



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

**SUMMARY  
ENGLISH**

Dementia in Cultural Mediation  
*recommendations publication*



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Dementia  
in Cultural Mediation



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‘Towards a dementia-inclusive society. An art?’ is the recommendations publication based on the experiences, knowledge and international exchange of good practices between the partners of the ‘Dementia in Cultural Mediation’ project.

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Cover picture: © Campaign ‘Vergeet dementie, onthou mens’ (Belgium), [www.onthoumens.be](http://www.onthoumens.be)

# Towards a dementia-inclusive society. An art?

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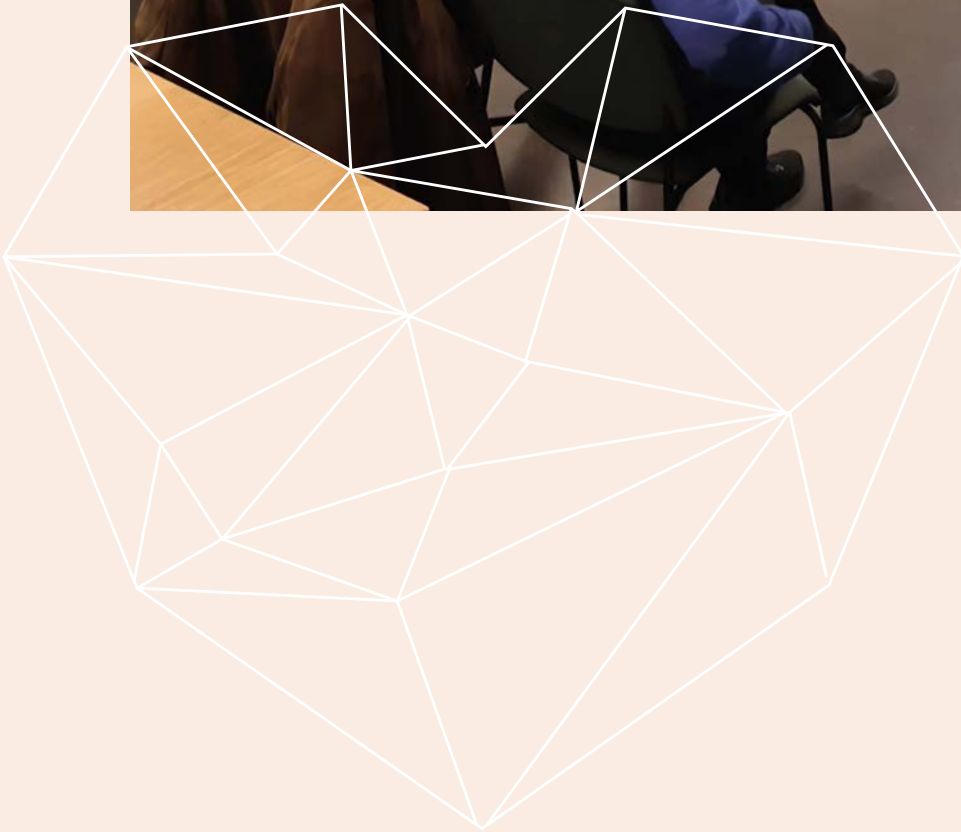
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# 1 | Introduction



Philosophical Dialogue (Denmark) with Anni Jensen, Brandts Klædefabrik.  
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"It is important to adapt cultural activities to the daily reality of people with dementia, but on the other hand 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.*

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 organizations 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 organization, 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 organizations, dementia-friendly communities, the local government, national policy makers, international umbrella organizations, end-user groups, schools, ...

