Busy in the garden

• An enabling smart flat for people with dementia
• Understanding disturbance and distress
The Dementia Care Garden: part of daily life and activity

People with dementia are more at risk for nature deprivation than any other group of older people. This principally occurs when freedom of movement between indoors and outdoors is curtailed. Ironically, nowhere is this more acute than in a care home environment. I have visited many care environments, both residential and nursing, in which the outdoor areas were not being used in the way the architect intended, either because incorrect assumptions were made about the realities of daily operations within the home, or no outdoor areas were intended for normal daily use by the residents. In such cases the benefits of connection to the natural world for people with dementia were not being realised.

Typically, there is a lack of awareness among architects of the needs of people with dementia. With few exceptions, the location and design of garden areas is an afterthought. Design guidance specifies that outdoor spaces should be 'visible, accessible and user friendly' (Pool 2007) and that 'gardens and access to garden areas are an essential source of interest, activity and stimulation' (Utton 2007). Also, small, domestic group living environments are recommended (Judd et al 1998; Chalfont 2006).

Taken together, such guidance implies that people with dementia need to be living in small groups on the ground floor. Despite such expert advice, long, wide hotel-style corridors on upper floors still seem to be the preferred location for 'EMI' corridors.

Fortunately, in some well-run person-centred homes good care is compensating for poor design. However, the troubling trend is to build larger homes with fewer opportunities for residents to interact with the natural world. This warehouse approach to care environments, because it is accepted as an economic solution, highlights the discrimination between caring for people with dementia and caring for other people with mental or terminal illness. We do not see care environments for people with learning difficulties or hospice care environments advocating this warehouse approach, and we should not accept it for anyone else.

What this article will do is put some practical knowledge into the hands of those working with and designing for people with dementia to improve their connection to the natural world. First, it will reflect on our continued fascination with 'sensory gardens' and the reasons why in theory this seems like a good idea, but in practice such places often fail to perform. It will then introduce a new agenda: The Dementia Care Garden, presenting a set of design criteria based on research evidence, practice-based knowledge and architectural design expertise. The article ends with a checklist.

The second part (in the next issue of JDC) will present design solutions from recently commissioned work by my landscape architecture practice.

Sensory garden – a limiting concept

It is time to revisit the concept of the 'sensory garden' for people with dementia. It has been four years since this topic was discussed in two JDC articles by Martin Cobley (Cobley 2003a,b). Since then we have learned much about walking, spirituality, activities, food, pet therapy, washing lines and multiculturalism, all of which can involve a sensory connection to nature. What exactly do we mean by 'sensory' garden? It has come to mean a garden that pleases the senses by providing fragrance, tactile sensation, sounds, sights and perhaps taste. The sensory garden concept has been encouraged in dementia care because of the known benefits of sensory stimulation. But think for a moment about the place where you work with people with dementia. What outdoor areas are there, and what does it physically feel like to sit in them at different times of the day throughout the year? This is the starting point of a 'sensory' garden – the sensation of being there.

Design guidance for a sensory garden might suggest that certain items be included, like fragrant plants, the sound of water, grasses rustling in the breeze, wind chimes and plants with furry leaves. But the process of creating a garden with these items included (in such a way that they can actually be enjoyed by a person with dementia) is quite a challenge. Few care environments have the necessary site conditions and care culture to sustain a garden that residents regularly use, never mind a sensory garden. But the idea of a sensory garden is still very attractive and they are still being designed and built.

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Garuth Chalfont’s book Design for Dementia Care: a comprehensive guide to designing the physical and social environment both indoors and outdoors is published this month by Jessica Kingsley, London.

Figure 1: Range of engagement a Dementia Care Garden facilitates.
While the general principle is still relevant, more must be done to ensure that gardens are used by the people for whom they were designed. Many fall into disuse because they were not conceived as an integral part of day to day life. A garden is a daily conversation we have with nature. It is not an object, but a process – a place made meaningful through relationship.

