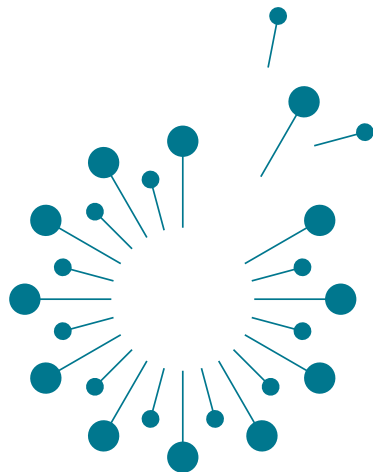


MINDFUL CO-DESIGN FOR DEMENTIA

A toolkit for designers, people living with dementia, care partners and other stakeholders to work together to create designs for better living.



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

Design can empower people living with dementia in everyday social situations.

Results are shown to be better when designs are created together with end-users in a process called co-design. The involvement of people living with dementia and care partners (experts by experience) in the design process is crucial for producing designs that are both relevant and fit for purpose.

This toolkit, which was developed as part of the MinD project, aims to provide practical information on how to co-design as a guide for everyone involved in the process.



About MinD

The aim of the European project MinD “Designing for People with Dementia: Designing for mindful self-empowerment and social engagement” is to help people with early to mid-stage dementia engage in social contexts to improve psychosocial wellbeing through design. The project has considered both personal needs as well as environmental contexts and influences.

In order to do so, MinD has applied mindfulness thinking and practices to both the design development process and its outcomes. 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 wellbeing and empowerment; the presentation of a robust methodological co-design framework for the development and evaluation of the designs in relevant settings, to give people with dementia a central voice and influence in the development of the designs.

digital diary
 (+) need - password
 or hand - can be
 writing - forgotten
 type in - power
 on - too much
 computer - choice
 - synchronise

(+) I pad:
 - synchronous
 (communication
 email)

Web: information
 at your
 fingertips
 Wikipedia
 book three

(+) not foolproof
 not error proof
 breakable
 too much choice
 size: normal
 size
 phone: support to
 manage technology
 help functions
 problematic

map

① know where
to go

② too small
to read

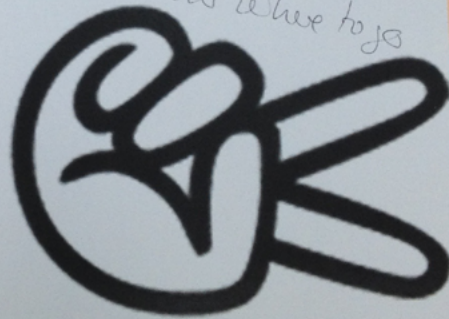
difficult in
car

diary/manual
calculator

- accessible/sharable
 - portable/light
 - foolproof
 - no batteries
 - no password

- limited space
 - legibility
 - difficult if
 cannot write

Compass:
 know where to go



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What is co-design?



We use the term **co-design** to describe work involving people with lived experience of dementia in the design process. In a truly shared approach, co-design means 'designing with' rather than 'deciding for' people who the design will be for. Co-design should start early and continue throughout the design process, including its various stages. We regard **co-production** as the process that facilitates partnership for and within co-design to happen.

1. Finding the design need

At the beginning of the design process, it is important to find out from experts with experience what problem(s) design can help with.

2. Generating ideas

Once a design problem has been identified, the next step is to generate design ideas (ideation), using various design techniques, such as brainstorming or sketching.

3. Design decision making

Once a number of ideas have been developed, a decision has to be made about which design ideas should be developed in more detail. The decision making should include a variety of experts of experience to consider all viewpoints.

4. Developing the design concept

Then follows the detailed development of the design idea into a fully specified design plan, which is called 'design concept'. This will again include some idea development and decision making in an iterative process.

5. Developing the design prototype

Finally, the design concept will be realized as a design prototype. Once again, the development of the prototype will require some decision making about further detail, in which experts by experience should be involved.

