



# Shared Reading: an expert's opinion

Psychiatrist Dr. Jan Raes:

*“Shared Reading helps people to forget about forgetting.”*

DIRK TERRYN IN  
CONVERSATION WITH  
DR. JAN RAES

## 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 Zorggezind.

The screen fades to blackness. The images and words that we have just seen and heard have had a powerful effect on psychiatrist Jan Raes and myself (Dirk Terry). With his film ‘Shared Reading – a remarkable methodology’, Dirk Elsen has captured the true value and meaning of Shared Reading and was able to touch us with the testimony of Magda Embrechts, the mother of her caregiver, Johan Terry. Jan Raes and myself look at each other in wonder and our thoughts seem to say the same thing: “This is why we started this initiative ten years ago.”

“I am deeply moved by the care that is given to creating a cosy and friendly atmosphere. The pleasant, light-filled space, the quaint cups, the fragrant coffee and the warm contact with Sandra and the volunteer, Ann. But I was also struck by the pleasure that the participants clearly take from this activity. That made a huge impression on me.” This is the first reaction of Dr. Jan Raes after watching the film. “We often have a distorted image of a care centre as a place of sadness, a kind of human scrap yard, where the body is kept going but all forms of pleasure and mental stimulation are disregarded. That image has been categorically disproved by this film.”



'Everything that is said here is right.' Sandra, reader leader

## *“Nobody corrects you during a Shared Reading session.”*

“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.”

### Waking up – with dignity



'My mother's focus is huge.'  
Johan Terryn, caregiver

According to Dr. Jan Raes, the film demonstrates the crucial importance of the role played by the reader leader. “The leader creates an atmosphere of **safety**, but also one of **dignity** and **acceptance**. As Sandra, the reader leader, puts it: ‘Everything that is said here is right.’ You should not underestimate the number of times that people with dementia are told that they have got something wrong, not in the least by their own children. But in a Shared Reading session no one is going to correct you. It is as though Sandra says: ‘We are just going to drink a cup of coffee together in an **easy-going atmosphere**.’

But there is more to that cup of coffee than just drinking. What strikes me in particular is the **heightened attention** and **focus** that Magda describes as a participant, which is also noticed by her son Johan.”

Jan Raes continues his analysis. “Don’t forget that the stimuli people receive when they get older have already been decreasing for quite some time. These stimuli are no longer *fresh* and *new*. People in the early stages of dementia search for something to hold on to and this usually takes the form of fixed patterns: the same actions, the same television programmes, and so on. In general, there is also less social contact as we get older.”

*“Stories open new worlds and revive old memories. You just want to be a part of it.”*

“You could describe the dementia process as a kind of slowly falling asleep against the background of life’s inconsequential murmurings. You only wake up when those murmurings say something out of the ordinary. If, for example, you feel spoken to. Sandra awakens something in the session’s participants. She has a strong story to tell. It is about ‘pesos’ and ‘curses’ and love-letters’... These words summon up images in the mind, generate a response. New worlds are opened and old memories revived. You just want to be a part of it,” concludes Jan Raes with conviction.

### Remember, share and forget the fight

I briefly break Jan’s train of thought to add: “There is a moment when Sandra says: ‘Everyone can fill that bit in for themselves.’ From the response and the hilarity that this arouses, you can see how **language** and **metaphors** also have the power to wake us up.”

“People do not forget words but often lose sight of them through lack of use. A literary text dusts them off and brings them back to the surface,” comments Jan Raes. “What’s more, words can evoke just about everything: thinking anew about *curses*, for example, can lead you almost anywhere. It is good for people to recall things that they thought they had forgotten and to talk about the experiences they associate with these things. At such a moment, they are no longer fighting with their forgetfulness, but are just calling up as many memories as they can and then sharing them. At the same time, rich language encourages you to make your own matching images. Reading the text out loud – preferably with a copy for each participant – supports this process.

This is probably what Isabelle Allende means when she talks about the **magical power** of storytelling. The story almost seems to spring off the page, fly around, and allow itself to be caught. The words become my words, your words, our words.



*“That day, Belisa Crepusculario learnt that words do not belong to anyone and they’re free to be used by all. She discovered that anyone with a little skill can train themselves to do wonders with words.”*

Isabelle Allende, author



## A second life

“Having a folder with texts in the person’s room: that is something else that we have learned from our contact with reading companions through Your Story Counts,” I say to Jan. “Once again, a highly worthwhile approach,” he responds immediately. “When people with dementia lose their memory, they often lose their sense of self-esteem as well. As they experience it, too much is being taken away from them: their house, their home, their furniture, their control of their own finances, sometimes even their partner.”



