

The last taboo: Dementia, intimacy and sexuality

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Intimacy and sexuality are basic human needs that are intrinsic to people's sense of self and wellbeing.

Regardless of age, individuals require companionship, intimacy and love, yet for older people this intrinsic right is often denied, ignored or stigmatised.

For older people with dementia the problem is even worse: they face the 'double jeopardy' of being old and cognitively impaired.

In this presentation, I would like to discuss this issue with you, an issue that can rightfully be called a taboo, by outlining a number of 'good' and 'bad' practices.

A prior warning: This presentation contains sexually explicit material, including texts and images. So I'd now like to give anyone under the age of 21 the opportunity to leave the room.

Ladies and gentlemen, that was my feeble attempt to make an introductory joke about a topic I truly believe is quite serious and utterly relevant to the quality of life of people with dementia, namely how they experience intimacy and sexuality.

In my introductory lectures to students of The Hague University of Applied Sciences on the topic of 'ageing', I always show the first scene of the film *Wolke 9*. The title of this German film from 2008 refers to the English expression 'I'm on Cloud 9'. This film tells a beautiful love story. Of course, countless films have been made about love, which plays an important role in all of our lives, but the main characters are always beautiful young people.

But in *this* film, *Wolke 9*, the lovers are over the age of 80!

It is a lovely and touching film that starts with a sex scene on the floor of the man's apartment. We see two elderly people making love, well-acted and tastefully filmed. The response of the 20-year-old students is not surprising: they start giggling and cheering.

These are their facial expressions. When I ask the students why they respond this way, I get two types of answers. The majority finds the scene 'distasteful', while the minority finds it 'touching'. I confront the students by saying that, in my mind, both reactions are equally odd; and I ask them to honestly answer

whether they would have responded differently if the actors had been young and beautiful. They admit it without hesitation.

I get similar reactions when I show them photographs taken by the famous Dutch photographer Marrie Bot.

This photographer created a beautiful report entitled 'Timeless love', in which she portrays the intimacy and sexuality of elderly couples.

This picture appeals to an ideal and accepted image and, consequently, the students are of the opinion that it is beautiful and touching. Here you see Jack and Lizzy, ages 84 and 85. They've been married for 60 years and here they are spooning in bed. It is a picture that portrays their trust, intimacy and love.

But, oh my, if the pictures also have a sexual connotation... This picture brings laughter to the classroom. And the giggling reaches gale force when this explicit picture is shown...

... which, incidentally, depicts a common sexual activity.

Apparently, intimacy and sexuality in older people is a strange and emotionally charged phenomenon for young students.

But these are only photographs. I'd now like to share a few real life stories.

Here are a few pictures of my father. He suffered from dementia for the last seven years of his life. With the support of my brother and me, my mother took care of him at home until it was no longer possible. He lived in a nursing home the last year of his life. By that time, he had advanced dementia. One day, the nursing home physician called me to say that there was a problem at night with my father: "Your father gets out of bed at night and crawls into bed with other people!" My first response was "Is that a problem?" and was met with silence on the other end. "Of course," said the physician, "because the other people are not amused, get scared or angry, and push him out of their bed." I had to admit that the physician was right: some might perceive this as a problem. At the nursing home, I asked the nurses whether there was a sexual component to my father's behaviour. They emphatically denied it. "Your father crawls into bed with both men and women," they explained. "And if he's not pushed out by the other person, we find the two of them happily fast asleep side by side." I went back to the physician and said to him: "I understand my father's behaviour. He slept next to my mother for 60 years. Before that, when he was a kid he shared a bed with his brothers, as he grew up in a large, poor family. He did not have his own bed and has never slept alone in his whole life. So I suggested that he was now waking up at night and feeling the need for the reassuring presence of another human body. He's looking for intimacy." I then returned to the nurses and asked them which other patients enjoyed having my father crawl into bed with them. They turned out to be two men and two women. So I talked to their families and explained the situation. Two of the four families – one of the men and one of the

women – had no problem with them sleeping together, as long as both persons benefited from it. Fortunately, the nurses shared this sentiment. And so, for the last year of his life, my father slept with ‘alternating partners’ to everyone’s satisfaction. And my mother was okay with this because she understood his need!

Research into the quality of life of people with and without dementia has convincingly shown that the need for social contact, affection, attachment, intimacy and sexuality is essential. In a study conducted by Dröes, Hoogeveen and others (2006), people with dementia were asked what they considered important regarding quality of life. The responses listed on this slide were mentioned most often, but can be illustrated even better and with greater impact with a number of images.

Incidentally, affection, attachment and intimacy come in many different forms.

For example, what about Jo, age 96, with advanced dementia and in the final months of her life? Her 70-year-old daughter gave her a baby doll. Just look at her response!! One of my students said the following about these pictures: “When I see these pictures, I don’t see an old demented woman with a doll, but a mother with her child.” And I agree with her.