6. User evaluation

Once a prototype is available, this should be evaluated with end users. This is likely to be a new group of experts by experience to provide a new and impartial assessment of the design, its relevance, function, use and the experience with it.

What is mindfulness?



Mindfulness can be defined as 'awareness that emerges through paying attention on purpose, in the present moment, and non-judgmentally to the unfolding of experience moment by moment'¹.

Mindfulness can help with awareness and self-awareness of emotions, relationships situations and perspectives that can be beneficial for working together. There are four key aspects to mindfulness.



Focusing on '**being-in-the-moment**' can offer empowerment to people with dementia, as it does not require 'memory', and can help with relaxation, and concentration.



Orientation to experience is based on 'an attitude of curiosity' as the mind wanders. 'All thoughts, feelings, and sensations that arise are initially seen as relevant and therefore subject to observation.'² It promotes acceptance of experience.



Mindful awareness is nurtured by one's orientation to the present³. It can help promote openness and alertness to novel ideas and contexts, and a shift in perspective^{4,5}



Mindful choices: Multiple perspectives encourage reflection and considering one's choices. Taking responsibility for oneself and one's life through choices can foster greater health and wellbeing⁶.

1. Kabat-Zinn (2003), 2. Bishop et al. (2004, p. 233), 3. Langer (1990), 4. Djikic, (2014, p.140), 5. Shapiro et al. (2006), 6. Langer, (1990: 82ff, 100ff)

Mindfulness and co-design in successful partnership



How can mindfulness help create the conditions for a successful co-design partnership?

Using mindful thinking and values in the co-design process can foster a considerate and inclusive environment, appropriate for working with people with dementia, their care partners and other stakeholders. Including mindfulness in the co-design process can help improve team work.

Being-in-the-moment...



Using creative activities that focus on 'being-in-the-moment' can create a level playing field for all participants.

Mindful awareness...



Joint exercises can be used to foster mindful awareness of mutual needs and wishes and enhance feelings of self-empowerment. Mindful awareness in turn can help sharing in a spirit of openness and fairness to create a collective spirit and genuine inclusion of less powerful voices. It can help embrace diverse understandings and ways of working to create a shared journey and horizons that enable mutual capacity building. It can enable creating open spaces to pool diverse ideas and different forms of knowledge to foster genuine collaborative creativity.

Mindful experience...



Joint activities for sharing experiences based on mindful qualities of trust, respect, consideration, honesty, kindness and compassion can help connect all co-design participants. They can help create a safe space to work together productively and to hold and explore positive experiences as well as difficult ones, e.g. shared successes, gratitude, amazement as well as tensions, dissent, or negative experiences.

