Defining the desirable characteristics of physical environments for the delivery of support and care to people in the late stage of dementia

Dementia Collaborative Research Centre
Assessment and Better Care

January 2014
Investigators:

Professor Richard Fleming, School of Nursing and Midwifery, University of Wollongong
Dr. Fiona Kelly, School of Applied Social Science, University of Stirling, Scotland
Dr. Gillian Stillfried, School of Nursing and Midwifery, University of Wollongong

Acknowledgements: This project has been funded by the Dementia Collaborative Research Centre – Assessment and Better Care, University of New South Wales as part of an Australian Government Initiative.

Thank you to everyone who helped organise the focus groups and made us welcome, particularly the members of the Alzheimer’s Australia Consumer Dementia Research Network and the practitioners who give their time to talk to us about their practice experience and thank you to people with dementia and family carers for sharing their experiences and hopes for the future. Thank you to the panel of experts whose input has contributed to the development of these design principles.

Disclaimer: The views expressed in this work are the views of its author/s and not necessarily those of the Australian Government.

Copyright: University of Wollongong, 2014
Defining the desirable characteristics of physical environments for the delivery of support and care to people in the late stage of dementia

Table of Contents
Background ........................................................................................................................................4
End of life care for people with dementia ...................................................................................5
Aims of the project .......................................................................................................................6
Methods .......................................................................................................................................6
Literature review ..........................................................................................................................7
Focus groups ...............................................................................................................................7
Survey .......................................................................................................................................8
Results .......................................................................................................................................8
Literature Review ......................................................................................................................8
Focus Groups ..........................................................................................................................10
Survey .....................................................................................................................................18
Discussion ................................................................................................................................19
Conclusions ...............................................................................................................................20
References .................................................................................................................................21
Appendix 1 Articles rated using NHMRC framework .................................................................24
Background

The importance of ensuring that the design of buildings meets the needs of people with dementia and makes sense to them has been championed by Marshall [1]. Marshall's [1] summary of the key principles of design and dementia from existing literature continues to be used as the quality standard of good design. She asserted that design should:

- Compensate for disability
- Maximise independence
- Enhance self-esteem and confidence
- Demonstrate care for staff
- Be orientating and understandable
- Reinforce personal identity
- Welcome relatives and the local community
- Allow for the control of stimuli

A review of the literature on the design of physical environments for people with dementia found substantial empirical support for these principles [2].

Fleming used a set of principles that informed Marshall's in his early work on the design of care settings for older people[3]; [4]. These were used as the basis for developing the Environmental Audit Tool [5]; [6]. These principles state that environments that are used to provide care 'aimed at maintaining the abilities of people with dementia should':

- Be safe and secure
- Be small
- Be simple and provide good ‘visual access’
- Reduce unwanted stimulation
- Highlight helpful stimuli
- Provide for planned wandering
- Be familiar
- Provide a variety of spaces with opportunities for both privacy and community
- Provide links to the community
- Be domestic and homelike

Fleming et al. [5] assert that working with such principles allows staff and management to gain an understanding of any problems that are caused by the environment in which people with dementia live, allowing for the implementation of short-term and long-term plans for improvement of their environment. Both Marshall’s and Fleming’s sets of principles describe the components of a ‘dementia friendly’ environment; described by Davis et al. (p.187)[7] as:

‘a cohesive system of support that recognises the experiences of the person with dementia and best provides assistance for the person to remain engaged in everyday life in a meaningful way’. However, any definition of a dementia friendly environment should consider both the importance for the person with dementia of his/her experiences within the environment and also the social, physical and organisational environments which impact on these experiences. Lyman (p.15)[8]
states that ‘care providers and care recipients inhabit the unique world of dementia care. If designers and programme planners can understand this world from the perspective of persons living with dementia, an “enabling” environment can minimise disability and provide opportunities to live a meaningful life, despite losses and challenges associated with dementing illnesses.’

This proposition highlights a shift in emphasis from care environments designed to keep people safe and meet their physical needs to care environments that are designed to maximise existing skills and retain independence. Chalfont and Rodiek [9] argue that we need to move away from designing for the purposes of control or surveillance or to diminish behavioural difficulties, to considering how environments can encourage curiosity and engagement in everyday activities. This is as important for the outside as inside environments [10].

It is clear, however, that the focus of dementia friendly environments is on maintaining independence and well-being and is therefore aimed at those who are relatively fit and mobile. With an increasing, and increasingly frail, population of people with dementia receiving care in formal care settings, these design principles might not accurately reflect their needs and wishes; this might particularly be the case for people with dementia approaching the end of their lives.

**End of life care for people with dementia**

There are growing calls for end of life care to be provided, not just to those with cancer [11], [12] but for people with coronary heart disease, older people [13] and indeed all people approaching the end of life regardless of age, diagnosis, gender, ethnicity, sexual orientation, religious belief, disability or socio-economic status [14]. In the UK, the Department of Health [14] also proposes that high quality care at end of life should be available wherever the person may be – at home, in a care home, a hospice, hospital or elsewhere.