And what about Mary Lou, age 92? In the picture at the upper left, she looks fearful and sad. But she has a wonderful smile in the bottom right picture. I took these pictures within a time span of 10 minutes. How can her mood change so radically in such a short time? That’s because we know how to make this happen. Mary Lou was very much in love with her husband, to whom she was married for 65 years. Sadly, he is no longer alive. But, because of her dementia, Mary Lou doesn’t know this. She never talks about him but her brain seems to still know that she loved him. And those feelings of love can be evoked by smells. For his entire life, her husband used the same brand of aftershave: Old Spice. This brand is still available. So if we put a drop of Old Spice on a handkerchief and let Mary Lou smell it, she becomes happy four out of five times.

Experiencing intimacy is vital for the quality of life of people with dementia. And this may include sexual behaviour as well. I’d like to present you with two cases: one bad practice and one good practice.

Mrs Mills and Mr Burns live in the same psychogeriatric ward of our nursing home. Mr Burns is a friendly but somewhat dominant man. Both of them have adult children. A few days after Mrs Mills is admitted, she and Mr Burns come into contact. It is not clear who made the first move, but those who observe them see a couple in love: they walk through the ward hand in hand all day long, lean against each other on the sofa and are fond of caressing each other. The staff’s initial response is mixed. Naturally, they want Mrs Mills and Mr Burns to be happy, but they also have their doubts and a number of questions. Isn’t this an

extremely awkward situation? After all, Mr Burns's wife, whom he loved very much, died only three months ago. And Mrs Mills still has a husband, even though their relationship is not a good one! We discuss it with their children. They see the relationship between their respective parents on a daily basis and understand it. Yet they also find it troubling and one of the daughters expresses the feeling they all share as follows: "As long as it doesn't go beyond holding hands and pecks on the cheek, I don't have a problem with it..." Mr Mills has not yet visited his wife since she was admitted. To his son, who has informed him about the situation, he says: "I don't want to see her for a while because, otherwise, I don't know how I'll respond!" In the meantime, Mrs Mills and Mr Burns seem to be very happy together. Mr Burns sometimes calls her 'Sue', the name of his deceased wife, but he is mostly aware that this is his new girlfriend. Mrs Mills says: "I've met another boy and he's so sweet!" The children recognise that their affection seems to be positive for both of them. But it does not stop at 'innocent' caressing: Mrs Mills and Mr Burns do more than that. Other residents and visitors often see them shamelessly making out on the sofa in the living room and are opposed to this. They also find their way to one of the bedrooms more and more, where more explicit sexual activities take place. The children are understanding to a certain point, even though they have expressed that they find more extreme sexual behaviour unacceptable. And the opinions and feelings of the staff are mixed too. In the meantime, Mrs Mills and Mr Burns are not aware that they are doing anything wrong and refuse to be reprimanded. All in all, the tension continues to grow. One day, this leads to a shouting match in the ward between the daughters. After three months of increasing problems, Mrs Mills is transferred to a different ward. In the new ward, she is sad and defiant. She appears to understand what has happened a lot better than most people think. When she is asked why she is so sad, she says no more than: "It was better before; now it's one big mess." But when Mr Burns is mentioned, she sincerely says that she misses him and that she thinks it's horrible 'they' are being kept from each other: "When I see him, they'll physically stand in front of him!" I call this a bad practice, with an unfortunate ending for those involved directly.

But a happy ending is also possible! Mr Benson, age 86, lives in a nursing home. He has had dementia for five years, but was cared for at home by his wife until recently. That ended abruptly when she took a nasty fall on the street and broke her hip. She had to recover for several months and, afterwards, moved into a convalescent home that, together with her husband's nursing home, forms a care centre. Mr Benson no longer recognises his wife. And this saddens her. She tells us she had a very good marriage and that he was a sweet and caring man. When Mrs Benson visits her husband, everything goes just fine. He does not know who she is, but good-heartedly accepts her caring for him. And she appears to accept the situation. But then something unexpected happens. We often see Mr

Benson in the company of Mrs Smith, a woman with dementia who also lives in his ward. They have become 'close' and walk through the ward hand in hand. Mrs Smith does not appear to be a flash in the pan. The bond between her and Mr Benson grows stronger. They seek out each other's company more and more and show each other signs of affection. Mrs Benson also notices this, but does not say anything. I ask to speak to her and prepare myself to explain how this kind of bond between two people with dementia can develop. But I'm mistaken. Mrs Benson beats me to the punch: "I know what you want to talk to me about, about my husband and Mrs Smith. I find it difficult to see, I admit. But I also see that it does him good. And you know what? He has my blessing because I love him so much." Her response really moved me. She then said: "But I do have a request of you. I visit him every other day between two-thirty and four-thirty. Can you make sure that woman is not around because, otherwise, it's difficult for me to get through to him." "Of course," I reply, "we can do that." And that's exactly what we did.

In conclusion: Experiencing intimacy is vital for the quality of life of people with dementia. This may include sexual behaviour as well. Professional caregivers should be aware of this and help to allow the fulfilment of these basic human needs.

Thank you for your attention.