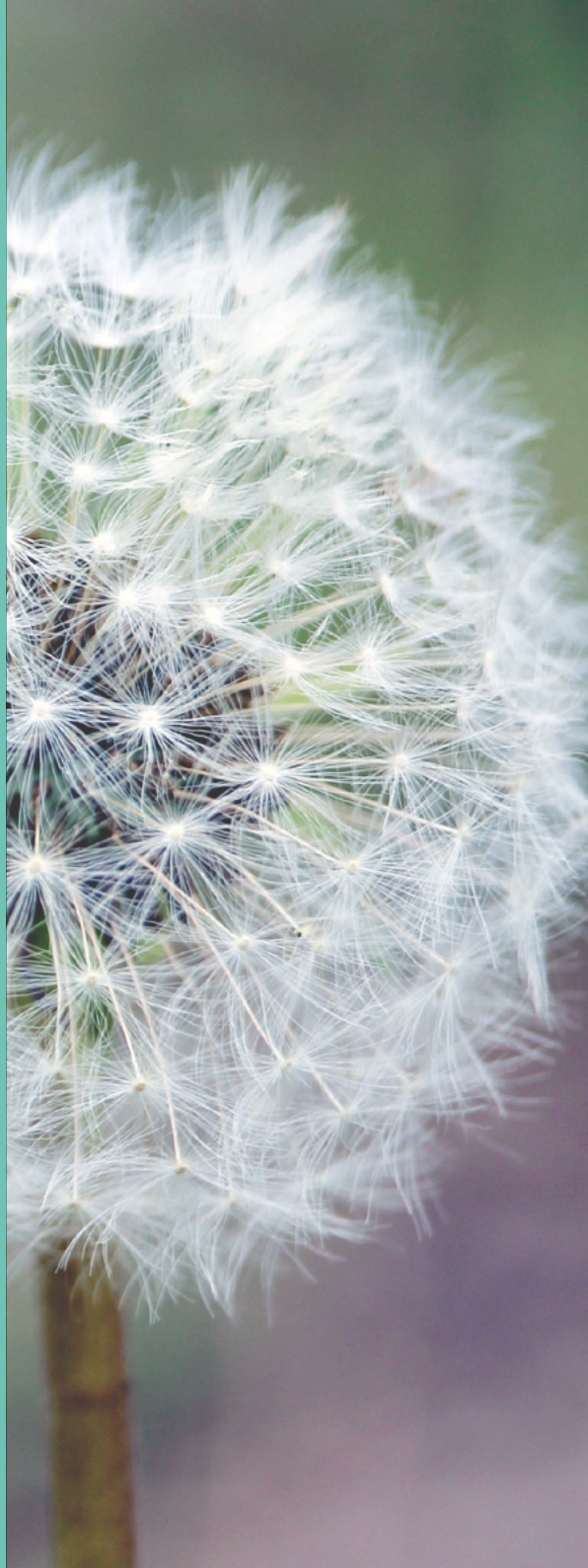
Mindful choices...



Recognising and considering one's options allows for mindful reflection and choice. In co-design, we can reflect and agree jointly on: the rights and obligations of all participants; shared values, aims and outcomes; the creation of participatory spaces to share tasks, responsibilities and acknowledgments, to enable equality and inclusion and an equitable distribution of power.



Activity



A Walk Around Myself

Mindfulness exercises can help with being in the moment, orientation to experience, mindful awareness and reflective choices. You can dedicate some minutes to these exercises which can help you with relaxation, focusing and wellbeing.

There are 6 simple mindful activities over the page, which may give you a new view on something you normally do. You can do as many activities as you like.

There is no right or wrong way to doing the mindful activities; just allow a few minutes for them.

Being mindful simply involves acknowledging your thoughts and feelings without reacting to them. Explore them, accept them and allow them to flow during the activity. If your mind wanders elsewhere it is also ok. Your experience will be different each time you do the exercise.

At the end, what experiences have you had?

A Walk Around Myself

It's good to **say 'thank you'**
– this can be for something very
small like a smile from a friend, or
feeling the warm sun on my face.



If I stop for a moment and **listen to my breathing**, feeling how
regular it is – I don't need to do
anything else, the rhythm of my
own breathing will calm me.



It's **time to give myself
a hug** or hold my own
hand. As I notice how I feel,
I say to myself 'I deserve
this hug.'



Select a mindful
exercise to try



If I close my eyes for a
moment and **focus on
my hearing**, is that a
bird, a car, a child's voice...
– what can I 'see' with my
ears? What pictures form
in my mind from these
sounds?

By walking (or imagining that I'm
walking) a few steps slowly, I **feel
how my feet make contact** with
the ground. I feel the support of the
earth beneath me, and I become aware
of how I'm moving around.



By **imagining a place where I
feel calm and safe** – picturing its
details, colours, sounds in my mind's
eye – I can rest in the warm sensations
and emotions this brings.



Our 3 Key Components to Mindful Co-Design

We can break down the mindful co-design process into three components

**Mindful
Teamwork**



**Mindful
Co-Design
Processes**



**Mindful
Co-Design
Outcomes**





Creating a great co-design team

Ideally your team will include **design experts, research experts, experts with lived experience** (of living with dementia or are living with someone with dementia), **experts on the facilitation of co-design workshops**, etc.

