



Shared Reading is a key that opens a door

Neuropsychologist Sonny Smet:

“If I can no longer remember the days, that makes each moment unforgettable.”

YOUR STORY MATTERS

Is a program in cooperation with Cera (finance and support) and the Expertise Centre for Dementia Flanders. After a pilot (2022-2023) in which we trained 24 reader leaders, we are now (2024-26) in the implementation in which we will set out Shared Reading in 200 new places: elderly homes, day care centers but also libraries who want to offer SR for people with dementia and their caregivers. 70% of them still live at home...

The implementation of Your Story Matters is realised with the umbrella organisations VLOZO, VVSG, Zorgnet-Icuro and Zorg-

Sonny Smet worked for 30 years as a clinical psychologist in an observation and diagnosis centre for people with dementia. In addition to neuropsychological research, one of her tasks was to give support and guidance to patients and their families. Over the years, she saw many different theories and approaches come and go, but to her mind there was one that was far superior to all the rest. For her, Shared Reading was the most efficient and most worthwhile methodology of them all.

“In my opinion, the magic of Shared Reading is hard to beat,” says Sonny. “Shared Reading opens up many different avenues and shows great respect for each participant, connecting them more closely with each other and deepening the experience as a whole. At the same time, communal reading also drives and directs the memories of people with dementia and helps to preserve their vocabulary.” She even sees positive results in people with serious forms of dementia, who have lost the power of speech. “I can see from their body language that they are calmer, that their breathing is deeper and often a smile appears on their face.”

Human dignity

For Sonny, approaching people with dementia in a humane and dignified manner is absolutely key. In this respect, her vision corresponds completely with that of the Media Manifesto, a joint initiative launched by the Flemish Alzheimer League, the Flemish Centre of Expertise for Dementia and the Flanders work group for people with dementia. “This initiative argues that a person is much more than the medical condition by which he or she is affected and that people with dementia have the same wishes and needs as the rest of us,” explains Sonny. “In each stage of their condition they must have the right to remain a full and integral part of a compassionate and understanding environment.”



Shared Reading as a way to learn from each other

“People with dementia have the same wishes and needs as the rest of us.”

That every person with dementia matters is something that she believes manifests itself during Shared Reading sessions. Since her retirement as a clinical psychologist, she has been a reader leader for Het Lezerscollectief. “Thanks to Shared Reading, I have deepened my connection with the target group still further. In our sessions, I do not act as a professional, but as just another participant in what is happening. If, in a session with eleven people who all have dementia, you are able to be fully present with all your heart in the moment, you create for the participants the necessary time and space that allows them to express their deepest inner feelings.”

“There is a danger that if you offer too much bodily pampering, this will soon be followed by too much mental pampering. This often happens with the best of intentions, but it means that we no longer really recognise the residents in their own right,” says Jan Raes. “In this sense, Shared Reading has a normalising function. We come together, drink a cup of coffee or tea, read a new text and talk about life in all its many aspects.”

Vulnerable revelations

Because of the intimate atmosphere that is created during the Shared Reading sessions, these deep inner feelings are given an opportunity to come to the surface. Sonny has also experienced how many of the participants are remarkably open about some of the most profound and poignant events in their lives. “After a number of sessions, one of the female participants confessed openly for the very first time that she had been raped when she was young. It was hugely liberating for her to finally be able to share this with others and the reactions of those others had a healing effect that helped her to deal better with the trauma. Of course, I also counselled her individually once the session was over.”



“Shared Reading helped him to free himself from his self-imposed prison of silence.”

Companionable togetherness not only encourages deep reflection. It sometimes encourages laughter as well. “During another session, a male participant, who used to be a sailor, told us about the day that Brigitte Bardot came to visit his ship. Later, he showed his mother a photo of himself with the famous film star and made her think that she was his girlfriend – and she believed him for at least a week!” recalls Sonny. Above all, however, the stories and poems that are read during the session are a key that can open the door on all kinds of surprising things. “I once had a man in one of my groups who had been in the residential care centre for two and a half years, without saying a single word. But during one of our sessions he suddenly began to talk about the fear he had felt during the Second World War. What makes this even more remarkable is the fact that he continued talking, even after the session was over! This gave me the feeling that the process of Shared Reading had helped him to free himself from his self-imposed prison of silence.”

Learning from each other

“Shared Reading is not about analysing texts. It is about allowing the magic of words to flow to your heart through your



eyes and ears.” Here, Sonny hits the nail neatly on the head. “The story or poem is simply a common thread that connects all the different group participants. Shared Reading with people with dementia reopens hidden inner paths and reactivates forgotten possibilities. This increases human potential and adds new dimensions to our human interactions.”

“We can also learn from people with dementia.”

