



designing for people with dementia
mindful self-empowerment & social engagement

Recognising Design as a Means for Enhancing Quality of Life, Self-Empowerment and Social Engagement for People with Dementia

Recommendations for Funders & Policymakers,
Designers, Design Researchers & Design Educators,
Design Regulators & Voluntary Organisations

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Universities



Dementia care & policy



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Design



About MinD

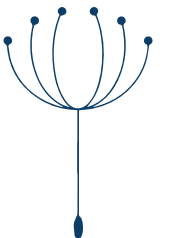
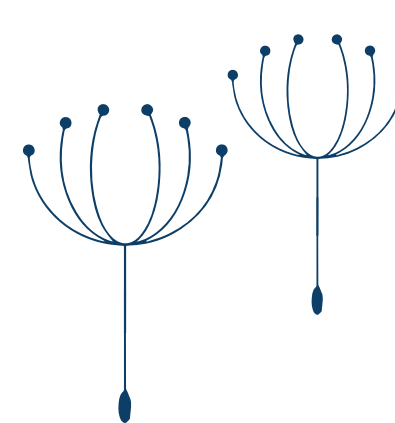
The aim of the European project MinD “Designing for People with Dementia: Designing for mindful self-empowerment and social engagement” (2016–2020) has been to help people with early to mid-stage dementia engage in social contexts to improve psychosocial wellbeing through design. In order to do so, MinD has applied mindfulness thinking and practices to both the design development process and its outcomes.

MinD has investigated how design and mindfulness can be used to support people living with dementia with regard to subjective and social wellbeing. The project has considered both personal needs as well as environmental contexts and influences.

Bringing together practices of co-design, co-production and public engagement, MinD has further developed processes for engaging with people with dementia in the research and design process from beginning to end, including design decision making stages.

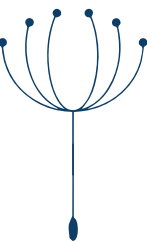
The outcomes and benefits of the MinD project include: the development of a holistic mindful model of designing; the development of new uses of mindful design to help people with dementia engage socially and improve subjective well-being and empowerment; the presentation of a robust methodological co-design framework for the development and evaluation of the designs in relevant settings, and giving people with dementia a central voice and influence in the development of the designs.

From these aims and outcomes of the MinD project, we have derived a set of recommendations for policymakers, dementia organisations, designers, design researchers, design educators, and design regulators regarding the inclusion of design within dementia care, presented in the following.



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Executive summary

MinD is committed to encompassing mindful design, co-design and co-production with and for the person with lived experience of dementia. The aim was to identify, develop and evaluate design solutions to help in everyday life. Mindfulness is a central concept throughout, defined as a form of awareness that emerges through paying attention on purpose, in the present moment. Design is a means for facilitating change, which can be used to embed mindfulness in people’s lives.

The MinD project comprised three phases: data collection, design development, and design evaluation. Engagement and partnership with people with lived experience of dementia has been central to this process, including initial consultations, data collection, choosing design ideas to take forward, and providing feedback on design concepts and prototypes at the various stages of development. We have worked with our four health and care partners, with Groups of Experts with lived Experience of dementia (GEE) and Public and Patient Involvement (PPI) Groups, enhanced by collaboration with Alzheimer Europe to enable inclusive public engagement. MinD has published on various aspects of the project, including insights and experiences of ethics and data collection, co-production and co-design. These insights have led to the present set of recommendations.

Our recommendations are:

FOR FUNDERS & POLICYMAKERS

1. The importance of design in supporting people with dementia, their families and caregivers in all aspects of their lives must be recognised and incorporated in decision making related to dementia.
2. The EU should recognise and fund design research as its own theme, including research that focuses on the application of design for people living with dementia and those living with disability more broadly.

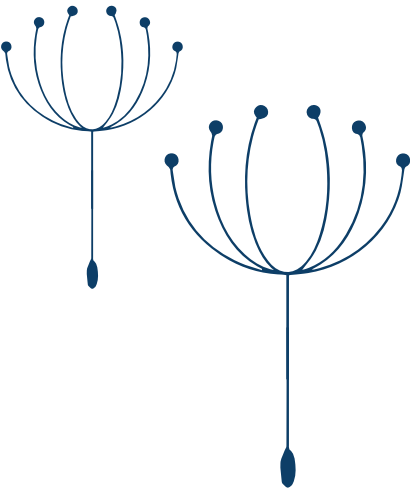
3. Funding applications and funded programmes should consider meeting the needs of people with dementia to enable co-design and development where possible.