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



Meet Me @ Middelheim Museum, © Jan Dirckx

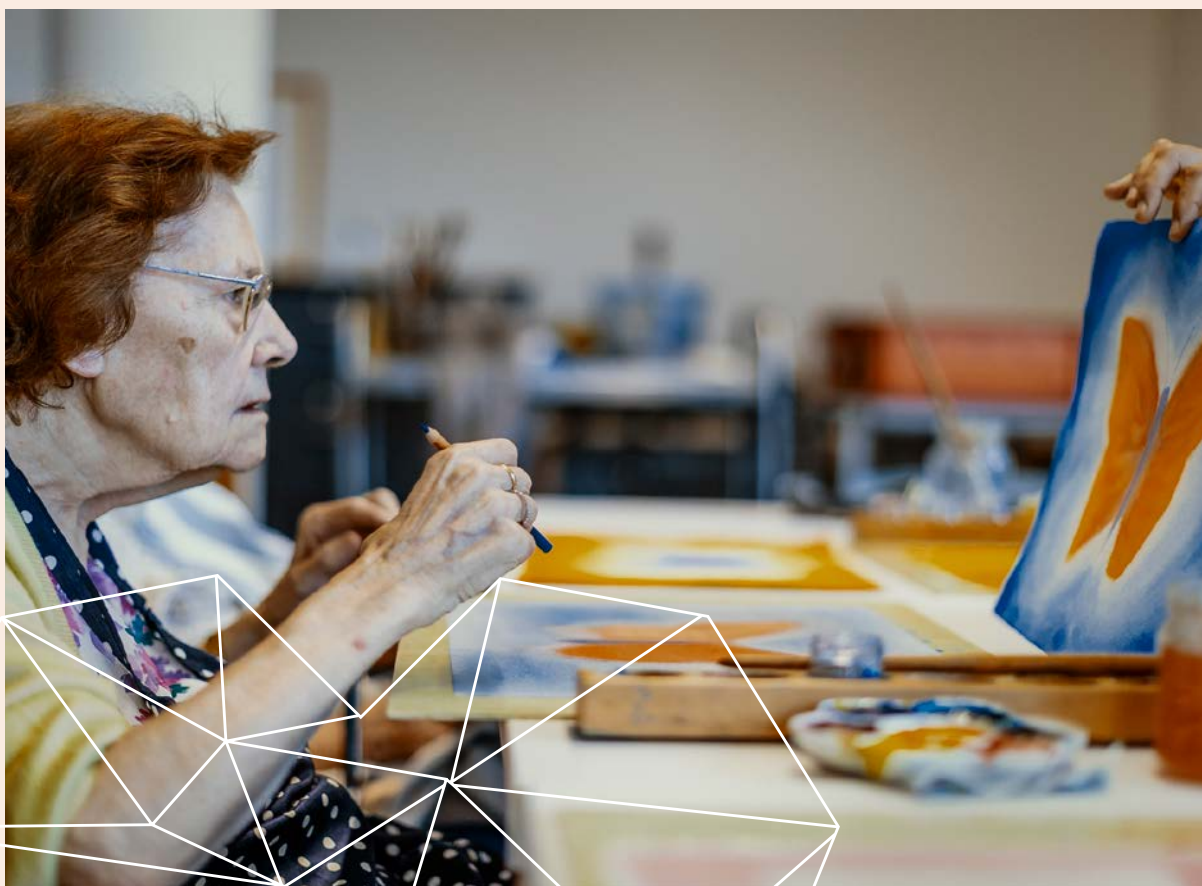


**Dementia** is a syndrome – usually of a chronic or progressive nature – that leads to deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from the usual consequences of biological ageing. It **affects memory, thinking, orientation, comprehension, 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.

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.

**There has been a shift towards non-pharmaceutical interventions, validation and a person-centered vision 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. For example, aesthetic experiences such as art can enhance the quality of life, well-being and inclusion of persons with dementia and their caregivers. Hence, over the past two decades, several art programs were developed for people with dementia. 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.

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



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. 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.

**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).

In the DCUM recommendations publication you can find an overview of the potential beneficial impact of arts programs on persons with dementia by artistic genre. Key research findings are described and points of attention are taken into account for future initiatives in the field of theatre, music, visual arts, literature and dance.



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



In order 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 our own 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

The recommendations publications identifies challenges and opportunities on the different levels and in this way provides a wide range of key points of attention for different stakeholders active in current and future initiatives at the intersection of arts, culture and dementia.



## 5 | How to enthuse a local community?



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



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?

**Six key topics and some valuable advice are discussed:**

- Get to know the neighbourhood
- Awareness
- Right location
- Connecting and empowering
- Neighbourhood communication
- Commitment

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.

## 6 | The DCUM platform

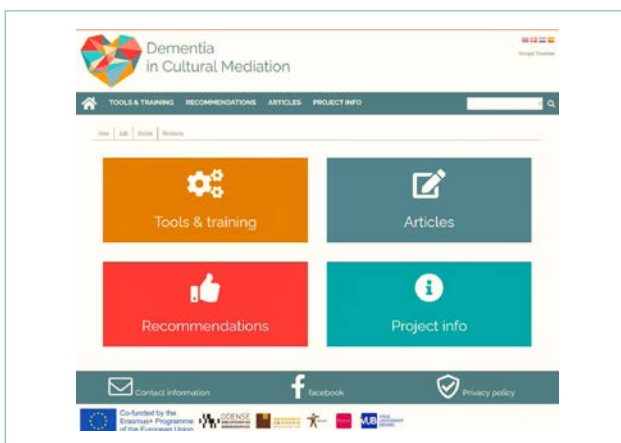


© Anne-Mette Kjærbye Jakobsen

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. 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 the extended recommendations publication based on the project's experiences, of which this text forms a summary.

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.





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



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 ROI of the project's good practices and in this way make them sustainable on a long-term basis. **The best way to break down this stigma, as a basic pillar to translate the 'Dementia in Cultural Mediation' project targets into practice, is looking at what we can still learn from people with dementia.** Not starting 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.

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. Involving the person with dementia as ambassador for your project is an innovative and effective way of storytelling that requires creativity. 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.
- 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.
- **Target the communication channel** on the capacities of the end-users and the additional value of the particular project.

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.

# 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 the cultural mediators in reaching people with dementia. In the last chapter of the ‘Dementia in Cultural Mediation’ publication we highlight the challenges we and our cultural partners encountered in ensuring continuation. Covid’s impact on this project is discussed and one of our cultural partners (Isabel Vermote, Royal Museums of Fine Arts of Belgium) brings in the perspective of the cultural mediator. Both examples identify the challenges (financial, organizational, 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. We also 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. The aim is to inspire cultural organizations 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.

**Strong and agile readiness for change of the project partners and the need for sustainability of good practices worldwide in digital and non-digital innovation are explained by tangible examples.** Also the current trend towards social prescribing is discussed. Social activities, such as art and cultural activities, have a beneficial effect on health and wellbeing and are therefore more and more subscribed by the general practitioner. 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. Having impact on these and other challenges forms also one of the key pillars of the ‘Dementia in Cultural Mediation’ initiative.

The final recommendations 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 our world and their daily reality.** And 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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<https://www.dementiainculturalmediation.eu>