

Towards a dementia-inclusive society. An art?

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Towards a
dementia-inclusive
society. *An art?*

Towards a dementia-inclusive society. An art?
Dementia in Cultural Mediation *recommendations publication*



Dementia
in Cultural Mediation



Erasmus+

Towards a dementia-inclusive society. An art?

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1 | Introduction

“It is important to adapt cultural activities to the daily reality of people with dementia, but people with dementia who still want and are able to do so must also be encouraged to take initiatives themselves. This not only concerns artistic activities with fellow people living with dementia, but also opportunities to remain active in regular cultural activities. In artistic and cultural activities, a good balance between stimulating capacities and understanding limitations of each person with dementia is vital to respect our autonomy and dignity.”

Jan Van Gils, painter living with dementia and member of the 'Flemish working group of people with dementia'

Interest in the added value of cultural participation for people living with dementia has risen over the last decades. The arts and cultural heritage sector expanded its offer and also health and wellbeing organisations are more and more looking for cross-sectoral collaboration to meet the needs of people living with dementia and their loved ones. In this recommendation report we will focus on the opportunities of culture and art for people with dementia and on the ‘Dementia in Cultural Mediation’ project we have been working on for two years. We are proud to present a wide range of new perspectives, insights and tools that will inspire many cultural mediators and healthcare professionals that are working with people with dementia and (in)formal caregivers.

1.1 | The project mission

‘Dementia in Cultural Mediation’ (DCUM) is a transnational project driven by the increasing number of people living with dementia in Europe. The initiative is based on the great potential of cultural and artistic activities as an innovative and dynamic approach to achieve social inclusion of people with dementia in local communities and to improve their quality of life. Through learning from the rich body of knowledge and experiences in the field of arts, culture and dementia care that the involved partners from Belgium, Denmark, Spain and the Netherlands have, the project has a clear ambition: *reaching out to local and regional cultural institutions, health and social authorities and end-user groups that want to embrace dementia in a more holistic way through cultural activities in order to create more dementia-inclusive communities.*



Philosophical Dialogue (Denmark) with Anni Jensen, Brandts Klædefabrik, © Birgitte Vestergaard

To realise this ambition, the project tries to increase the competencies of cultural mediators working in cultural institutions such as libraries, museums and civil society organisations but also healthcare professionals and policy stakeholders through exchange of tools and learning of new ways to practice cultural mediation aimed at people with dementia. The lived experience and valuable knowledge from people with dementia and their caregivers offered the guidance and quality check throughout the whole project development process.

1.2 | The project output

The 'Dementia in Cultural Mediation' initiative will deliver **three main outputs**: an open-source **digital toolkit of good practices** shared through a customized website, audio-visual productions and social media, accompanying **didactic training material** and a set of recommendations in this **report** to contribute to future European efforts in the field of cultural mediation for people with dementia. The recommendations are based on the project experiences and results which are continuously reviewed by a European reference group consisting of highly experienced experts in the field of dementia, research and the arts and representatives of the end-user group (informal caregivers and people living with dementia). All the project deliverables, updates and opportunities to interact are also offered through the dedicated social media platform on Facebook, Twitter and YouTube.



<https://www.facebook.com/DementiaInCulturalMediation>



<https://twitter.com/dcumproject>



<https://www.youtube.com/channel/UCCIsCeNYAcuufXnXbPfutGw>

1.3 | Publication goals and target groups

With this publication, as a finalization of the ‘Dementia in Cultural Mediation’ collaboration initiative, the project partners have three clear targets:

- Offering a **set of reflections and recommendations** about organizing cultural activities for people with dementia and (in)formal caregivers.
- **Informing the broader audience** about the ‘Dementia in Cultural Mediation’ mission and lessons learned.
- Reaching out to important actors in the field by providing an inspirational guide for building a **sustainable offer on culture and dementia** within their organisation, city or country.

The **main actors** where the ‘Dementia in Cultural Mediation’-recommendations publication is designed for, are in the first place anyone who’s active in the field of arts or culture, but the audience is much broader than that. We also want to reach out to health care professionals and social-care organisations, dementia-friendly communities, the local government, national policy makers, international umbrella organisations, end-user groups, schools, ...



2 | Dementia: why a person-centered vision is needed

"Music is the best medicine for dementia. Thanks to it my husband has smiled again. The choir gives the opportunity to be himself again, even if it's only for a moment...".

Wife of a choir member with dementia of Sonidos de la memoria, a contact choir in Spain

2.1 | Dementia: facts and figures

Dementia is a syndrome – usually of a chronic or progressive nature – that leads to deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from the usual consequences of biological ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by changes in mood, emotional control, behaviour, or motivation.



Meet Me @ Middelheim Museum, © Jan Dirckx

Dementia results from a variety of diseases and injuries that primarily or secondarily affect the brain, such as Alzheimer's disease or stroke (WHO, 2021). Alzheimer's disease is the most common form of dementia, representing about 60% to 80% of the cases. There is currently no cure or disease-modifying treatment, but better policies can improve the lives of people with dementia by helping them and their families adjust to living with the condition and ensuring that they have access to high quality health and social care. In 2018, an estimated 9.1 million people aged over 60 are living with dementia in EU member states, up from 5.9 million in 2000. If the age-specific prevalence of dementia remains the same, ageing populations mean that this number will continue to grow substantially in the future. The overall number of people living with dementia in EU countries is expected to rise by about 60% over the next two decades to reach 14.3 million in 2040, with the oldest people (those aged over 90) accounting for a growing share (OECD, 2018).

Dementia is currently the seventh leading cause of death among all health conditions and one of the major causes of disability and dependency among older people worldwide. Dementia has physical, psychological, social and economic impacts, not only for people living with dementia, but also for their carers, families and society at large. There is often a lack of awareness and understanding of dementia, resulting in stigmatization and barriers to diagnosis and care. There is a growing sense of urgency and perspective shift to address the challenges of dementia at different policy levels (*health in all policies*) and in various initiatives throughout society.

2.2 | Validation

Both the cultural landscape and the vision on good dementia care have changed drastically over the last decades. There has long been thought that bringing the person again to reality and correct him when they say or do things wrong was the solution for dementia. Therapists wanted patients to connect with their surroundings, by orienting them in time, place and person. Although some people with mild dementia might benefit from it, for most people it leads to frustration and disappointment. In the sixties Validation Therapy from Naomi Feil became popular. It is based on empathy and connection with the person with dementia and can lead to meaningful interaction. Feil's model sought to classify the stage of dementia that an individual has reached according to cognitive and behavioural signs. Its development was the result of an attempt to provide practical solutions for difficulties experienced by patients and caregivers.