The case for making palliative care available for people with dementia has been made on the grounds of equity, need and on the basis that adopting a palliative approach would improve the quality of care available to people with dementia; throughout their journey [15]. In the United Kingdom, the philosophy of palliative care emphasizes care and communication rather than intervention and treatment [16]; it attempts to redirect the emphasis on technology-driven medicine. In Australia, guidance on palliative and end of life care emphasizes a person-centered [17] approach which meets physical, psycho-social and spiritual needs and addresses aspects of the environment such as ensuring bedrooms are of sufficient size to accommodate visitors and equipment and that sensory support is offered [18].

The National End of Life Care Intelligence Network [19] report that the largest percentages of deaths of people with dementia occur in hospital (36%), followed by nursing homes (30%) and old people’s homes (26%). Relatively small percentages die in their own homes, in hospices, or elsewhere. In a study looking at place of death of people with dementia in five European countries (Belgium, the Netherlands, England, Wales and Scotland), Houttekier et al. [20] found a similar pattern, apart from the Netherlands where the majority (92.3%) of people with dementia die in nursing homes with 3.8% dying at home and 2.8% dying in hospital. The Netherlands has developed nursing home provision to include long-term end of life care, with 24 hour nursing care and staffed by specialist nursing home physicians. They are therefore well equipped to offer specialist care to people in nursing homes until they die.
Australian Institute of Health and Welfare (AIHW) [21] statistics demonstrate that in 2006-2007, 72.7% of people admitted to care homes were 80+ years of age, an increase from 64.1% in 1998-1999 [21]. The association between advanced age and dementia indicates a rapidly increasing prevalence of people with dementia resident in the care home sector. These statistics represent a worldwide phenomenon, with Prince et al. [22] estimating that four fifths of people in care homes have a dementia.

The increasing numbers of people entering care homes in a frailer state and policy drivers to provide high quality palliative and end of life care to people with dementia [14][23] prompt the following questions:

- What is the evidence base for designing for people with dementia who are nearing the end of their lives?
- What are the needs and wishes (in terms of the design of care settings) of people with dementia who are nearing the end of their lives?
- What are the needs and wishes (in terms of the design of care settings) of family members of people with dementia who are nearing the end of their lives?
- What are the needs and wishes (in terms of the design of care settings) of practitioners caring for people with dementia who are nearing the end of their lives?
- What (if anything) needs to be changed in existing design principles to meet all their needs?

**Aims of the project**

- To gain a better understanding of the needs of people with dementia in the final stages of their lives and the physical resources required by the staff caring for them.
- To identify a set of principles that will inform the design of physical environments that accommodate the needs of people with dementia in the final stages of their lives.

**Methods**

The study progressed through three stages. An initial review of relevant literature provided key themes. The key themes were used to guide focus groups in which the views of people with dementia, family carers and professional carers on the desirable characteristics of the environment were explored. This resulted in a provisional list of principles that was then reviewed, via an online survey, by a panel of experts to provide a final list of principles.

Ethical approval for the study was obtained from the University of Wollongong/South Eastern Sydney and Illawarra Area Health Service Human Research Ethics Committee (Australia) and the School of Applied Social Science Ethics Committee, University of Stirling (Scotland). Ethical processes to ensure informed consent, anonymity, confidentiality and prevention of harm were followed.
Literature review

Data bases searched for English language literature dating from 1980-2012 were CINHAI, Psychinfo, Health Source, Web of knowledge, Cochrane, Bandolier, CSA Illumina (including Medline, Sociological Abstracts and Social Services Abstracts). Google was also searched for grey or policy literature. The term ‘dementia or Alzheimer’s disease’ was accompanied in different combinations by ‘design’, ‘palliative care’, ‘spiritual’, ‘hospice’, ‘hospice care’, ‘end of life’, ‘physical environment’ and ‘nursing homes’ to identify literature that was relevant to the topic area: namely empirical literature on elements of design of a care setting appropriate to meeting the needs of people with dementia who are nearing the end of life or dying, and to facilitate good practice. A hand search of any literature derived from the searches or identified subsequent to searches was carried out.

In total, 164 articles were selected for review, of which 40 were not specifically design related but covered areas such as spirituality or practices at end of life that warranted further scrutiny. The abstracts of all articles were examined (FK) for their relevance to the topic and those without reference to design were discarded. 17 empirical articles or systematic reviews were identified as being potentially useful and these were independently evaluated by FK and RF using the Australian National Health and Medical Research Council [24] framework to grade the level of evidence of empirical studies (See Appendix 1).

Focus groups

Three focus groups (FG) were carried out by FK and RF in three cities along the East coast of Australia. Focus groups comprised recently bereaved family carers of people with dementia (FG1), people with dementia and family carers of people with dementia (FG2) and practitioners caring for people with dementia nearing or at the end of their lives (FG3).

Participants with dementia and family carers were recruited via Alzheimer's Australia Consumer Dementia Research Network. Members of the Dementia Research Network are people in the early stages of dementia who volunteer to provide comments on research applications and to offer suggestions for areas of research.

Practitioners were recruited by invitation via NSW/ACT Dementia Training Study Centre mailing list.

