

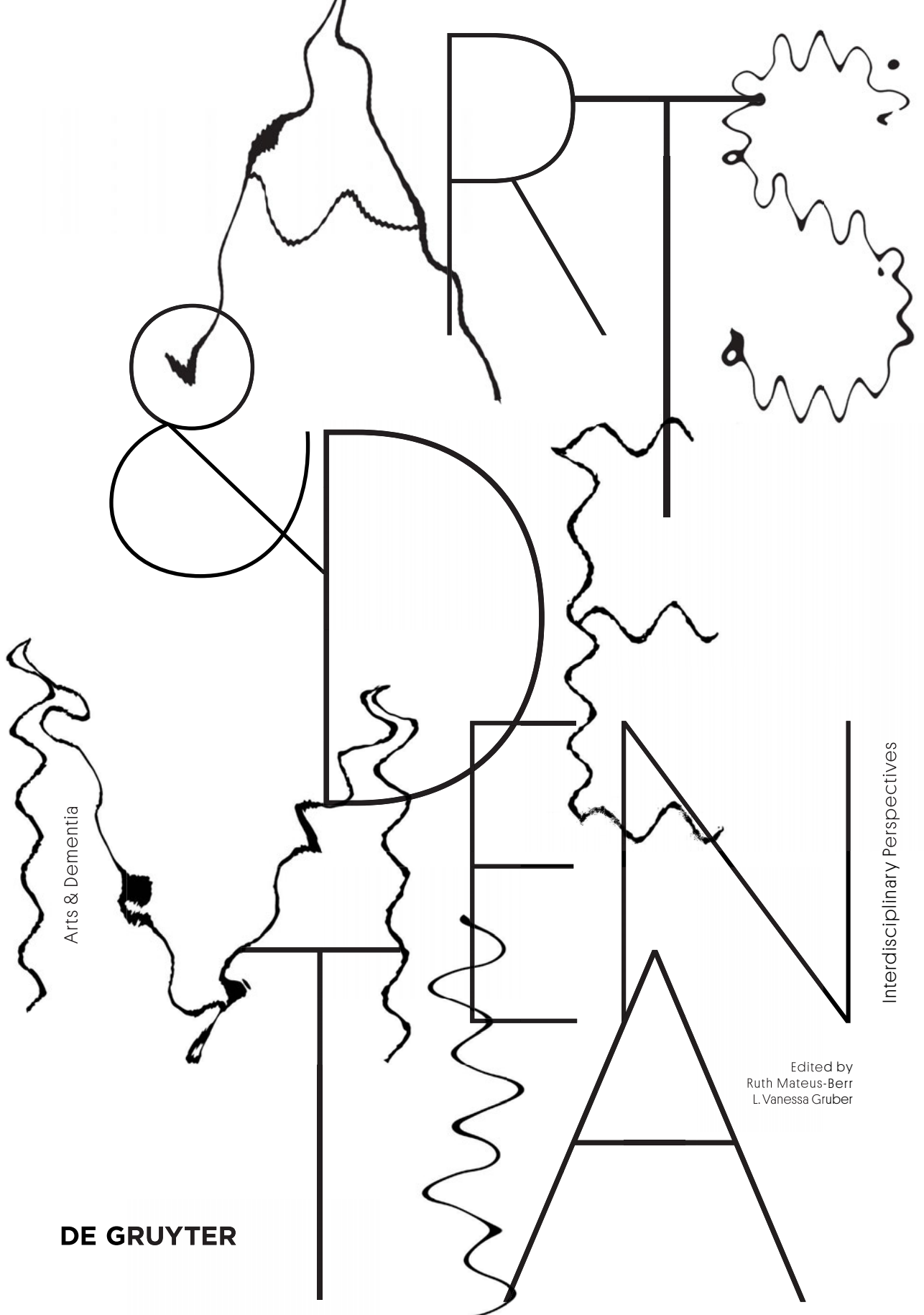
A green line drawing of a stylized landscape. The word "RAIN" is written vertically in large, bold, sans-serif capital letters. To the left of the letters, there are several wavy vertical lines representing rain. Above the letters, there are stylized clouds and a sun with a wavy, irregular outline. A small circle with a checkmark inside is located near the top left. The entire drawing is composed of green lines on a white background.

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Edited by
Gerald Bast, Rector



Arts & Dementia

Interdisciplinary Perspectives

Edited by
Ruth Mateus-Berr
L. Vanessa Gruber

DE GRUYTER

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Preface

Arts & Dementia – Interdisciplinary Perspectives builds bridges between the terms ‘art’ and ‘dementia’, showing how life with dementia can be enriched through art, architecture, design, music and museum education, and how artistic research can have an impact on the cross-generational well-being of people living with the condition, as well as that of their relatives and carers. We are delighted to present this brief overview of the research and its results, as well as the experiences, opinions and interventions that have been, and are still being, implemented worldwide.

This is a pioneering work on interdisciplinary approaches, addressing people both conducting research in the field and those working ‘on the front line’ with individuals who live with the condition. It is one of the first joint publications of its kind, featuring a major collection of new and wide-ranging contributions and providing insight into the opportunities art-related activities can offer when working with people living with dementia. The expertise and experience our contributors have provided show, across a variety of disciplines and approaches, the opportunities art can provide for improving the well-being of those facing a life with dementia.

This book is intended to serve as a companion for artists, architects, (social) designers, artistic researchers, museum educators, musicians, carers and relatives. In publishing these texts, we seek to widen the discourse on the role of the arts in treating dementia, the creative potential of people living with dementia and examples of co-creation.

Arts & Dementia aims to exemplify how the arts foster empathy and empower people living both with and without dementia. With this interdisciplinary anthology, we encourage our readers to look to the future, to engage both with art and with dementia and, above all, to continue to drive research in this field forwards and to initiate new projects.

