

Stella Braam - *I have Alzheimer's; the Story of My Father*



'I have Alzheimer's? I completely forgot.'

Over 24 million people around the world suffer from dementia. To this number, a new patient is added **every seven seconds**.

'Don't ask what I did yesterday: I haven't got a clue. And let's not talk about tomorrow because I have to try and remember today first.'

I have Alzheimer's

Over 24 million people around the world suffer from dementia. To this number, a new patient is added every seven seconds. But while much has been said and written about Alzheimer's, little comes from those who themselves suffer the condition.

People with dementia are often assumed not to realise what is happening to them but Stella Braam and her father, René van Neer, demonstrate categorically that this not always the case. *I have Alzheimer's* is a disconcerting, moving and hilarious account of a militant Alzheimer's patient revolting against the prejudice and the patronizing attitude of social services, medical professionals and society as a whole.

Original title: *Ik heb Alzheimer. Het verhaal van mijn vader.*

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www.nijghenvanditmar.nl

Rene van Neer and Stella Braam



'The very symptoms of dementia are a license to take away your civil rights,' Van Neer told his daughter as the condition took hold - and at his request she began closely to follow and describe his changing world since the day in 2003 when he was diagnosed.

René van Neer is a psychologist, author, and journalist. His daughter Stella Braam has worked as an undercover journalist for many years and has previously published two books. *I have Alzheimer's; The Story of My Father* was first published in 2005 and has since sold 48.000 copies.

Stella Braam has arranged a program to assist the social service sector. Looking from the perspective of the clients she helps them to find new ways of taking care of the Alzheimer's patients. She is organising workshops and is often asked as guest speaker on conferences. For more information : www.doordeogenvanclienten.nl.

Together with photographer Cees Hilhorst she has made a dvd on this subject (available on request).

Elderly toddlers

As though every day you exist less and less – that's how the life of an Alzheimer's patient goes. When journalist Stella Braam wrote a book about her father's mental decline, she was inundated with questions from nursing homes.

Psychologist René van Neer wakes up every morning in a room that is completely unfamiliar to him: where's the light switch, where's the toilet? He is constantly getting to know everyone in the nursing home where he lives. And he has so many things on his mind: he has to get to work, the library books need to be returned and the shopping hasn't been done yet. 'And I suppose I haven't got a ticket for the train, have I?'

His daughter, journalist Stella Braam, recently told the story of her father's mental decline at a meeting for doctors who work in nursing homes: 'Imagine for a moment that you have a new job in an unfamiliar building, and it's not clear what the position actually entails, the computer is nowhere to be found, you're being undermined by your colleagues and you're not allowed to go outside.' Complete, overwhelming chaos. Or, in the words of René van Neer: 'It's just as though every day you exist less and less.'

In the homes where Van Neer has been admitted, the care assistants work like fury to get the residents to the breakfast table on time every morning, but expertise in dementia is in rather short supply. From the patient-care notes: 'Talking to Mr. Van Neer doesn't do much good. He only believes himself.' Van Neer became agitated, sometimes aggressive and was finally given a load of sedatives. 'Am I the main suspect?' he asked when he ended up in the locked ward.

The book Stella Braam has written about her father, *I Have Alzheimer's*, is a condemnation of patronising care and incorrect treatment of the patient. 'A person with Alzheimer's has the status of an elderly toddler,' says Braam. 'People no longer talk to them, but about them.'

Three months after the book came out, her message has become a mission. She does talks, speaks at conferences and is setting up workshops. Tuesday sees the premiere of a short film about her father, intended to be shown in nursing homes. The health-insurance company Achmea is going to distribute posters and postcards in three hundred residential and nursing homes with tips on how to communicate with Alzheimer's patients.

The ten tips come from her father, an 80-year-old retired psychologist and the author of several standard works about his field of study. 'They're the result of our quest to find out how we can remain in contact with each other,' says Braam. At the hospital where her father was admitted with a broken hip, she has already given the nurse a 'crash course in Alzheimer's communication': go and stand by him, say his name, say where he is, tell him who you are, use simple sentences.

She admits that she herself committed the worst mistakes in the beginning. 'I was constantly correcting him, but it made him thoroughly miserable. It only made him all the more aware of the fact that he was getting worse.' She has now learned that you should never ask what yesterday was like. 'First I have to make sure I can remember today,' says her father.

Raymond Koopmans, professor of nursing-home medicine at the Universitair Medisch Centrum St Radboud in Nijmegen, says that he was 'deeply moved' by the mission of this father and daughter. 'I am convinced that at an emotional level a certain awareness remains right until the last stages of dementia. That's why intimacy is so important. I try to convince

family members who don't want to visit any more, because their father or mother doesn't recognise them anyway, that they really should come to see them. Contact is always possible. We need to keep seeing Alzheimer's patients as people with a soul and a personality, not as empty shells.'