So let’s step back for a minute, look at the whole picture and re-evaluate the need, the potential and a possible way forward. For the best chance of success the garden areas and indoors must be conceived simultaneously during the design of the building as a whole, not as an afterthought. This is because views, microclimate, access, comfort, shelter, connection to indoor areas and connection to the community are largely a result of the orientation of the building on the land and the path the sun travels as it passes over the building during the day and year. Once the house is built, these factors are literally set in stone. If the experience of being there is uncomfortable because of factors that cannot be changed (sunlight, temperature, wind, location) then investment in furnishings, plants and features will not improve the person’s sensory experience because they will simply not be outside enjoying it. The indoors and outdoors should be integrated by design, not segregated by lack of it.

A new agenda: The Dementia Care Garden

Every good garden offers the visitor a positive sensory experience. But a garden is more than its sensory qualities. Sensing is passive, an experience during which a person simply receives stimuli. (Sensation is followed by perception, which is how a person interprets sensations received. Perception is followed by action, which is how a person physically responds to information from their surroundings.) To focus only on the sensory qualities of a garden is to underestimate its full potential, and to ignore the diverse and complex needs of individuals.

Current good practice encourages normal domestic activities for people with dementia such as peeling potatoes, sweeping the path, hanging out the washing to dry or pottering in the shed. Such activities are a part of older people’s lives, enable them to participate and contribute, preserve personal identity and sense of self, afford ongoing meaningful roles within the communal setting and make a place feel less institutional and more like home.

A Dementia Care Garden is designed to stimulate active as well as passive engagement and also provides opportunities for normal and domestic, as well as facilitated and therapeutic activities. It is therefore a practical, beneficial model to adopt if we are designing gardens to enhance the care environment experience, not only for the person with dementia who lives there, but for all who work in and visit the home.

Therapeutic gardens

‘Therapeutic’ is a term we hear a lot, especially in relation to gardens. Hospital, cancer treatment centres and other healthcare environments are increasingly interested in the healing qualities of gardens, especially since research shows that nature experiences improve medical outcomes. Natural environments are also known to reduce agitation and aggression in people with late-stage dementia. But what exactly is the link between health and well-being? We know that the natural world satisfies our need for contemplation, escape, restoration and distraction (Kaplan 1995). A connection to nature has also been shown to enhance verbal expression in people with dementia (Chalfont 2006). Outdoor greenery can support competence among people with dementia (Rappe & Topo 2007). Exercise can enhance brain health (Cotman & Berchtold 2002), and walking and talking can positively affect communication and function (Cott et al 2002). In a study by Rappe, Kivela and Rita (2008) of nursing home residents, a strong positive association was established between how often they visited an outdoor green environment and how they rated their health. Studies have also attributed an increase in appetite, verbal ability, concentration, stamina, sleep patterns, social interaction and positive mood to involvement in various activities.

What we are seeing is a relationship between care needs, health needs, social needs and spiritual needs. Heart, body, mind and spirit are connected. This may explain why interest in areas such as art, music, dance, storytelling and gardening for people with dementia is greater than ever before. Previously latent artistic abilities have been known to develop in people with dementia (Gordon 2005). Likewise, care environments that facilitate engagement through physical design and the efforts of skilled caring people, are finding these activities to be potentially therapeutic.
day? For what reasons? Alone or accompanied? The outdoors can be designed to accommodate a wide spectrum of participation from normal domestic activities associated with daily, year-round home life (simple enjoyments for fun and pleasure, chores and housekeeping tasks, as well as sporting and recreational activities) through to facilitated therapeutic interventions with a trained practitioner (see Figure 1). The outdoor areas in dementia care environments must be designed ‘fit for purpose’ across this broad spectrum of need in order to enable high quality person-centred or relationship-centred care to be delivered.

