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The art of medicine

Protecting our second harvest

Among the saddest aspects of the COVID-19 pandemic was the laying bare of how older people are devalued by our politicians and the medical establishment. Although older people, and particularly those resident in care homes, were the demographic group most affected by mortality and morbidity from COVID-19, in the early stages of the pandemic advisory sites from many international and national medical organisations and professional bodies did not sufficiently prioritise effective prevention and management for older people in COVID-19 guidance documents and educational updates. Additionally, in many countries health-care systems generally did too little and too late in care home sectors already impoverished in resilience through social care policy failures. There was also a seemingly casual acceptance of large numbers of older people dying in certain political milieus in the UK and USA that would be unimaginable if it related to younger people, as well as the defence of age-based rationing of critical care. These disturbing lapses in political and professional focus allied to the dreadful toll of COVID-19 among older people emphasise the need for those who provide specialist care for older people to highlight narratives that clarify the huge value of living into later life, irrespective of age-related disabilities or residence in a care home.

My own personal narrative springs from a cinematic discovery I made during a student gap year when I worked with older people in the south of France. *Regain (Second Harvest)* is a film from 1937: the title refers to fortunate climatic conditions that enable a second crop in a year, a metaphor for a fresh start for a decaying village in rural Provence. Some 40 years later, this analogy reflected my own personal second harvest arising from the longevity of my mother. Her dementia had been progressing and nursing home care beckoned after home care with an increasingly complex package of family and community care for nearly 3 years. Even as a geriatrician, I was astounded by what I gained from the time I shared with her during the last 2 years of her life when she lived, chair and bed-bound, in a nursing home.

While I am not an impartial witness, my mother was a remarkable woman, fluent in several languages, who bore her learning and interests lightly. Graduating from school at a time when medicine was not encouraged as a career for women, she was consecutively a nurse, airline stewardess, and, eventually, a doctor—between her third and eighth child. My experience and insights from working in dementia care made it easier for me to live with the progressive deterioration of her spontaneous output of speech. This was underpinned by the childhood memories of the love and care that my parents showed for all four of my grandparents, each

of whom developed dementia in later life, and all of whom retained much of their personalities and humour. These experiences fed into some of the sources about the interior life of people with dementia that I use in teaching students and trainees, such as *The Moral Challenge of Alzheimer Disease* by Stephen Post.

My mother retreated into herself while adapting to the nursing home but gradually settled in. Over the course of visits she uttered little by way of speech, but we engaged emotionally and through eye contact and body language: I would generally sit by her bed with laptop, book, or newspaper. I sought to explore past and future worlds through watching DVDs together related to her interests, including musicals, cooking, travel, and gardening. The greatest surprise was how my relationship with my mother deepened and matured during this time; there developed a sense of an equal partnership. Although I have never doubted that my mother loved me and I her, our family emotions are not worn on sleeves and their outward expression is nearly always elliptical. At the end of an hour together during which she had uttered little, she would nearly always say that she had enjoyed the company or told me to remember that she loved me. Although a cynic might suggest that this was a release of frontal control with dementia, there was no other sign of disinhibition in her daily routines. The impact of the articulation of these emotions was for me akin to the moment in opera when an aria plumbs the heights and depths and the stage seems to freeze, all the while in the prosaic setting of a room in her care home.

An added surprise was my own sense of growing up, even approaching the age of 60 years, and reflecting on my personal ageing and its present and future possibilities



Signature HealthCARE picture taken in April, 2018. Wendy's Neverland, a collaboration between Signature HealthCARE and Timeslips

and challenges with my own family. There is an element of truth in the maxim that people never grow up as life is too short. However, medicine's collective success at increasing our lifespan has softened this aphorism, and for my mother and myself allowed us to spend time together in a new framework and relational dynamics in which we were more equal and in partnership than ever before. I looked forward to these times with her—a sentiment which some outsiders might find surprising given public perceptions of thriving and life in nursing homes and when the caring impulse is unfortunately all too often characterised in the public domain predominantly in terms of a burden. Yet caring is an important and positive aspect in the development of our relationships, and the inherent challenges are better described as the burdensome aspects of care rather than carer burden.

The sense of not only the present moment with my mother but also of future possibilities, even if in some ways circumscribed, were vivid. Indeed, these very limitations may themselves be catalysts for creativity and change. My experiences resonated with the pioneering work of University of Wisconsin Milwaukee Professor of English Anne Basting, who has developed a story-telling programme with older people, *TimeSlips*, that emphasises playing it forward. She noted how older people with memory problems were often embarrassed when they could not remember aspects of their lives when nursing home staff tried to record biographical profiles but responded well to creating stories, prioritising the present and the future over the past. Equally, her *Penelope Project* that promotes theatre work with people living with dementia in nursing homes showed how sensitive co-curation of theatre unlocked not only shared and pleasurable experiences but also displayed new possibilities for growth for residents, families, and staff.

The narrative of a second chance for relationships and love is one I have heard from many relatives who have cared for loved ones living with dementia in my work as a geriatrician. However, I am also mindful of cases where this recognition and communication cannot be achieved. Health professionals and others who work in care settings need to prioritise the development of pathways to hone skills and perception to understand the inner life of those with barriers of memory and communication. Communication training improves carer knowledge, skills, and communication and should become a core element of support in dementia care. More emphasis should be placed on exploring the possibilities of using previous hobbies, interests, and passions in unlocking gateways to connection with the person living with dementia. Instruments such as the *Pleasant Events Schedule* allow us to formulate bite-sized and approachable elements of such key aspects of life. While arts and creativity have made an impact in communication with dementia, we also need to include other fields, such as sport, a pre-existing shared passion for many and potential catalyst for warm interaction,

and be alert to a wider range of personal interests than those covered by current assessment schedules.

My journey with my mother fuelled my determination to restate and evangelise that the mission of geriatric medicine and gerontological care is not some worthy salvage and maintenance of a lesser and diminished version of our past selves but rather hugely worthwhile because we, our relatives, and co-citizens are increasingly valuable as we grow into later life. We need to develop an everyday articulacy on the possibilities for intergenerational synergy and mature relationships arising from growing as adults with our parents and older relatives. This has been expressed eloquently by Marc Agronin in his interaction with a 100-year-old woman and her sons in their seventies, noting how “someone living with the daily infirmities of aging and approaching death could still enjoy most of the same human experiences we find so precious in younger years”. Additionally, it is important that we foster opportunities for those living with dementia and those who love them to engage in personalised and playful forms of creativity to support communication and the pleasures of relationships. Such efforts will require investment in training of staff, as well the support of insightful arts and health practitioners and therapists.

As I have worked in dementia service, education, and research for many years, I am, of course, aware of the downsides and difficulties of life with dementia. However, there are many other difficult diagnoses that can challenge us, and we must not allow the diagnostic label to obscure the relational and joyful possibilities that we may yet create.

The sense of what I, and I hope my mother and siblings too, had gained was brought into sharp relief in her last few days when what I presume was a small stroke removed her overt recognition of us, and she seemed almost fretful in our presence. A danger is that we would let the memory of this very short period outweigh the 2 years of fruitful and novel exchanges that had so enlivened our lives. While I deeply miss our visits, I am glad that she is at peace and that we had this extended communion in later life.

Just as a favourable climate fosters a second harvest in rural Provence, we have increasingly the knowledge and wherewithal to promote and support a personal second harvest for all of us in the wonder that is old age in its glory and pain. Developing powerful narratives of the richness of this our second harvest of our later lives in care homes may prove valuable in countering the threat to our ultimate flourishing from COVID-19 and amplified by widespread and uncritical ageism.

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