

## In and outside the nursing home: On the (im)possibilities of meaningful contact while being held apart

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By

*Weer  
n dag zonder  
jou te voelen.  
De alzheimer-keik moet helemaal  
leeg*

*Maanden  
los van  
elkaar; corona ons  
kruis, heeft elkaar doen  
verlaten*

*Nog  
nooit zo-lang  
gescheiden; nog nooit  
zo dicht bij de  
dood*

*Nooit-zo  
voelde ik  
de kracht van aanraken,  
nu het er niet meer  
is*

*Again  
a day without  
feeling you.  
The chalice of Alzheimer must be utterly  
drained*

*Months  
parted from  
each other; corona our  
cross, has brought us to abandon  
one another*

*Never  
ever for so long  
severed; never ever  
so close to  
death*

*Never ever  
have I felt  
the power of touch,  
now that it no longer  
is*

Ben (77) wrote this poem when he became unable to visit his wife Lise in the nursing home where she lived, expressing the loss and desperation of suddenly and indefinitely being held apart. As part of the measures taken in the Netherlands to prevent the spread of COVID-19, a visit ban had been imposed on nursing homes. Apart from staff, no visitors were allowed. Residents were not allowed to go outside, and family members, like Ben, had to stay away. This policy aimed at minimizing the risk of contamination for residents.

As older adults are considered to be especially vulnerable to corona, the restrictions on nursing homes have been more strict than in other segments of society. While schools, bars, restaurants, and cultural institutions were closed, no total lockdown was enforced in the Netherlands. Social contact beyond the household was initially allowed on

the condition that it was restricted to a maximum of three persons at a distance of at least 1.5 meters. Vulnerable groups and older adults, however, were advised to stay inside and avoid physical contact altogether.

The strict regulations in nursing homes have led to a strong separation between life inside and outside of the homes. Here we share the stories of two people: Catherine, who experiences loneliness, not being allowed to leave her room in the institution she lives in, and Ben, who feels the loss and grief of not being allowed to visit his wife Lise, who suffers from dementia, in the nursing home. Their stories illustrate the hardships of staying in touch when a strong physical barrier separates life inside the home from life outside. We question how this renewed boundary delineation challenges ways of being engaged with the world and each other.



Illustration by Margriet Osinga

### **Catherine: Reaching out**

I have always been a “people’s person,” Catherine says. She is 95 years old, visually impaired, and lives in a nursing home where several residents have fallen ill with COVID-19 symptoms. She says that before corona she used to receive visitors on a daily basis. Family, friends, and former neighbors used to visit regularly. “I always enjoyed these visits.”

However, when the corona policy was implemented, these visits ended. No visitors were allowed in the nursing home, and residents were not allowed out. Contact with other residents was also impossible since they were not allowed to leave their rooms. “I do not see anyone. It is as if I am

in a prison,” she says, and explains that she finds this extremely difficult, especially because she cannot see her children. Although she speaks to friends and family over the telephone on a daily basis, she still misses *being* with others, “I feel lonely.” She explains that she never used to take a nap in the afternoon, but now considers doing so, to pass the time. “The days take so long. I get so cold inside, cold from being lonely.” When asked what she means by this, she answers: “I am just cold inside, I miss physical contact, touch.”

Several of Catherine’s neighbors in the nursing home have died from COVID-19. Some of them were close friends. While she is still grieving their loss, she is also afraid of catching the virus herself. If she would fall ill or if she would die, her children would not be allowed to be with her. “That would be terrible. That is a great fear.” The situation makes her anxious, she worries much, and has little to distract her from her thoughts. Several times, Catherine emphasizes that being with others would make her feel better. “I need people! People, who talk to me. It is so important to have someone who spends time with me. I like to talk and I want to be involved.”



Illustration

by Margriet Osinga

### **Ben and Lise: Reaching in**

Ben vividly recalls how, eleven years ago, they had been sitting in the waiting room, waiting for the outcomes of her Alzheimer's tests. Whatever the outcome, it does not matter, Lise had told him. "As long as we hold onto our bond." Ever since Lise's diagnosis with Alzheimer's Disease in 2009, Ben and Lise have been seeking new ways of keeping contact. "I've heard partners telling me that they lost their spouse to dementia," Ben said. "I wondered what is behind such comments. I think it has something to do with the contact. For there is one thing about Alzheimer's you know for sure: it is more difficult to maintain contact, than to lose it."

Lise has been living in a nursing home for five months now, and Ben was a daily guest to the home until halfway March, when corona entered the scene. After 1.5 months, they are allowed to see each other again through

an open window, a screen of Plexiglas separating them.

Over the last couple of weeks, Ben has felt hopeless, an activist, writing to different media. “The thing is: talking doesn’t work anymore,” he explains in tears. “I’m just standing there moving up and down. I think I am somewhat erased from her aware memory at this point. So the only real form of contact we’ve got is touch, holding hands. But that is not allowed.” This is part of the loss involved in Alzheimer’s Disease, Ben explains. “But up to this moment I still had a little control over the process. But then, all of a sudden there is corona and they say we can’t see each other anymore.” Ben stresses that he is fighting to uphold his bond with Lise, and continues: “My biggest fear is that these restrictions will last for months, and that if Lise dies, whether or not from corona, I will not have seen her for months, or perhaps even half a year. I would then only be called in twenty-four hours before her death. I find that thought horrific! I think it is such a crude way of saying good bye!”

### **When missing social connectedness**

Catherine’s and Ben’s experiences are exemplary for those of many older adults and their family members. With the strict separation between the inside and outside of the nursing home, Ben and Catherine both find themselves in a situation they consider most unwanted. In different ways, both are deeply affected by the impediments in doing things they find important. For Catherine this is being with other people; for Ben this is keeping up the work Lise and himself have committed to ever since Lise’s Alzheimer’s diagnosis: the work of staying in touch. These impediments evoke frustration, anger and sadness. The uncertainty of not knowing how long the situation will last increases their disquietude.

While they mention the risk of contamination, it is not death itself they fear most. Catherine, who has already lost several neighbors in the nursing home, and Ben, who is concerned with the advance of Lise’s Alzheimer’s, have both thought about what it would mean to die while the restrictions are in place, whether or not from COVID-19 itself. Both mention that they are aware of the nearness of death, but what they find frightening about this would be precisely the impossibility of being together at life’s end.

Besides frustration and anxiety, as revealed both in their words and in the emotional intensity of their narratives, being isolated from loved ones also affects their sense of self. While they have been able to maintain some forms of contact, Catherine with friends and family through telephone conversations and Ben with Lise through Plexiglas-separated visits, their experiences also confront us with the limits of these forms of contact. What is missing from this is precisely the possibility of touch and being

with one another, or what Catherine called “being human together.” They make explicit the need to be involved, embodied and viscerally, in someone else’s world and to have an affective, meaningful part in it.

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*This research project looks at how vulnerable older adults experience the COVID-19 measures, what particular difficulties they encounter, and what solutions are being found. It is part of a broader project on the Social Impact of Physical Distancing on Vulnerable Populations at the University of Amsterdam in collaboration with research partners. For more information, see [www.coronatijden.nl](http://www.coronatijden.nl)*

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