Important features of validation therapy include: a means of classifying behaviours; provision of simple, practical techniques that help restore dignity; prevention of deterioration into a vegetative state; provision of an empathic listener; respect and empathy for older adults with Alzheimer's disease who are struggling to resolve unfinished business before they die; and acceptance of the person's reality (Takeda et al., 2012). Unfortunately, evidence for this method is lacking (Kroes et al., 2011). Over the years we slowly saw a transition to expe-

rience-oriented care, culminating in the birth of person-centered care pioneered by Tom Kitwood.

In 1997, Tom Kitwood, with his book *Dementia reconsidered, the person comes first*, put person-centred care on the map. Kitwood sees people with dementia first and foremost as people, which is why he uses the term person-centred care. Respect and attention, both for the person with dementia as for the persons taking care of him, are important pillars in his vision on care. Kitwood emphasises how important it is to establish an emotional connection with the person with dementia, both verbally and non-verbally. When language disappears and it becomes increasingly difficult to detect someone's emotions and desires, we fall back on reading their body language. Giving sincere attention is then a key to connecting with the inner world of the person with dementia. Kitwood was the first to emphasise the importance of the reactions of the environment to the wellbeing of the person with dementia. He calls them person-enhancing and person-undermining factors (Kitwood, 1997).



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Do you know Death Valley? Once every ten years Death Valley, one of the hottest places on earth, turns into a gigantic sea of flowers. The right amount of rain turns even this place into a stunning flower field full of life. So what about dementia? Even when people seem locked in or on their own, the right approach might lead to meaningful interaction.

Fortunately, the former one-sided pharmaceutical and medical approach to dementia has disappeared (Dely, 2016). There has been a shift towards non-pharmaceutical interventions which show to have several benefits for people living with dementia. Non-pharmaceutical approaches have potential to slow down cognitive decline and other symptoms of dementia

(Windle, 2019). For example, aesthetic experiences such as art can enhance the quality of life, well-being and inclusion of persons with dementia and their caregivers (Mastandrea et al., 2019; Schneider, 2018; Windle, 2019). Hence, over the past two decades, several art programs were developed for people with dementia (Dassa & Harel, 2019). The range of activities is highly varied, including participatory activities such as singing, drama, visual arts, photography, puppetry, ... All stages of dementia are considered, so people with advanced dementia are also included in the activities (Zeilig et al., 2018).

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3 | The impact of art and culture on people with dementia

«You have given us wings, you are not afraid of us.»

Quote from a participant at the Royal Museums of Fine Arts of Belgium

Creativity and phantasy are long retained in people with dementia. It is therefore not surprising that many people that live with dementia enjoy art and culture. It evokes associations with colours, feelings, objects or memories and can be an expression of what they feel and think. Contemporary and classical art have the power to enhance quality of life. It is widely accepted that artistic and cultural practices can have a positive impact on the quality of life of persons with dementia. As a result, the arts are increasingly included in health care provision (Zeilig et al., 2014, 2018). Artistic programs for people with dementia usually put the person with dementia at the center. The programs are based on the premise that creativity remains intact despite any cognitive decline caused by the condition (Dassa & Harel, 2019).

It is generally believed that:

- Participating in an arts activity can re-trigger individuals with dementia, and stimulate **cognitive functioning** (Camic & Chatterjee, 2013; Goulding, 2013; Tan, 2018).
- Participating in an arts activity can provide a successful experience that can counteract stress, damaged self-esteem and depression, and can contribute to **improved self-esteem** (Dassa & Harel, 2019; Goulding, 2013).
- Participating in an arts activity allows persons with dementia to **express their feelings and identity** in several ways, as often the verbal is less prominent in art, and the physical is more central (Dassa & Harel, 2019; van Dijk et al., 2012).
- Arts activities can provide a platform to share interests and **strengthen social relationships and bonds** (Goulding, 2013).

Presented below is **an overview of the potential beneficial impact of arts programs on persons with dementia by artistic genre**. We would like to point out that although there are many scientific studies that focus on the positive impact of arts interventions on persons with dementia, it is difficult to translate the effect to current scientific standards. This means that there is little robust scientific evidence for it. Most evidence on the program effectiveness is observational and/or based on anecdotes (Jaaniste et al., 2015).

Few studies provide information on important variables such as the specific context, participants' types/stages of dementia, and the course and structure of the interventions (Lyons et al., 2018). Results are often generalized by artistic medium, without considering differences in impact of different methods or styles within a single medium, for instance, dance (Mabire et al., 2019). Additionally, there is little research on the long-term outcomes that arts programs can produce (van Dijk et al., 2012). Finally, there has been limited attention to the effects that arts interventions can have on the social inclusion of people with dementia (Skinner et al., 2018).

3.1 | Theatre

Theatre interventions have been shown to have beneficial effects on (a) the memory functions, learning and self-esteem of people with dementia (Dassa & Harel, 2019). In addition, drama-based interventions also contribute to (b) their communication skills and ability to express themselves (Dassa & Harel, 2019; Jaaniste et al., 2015). Theatre activities also have a positive impact on (c) difficult and changing behavior of people with dementia as they learn to trust each other (Jaaniste et al., 2015). Last, (d) theater programs offer an opportunity to



socialize and relate to others differently. Results are better when the activities are facilitated by professional actors instead of caregivers (van Dijk et al., 2012).

Theatre interventions appear to have a positive effect on the memory functions, learning and self-esteem of people with dementia. Throughout the process of the condition, people with dementia often lose their freedom, their loved ones, partners, memories, as well as any significant life roles that they had. They may feel that they are no longer who they thought they were. Theatre programs can help people with dementia regain self-confidence in a playful way. A focus on their creativity and spontaneity shifts the focus from their loss (Jaaniste et al., 2015). Exercises that focus on the retrieval of memories may create a positive self-image (Dassa & Harel, 2019).

In addition, **drama-based interventions also contribute to the communication skills of participants** (Dassa & Harel, 2019; Jaaniste et al., 2015). By encouraging them to express themselves, participants are able to tell their stories, express their emotions, formulate goals and try out new roles and identities. Through the use of humor and improvisation, theatre practice can reduce stigma and help participants to deal with difficult topics, related to loss, mourning and end-of-life issues. Research shows that theater programs that deal with these issues do not increase negative feelings of participants, but rather improve their quality of life, bring joy and help people with dementia to understand each other better.

