DESIGNING FOR DEMENTIA

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1. INTRODUCTION
Dementia is an increasing problem worldwide because of an ageing population. The costs of dementia are staggering. In 2018, they were estimated at $1 trillion worldwide, which is more than the costs of cancer and heart disease combined. Most of the costs are for informal care, to be carried by people with dementia and their family, who take care of them and have to reduce their own productivity as a result¹. High costs are also encountered when carers have burn-out and/or are no longer able to take care of the person with dementia, resulting in institutionalisation.

Understandably, older people prefer to stay at home. Research from Maastricht University ii has shown that older people with dementia and their carers also spend most of their time at home. Home needs to be a safe space, to optimise independent living, keep active and engaged, experience well-being and prevent falls. The risk for falls is doubled with dementia, because of changes in gait and contrast perception iii. Once older people have falls resulting in fractures, their risk for reduced mobility, prolonged hospitalisation, institutionalisation and mortality increases significantly. Preventing falls in older people, particularly in those with dementia, is thus of the essence.

2. DESIGNING FOR DEMENTIA

2.1. Professional partners involved
Many guidelines exist for designing for dementia, but these are often not rooted in evidence-based findings. In this paper we describe the development of the Chris and Sally house in Watford iv, London, in collaboration with Halsall Lloyd Partnership (HLP), architects who specialise in dementia design and the Building Research Establishment (BRE) v. The BRE showcases novel building materials and design ideas using sustainable and innovative ways to develop buildings, e.g. for disaster areas (e.g. quick to build, flooding, etc), zero energy bills, or other calls, and this included a house designed for dementia friendly living. The BRE often produces building guidelines and has around 25000 visitors a year. From Loughborough University, who were a major funder of the project, included were specialists in Civil and Building Engineering (thermoregulation), Healthcare Design and Ergonomics, and Mental Health Sciences, with a focus on dementia, and collaborative input from Mechanical and Electrical Engineering (robotics). The Technical University Delft (Prof Tischa vd Cammen/Gubing Wang) and Liverpool John Mores (Robert MacDonald) also gave input to the design vii.
2.2. Patent and public involvement

Patient and Public Involvement (PPI) was had at all stages of the design of the house. HLP had previous experience co-designing with Silver Surfers, which was combined with that of Derby U3A, the Loughborough dementia patient cohort, contacts with charities and other PPI (e.g. various service providers) to allow considerable input in the initial development, but also to incorporate their feed-back on the final design. Different methods were used to gain PPI input including focus groups, sand play, drawing, photo-cue cards, oral feed-back on 2 and 3D models, interviews etc.

While PPI is very useful, to account for change both within and between individuals with dementia, we developed 5 persona to help guide the design. These persona were characterised by dementia symptoms appropriate to a particular stage of progression seen and with variation in these symptoms over good, average and bad days.

The persona also included needs related to the dementia symptoms and design solutions related to the symptoms and needs to help guide architects and designers. The persona were derived through extensive work with service providers and experts. The persona were then used to help architects and builders design different areas of the house to be dementia friendly for different dementia stages.

Fig 1. Example of developed persona

2.1. The setting

The house that was to be renovated represented a typical English terraced house, many of which were built during the Victorian era. The original house, typical of its kind, would have had several issues. Firstly, the house would be quite dark, often with mould on the walls, due to inadequate ventilation, without wall cavities and 9 inch solid brickwork. It would be cold in the Winter and hot in the Summer. The light would be poor in the North facing rooms and access throughout the house would be difficult with thresholds, loose rugs and thick carpets and many doors not suitable for wheelchair access. There would be slippery, shiny floors in the kitchen and upstairs bathroom, which would be difficult to reach via ill-lit patterned steep and uneven stairs, leading to increased risk of falls.
Fig 2. The Chris and Sally house (last unit on the right-hand side of the block)

The kitchen may have had old appliances with increased fire risk and risk for injury due to sharp corners on appliances and surfaces, scalding hot water and hot hobs, which might be forgotten to be turned off after use. The washing machine would be in the kitchen and the white goods including a small fridge in the kitchen and an old boiler upstairs would be noisy and inefficient energy-wise. Throughout the house, there could be many patterns on the loose rugs, carpets, walls and curtains and much clutter on all surfaces, further contributing to confusion, possible hallucinations, delusions, restlessness and other behavioural issues. Often things would be lost (e.g. keys) and appointments would be missed due to the clutter and no time to deal with mail and organise this. The bedrooms and hallway upstairs could be difficult to navigate with thick patterned carpet, which would also be an issue if incontinence accidents occurred.