Shaun McNiff

University Professor, Lesley University,
Cambridge, Massachusetts, USA

Foreword

As a person publicly immersed in advancing the process of art healing while privately challenged by close family members living with Alzheimer's, I welcome and celebrate *Arts & Dementia*, edited by Ruth Mateus-Berr and L. Vanessa Gruber. This book addresses one of the most pressing needs of our times. I especially admire its emphasis on community support, empathy, and compassion. When combined with the life affirming expressions of art, this egalitarian vision might arguably be the most effective ways of mobilizing society in response to the conditions of individuals experiencing dementia. The communal approach, and especially this book's documentation of how to achieve these aspirations through public participation, is timely in that it also supports the ever increasing number of families and carers who are all too often required to deal with formidable responsibilities in isolation.

From the first chapter to the last, the book is pervaded by the spirit of co-creating with people living with dementia, learning from them about their experience of the world and affirming their contributing role in society. Rather than focusing exclusively on their condition and the stigma often attached to it, creative engagement can help us become a better and more complete world. These ideas, and especially the encouragement to focus on what the dementia experience can teach society, give hope to those currently dealing with the condition and the many who fear it. In my work with art and healing, I have always practiced with groups and communities in a context where we create together. I have reliably found that, when led in supportive ways, these environments augment the medicines of art, which are infused with creative energy, transforming difficulties into affirmations of life. The community approach not only holds and validates the expressions of individuals living with dementia, it potentially enhances life for everyone who participates with empathy and commitment – families and neighbors as well the person experiencing dementia. The communities themselves are strengthened

and renewed by compassionately engaging, and creatively transforming life conditions in ways that instill confidence in what people can do for one another in times of need.

As the various spiritual traditions of the world acknowledge, when one person in an empathetic community is in difficulty, this feeling is shared by all. Community support through creative expression sustains millennia of transcultural healing practices, in which each individual person is considered a vital and necessary contributor to the natural world we live in. The same sense of mutuality applies to setbacks, losses, and obstructions within our individual lives. When a sphere of experience is lost or impaired, others can potentially offset it and assist with the functioning of the whole.

The idea of community support and cooperation applies not just to the actual gatherings of people in places throughout the world, but also to the process of creation within a person. Communities of creation exist inside and outside of us, in keeping with the ecological processes of nature in all aspects of life. Creative expression involves a gathering and cooperation of the various facets of experience working together in an integral way. The significant growth and appeal of artistic expression in therapy and healthcare can be attributed to how the various forms of sensory perception and expression through movement, sound, touch, vision, imagination and dreaming, offer alternatives to the usual and more exclusive reliance on discursive communication and the cognitive functions on which it is based. Although every person can benefit from more complete access to creative expression, these opportunities are especially compelling in relation to dementia where there is a loss of intellectual faculties, but where various forms of more direct sensory perception and expression are not only accessible, but fully alive.

Creative expression within the context of dementia care addresses what people can do when so much is lost. We can communicate, feel, and receive expression when certain forms of consciousness are no longer available. When one

mode of expression and thought is compromised, others can be engaged since the various senses and modes of expression complement and support one other. These holistic principles have a long history in the German-speaking world from where this book originates, expressed nicely by Jean Paul Richter who in 1804 described imagination as the 'faculty of faculties' where all of our human sensibilities 'are in bloom at once' (1973, 35). The different senses not only work together as a necessary and interdependent Gestalt, but they compensate for one another, like a supportive community, when certain capacities are limited.

I am confident that, where life exists, there is sensibility and emotion, feelings of empathy for soulful communication, and the survival of the most human capacity to be moved by one's own creative expressions and those of others.

This book offers many inspirations and concrete suggestions as to what can be done to transform public and personal perceptions of dementia and create a more 'empathetic society' (Ruth Mateus-Berr) through art. There is a sustained call throughout the chapters to change perspectives on how society perceives dementia; how to shift attitudes from illness to participation in an all-encompassing creative process of life. This task aligns with the need to view artistic expression within the context of communities of creation, in which all senses and experiences play a necessary role.

The authors, working in various regions of the world, write from perspectives in the visual arts, performance, architecture, design, museum and gallery engagement, medicine, music, touch, and the movement basis of all artistic expression. They present comprehensive and convincing evidence of how the creative expressions of people living with dementia offer vital contributions to our communities. The book's public and positive message and call for action is underscored by its unique artistic design presenting copious illustrations which demonstrate methods, show outcomes, and inspire participation. As an advocate for art-based research, I have encouraged public presentations that look, feel, and sound like what we do rather than translation into more

socially approved and scientized formats that do not convey the art evidence (2014a, 2014b, 2017, in press). Closely following the publication of *Teaching Artistic Research* (Mateus-Berr & Jochum 2020), Ruth Mateus-Berr and L. Vanessa Gruber, together with their contributing authors, graphic designers and the publisher, have delivered yet another model presentation of how art maximizes its ability to further understanding and social change when it speaks for itself.

It is my hope that this book incites worldwide 'imagination in action' (McNiff 2015) and the creation of artistic communities to support people living with dementia and their families. The difficulties cannot be properly engaged and transformed in isolation and in the absence of society's medical, psychological, economic, spiritual, and artistic resources. It requires a new and imaginative public response, one that no longer makes it necessary for families to 'go it alone.' The same applies to professions that will benefit by closer partnerships with all sectors of society. Beginning with an experimental art museum program in the early 1970s, I have urged the separate arts in therapy disciplines to work closer with each other while also embracing what artists, volunteers, and cultural institutions can do to further more comprehensive community approaches to art healing for all. The authors who have contributed to this book show how to realize this vision quite convincingly.

Arts & Dementia shows how art can lead the way in addressing one of the most urgent needs of a compassionate society. Artistic expressions offer evidence of the creative life that continues through dementia, generating alternatives to the exclusive perception of progressive and incurable deterioration and the attendant feelings of helplessness. They present opportunities for transformative change by affirming individual uniqueness and dignity together with a sense of belonging in the more comprehensive human community.

