

Dementia in the era of modern medicine¹

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The chairman of this session, 'Ethical questions raised by dementia', professor Pim van Gool, has asked me to present here a first-person caregiver's perspective on dementia, but a perspective also toned with my life-long experience in the medical field both as a practice and as a science.

To explain what impact the diagnosis of dementia of my wife has made on her and me as her caregiver, I will first describe the events leading up to this diagnosis, which I hope are not too personal to be informative. Then, because I am, or at least have been, familiar with the medical profession and the biosciences, I will briefly reflect on our experiences against the background of what *I* think is modern medicine. Don't expect a scientific discourse however - I am a surgeon who in his spare moments has been meddling along in the fields of history, philosophy, ethics and literature in search of insight. Insights that could help me understand the explosive developments in the field of medicine during my medical career, spanning the second half of the past century.

In November 2012 my wife and I decided to see the family doctor. But why? Let me explore a few haunting experiences to make clear to you how slowly and cruelly dementia creeps up on you.

One day my wife came home from teaching English to an alderman in the town hall of Rotterdam. While putting her bag on the table, she said: "I'll stop this". When I asked her why, she said: "I needed to use the dictionary as much as he did". She, who always has been so fluent in English that once on holiday in the UK she was asked from which district she came.

Later, during a dinner party with some English-speaking guests, she embarked on a story, but all of a sudden stopped, because she could not find the words to express her thoughts. And I had to finish the story.

Always having been an excellent driver, she began making driving errors, making me feel unsafe in the passenger seat. She even took driving lessons again, but to no avail.

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The family doctor we visited, recommended to take a Mini-Mental State Examination. A nurse practitioner visited our home to perform the test. Halfway through the test my wife started to cry. In the end, she received only 16 of the maximal 30 points.

So we entered the medical circuit of a so-called Alzheimer Center. First, she partook in an intake interview with the geriatrician, then with the neuropsychologist, who after the interview told me that my wife most likely had dementia. This was then confirmed by several tests and, finally, a brain MRI. My wife endured everything patiently, but found it very unpleasant. Finally after three months we met the geriatrician again. She told my wife: “Mrs. Molenaar, you have Alzheimer’s disease in an advanced state. Unfortunately we cannot do anything for you. Medical treatment will be to no avail. I will ask the Social Work Department to call you within two weeks”.

Receiving the bad news straight away, without any introduction, we were too stupefied and paralyzed to take in the message properly and to ask the relevant questions. I remember two that reflexively came up: one about euthanasia and the other one about whether we would need to move and find a nursing-home. Both questions, looking back after four years, were totally irrelevant. The geriatrician, however, advised us to discuss euthanasia with the family doctor and the nursing-home with the social worker and to come back to her for follow up after half a year. Which we did not.

Some years ago, Arthur Kleinman, a medical anthropologist at Harvard Medical School, wrote an article in the *Lancet* under the title: *Catastrophe and caregiving: the failure of medicine as an art*.³ That’s exactly what happened here.

Two weeks later, we got a phone call from the social worker of the Alzheimer Center. A question - not how are you doing? - but: What home care organization we were connected to. None, because so far we never needed one. Then, a so-called case-manager was finally appointed and she visited us after another two weeks.

She – an experienced district nurse – was the first who clearly explained to us what dementia is and what we had to expect. Eventually, looking kindly

³ Arthur Kleinman, *Catastrophe and caregiving : the failure of medicine as an art*.

The *Lancet*, 5 January 2008, Volume 371, Issue 9606, pp 22-23

at us, she said that to her euthanasia did not seem like an urgent wish of ours. Looking around our house and garden, she did not think that moving was a pressing decision to be made either. This brought us some relief and she promised to come back soon.

To you, this might seem like an unreal, querulous and peevish story, but it is true and was at least 4 years ago not exceptional.

During the following years my wife's condition deteriorated slowly but progressively.

Here I shall give you a few examples.

Generally, in our daily lives, our internal perceptions, thoughts, and wordless vagaries of pleasure, pain, need and desire, always murmur under the surface of our consciousness. They become sufficiently real to acquire the solidity of a name, of a word⁴. A mysterious process indeed! But what happens to us when it is distorted? Try to imagine what happens to you when you are no longer able to transpose your thoughts and feelings in sounds and symbols, in speech and writing, properly for others to understand? When only words for small talk are within reach?

In get-togethers with friends or family, where people tend to quickly move from topic to topic, my wife found it increasingly difficult to follow the tittle-tattle, and rapidly lost track. It has become a common experience to me that many people after a while no longer talk to her, or when they do, talk down to her as if she were a child. This happens even with most of the professionals who have been visiting our home over time - and I must admit, I catch myself from time to time doing the same.

In our daily lives, where we are somehow constantly aware of space and time, we take it for granted that we move, walk, talk, gesture, eat, drink, that we take care of ourselves, remember what day it is and decide what we are and are not going to do.

As a thought experiment, try to imagine what happens when you lose the sequence of steps in these processes. Like a man who begins shaving while neglecting to use first shaving cream. Try to imagine - what happens occasionally to my wife - fortunately not often - will one day happen to you. Once, after waking up, she visited the toilet and came out completely terrified and in panic, with her hands full of dirt, asking me what happened and what to do.