All focus groups started with the researchers serving tea and coffee and offering participants food such as fruit and cakes. In this way an informal atmosphere was created in which participants who knew each other could catch up and those who didn’t could be introduced to each other. Formal introductions were made, information sheets reviewed and consent forms signed. Topic guides developed using key themes arising from the literature review were used to structure the focus groups. The focus groups were lively, with participants expressing opinions and experiences quite freely and, particularly in focus group 2, listening respectfully to each person’s contributions. Each focus group lasted approximately one and a half hours and was audio-recorded with participants’ consent. Fieldnotes and notes of debriefing sessions following the focus groups were made to record developments in thinking and researchers’ impressions.

Analysis of the focus group data resulted in the identification of 11 desirable characteristics, as discussed below.
Survey

A total of 22 professionals in the areas of architecture and interior design for aged care and end-of-life and palliative care were invited to participate in the survey. Twenty consented and one who declined offered an alternate who accepted.

The list of desirable characteristics identified in the focus groups was developed into a series of questions, each asking the participant to rate their perception of the level of importance of that feature to people in the final stages of dementia on a 5-point Likert scale. The questionnaire then asked for examples of how this feature might be seen in practice and for any features that may be missing from the list presented. The questionnaire also asked a number of demographic questions and questions about level of experience and area of practice. The survey was administered using the online survey program, SurveyMonkey.

The survey ran for five and a half weeks and one personalised reminder was sent during the survey period.

Individual survey completions were not able to be determined as the survey was anonymous. At the closing date 20 participants had contributed to the survey and 18 had completed all questions.

The list of desirable environmental features was refined following analysis of responses to the first survey. The refined list was then circulated to all survey participants who were asked to consider if any of the features should not be included, to provide any comments if they wished and to provide any additional features if they felt any of high importance to people in the final stages of dementia were missing. Provision of comments was optional and participants were given 3 weeks to provide comment. A total of 11 participants contributed to the second round of the survey, nine participants completed all questions.

Results

Literature Review

With a focus on the first component of the NHMRC Evidence Statement Form, which examines the evidence base, in terms of the number of studies, levels of evidence and quality of studies (risk of bias), the consensus from FK and RF was that none of the literature met the highest grade (a systematic review of randomised controlled trials), 8 were not rateable as they were more descriptive or opinion pieces than empirical studies with the remaining 9 falling between III-2 (comparative studies) and IV (case or cohort studies). Although under the NHMRC framework, these offered the lowest level of evidence, methodological and ethical constraints (frail population, access, sensitivity of topic) necessitate that smaller, qualitative studies are best suited to addressing this topic. Therefore any key design-related themes or findings were identified from these papers and used to develop the topic guide for focus groups.

Key points arising from the 17 papers reviewed will be discussed under the following themes: environmental factors, practices at end of life and spiritual care. These reflect key areas addressed in the literature.
Environmental factors

Despite the relatively large body of work on identifying optimum design principles for people with dementia [25][2] with a focus on maintaining independence and balancing sensory stimulation according to needs, there is little literature and even less research into design that focuses on the needs of those with advanced dementia [26], or those with dementia who are nearing the end of life or dying. Martin et al. [26] advocate extending the definition of the physical environment beyond that of the immediate setting (furniture, windows etc) to thinking about the mood, atmosphere and feel of the setting for those who live there. Their concept of ‘milieu’ captures the therapeutic essence of a space, one that does not require cognition to influence well-being and ensure comfort.

In a rare example of studies aimed at eliciting the views of people with dementia Godwin and Water [27] interviewed 12 people with dementia on their wishes or discussion they had engaged in with others (family members or professionals) on end of life care. Their views on what constituted a helpful environment for them included maintaining contact with family, a quiet, tranquil space, privacy, access to the outdoors, comfort (soft toys, nice smells), minimal physical intervention and consideration of religious needs. This study illustrates the ability of people with advanced dementia to know and express their views on end of life care.

Practices at end of life

Despite policy goals to improve palliative and end of life care for people with dementia, the concept of palliative care seems to be poorly understood amongst professionals [28]. Sampson et al. [29] noted that people with dementia admitted to acute hospitals received different end of life care to those without dementia, including less invasive procedures, possibly in recognition of their poor prognosis, however, they were significantly less likely to be referred to specialist palliative care teams prior to death. This seems to reflect a lack of awareness by staff of the appropriateness of palliative care for people with dementia, as identified by Powers and Watson [28]. Sloane et al. [30] interviewed long-term care staff who had cared for people with dementia and people without dementia who had died and they also interviewed the family members of some of those who had died. They concluded that people with dementia who were dying experienced more physical restraints and sedative medications than those without dementia who were dying. Mitchell et al. [31] also identified higher levels of physical restraint of people dying from dementia as opposed to those dying from cancer, but also increased rates of tube feeding. Allen et al. [32] had similar findings from their study: identifying that residents in nursing homes who died during a 6-month period displayed more verbal agitation, less time in verbal interaction and spent almost twice as much time restrained in bed than those who did not die during the 6-month period. Reid [33], exploring the effect of quality of care on resident mortality during 12 months following admission to long-term facilities throughout the Canadian province of British Columbia, identified that physical restraint was associated with higher risk of death. Aminoff and Adunsky [34, 35], in their study of people with dementia who were dying suggested they experienced a higher degree of suffering, including restlessness and screaming. Although there was no attempt by Aminoff and Adunsky [34] to look at environmental factors, these may play a role in exacerbating or ameliorating this kind of distress.
**Spiritual care**