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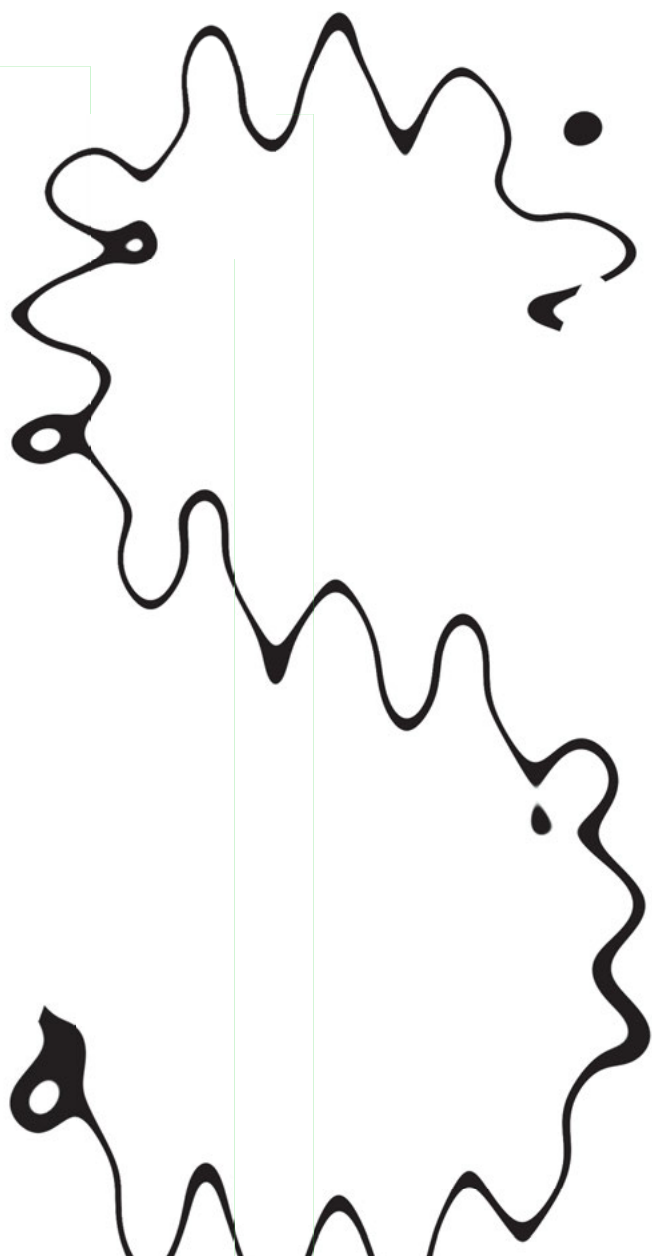
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Arts & Dementia Care



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A Manifesto for the Individual Narrative



**Visual Art as More than a
Therapeutic Tool**

A Manifesto for the Individual Narrative

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Patricia Fleming

is a curator representing Scotland's leading contemporary artists. Fleming established the ground-breaking arts initiative *Fuse [1991–2000]*, providing free studios, exhibitions and a monthly stipend. It supported over 500 artists, including; Martin Boyce, Jaqueline Donachie and Douglas Gordon. She was curator at the CCA [1999–2002]. In 2003, she curated the critically acclaimed exhibition *Further, Wales* at the International Venice Biennale. In 2008, she was curator of *A Gathering Space*, Gareth Hoskins Architects at the International Architecture Exhibition, Venice. She often features as a guest lecturer at establishments within the UK and internationally.

Abstract

A discourse exists within dementia care that establishes visual art as a psychosocial therapeutic tool to aid memory, communication and behaviour, and self-expression. The application of art therapy for people living with dementia is wide ranging, with several studies reporting improvements in social skills, increased self-awareness, reduced anxiety and agitation. In this chapter, we seek to widen this discourse and to explore the application of art – specifically visual art – and the adoption of evidence-based art as a medium to deepen our understanding of dementia and to encourage transdisciplinary practice and knowledge exchange.

Keywords

**Visual Art, Therapeutic Tool,
Design, Narrative**

**‘Collaborative process and the coalition of expert knowledge are essential tools for advancing research across many fields. Communication and observation are a cornerstone of the art-making process I was trained in, a process that at times overlaps in approach with other disciplines from genetics to social sciences.’
(Donachie 2017, 8)**

Visual Art Therapy: The Dominant Discourse

There is a dominant discourse within dementia care that establishes visual art as a psychosocial therapeutic tool to aid memory (through reminiscence), communication and behaviour (establishing a non-verbal channel), and self-expression (through the creation of one’s own art) to name but a few. The application of visual art therapy for people living with dementia is wide ranging, from structured of painting and drawing lessons, to art appreciation sessions within public galleries. The reported benefits of this therapeutic approach for the person living with dementia include improvements in Quality of Life, increased self-awareness and agency, reduced anxiety and agitation (Guseva 2019).

Supporters of art therapy have long advocated for the integration of art-making into the operational models and physical design of long-term care environments. Indeed, the University of Stirling’s Dementia Services Development Centre, *Dementia Design Audit* tool recommends the provision of physical space for undertaking arts and crafts and for there to be space to exhibit the resident’s own work (Cunninghame et al. 2012). Engagement in art making in this context is considered a ‘meaningful occupation’ to support enhancement of self-esteem, improve Quality of Life for the person living with dementia and enhance relationships with their carers. The provision of this art-space is encouraged at design stages for the purposes of inferring an intended use on the operator once the building is complete and occupied.

