

# How do we create attractive personalised and customised care?

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This position paper contends that care can only be useful when it understands the personal context of care and can be shaped to accommodate individual needs. To design with care and to care through design we need to develop a designerly empathic attitude that listens to and 'feels with' others. This requires the designer to be observant, curious, non-judgmental and open to understand the perspectives and issues of others.

Compassion may provide a good way forward and is currently rising on the national agenda within the care sector<sup>36</sup> (NHS, 2014<sup>37</sup>; Cole-King and Gilbert 2011<sup>38</sup>). A compassionate approach is respectful, non-judgmental and open to hear the other voices. It tries to personalise rather than generalize. It sees the intertwined complexities rather than the simple components – it is a rainbow of colours rather than black and white, four dimensional rather than three. Caring design evidences that it listens to others and works collaboratively to propose alternative perspectives that are bespoke, personalised rather than universal. Caring design approaches are democratic and empowering.

We live in a fast world, dominated by data, speed of communication, numbers, stats, quant. In the rush for big data the individual may be lost, the detail ignored, the context generalized.

Care is not quantitative; it is without clearly defined edges, it is difficult to measure – it is about values, personal experiences, attitudes, contextualization and strives to challenge unconscious bias. Care implies human values: it is physical, practical and involves sensory knowledge informed by lived experience;

36 <https://ageingissues.wordpress.com/2015/03/18/on-compassionate-care/>

37 NHS England (2014) Safe, compassionate care for frail older people using an integrated care pathway

38 Cole-King, A. & Gilbert, P. (2011) Compassionate Care: the theory and the reality

it is a continuum of iterative and reflective change. We care from our own perspective. If we want to customize care we may need to open up to new experiences and listen to and feel the pain and joy of others.

Compassionate Design is an approach that has evolved from design research with people with advanced dementia<sup>39</sup>. These are often some of the most marginalized and vulnerable people in society. Their care requires personalized approaches that affirm their sense of identity, even when they themselves can no longer remember who they are. Compassionate Design can help people living with dementia to retain their dignity as a valued member of society<sup>40</sup> (Hughes 2014). Universal designs are often not 'universal' for people living with advanced dementia – colours, shapes tonal relationships are perceived differently. Lines, shape and colours misbehave by normal design rules. For individuals living with dementia, design can be over-stimulating or under-stimulating and perception can change as the disease progresses. There are no fixed points; it is a spectrum of constant variation from hour to hour. Compassionate Design has evolved and been tested through design practice and research<sup>41</sup>. It proposes three key components to be considered and prioritised when addressing needs of those in the advanced stages of dementia: designs should be personalized, be stimulating to the senses and help the person living with dementia to connect with others. By taking this approach it is possible to create appropriate personalised and customised designs that help craft a more caring world.

Using Compassionate Design to underpin the design problem requires researchers to explore the foundational constituents essential for all human beings to thrive. These 'core needs' shape our ability to flourish and live well; they are universal and include connection with others, the desire to nurture and be nurtured and the deep emotional responses that arise (often beyond conscious thought) as a result of sensory stimulation. Lived experience shapes our sense of self, builds personhood; it is sedimented through memory, both explicit (cognitive) and procedural (tacitly through bodily knowledge or muscle

39 [www.compassionatedesign.org](http://www.compassionatedesign.org)

40 Hughes, Julian C. (2014). *How we think about dementia: personhood, rights, ethics, the arts and what they mean for care*. London: Jessica Kingsley Publishers

41 [www.LAUGHproject.info](http://www.LAUGHproject.info)

memory) to build a person's identity<sup>42</sup>. To develop appropriate designs for those who are cognitively impaired, or no longer know who they are, requires the researcher to find ways to reveal and connect with these much deeper aspects of an individual's humanity.