Fig 3. Existing downstairs ground plan of the house on the BRE Watford site

2.2. Existing regulations

Part M of building regulations was introduced to ensure that houses build thereafter would not have had many of these features mentioned and would instead have inclusive design. Wheelchair access, slip resistant floors in the bathrooms with no patterns, and sockets at wheelchair height, for instance, are included in part M4.3 aspects as per building regulations.
Hence, many of the previous issues in the house mentioned above would be solved by adhering to part M for renovation. The house was designed firstly by implementing these aspects, including rewiring, moving sockets, putting in slip resistant flooring without patterns, including railings where needed (bathrooms, stairs, beds etc), improving the stairs (light, height), removal of thresholds, walls and doors or widening these, to allow improved access by creating an open plan living/dining/kitchen space.

Secondly, the suggestions of PPI were implemented and combined with an evidence-based literature review on design features that were shown to work to improve the life of people with dementia and their partners or carers. The improvements (also see table of key objectives) are discussed per symptom encountered in dementia and in each part of the house. In each part of the house, persona were used to illustrate how design could address different needs per stage of dementia. This paper addresses how design could improve independent (instrumental) activities of daily life (IADL) by addressing the various needs of people with dementia.

3. Innovative design solutions based on symptoms and need

3.1. Memory, orientation, language and planning: cognitive changes in dementia

3.1.1. Symptoms and needs related to cognitive issues in dementia

Loss of memory is a hallmark in dementia and both subjective as well as objective loss of memory can be an early marker, particularly in Alzheimer’s disease, the most common type of dementia. These memory issues can start from forgetting shopping lists and appointments, to not being able to remember one’s child or partner. Linked to this is lack of orientation in time, place and person. Language issues can present with word finding problems but also in the inability to produce understandable language or to understand written/spoken language, making communication and understanding instructions difficult.

Planning disturbances are initially more common in people with vascular dementia, but as dementia progresses, usually become an issue for all dementia types and can result in problems cooking, dressing, banking, planning and executing trips and other instrumental activities of daily life. Loss of weight is often seen very early in dementia and can lead to dangerous loss of muscle mass, leading to falls and immobility. It is probably related to forgetting to eat, cook and/or shop.

3.1.2. Design solutions for cognitive change affecting (I)ADL

Cooking requires all cognitive functions and is a complex activity of daily living. To aid with memory loss, the kitchen could have glass fronted cabinets, to allow easy identification of material needed. The fridge is upgraded, is more energy efficient and has a self-closing door. This fridge door could also have a sensor, and if it had not been opened for 24 hours, a voice-over could ask if the occupier was peckish and wanted to eat. There could also be a computer tablet on the wall, which could be activated at mealtimes, with pictures of personalised meal choices shown, which -when touched- could be connected to producing online shopping lists for ingredients and a plan shown in pictures how to prepare and cook the food once it had arrived. The hobs and kettle could turn themselves off when not occupied or used and taps are programmed to not scald the skin (part M).
If water taps had not been not used for 4 hours, sensors could activate a voice-overs to suggest having a drink, as dehydration is an important factor in memory loss. As a sense of thirst is often lost with age, it is important to remind people to take in sufficient fluids, especially in hot weather. Taps are colour coded (red and blue) to help identify hot and cold taps easier. All boxes and tins contain picture labels for easy detection of ingredients (bread, coffee, tea, etc). The kitchen wall, where a small round dinner table for two sits, could also contain a tablet, with reminders for appointments, dates, time etc for orientation in time and planning activities.