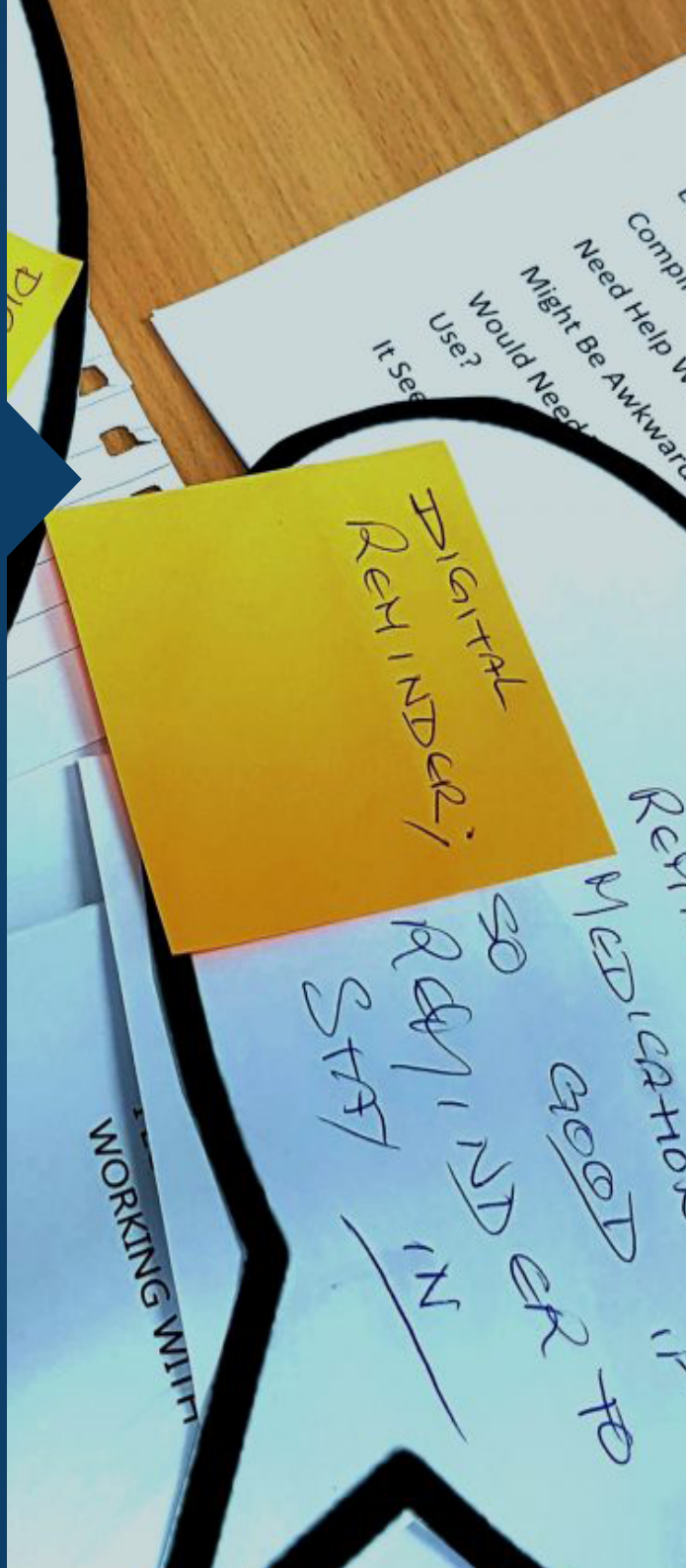
Effort should also be made to involve **lived experience partners**, including carers or people from ethnic minorities and/or other under-represented groups) to ensure as much *relevant* diversity as possible.



Mindful
Teamwork



Creating mindful communication



Collaborating as partners is different from the usual practitioner-client relationship. Talk using the shared language of 'we' rather than 'us and them'.