⁴ Freud in *The Ego and the ID*, quoted in *The Private Life*, Why we remain in the dark, Josh Cohen 2015 Counterpoint Berkeley

All she needed then was for me to give love, reassuring care and comfort and restore her human dignity. In practice this means: turn on the shower, wash her, find and put on clean clothes, clean the toilet, open the curtains and bring light in for a new day.

These were only two examples of what happened in these first four years of our life with dementia. I will attempt to define how I see the phenomenon and its impact in a few words:

Dementia is a slowly mind-distorting terminal disease with an inconceivable and unpredictable phenotype, characterised by an increasing spatial and time disorientation and impaired capacity to express oneself and communicate with others in both speech and writing. Following its course from close by is frightening and often brings you to your wits' end. Bouts of anxiety and panic always lie in ambush and depression tends to dominate your state of mind.

To put you at ease, however, I can assure you that during this last journey in our life we also celebrate many moments of victory and joy.

Now, I will keep my promise to reflect on these personal experiences with dementia against the background of what I think has happened over the years with medicine.

Until the Second World War the field of medicine, with the exception of surgery, was largely in a kind of state of therapeutic nihilism: there was not much the doctor could do for his patients. This situation did not change until the era of post-war developments in the life sciences and bio-techniques.

In our days, it goes without saying that a doctor tries to relate a patient's symptoms to a site in the body where something has gone wrong: an organ, tissue or cell type – and today also complex molecules such as proteins or genes.

Disease is seen as caused by those molecular, minuscule defects that escape the constant repair processes in our bodies. In this view, disease is a defect that needs to be repaired. The chances of successful repair have been increasing, owing to the rapid advances in life sciences and techniques - culminating in gene editing with methods like CRISPR/cas9, tomorrow morning's topic.

Nowadays doctors, just like carpenters or plumbers, are held responsible for the result, and is not, as it used to be, appreciated for the professional

efforts they have made. To tell the patient that all treatment options have been exhausted, that nothing can be done and then discuss the inevitability of disease and the end of life, does not fit with this approach and therefore is no part of modern medical practice.

However, we might say that the success of modern medicine is unsurpassed. Never before have the chances of recovery been so high and so easily predictable. This holds for all age groups, young and old - from infants born too early to the very elderly. And what's more, some doctors consider the ageing process as a disease that must be treated or even prevented. Bioscientists predict that higher ages can be reached within the foreseeable future⁵. Some even say that 'we are now witnessing one of the last generations for which dying is no option'.⁶

But on the other hand, never before in history has healthcare been so expensive. And never before have so many treatments been associated with serious side effects affecting the quality of the life being fought for. Solidarity in health care and the wellbeing of the patient have come under pressure.

One could say that the practice of modern medicine is being dominated by the biosciences and -techniques.

Once medicine is reduced to bioscience and techniques, however, then the art of medicine will be divorced from the practice of care.

The natural sciences seek to understand our world and the biosciences seek to understand living nature - what nature is and how it works. They have developed visualization techniques to bring their findings into human perception. We understand things better and better and this gives us more and more power over nature. It's kind of an ascending helix.

But from the sciences we learn also that nature is lacking in any attitude towards us. There is no *Anima mundi* of which we are part of. We do not matter to nature. It is indifferent to us, to our fragility, to our suffering and to our joy, to what we think is right or wrong, just or unjust.

We are here this afternoon because we presume that our lives matter. We can't pursue our lives without adopting this presumption for which there is no justification, but it is our survival instinct.⁷

⁵ professor Clevers H in TV programme *De Wereld Draait Door*, 21 januari 2015

⁶ professor Clemens van Blitterswijk in FD Outlook 14 februari 2015

⁷ "The Mattering Instinct" A conversation with Rebecca Newberger Goldstein
www.edge.org

And that is where care comes in. In the *art* of medicine, human beings matter. And the core of the moral point of view is that we all matter equally.

This is why the art of medicine embraces both care and science. Medicine as a science should be both bioscience and social science. In medicine as a practice, science should be the servant of the comfort of the patient, his and her well-being. I have been educated and trained at a university which held the motto: *Medicina ministra mesericordiae*. Medicine in service of mercifulness. In the tradition of antiquity where doctors had to obey only one fundamental law, the 'suprema lex' - the supreme law which is 'salus aegroti' - the 'well-being of the patient'.

Therefore, if cure is not available for a human being diagnosed with dementia, the least we can do is invest in care, preferably to begin with in the earliest stage of dementia. And as care is more a verb than a noun, we must invest in those who *do* care for their fellow human beings with dementia - the caregivers. Because caregiving is the spiritual ferment, needed for a society to mature.

These are some reflections on my personal experiences with dementia against the background of what I think has happened over the years with medicine, and what *I* think should be brought back into medicine, making it both a science and an art again.

I am fully aware that what I am suggesting here is more a dream than reality. The easiest part is to set a standard. I hope that during the discussion there is room to explore in more detail what is needed to meet the practical consequences.