Providing high-quality independent life support to people living with dementia: ‘Dementia with Dutch treat’

As a result of aging, the number of people with dementia in the Netherlands will rise to more than half a million in 2040. It is expected that the number of people with dementia will reach a peak of over 690,000 in 2055.

Dementia has a substantial impact on the lives of people with dementia, their families and also on healthcare and society. Dementia has a higher disease burden than any other disease. In addition, dementia has a significant health and economic burden. The collective burden is expected to be almost 14 billion euros in 2050. Seventy percent of people with dementia lives at home and receives care from so-called ‘caregivers’. Over 50% of these caregivers is overburdened. The strong increase in people with dementia coincides with a decrease of the working population. There were still 37 potential workers for every person with dementia in 2010 and this number is expected to decline to 16 in 2050.

Research focuses on potentially influential risk factors and risk profiles in order to reverse the trend. Unhealthy lifestyle habits are an important risk factor for dementia. However, only between 5 and 10 percent of all cases of dementia might have been prevented by a healthy lifestyle.

At the same time, in the Netherlands the transformation takes place from a welfare state to a participation society. This changes the social and professional views on health, shifting from ‘Disease and Care’ to ‘Health and Behaviour’, to ‘People and Society’. This means that health no longer means 'not being sick', but health is more frequently seen in terms of the options still available to the patient to lead a fulfilling life.

This so-called paradigm shift, the increasing human and financial burden of dementia care, and the general demand for higher quality of care calls for the development and implementation of new housing and care concepts. Vitality and the ability of people to participate in society should be the central focus of these new housing and care concepts.

It is expected that the stay of the elderly in nursing homes in the Netherlands will be limited to the terminal phase of life and that people with dementia will live at home for as long as possible. However, at some stage living in a domestic environment

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1 Alzheimer Nederland. Neemt het aantal mensen met dementie toe of af?, 2014
2 Vos et al. Modifiable Risk Factors for Prevention of Dementia in Midlife, Late Life and the Oldest-Old: Validation of the LIBRA Index, J Alzheimers Dis, 2017
may no longer be possible for people with dementia despite the availability of informal and formal care, domotics and neighbourhood facilities. At that time a move to alternative, clustered forms of residential care concepts could be considered.

One of these residential care concepts is offered by 'Royal Rustique' (Saffier, The Hague\(^4\)) to people with dementia and to other frail elderly people\(^5\). Key concepts are living and welfare centralisation, care normalisation (i.e. as little care as possible and as much care as necessary), financial flexibility, affordability for all residents, and cooperation between informal and formal care. Royal Rustique consists of 42 independent residential units in 4 separate mansions. The residents manage their own life aided by their relatives for as long as possible. Guidance and care are tailor made (i.e. demand–based care).

A scientific evaluation study carried out by TNO\(^6\) has shown that residents are satisfied with their new living environment, which ultimately translates into a lower need for care (i.e. less need for professional attention). Residents report a higher quality of life because they keep their autonomy and make their own decisions. The building is designed to support their individual needs and their social network remains intact.

Care professionals experience a similar or higher job satisfaction than care professionals in a traditional nursing home. The time investment of care professionals is significantly lower (up to 25\%) and labour productivity is equal or higher than in a traditional nursing home.

One of the main overall results was that ‘own direction in life’, even for vulnerable people with dementia, has a direct relationship with higher quality of life. ‘Own direction’ can be described as choosing one’s own activities, making decisions and pursuing personal goals. The core question is ‘what do I want?’ instead of ‘what can I do?’\(^7\).

The concepts of ‘quality of care’ and ‘quality of life’ are often used interchangeably. However, quality of life differs from quality of care. Sufficient quality of care does not automatically result in quality of life. Quality of life is a unique concept with quality of care as one of the possible determinants. Own direction in life is a unique predictor of the quality of life in dementia.

\(^4\) http://www.saffiergroep.nl
\(^5\) Woonvorm is eveneens geschikt voor mensen met zware somatische aandoeningen, niet-aangeboren hersenletsel en een verstandelijke handicap.
\(^7\) C. Brink, N. van der Veen. Zelfregie, eigen kracht, zelfredzaamheid en eigen verantwoordelijkheid. De begrippen ontward, Kennisdossier 5 van Movisie, 2013

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Successful elements of the Royal Rustique concept are now adopted by many small-scale housing initiatives. The expectation is that also in traditional residential care concepts, supporting autonomy and own decision making will ultimately lead to a higher quality of life.

It becomes increasingly clear that a different competence profile and skill set are required for care professionals. Autonomy of the resident demands a more coaching and facilitating role of professionals. For example, they should dare to rely on the resident’s skills and decision-making capabilities and assist residents in formulating their own needs and wants.

Furthermore cooperation of residents, informal caregivers and care professionals are of utmost importance. Open communication, including discussing mutual expectations, is essential. Each resident requires a tailor made form of cooperation within the triad of residents, informal caregiver and professionals. They should all be regarded as equal partners in determining the individual needs of the resident.

At times it is difficult for caregivers and professionals to accept the consequences of autonomy in people with dementia. Because people with dementia have limited insight in their disease, they are sometimes unable to assess situations and the burden to caregivers. They may find it difficult to express their own thoughts and needs. Caregivers and professionals may have different standards and values from the person with dementia.

The crucial question is which party of the triad is in the lead and how the others deal with that? Different scenarios are possible ranging from maintaining autonomy to involuntary surrender of autonomy (which may result in passive resistance) to voluntary surrender of autonomy. In extreme cases maintaining autonomy may lead to neglect and insecurity, while surrender of autonomy may cause informal caregivers to become overburdened and possibly even mental and physical abuse of either residents or caregivers.

We should face up to the ethical dilemmas of autonomy and quality of life in dementia. Own direction indisputably involves (other) risks; The premise is that quality prevails over quantity of life. Even though quality of care is a predictor of quality of life, quality of care may sometimes also violate the quality of life. Although risk management is an important aspect of quality of care, we must make sure not to forcibly control and rule out all risks. As society we need to have the courage to accept mortality and face the consequences. This means that the different risks must be balanced and fair as long as they serve the quality of life. Restricting the freedom of elderly people with dementia may reduce the risks but should never be at the expense of the quality of life.