Medicine cabinets in the bathroom could be fitted with sensors supplied by Bendigo or other similar providers to remind people to take their medicine, if the cabinet doors had not been used at the expected time and also to brush their teeth. A loss of teeth doubles the risk for dementia and may be linked to loss of weight and not eating. Clothes wardrobes in the bedrooms could also have sensors in the doors supplied by Bendigo to remind people to get dressed and washed in the morning, once the bed sensors would be activated.

One of the most important and best evaluated elements, suggested by US-based research and PPI, is a downstairs loo, where bits of the porcelain are visible from all angles downstairs. This wet room is installed in the middle of the downstairs area, with glimpses of the loo acting as reminders of where to find to loo which helps reduce anxiety and agitation. Incontinence is a problem in the later stages of dementia and this central wet room feature helps maintain independence in toileting, also in the later stages of dementia.
3.2. Vision, gait and other psychomotor changes

3.2.1. Symptoms and needs related to sensorimotor changes

There are several sensorimotor changes in dementia and these can present early in the disease. Firstly, best known are changes in contrast sensitivity, which make navigation and getting around more difficult. Especially in conditions of poor light (stairs, dusk), this can lead to falls. Second, there is the known loss of blue/green colour perception, rendering the much debated red toilet seats design, which may not be needed, provided there is sufficient contrast. To help with these two issues, a 30% light reflectance value (LRV) between floors, skirting boards, walls and furniture was suggested to be optimal for navigation in space.

The risk for falls is compounded by changes in gait. Toes tend to touch the surface before the heel in dementia, which can lead to trips and falls. Loss of balance can also be seen to occur in dementia (due to orthostatic hypotension), leading to falls. Grip strength reduces with age and can predict dementia onset and can affect activities of daily living (opening cans, doors etc). Lastly, there are issues in purposeful direction of gaze, which can lead to problems recognising faces and features which explain some of the memory issues. Work is ongoing for this as an early feature in dementia diagnostics. This will affect how people engage with the computer tablets and visitors.
3.2.2. **Design solutions for sensorimotor changes**

For grip strength issues, taps and locks (using fingerprint ID) are replaced to be easier to use. Aids to open cans can be bought online in specialist stores. All surfaces, cupboards and tables are rounded off to remove risk of injury in case of loss of balance. Stairs and bathrooms have grab railings to help people get around independently and reduce falls. All floors have underfloor heating with slip resistant, neutral coloured fabrics, which are easy to clean, but look and feel like carpet, with adequate contrast between skirting boards, walls and floor (30% difference in LRV). Light bulbs are installed with double the strength throughout the house.

To further allow easy access and reduce injury, the path was cleared, thresholds and walls were removed to render an open plan kitchen/lounge. Lose rugs and mats were removed. To reduce noise disturbance, the washing machine is situated in a separate utility store insulated by rockwool to be sound poor. This store is adjacent to the ground floor bathrooms. A lift could be installed to allow easy access to the upstairs areas in the later stages of dementia. Stairlifts in frailty are often not practical and hard to navigate in limited space. In hospital settings most falls occur around the bed (due to bad use of bedrails) and in the bathroom. Sensors could be placed in the bathroom to alert third parties if someone spent longer than 30 min there, indicating a possible fall. An activated voice over could ask people if they were ok and contact emergency services. The visible wet room is also downstairs, to be reached more easily.
3.3. Behavioural and Psychiatric Symptoms associated with Dementia (BPSD)