Next, through the use of theatre, **anger, frustration and loss can be expressed in a safe environment.** Jaaniste et al. (2015) found that people with dementia who participated in the sessions that they studied became calmer over time. Moreover, theatre programs also seem to contribute to sociability (Dassa & Harel, 2019; Jaaniste et al., 2015). During theatre activities, the people with dementia connect and interact with each other in another, often very spontaneous way. Through the activities, they learn to trust each other. This may also lead to benefits in their every-day life, as through theatre, they learn to trust themselves to be more independent (Jaaniste et al., 2015).

A note of attention

These generalized findings obscure the fact that there are many different forms and formats of theatre. Research about the impact of specific theatre methods or forms is however on the rise. As example, we can refer to the Veder method, which is widely used and much researched. It has been found to lead to many positive effects. If the method is applied by professional actors, it has clear positive effects on the behavior, mood and quality of life of people with dementia. They show less isolated behavior, up to two hours after the intervention. Participants laugh a lot during the intervention and are less confused compared to people with dementia who did not undergo the



same intervention. In general, people who have participated are happier afterwards than others. Moreover, people who participate in the Veder method also dare to touch each other more (van Dijk et al., 2012). Thus, their social relationships improve (Boersma et al., 2019). Participants also indicate that they feel more at home. In addition, they remember more memories, even two hours after the intervention (van Dijk et al., 2012).

3.2 | Music

People with dementia are still able to listen to music and remain sensitive to it until the final stages of dementia (van Dijk et al., 2012). Moreover, **research claims that of several non-pharmacological interventions, activities with music are most successful in reducing behavioral symptoms of dementia** (Leggieri et al., 2019; Ueda et al., 2013). Music has been shown to have a positive effect on the state of mind of persons with dementia, in reducing feelings of depression and anxiety (Dassa & Harel, 2019; Gaviola et al., 2020; Scott & Kidd, 2016; Zhang et al., 2017). There are also positive effects noted in terms of disruptive and aggressive behavior (Gaviola et al., 2020; Leggieri et al., 2019; Scott & Kidd, 2016; Sherratt et al., 2004; Ueda et al., 2013; Zhang et al., 2017). Furthermore, studies claim that musical activities have a positive impact on the cognitive functions of persons with dementia (Gaviola et al., 2020; Leggieri et al., 2019; Scott & Kidd, 2016; Sherratt et al., 2004; Zhang et al., 2017). **Music interventions are also found to have a positive impact on the levels of engagement, participation and social behavior of persons with dementia** (Dassa & Harel, 2019;



Gaviola et al., 2020; Leggieri et al., 2019; Sherratt et al., 2004). Interventions lead to better relationships of people with dementia amongst themselves and with their caregivers. Last, Leggieri et al. (2019) observed an improvement in sleep by increasing melatonin levels and balancing hormones. Researchers also found that people who participated in music programs spent more time with their meal (Sherratt et al., 2004). Singing even adds to the abovementioned positive effects. Research shows a better short term and long-term memory. Singing together with people with dementia and their families stimulates social contact and connection.

A note of attention

Two important aspects to consider are the duration of the program and the way it is organized.

Duration

A study by Gaviola et al. (2020) shows that a strong decrease in anxiety only occurred when music interventions lasted longer than three months.

In group or on an individual basis

Individual sessions seem to have the best overall results, while group activities are more effective in reducing agitation, anxiety and irritability, especially in people with mild and moderate dementia (Ing-Randolph et al., 2015; Leggieri et al., 2019; Scott & Kidd, 2016). Moreover, activities organized in groups have a more positive influence on the social behavior and state of mind of people with dementia and (in)formal caregivers (Ing-Randolph et al., 2015).



3.3 | Visual arts

The museum context is believed to serve as a free space where persons with dementia can participate in art activities unconstrained (Camic & Chatterjee, 2013; Tan, 2018). It is considered ideal for promoting the general well-being and social inclusion of persons with dementia (Hernández Belver & Hernández, 2019). **The pioneer in organizing art activities aimed at people with dementia in a museum context is the Museum of Modern Art in New York** (Rosenberg et al., 2009). In 2006, they launched the ‘Meet Me at MoMA’ program, an activity for individual visitors with dementia and their caregivers (Rosenberg et al., 2009). Since then, several museums followed with their own program or integrated the Meet Me program into their own offerings (Kinsey et al., 2021).

Regier et al. (2017) analyzed 158 museum activities for people with dementia and came to two observations. First, they found that **all persons with dementia, from an early stage**



Expertisecentrum Dementie Vlaanderen (Belgium) - Cera © leodebockphotography.com

to an advanced stage, can be meaningfully involved in museum activities. Second, their analysis showed that depending on the progression of dementia, activities for persons with dementia need to be simplified on the one hand and supported by auditory and tactile interventions on the other hand (Regier et al., 2017). Although everyone can be meaningfully involved, it should not be assumed that every person with dementia finds all activities appealing and should be encouraged to participate at all times (Nyman & Szymczynska, 2016).

3.4 | Dance

Dance programs gain popularity, because of the perceived benefits that they offer. **A dance intervention combines the benefits of physical exercise with cognitive, behavioral, emotional, social and psychological benefits** (Mabire et al., 2019). Dance is also multidimensional. Music, exercise, senses and social factors are all integrated in dance (Guzmán et al., 2016). Dance programs are therefore found especially suitable for engaging people with dementia, despite the cognitive changes and social and physical challenges that the condition brings (Skinner et al., 2018). People with dementia who cannot stand up for long can for instance be involved in dance activities by having them sit on a chair (Mabire et al., 2019).

Dance interventions can have a positive impact on the physical activity of people with dementia (Mabire et al., 2019). Older people are increasingly at risk of falling, especially people with dementia. Falling is associated with pain and loss of self-confidence (Abreu &

Hartley, 2013). Researchers cite that motor learning is relatively well preserved in people living with dementia (Ho et al., 2018). **Dance interventions can help people to become more aware of their bodies and how the body moves and functions** (Ho et al. 2018). Through dance, individuals with dementia can experience improvements in strength, balance, functional mobility, speed and walking distance (Abreu & Hartley, 2013). Dance interventions have been shown to have positive effects on older people's risk of falling (Abreu & Hartley, 2013; Mabire et al., 2019).

Dance-based interventions slow down the progression of dementia, as they activate brain areas affected by the condition and linked to perception, emotions, executive tasks, memory and motor skills. By activating these areas and mechanisms through movement, an improvement in cognition can occur (Ho et al., 2015; Mabire et al., 2019). An improvement in brain plasticity can already be obtained through activities that are not demanding on a physical level, and through one hour of dancing a week. **It has been found that the hippocampus, which is responsible for memory and is one of the first areas to deteriorate, increases in volume during aerobic exercises involving rhythm.** The memory of people with dementia therefore improves with such physical activities. Long-term memories and the associated emotions can be restored (Ho et al., 2015).