Consider the listed activities in the chart (Figure 2) and where they might fit on the diagram. An activity may need to be facilitated depending on the person’s dementia as well as physical conditions such as strength, dexterity and frailty.

What do we mean by ‘therapeutic’?
We’ve all heard people say ‘I love to work in my garden, it’s so therapeutic’. For that person it is, but we must be careful when using the word ‘therapeutic’ in a care environment. If the service user could facilitate such benefits for themselves they would not be in need of care. Depending on a person’s dementia and physical conditions such as strength, balance and dexterity, an activity may need to be facilitated by another person. When this occurs, an activity is potentially therapeutic (see box on Therapeutic Gardens).

An activity such as growing plants, going for a walk or using the clothes line, that involves somebody else, may end up being a therapeutic experience for the person with dementia, based on the connection between physical, mental and spiritual health and wellbeing. Even though occupational or horticultural therapists are trained to facilitate therapeutic experiences by involving a person in activities, care workers, domestic workers, activity workers, volunteers, family members, neighbours and friends can all help a person with dementia enjoy the outdoors. The beauty of nature and the pleasure of being outside are experiences which can be shared and enjoyed by all.

Principles and design criteria for a Dementia Care Garden
Just as every person is an individual, so every garden must be designed on a case by case basis, considering the existing constraints and opportunities. Designing a garden is not beyond the scope of non-professionals, so if you are especially inspired, do not be put off from attempting it. You may also want a garden designer, landscape gardener or landscape architect to look over your plans or manage the project for you. Whoever designs the garden area, be sure you and the staff, residents, families and visitors have plenty of input into the design. Together you know your home and your needs better than a stranger, although a design professional will be able to take your input and use it to create a place that works.

Beware that hiring a designer with dementia expertise will not guarantee a caring environment. Even garden areas appearing on concept plans for brand new dementia care buildings are often based on out-moded ways of thinking. For instance, having a large enclosed courtyard in the centre of the building where residents can ‘wander around freely without getting lost’ shows an appalling lack of concern for quality of life. The term ‘wandering’ can sometimes imply ‘aimless’, which is not the case for people with dementia.

If the garden areas and the building were not designed simultaneously, a well-performing dementia care garden is still possible to build. It may be more expensive than if it had been considered in the planning stages of the building. It may also take more effort from care staff if the residents are to regularly use and benefit from the garden. And some activities will simply be impossible to programme. But a pleasant space to sit, an area for growing plants and some provision for sensory stimulation should be possible in most homes.

Here are the basic principles. A Dementia Care Garden will:
• Enable active and passive activities
• Enable normal, domestic activities
• Enable facilitated, therapeutic activities
• Be used daily and routinely
• Have an open-door policy

Design criteria for the physical environment:
Enable activity
1. Encourage movement and engagement – provide places of interest, ways to get there and worthwhile things to see and do.
2. Encourage participation by putting garden elements within reach.
3. Provide easy physical accessibility.
Activities such as potting up plants or hanging out washing offer meaningful roles

4. Provide sturdy, permanent seating as well as moveable chairs.

Enable daily and routine use
5. Maximise nearby visible areas – make the garden close to indoor communal areas where people already spend time and where they can see it from indoors.
6. Create a pleasant microclimate – consider the time of day it will be used; yearly fluctuations in weather, temperature and climate; wind and breeze; sun, heat and warmth when locating the garden and design it accordingly.

Have an open-door policy
7. Secure the perimeter of the garden area so the door to the home can be left open during daylight hours.

