

**Giving people living with dementia a strong voice:
reflecting on the role of design to create enabling activities**

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Giving people living with dementia a strong voice: reflecting on the role of design to create enabling activities

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Designing for and with people living with dementia

Dementia is named by the WHO as the leading cause of disability globally (WHO, 2017). Not surprisingly, more general attention and funding is being allocated to support individuals living with this condition.

The role of design is being increasingly recognised. In part, design has always played a role particularly in relation to design of dementia friendly environments to help compensate for some of the perceptual challenges individuals might face and mitigate against some of the symptoms individuals living with dementia experience (Brawley, 1997). However as dementia is diagnosed at an earlier point, and more people live in the community, the design of products and environments and services is seen to be even more integral (Fleming & Purandare, 2010).

As a consequence, more designers are working in this field to support the development of products, environments and services to compensate for some of the challenges these individuals face (Rodgers, 2017). However, the challenge is that rather than offering new perspectives and bringing an alternative way of thinking about dementia to enable individuals to live more independently, designers are following existing medical paradigms which over-emphasise the diagnosis, focus on disability and loss, and label individuals as patients rather than as partners in the design process.

This opinion piece questions, reflects on, and highlights some of the challenges that prevent the potential of design being realised in the context of people with dementia to create products and services that do not further stigmatise individuals but that celebrate and tap into the innate resilience individuals possess. We begin by reflecting on the current state of the art in the context of design and dementia and then highlight some of the dangers that an over-reliance on the medical model presents. We conclude with considering some of the ways that designers of the future may wish to learn and draw inspiration from people with dementia and the positioning of dementia as a disability (social model of disability) than purely a disease process.

Dementia is an umbrella term for over 100 conditions that share similar symptoms including loss of short term memory, challenges in communication, planned purposeful movement, and higher processing skills (Vink et al, 2003). Dementia is the leading cause of disability with projections suggesting dementia numbers to increase fourfold in the vicinity of 135 million by 2050 (Alzheimer's Disease International, 2013.). At present there is no cure for dementia and health-policies globally have placed emphasis on supporting individuals to find ways to live well with the condition.

Main barriers to higher quality of life for people living with dementia

Here we summarise the main barriers for effective support.

A homogeneous group perspective and focus on disease: Whilst people with dementia are not a homogeneous group and whilst individuals can live with dementia for decades at present there is still a tendency to very much focus on the disease and the losses individuals experience rather than seeing the person's individual interests and the assets and strengths that they have developed over a lifetime. The impact of dementia on the person is not only a consequence of the physical condition but individuals are equally disabled by the prevalent preconceptions, lack of understanding and assumptions that are made in respect of the condition. In the words of one person with dementia:

"People get to hear the word dementia and it's all lumped together and they think you are finished. You are not finished at all." (quote from participant living with dementia).

Medical model neglecting everyday life experience: Part of the challenge is that dementia is commonly described within the context of the medical model and of the changes that occur in the brain tissue rather than seeking to understand the impact of dementia on the person on a day to day basis and on activities of every-day living. As dementia is conceptualised under this disease model which places emphasis on decline, the challenge is how to identify, engage with and meet individuals living with the condition. Medics are gatekeepers. Broader health and social care providers act as filters granting or denying access to individuals. Consequently, it can be difficult at times to hear the voice of people with dementia. This is compounded by the stringent ethical frameworks that deem people with dementia as either with or without capacity and the complexities then of involving individuals in research and of building understanding of

the world from their perspective and of the opportunities and of the challenges that dementia can present.

People living with dementia not given a voice: This narrow view does not only manifest itself in the research arena but in every element of the dementia care pathway from how individuals are addressed, the way information and to whom information is provided and the way products and services are designed. People living with dementia are hardly addressed and equipped with the skills to manage everyday life, leading to both visibility and invisibility, and a self-fulfilling prophecy. If individuals are not consulted and provided with the tools to be able to undertake everyday meaningful activities, they lose the skills to be able to continue to engage. The little spoken about psychological consequences of living with dementia and its impact on mood, and the increasing social isolation that individuals can experience, means that the symptoms of dementia are compounded.

Yet people with dementia, and research about them, tells us that when people are supported to build community connectivity, individuals can maintain valued life roles and experience wellbeing.

Design in this context has a key role to play in enabling individuals to access and engage in meaningful activities such as the CIRCLES project to include people living with dementia (NDTI, 2014), music based activities such as touchscreen ensemble music (Favilla & Pedell, 2014) and music therapy (Ingram, 2012).

However what we see commonly is an over emphasis on tracking, monitoring and brain training. On products that rather than de-stigmatizing dementia serve to reinforce some of the stereotypes that exist and that over-emphasise/ risk and risk culture.

In order for design to realise its potential in this area need a power shift. Historically much focuses on later stages of dementia rather than seeking to empower and support people in the early stage of the condition or people experiencing mild cognitive impairment. The key here is to find ways of listening to people and to creating products and interventions that help them to maintain their part take in social activities.

Concluding recommendations to designers

Adopt a reflexive approach: Recognise own motivations and the assumptions that most designs for people with dementia are driven by.

Co-design with people living with dementia: be prepared to see individuals' creativity and resilience, have confidence in design and creative practice as methods and modes to engage and to offer individuals structures and vehicles through which to be heard.

Formulate evaluation criteria: Re-write with people how we should decide what success means and how we should evaluate this.

Focus on positives: Be prepared to let go fear and fearfulness and hear the positives instead. Understand what people have gained as well as lost and recognise that people are people and life has complexity – people are not just coping with dementia but are living a life. This includes humour.

Challenge ethical frameworks: when autonomy is denied, stigmatising language used and gaining feedback should take other ways. Seek to shape ethical processes around the person rather than expecting the person to fit into rigid ethical processes.

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