



HOMEDM

Codesigning a home
with dementia

A Marie Curie Doctoral network on design, care & dementia.

Focusing on the recent move across Europe towards supporting people with dementia living at home for as long as possible with appropriate care.

What is dementia?

Dementia is an umbrella term for a range of major cognitive disorders, the most common being Alzheimer's disease, comprising progressive deterioration in cognitive function, especially memory loss, often accompanied by a heterogeneous array of behavioural and psychological symptoms such as depression, irritability, apathy, agitation, aggression, and sleep disruption. Dementia affects approximately nine million people in Europe, a number that will double in the coming decades as population ageing continues to advance in almost every country. Dementia mainly affects older adults, but early onset is becoming more frequent bringing new challenges for families and governments. The progressive nature of the disease leads to a decline in an individual's ability to perform activities of daily living, both physical and instrumental, as well as other more cognitively demanding tasks, resulting in higher levels of formal and informal care needs leading to significantly high costs of care.

Care in the home

The Doctoral Network "Co-designing a Home with Dementia" (HOMEDEM) will provide high-level training in design and dementia caregiving to a new generation of high achieving, early-stage researchers. The focus is on people with dementia living at home and their care constellations, incorporating formal care providers, families, volunteers and wider communities. Home is used to refer to: the people that combine to make or create a homely environment and sense of belonging; the places, spaces, objects and technologies that constitute materialisations of meaning, identity and care for people living at home; and the institutional arrangements across the multitude of organizations, groups, agencies providing care and support to enable people with dementia to live well at home. HOMEDEM comprises 8 doctoral candidates supported by 7 academic institutions and 15 associated partners.

Role of design

Within HOMEDEM, design for dementia incorporates methodology, concept and practice that combine to produce new and innovative approaches to care that have the potential to impact on the personhood and citizenship of people with dementia. Design plays an important role in maintaining autonomy and choice for people with dementia. It can impact both the infrastructure and landscape of care thereby helping to challenge conventional and conservative approaches to caring that see people with dementia as patients rather than people. HOMEDEM therefore employs a participatory approach, seeing co-design as way to enable participation of people with dementia in design as well in other contexts (such as the care process or the relations between a person with dementia and a partner or a child). Good design within the home and across local neighbourhoods allows people with dementia to maintain mobility and connectivity, even with significant cognitive decline, helping them to maintain friendships and relationships that might otherwise be lost. The World Alzheimer Report 2020 specifically identifies the importance of design to support people with dementia to live well and calls for additional application and expansion of dementia-related design in care provision, praxis and policy-making.



HOMEDEM

Codesigning a home
with dementia

Why is this doctoral programme important?

The projected increase in the number of people with dementia in Europe brings additional urgency to researching, designing, and delivering care and supports for people with dementia that improve their overall well-being and quality of life. Expectations around dementia have changed in recent decades due in part to the work of Tom Kitwood – quality of life, well-being and health outcomes matter much more nowadays. Supporting personhood and the nurturing of the self remain ongoing issues within dementia, originating from a concern about the restrictive nature and form of traditional care relationships between health and social care providers and people with dementia. Much of current dementia care is oppressive because it is not based on the mutual values of trust, respect, and communication within caring relationships, leading to a diminution of autonomy, agency, and capacity among people with dementia. This is exacerbated sometimes by the unnecessary displacement of people with dementia from their own home and place creating a sharp disjuncture, not only in physical terms, but between what was and what is, what was known and is now unknown.

What is the philosophy underpinning this research?

HOMEDEM is firmly rooted in extending and expanding the potential of home-care solutions for people with dementia across Europe. Dementia is slowly being reframed from a medical condition to be managed to a psychosocial narrative, so much so that many people with dementia now talk about 'living well with dementia' and proactively supporting personhood as part of a wider quality of life agenda. Informed by the disability rights movement, there are increasing demands for individualised and well-designed public services and supports that address the needs of the whole person. Personalised care both reflects and enhances the abilities, interests and social contacts of people with dementia allowing them to stay in their own homes for as long as possible and practicable. A social model of dementia care is increasingly referenced within dementia policy frameworks, both nationally and internationally, as a way of providing greater visibility and connectedness for people with dementia and their family carers. Unfortunately, policy rhetoric for home-based living has not always been matched by an increase in resources or funding, especially for design, infrastructure and technology.

What will doctoral candidates learn?

Participation within this integrated and cross-disciplinary Network will provide doctoral candidates with the transferable and collaborative skills required for succeeding in careers at the intersection of design and disciplines like psychosocial health sciences, economics and policy evaluation. These skills will allow them to respond to current and future care contexts by developing innovative people-centred products, services, information, technologies, environments and reflections across a range of diverse countries, cultures and disciplines. Having completed their training, researchers will be able to influence the way community-based care for people with dementia and their care constellation is organised, and how products, services and tools are co-designed and implemented within care contexts across Europe. Their influence will extend to micro, macro and meso elements focusing on: the relationships between the person with dementia and his/her care constellations; the changing needs of the home living environment (physical spaces, technologies and products); and the complex care ecosystem provided by municipalities, governments and industry (home care services, community-based support, housing and public spaces for people with dementia).