Furthermore, there is substantial evidence that dance activities can have a positive impact on behavioral and psychological symptoms (Mabire et al., 2019). Activities improve quality



'Dancing Stories' (The Netherlands) - Marjan Oostmeijer and a participant, © HANNN

of life, have a positive impact on the mood of people with dementia and counter depression (Goldstein-Levitas, 2016; Ho et al., 2018). In the study by Ho et al. (2018), people who had been living with the condition for one year reported feeling less lonely. People with dementia found dance interventions enjoyable and felt that it had made them stronger and helped them to make links between their thoughts, feelings and physical stimuli (Lyons et al., 2018).

In addition, as non-verbal medium, dance provides an opportunity for people with dementia - as their verbal abilities decrease - to express their thoughts, emotions and memories through movement and the body's power of expression (Ho et al., 2015). First, this can increase their self-confidence and self-image (Jaaniste et al., 2015; Goldstein-Levitas, 2016; Ho et al., 2018). Second, it can make people accept their dementia better and make them express and share their feelings about it (Ho et al., 2015). Next, group dance classes can have a positive effect on the social interactions between people with dementia (Mabire et al., 2019). The dance activity can provide the opportunity to physically touch each other, depending on the dance style (Skinner et al., 2018). People feel more connected and integrated with each other (Ho et al., 2015; Jaaniste et al., 2015). Group classes can also counteract feelings of anxiety and isolation (Ho et al., 2015).

A note of attention

Despite the benefits that dance can bring, Ho et al. (2018) stress that it is important that the activity is frequent and intense enough to really see an improvement on a cognitive level. Furthermore, the dance activities should challenge the individual's physical abilities (Ho et al., 2018).

Dance interventions are not limited to one genre, there are many different dance forms and styles. The above-mentioned findings are therefore generalizing in nature. Research about the impact of specific dance styles or forms is however on the rise. As example, we can mention the DANCIN method, as researched by Guzmán et al. (2016). The music used in the method, namely 'Latin ballroom' music, evokes positive emotions, as it was described as 'cheerful music'. This method can improve the state of mind of people with dementia and have a positive impact on behavior. The intervention can be used to combat depression or irritability and increase self-esteem (Guzmán et al., 2016). The study by Guzmán et al. (2016) furthermore shows that the appetite of participants increased. Finally, the DANCIN method also has a positive influence on the physical abilities of people with dementia, as they increase. There is also a change in terms of mobility.





'Books & Do' - Biblionet Groningen (The Netherlands) - Ida Buijs and a participant, © HANNN

3.5 | Literature and poetry

Reading is an important skill in life, not only to navigate daily activities and participate in the labour market, but also to enjoy the richness of literature in any form. Whether it is novels, short stories or poetry, written words can take you out of the here and now and allow you to travel to unknown and even non-existent places.

Research indicates that literature-based interventions may have value in terms of the well-being of persons with dementia (Longden et al., 2016). For example, **shared reading** is a social-psychological intervention developed by Jane Davis, director of 'The reader' in Liverpool , in close cooperation with Philip Davis of the Centre for research into reading, literature and society (CRILS) of the University of Liverpool (Davis, 2020). The key ingredient of the intervention is **reading a text aloud in a group and sharing how the text is experienced**. The focus is on these experiences, not on what is exactly in the text or on a literary analysis. Timely pauses and rereading allow all participants to engage with the text. According to the initiators, shared reading is for people of all ages, backgrounds and life situations and is therefore organised in, for example, local libraries or local community centres. The organisation 'The reader' has also started to organise shared reading sessions for specific groups, for example persons living in poverty or dealing with a severe illness, including persons with dementia. Research confirms that reading has beneficial effects (Billington, 2019).

In Flanders, the shared reading intervention is organised by ‘Het Lezerscollectief’ . They organise training for reader companions, provide a library of texts including short stories and poetry and continuously develop the shared reading intervention further, in cooperation with ‘The reader’ in Liverpool. In recent years, shared reading has also been organised for persons in need of care: *“Shared reading seeks to reach, among others, people who are vulnerable: persons with physical or mental difficulties or limitations, those living in poverty, those confined to prisons, ... People in these categories do not always have access to thought-provoking literature or else their social background often leads them to be categorised as ‘people who are not interested in books’.”* (Raes, 2021, p. 15).

In this context, ‘Het Lezerscollectief’ has also started to train reader companions who, as volunteers or staff members, organise shared reading for persons with dementia in nursing homes. In 2022 and 2023, the existing work will be expanded to include training twice a group of twelve additional reader companions and learning about critical success factors for reading with persons with dementia.

In the Netherlands, shared reading for persons with dementia is organised by ‘De Culturele Apotheek’ .

In Denmark shared reading is organised in many libraries. The library sector is currently training its master trainers to spread the method as a form of core service in the libraries. The Reading Association IE Læseforeningen is the most experienced in training reading guides in Denmark.

Since many people in the target group lose the ability to read, it is essential to bring other senses into play when mediating literature, like Spoken Word or Multisensory Storytelling.

A note of attention

Although shared reading with persons with dementia is an innovative and therefore recent intervention, there are several points of attention, most of them not too surprising but nevertheless useful to mention.

- Don't read long novels or stories that stretch over multiple sessions and do not expect participants to remember the parts read weeks ago.
- Although some of the participants may no longer be able to read, provide (in large font) copies of the texts being read. Otherwise, some participants may feel excluded.



- Given this group is often of advanced age, pay attention that the hearing aids work properly.
- Make sure you have a quiet location, where there can be no disturbance, for example from other caregivers who are already setting up for lunch.
- Allow an hour to maximum an hour and a half per session and try to limit the number of participants to 8 or 10.



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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



but instead of not celebrating grandpa's birthday because he forgets it, we could celebrate his birthday EVERY day!

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.

5 | How to enthuse a local community?

"I noticed that as a daughter I am already doing a lot of things in a good way, but it is so valuable to learn how I can actually do just that little bit better to be able to be there even more for my father with dementia."

Participant of the 'Gedragsgenerator' intervention, coping with changing behavior through role play, in the Netherlands

A dementia-inclusive society is a task for everyone. It is a place or culture that is committed to work together and promote a better understanding of dementia, raise public awareness and facilitate social inclusion. **For people living with dementia, it is important to prevent social exclusion and therefore keep triggering their senses at different levels.** Art and cultural activities can play an important role in achieving this. A cultural activity or an art experience gives the person with dementia a feeling of inclusion for that moment and a better wellbeing on many different levels.