Despite a growing adoption of visual art therapy as a nonpharmacological approach to supporting people living with dementia, there is little adoption of the visual arts as a method to disseminate a narrative from the perspective of the person living with the condition. The process of creating art as a therapeutic experience dominates. The focus of many dementia arts projects is not to make high-quality art but to use art as a functional tool with measurable therapeutic outcomes (Camic et al. 2018) with many aimed at the treatment

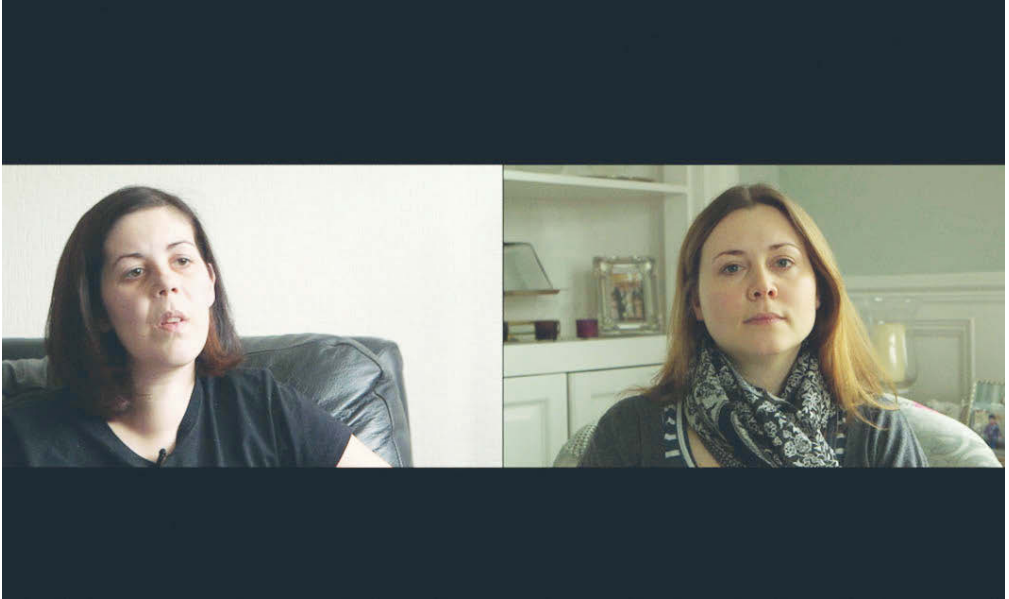


Figure 1. Sally + Lucie

© Jacqueline Donachie & Patricia Fleming Gallery



Figure 2. Hazel

© Jacqueline Donachie & Patricia Fleming Gallery

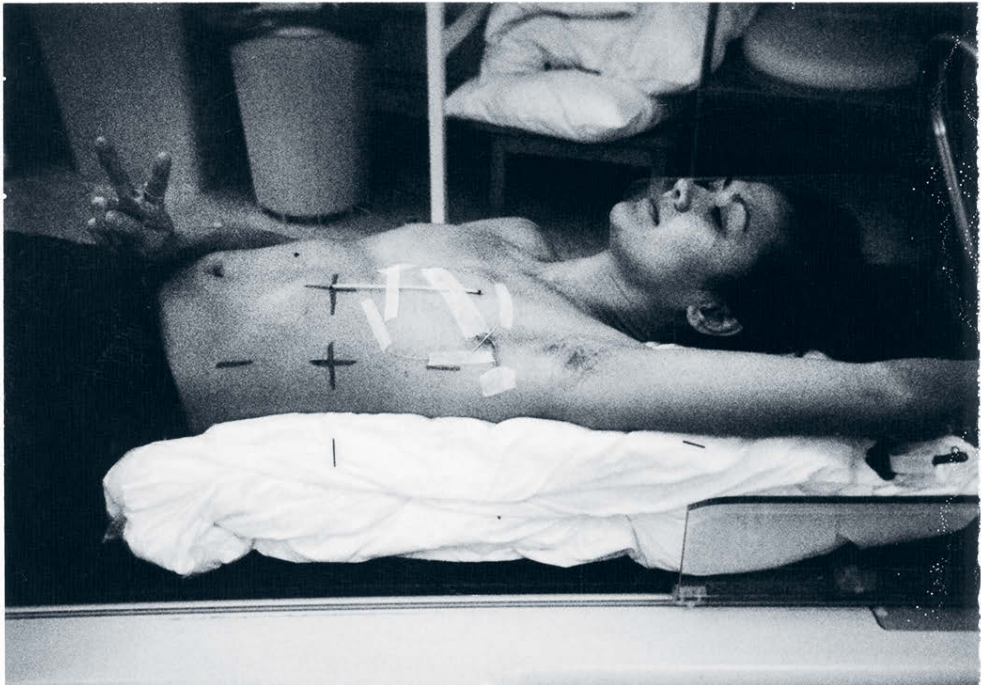


Figure 3. påsikt007

© the estate of Ellinor Westin

potential of managing behavioural and psychological symptoms of dementia (Beard 2011).

In this dominant model, the Arts, so frequently recognised as a medium that provokes, agitates and questions our assumed norms, are reduced to a leisure activity undertaken by the person living with dementia, facilitated by a carer and scheduled within the daily work flow – to be carried out in a dedicated and wipeable space.

Visual art can offer much more to this field than just a tool for therapeutic engagement. The language of art can help disseminate the narrative of those living with dementia and generate discussion with those who are not. It can act as a knowledge broker between researcher, artist and individual, as is evidenced in many other biomedical fields. It can challenge our preconceptions and alleviate our fears. It can address those important questions that we dare not ask.

Visual Art: More than a Therapeutic Tool

The work of international artist Dr. Jacqueline Donachie exemplifies such an approach. *Tomorrow Belongs to Me* (Donachie et al. 2006), a collaboration between an artist and a geneticist examines the phenomenon of the inherited genetic condition myotonic dystrophy (DM). In this work, Donachie and Monckton compel us to see DM in a new way and, from this, we garner a deeper understanding of the condition and its impact on the person and their family.

