent once more. Plus ça change.

Isolation and confinement: two words guaranteed to strike fear in the hearts of most older people. Cut off from the most basic quotidian activities: shopping, going for a walk, greeting our neighbours, getting the bus. There is no law against these activities, but the tone of government 'advice' is severely monitory. You must... You must not... You will... Cowed into acquiescence, many older people believe they may be stopped by the Gardai or fined for leaving their homes . Repeatedly I hear of people terrified to put so much as their nose outside their front door for fear of breaking the law and (therefore) catching 'the Covid'.

This is incarceration although we are guilty of no crime except to be our age. That's the problem. Being old is high risk, being very old is very high risk. Other people, especially children they said, are dangerous, potentially fatal. The world is your enemy. The only way we can protect you is to lock you up and pocket the key. For your own good.

We're not stupid. Older people are aware of the danger: a global fatality rate for the over 80s five times higher than the average; over 65s accounting for 90% of all Covid 19 deaths in Ireland (most, it should be said, with underlying medical conditions). We're not likely to be taking risks. But the thing is, from our perspective we're not the problem. You, out there looking in at us, are the problem. You out there may infect us. So we need you to respect our needs and refrain from engaging in risky behaviours that could endanger our lives. We know very well there's a balance to be achieved here, and everyone has to assume their responsibilities. For the good of all.

But there was to be no balance. In the early panic and chaos, we got locked up. They didn't call it that of course.

Cocooning

In the beginning was the word, and the word was 'cocooning'. Over 70s were to be wrapped in cotton wool, put into hibernation, minimally fed and watered and forgotten about for the duration. There would be no regard for the sharp inequalities and wide variations in the lives and circumstances of older people, just the same (what a surprise) as the deep rifts of inequality that mark all lives in our everyday world. There would be no need for any special financial or social care provision. Sure weren't we all safe in our own homes, didn't we all have the pension, weren't we all able to look after ourselves ,whatever our levels of health, capacity and fitness, and despite being cut off from the vital lifelines of our families, carers, and social networks.

After much palaver, the fuel allowance was extended eventually for those in receipt of the old age pension. That was it. We were on our own with our very real fears, our frustration, our loneliness, misery and deprivation. The world had far more important business to be getting on with. It would be very inconvenient to have to be looking after us, and to have us clogging up the hospitals. If that happened, difficult choices might have to be made.

They didn't think to consult us. NEPHET (the National Public Health Emergency Team) had no members aged over 70, nor from any of the organisations representing older people. Our views didn't count, our agency, dignity and autonomy didn't count. It was quick march, get them out of the way, stack them up where they can come to no harm, hugger mugger. And it will all be grand.

But it wasn't and it isn't.

Because when the chips are down, and this time, they were well and truly down, older people didn't count.

That patronising word 'cocooning '(perfectly described by our President as 'infantilising') tells a brutal truth about our society's ambivalent attitudes towards older age. We pay lip service to the venerable status, wisdom and experience of older people, but we don't want to be old and we don't want to be reminded that one day we will be. We are obsessed with youth, or more accurately with not ageing.

It is hard to see how such a society can *not* be ageist.

'Cocooning' was heedless of diverse and unequal health, material, social and relational circumstances. Our leaders were disinclined (or unable) to go beyond the dinosauric view of older people as frail, vulnerable and dependent. No one thought to query the rationale of lumping us all together in a 'one-size fits all' box. Why not lower (over 65) or higher (over 80)? Why assume that age is the sole determinant of inclusion in the box – not the existence of underlying medical conditions, not any of the multiple social, economic and other disadvantages which can intersect with age?

Ageing in the 21st century is a far more nuanced affair than it was for previous generations and we need to adjust our perception of the stages of ageing accordingly. Medical advances, better health care and education lead to increased longevity for an increasing number of people (although not all, which is sadly true). This means self-evidently that 70 isn't what it used to be, or 80. Or 90 for that matter. We live now in a world where the majority of people aged over 70 are and expect to be active, engaged, often working and healthy, well into their 80s and beyond.

