

7 | The art of storytelling: end-users as ambassadors to disseminate the project and reduce the stigma on dementia

"As an art historian, teacher and art lover, art is an integral part of my life. Dementia doesn't change the essence of who I am, what I enjoy and what gives meaning to my life. In fact, each person is an artist and creatively shapes his or her life. Art can be healing and helps us to give things a place. Life itself is one process of shaping and sculpting ..."

Kris Mees, former art history teacher and member of the 'Flemish working group of people with dementia'

The key mission of the 'Dementia in Cultural Mediation'-project is exploring the value of arts and culture to improve the quality of life for people with dementia and their loved ones. Therefore it is crucial to move forward on reducing the stigma on dementia. The most effective and powerful way to reach this target is involving the end-users as ambassadors in the project's communication. The everyday life and experiences of people with dementia and their loved ones are not only a rich source of information in setting up or evaluating artistic and cultural activities. They are also vital when it comes to communicate about the benefits and return on investment of the project's good practices and in this way make them sustainable on a long-term basis.

7.1 | Valuing the experts by experience

If we focus on the capacities of people with dementia instead of their limitations, their dementia will disappear behind their talents and not the other way around. That was the starting point of the Flemish awareness raising campaign 'Vergeet dementia, onthou mens' ('Forget dementia, remember the person') in 2019 and this vision is also that beating heart



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of the 'Dementia in Cultural Mediation' project: **respectful communication is the basis for tailored cultural and artistic activities, for person-centered care and support and for an emancipatory society** (Constant, 2019).

People with dementia and their loved ones have the same needs and rights as all of us: they want to be valued, understood and included, but due to the stigma still surrounding the condition people with dementia and informal caregivers live with feelings of shame, isolation and decreasing resilience. As a result, we risk burdening them with 'excess disability': the additional limitations, pain and inconvenience caused by social stigma that come on top of the physical and mental problems caused by the medical condition (Sabat, 2001).

The best way to break down this stigma, as a basic pillar for putting the 'Dementia in Cultural Mediation' project targets into practice, is to look at what we can still learn from people with dementia. Not from a well-intended kind of pity for people with dementia, but from sincere compassion and a firm belief in their everlasting capacities. Not only right after their diagnosis but in all stages of the condition (Constant, 2019). The acknowledgement that dementia is seemingly made worse by the overall negative 'framing' in which the condition is portrayed by society and the media (Van Gorp & Vercruyse, 2012) challenges the 'Dementia in Cultural Mediation' communication strategy to offer a dynamic approach that enhances a more realistic perception of the condition. The additional value of artistic and cultural activities should be communicated through a bottom-up approach that empowers the person in his abilities and validates his unique experience.

7.2 | Personal experiences as communication compass

Storytelling is a creative process that encourages people to use their imagination to tell stories about people or objects that are presented to them (Creative storytelling and drama in dementia care, 2020). Skillful storytelling helps listeners or viewers to understand the essence of a project in meaningful ways based on the lived experience of the storyteller. It has the power to translate information into a call to action. **Involving the person with dementia as ambassador for your project is an innovative and effective way of storytelling that requires creativity.**

It asks for a new definition of the narrative, based on the mental, physical and emotional capacities, limitations and needs of the person with dementia. The narrative environment shapes how particular stories make sense of a project's values, opportunities, strengths and challenges.