FOR DESIGNERS, DESIGN RESEARCHERS & DESIGN EDUCATORS

1. It is important to recognise that the starting point for design should not be with a product but with identifying people’s needs, wants, wishes, dreams and aspirations.
2. Emphasis should be given to including or partnering with relevant stakeholders, including people living with dementia, at all stages of the design process from start to finish.
3. Design should be evidence-based and informed by relevant policy and legislation, e.g. EU Accessibility Act, EU standard ‘Design for All’ and MinD design guidance, and awareness and knowledge regarding design accessibility should be promoted.

FOR DESIGN REGULATORS AND VOLUNTARY ORGANISATIONS

1. Explore and develop a systematic open-access repository for relevant design guidance for the development of user-friendly designs.
2. Explore and develop the potential for dementia-friendly specification or standards for dementia-friendly products and services taking into account relevant guidance and criteria.
3. Promote awareness of potential transferability and availability of designs for specific user groups, such as dementia, for application with wider groups and audiences.



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Introduction to the MinD project

Dementia is characterized by the progressive
decline in cognitive, social and emotional
abilities. It is a significant and growing global
challenge that is now widely recognised as a
disability.

Dementia can affect all aspects of a person's
life, including their relationships with other
people and their social life and interactions.
Using design and mindfulness, the MinD project
aims to help people with early to mid-stage
dementia engage in social contexts to improve
psychosocial wellbeing. The project has brought
together 18 partners with different types of
expertise from eight European and international
countries to work together on identifying and
developing design solutions that can help people
with dementia manage and enjoy their daily
lives.

Besides developing new design solutions, a
central aim has been to develop a mindful
design, co-design and co-production approach
that enabled the collaborative development of
mindful design ideas from the start to the end.
The concept of mindfulness was introduced
within the MinD project to help enhance
perceptions of personhood and to embed them
in people's lives through design. Mindfulness
has been defined as a form of awareness that
emerges through paying attention on purpose,
in the present moment. Focusing on 'being-in-
the-moment' – as it does not require 'memory'
– can enable taking novel perspectives and offer
empowerment to people with dementia.

THE PROJECT ADDRESSED THE FOLLOWING RESEARCH OBJECTIVES:

1) To investigate the challenges and
opportunities of increasing subjective
wellbeing and social engagement for people
with dementia through design from a
mindfulness perspective;

- 2) To develop mindful co-design approaches to
empower people with dementia to express
their needs and challenges with social
engagement during the design process;
- 3) To develop a mindful design approach to
developing design product solutions to
empower people with dementia to engage in
social contexts;
- 4) To investigate and test the conceptual
and technical development of tangible
mindful design solutions, both personal
and environmental, supportive of personal
well-being and social inclusion within a
dementia care context;
- 5) To develop a holistic model of mindful
design-integrated dementia care with regard
to the challenges and opportunities of social
engagement.

The central purpose of MinD was not only to
achieve these objectives but, by doing so, to
raise awareness of the importance of design and
its potential to support people with dementia,
their families and carers, and to improve their
quality of life.

The aim of this document is to promote the
insights about mindful design and co-production
so that they will become embedded in design
research, teaching and practice as well as in the
care provision, and thus become more widely
available to people with dementia, their carers
and loved ones.

In the following, we summarise the details of the
project, and then discuss one by one the areas
where design awareness needs to be raised and
embedded to achieve these goals.

The MinD design process

MinD had three phases that informed the overall design process: phase 1, data collection; phase 2, design development; phase 3, design evaluation. We have been influenced by previous research and by our own conceptual work on mindful design and AIR (Activities-Internal world- Relationships) models.

PHASE 1: DATA COLLECTION

The first stage comprised data collection from people with dementia about their needs and wants concerning subjective wellbeing, self-empowerment and social engagement through three of our health and care partners. This included the development of data collection instruments tailored and appropriate to the nature of the design research project. For example, we used qualitative interview scripts, visual cards of daily activities to support discussion in the interviews, and visual probes – a method from design to collect visual and experiential information to complement the data collected through the interviews. Instruments were developed with feedback from GEE/PPI consultants to ensure appropriate language and presentation. The data were subsequently analysed and synthesised into 11 ‘design themes’ which were key in informing and providing a basis for the design phase.

PHASE 2: DESIGN DEVELOPMENT

The design development comprised a number of steps, including brainstorming and ideation based on the design themes, the initial design concept development and decision-making about which design solutions to take forward to realisation, then the full concept development of the selected ideas, and finally the prototype development. Public engagement with GEE/PPI participants has been an important part of the design development and decision making in all these stages.

