

4 | Building bridges between art, culture and dementia: challenges and opportunities

“Art makes life more enjoyable and helps us to still be involved in society. I am also convinced that art and culture can help to raise awareness on dementia and communicate about it in an open discussion without taboos. However, the cultural experience should be more tailored to the person with dementia if necessary. For example adjusting the explanation to the pace of the person with dementia during guided tours and enhancing the accessibility of the infrastructure are still challenges to address.”

Paul Goossens, living with dementia and member of the ‘Flemish working group of people with dementia’

To build a wide and diverse cultural offer tailored to the different needs and capacities of people with dementia, we need to map the different barriers and enablers for experiencing art and culture. In April 2021 the ‘Dementia in Cultural Mediation’ project consortium organised an online brainstorm meeting with partner organisations, reference group members and end-users to list them up, based on experiences and knowledge.

We looked at barriers and enablers on three levels:

- **Microlevel:** on the level of the activity, one-on-one or in group
- **Mesolevel:** on the level of the organisation
- **Macrolevel:** on the level of society

4.1 Barriers for experiencing art and culture

On a microlevel

- **Stereotypes** about the cognitive abilities of people with dementia: e.g. “they don’t understand”, “they are not able to participate”, ...
- **Lack of improvisation** by the staff: when working with people with dementia, you need to be creative and flexible. For instance people with dementia may sometimes decide at the start of the activity that they do not want to go or participate.
- **Lack of knowledge** on how to deal and communicate with people with dementia.
- **‘Secondary’ difficulties**: e.g. incontinence, lack of adapted toilets, ...
- **Fear of the possible reactions** of people with dementia
- **Financial barriers**: due to the high care costs, participating in paid activities is not feasible.
- **Activities are often planned without the involvement of people with dementia** and then found not to correspond to their likes and interests and they do not want to participate.



Sonidos de la memoria choir (Spain). © Fundacion Instituto Gerontologico Matia-Ingema

- **The burden of the informal caregiver is too high:** for some people going to a museum is not on their priority list because they feel troubled and worried. A condition for people to participate in cultural activities is an alleviation or reduction of the perceived burden of the informal caregiver.
- **Activities are sometimes infantilising or too far removed from their customs and culture.** Not patronizing and paying attention to cultural diversity are key!
- **Sensory barriers:** inappropriate temperature, lighting, noise, smells. Reduce the number of people in one room.
- **Cognitive barriers:** over/under stimulation, attentional overload, language, visual perception, ...

On a mesolevel

- **Physical barriers in the building:** stairs, doors, carpets, ...
- **Transport** difficulties.
- Difficulties in organising **timetables** and making them compatible with the timetables of services: e.g. day centre, residences, ...
- **Uncoordinated schedules of cultural activities** (afternoon, evening/evening) with optimal schedules for people with dementia (mornings?).
- **Lack of staff** to accompany people with dementia.
- **Budget/financial restraints:** appropriate finances are needed in order to build a sustainable and accessible offer.
- **Lack of awareness** of the existence of activities for people with dementia.
- In some organisations they are not used to connect to people with dementia. In several countries we fortunately see a shift towards **lowering the thresholds** for many vulnerable groups. There are autism friendly-musea, dementia-friendly initiatives, tours for people with hearing disabilities, ...

On a macrolevel

- **Social stereotypes** : some families and/or organisations do not consider cultural activities necessary or appropriate.



E.g. “People with dementia are no longer able or interested in participating in cultural activities.”

E.g. “They are not perceiving, not conscious of the activities.”

- **Language** used before, during or after the activity **is inappropriate** and does not stress the human being.
E.g. “People with dementia are referred to as ‘demented’.”
- **Lack of information** in the city or region about the cultural offer. The availability of activities for people with dementia has to be embedded in a dementia-friendly community policy strategy.

4.2 Enablers for experiencing art and culture

On a microlevel


- **Co-creation:** create the activity together with people with dementia.
- **Introduce activities gradually** to allow people with dementia to get used to the situation (people, activity, time, place). Work beforehand with the people who are going to participate (context, familiarisation, habituation, ...).
- Flexibility of time and acceptance of last-minute decision making by people with dementia, which may be unforeseen. **Try to be flexible and don’t be afraid to improvise.**

- **No reservation in advance** is needed.
- **Group sizes:** choose a group size that seems appropriate to the kind of people and the activity.
- **In-depth knowledge of each of the people with dementia who participate** is an asset (interests, likes, dislikes, abilities). This helps you to match the activity to the abilities of the participants.
- **Try to empower decision-making for people with dementia.**
- **Treat people with dementia as people in their own right** and in need of experiencing art and culture like everyone else.
- **Combine ‘active’ and ‘passive’** (more observational) **participation** for different styles of people or different moments of the same person.
- **Respect the decisions of people with dementia**, even if they seem not logical or not optimal.
- **Pay attention to and understand verbal and non-verbal messages** about how the person with dementia is feeling during the activity. Try to avoid frustration or negative moods and encourage and reinforce positive moods.