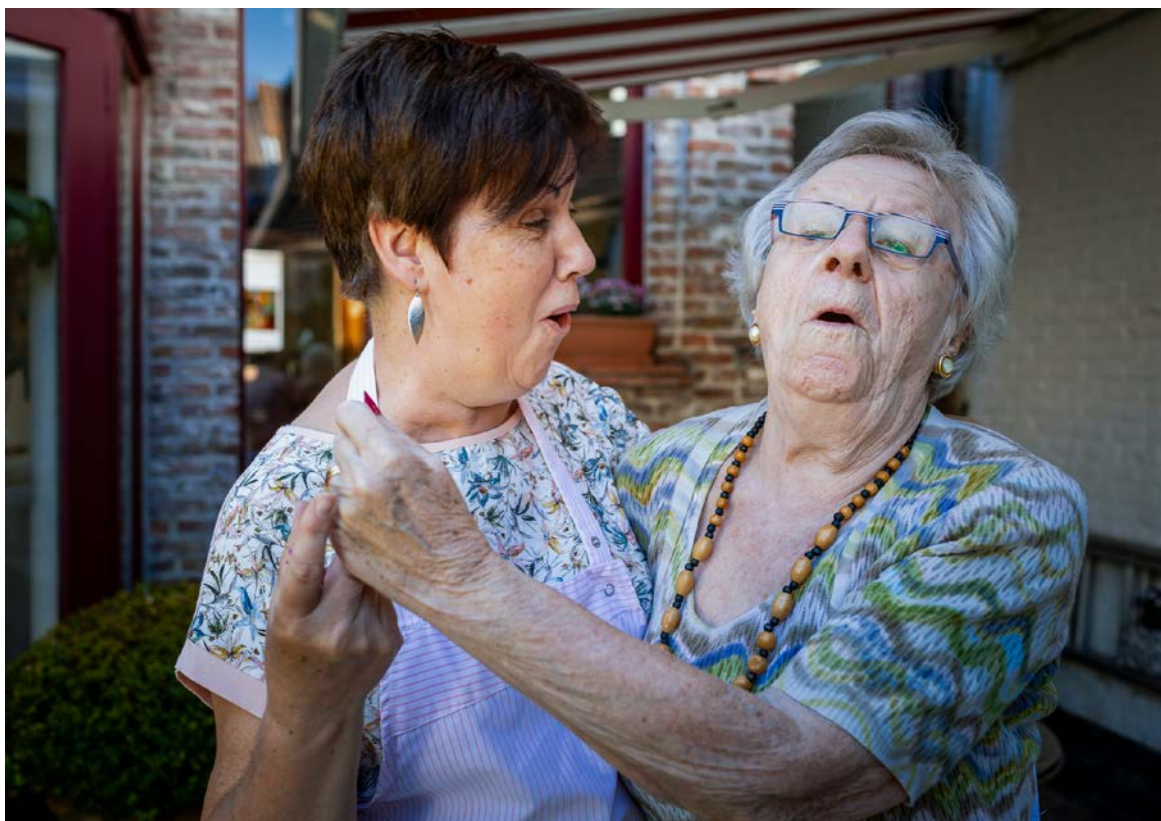
Within the 'Dementia in Cultural Mediation'-project we like to urge for an open and dynamic communication perspective where the non-verbal is equally important as the verbal communication. The specific environment of a project and the chosen communication channel can make or break the strength of the message for people with dementia. That is why we have opted for a focus on audiovisual communication. Video narratives and their corresponding online dissemination have the ability to incorporate not only different artistic forms of expressions but also generate opportunities to include the voice of people with dementia in different stages of their condition, with or without words.



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7.3 | Dissemination and respectful communication

Including the voice of the end-users in the global communication strategy is not only an effective way to translate the project's emancipatory and innovative bottom-up approach



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in the field of arts, culture and care. It is also the reference point to discuss, write and visualize the wide range of initiatives in a way that values the uniqueness of the particular project or person portrayed. **Engaging people with dementia directly in the project's communication process provides them with a sense of purpose and gives them additional tools to express their identity either verbally or through their bodily movements as well as an opportunity for meaningful social connection** (Creative storytelling and drama in dementia care, 2020).

The language we use to talk about dementia influences how people with dementia are viewed and also how they feel about themselves. **People with dementia prefer words and descriptions that are accurate, balanced and respectful.** The language recommendations of DEEP (Dementia Engagement and Empowerment Network) offer clear and helpful communication advice that does justice to the dignity and personal needs of people with dementia. The guidelines were written by 20 people with dementia and provide guidance for future project communication within arts and cultural projects on the microlevel of the activity, on the mesolevel of the organisation and on the macrolevel of the dissemination through online and offline media (Dementia words matter, 2015).

To enhance the process of involvement of people with dementia in the storytelling process, it is important to realize a safe and emancipatory communication environment. The

following points of attention can help to move towards an effective and respectful communication strategy:

- Make sure all the **privacy concerns** are clear and well-documented for all people involved in the content creation and communication process.
- Give **people with dementia an active role** in each step of the communication process where possible.
- Look for a right **balance between verbal and non-verbal communication** based on the project's mission and the project's audience.
- Silence speaks when words can't: **try to capture the process** of the project and the person's experience rather than only describing the project's goals and results.
- **Target the communication channel** on the capacities of the end-users and the additional value of the particular project.
- Work towards a **complementary social media approach** for audiovisual (e.g. project videos on YouTube), written (e.g. quotes of participants on Facebook or Twitter) and pictorial communication (e.g. project stills on Instagram). People with dementia could also be social media ambassadors on channels like Twitter or Facebook!
- **Avoid elderspeak: don't patronize people with dementia** by portraying them in a childish interaction or by overcorrecting them in the process.

Involving the end-users as ambassadors has the power to affirm their dignity and self-worth (Ong, 2021). It also provides more credibility for and insights in artistic and cultural projects of which the effects and additional value are not always easy to quantify. It generates a mutual learning process for all actors involved, which is explored more in detail in the didactic training material of the 'Dementia in Cultural Mediation'-project.

List of references chapter 7

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