Make sure everybody receives enough **clear information** about the project, their involvement and what it will entail. Their expectations should be considered.

Find a **shared language**: Provide a glossary of words, such as workshop, design, facilitator, affordance. Use respectful, appropriate and accessible language in all communication. All terms used must be acceptable to the user group and fit for purpose.

Communicate clearly. Make it a habit to communicate clearly how peoples input will be integrated and will influence the project.

Ensure everyone is **comfortable** to ask if they don't understand and to say if they disagree or feel uncomfortable.

Engage in **individual or group exercises** which increase familiarity with words and their definitions. E.g. exercises where words and their meanings are paired together.

Each activity needs to be accompanied by clear instructions, discussions and examples, to prepare users for the different types of activities they will carry out.

Alternative materials for enhancing communication (e.g. pictures, objects, sounds) can be useful.



Working together as a mindful team



- **Collaboration** with all partners should start as early as possible and last for as long as possible.
- Consider everybody an **equally important** expert and make sure they are all on board with your team.
- ▲ Choose your team size wisely: working with a **small group** of people living with dementia can help them work better together and share their enthusiasm and may be more suitable than working individually or in large groups.
- A sense of **continuity and familiarity** of team members can be important for some participants with dementia.
- Plan for the **involvement** of all team members. In co-design projects, while it is recognised that everyone has needs when co-working in meetings and workshops, there may be additional practical challenges that can arise for experts with healthcare needs or care responsibilities. Overcoming these requires appropriate consideration beforehand including **timings, venues, travel, flexibility, payments and sensitivity towards health or care requirements.**

- Make meetings collaborative. Start **collaborative meetings** immediately by breaking down and sharing all tasks (such as serving coffee, badge making etc.) In doing so you ensure that everybody is engaged and feels able to offer their help and support their fellow team members.
- ▲ Work ethic based on **mindfulness values**. Embed mindful principles within the work ethic of the group. Mindfulness promotes an awareness of self and one's own experiences and feelings as well as promoting awareness of and consideration for others' experiences and feelings. A mindful approach to co-design will influence directions and enhance creativity among partners.
- **Jointly create** lived experience designed tools for workshops, including means to express and record outcomes of the process, their values and shared aims. Create tools for workshops to raise awareness of, and share lived experiences.

[Use this space to make notes regarding any challenges you or your team may face and how you plan to overcome these.]





When planning your design project, take these steps into account

The co-design process

Team exercise

Start with a mutual capacity building exercise to assist all partners to recognise their own creative abilities and those of others, to break down barriers and to build on collective capacity. This can be about experiences or memories or include creative story telling.

Explain

Explain how the project will flow from the initial identification of needs to the development and evaluation of design prototypes

Concrete proposal

Design proposals that are presented have to be quite concrete – having something tangible in the room works better than an abstract notion or just a picture.

Recognise

Recognising openly that everyone can find socialising difficult, along with the fact that we all have problems of memory and thought processing, can help to reduce the distancing of 'special needs' that segregates and even stigmatises some people as less capable than others.