With regard to spiritual care, Keast et al. [36], in their systematic review of spirituality and dementia in long-term care, identified three themes related to spirituality: preserving a sense of purpose, fostering meaningful connections with the surrounding world and retaining a relationship with God. While not specifically related to end of life, this work illustrates a broader view of spirituality that encompasses connectedness with others. Sampson et al. [29] however, in their retrospective analysis of 150 sets of case notes of people with dementia admitted to an acute hospital ward in the UK noted that very few had their spiritual needs assessed or addressed while they were dying. Brandt et al. [37] report nursing home staffs' beliefs that psycho-social and spiritual aspects of care need to be addressed more in the last days of the person’s life. This might reflect Bursell and Mayers' [38] findings of professionals' lack of confidence with spiritual care and their desire for training in how to approach this for people with dementia.

**Focus Groups**

FG1 involved four participants, all female. Three were the wives of recently deceased people with dementia, the fourth was the daughter of a person with dementia in residential aged care.

FG2 involved nine participants, seven female. Five were the spouses of deceased people with dementia, two daughters of deceased people with dementia and two were people with younger onset dementia.

FG3 involved five participants, all female. Two were care workers, one care home manager, one dementia care educator and one palliative care nurse researcher.

All voice files from audio recordings were transcribed verbatim. Transcripts were read thoroughly alongside audio files to ensure accuracy of transcription and to gain a feel for what participants were saying. Transcripts were then read carefully several times by one researcher (FK) to identify initial codes and themes based on the topic guides and issues arising during the focus groups. They were then reviewed by the other researcher (RF) alongside initial codes and themes to ensure accuracy. Discussions were held on emerging ideas and themes that would inform the development or adaptation of existing design principles. All focus group data were managed using qualitative data management software Nvivo8.

Key themes common to both people with dementia and family carers, although with some differences in emphases, were comfort through engagement, feeling at home/familiar, calm environment, privacy, dignity and useful technology.

Key themes derived from analysis of focus groups with practitioners were: practice at end of life, design to improve working lives and systems and institutional influences. These will be described below and key differences in perspectives will be explored.
Views of people with dementia and family carers

Comfort through engagement
Family carers spoke spontaneously and movingly about how they worked to maintain engagement with the person with dementia they were caring for, up until the end of life. This ranged from engagement with the senses, spiritual engagement and social engagement, with the goal of providing comfort to the person. The two participants with dementia were also clear that being able (and helped) to engage by whatever means was possible would also be important to them as they neared the end of their lives. Participants talked in different ways about how the environment might soothe or comfort the person with dementia. They were clear that attempts must be made to ensure that care was aimed at ensuring comfort through engagement with the senses, even towards the end of life:

Perhaps if they're not well anymore, right at the end, and comfort is something that can be adjusted, adjustable bed with, you know, ventilation and a window nearby and, you know, music nearby, so that if you sense that's what's of comfort to them, would be important. (FG1F4)

This family carer describes how she worked to help her husband engage his senses with the things that had been important to him: bird song, sunshine and the scent of flowers:

We got (husband) out every day that the sun was shining and when it wasn't freezing cold, he came home mid winter and we'd put his beanie on and get him into the recliner wheelchair, I got temporary ramps put in... and we got a few little internal steps in doors because, it's a Gerry built house and got him out over our rickety old cobble stones in the back garden and out into the grass in the garden... lots of garden, lots of birds. He's an ornithologist, loved birds, could tell them all by their sound, you know, and we've got lots of jasmine, and stuff like that, around so, very early spring, like now, the smell of the jasmine was around and you could see him responding to it. So, in terms of those things, and just feeling the sun, just feeling the warmth of the sun was incredibly important. (FG1F4)

Using outside spaces to facilitate engagement with the senses was seen as very important by carers, even for those who were nearing the end of their lives:

I do think it's... most people like outdoors, there are very few people who don’t like looking at the leaves fluttering on the trees and being outdoors, I think, there isn’t enough attention and enough space for people to be taken outside, to be able to be taken outside, I think, that’s crucial. (FG1F5)

Spiritual engagement was seen in broader terms by a few participants, for example, this participant with dementia viewed spirituality (in its broadest sense) as a way of nurturing her core self:

It depends how you define spirituality, I always say you’ve got your cognition and then you've got your emotions and then there's the inner you. That could be the herb garden or the music or the pets, or it could be your faith system or all of the above. But I think it does becomes much more important (near the end of life), because if you can't do all of that remembering and factual things, and you can't do the talking and the emotional, who everybody is, then you really are your true self, and you can be nurtured as your true self. (FG2F1)
The importance of social engagement was raised by several participants and included engaging with family, friends, the community of residents if in long-term care and pets or dolls. For example, this carer was clear that people, regardless of mobility or frailty, should experience the company of others:

*But, even, in residential care, I don’t think that the focus should be keeping a person in their room, even if they’re no longer mobile, they have to get out of that room, I think that’s terribly important and I don’t know that all facilities are geared for that.* (FG1F5)