PHASE 3: DESIGN EVALUATION

Finally, mindful evaluation instruments were co-developed, and the designs were evaluated with participants through interviews and focus groups with regard to usability and user experience. The development of the three phases of the research was underpinned by the development of relevant conceptual frameworks including:

1. The mindful design framework which brings mindfulness thinking and practice into people’s lives through design in order to help with developing subjective wellbeing and self-empowerment in the dementia context;
2. Based on the data collection findings, the AIR model was developed to help explain the parameters of people with dementia with regard to their personal concerns as well as social and environmental contexts;
3. A mindful co-design model has provided essential guidance in working together with people with dementia, carers and healthcare professionals within the design process.

A key feature of MinD was user involvement from the outset. This included identification and verification of the needs to be worked upon; involvement in data collection; choosing which concepts should progress to the design stage; and providing feedback at various stages of prototype development. GEE/PPI participation has been enhanced by collaboration with Alzheimer Europe and the European Working Group of People with Dementia (EWGPWD), and also by the contribution of a lived experience researcher who has helped lead the PPI work.

MinD insights and their implications for policy

Besides the design outcomes, the MinD project has generated different types of findings that can be useful for various different groups.

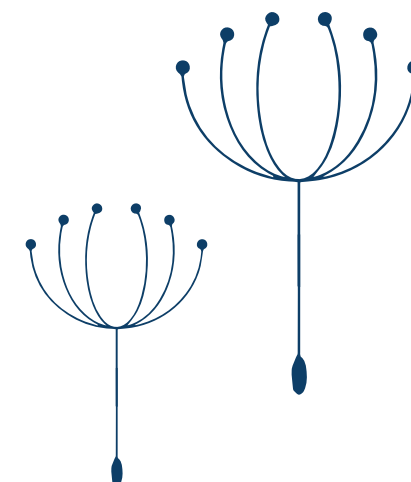
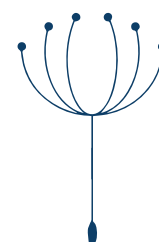
KEY INSIGHTS INCLUDE:

1. The explicit understanding of the role and potential impact of design research projects for societal benefit and change.
2. A better understanding of the benefits of design in supporting people with dementia and helping them improve their everyday lives.
3. A clear understanding of the importance of evidence-based designing through the inclusion of relevant stake holders in the research and design process.
4. Guidance for collaborative working within research teams and with diverse stakeholders.
5. Guidance on the processes and terms of engagement for including vulnerable end-user groups in the research and design process.
6. An understanding of the importance (and current lack) of dementia-friendly specifications or standards for dementia-friendly products and services.
7. An understanding of the potential of design solutions to be relevant for and transferable to different user groups.

The work underpinning these findings and insights are published in a number of academic and non-academic publications, including journal papers, chapters, design guidelines, and web-contributions on the MinD website:

www.designingfordementia.eu

The key findings from MinD are important not just for groups immediately involved in design research, but also have implications for a wider audience. In particular, we suggest that there are messages for policymakers, funders, designers, design researchers, design educators and design regulators as well as for organisations concerned with the care and well-being of older people and people with dementia. In the following, we discuss the three areas of our recommendations, offering some background and a summary of the research to frame and explain our recommendations.



Recommendations for funders & policymakers

Design surrounds us everyday, everywhere. We encounter design products for example in the form of clothes, tableware, furniture, cars, houses. In the form of service design, it determines how we access goods, places or various services, such as health and social care as well as social and leisure activities. Design can be broadly defined as ‘courses of action aimed at changing existing situations into preferred ones’ [1]. In this sense, design includes not just the creation of objects, but also of services and systems, architecture and the environment. Design can offer support within medical, therapy and care settings but also beyond these settings in everyday life situations [2]. Design can also support older people and people with early stage dementia who are still living mostly independently at home in various ways, and can enable them to continue to live there better for longer, although more robust research in this area is needed [3, 4, 5, 6].

And yet, while design can provide support in many situations of life, design is rarely recognised in relation to dementia, or more broadly in the context of mental health and disability. Where it is recognised, it is usually as ‘assistive technology’ [7]. Draw-backs of this are that assistive technology is too often technology-driven rather than developed from the perspective of the needs and wishes of the people who are meant to use it. Also, such interventions, when targeting people with dementia, tend to focus on functional and cognitive support, such as memory and orientation aids, devices for personal safety or for enabling independence [6, 7] while there is great potential for design to provide support e.g. in the context of reducing stress, anxiety or depression, supporting relationships and communication, or maintaining quality of life.

Therefore, there is the need to recognise the potential of design in the context of health and social care in general, and with regard to supporting people with dementia in particular.