Design criteria for the social environment:
1. Make garden use regular and habitual – organise the daily life of the home to facilitate spending some time outside every day, either sitting or walking for everyone who chooses to participate.
2. Invest in therapeutic activity workers such as occupational and horticultural therapists to engage people in the outdoor environment.
3. Write garden use into residents’ care plans.
   (Criteria from Design for nature in dementia care, Challont 2008)

Sustainability
When we use the word ‘sustainability’ we might be talking about the ecology of the planet. But a garden also needs to be sustainable. Design can only ensure that the seating, paving, plants and access are in place. Gardens need people, and a steady supply of human energy will make sure the garden is used and enjoyed. Also, be aware of factors that negatively affect your garden and seek ways of engaging with them. For example, instead of addressing vandalism (which you find increases during school holidays) with a higher fence, try to break down barriers by strengthening links between the home and the local school. An intergenerational programme where students living nearby adopt a ‘grandparent’ in the home could foster positive engagement. Although ‘independence’ is highly regarded, in reality we are all dependent on a wide web of support. Strengthening our interdependencies on people and places is the key to sustainability, whether you are working at the scale of a garden or a planet.

Part of daily life
By considering both the physical and the social environment, the Dementia Care Garden will be fully integrated into the structure of the building and the daily life of the home. Design criteria will be based on the desire to make things happen – not to control people, control risk and limit potential to the point where enjoyment is impossible, the space is meaningless and nothing can happen there. While every outside area will not facilitate a full range of experiences, rather than leaving it to chance, the garden is intentionally designed so that active, passive, normal, domestic, facilitated and therapeutic activities are all possible somewhere.

Checklist for a Dementia Care Garden

Visual access
• Can all parts of the garden be seen by staff from indoors?
• Can the garden be seen from indoor areas where residents spend their time?
• Can outdoor seating areas be seen from the doorway leading to the garden?
• While residents are outdoors, can they see into the home?

Seating and microclimate
• Is there some seating fairly close to the door?
• Is there a choice of sunny and shady seating at any time of the day?
• Is there dry, sheltered seating outside even on a rainy day?
• Is there warm, sunny seating sheltered from the breeze?
• Is there equitable, comfortable seating for smokers and non-smokers simultaneously?
• Are there permanent as well as moveable chairs?
• Are there cushions for the wooden benches?

Structures, furniture and fixtures
• Is there a permanent table in the garden for meals or gardening activities?
• Is there a greenhouse or a potting bench that residents routinely use?
• Is the garden storage for tools, chairs and umbrellas?
• Is there a convenient, reachable clothes line that residents use?
Disclosing a diagnosis: the Alzheimer Europe position

Jean Georges and Dianne Gove present Alzheimer Europe’s newly drafted position on the disclosure of the diagnosis to people with dementia and carers.

In 2006, Alzheimer Europe’s member associations unanimously adopted its position paper on the disclosure of the diagnosis to people with dementia and carers. This position was the outcome of previous work on the legal rights and protection of people with dementia, a survey carried out by Alzheimer Europe and recent research. In this article, we present some of the issues surrounding the disclosure of the diagnosis. We also include the key points of our position on this issue.

To disclose or not?
Several studies confirm that most people with dementia prefer to be informed of the diagnosis of dementia (Marzanski 2000; Jha et al. 2001; Clare 2003; Dautzenberg et al. 2005; Van Hout 2006). Bamford et al. (2004) found that non-disclosure or vagueness was reported by people with dementia as being confusing or upsetting. Other studies also confirm that most people with suspected dementia want to be informed of the diagnosis and are distressed if not provided with adequate information (Clare 2003; Pratt & Wilkinson 2003). Jha et al. (2001) found that even people with severe dementia often want to know the diagnosis.

There are numerous reasons why people with dementia should have the right to be informed of their diagnosis. For example, disclosing the diagnosis to people with dementia can give them the opportunity to:

- understand changes within themselves
- make the most of their lives while they are still able, for example go on holiday or travel
- discuss the illness and inform themselves about it
- access support, state benefits and services more easily
- think more actively about coping strategies
- understand the necessity of certain precautions (for example, with regard to driving and/or the use of certain machinery)
- take care of their financial, business and legal matters

Alzheimer Europe is an umbrella organisation representing the interests of people with dementia and their carers in Europe. Founded in 1991, it now has 29 member associations in 25 countries.