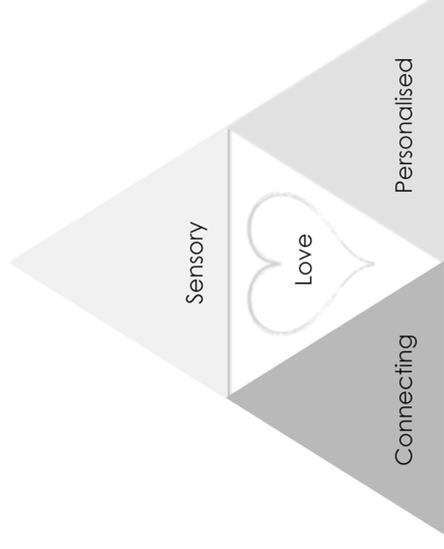


Fig 1. Compassionate Design

### Research Methods

The help of care experts is essential when dealing with complex problems such as dementia. The 'expert' in this situation will include the end user as well as those that know them well, such as family and professional carers. Bottom-up approaches, which listen to the voices of others, democratize the design process and empower those who have deep understanding of what is needed, to have a voice<sup>43</sup>. Participatory design, expert group panels and focus groups provide opportunities for knowledge to be shared. By bringing together interdisciplinary groups that represent a variety of viewpoints along with professional expertise

42 Hughes, Julian C. (2014). *How we think about dementia: personhood, rights, ethics, the arts and what they mean for care*. London: Jessica Kingsley Publishers

43 'Design for Dementia Care: making a difference' Jakob, A., Manchester H., and Treadaway, C., (2017); Nordes 2017: DESIGN+POWER, 7th Nordic Design Research Conference 15 - 17 June 2017 AHO · Oslo, Norway ISSN 1604-9705. Oslo, <http://www.nordes.org/nordes2017>

it is possible to gain insights into the design problem that can be discovered no other way<sup>44</sup>. Family members may have their own particular bias and opinion about what their relative requires, based on their own preferences and life history, or relationship with the person being designed for. By including the user in the design process, the assumptions of family and friends can be validated or challenged through their observable responses to evolving design concepts, even when verbal communication is difficult. Professional carers often do not have the detailed personal history (known only to family members) that can inform design in order to rekindle past memories and provoke conversation, but they may understand the 'in the moment' pleasures and preferences of someone living with the disease, for whom they care for daily. Medical and healthcare experts can identify problems with design in terms of infection control, physical limitations or integration into care practice. By bringing teams together with a wide range of experience and expertise, new avenues for design potential can be explored and greater understanding generated for all involved. In order to reveal and capture these insights, participants need to feel valued, relaxed and safe. Playful and creative hands-on activities can facilitate this and contribute to the design process in a practical way, through paper prototyping, sketching, storyboarding etc<sup>45</sup>.

Live Labs have been shown to be useful ways of evaluating developing design concepts and providing useful feedback loops that enable designers to iteratively hone and refine ideas and prototype designs<sup>46</sup>. By capturing and analyzing the ways designs are experienced in every day care environments it is possible to ensure that practical needs are met and designs are appropriate, not only for the user but also within the context of everyday care and with those who provide it. Video is a useful way to help understand the context and evaluation frameworks can focus researchers' observations on key design aspects needing to be developed (such as ease of use or stimulation of positive emotions).

44 Krippendorff, K. (2006). *The semantic turn: a new foundation for design*. Boca Raton, CRC/Taylor & Francis.

45 'In the Moment: designing for late stage dementia.' Treadaway, C., Prytherch, D., Kenning, G. and Fennell, J. in: P. Lloyd & E. Bohemia, eds. *Proceedings of DRS2016: Design + Research + Society - Future-Focused Thinking*, Volume 4, pp 1442-1457. DOI: 10.21606/drs.2016.107 ISSN 2398-3132 Design Research Society Conference 2016, Brighton, June 27-30

46 Brankaert, R., den Ouden, E. & Brombacher, A. (2015), "Innovate dementia: the development of a living lab protocol to evaluate interventions in context", info, Vol. 17 Iss 4 pp. 40 - 52