There further is a need to support this recognition through appropriate resources for design research and development in this area. Furthermore, for design to be meaningful and useful, it is essential to engage and involve the users in the design process, in this context people with the lived experience of dementia, their families, caregivers and all other relevant stakeholders.

IN SUMMARY, WE RECOMMEND THAT:

1. The importance of design in supporting people with dementia, their families and caregivers in all aspects of their lives must be recognised and incorporated in decision making related to dementia.
2. The EU should recognise and fund design research as its own theme, including research that focuses on the application of design for people living with dementia and those living with disability more broadly.
3. Funded programmes and funding applications should consider meeting the needs of people with dementia to enable co-design and development where possible.

Recommendations for designers, design researchers & design educators

For future studies involving designing with people with dementia, the MinD team has developed a set of MinD design guidelines [8]. They cover topics such as design research frameworks, design methods, co-production alongside people with dementia, and mindful co-design guidance. We have synthesised key points from these guidelines to offer relevant recommendations for designers, design researchers and design educators below.

For design to be able to offer positive change to people in their lives, it is important for designers to start with the person, by understanding their situation and their needs, wants, wishes, dreams and aspirations. This means obtaining any baseline data for the design directly from end users and relevant stakeholders, and to include them throughout the design process, e.g. data collection, design ideation, decision making, design concept and prototype development, and evaluation. The inclusion of participants from start to finish enables the evidence-based development of solutions that are both relevant to people and appropriately designed.

To enable successful user involvement and co-design, it is essential to give clear definitions of processes, including issues such as engagement and equality for all involved. Participatory co-design usually benefits from mixed teams of designers, health/social care professionals and other stakeholders. Partnership with people with lived experiences of dementia is invaluable and can work well if all parties share in a spirit of mutual respect, fairness and honesty, and if collaboration is facilitated creatively, sensitively, supportively. ‘Soft’ evaluations, focusing on experiences, attitudes and behaviours are likely to be most productive, and people with dementia as well as all other stakeholders should receive clear information about a project, their involvement, and what

it will entail. Reasonable expectations should be accommodated and public engagement workshops and consultations should be carefully planned and facilitated by persons with the necessary knowledge and skills. Considering verbal and non-verbal communication within interactions, and using respectful, appropriate and accessible language is important while alternative materials for enhancing communication (e.g. pictures) can also be useful. Space for mindful reflection at the end of activities is valuable.

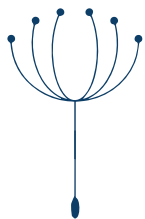
In this context, we offer the MinD design guidelines [8] as an addition to improve the base for evidence-based working and research in design.

In addition to working with users and other relevant stakeholders, it is important to consider any existing good design practices or designs that are appropriate and fitting for application or adoption for future development. It is also important to consider any relevant policy and legislation during the design process, such as European Accessibility Act [9] European Standard EN 17161 ‘Design for All’ [10]. This generally relates to the ergonomics and human factors of a product as well as aspects of health and safety, e.g. by using or developing shapes and materials that fit the human body and are safe to use, by considering cognitive capabilities, visibility and legibility, etc. There is also a large body of research and guidelines relating to emotional aspects and how we read design, including product semantics – how a product is read and used, semiotics – what story a product tells beyond its function, user experience, and emotion design – how a product (or service) is being perceived and/or emotionally impacts the person using it.

Recommendations for designers, design researchers & design educators

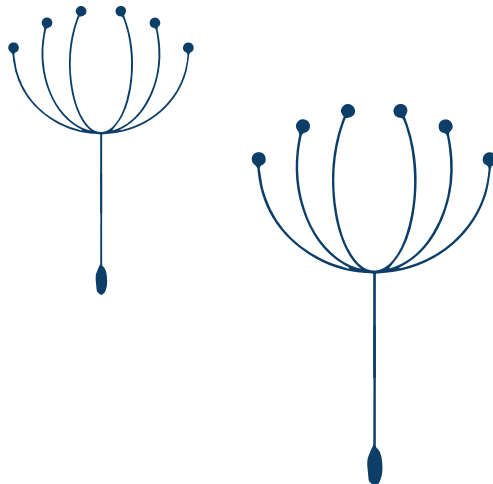
The above criteria and guidelines for designing with and for people with dementia are of importance to designers, design researchers and educators alike who have the responsibilities to continuously up-date their knowledge of design developments in the field in order to be able develop relevant and appropriate new solutions, and to share their knowledge and experience with, and prepare the new generation of designers. In order to address them, it is important to include evidence-based designing to complement the creative and imaginative aspect of design and to develop a successful product, service, environment etc. Evidence-based working needs to include awareness of guidelines and regulations as well as rigorous empirical work and the consultation with end-users and other relevant stakeholders.

