

Psychologies of Ageing

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Editors

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Foreword

I feel honoured to be invited to write this Foreword, to a positive presentation of the psychologies of ageing and of dementia. So much has changed since 1995, when I was diagnosed with dementia. I was only 46 and a recently divorced single mother of three girls aged 9, 13, and 19. We had just moved at the weekend into our new house and were looking forward to a bright new future. However, on the Monday after our move, I had a follow-up appointment with a neurologist, taking an hour off from work to do this. I had been suffering from extreme headaches each week, and what I thought were symptoms of stress, such as occasionally becoming confused with words, as well as with finding my way on familiar routes. There had been a few months of scans and tests, and now I was looking forward to finding out what was wrong.

With his back towards me, while looking at my scans and test results, the specialist calmly said that my symptoms of what I thought were stress were in fact due to dementia. I exclaimed: “How could that possibly be, as this is something that affects much older people!” Then, with an impassive face, the neurologist told me he had diagnosed quite a few younger people, even a pregnant woman in her early 30s. He told me to get my affairs in order, as soon as possible, as I might not even be able to sign my name by the end of the year. There was no treatment and no hope for the future.

Coming out of his room, I was reeling with shock, and driving back to work was a nightmare: what would happen to my girls; could my 19-year-old look after my affairs? Questions swirled around in my head, and it was very hard to concentrate for the rest of that day, let alone the week. I took some much-needed leave in order to seek a second opinion, as well as to begin to deal with the implications of this truly awful diagnosis. Diagnosis with dementia at the age of 46 was earth shattering and quickly led to my isolation from friends and former work colleagues, as I became withdrawn, depressed, and unable to cope.

Where would I find psychological support? When I rang the Alzheimer's Association, I was asked for whom I was caring. When I said that I needed this support for me, I was told there was nothing for the person with dementia, only for older carers, facing an awful journey ahead. However, what about the person with dementia and their own grief and loss? What about younger carers? My eldest daughter was only 19 and away at university. There was no support for me or for my young carers. As a family, we did not fit into the usual picture for dementia.

Back then, in the mid-1990s, people with dementia were thought to be unable to speak and lack insight and to be around 80 or 90 years old. The common view was that dementia is a normal part of ageing and not the consequence of a range of diseases that could occur even at a young age. Support for people with dementia was not thought to be feasible, nor even necessary, as we lacked insight and were unable to speak. Indeed, if you could speak or have insight, the diagnosis was questioned. So I was left struggling without support for my girls or me and became increasingly lonely and isolated. The question that was foremost in my mind was: Who will I be when I die? I had been told that I would decline, probably rapidly for about five years, and then go into full-time care, until I died within about eight years. I believed this dismal prognosis, so my function did in fact become more impaired due to depression; yet there was no support to help me to cope during this time.

It has been a long and lonely struggle after my diagnosis, surrounded by negative assumptions about dementia. I began a journey of writing and speaking about dementia from an insider's perspective, trying to provide an alternative discourse. I wanted to highlight the need for ongoing psychological support, beyond simply the clinical testing that assesses our

functional abilities. I argued for social support and empathy, and an acknowledgement of our continuing identity, despite negative views about a so-called future loss of personhood, when it seems as if our identity would become dependent on others to sustain.

I wanted the community to recognise that people with dementia, even at a younger age, should have access to appropriate in-home and residential care, which gives positive support. Importantly, we need recognition of our feelings of isolation, when we can no longer drive. Not only do we lose our sense of independence but also become increasingly reliant on public transport, which could well become confusing. When I looked into the options for residential care, I realised that much older people would surround me, with therapy designed for this age group. Again, the assumptions were that dementia was a normal part of ageing and not a condition of younger people.

Importantly, only recently has there been any information about what can be done in terms of lifestyle changes to improve our function, or indeed for the prevention of dementia. After diagnosis, I faced a bleak picture of future decline with no hope, where there was nothing that could be done. Indeed, even the anti-dementia medications were not thought to be useful, so were often not prescribed. This lack of future hope drove my efforts to change the narrative towards more positive views of people with dementia and increasing efforts to provide a range of supports.

However, I have outlasted the prognosis of a decline until death with dementia within 8 years, as it has now been over 20 years since that fateful day, which dramatically changed my life story. As I often say, “I’m still here!” Now I am almost 70, and perhaps it is finally more appropriate to have a diagnosis of dementia. Looking to the future, this will no doubt be a time of reflection on my past, as well as the years that might still lie ahead.

Now I face both ageing and dementia, which present me with the “double whammy” of negative social perceptions, where both social groups are thought to be a costly burden to society. Rarely do we hear the counter-story of our having contributed to the society that we enjoy today, nor indeed any reference to the wisdom we might have accumulated over a lifetime of achievement. Yet the aged, as well as people with

dementia, are just as diverse as we once were, still worthy of support and inclusion, and of being given dignity and respect.

However, increasing age has brought with it another issue: that of frailty. A few years ago, I had a fall and broke my hip, arm, and cheek. It took around a year or so to recover, but even then I was still cautious and uncertain. I felt frail and fearful of further falls. It took quite a few years for me to regain my confidence and the resilience that I needed to cope with the possibility of falling once more. Again, just as had been my experience with dementia, I found there was little support available to overcome frailty and my fear of falling. However, finally now I am able to exercise again without fear, although I always take my mobile phone with me just in case.

If only this book had been available many years ago! It provides an excellent and comprehensive overview of many of the concerns that have troubled me over the years and would have overcome many of the issues that I faced as a person with dementia, who was diagnosed at the age of only 46.

Now, as I become older and frail, the book counters the negative social views of ageing, where even the political narrative is changing. Challenging negative views has an enormous, often under-recognised impact on the individual with dementia and/or who is ageing. As a person who has struggled to overcome negativity for over 20 years, I welcome this wonderful book.

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