But the reality does not present a reassuring picture. Koopmans has worked for twenty years as a staff doctor at a nursing home and says that the sector is constantly dividing up already limited resources. More and more patients with Alzheimer's, fewer and fewer skilled staff members – that's the big problem, says Koopmans. Braam acknowledges this: 'If two of you have to get eighteen senile residents out of bed in one morning, no matter how good your ideas about treatment are, you just don't have the time.'

Koopmans says that he was shocked by Braam's book. He stresses that dealing with Alzheimer's patients is difficult and that staff members, who are often young, have to contend with complex problems on the wards, which are frequently exacerbated by feelings of guilt and grief from the family.

Dementia is a trauma that cuts a lot more deeply than many other disasters, said Bère Miesen, lecturer in psychogeriatrics at the Haagse Hogeschool, last week in his inaugural speech. The idea that Alzheimer's patients 'don't realise what's happening to them anyway' urgently needs to be corrected, says Miesen. 'Patients are fighting a constant battle against the loss of control and security and they retain a certain understanding of the consequences of their disease for a long time.'

He argues that an advance directive should be drawn up for every Alzheimer's patient, a 'personal contingency plan' that records how the patient should be treated. This contingency plan must be adjusted regularly, because the advance of the dementia requires adaptation of the approach.

Stella Braam has the feeling that she began her mission at precisely the right time. 'Emotion-oriented' care, which is geared to the needs of individual residents, is on the rise. 'I have noticed that the desire for change is very strong.'

Her father's tips have been used at the St. Jansgeleen nursing home in Limburg for a number of years. On every ward there are posters with dozens of recommendations for behaviour, organised according to the stage of dementia. All of the care assistants take part in courses twice a year and have a book that lists the do's and don'ts.

The recommendations are based on experience and have been supplied by the care assistants themselves, says psychologist Teun Hamer. One of the golden rules is: do not confront or correct the patient. Never tell a patient who is looking for his mother that she's been dead for years, because he's hearing the news for the first time. And don't test out the patient, says Hamer. That means no questions such as: Do you know who I am? What have you had to eat, Dad? Has Aunt Loes been to visit?'

A great sense of calm has been created on the wards of the St. Jansgeleen nursing home, says Hamer. 'If residents do become agitated, it's our job to find out what we're doing wrong. Maybe we're in too much of a hurry or they become overwhelmed when two of us enter the room. If we can see to their needs, they become happier. And happy people are calmer. That's also more pleasant for the staff.'

The nursing home has already sold the set of recommendations to so many other institutions that the development costs have been recouped,' says Hamer. There is even an American hospital organisation that wants to use the St. Jansgeleen approach.

René van Neer is doing reasonably well, says his daughter. 'He isn't really happy. He perks up when he has someone around him.' In the 'list of demands' that he drew up with his daughter, he calls for the introduction of the 'Juliana model': all Alzheimer's patients should have their own care assistant.

Professor Koopmans thinks that's a wonderful idea: security and intimacy are indeed the solutions. 'But try telling that to the government in The Hague.'

Stella Braam has told her father about the book they have written together, but she says that the information obviously doesn't sink in. 'I can make him happy every time I show him our book. It's always the first time.' She has learned that she's also allowed to laugh. With her father and about her father. 'I'm starting to have fun with it now. Last week we were in the restaurant at the nursing home and he thought we were at the V&D department store. I completely went along with it. I said: It's fun, eh? We'll go and do some shopping in a bit.'

He still recognises her, although he recently asked her how Stella was, how she was getting on at school. For a moment she shot back into the old pattern of behaviour, and pointed out that his daughter was sitting there opposite him. When she saw his bewildered face, she knew that it was the wrong approach. She roars with laughter: 'Now I say: Stella's fine – she told me to say hello.'

The correct care

Dementia is characterised by depletion of the memory and of the ability to think, perceive and act. Slowly but surely, patients lose touch with the here and now and lose the ability to identify objects, situations and people. In the long term, the ability to use and understand language disappears completely. Patients finally become debilitated and die.

There is no cure for dementia, but the symptoms can be alleviated with the correct care and support, says the Gezondheidsraad (Health Council of the Netherlands). In order to discover what Alzheimer's patients want, the Council says care assistants must take the time to communicate with them and not about them.

The problem is that the number of patients is rapidly increasing: around 250 thousand Dutch people are now suffering from the disease, but predictions say that there will be around 500 thousand sufferers by 2050. Because the working population is shrinking, there is the threat of a severe shortfall of staff to take care of them. In 2000, there were 63 potential workers per Alzheimer's patient; by 2050 this will have decreased to 27.



Poster designed by Achmea Health Insurance and distributed to all the hospitals and care homes to instruct the nursing staff.

I suffer from dementia, how do you communicate with me?

Stand close to me.

Call me by my name.

Touch me.

Speak calmly and use simple words.

Avoid double information in one sentence.

Listen carefully and pose simple questions.

Let the subject rest if it's not immediately understood.

Don't ask what I did yesterday as that information is already gone.

Know my past.

Don't correct me as I live in a different reality.

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