“It is almost as though it was written especially for me.”  
Participant Magda, with the text folder in her room.

*“You feel that you are being carried along by the script but at the same time are participating fully in the theatre of life.”*

“Shared Reading helps to add grace and warmth to this situation. As a result, a good text can be given a second life. In the film, Magda reads the text for her son. The words of the poet have been given a new owner: in them, Magda recognises the love of her husband, a love that she feels is still strongly present. She reads the text with great care and emotion, and in that way explains to her son what is going on inside her, what she feels and experiences. These are things that she would probably never be able to express otherwise. And her son receives what she has to tell him, taking the necessary time to listen to her words. There is **acknowledgement** and **intimacy**.

“And when the film shows other participants’ faces, catching their equally strong presence in the moment and their various non-verbal responses, it is easy to imagine that they, too, are also missing loved-ones. Offering people a language in which to express their loss is especially valuable,” observes Jan Raes.

## Keep tight hold of the script – at all times

“There are two Greek gods of time: Chronos and Kairos. The first represents quantitative or linear time; the second



*"I even forgot to drink my coffee!"*  
Ida, a participant



*"If an activity has to be scrapped, it must not be Shared Reading!"*  
Alice, a participant

represents qualitative time, the right moment or opportunity. People with dementia lose their grip on Chronos time, also known as clock time. But powerful stories can take us unexpectedly into Kairos time. Once there, we forget about time and engage instead with qualitative experiences. As a result, time itself is also experienced in a different way." Jan Raes clarifies this with an example. "Lots of people in Shared Reading sessions forget all about their cup of coffee... That is quite a statement! **Kairos time is a time of enjoyment.** You are pulled out of linear time, so that you live life more deeply, more intensely and 100 percent in the here and now."

*"Reading activities are high-end care, warm and concerned care but with absolutely no pampering."*

Jan pauses for a moment's thought. "I always imagine that in their own heads the participants are running around on a kind of stage, but no longer know in which play they are taking part. They look around and see others doing their own thing, but have the feeling that they have forgotten their own lines or have wandered into the wrong theatre. Someone else suddenly breaks in on this doubt and confusion, and says: 'I have come to tell you a story and have brought along a text.' You don't leave the stage; you don't lose your identity or your roll. Instead, the story unfolds itself in your mind and you also experience your fellow players, without needing to worry about the script. In fact, it is almost as if you suddenly find yourself playing a role in a stronger script, a script in which you feel supported and carried along, whilst at the same time fully participating in the theatre of life."

## Grab hold

I point out that Alice, one of the participants in the film, ends on a strong note: "Whatever else they scrap," she says, "Shared Reading has to stay!" Jan Raes enthusiastically agrees. "She is right! Reading activities are high-end care, warm and concerned care without any pampering. We take nothing out of the participants' hands. On the contrary, put something into their hands in the form of an important story and challenge them to





do something with it. And do you see those hands? They reach out and grab hold.”

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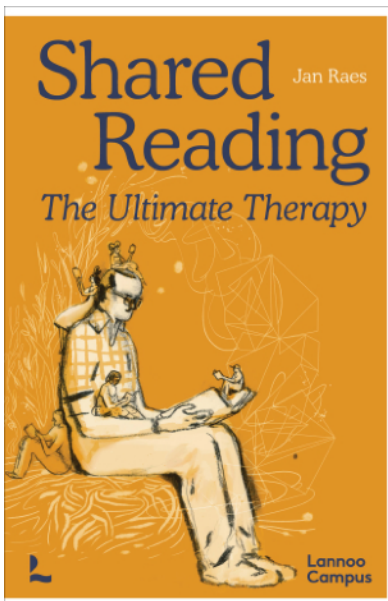
Text Dirk Terry

Pictures: Dirk Terry/Dirk Elsen

Translation Ian Connerty

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

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More than ever, people in a position of vulnerability need accessible and efficient care that helps them to grow, learn and change. Sharing the experience of reading powerful stories and poems can be an active power towards that goal.

The practice of Shared Reading kicks off a process of change that follows a recurring pattern, in a dynamic cycle of starting, growing, harvesting, learning and relaxing. In small groups, people read literary texts together with a reading companion who reads out loud and asks questions. By talking about the text and reflecting on it, people learn from each other and increase their inner mental-emotional space. By connecting with other people, they experience powerful therapeutic effects, outside the context of regular therapy.

*Shared Reading. The Ultimate Therapy* demonstrates the transformative power of Shared Reading, illustrates it with cases out of day-to-day health care practice.

**Sold in The Reader Bookshop or <https://www.amazon.co.uk/>**