Similarly, in Donachie's film installation *Hazel* (2016) for the *Deep in the Heart of Your Brain* exhibition, a juxtaposition between the person and the condition is explored (see Figure 1). The scientific gaze of physician versus the familial gaze of the family and that of the lay audience is challenged. On one screen, a sister is speaking; she has inherited the gene for myotonic dystrophy. On the other, we see the sister who has not, sitting in silence. Where the lay audience may watch the interviewee and see the person (not knowing which of them has DM), the families could see the condition manifested in facial expression, features and gait. The physicist, focussed on the genetic science, may not see either. *Deep in the Heart of Your Brain* was a major solo exhibition at the Gallery of Modern Art in Glasgow, Scotland, which included a body of new work by Donachie that explored themes of disability, care and loss seen within her practice through the media of films, books and sculpture. *Deep in the Heart of Your Brain* was commissioned for Glasgow Museums and supported by a Wellcome Trust Arts Award to 'bring artists, institutions, academics and interested individuals together to discuss care, bravery, lived experience, autoethnography and expert cultures in relation to the ethics and practice of knowledge exchange / public engagement in the art / medical research field' (Donachie 2017, 198).

In both projects, Donachie's autoethnographic response (the DM gene is present in her family) translates the medical data into the personal and reminds us that, at the centre of the condition,

there is always a person. Her observational artistic response sheds new light on the condition for the benefit of the researcher, families living with the condition and the general public (see Figure 2).

The visual arts have demonstrated, in other fields, an ability by the diagnosed individual to create or co-create high-quality art in relation to their experience of the condition. This is demonstrated in the work of Ellinor Westin (Boström et al. 2015). Here, the artist's autoethnographic imagery demonstrates how visual art has the potential to change the representation of a condition through the narrative of the individual's experience of it. Using self-portraiture, Westin documents her experience of motherhood and terminal cancer. Images of her naked torso depict the stark reality of invasive procedures, surgeries and her changing body-image, thus educating the viewer on aspects of breast cancer that are not typically publicised so openly (see Figure 3).

It is broadly established that people living with dementia are willing and able to contribute to the global narrative on the condition and bring their own experiences to it. Several letters and autobiographies have been published by individuals living with dementia, all of which tell their stories and enable the voice of the individual to be heard. In addition, there are approaches within the dementia community that recognise and value co-production and collaboration as a method for delivering service improvement and development of policies and products. These include development of research design methods, product development, care modelling and even built-environment consultation. It is, therefore, conceivable that the person living with dementia can create autoethnographic works which disseminate their narrative through the creation or co-creation of high-quality evidence-based art that can reach a wide and diverse public. It is also conceivable that artists (living with or without dementia) can utilise visual arts as a method to broker knowledge exchange between the researcher and the general public.

Conclusion

In sharing with you three examples of where high-quality contemporary visual art has been created by, and with, the individual with a diagnosis, we seek to widen the discourse of the role of visual arts in dementia. We recognise and value the use of visual art as a therapeutic tool and welcome the benefits it brings to the individual, their family and their carers. However, we posit that art is a powerful and currently underutilised tool with which to ask the big questions on dementia, disrupt normative thinking and challenge preconceptions. The creation of high-quality visual art offers the potential to shed light on aspects currently in the shadows and to project the lived experience of those living with dementia. The examples illustrated in this text go beyond the dominant approach of visual art as a psychosocial therapeutic tool. They challenge us, they educate and they inspire.

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Cornelia Bast,
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Changing the Social Fabric

**How Art and Social Design
Can Contribute to Recognizing
People with Dementia as an Essential
Part of Vibrant Societies**

Changing the Social Fabric

Cornelia Bast

is an artist, social designer and art-based researcher. After graduating from university in Biochemistry, she worked as a midwife at the University Clinic, earned a BA in Applied Arts and Design Communication and an MA in Social Design at the University of Applied Arts Vienna. Oscillating between art, design and public performative interventions, and often collaborating with non-profit institutions, her work appears primarily as media for social communication. She has worked for 'radio d rive – Radio for Urban Research' and presented her work at various international conferences and exhibitions.

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Abstract

As the average age of our population rises, the number of people living with dementia does, too. This, of course, is changing our social fabric. However, this change presents us with an excellent opportunity to support people living with dementia and help them find their place in our modern, fast-paced and ever-demanding world. Indeed, it might even provide them with an added perspective, beyond consumerism and the need to compete with people who are not living with dementia.

Many of us will know someone living with dementia, but who among us truly knows how it feels not to be able to trust our own senses anymore? Who among us truly knows what it means to switch between realities without realizing which of them our friends and families refer to as ‘normality’?

This paper demonstrates that objects and processes developed by art-based research can be of value to people living with dementia, at all stages of the condition. It shows how, through the medium of interactive artistic acts, we can help people who do not live with dementia to better understand the problems of those that do by having them experience the same confusion, disorientation and insecurity they often feel. The first of our senses that we use as human beings is touch – and this remains intact throughout life, even in later stages of dementia, and activating the language of haptic expression can create empathy and stimulate communication. People living with dementia, and their surrounding environments, are changing society and we can have a clear influence on how this happens, especially through art and social design.

Keywords

Art, Social Design, Society, Senses

Introduction

What does 'belonging to a society' mean? Weaving a social fabric is about creating the necessary communication, interaction and solidarity between its members. Its strength is dependent upon both the manner and the extent to which these members engage in how this fabric is woven. In a strong and resilient society, social communication, interaction and solidarity between everybody is key.

The topic of inclusion (...) is accompanied by the questioning of prevailing norms and values. This paradigm shift is necessary if we wish to conceive inclusion as real participation; as a type of participation for everyone, both for people with general disabilities and for people living with dementia. In times when solidarity and cohesion are disappearing and we are affected by an increasingly unjustified economic redistribution, this is a politically volatile demand. (Bez 2016, 10. Translation by C. Bast)

The demographic transformation of society always poses a challenge, sometimes even a risk, to the social fabric.

In this context, as the average age of our population rises, so does the number of people living with dementia, which, of course, alters our social fabric. However, we can have a clear influence on how this happens, especially through art and social design.

Many of us will know someone living with dementia, but who among us truly knows how it feels not to be able to trust our own senses anymore? Who among us truly knows what it means to switch between realities without realizing which of them our friends and families refer to as 'normality'?