Others described the sense of peace that can arise with the quiet, gentle, loving company of family:

*But, it was having (his son) sitting next to him, holding his hand, talking about some of the things that were there, just, periodically, feeding him, talking some more, just sitting quietly together, just that sense, gentle light in the room, you know, moderate sounds, just, they were the things in terms of the make up of the environment.* (FG1F4)
*Creating this really, gentle, warm, loving atmosphere.* (FG1F2)

In an example of recognising the potential of social engagement for providing comfort, this carer described the comfort her father gained from having the cat sleep on the bed with him:

*Something I did with my dad is he used to get up and wander every night and purely by accident one night the cat got stuck in his room, and the next morning, he actually didn't get up that morning, and the next morning when I went into his room the cat was curled up in bed with him. And so from then on for the last two years, every night, I put the cat in bed with him, and he actually died at home with the cat around him.* (FG2F6)

As this might not always be feasible, an alternative was suggested by some carers: pretend dogs and cats, which look very realistic and may also meet comfort needs. For example:

*I don't know, I was just going to say there was a lady here a few weeks back and her family said she was very restless so as soon as they gave her this little (pretend) cat and a basket or a rug or whatever it was, anyway, she just sat there like this and she was…* (FG2F8)
*And she began to open up and speak.* (FG2M2)

Another participant also recognised the importance of being able to engage socially with who or whatever could provide comfort at that particular time:

*I find that where (wife) is, everybody's different and they have different things. One lady has a doll, a big doll, it's almost life-like. I thought it was a doll. Others have dogs and octopuses, all kinds of things. But a lady has a little poodle, and she takes it round to the various ones that she knows loves a dog and puts it in the bed with her. And just to see the reaction on people is just wonderful.* (FG2M3)

All of these accounts have one core assumption: that it is possible to provide comfort to people with dementia until they die and that this can be achieved through engaging the person either through whatever senses are possible or appropriate, through spiritual means and through the company of family, friends or other means such as dolls or pets.
**Feeling at home/familiar**

Feeling at home or the sense that the environment or aspects of it were familiar to the person with dementia was seen as important to participants in focus groups 1 and 2. For example:

*I tend to think that people with dementia do want familiar; it’s the change that is difficult to cope with and the familiar things are personal things, if we’re talking about residential care, to bring in personal things of theirs, whether it was his music, I know my husband did a lot of photography as a hobby... and he had the photographs there, we had had them in the room upstairs but when we came down we brought the same things down and when he did go into respite, we took the same pictures, well, not all of them but, you know, some of them, enough to have familiar there, I think, that was important to him.* (FG1F5)

This participant with dementia was clear in her wishes for the end of life and referred to the concept of aging in place, where people will live and die in the same familiar place:

*Because the last thing I want to happen to me is to be moved. I want to feel at home.* (FG2F1)

This carer describes the facility where his wife is and stresses the importance of the familiar feel her own possessions give to it:

*Can I just mention, where my wife is at present, she has the most wonderful room, it’s an ensuite, incredible facilities for clothing, and they told me when I went there to make it like it was her home. So I brought in some of her paintings and photographs, everything that’s all around the wall, TV. And outside she’s got a door that opens out into a little porch which has a table on it and two chairs, and she can look straight out into the car park and see me coming in. So it is a really wonderful facility.* (FG2M3)

The overwhelming opinion of carers and people with dementia is that care settings must have a homely feel; this will be achieved through having the person’s own belongings, ornaments, pictures, television etc in it.

**Calm environment**

The importance of ensuring a calm environment was stressed by carers and people with dementia, whether this was at home or in a care setting. This participant with dementia was clear she did not want to be in a noisy environment, what was important for her was calm, peace and quiet:

*I think the calm and peaceful environment is...for me, walking into an environment where there’s lots of noise and other surroundings going on seems to affect my coping skills and how I would interact. And I feel that certainly that will stay until the end, the quiet peaceful, serene surroundings seems to be the most important thing, it does impact greatly I feel.* (FG2F9)

This participant with dementia also expressed her distaste of noise and overwhelming stimuli:

*Nobody seems to understand, but it’s visual stuff, visual clutter. When I was visiting last year in a dementia ward, was not only obviously the sound level, the TV and the radio and the staff talking loudly to each other, but it was a smaller area, there were lots of people, lots of tables, people coming in and out and then the occupational therapist had made stuff, which was hanging everywhere and it was just...And then there were loads of those walkers everywhere; it was just visually ... really, really stressful. I would just go there for an hour and I’d be exhausted, And I often think no wonder people in nursing homes are just*
sitting there like that, because I felt like that when I went in, that I wanted just to sit, close my eyes, because it was too much. (FG2F1)

This was also reiterated by the carers who described how they worked to ensure the environment was calm and peaceful:

So one of the things that I’d do at the…was our thing was, we had the candles, not that he could smell anything, but it was that nice soft light, and we’d have…I’d have the classical music on, which I just left on until he went to sleep at night and, then, I turned it off and it was just all that softness and calm and it’s very hard to be calm when you’re not a calm person but, for eighteen months we managed because you do need that, you need to have no conflict, totally conflict free, totally and utterly. (FG1F2)

In a similar manner to ensuring comfort through engagement, carers were able to recognise when the person with dementia needed peace, stimulation appropriate to their needs and abilities and an environment free of conflict (excessive noise or visual stimuli).