3.3.1. Symptoms and needs associated with BPSD

BPSD including aggression, depression, apathy, agitation, drowsiness, sundowning, nightwandering, hallucinations and delusions are difficult to deal with in dementia and are the most likely reasons for carers to reach burn-out and for patients to require institutionalisation. Many BPSD are probably related to anxiety and disorientation and/or frustration in the inability to communicate, plan or remember effectively. Issues with auditory and visual perception and a lack of reality testing can lead to hallucinations, agitation and delusions, but can be reduced through design features. Especially in Lewy Body dementia, the following perceptual issues can be
prominent: Patterns in curtains and on floors can be perceived as moving (‘snakes’) and create anxiety; People do not recognise themselves in the mirror (should thus be removed), leading to anxiety; Shiny floors can be perceived as ‘wet’ (and therefore not crossed) and should be mat and non-slip; Dark rugs and mats can be perceived as holes in the floor (and therefore not crossed); Extreme contrast in flooring materials can be perceived as having different heights and lead to trips; Noise of the washing machine can be misinterpreted, and also lead to agitation and restlessness; Many older people’s homes are stuffy, badly ventilated and overheated. This can affect alertness and induce drowsiness. In addition, poor ventilation can increase eye discomfort and dryness, further reducing vision and wellbeing.

3.3.2. Design solutions to reduce BPSD

Sensors in the floors, bed and on doors linked to timers could identify night wandering and sundowning. If people get up and try to leave the house at night, a gentle voice would remind them of the time and ask them to get back to bed. Calming colours developed via Dulux mood boards include greens (lounge, kitchen), purples (bedroom) and blues (dayroom), while the kitchen wall has an uplifting colour, yellow. Large windows were installed for optimal natural light to aid circadian rhythm. These windows also provided ‘views to greens’, which have been found to uplift mood and reduce stress, as does easy access to safe gardens outside (but beware of slippery garden paths or ponds). Alternatively, raised beds in limited outside space or plant boxes inside or outside on balconies could be installed for people to garden and tend to vegetables and flowers for sensory stimulation and possibly reminiscence.

Exposure to daylight with regular walks outside is important for circadian rhythm maintenance, and well-being. Phone or other GPS based locators, such as My-SOS tracker can allow carers to locate people with dementia without hindering them in their freedom. Some bus and train companies recognise bracelets with programmed chips to help bring people to their destination. Shopping trips to the local market and trips to activity centres with dementia groups can also be highly beneficial. However, as said, research has shown that older people spend most of their time at home, being sedentary. For this purpose, we developed the Actichair together with people with dementia. The Actichair has resistance bands with electronic feedback to allow people to do resistance band exercises safely at home. These exercises were shown to improve memory in middle-aged and older people with and without dementia. The exercises can also improve leg strength which helps reduce falls and increases mobility. People did not like feedback on their performance via Avatars on TV, but did welcome the possibility to use the TV screen to communicate with friends and family using adapted Skype and Facetime. Feedback on the correct use of the resistance bands (speed, orientation, strength) was given through colour changing of the handlebars of the bands instead.

Insulation and underfloor heating were installed with sun-energy panels on the roof for efficient heating and provision of energy. In addition, an automated ventilation system was installed with sensors to allow circulation of air through automatically opening and closing windows (using buoyancy driven natural ventilation). To reduce overheating in the Summer, solar analysis was conducted using computer modelling and used to design external solar shading to protect the rooms inside from direct sunshine.
3.4. The later stages of dementia and feed-back by PPI

As dementia progresses, basic activities of life cannot be carried out independently any longer and people need constant care. A dayroom was installed downstairs for people to take a nap. The glass wall to the lounge still allowed visual contact with carers. However, this feature was not considered desirable by several of our PPI Day-time naps can affect night-time sleep and should perhaps thus be avoided. The lift, which was considered to be highly desirable, also allowed easy access to the upstairs. Cheaper versions should be explored as this desirable feature is very expensive to install (£25,000+).

However, the kitchenette upstairs was considered superfluous, with a sense to keep the house as ‘normal’ as possible. The lift allowed easy transfer of meals, so this rendered the kitchenette upstairs somewhat obsolete. In the later stages of dementia, most people will be bedridden and no longer mobile. Separate rooms for carer and patient were considered desirable for better sleep. A hoist to allow access to the wet room upstairs was also considered to be a good, but expensive feature to aid washing and toileting by a non-trained carer.