Evaluate

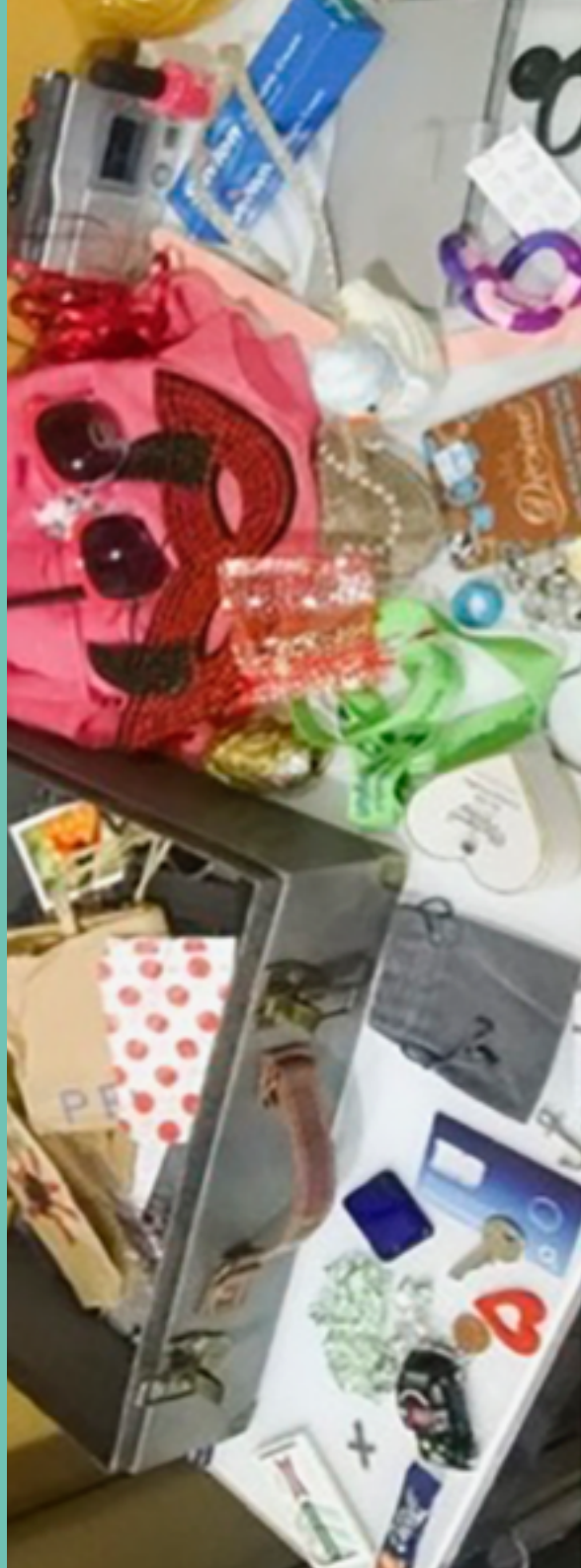
When evaluating designs, be clear about/plan for what is being evaluated: functionality of end user experience with design or formally measured effectiveness in longitudinal assessments of impact. Be clear about how this is done.

Design methods

Consider using useful design methods, such as creating personas (<https://designingfordementia.eu/resources/mind-tools/persona-toolkit>) and complement it with Mindful Scenario Task Analysis



Activity



Story in a Suitcase

This storytelling activity is designed to help develop a safe co-production space.

This is an activity around a creative space where all participants are asked to pick an object of their choice from a 'magic suitcase' (a box of assorted random items). Participants then work in groups telling each other who they are and why they had selected 'their' object before working together to create a joint storyline in which all the group members objects are embedded. To create a convivial atmosphere, each group then tell their story to the others, and finally, join together to reflect on what they have learned about themselves, the other participants and about working together creatively. These sessions take about one hour in total.



Considerations for co-design outcomes

When creating designs, it's important to consider them well to ensure they are relevant and appropriate. Useful points to consider include:



Designs should be flexible. Designs developed for use by people with early-mid-stage dementia in social contexts should be suitable for use at home with family as well as other settings, e.g. day activity groups.

Aspirational:
Design should be non-stigmatising. Make sure it focusses on aspirations, not limitations such as illness or disability.

Consider how families and caregivers may interact with the prototypes.

Consider the potential application of the design to other groups, e.g. other long-term conditions / illnesses.



Acknowledgements / References

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Dening, T., Gosling, J., Craven, M. & Niedderer, K. (2020). Guidelines for Designing with and for People with Dementia. MinD & project partners. Available from:
<https://designingfordementia.eu/wp-content/uploads/2020/02/Design-Guidelines-v3.pdf>

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Universities



Dementia care & policy



Design



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