Foreword

For most of the past century, people with dementia were viewed through a biomedical lens and treated accordingly. This was logical to a degree because dementia is a syndrome produced by many different diseases that damage the brain and it is true that dementia is defined by dysfunctions in particular aspects of explicit memory, language, visual perception, and the organization of movement as demonstrated on standard neuropsychological tests. The use of a biomedical lens alone, however, is inappropriate if one seeks to understand the subjective experience and remaining abilities of people living with dementia.

In the past thirty years, through the increased use of a biopsychosocial lens, we have learned that the actions of people living with dementia are not due solely to brain damage, but also involve (1) their psychological reactions to the effects of brain damage, (2) how they are treated in social situations, and (3) their reactions to said treatment. We have learned also that people with dementia are semiotic subjects: they can act intentionally and appropriately in response to the meaning of social situations. As well, they are able to evaluate those situations in terms of the values and meanings they have held dear for the balance of their adult lives. For example, they can respond appropriately to the emotional needs of others, seek to avoid potentially embarrassing and humiliating situations, feel and demonstrate self-respect and proper pride, feel and demonstrate loneliness as well as being loved and respected, miss their loved ones, express themselves creatively, appreciate and display humour, along with a host of other healthy socio-cognitive abilities. People living with dementia share much social and emotional common ground with people who are deemed healthy. This has become increasingly apparent as their voices have been heard and respected as meaningful rather than being summarily dismissed as reflections of pathology and as they have been engaged in places other than hospital and memory clinics. Indeed, although a person with dementia may have difficulty finding and pronouncing words and organizing them syntactically, if we assume that the person is trying to tell us something meaningful, it is possible to facilitate the person's expression of his or her thoughts and open lines of communication.

Our increased understanding of the remaining strengths possessed by people with dementia requires that we attend ever more carefully to how they are treated with respect to their rights as human beings and the obligations and duties of those deemed healthy when interacting with them. All too often, people with dementia are unintentionally treated in depersonalizing ways that Tom Kitwood described as 'malignant social psychology', that attack their feelings of self-worth. If misunderstood, a diagnosis of dementia can lead to a person being stripped of the right to be treated with the same respect and care and the same legal rights that that person enjoyed years before – indeed, the day before – he or she was diagnosed. Should a person with dementia lose the right to make decisions about important matters in his or her life? What criteria should be used to support some kind of limitation on decision-making and what sorts of treatment ought to be sanctioned or disallowed? What 'top-down' governmental legal steps ought to be taken with the input of people with dementia to protect their human rights and improve their care? What sorts of 'bottom up' educational efforts should be undertaken to provide people in the everyday social world with an informed understanding of the cognitive strengths possessed by people diagnosed so as to supplant the stereotyped negative version presented so often in the mass media? Would treating dementia as a disability provide people diagnosed with fundamental human rights as understood by the World Health Organization and the UN Convention on Rights of Persons with Disabilities?

These are a few of the extremely important, complex nuanced matters that Suzanne Cahill addresses from a policy and practice perspective in *Dementia and human rights*. One of the central ideas in the book is that the voices of people with dementia must be heard, honoured, facilitated, and supported. This is altogether appropriate especially if their rights and privileges regarding their treatment and decision-making ability are at stake. The fact that a person has dementia according to standard tests of cognitive function may have little to nothing to do with his or her ability to choose not to have a colostomy operation, for example. It is quite possible, at least in the United States, for someone to obtain the legal right, via plenary guardianship, to force a person with dementia to have such an operation against his or her will. This is but one example of any number of ways in which the rights of people with dementia can be summarily abrogated.

How a society treats its most vulnerable members clearly reflects that society's character. A 'right' is something that requires no justification. People possess human rights as a matter of definition. People living with dementia have not, as a result of their diagnosis, lost their humanity or their human rights unless those of us deemed healthy decide to strip that humanity and those rights from them, in which case dementia alone is not to blame.

It is rather easy for me to say all this. The case must be made far more deliberately, logically, and legally, and that is what Suzanne Cahill has done by applying a human rights lens and drawing on supporting evidence in this important book that is not really about ‘them’ who are diagnosed with dementia, but truly about all of us and the shared humanity that is ours to keep and respect or to lose.

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