People living with dementia require different modes of communication and interaction. This is a clear challenge because it means deviating from accustomed routes and patterns, however, such a challenge can also be seen as an opportunity –

the opportunity to support people living with dementia in finding their place in our modern, fast-paced and ever-demanding world. Indeed, it might even provide them with an added perspective, beyond consumerism and the need to compete with people who are not living with dementia.

On one hand, objects and processes developed in the course of art-based research can raise public awareness about dementia, while helping us learn the best ways to help people living with dementia, in all stages of the condition, on the other.

In this context, therefore, there are two main groups of art-based objects and processes focusing on different objectives:

1. Through the medium of an interactive artistic act, helping people who do not live with dementia to better understand the problems of those that do by experiencing the confusion, disorientation and insecurity they often feel. Understanding the problems and participating in such activities creates empathy and subsequently also reduces the stigmatization of people living with dementia within society.
2. Activating the language of haptic expression to stimulate communication between people both living with and without dementia.

Two examples from the various works resulting from my research, one for each group, are outlined in the following.

Kurt Ticciati

Wiener Symphoniker
Christian Tetzlaff *Konze*

ROBERT SCHUMANN *Klavierkonzert d-moll (Wd. 1)*
ANTON BRUCKNER *Symphonie Nr. 4 Es-Dur «Romanzische»*

wiener  konzerthaus

Paavo Järvi

Wiener Symphoniker
Piotr Anderszewski *Konze*

WOLFGANG AMADEUS MOZART *Klavierkonzert C-Dur K 503*
ANTON BRUCKNER *Symphonie Nr. 2 e-moll*

wiener  konzerthaus

MICHAEL
HELTAU

Müller-Lieder
Für Lindenbaum

YES, SIR!
Benedictine
Zoe Lister-Jones
Tamara
Tajani
stantin
ink
in
STER

Wegen großer Erfolgs, Wiederholung im
RTHAUS 9. MAI 2015 19:30
AB
2013/2014
GROSSE
MUSEUM

UNTER
BLINDE

THEATERN
KOF

THEATERN
KOF



Fokung Wirkus

Originally created as purely an art object, *Fokung Wirkus* is a ball-shaped, felt helmet with built-in optical lenses. Inspired by Plato's allegory of the cave, projection-surfaces inside the object show the viewer a fragmented, distorted, inverted and twisted world in which nothing seems to reflect our reality.

Fokung Wirkus was originally designed as an art piece and was exhibited for the first time at the *Arte Laguna* in Venice, Italy, in 2015. Subsequently, as part of the *Feel Dementia* project (www.corneliabast.com), established by Cornelia Bast and Antonia Eggeling, *Fokung Wirkus* was re-defined and re-purposed as an interactive activity and art-based process related to the topic of dementia.

When used as part of a participatory performative act, this object can impressively mimic the optical challenges dementia can cause. The wearer experiences what it must feel like not to be able to trust their own senses, thus learning both how to deal with disorientation, insecurity and shame, as well as how to accept help in the best possible way. The object makes the world appear unfamiliar and that drastic change in habitual patterns of perception causes confusion and stress. How do I change direction? What do I need to do to achieve my goal? How should help be offered? What kind of help would I need, and would I be able to get it?

Experiencing changes in perception using *Fokung Wirkus* helps people not living with dementia to better understand the problems disorientation and insecurity can cause for those living with the condition.

Indeed, using *Fokung Wirkus* is not about experiencing the world around you just like a person living with dementia would. Of course, you do not experience the condition itself, rather only some of its symptoms. The effect instills a sense of empathy in the wearer.

Using *Fokung Wirkus* allows the wearer to experience a similar state of disorientation, insecurity and shame to that which people living with

dementia have to go through daily, on different levels, depending on the situation. As your sense of shame increases, your relationships with other people suffer. This, in turn, leads to social withdrawal, which can cause the condition to worsen. It is helpful for people who are not living with dementia to gain an insight into the alternate realities that people living with dementia find themselves in, to feel empathy for them. This is crucial for understanding their situation and interacting with them appropriately, based on their needs.

Empathy depends on a person's actual or perceived closeness to others. It is essential to be in touch with others to feel close to oneself. People who have no social bonds tend to waste away. People who have no social relationships eventually become seriously ill and die earlier. Loneliness gnaws at both the mind and body. (Bartens 2015, 59. Translation by C. Bast)

As soon as you put the *Fokung Wirkus* on, you suddenly lose your orientation and are forced to decide whether to accept help and how. Part of the *Feel Dementia* performative activity is intended to make you aware that there is someone next to you, that someone is there to help while you nevertheless try to retain as much of your independence as possible. The challenge of participating in social life despite having dementia lies, therefore, in finding the balance between support and autonomy. This is what *Fokung Wirkus* is all about. Of course, there is a noticeable gap between how people living both with and without dementia perceive reality. The challenge is to bridge that gap. Helga Rohra, who lives with the condition, sums meeting this challenge up excellently:

If you want to enter my world, accept me as I am and come to meet me. If you want to, you can do it! But you will have to build the bridges. I cannot do it anymore. Come and meet me at eye level! (Rohra 2016, 15.

Translation by C. Bast)

After the *Feel Dementia* activity, all participants were interviewed and asked how they felt, what had helped them achieve their goal and if



Figure 2. Feel Dementia 2

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there had been anything else that would have helped them succeed even better. Finally, they were asked how they would link their experiences to dementia. Quite often, a lot of the responses to these questions were emotional. Indeed, when asked what they associated with dementia, the participants reflected inwardly and wondered what it would be like for them to live with the condition. It was, therefore, a question that would also apply to the future and would require reflection to formulate an answer. Although it is helpful to approach the subject in a solution-oriented manner, reactions showed that it also caused distress: 'For God's sake!' and 'What a disaster! This is terrible!' being just two examples. Of course, for some, their first reaction was to say

that, if they had dementia, they would just want to stay at home and do nothing at all.