**Privacy and dignity**

While all participants agreed on the need to ensure the person’s dignity was respected while carrying out care, there were some differences in opinion on the necessity of ensuring privacy – ensuite or shared bathroom, single bedroom or shared bedroom.

Carers had mixed views, although these shifted with changing needs of the people they cared for. For example,

I have had to go in the back corridors between two houses to cry sometimes because I’m so upset, because I can’t do it where (husband) is. And here I am standing out in a hallway where the laundry comes in. And also a few times there have been a couple of us who’ve wanted to just chat together, but there’s nowhere where we can go, other than to the coffee shop or something like that. So in an ideal world could there be, as they have in hospitals, a small intimate space for families, or you can go and you can have a cry and then go back and face it again. (FG2F8)

From these accounts, respecting dignity and privacy are important and, crucially, become more important as dementia progresses; having ensuite bathrooms ensures that dignity and privacy are maintained when increasing frailty necessitates more personal care.

**Use of technology**

Carers and people with dementia viewed technology as a means of remaining connected to others (family) and of alerting others (practitioners) of a need. For example, one participant with dementia wanted to be able to connect with her husband, and wanted him to be able to check in on her, through a webcam:

Well, when I get to that stage I would like my husband to be able to check on the webcam. (FG2F1)

Technology could also be used to engage with the senses, for example a visual projection onto the ceiling for people who are in reclining chairs or confined to bed was suggested as a useful way to ensure a more interesting experience. Other technology, such as sensor mats or monitoring
equipment were also suggested as possible ways of ensuring the person remained safe, particularly in busy settings when staff might not have time to regularly check on people.

There was some discussion about safety, particularly with maintaining the person’s safety when they are confined to bed. There was a general feeling that bed rails would be acceptable, if there was a risk the person might fall out of bed, as this participant with dementia said:

Well, I’d be happy to have that for myself rather than fall. And I was happy to have it for my mum because in the last few days she really needed it. (FG2F1)

Technology should, however, be used with awareness of how it might be interpreted or understood by people with dementia, for example a hoist might not be well tolerated, as this carer identified:

Well, the thing with dementia, we know, is that the person’s awareness and understanding of their environment, and everything going on in it, is not the same as someone that doesn’t have dementia, so they’ve got a considerably huge burden, I think, of coping with that whole process of losing more, losing more capacities, and so on, when their environment is so confounding for them, for a whole variety of reasons… and (husband) at one point, thought the electronic hoist, in the room, was something that was very fearsome. (FG1F4)

These accounts highlight the ways in which technology can be used to help people with dementia and their families remain connected with each other and to alert professionals of need, yet they also provide a reminder of the sensitivity with which practitioners and families need to approach the use of technology, so that it is understandable and acceptable to the person regardless of cognitive ability.

**Views of practitioners**

**Practice at end of life**

Practitioners spoke in terms of their practice rather than in terms of their understanding of the needs or wishes of people with dementia as they neared the end of their lives. One practice at the end of life seemed to be the setting up of a syringe driver with morphine and other drugs aimed at sedating the person once it was established they were approaching death:

The drivers really are a great idea. (FG3F5)

This appeared to be instigated because dying was seen to be an uncomfortable process:

Well, dying is not necessarily particularly comfortable. (FG3F1)

But also as a pragmatic response to under-staffing of the setting in which one care worker might be looking after 18 patients on his/her own.

The workload reduces, you’re not doing PRNs¹ every evening. (FG3F5)

Practitioners talked of the consequences of sedating patients as they near the end of life:

...keep it nice and simple, once they get to palliative with a syringe driver, they usually won’t hit out, they don’t kick, they don’t walk, they won’t bite, they don’t scratch...they are so peaceful and calm and they just lie there, they’re basically asleep the entire time... so it really doesn’t...the environment around them doesn’t matter... (FG3F1)

¹ PRN (Pro Re Nata) = ‘as needed’. Usually refers to administration of medications.
These accounts indicate that practitioners’ understandings of the needs and experiences of people with dementia nearing the end of life appear to be influenced by their practice and the impact of their practice on them, rather than on an understanding of their needs and wishes as individuals. If, as is suggested, syringe drivers containing morphine are used, this will inevitably influence practitioners’ views of the experiences of people with dementia as they near the end of life; thus influencing their views on the necessity or otherwise of ensuring the design of the environment meets their engagement, spiritual and social needs.

Design to improve working lives
Practitioners had strong views on the extent to which the design of their work settings was safe for their patients and the extent to which it helped or hindered their work.

*I mean I will say, the layout of our dementia floor is ridiculous. Absolutely ridiculous. It just needs to be erased or rebuild a new one. It's just...as a care staff, it's a nightmare. An absolute nightmare.* (FG3F1)

Buildings with long corridors and ‘nooks and crannies’ were deemed unsafe as these encouraged patients ‘wandering’. An ideal design put forward by one participant would be a circle so that people would not arrive at a dead end. Some recounted creative ways to disguise dead ends, such as a mural or other feature to hide an area that was off limits to the person with dementia. Wide corridors and wide doorways were seen as vital for easy access for those with wheelchairs, and electronic beds that would raise and lower were also reported as useful.