Living with dementia is challenging as it is, but by engaging communities and helping each other, an environment can be created where people with dementia and their relatives will be more supported and accepted just as they are. A connected and engaged community where people work together, is more resilient and better equipped to deal with certain situations and problems. **The challenge in this is involving the local residents in the dementia-friendly part and discovering what they can and want to contribute.** It starts with togetherness and awareness: together we can ensure that vulnerable people continue to count and participate! But how do you enthuse the local community to be part of this (Van der Klein, n.d.)?



5.1 | Get to know the neighbourhood

The starting point is **taking a close look at what is already being organised in the community** for people with dementia and what is the scope, like (cultural) activities, trainings in the field of dementia, care facilities and volunteer opportunities. How many residents does the neighbourhood have? What are their ages and backgrounds? What does the daily routine look like? What questions do they have? Are they aware of how people with dementia can react and behave? Do they have experience with people living with dementia and would they be interested in receiving information or participating in a workshop?

Look for the answers to these and other questions. Put on your shoes and hit the road! Start a conversation with, for example, the elderly in the coffee corner of the supermarket, the parents on the schoolyard and the youth at the playground (Salih, 2016). Also, look at the kind of stores there are in the neighbourhood and if the retailers are aware of how to interact with people with dementia. If there are cultural activities being organised, did the staff have a training or workshop so they know the things to consider regarding visitors with dementia? Remember that the resident is not one target audience. **Vulnerable people are different in backgrounds, so keep these differences in mind.**

5.2 | Awareness

While exploring the neighbourhood, it is important to find out the level of awareness and knowledge the community members have regarding dementia. **Try to involve the whole neighbourhood:** residents, shop keepers, cultural and civil society organisations, professionals, local decision makers, relatives, caregivers and people with dementia. To increase the awareness role play can be used but also info-commercials on television or social media. It can be integrated in a local play or acted out on the streets. Stories of people with dementia, relatives or professionals can be printed in local papers to create awareness.

5.3 | Right location

It is important that you are on the right location to get in touch with the local community members. For some, the threshold is too high to go to a meeting in the townhall while the community centre around the corner is more accessible. **Ask cooperation partners what the meeting points are in the neighbourhood for your target group.** Examples of cooperation partners are neighbourhood teams, local governments, health and social care organisations, religious institutes, childcare, community centres or contacts within your own network. Tailor your locations to the variety of target groups involved and be creative (Bereiken en betrekken, 2020).

5.4 | Connecting and empowering

Considering the points above, try to connect people from different target groups to create more awareness of including people with dementia in an active manner. **Get people together to connect, share stories, share knowledge, ask questions and share ideas.** A shopkeeper can talk to a person with dementia to find out how they are feeling in a certain situation, while a neighbour can talk to the caregiver about their personal experiences. This can inspire people to help in their own way and within their own possibilities. It might also inspire a person with dementia and their relative to reach out for help. It can strengthen the collaboration and communication between all involved. By including people with dementia in this whole process, professionals and other community members become more aware of their needs and wishes. Including people with dementia also means empowering them, recognizing they are still part of the community.

5.5 | Neighbourhood communication

Participation and involvement of residents in a community is a goal of most local governments. Communication with the neighbourhood may be the key to success in this. People



Culture Club having a city walk (Denmark), © Birgitte Vestergaard

can only give their opinion and act on it if they are well informed. Local governments use various ways for communication, like websites and local newspapers. These resources are effective for a certain target group. But **how do you ensure that you reach the right community members?**

Here are five examples of other ways of communication in the neighbourhood

1. **Street interview:** you can place an advertisement in the local newspaper, but you can also actively look for information through a street interview. Talk to the people on the street and ask questions about relevant things. The advantage is that when they get to know you, you will become a familiar face in the neighbourhood.
2. **Connect with (existing) events:** neighbourhood meetings, with a central theme like keeping the neighbourhood clean of safety, are sometimes organized by the local government. Engaged community members often attend these meetings. To reach

others, it is better to participate in an (existing) event. Arrange an attractive (but modest) stand with the necessary information and actively engage in conversations with the people.

3. **Neighbourhood app:** WhatsApp is increasingly being used as a means of communication. In addition, there are more apps that make it easy to communicate with the local community, for example the apps *Nextdoor* or *Hoplr*. Townhalls also use these apps to share relevant information, post invitations or to ask a question. Everyone can decide for themselves which information they want to respond to. These apps were originally intended for communication between community members.
4. **Wall:** with a neighbourhood project you want to collect the ideas and opinions of the local community members. You can use the usual neighbourhood panel or an online survey. But you can also use another, more creative way. Look for a suitable, outside wall. Think of the 'Wall of Love' in Paris to collect ideas and messages. Choose a spot where many people come and make it noticeable.
5. **Home visits:** this is a more personal way of reaching the community members. Ring the bell to collect ideas and share information. Think of it as kind of a 'kitchen table conversation', where you start a conversation in a very personal way. Find out what is going on in the community so that you can respond well to it (Vijf 'andere' manieren van wijkcommunicatie, 2020).



'A box with (your) stories' – Hunebedcentrum (The Netherlands) - A guide, three participants and videographer Janneke Annema, © HANNN

5.6 | Commitment

If you want to work with the local community members, it is essential that you **build and maintain a relationship of trust**. This takes time and you should not be too goal-oriented. The right attitude is important in building a relationship of trust:

1. **Work connecting (outreaching):** go out on the street and make contact with the concerning neighbourhood residents.
2. **Be culturally sensitive:** learn about the cultural values and backgrounds of the target group.
3. **Be open:** show interest in the other person and don't assume your personal norms and values (Bereiken en betrekken, 2020).

Take the time to get to know each other. Everyone involved can participate in their own field of expertise and interest. This creates a better understanding of the needs and wishes of people with dementia, the willingness and knowledge of volunteers and the possibilities regarding the available activities and local policies. To create a lasting commitment of the community and volunteers, it is important to keep communicating, listening to each other and share experiences. Offer training and information material, let them know the difference they are making and show your appreciation.

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6 | The DCUM platform

"The library is a neutral place for activities, where the person and not the condition dementia is the focus point."

Participant in the Library Culture Club in Odense, Denmark

6.1 | Needs analysis: a summary

To gain a clear idea of the needs in the field from the start, **we consulted 74 respondents spread over four countries** (Belgium, Denmark, Spain and the Netherlands) **from different cultural areas**. Respondents were affiliated with different types of museums; libraries; civil organisations; learning, teaching and training institutions; home care organisations; end-users and civil society networks. Respondents reported a wide range of activities tailored to people with dementia, irrespective of stage. The activities were situated in different disciplines (e.g., visual arts, theatre, dance), different locations (e.g., museum,



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

nursing home), targeting different senses (e.g. multisensory, listening, tactile expression) and using a variety of methods (e.g., role play, reminiscence, singing). Some activities took place individually (one on one) or in groups, but the majority occurred in groups where others were also involved (e.g., family members, primary school pupils, care givers).