Helga Rohra, describes her situation after being diagnosed with dementia as follows:

All relationships had to be rethought and reordered. Nothing's the same as before, in the truest sense of the word. Regardless of who's right next to me, be it my son, a friend or an acquaintance: there is always the fear of not being understood. I am absolutely dissatisfied with myself. I forget things, I make mistakes. A feeling of powerlessness that is always there. All perceptions in the relationship system shift. Despair has taken control of my life. What can I do about it? My strategy to escape from this crisis was to

remember the inner strength that is hidden in every human being. If I went deep inside, I knew, it would go on anyway. Trust is essential here. Trust in me. (Rohra 2016, 12ff.

Translation by C. Bast)

The *Feel Dementia* activity using the *Fokung Wirkus* is intended to offer as many approaches as possible to escape the fear. It is not just about dementia in an abstract way, or even somebody else's dementia, but about the possibility of the wearer having to live with dementia as well. This is an experience that also helps people who are not living with the condition to contemplate questions such as 'how would I be able to shape my own life if I had dementia?' and 'would it really be a good idea to just give up or could I research my options and the kind of support I would need to lead a relatively good life for as long as possible?'.

Not only does the *Fokung Wirkus* experience affect the current relationships between people living both with and without dementia by creating insight and empathy, it also makes us pause for a moment and ask ourselves what we might do and how we might react if we were suddenly told one day that we had the condition. In the interview phase, participants were asked what they would do if this happened, as well as what they would do if they felt confused, ashamed, or maybe if they had a problem accepting help. At first, people tend to think about others, about those affected by the condition, but you also cannot help but think about yourself as well. This is because, essentially, it all boils down to fear, which is human nature. With dementia, it is the fear of no longer being accepted by society, of being considered useless and obsolete. This fear resonates with everyone involved in this activity.

Many people living with dementia face its challenges the conditions on a daily basis, yet, instead of hiding, they gather themselves together, get outside and interact with people. This is similar to someone putting on the *Fokung Wirkus* and being determined not to give up, no matter how challenging the task may be. Everything appears murky and you can hardly see a thing. You are constantly looking for a better lens that you will

never find. However, despite all this adversity, you persevere and press on, just like people living with dementia perhaps would if people not living with the condition were able to bridge the gap to their way of seeing the world. Indeed, the *Fokung Wirkus* shows that this bridge still needs building – and this can be achieved with the additional help of art and art therapy.

Preferences

Raising awareness and fostering empathy is important and, even, necessary for any society. However, what is the point of appreciating that it is important for all of us to realize that people living with dementia are an active and important part of our society if we still have no idea how to interact with them? Communicating with people who are unwell is a major challenge, and this is especially true for those living with dementia, especially at the stage when they begin to lose their vocal and verbal capacities.

The first of our senses that we use as human beings is touch – and this remains intact throughout life, even in later stages of dementia. Indeed, Denis Diderot explains that, of all the senses, touch is the most profound and philosophical (Diderot 1749).

Touch is the ‘singular sense that corresponds to no single organ. Physiologically, touch is a modality resulting from the combined information of innumerable receptors and nerve endings concerned with pressure, temperature, pain and movement. But there is more to touch. It is a sense of communication. It is receptive, expressive, can communicate empathy. It can bring distant objects and people into proximity’ (Paterson 2007, 5).

The focus on the sense of touch opens up a level of communication between people living both with and without dementia, it is experienced by both sides, beyond verbal exchanges and cognitive interactions. ‘Touch [...] articulates an equally rich, complex world [...] of non-verbal social communication’ (Paterson 2007, 6).

The increasing decline of verbal communication skills is one of the most substantial problems for people living with dementia. They have difficulties in finding the right terms or words during a conversation, which causes insecurity in social contexts, which can lead to shame and, ultimately, to social withdrawal. Progressive amnesic aphasia, i.e. the loss of the ability to name objects, states or conditions, restricts verbal communication and makes it almost impossible, depending on the stage of the condition. Nonverbal communication,



Figure 3. Preferences 1

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therefore, becomes more and more important, either in addition to verbal communication or – in the latter stages of dementia – as the only form of communication.

This is why a social designer might work with the sense of touch and it is for precisely this reason that the *Preferences* set, consisting of a box of materials, eight prefabricated of frames with folding covers and a picture-based instruction manual, was developed. The tactile qualities of the materials is broad, from smooth to abrasive, soft to sharp, and delicate to coarse.

The *Preferences* set consists of a box of materials, eight prefabricated of frames with folding covers and a picture-based instruction manual. The tactile qualities of the materials is broad, from smooth to abrasive, soft to sharp, and delicate to coarse.

Martin Jay indicates the ‘importance of material and sensual vehicles for conveying meaning’ and discusses the translatability between conventional spoken and written languages and the ‘languages’ of images, sounds, smells, tastes, and touches (Jay 2011, 308).

Preferences represents very personal choice of materials, assembled to form an object that feels personal, one that reveals something about the user’s individual preferences and emotions. People living with dementia using the kit can, therefore, experience the pleasure of completing something of their own, thus learning that their own creations can be used as a basis for contact and communication.



Figure 4. Preferences 2, C. Bast D.A.S.;
© Lea Fabienne

It is possible to use the *Preferences* set in a variety of settings and configurations: people living with dementia working with people who are not, people living with dementia working with professional carers, groups of two or more people and residents of care homes working with their visitors, with other residents, or accompanied by professional carers, as well as in private homes, in day-care centers or in care homes.

The *Preferences* kit is equally effective for people living with dementia, in any stage of the condition, or those without. Even those in extremely advanced stages of the condition, with whom verbal communication is either rarely possible or completely impossible, can benefit from using it. Depending on the stage of the condition, users will require varying levels of support and motivation, but it is definitely something with which they can interact in a pleasurable way.

The set can be used either in workshop-like settings, under the guidance of the artist who designed it, or completely independently.