And we do, actually, have views about our lives.

Nothing about us without us! I seem to have been shouting that about one issue and another all my adult life. And on it goes, without end. We have to resist!

Caring

There is any number of crises confronting – in fact already erupting – all around our post-pandemic world: from late consumer capitalism to racism, migration, and of course health, the economy and the future of our planet. One raised surprisingly rarely but of immense importance is the crisis of care.

As the corona virus cut swathes across the planet mowing down all in its indifferent wake, the response from country after country was to counter it with CARE. Because, for all our braggadoccio and rockets into space, we are not masters of the universe. Until we find a vaccine, the only weapon we have to slow it down if not to actually halt it is care. Care by, for and of people.

The countries best prepared for the pandemic seem to be those with strong public health systems and universal, free health care. Most countries, to different degrees, were not 'best prepared'. Including Ireland. It is thanks to the herculean efforts of dedicated health care and other essential workers that we have done better than might have been expected, although less well than we should.

Where Ireland failed catastrophically, although by no means uniquely, was in the protection of people in nursing and care homes and other congregated residential settings (including for example care facilities for people with disabilities; direct provision accommodation centres for asylum seekers and refugees, among others).

The majority of people in nursing and care homes are older adults, and the death rate in these settings has been horrific: 62% of Covid 19 deaths in Ireland are associated with care homes (reckoned to be the second highest rate in the world, although the rankings game is hazardous, I know).

The scandal is that for months there was effectively little or no protection for people living or working in these settings, despite the example of other countries, and the warnings, requests and pleas of nursing and care home management and care workers from the start.

The fact that 80% of these homes are privately owned may have been a contributory factor to the failure to support them. It may partly explain NEPHET and government oversight and inaction but it does not pardon it.

Fundamentally, this was a failure to recognise the extreme vulnerability to Covid 19 of the frailest people in our society. In the maelstrom of initial planning in early March, the needs of this significant group of older adults were not so much at the bottom of the pile, as simply not seen at all.

How this 'oversight' continued for so long can only be explained in terms of the abysmally low status of frail older people. They are among the most voiceless, and (living behind closed doors) the least visible members of our society. They were unseen, unheard, untouched – and too many died as a consequence.

That is a disgrace. It raises far-reaching questions about our attitudes to people in 'older' old age and indeed to all those who are frail, debilitated, or disabled. About how we shunt their care out of our homes, out of our sight, into places apart which one can only think of as 'dying houses'. This holds true for Ireland, the UK, and very many other countries. That doesn't make it any more acceptable.

One of the key lessons from the pandemic is surely that it is our collective responsibility to ensure that such a care-less and, bluntly, uncaring catastrophe will never happen again.

Framing

I was once in a photography class where one of our assignments was to make a family portrait, interpreting 'family 'however we wished. I photographed myself sitting on a chair with a paper bag over my head, and called it 'Not in the Picture'. That was how I experienced my life as a lesbian at that time, many years ago.

That has changed in Ireland and I can now be out and proud of my sexuality. But the paper bag still applies to people in many contexts, including older adults. That makes me sad and also angry. We need to change that. We need, in the words of Prof Laura Carstersen, a 'new map of life' and we need it fast.

I notice I am often bone weary by the time evening comes. I think it's the effort of will needed to survive this solitary life, hermetically sealed off from the rest of the world; the energy required to resist invisibility, absence, isolation, silence, the sheer unendingness of it all. Sometimes, I shout out loud: I AM HERE, I EXIST, MY NAME IS AILBHE, and hope that someone will hear. I worry that I am on the road to madness. Because it's there, waiting for us, under the pandemic. You have to guard against that. And it's very hard to do without a helping hand.

Coda

As I review this in late June, restrictions have been considerably relaxed. There is now very little group- specific advice for those considered to be 'high risk' for Covid 19, including the over-70s, except that we should use our 'judgement' in deciding which activities we can now participate in. Effectively deprived of agency for almost three and a half months, it turns out that we can now re-activate this faculty. If it's still intact of course. Here's hoping.

Ailbhe Smyth, 25 June 2020