Respondents indicated different needs and wishes for the development of a toolkit for cultural mediators to work with people with dementia. The reported needs and wishes related to different aspects of content and use. In terms of use, the toolkit we would create in this project should be free of charge, use an understandable language, preferably the native language, be user-friendly, and be attractive to encourage participation. The style should be concise, clear and coherent, and this both in text and video format. Some asked for simple and inexpensive activities, but **generally the focus is on good practices for inspiration that are also adaptable and flexible:** starting with knowledge about the target group's needs, to preparation, communication (strategies), recruitment (of people with dementia and partner organisations) and interdisciplinary methods.

The tips should focus on what to bear in mind (e.g. size of the group), what can go wrong and how best to react and how all this can be made sustainable. All in all, with the intention of making both the staff and the infrastructure dementia-friendly. Some respondents also gave their own tips, such as shake hands when entering and look at them to assess how someone is feeling, presence of professional staff at the activity, time to get to know each other and focus on the opportunities and strengths rather than on the problems.

6.2 | What did we create?

A website full of inspirational tools with 30 videos in which a tool is explained and accompanying didactic training material free for download



an available in four different

languages. The DCUM website is

designed as a toolkit containing tools free for use for cultural mediators in cultural activities with people living with dementia, healthcare professionals active in social-artistic activities, end-users interested to learn more on certain projects and policy

makers that want to move forward on this topic at a policy level.



6.3 | How to use it

The DCUM platform is a website and it has multiple of layers ranging from general advice on how to approach people living with dementia as well as didactic methods targeting the end user group as well as cultural mediators. **Going through the materials from the DCUM project the visitors will get a deeper, more detailed knowledge about how to create cultural activities for people living with dementia.** Using the platform, you will get good and reality tested advice and instructions, e.g. description of a cultural activity, the suitable number of participants to involve in the activity and the right settings for the activity.

Each partner has produced 6 videos on cultural activities for people living with dementia. You can find all the videos on the [DCUM-website](#) . In the videos the cultural mediators and end-users tell about the activity and show footage from live events. The length of each video is about 3 to 5 minutes. In addition to the website the DCUM-project is present on **Facebook, Twitter and YouTube** where a lot of inspirational examples of

cultural activities and relevant information on dementia and culture are shared by the project partners.



Facebook: <https://www.facebook.com/DementiaInCulturalMediation>



Twitter: <https://twitter.com/dcumproject>



YouTube: <https://www.youtube.com/channel/UCCLsCeNYAcuufXnXbPfutGw>

6.4 | A short navigation through the DCUM website?

At <https://www.dementiainculturalmediation.eu>, the European cultural mediators are welcomed by a site full of colors that symbolize the diverse palette of culture. **The website structure has a universal and stylistic design that reflects the project's 3 intellectual outputs: Tools, Didactic Training Material and Recommendations.**

- The **Tools** are presented videos that convey content, approaches and reflections on different methods of involving people living with dementia in cultural activities. In most videos, a local cultural mediator describes how the cultural method and activities can be planned and carried out, as well as some best practice advice to interested viewers. The tools are categorized within the cultural areas such as: Music, Literature, Theatre, Physical activity, Visual arts and Nature.
- The **Didactic Training Material** has been prepared to supplement the videos. For each of the videos, an extended didactic description has been created containing good advice and points of attention. The didactic material supports the professional cultural mediators during their inspirational process, the practical planning and hosting of cultural activities and implementation of the tools in their own practice. The Didactic Training Material can be downloaded and shared in the professional network of the cultural mediators.
- The website also contains this digital publication with a set of **recommendations** based on the project's experiences and development of cultural mediation for people living with dementia.

6.5 | Transferability beyond the project in partner countries and at a European level

The main purpose of the DCUM-project has been to improve the life of people with dementia through participation in cultural activities from the local care home to the local museum or library. These initiatives take place in multiple locations, in different groups



'Playful Mind' - (The Netherlands) - Zainal Palmans, two participants and videographer Janneke Annema, © HANNN

and at all possible levels in society. The activities can to a very large extent be angled and adapted to different groups. **The DCUM-platform is built up to support the sharing of local activities and to inspire all cultural mediators across the partner countries and outside the project consortium.**

All videos are recorded in local languages of the presenting cultural mediator and the subtitles of the videos are accessible both in English and local languages of each project partner country. The expanded effort on language increases accessibility and transferability of the tools as the use of the toolbox is not limited by the language skills of the cultural mediator.

Dementia is a universal condition not limited by borders, languages, or other human created boundaries. **The cultural activities found on the DCUM-platform are developed in local contexts of the partner organisations and lifted to a more universal level through the combination of videos and affiliated training material containing more details on the activity and tips for local planning of cultural activities.** The method of the DCUM-project was sharing good practices between organisations and on the practical level between cultural mediators. During the project the cultural mediators have tried out new activities in their local contexts based on the good practices presented by other cultural mediators. Through the DCUM-platform this set of methodologies and artistic practices is extended beyond the project participants and made available and adaptable to any cultural mediator or organisation outside the DCUM-project.

The ambition of the DCUM-project was to move from local cultural activities towards a European and international level through sharing good practices. **The diverse professional expertise among the five partners has enabled the project to disseminate and promote the project development and results on different local, regional and European levels.** The combination of a local dissemination strategy and a common strategy results in an integrated dissemination approach. The common dissemination actions have mostly focused on the digital channels, primarily through presence on social media and the project's website.

In addition to the digital channels, the project collaborates with local experts and people of knowledge on culture and dementia including end-users, through the association of a reference group. **The task of the reference group is to act as advisors and ambassadors of the project and its results both nationally and through their very diverse European and international networks.** The platform is structurally and substantively designed for universal use, and it is therefore relevant to other European organisations like museums, civil society organisations, schools and universities, libraries, healthcare institutions, care homes, ...



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 dementie, 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.