The *Preferences* kit is usually used in stages. In stage one, the participants focus on themselves, on their sense of touch, on looking at different colors or even smelling different aromas, all of which are based on the materials provided. Stage two is about designing, about putting together or (depending on the stage of their condition) just completing a 'feeling picture' that is personal to them. The fact that many people living with dementia are no longer used to doing anything by themselves makes this experience all the more special. Stage three focuses on interpersonal exchange, on communication about the materials they have chosen, maybe what it means to them and how the completed 'feeling picture' makes them feel. This third stage often overlaps with stage two, in which the participants comment,



Figure 5. Preferences 3
© C. Bast

either verbally or nonverbally, on the characteristics of the materials they are touching.

The exchange on the completed 'feeling picture' may be a nonverbal expression of happiness and pride in their accomplishment, or a verbal explanation of the finished result. In any event, it constitutes a starting point for interaction and for further communication, even more so when the 'feeling picture' is mounted on a wall and displayed for all to see. Therefore, *Preferences* is not only effective while the participant is creating their 'feeling picture', rather it also has the potential of using the resultant creation to stimulate different kinds of communication later on – usually, no reference is made to the time when the object was produced, the conversation or interaction rather focuses on the different qualities of the materials the picture is made of.

It is important for each individual to design their own object. Moreover, a participant living

with dementia should only be given as much help as necessary and this help should not become overbearing. Experience has demonstrated that people in different stages of dementia accept and willingly use the *Preferences* set as a communication tool. On one hand, it was shown that people in very advanced stages of the condition living passively in a nursing home suddenly responded to the application of the *Preferences* set because their sense of touch was stimulated. They seemed to notice that they were getting personally involved, which was something they were no longer accustomed to. On the other hand, some people not only used their hands, but also their tongue to explore the characteristics of a specific material, which is quite logical, given the tactile sensibility of the tongue is much greater than that of the fingers.

Conversely, however, using the *Preferences* set can facilitate an invaluable joint experience for all participants. Focusing on joint activity as part

of a group of two or more, where all participants share the same ambitions and enjoy the pleasure of touch, is an important aspect not only of creating an object, but also of fostering a sense of community and proximity at the same time.

For people living with dementia, this kind of mutual exchange on a tactile and personal level is often the only way to experience proximity to another person. The same is true of conversations, which are more likely to create a connection, or even a sense of closeness, the more the interlocutors get to know each other.

People who cannot remember the last sentence they have uttered realize, at least subconsciously, that they are no longer in the mood for conversation in a way they would like. A situation that requires you to find common conversation topics, to keep a conversation flowing, to respond verbally to arguments and/or to ask and answer questions – all of this causes stress and fear if the cognitive communication conditions are unequally distributed among all those involved. Even people living in an early-stage of dementia quickly feel ashamed because of their difficulties in making conversation, and people not living with dementia often feel awkward if the manner of verbal communication they are used to becomes difficult or almost impossible. In such situations, the *Preferences* kit creates naturalness, reduces fears and enables open, pleasurable communication, as all participants communicate on a common nonverbal level. It can even act as an icebreaker in an embarrassing or emotionally uncomfortable situation as it makes interpersonal exchanges beyond the level of verbal communication much easier. In addition, *Preferences* allows communication to drift from nonverbal to verbal and back again whenever possible. Focusing on the sense of touch levels the playing field. This means, then, that this type of communication is a great help for participants living both with and without dementia. Moreover, the effect goes far beyond the time spent designing and making the ‘feeling picture’ because the object then exists and can offer an appropriate stimulus for exploring thoughts and emotions.

Preferences was developed as part of the D.A.S. (Dementia. Arts. Society.) research project, funded by the FWF.

Ulrike Bez indicates that ‘being weak does not mean being incapable of action, but can mean active shaping and self-initiative action’ (Bez 2016, 10). In that sense, it is important to maintain the ability of people living with dementia to act independently, as well as to promote communication and interaction between people living with and without dementia for as long as possible. This is not only in the interest of people living with the condition, but, on a larger scale, it has an impact on the state of society as a whole because it ‘ultimately shows the maturity of a society in dealing with their weaker members’ (Bez 2016, 12).

Above all, stressing the importance of nonverbal communication can be seen as an opportunity, especially for people not living with dementia. Indeed, Diane Ackerman states that ‘we’re living in sensory poverty, learning about the world without experiencing it up close, right here, right now, in all its messy, majestic, riotous detail. The further we distance ourselves from the spell of the present, explored by our senses, the harder it will be to understand and protect nature’s precarious balance, let alone the balance of our own human nature. [...] We’re losing track of our senses, and spending less and less time experiencing the world first hand’. (Ackerman 2011). In times when technology is in a position to take over how we interact with each other, we all need spaces and opportunities where materiality, physicality and the use of touch once again become highly valued in the range of interpersonal communication.



Figure 6. Preferences 4
© C. Bast

Artistic Potentials

People living with dementia, and their surrounding environments, are changing society and we can have a clear influence on how this happens, especially through art and social design. Engaging even more with people living with dementia, i.e. understanding how they perceive the world and recognizing their specific needs, can only be a great benefit to those not living with the condition. New perspectives can be gained on what they hold certain, how they experience life, what their attitudes are, and how they use their senses. Accepting dementia as an aspect of our society and working to help those affected does not only require medical knowledge, rather, at the very least, what is also needed is creativity and social intelligence in equal measure. Artists with a relevant understanding of how using their artistic methods can help people living with dementia can be an effective part of working to solve this social challenge. Indeed, Peter Sellars most wonderfully described the potential artists have in this area in his speech at the opening of the Salzburg Festival in 2019: ‘Artists have to look ahead, to see what is missing from today’s picture, what is not yet there, or what has been there for a long time but is waiting to be seen. Artists open the eyes and minds of a generation to new possibilities, new feelings, new stirrings’ (Sellars 2019).

Living with dementia is about living with unexpected change; it is about living with the fact that new realities and perceptions of the world seem to be emerging constantly. To people not living with dementia, these new realities will appear strange, yet they are also very real. Through art, new realities can also be created. Indeed, artists know all about change and uncertainty as it is their job to create it, not least by using new forms of communication to help people better understand unexpected situations and developments, such as those both people living with dementia and those caring for them experience.