HOMEDEM

Codesigning a home
with dementia

Research themes

The programme will generate research across three broad themes. Theme 1 will focus on personal relationships within the care constellations of the person with dementia, the effect that dementia has on their life, and how relationships change as dementia progresses. The research lens will focus on care expectations, formal care provision, informal care and the day-to-day micro-level interactions of people with dementia and their carers. A diagnosis of dementia in a person leads to changes in roles within relationships, for instance, from being a spouse to becoming a caregiver or a care receiver; being a parent and receiving care from a child. These changes demand constant adaptation and resetting of relationships. Caregiving can generate joy and satisfaction and burden in equal measure. The work will create co-designing frameworks to support joint decision-making, interaction, and communication within the care constellations through the delivery of psycho-educational programmes and interventions, ehealth innovation and technological applications.

Theme 2 will focus on the home living physical environment, especially on how design and new technologies can enhance living at home for people with dementia. Investment in design through the modification of physical space within the home and outside can help to promote greater autonomy for the person with dementia allowing them to live better within familiar places. Attention to internal and external design features can also keep people living at home for longer, postponing admission to expensive long-stay residential care. Living environments also comprise the surrounding community and the wider walking and transport corridors that connect people with dementia to other people and places. The creative use and maintenance of public spaces can help to sustain existing connections and friendships and relationships, as well as facilitating inclusion and visibility for people with dementia and their family carers. Researchers will explore ways on how the living environment can contribute to the quality of life of the person with dementia and their care constellation. There will be specific focus on designing technology that fosters autonomy and participation for people with dementia, as well as an investigation of home-making processes within an urban integrated dementia village.

Theme 3 looks at the ecosystem surrounding the care a person with dementia receives at home. A diagnosis of dementia results in a myriad of complex and complicated organisational issues that impact on the ability of the person with dementia to cope with an uncertain future. Accessing and navigating community-based support services and structures is often difficult during diagnosis, but problems may also arise post-diagnosis and at critical transitions along the dementia journey. Information is sometimes absent, often fragmented, and services can be under-developed, especially in relation to personalised care and psychosocial supports that are crucial for the sustainability of the care ecosystem. The person with dementia can often feel excluded from decisions about their own care. This will affect their personhood and their autonomy, thereby making it less likely they will receive the care they want. Researchers will examine the role of people with dementia in making decisions about the care they receive within the formal system. The duality of the care relationship between the person with dementia and their family carer is an important part of this process; so too is the strength of the integrated care platform within which care occurs. Researchers will investigate care decision-making along the continuum of care, especially at the margin between home and residential care, mindful of the key transition points along the continuum of care. The economics of care for people with dementia will also be investigated, especially the willingness of tax-paying citizens and policy-makers to support and fund new models of care that enhance choice and autonomy for people with dementia.



HOMEDEM

Codesigning a home
with dementia

Policy impact

The HOMEDEM doctoral programme will lead to an increased understanding of the design needs, care challenges and potential care pathways for people with dementia living at home in the community. For the most part, people with dementia should live in well-designed homes where images of self and identity are easier to preserve in the face of on-going cognitive decline. New ways of recognising and maintaining personhood through better design and new technologies will allow that to happen. The development of a social model of care will also help to keep people living at home for longer and keep some people out of residential care entirely.

Replacing the current biological orientation with a collective social focus, supported by good design, will lead to dementia becoming more public, more mainstream, more visible and more explicit. It will allow greater discussion of the meaning of attachment, place, identity and relationships, thereby challenging governments to develop and maintain a communal approach to care that prioritises connectivity and mutual support systems. It will reinforce the need for, and benefit of, dementia friendly infrastructure and landscapes.

People with dementia have physical, emotional and spiritual needs that require nurturing, very often through psychosocial support and interventions. This requires investment in care structures and care processes that allow people with dementia to live as normally as possible in flexible, accessible and carefully designed environments that promote connection and participation. Even if people with dementia are admitted to residential care, the emphasis should be on homely, small-scale, well designed provision where biography and personality are central to the care process and autonomy is preserved as much as possible.

The research from this programme will be communicated in a variety of different ways to a wide audience of policy makers, health care providers, researchers, designers, patient groups, family groups, interest groups, and the general public. The research will ultimately lead to new approaches to care and different types of interventions to be trialled and eventually implemented, thus increasing the wellbeing of people with dementia and their care constellations, Doctoral candidates will graduate with an enhanced view of the power and potential of people with dementia and will become change agents for a more compassionate and life-enhancing public policy for people with dementia and their carers.