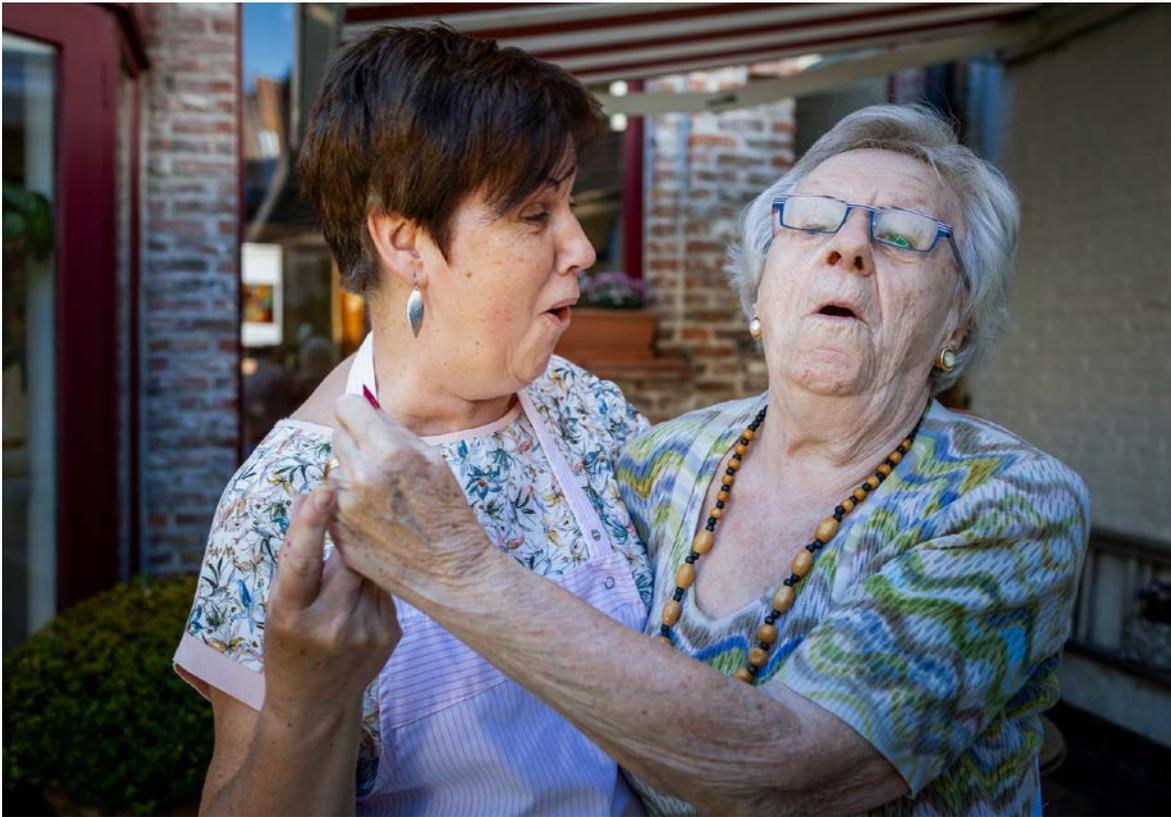
Within the 'Dementia in Cultural Mediation'-project we like to urge for an open and dynamic communication perspective where the non-verbal is equally important as the verbal communication. The specific environment of a project and the chosen communication channel can make or break the strength of the 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



Expertisecentrum Dementie Vlaanderen (Belgium) - Cera © leodebockphotography.com

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.

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8 | The impact of the COVID-19 pandemic and a look into the future

Covid-19 challenged all of us, both the project partners in organizing this project and our cultural mediators in reaching people with dementia. In this chapter, we will highlight the challenges we and our cultural partners encountered in ensuring continuation. First, we will discuss Covid's impact on this project. Second, one of our cultural partners (Isabel Vermote, Royal Museums of Fine Arts of Belgium) will bring in the perspective of our cultural partners/mediators. Both examples will identify the challenges (financial, organisational, productional, ...) that Covid-19 posed, explain how these challenges were addressed, and elaborate on negative as well as positive implications for both organizers and participants. Third, we highlight some of the initiatives taken by cultural institutions worldwide to address the constraints Covid-19 posed to arts and culture for people with dementia. This aims to inspire cultural organisations in times of pandemics/restrictions or in reaching an audience that is not mobile anyway and therefore often excluded from social contacts and cultural participation.

8.1 | Strong and agile readiness for change of the project partners

As project managers and project participants in 'Dementia in Cultural Mediation', there have been new levels of challenges related to the coronavirus that spread in Europe and the rest of the world shortly after the DCUM project started. Luckily, the project group just managed to meet in Denmark for an important start-up seminar in November 2019.

Start-up meeting of the DCUM project consortium
@ Odense (Denmark) in November 2019



The perspective of the project partners

To meet the corona related challenges, it required special qualities, transformations and readiness to transform physical activities into digital environments. That challenge was taken up by the members of the project group and the cultural mediators who presented methods for use in cultural mediation with people living with dementia and showed their strong competencies in the use of audio-visual online presentations as well as dialogues and discussions between the presentations.

The following summarizes some pros and cons in relation to online activities, such as presentations, discussions, breaks, finances, ...

Pros:

1. Opportunity to invite more participants: presenters, cultural mediators, reference group members and others with interest in the area.
2. Opportunity for online enhancements from LTT-1 to LTT-2.
3. Informal social activities, like dancing. An extended opportunity for participation 'behind a screen'.
4. Re-prioritization of the economy between budget lines, without extensive administration.

Cons:

1. Lack of opportunity for informal networking, conversation and workshops between the presentations.
2. Occasionally technical issues regarding internet connections and limitations of the streaming software.
3. Limited opportunities for intercultural exchange between the partners due to cancellation of physical meeting in the different countries.

Tryouts have been limited due to restrictions regarding the coronavirus pandemic, but in Denmark the project partners from Odense managed to make a few cultural mediated walks, inspired by some of the presentations from the project partners in the webinars. The end-users have responded very well to these activities, being grateful for having the opportunity to experience a sort of normal life in a situation where they have been isolated, seeing only a very limited number of people.

The perspective from the cultural mediators and end-users

During the pandemic many found their way to digital art exhibitions all over the world, as a partial alternative for the non-digital offer that was temporarily less available. For Isabel Vermote and her colleagues - **art mediators from the Royal Museums of Fine Arts of Belgium (Brussels)**, the main challenge during the Covid crisis was: **How to maintain**



Art and care in dialogue. © Royal Museums of Fine Arts of Belgium

contact with their target groups, like people with dementia and their caregivers?

Direct contact, whether on-site (e.g., in nursing homes) or at the museum, is key to their approach. However, during Covid, the museum was closed for a long time, and the staff was asked to work from home. At first, the department of art education decided to shift focus towards digital communication, in organising for instance virtual tours, or producing videos. Soon, they discovered that these initiatives did not reach people with a vulnerable condition, for instance dementia. At the same time, the team felt that these people were especially affected by the corona crisis.