Practitioners’ ideas for good design were focused on monitoring patients, particularly as they become frailer, and included Florence Nightingale wards (large long wards with beds along each wall) and ‘palliative suites’ which are rooms that are set up to care for patients reaching the end of life. These were seen as appropriate for delivering good care, although this was viewed more in terms of practicalities rather than in terms of how this might influence the experience of people with dementia and their families. For example:

*Palliative care suites are beautiful, I don’t know if you’ve had anything to do with them? They’re absolutely delightful. And more often than not, they have more than one room; there’s like a bedroom and an associated room, so you have space for both the family and the person.* (FG3F3)

Some practitioners also spoke of the preparations they would make when they know the person was dying – they would take out the ‘dying box’ which contained candles, incense, a vase and objects to create a ‘calming atmosphere’.

From these accounts, the design of the building has relevance for practitioners if it can make their working lives easier – if it can allow for easier monitoring of patients, prevent them ‘wandering’ and ensure their safety. While there was some thought into creating a nice, calm atmosphere for the person at the end of life, this was not central to their views about the design of a care setting, possibly because their practice experience is one of caring for people who are sedated and therefore unable to engage with their environment.
**Systems and institutional influences**

A key area of concern for practitioners was lack of staff to provide sufficient care to their patients. There seemed to be a sense of juggling their time between those who were mobile and who needed monitoring and those who were becoming frail and needed more one-to-one care. They recognised the need to have more intensive one-to-one care when someone is dying, but current staffing levels prevent this and this seemed to be a source of frustration for some practitioners.

>*You don’t have the resources to... And if you could take two off to look after the one that was dying...* (FG3F2)

Another key area of concern was the funding of aged care and the difficulty of securing enough resources (in a timely manner) to cope with patients’ changing needs. This seemed to require a knowledge of the system and strategies to ‘play’ it. Practitioners described a constant battle to secure resources and if they didn’t manage to secure them they would have to do without extra resources (usually more staff) and this inevitably has an impact on the quality of care.

Practitioners’ use of language revealed their embeddedness within institutional systems and processes and this was particularly evident when they referred to their patients. The use of words such as ‘dementias’, ‘dementia cases’, ‘the respites’, ‘behaviours’, ‘wheelchairs’, ‘lifters’ indicated they viewed their patients predominately in terms of the tasks required by them, their needs or their disability resulting from dementia rather than as unique individuals. For example:

>*I was just thinking of two dementia cases that we have; one who, like you were saying, wandering, wandering, still running around.* (FG3F5)

Practitioners’ accounts of the constraints of the systems they had to work in illustrate the difficulties of thinking beyond the day to day practicalities of carrying out care. This might explain the difficulty they had thinking about design in relation to the experiences of people with dementia who are nearing the end of life.

**Main themes**

Notwithstanding the difference in emphasis between the focus group participants, several main themes emerged concerning the provision of:

1. an environment that supports the continued use of the senses
2. opportunities for social engagement
3. opportunities for spiritual engagement
4. familiarity and homeliness
5. calmness
6. the means to control levels of stimulation
7. opportunities for the family to be with the person with dementia
8. privacy
9. the maintenance of dignity by, for example, providing all of the facilities required for personal care
10. opportunities for monitoring of residents by care staff
11. technology, particularly communication technology
Survey

The 21 experts surveyed included 10 experts in environmental design of care facilities for older people, 8 experts in palliative and/or end of life care, 1 expert in advance dementia care, 1 expert in hospital intercommunication and 1 expert in end of life environments. Experts were from research (7) and practice (12) or both (2). Fifteen were based in Australia and six in the UK. The average number of years of experience providing, developing or researching services for people with dementia was 18.3 and ranged from 5 to 30 years.

Having been presented with the 11 items derived from focus group analysis, the following nine features of the physical environment received strong support (more than 50% thought they were extremely or very important) from panel members in terms of their importance to people in the final stages of dementia:

- Support of the continued use of the senses
- Provision of opportunities for engagement with spiritual aspects of life
- Provision of opportunities for social engagement
- Promotion of a sense of familiarity and homeliness
- Promotion of calmness
- Provision of opportunities to be with family
- Provision of privacy
- Fostering of dignity
- Enabling of visual monitoring by staff – via human contact and not through the resident being placed in a public area

Underpinning all of these was the importance for the design of the physical environment to support a personalised approach and a sense of homeliness/domesticity.

The following features were identified by panel members as missing from the original list.