Learning to include end-users and other stakeholders in the design process needs to start early in the learning process for novice designers to become familiar and comfortable with such processes. It requires expanding traditional design processes that focus on ideation and model making into participatory and co-design processes, including knowledge and processes more common to health and social sciences. Such processes might include a good understanding of ethics processes and their purpose, ethnographic methods or participatory engagement with users in workshops, constructing personas and acting out potential scenarios to understand them better.



IN SUMMARY, WE RECOMMEND THAT:

1. It is important to recognise that the starting point for design should not be with a product but with identifying people’s needs, wants, wishes, dreams and aspirations.
2. Empasis should be given to including or partnering with relevant stakeholders, including people living with dementia, at all stages of the design process from start to finish.
3. Design should be evidence-based and informed by relevant policy and legislation, e.g. EU Accessibility Act, EU standard ‘Design for All’ and MinD design guidance, and awareness and knowledge regarding design accessibility should be promoted.



Recommendations for design regulators & voluntary organisations

Above, we have argued for the importance of recognising design as well as for the importance of getting it right, and that this requires appropriate guidance for designers and other stakeholders involved in the design commissioning and development process.

While a plethora of design guidelines are available, they are varied in their quality, how systematic they are, whether they are evidence-based, whether they have been evaluated or tested, and where and how they are available. While there are ISO specifications and other technical specifications, these tend to relate to the technical realisation and safety of products rather than their actual design and only come into play at the production stage. Furthermore, these can be difficult and expensive to access. At present, there is no European design body or repository that is having an oversight and providing a systematic and accessible resource for designers or other stakeholders wanting to inform themselves about options and best practice for designing and co-designing dementia-friendly products. Besides accessible information and systematic guidance for the process of designing with and for people with dementia, more coherent designer and user-friendly specifications are needed to support evidence-based designing that takes into account user needs and wishes, designing affordances, emotions, ergonomics and (health &) safety.

Such design guidance could also be helpfully integrated with standards for dementia-friendly products through end-user (dementia) organisations. Through their access to and familiarity with people with dementia, they are perfectly placed to conduct product-user evaluations to make recommendations and develop standards independently or in collaboration with designers.

One further point here is that the best and most user-friendly products tend to be non-stigmatising. They are not easy to recognise and identify by the end-user or any other stakeholders.

Therefore, knowledge of helpful products often remains local and limited. Guidance for end-users through explicit description and categorisation of dementia-friendly products and recommendation by dementia organisation would here be helpful

Therefore, the creation of a European repository for design guidelines and regulations as well as ‘dementia-friendly’ products would be valuable to make them accessible and improve the application and quality of design in this area.

Finally, many of the most user-friendly products offer benefits for a wide range of potential users. For example, a product to help people with dementia relax or engage socially may potentially be equally helpful for people with depression or autism. It is therefore important to recognise that many products can be transferable and useful for other people with other mental health conditions. It is therefore important to evaluate and make products available to different relevant user groups, for example through widening networks of relevant voluntary and user organisations.

IN SUMMARY, WE RECOMMEND TO:

1. Develop a systematic open-access repository for relevant design guidance for the development of user-friendly designs.
2. Explore and develop the potential for dementia-friendly specification or standards for dementia-friendly products and services taking into account relevant guidance and criteria.
3. Promote awareness of potential transferability and availability of designs for specific user groups, such as dementia, for application with wider groups and audiences.

Conclusions

The MinD project has applied principles of mindful design to designing and developing products and services that meet social needs directly identified from people living with dementia. MinD has sought to derive frameworks for mindful design in the dementia and care context to make insights more widely available. It has further sought to develop and make explicit best practice for co-design processes, and the mutual benefit of interdisciplinary and intersectoral collaboration as well as participation by end users and other relevant stakeholders in the research to provide a robust evidence base.

In this report, we have summarised the key insights from our research to underline the importance of good design for enhancing the lives of people with dementia, their families and caregiver, especially in relation to subjective wellbeing, relationships and social activity.

Furthermore, good design is not necessarily more expensive than poor design or no design at all: it is more a way of thinking about how products and services should be.

Based on these insights, we argue that design should be given more attention as a means of achieving quality in people's social and everyday lives. This should be reflected in professional practice, in education, in further research and in policy and funding.

This report presents our recommendations for policymakers, designers, researchers, educators, design regulators and voluntary organisations. Adoption of these recommendations will make a positive contribution to the lives of people with dementia and their families.

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