Shared Reading not only allows people with dementia to express themselves, but also provides the lesson mentor with opportunities to see things differently. “By listening to the alternative interpretations that the participants give to the story or poem, you soon realise that your own interpretation is not the only one and that there are many other ways of looking at the world . In this way, we mentors can also learn from people with dementia.”

Accepting confrontations

Sometimes, the themes of the stories are very close to the experiences of the participants. This persuades some mentors to back away from these potentially confrontational situations. They wish to avoid exciting emotions that could be painful for the participants concerned. Sonny, however, does not agree with this approach. “I never shrink from reading stories or poems about their illness. Some participants refuse to recognise the reality of their condition and I respect this. But I know that others find it a relief to finally be able to talk about how their illness makes them feel.”

“Some participants appreciate that we have the courage to talk about dementia, because it is a subject that is often misunderstood or swept under the carpet.”



De Kluizerij: heart of what we do



“One of the participants once said to me: ‘Sometimes my head doesn’t do what I want it to do, so that I no longer know where I am. When that happens, it makes me mad but also angry with myself.’ For many sufferers of dementia, it is a comfort to know that they are not alone with their problem and that what they are experiencing is no one’s fault but is simply a consequence of their illness and a normal reaction to their changed situation.” Many of the participants are willing (and grateful) to accept the risks that confrontational texts of this kind may involve. “Some of them are glad that the subject is being talked about, because dementia is something that non-sufferers often misunderstand or are keen to avoid. Many people with dementia do not have a dialogue with their family about their condition, so that they often wrap themselves up in their own silence because they do not want to cause pain to those they love. In these circumstances, Shared Reading can have a liberating effect. In contrast, others prefer to focus not on what they can no longer do, but on the things that are still possible for them and on the fact that they are still capable of learning, in spite of their condition. For example, one man learned how to play the guitar after my diagnosis.”

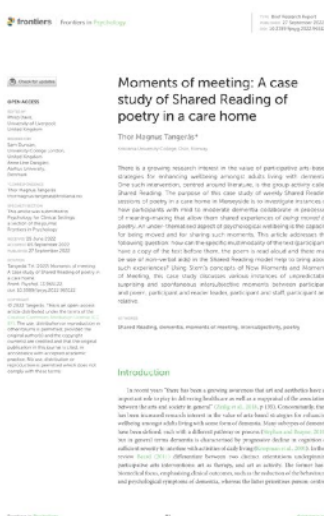
Personal enrichment

The impact of Shared Reading on people with dementia has been clearly demonstrated, but it also has an effect on the lesson mentor. Sonny’s experiences during Shared Reading sessions have meant a lot to her. “In the first place, my perception of time has changed. For people who have dementia yesterday no longer exists and tomorrow is just a black hole. They live entirely in the present, which has helped to deepen my own grounding and made me better able to put things in a proper perspective. I am cutting the word ‘urgent’ out of my vocabulary more and more.”

“Shared Reading with people who have dementia is hugely enriching in so many ways... not only for the participants but also for the mentors.”

Sonny has learnt other valuable life lessons as a result of her Shared Reading with people with dementia. “Having contact with people whose cognitive powers have been damaged has helped me to recognise the limitations of my own logical reasoning and has taught me to place greater reliance on the wisdom of my heart,” she explains. “Although I know as a psychologist that 70 percent of all communication is non-verbal, which of course is something that I take into account during my psychotherapy, it is above all the reactions of people with dementia who have lost control over their speech that have persuaded me that from now on the language of the heart should be my main language. Having said that, I will never underestimate the power of the spoken word.” She has also seen how people with dementia are freed from all their inhibitions, so that they can be 100 percent themselves. “This has led me to be less embarrassed about showing who I am and has helped me to become more self-confident. I now understand and accept that I am who I am and by taking part in Shared Reading with people with dementia I have learnt that having preconceptions and expectations is not constructive. In short, I have become a more complete person and am rooted more firmly in life.”

As a result of all these experiences, Sonny has reached the following simple conclusion: “Shared Reading with people who have dementia is hugely enriching in so many ways... not only for the participants but also for the reader leaders.”



In ‘Moments of meeting: A case study of the Shared Reading of poetry in a care home’ (Frontiers in Psychology, 2022) researcher Thor Magnus Tangeras refers to the following effects of Shared Reading on people with dementia: strengthened connectiveness with others, strengthened experience of the now-moment (activation), greater acknowledgement of expression, and an increase in general well-being. From 2024 to 2026, the Readers’ Collective will invest further in research into the effects of Shared Reading on the (growth trajectory of) the lesson mentor, ranging from burn-out prevention for employees to sustainab“

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Note: *In other translations we also use ‘reading companion’ in stead of ‘reader leader’*