

Change the hallway in a street full of stimuli

"Twenty years of research has still yielded no cure for Alzheimer's disease. Where's the holdup? 'Says de *Volkskrant* newspaper dated February 8, 2014.

'Eighty thousand people with dementia are living by themselves' reported the *NRC Handelsblad* on October 5, 2013. 'The Netherlands are awaiting an explosive growth in the number of dementia patients between the age of 50 and 60. This is largely due to an unhealthy lifestyle.' This is the expectation of four professors at the VU Medical Centre in Amsterdam.

This is the kind of messages we hear and read regularly in the media. It is only when you are intimately familiar with dementia, that it touches you. From my own experience I can say that Alzheimer's is terrible, perhaps even degrading. This is especially since it is beyond comprehension; what goes on in the brain of a person with dementia? It must be one of the worst diseases to undergo: your head, as it were, is separated from your body.

Thus far, there is no medication that stops or reduces the disease. The pharmaceutical industry is reluctant because successful development of a working drug is not an easy grab. Dementia is second only to disability care with nearly 4 billion Euro in health care costs, the most expensive disease in our country. But soon these will swap places; the number of people with dementia will skyrocket, due to a greying population, to over half a million within forty years.

Simultaneously with this increase the Government is significantly cutting down on 24-hour care. People with dementia have to live and be cared for at home, with serious consequences.¹ Dementia will also become increasingly visible in the public sphere. How do we deal with it? Do you help someone who doesn't know the way home anymore? And someone who doesn't know how to use a debit card at the ATM where you've been waiting in line? My mother, who has Alzheimer's, sometimes bought a loaf of bread from the bakery up to 5 times per day while she was still living independently. Too bad that the baker did not openly wonder if that was not a lot for a single household.

¹ Chairman of the National General Practitioners Organisation (LHV) Steven van Eijck has said to the NOS 21st March 2014: "This is a reason to sound the alarm." According to Van Eijck a cliff is forming because nursing homes are being closed down while there is not yet enough neighbourhood care.

Fortunately, the government has announced a spending of an extra 32.5 million Euro over the coming four years to improve the in-home care for people suffering from dementia. The money will go to the Deltaplan Dementia, to provide more scientific research into better treatment, cure and prevention of dementia. Secretary of State Martin van Rijn from the Health department has this to say about it: "as long as it is not possible to cure dementia, we must make the disease as bearable as possible for the patients, family and caregivers. Besides fundamental research into the causes and symptoms we can improve the care."

When my mother could eventually no longer live independently after years of in-home care and day-care, we went looking for a good nursing home; and that was not easy. As an architect I noticed the significant differences in quality within these specific so called *healing environments*. How could those differences be so great, I wondered. That question has never left me. In the period after my mother moved to a nursing home, I decided to study the possibilities to improve the quality of living for people with dementia hitherto unbeknownst to me.

We can hardly call the living environment of people with dementia *healing environments*, as this disease is irreversible and often their final living quarters before they pass away. In this specific situation we could improve the description by calling it a *care environment*.²

A determining factor in the diagnosis of dementia is that their world is becoming continuously smaller during the last phase of their lives. Eventually they require round the clock care. Thinking, orientation ability, understanding, learning and judgement ability as well as language continue to decline gradually with dementia. The physical and mental environment seems to fade away until only the primary senses remain, an elementary world of listening, looking, feeling, tasting and touching. The process of physical deterioration is natural and requires an environment that is not primarily aimed at prolonging life, but in improving its quality. Spaces that relieve and alleviate suffering, past the distressing feeling of alienation.

Quest from within

For the last five years, from the office of Alzheimer-Architecture and along with a variety of students and

² Quote from Drs. Jan Hoff, Director of Housing Cordaan 2014.

specialist I have been undertaking experimental research particularly into dementia and movement, and haptic (sensorial) architecture. In order to shape the future of this specific target group, scientific knowledge, creativity, experimentation, observation ability and empathy are required alongside specialized knowledge of healthcare professionals. The ambition is to work with professionals from all sides in order to arrive at integrated, future-oriented solutions.