Therefore, from the beginning of the Covid crisis, the team of art mediators kept in touch with Brussels residential care centres and their regular partners in particular through amongst others regular phone calls or letters. A very successful initiative was the **'Four leaf clover' project**. The museum team presented four works on the same theme from their museum collection. They suggested that care centres could display these on an iPad or print them out, hang them up in the corridor or show them for example during meals. Next, the residents (but also volunteers and/or care staff) were asked to choose their favourite work. The participating centres received an enlarged poster of the most successful artwork.

Besides urging them to develop such creative initiatives, Isabel and her colleagues also see some positive repercussions about the Covid crisis. They finally had the time to evaluate their program for people with a health condition and write it down. This will lead to a publication in which the different care partners that the museum works with, describe how they experience the museum program: the positive aspects, but also the pitfalls and points of attention. Also, different expert organisations in art mediation, such as Culture and Democracy, Demos and Open Museum were asked to contribute to the publication. However, the team was extremely happy to be able to resume the guided tours as soon as it was possible again (first on site, extra muros, and later in the museum), for which there was a great demand. There was a clear need for people to get back together and talk about something different than corona. The team is unanimous: **nothing beats a live encounter, especially when working with art.**

8.2 | Good practices worldwide and (non-)digital innovation

Research shows that COVID-19 has had a significant impact on people with dementia. Not only are these people at relatively high risk of becoming seriously infected, they are also susceptible to social isolation (Numbers & Brodaty, 2021). Various initiatives arose to make art and culture more accessible and thus counteract the adverse effects of physical and social isolation on this group. Some have relied on professional and informal care networks to ensure the smooth functioning of their activities. Initiatives were taken that focused on technological or digital solutions. However, people with dementia are less likely to access or participate in online activities than the general population (Dowson et al., 2021). It was therefore promising that during COVID-19 the cultural sector also launched non-digital initiatives to combat digital exclusion. In some cases, initiatives were accompanied by research in order to better understand how arts and culture could alleviate isolation during the pandemic. However, continuing research in this area is important so that policy and practice can make informed decisions.

SOME INSPIRING EXAMPLES:

- Several museums across the globe have embraced **online exhibition initiatives**. FARO (2021) lists six types: virtual 360° tours, live tours, online expo or digital exhibition websites, digital storytelling and museum podcasts and online exhibitions in 3D. For example, in Bristol, Brunel's SS Great Britain, a museum ship, provided online sessions including a virtual tour of the ship using video footage to stay engaged with people with dementia (Alzheimer's Society, 2020). Another example is the Frye Art Museum (n.d.) in Washington offering a YouTube channel to engage with art. They developed short videos for adults living with dementia, such as



guided art discussions. A third example is the American Folk Art Museum (n.d.) in New York offering virtual folk art discussion sessions.

- In England, **several music making activities for people with dementia and their supporters have been transformed into an online format**, such as group singing which is the most widespread and accessible type of live music activity (Dowson et al., 2021). Activities range from live sessions (from fully interactive to semi or no interaction) to pre-recorded sessions and carer-facilitated sessions, using online resources. Dowson and colleagues (2021) examined the associated challenges and also formulated recommendations in terms of accessibility (technology), the well-being and safety of participants, the musical experience (quality control) and the practitioners, specifically the importance of self-preservation in order to carry out digital music activities in a sustainable way.
- A company in England received a grant to develop a six-week pilot programme for older people that helps them participate in **live, interactive artistic sessions online**. The sessions are based on cognitive stimulation therapy. Each participant can choose from nine disciplines (from photography and creative writing to history and music), based on their preference. The online sessions are designed to respond to everyday experiences or evoke memories. One of their biggest challenges was finding the right balance between human interaction and the technology itself (UK Research and Innovation, 2021).

8.3 | Social prescribing

Social activities, such as art and cultural activities, have a beneficial effect on health and wellbeing and are therefore subscribed by the general practitioner. This is called social prescription . Some countries, such as the United Kingdom, Canada and Denmark, are already applying it. In Montreal the Museum for Fine Arts (MMFA) collaborates with the local doctor's association. Some patients with physical or psychological challenges get a prescription for the museum. In Denmark '**Culture on prescription**'  is being offered to people suffering from mild to moderate stress, anxiety or depression through some of the local municipalities. The aim is to create a cultural community and cultural activities to the participants a supplement to the health system and medication. Prescribing culture like you prescribe a pill.

Social prescribing helps patients to access non-clinical sources of support, predominantly in the community sector (South et al., 2008) and is a means to address the well documented social and economic factors that accompany long-term illness beyond the healthcare setting (Mossabir et al., 2015). In the last couple of years it is more and more implemented all over the world. In this report we narrow it down to arts and culture on prescription.

Many benefits of museum-based community referred activities (broader than only people with dementia) have been described in literature and pilot projects. Key outcomes of social prescribing include increased self-esteem, confidence and sense of control, improved psychological wellbeing and positive mood, reduced negative mood, anxiety and/or depression, provision of holistic options to complement medical care and the potential to reduce inappropriate prescribing of antidepressants (Veall et al., 2017). A project in London and Kent showed that museums on prescription may lead to a sense of belonging and improved quality of life, renewed interest in learning and acquisition of new skills, something to look forward to, increased social and creative activity, continued visits to museums and healthier lifestyle changes (Veall, 2017).

8.4 | Where do we go from here?

As it is very important for the DCUM strategic partnership that as many cultural mediators and end-users as possible will benefit from the website and training material that we have developed, it is crucial that these tools become well-known and that we reach out proactively. That's why the third and final work package of the project, of which this publication is an important part, focused on **the sustainability and use of project results** beyond the project period. This way we want to embed our project results in local and regional initiatives, but we also want to provide answers to **future challenges and opportunities in the field of culture, arts and dementia policy** at an international level.



This publication covered a wide range of topics, research and inspiring initiatives, but they all share a common goal: inclusion of vulnerable people, looking through their perspective and building bridges between the world and their daily reality. That's exactly the heart and soul of 'Dementia in Cultural Mediation': **exploring the value of arts and culture to improve the quality of life for people with dementia and their loved ones**. The coronavirus pandemic had a massive impact on society in general and also on the 'Dementia in Cultural Mediation' initiative, but despite the additional challenges it also made clear that the need to connect is more urgent than ever. We are therefore convinced that the value of this project reaches far broader than the participating countries and sincerely hope that this publication is not the finish but a first step towards more international collaboration on the value of arts and culture for vulnerable people.

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