4. CONCLUSIONS

The objectives, steps and costs needed are outlined in the tables below. This multidisciplinary project was developed with PPI and their feed-back showed that some features were considered more desirable than others. As said, the lift, the hoist and the visible central downstairs wet room/loo were considered excellent features by visitors with and without dementia. However, as these require substantial structural work and costs, these should be implemented as early as possible to avoid the least disruption. Ideally, part M would allow inclusion of these potential features in the planning the location of structural weight bearing walls, stairs, plumbing, wiring etc.

Also, the Acti-Chair was considered an excellent feature and this should be introduced sooner rather than later, to develop experience using the sensoried resistance bands with feed-back and doing the exercises as part of a routine, as an overlearned skill, which could then be maintained as dementia progresses. The chair could be used alongside watching a favourite TV programme, for instance.

People should also be encouraged to use the stairs as long as possible for leg and arm strength (using the grab rails) exercises. Good lightning, non-patterned, slip resistance steps and borders on the steps are thus crucial. Our talking cushion to encourage people to get up and get a drink to reduce sedentary time and dehydration risk was voted down, however; people found this creepy.

Additional features, such as a dayroom and kitchenette upstairs, were considered less important by some visitors, possibly to reduce a sense of institutionalisation. These areas could be converted, e.g. the downstairs dayroom into a study/dining and the upstairs kitchenette as an additional storage space, small bedroom or study. The ability to personalise and adapt the living scheme suggested is crucial and building regulations and guidelines developed from this project should reflect this.

The colour scheme requires more research. While overall perceived as calming, the 30% LRV difference between coloured surfaces and soft furnishings was not always met. However, additional testing will indicate whether this 30% LRV difference is needed and/or whether the red/orange/yellow spectrum is favoured for better navigation, over the more calming greens, tans, purples and blues used in the house. Most people really liked the colour scheme, which had been
developed by Dulux. Most people with dementia visiting the house also seemed to easily navigate the colour scheme and all visitors enjoyed the light and access of the open plan living space.

Good responses have been had with regards to features not yet installed, which could be further tested in the house, such as sensor activated voice-overs, including those used by Bendigo and other companies, such as Alcuris. The Bendigo system reported that use of their system reduced progression to institutionalisation by between 6 months to 2 years and could thus lead to substantial cost-savings, with average nursing and institutionalisation care costs at an average £3000/monthxv.

Most importantly, people want to stay in their own homes and be independent as long as possible. The Government can aid by giving subsidies for inclusive and independent living and by providing building regulations and guidelines. These would bring down the costs of hospitalisation due to falls and not having care provisions for the later stages of dementia. This policy would also encourage older people to move from larger unsuitable homes to newly developed adapted smaller housing and flats, to allow influx of a younger generation currently unable to get on the property ladder.

5. ACKNOWLEDGMENT
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xv http://bendigosystems.co.uk/
A summary of key design objectives

- Bedrom for carer
- Interior finishes appropriate for dementia
- Open plan kitchen / dining / living area with easy access to the garden
- Easy access between garden and wc
- Energy efficient low carbon design and specification - cheap to run
- SMART technology (see research objectives)
- Level access throughout including thresholds
- Spaces large enough to provide good ease of movement (walkability as well as wheelchair routes and turning circles)
- Natural ventilation
- Clearly visible front entrance
- Easy natural ‘flow’ between rooms
- Higher level of artificial light (twice normal)
- Task focused lighting
- Reduce the number of doors (or removable doors)
- Good views from seated position to front and rear
- Views to ‘green’ and communal activity
- Tonal contrast between floors, walls and doors (also furniture, fixtures and fittings)
- For the carer - balance privacy and access
- Views of approach to the front entrance
- ‘Wearable’ kitchen / bedroom / bathroom
- Storage - easy to find things
- Walkability as well as wheelchair accessibility
- Low noise levels from both internal and external sources