- Provision of access to the outdoors/natural environment
- Access to nature (e.g. plants, natural light, fresh air)
- Support of safety and security
- A focus on legibility (e.g. ability of staff, residents and visitors to find their way around/know where things are)
- Reduce physical stress (e.g. provision of appropriate beds/mattresses)
- Facilitate nursing care (e.g. facilitate bathing, feeding, going to the toilet, lifting)

Survey participants were invited to comment on the revised list of nine strongly supported characteristics and six additional characteristics. There was unanimous agreement on the inclusion of both the strongly supported and the additional characteristics.
Discussion

It was clear from the analysis that participants with dementia and family carers differed from practitioners in terms of what might be important design principles in the care of people with dementia nearing the end of life and in ensuring an optimum experience for the person nearing the end of life. People with dementia and family carers placed a strong emphasis on provision of comfort through engaging with the senses, through remaining socially connected (whether through family, friends, pets or soft toys) and through spiritual engagement. These ideas assume some degree of awareness or ability to engage and family cares worked hard to ensure they engaged with the person appropriately and in a way that comforted them. Practitioners seemed to have a different way of offering comfort – to administer morphine through a syringe driver and this had the effect of sedating the person so that they were no longer aware of their surroundings. The implication of this is that there is no need to work to engage spiritually, socially or through the senses and therefore no need to consider how aspects of design might improve their experience.

Participants with dementia and carers were clear they wanted to be, and remain in, a familiar environment, with their own belongings and familiar things. Practitioners, however, liked the idea of a dying room to which they could move a person who is dying and in which they could create an atmosphere of calm. Practitioners also liked the idea of a dying box from which they could select items to create a calming, homely space. The paradox here is, that by moving people who are nearing the end of life, practitioners would be moving them from their familiar space to a space set up to be familiar, but is unfamiliar.

Participants with dementia and family carers were clear they wanted care and an environment that ensured dignity and privacy. Most of them were also clear that the need to ensure this increases with increasing cognitive impairment and this particularly related to having and being able to use ensuite bathrooms. Practitioners were concerned about the balance between privacy and safety – a reflection of their focus on design to improve their working lives. All participants recognised the need for family members to have access to a quiet, private space to rest in and take time out in. The availability of such spaces varies from setting to setting.

Practitioners recognised their practice was constrained by organisational and institutional factors, such as funding arrangements for delivering care, resource and staffing levels and inadequate design of care settings. They also appeared to be unconsciously constrained by unquestioned practices, such as instituting a syringe driver on recognition that someone is dying and the practice of labelling patients according to their needs or levels of impairment. These seemed to influence their perceptions on the importance or otherwise of aspects of the environment for people with dementia nearing the end of life.

When presented with the list of desirable characteristics derived from the literature review and expanded on by the focus groups the panel of experts showed a high degree of agreement on a set of desirable characteristics and were able to identify, and agree on, a set of additional characteristics.
Conclusions

The following represent the desirable features of the physical environment for the care of people in the final stages of dementia, as determined by a review of the academic literature, a series of focus groups with people with dementia, families of people with dementia in the final stages, and health professionals and consultation with experts in the fields of environmental design for aged care and architecture and palliative and end of life care both in Australia and the UK.

The environment should:

1. Support of the continued use of the senses
2. Provide access to the outdoors/natural environment
3. Provide access to nature indoors (e.g. plants, natural light, fresh air)
4. Provide opportunities for engagement with spiritual aspects of life
5. Provide opportunities for social engagement
6. Promote of a sense of familiarity and homeliness
7. Provide opportunities to be with family
8. Promote calmness
9. Provide privacy
10. Foster dignity
11. Support safety and security
12. Support staff, residents and visitors to find their way around/know where things are)
13. Enable visual monitoring by staff – via human contact and not through the resident being placed in a public area
14. Reduce physical stress (e.g. provision of appropriate beds/mattresses)
15. Facilitate nursing care (e.g. facilitate bathing, feeding, going to the toilet , lifting)

These characteristics are compatible with the principles currently used in the design of environments for mobile people with dementia. They are offered as a supplement to these that will ensure their applicability to those people with dementia who are less mobile and those who are dying. We suggest that considering these characteristics as part of a continuum of care will support good practice and offer those with dementia and their families a more positive experience in the last days of their lives together.
References


Appendix 1 Articles rated using NHMRC framework

<table>
<thead>
<tr>
<th>Author Year</th>
<th>Title</th>
<th>Citation</th>
<th>NHMRC level of evidence</th>
<th>Key points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sloane, P., Zimmerman , S., Williams, C. and Hanson, L. (2008)</td>
<td>Dying with Dementia in Long-Term Care</td>
<td>Gerontologist 48(6):741-751</td>
<td>Level III-3</td>
<td>Reports on excessive use of restraint of people dying with dementia as opposed to people dying without dementia in US</td>
</tr>
<tr>
<td>Year</td>
<td>Authors</td>
<td>Title</td>
<td>Journal</td>
<td>Level</td>
</tr>
<tr>
<td>-------</td>
<td>-------------------------------</td>
<td>----------------------------------------------------------------------</td>
<td>----------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>2005</td>
<td>O'Malley, L. and Croucher, K.</td>
<td>Housing and dementia care – a scoping review of the literature</td>
<td>Health &amp; Social Care in the Community 13 Issue 6, p570-577</td>
<td>Not rateable</td>
</tr>
<tr>
<td></td>
<td>Brandt, H., Deliens, L., van der Steen, J., Ooms, M., Ribbe, M. and van der Wal, G. (2005)</td>
<td>The last days of life of nursing home patients with and without dementia assessed with the Palliative care Outcome Scale</td>
<td>Palliative Medicine 19(4) 334-342</td>
<td>Level III-3</td>
</tr>
</tbody>
</table>