A quest from within into the experiences of people with dementia in their environment and the effects they have on their physical and emotional wellbeing could be crucial in improving their living conditions. In the last few years I have been searching together with students (the designers of the future), scientists and healthcare experts for new ways. The emphasis is on gathering insights into the behaviour of people and the disease, the promotion of 'moving with dementia' and the encouragement of 'multi-sensory experience of space'. In order to formulate more precisely how we can improve the future care for this specific group of people.

In order to almost literally wear the shoes of our research target group, we undertook various experiments in an unorthodox manner. We worked in the daily care process on a regular basis with a number of different health care institutions. As one of the participants said: "to build a bridge and get in touch with the clients, it is important to be curious and to have the desire to meet the other wherever that (mentally speaking) may be." ³

This has led to new insights into the physical and emotional responses of the clients. We noticed how meaningful it is to undertake activities and to stimulate the client, but not to overstimulate. Exercise was an important motive; research shows that exercise is a very good way to keep people with dementia mentally and physically in good shape. ⁴

We researched into the physical limitations that older people experience in different locations in the 'semi-public' space (hallways, lobbies, entrances). In addition, we employed the method that is widely used in the education programs for elderly care in American universities. We walked around with fogged up glasses (poor visibility), with headphones on in order to minimize sound (as if you're deaf), with a nose plug to block the smell and we put a stone in one of the shoes in

³ Ganna Poppea Veenhuysen, clown and theatre producer

⁴ Prof. Dr. Erik Scherder, dementia and exercise

order to make walking more difficult. The effect was shocking and positive at the same time. We experienced first hand that the ears are the eyes of the back of the head. If they are closed, this affects your sense of direction and space perception in a negative sense. Vision is important for precise distance measurement and total overview. Sense of smell arouses curiosity and establishes blazingly fast connections with the past. Its absence promotes indifference.

I currently work with a care agency in the implementation of biodynamic light, in order to increase range of motion for the purpose of daily activities. The brightness is adjusted in relation to the activity. Light works miracles for people with dementia.⁵ Less depression, less deterioration of the mind and memory, more exercise, a better mood and improved vision.

I also work with students and participants from Odensehuis in Amsterdam South (a meeting place for people with dementia and their families) to study how navigation can be improved in the 'semi-public' space.

The interactive nursing home

Many initiatives have been undertaken in care institutions over the last few decades in order to improve the interactions with the residents. One of the now widespread newer forms of policy is called 'snoezelen', or sensory activation. Snoezelen⁶ was developed in the seventies and became known as an activity in which mentally disabled people are taken to special multi-sensory stimulation spaces.

In the last ten years, approximately 75% of the Dutch nursing homes have integrated a sensory stimulation room into the care offering. In practice, the pressure on the staff is unfortunately too great, leaving little time to spend time with clients in the sensory room.

Sensory activation should be an integral part of 24-hour care in nursing homes. Then it would clearly provide added value both to the residents as well as their carers. It has been shown that clients who live in a department where their senses are being activated throughout the day during care are less apathetic, less depressed, less aggressive and less rebellious. Their carers have more confidence in their own abilities and

⁵ Prof. Dr. Eus van Someren (2008). The Journal of the American Medical Association.

⁶ In 1974 Ad Verheul and his colleague Jan Hulsegge introduced the phenomena snoezelen

find it easier to deal with residents' behavioural issues.⁷

Architecture can play an important role when it comes to all these issues. Opportunities for stimulating activities can be well integrated into the semi-public spaces (e.g. corridors) in new, but also in existing, nursing homes. Ideally this is an integrated approach whereby biodynamic light stimulation and sensory activations go hand in hand.

In this way, the hallway returns to the role of the street, where one is not corrected or patronized, but invited to experience all sorts of stimulations which are both understandable and enriching. No matter how small the world of someone with dementia can become, no world is too small for positive challenges and new experiences. Our challenge is to ensure that people with dementia can also keep access to these experiences for as long as possible.

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Henri Snel, June 2014

Alzheimer-Architecture.nl

⁷ Dr. Julia van Weert, Nivel 2004.