THE DEMONSTRATION PROJECT

KEY DESIGN OBJECTIVES OF THE DEMONSTRATION PROJECT
- Satisfy a range of standards including Lifetime Homes, Secured by Design and Part M4 of the Building Regulations
- Simple layout, easily navigable
- Visual cues to assist orientation
- Visual connection and easy access between living room, bedroom and wcs
- Sight lines to the wcs
- Low level window cills - view out from a low position
- Hoist route from bedroom to bathroom
- Option between shower or bath (decision to opt for a shower solution)
- Separate utility area/washing machine
- Natural light into the middle of the plan
- Car port with direct access to the home (subject to limitations of the site)
- Garden with patio area and raised planting beds for easy gardening (on an adjacent site due to the location of the stable block)
### The Requirements of the Research Platform

<table>
<thead>
<tr>
<th>Level</th>
<th>Room</th>
<th>Proposed Change / Solution</th>
<th>Space</th>
<th>What</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ground Floor</td>
<td>Kitchen</td>
<td>Reality orientation</td>
<td>Empty wall</td>
<td>Board/electric agenda (wiring)</td>
<td>£10 - £50</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Recipes and cooking actions on a tablet</td>
<td>Kitchen counter</td>
<td>Tablet (wiring, sockets and wifi)</td>
<td>£100</td>
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<td></td>
<td></td>
<td>Healthy diet (reminding to eat and drink)</td>
<td>Kitchen counter wall</td>
<td>Tablet (wiring, sockets and wifi)</td>
<td>£100</td>
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<tr>
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<td></td>
<td>Interface for cognitive and physical activity</td>
<td>Interactive table</td>
<td></td>
<td>TBC</td>
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<tr>
<td></td>
<td>Dining / Living</td>
<td>Interface for cognitive and physical activity - Avatar</td>
<td>Empty wall</td>
<td>1 TV screen/projector (wiring, sockets and wifi)</td>
<td>£200 - £500</td>
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<td></td>
<td>Physical activity (elastic band training)</td>
<td>Free space</td>
<td>2 arm chairs/elastic band</td>
<td>Already</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stepping / dance activity</td>
<td>Free space</td>
<td>Mat/rails (2 x 2 meters) (wiring, sockets and wifi)</td>
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<tr>
<td></td>
<td>Dayroom</td>
<td>Reminiscence activity</td>
<td>Empty wall</td>
<td>Board / tablet (wiring, sockets and wifi)</td>
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<td></td>
<td></td>
<td>Light and music therapy</td>
<td>Room corners</td>
<td>Light (lamp or bubble tube) and speakers (wiring)</td>
<td>£500 / £200</td>
</tr>
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<td></td>
<td>Bathroom</td>
<td>IADL activity sequence</td>
<td>Empty wall</td>
<td>Board / tablet (wiring, sockets and wifi)</td>
<td>£30 - £100</td>
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<td>Stairs</td>
<td>Environmental stimulation / tactile stimulation</td>
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<td>Cognitive / physical activity</td>
<td>Empty wall</td>
<td>Interactive wall (wiring)</td>
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<td></td>
<td></td>
<td>Light and music therapy</td>
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<td>Kitchen counter wall</td>
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<td></td>
<td>Bathroom</td>
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<td>General Needs</td>
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<td>General Comment on Technology</td>
<td>Activity of daily living</td>
<td>Throughout the house</td>
<td>Bendigo Assistive Technology; schedule monitoring, voice prompts, TV programs, musicPlayback, indoor</td>
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<td>Happy or not feedback system: one tablet (with multiple choice questions)</td>
<td>Throughout the house</td>
<td>One tablet for each room (Table x 10 and wiring)</td>
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<td></td>
<td>Info about dementia and changes in daily activity and adaptations</td>
<td>Throughout the house</td>
<td>Panels with storyboards and info.</td>
</tr>
</tbody>
</table>

A summary of proposed changes in the house and estimated costs.
### DESIGNING FOR DEMENTIA

A summary table of complaints, symptoms, risks, needs and design solutions with costs, which could be used as an app to help guide PPI to choose the most suitable design options (Copyright Eef Hogervorst)