Finding ways to inform design through incorporating the voices of expert carers and users as participants in the design process requires time to build trusting relationships and a common shared language with all involved. Helping people to open up and distribute their knowledge requires creative approaches that can break down communication and psychological barriers. It also requires empathic researchers who can foster a safe space with clear goals and adherence to ethical guidelines. A number of recent CARIAD design research projects have been incorporating expert groups comprising care and health professionals as well as end users with severe cognitive and communication difficulties, in order to develop designs for people living with advanced dementia. Guided by the Compassionate Design approach, the design solutions have placed the needs of the individual at the heart of the process and specifically looked for ways to personalise designs, stimulate the senses and encourage connections between the person living with dementia and their carers and loved ones. By using embedded technology it has been possible to create design solutions that can be highly personal but easily transferrable. An example of this is the use of favourite music accessed from embedded sound files, evocative smells or tactile feedback.

### Design Examples

The CARIAD Sensor e-Textile project used participatory design research with care experts and health professionals to develop textiles with embedded electronics to support the wellbeing of people living with advanced dementia. One of the artefacts developed was a textile dog made as part of a 'dementia apron' garment. The dog was no ordinary soft toy but an object that was designed to tap into the emotional memories of a particular lady's favorite pet – a white West Highland terrier called Kim. The dog contained simple touch sensors and embedded microcontroller with a number of West Highland terrier sound files, including barking, growling and scurrying around noises. Although the lady no longer remembered the pet, nor recognised the members of her family, she was able to respond positively by touching the dog, expressing pleasure and sharing her joy with members of her family that came to visit. Although her normal attention span was about 5 minutes, researchers observed her communicate, laugh and play with several members of her family for over half an hour using the dog to broker conversation and connections.



Fig 2. *Sensor e-Textile project: Dog connecting the family*

CARIAD researchers have developed a design for a steering wheel activity as part of the LAUGH project. This highly personalised object has been developed for a man who had worked as a car mechanic and loved driving throughout his active life. LAUGH research with expert groups has found that loss of the ability to drive is particularly distressing for men living with dementia and that an object to replicate the sensory activity of driving would be being something that many people would enjoy. The object, although potentially a generic activity for those who have enjoyed driving, was developed into a highly personalised object through the inclusion of the end user's favorite music - activated by tuning the radio on the dashboard. He was delighted with the steering wheel and could 'drive' his wheelchair into the lounge and then 'take a road trip to the seaside'. His carers imaginatively encouraged the sensation of going around bends and parking the car. The steering wheel has embedded electronics that provide vibration to evoke the running engine, flashing indicators and a dashboard with speedometer, fuel gauge etc. The steering wheel provides sensory stimulation, is highly personalized, provides opportunities to connect with carers and family through playful imaginative activity and stimulates conversation through reminiscence.

## Discussion

Both *person centered*<sup>47</sup> and *relational*<sup>48</sup> approaches to care demand a greater understanding of the needs and lived experiences of the end user. Where severe cognitive, perceptual and communications difficulties are involved, designing appropriate and attractive designs is complicated. There is often no 'one size fits all' solution; however, technology can provide useful methods for extending functionality and ensuring that it is personalised and appropriate. By ensuring that the person is kept at the heart of the design process it is possible to design with compassion, consider individual needs and help them to continue to live with dignity and pleasure. The more complex the care needs the more likely a person will become withdrawn from those around them. Specifically looking for ways to develop designs that can be used to reconnect people in care relationships not only supports the wellbeing of those being cared for but also enhances compassionate relationships in the care environment. Compassionate Design approaches encourage designers to ensure that all people are valued in society and that love remains at the heart of the design process.

47 Kitwood, T. M. (1997). 'Dementia reconsidered: The person comes first'. Buckingham, Open University Press.

48 Morhardt, D and Spira, M (2013) 'From Person-Centered Care to Relational-Centered Care' Generations, Fall 2013