



## 2 | Dementia: why a person-centered vision is needed

"Music is the best medicine for dementia. Thanks to it my husband has smiled again. The choir gives the opportunity to be himself again, even if it's only for a moment...".

Wife of a choir member with dementia of Sonidos de la memoria, a contact choir in Spain

### 2.1 | Dementia: facts and figures

Dementia is a syndrome – usually of a chronic or progressive nature – that leads to deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from the usual consequences of biological ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by changes in mood, emotional control, behaviour, or motivation.



Meet Me @ Middelheim Museum, © Jan Dirckx

Dementia results from a variety of diseases and injuries that primarily or secondarily affect the brain, such as Alzheimer's disease or stroke (WHO, 2021). Alzheimer's disease is the most common form of dementia, representing about 60% to 80% of the cases. There is currently no cure or disease-modifying treatment, but better policies can improve the lives of people with dementia by helping them and their families adjust to living with the condition and ensuring that they have access to high quality health and social care. In 2018, an estimated 9.1 million people aged over 60 are living with dementia in EU member states, up from 5.9 million in 2000. If the age-specific prevalence of dementia remains the same, ageing populations mean that this number will continue to grow substantially in the future. The overall number of people living with dementia in EU countries is expected to rise by about 60% over the next two decades to reach 14.3 million in 2040, with the oldest people (those aged over 90) accounting for a growing share (OECD, 2018).

Dementia is currently the seventh leading cause of death among all health conditions and one of the major causes of disability and dependency among older people worldwide. Dementia has physical, psychological, social and economic impacts, not only for people living with dementia, but also for their carers, families and society at large. There is often a lack of awareness and understanding of dementia, resulting in stigmatization and barriers to diagnosis and care. There is a growing sense of urgency and perspective shift to address the challenges of dementia at different policy levels (*health in all policies*) and in various initiatives throughout society.

## 2.2 | Validation

Both the cultural landscape and the vision on good dementia care have changed drastically over the last decades. There has long been thought that bringing the person again to reality and correct him when they say or do things wrong was the solution for dementia. Therapists wanted patients to connect with their surroundings, by orienting them in time, place and person. Although some people with mild dementia might benefit from it, for most people it leads to frustration and disappointment. In the sixties Validation Therapy from Naomi Feil became popular. It is based on empathy and connection with the person with dementia and can lead to meaningful interaction. Feil's model sought to classify the stage of dementia that an individual has reached according to cognitive and behavioural signs. Its development was the result of an attempt to provide practical solutions for difficulties experienced by patients and caregivers.

Important features of validation therapy include: a means of classifying behaviours; provision of simple, practical techniques that help restore dignity; prevention of deterioration into a vegetative state; provision of an empathic listener; respect and empathy for older adults with Alzheimer's disease who are struggling to resolve unfinished business before they die; and acceptance of the person's reality (Takeda et al., 2012). Unfortunately, evidence for this method is lacking (Kroes et al., 2011). Over the years we slowly saw a transition to expe-



rience-oriented care, culminating in the birth of person-centered care pioneered by Tom Kitwood.

In 1997, Tom Kitwood, with his book *Dementia reconsidered, the person comes first*, put person-centred care on the map. Kitwood sees people with dementia first and foremost as people, which is why he uses the term person-centred care. Respect and attention, both for the person with dementia as for the persons taking care of him, are important pillars in his vision on care. Kitwood emphasises how important it is to establish an emotional connection with the person with dementia, both verbally and non-verbally. When language disappears and it becomes increasingly difficult to detect someone's emotions and desires, we fall back on reading their body language. Giving sincere attention is then a key to connecting with the inner world of the person with dementia. Kitwood was the first to emphasise the importance of the reactions of the environment to the wellbeing of the person with dementia. He calls them person-enhancing and person-undermining factors (Kitwood, 1997).



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*Do you know Death Valley? Once every ten years Death Valley, one of the hottest places on earth, turns into a gigantic sea of flowers. The right amount of rain turns even this place into a stunning flower field full of life. So what about dementia? Even when people seem locked in or on their own, the right approach might lead to meaningful interaction.*

Fortunately, the former one-sided pharmaceutical and medical approach to dementia has disappeared (Dely, 2016). There has been a shift towards non-pharmaceutical interventions which show to have several benefits for people living with dementia. Non-pharmaceutical approaches have potential to slow down cognitive decline and other symptoms of dementia

(Windle, 2019). For example, aesthetic experiences such as art can enhance the quality of life, well-being and inclusion of persons with dementia and their caregivers (Mastandrea et al., 2019; Schneider, 2018; Windle, 2019). Hence, over the past two decades, several art programs were developed for people with dementia (Dassa & Harel, 2019). The range of activities is highly varied, including participatory activities such as singing, drama, visual arts, photography, puppetry, ... All stages of dementia are considered, so people with advanced dementia are also included in the activities (Zeilig et al., 2018).

## List of references chapter 2

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