- **One-on-one accompaniment:** It is recommended that each person with dementia is accompanied by a specific person (the informal caregiver or a volunteer). Preferably this is always the same person.
- **Trained staff and volunteers, with a heart for dementia:** The facilitators (animator, artist, museum guide, ...) and volunteers involved in the activity should preferably have a feeling for both art/cultural heritage and dementia. They have had at least a basic training in ‘dealing with dementia’. They look for the person’s possibilities, adjust and support where necessary, without taking over too much. Research shows that such qualities have a positive effect on cognition and on the social connection that people with (early) dementia experience. For each activity, consider which staff members the people with dementia will come into contact with: from the museum curator to the cleaning staff.
- **A cosy and welcoming environment**
 - For some people with dementia a familiar environment works best: they need the comfort of a familiar and relaxed surrounding.
 - For some people a new environment works best. They feel inspired by visiting a building, a room, ... outside of their house or home.
E.g. a museum, library, school of arts, ... They want to have the full and ‘normal’ experience.
 - The location can be a bit frightful at the beginning. Take that into account and comfort them. Decorate the room in a homely and cosy way. Make sure there is coffee, tea, a cookie, ...
- **Try to find ways in which the activity continues:** additional initiatives, pictures, a reminder, ...
- **Avoid unnecessary waiting**
- Do not offer long verbal explanations (e.g. museum guide). **Focus on modelling and non-verbal language.**
- **Adjust the pace and total duration of the activity** (better many, small, slow activities than all at once)
- **Stress the positive impact of participating in cultural activities.**
- Ask people with dementia and their families what they liked and disliked about the activity you organised. This gives you valuable information for the next edition. **Don’t be afraid of feedback.**

On a mesolevel

- **Write down the experiences of people with dementia** on your website. Show people what they can expect from your activity. Ask people with dementia and their families to write a review. Storytelling does work!
- **Key figures** who enthusiastically organise the activity and enthuse other colleagues and volunteers.
- **Conduct tailored research and/or report** on the impact of participation in cultural activities for people with dementia.
- **Offer complementary materials and experiences:** combine multi-sensory information but appropriate in size and time for each sensory modality, so that it is easily perceived and assimilated by the person with dementia.
- Make sure you have **appropriate rooms** for cultural activities.
- **Work with organisations of people with dementia to raise awareness**, involve them in and generate adapted cultural activities.
- **Use respectful language** on your website, in flyers, during real-life-contact, ... The DEEP Guidelines can help you with this. 



'Memory Walk' - Odensehuis Emmen and HANNN (The Netherlands) - Two participants and videographer Janneke Annema, © HANNN

- **Increase the accessibility of your initiatives:** financially, wheelchair accessibility, ...
A cooperation with local services, for example local taxi services.
- **Make sure every participant gets home safely.** Some projects call the people at home (or the main informal caregiver) after they have left the activity.
- **Education of all staff members and volunteers**
- **Build up a whole team of volunteers to support,** for example for bringing the participants, as a back-up in case one of the cultural mediators is ill.
- **Combine art and being outside/physical exercise**
- It is possible to involve people with dementia in many of the same activities they were part of before they became ill, as long as the activities are **differentiated**.
- You don't need to reinvent the wheel. **Search for other projects and initiatives and exchange experiences.** Learn from them and start your own project based on the strengths of your organisation. What talents do your colleagues have? There is often more expertise than you might have thought.

On a macrolevel

- A dementia-friendly community is a good basis for any cultural activity that focusses on people living with dementia. Within this network several organisations work together



to create a diverse and meaningful offer for this target group. **Working under the umbrella of a dementia-friendly community is a guarantee for sustainability:** recurring projects, a continuous focus on dementia-friendliness, societal projects that raise awareness about dementia, ...

- If there is no dementia-friendly community, a **local network of cultural institutions** (library, Odense houses, volunteer groups, schools, civil society organisations, ...) **and health care institutions** is an enabler.
- **Work with community agents** to raise awareness of the abilities, needs and desires that favour the integration of people with dementia in all significant community activities.
- **Receiving specific public and private funding** for these activities.
- A nuanced public perception on dementia - **a society without stigma, prejudice or ageism**
- **A regional or countrywide dementia strategy** gives a firm basis for all local initiatives for people with dementia. It puts dementia on the societal and political agenda and usually comes with specific financing of dementia-friendly initiatives.