REFLECTIONS ON A VISIT TO A DEMENTIA CARE VILLAGE

Catharine Jenkins and Analisa Smythe discuss what the UK can learn from a Dutch model of care, where residents live in an environment carefully crafted to emulate their previous lifestyles.

Abstract

Hogewey village in Holland offers an alternative lifestyle for people with dementia. The model minimises disability and maximises wellbeing by providing a physical and social environment congruent with people’s lifestyles. Residents live with those who have shared similar previous lifestyles and take an active role in all aspects of daily life, reflecting their interests and social norms.

The village is staffed by healthcare professionals and well-supported volunteers, who promote personhood in small social groups and facilitate normal life.

The authors explore how this approach contrasts with those used in the UK and draw conclusions about applying the model in the UK. They believe that healthcare professionals can learn from the Dutch example and adapt existing environments to reflect some of the concepts that are applied successfully at Hogewey.

Well-supported volunteers, integrated into teams, could take on the role of supportive friends rather than clinically orientated problem-solvers and help to reintegrate people with dementia into local communities.

Keywords
Culture, dementia, dementia-friendly communities, personhood, quality of life

People in the later stages of dementia experience problems that include poor short-term memory, language and communication difficulties, managing activities of daily living and personality changes (Banerjee 2009). Later stages can be associated with difficulties in accepting help from others and signs of psychological distress, such as ‘wandering’, aggression, agitation, repetitive questioning and disturbed sleep patterns (Alzheimer’s Society 2011).

Some individuals become apathetic, low in mood and withdrawn (Cerejeira et al 2012). In addition, people develop vulnerability to risk, for example, with cooking, crossing roads or getting lost. People may also be vulnerable to exploitation by others. There is a correlation between the later stages of dementia, behavioural and psychological symptoms and needing full-time professional care (Cerejeira et al 2012), which means that in the later stages of dementia people tend not to live alone. They require support to maintain their wellbeing and stay safe.

Many people with the disease are prescribed antipsychotics for behavioural and psychological symptoms, despite the associated risks of increased morbidity and mortality (Banerjee 2009) and subsequent recent targets for reducing these prescriptions (Alzheimer’s Society 2012, Clinical Audit Support Unit 2012).

Alternatives to medication include a sensitive, person-centred approach in which distressed behaviour is seen as an indication of unmet need, advanced communication skills to enhance understanding and reduce frustration, and therapeutic approaches including validation,
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reality orientation, reminiscence, music and art (Adams 2008). These interventions can be offered to people with dementia in care environments, but for many the reality involves basic care with little personal interaction and minimal therapeutic intervention, so that people are not recognised as individuals nor engaged with others or with their environment (Alzheimer’s Society 2012, Which? 2013).

Of the population with dementia, one third in the UK and one fifth in Holland live in care homes (Willemsen et al 2011, Alzheimer’s Society 2012). Many older people fear dementia and the range of negative consequences (Ballard 2010), including the quality of care and its associated costs (Humphries 2013).

The Hogewey alternative
There are alternatives to this bleak picture. Small group living for people with dementia is already common in Northern Europe (van Zadelhoff et al 2011), while in the UK smaller groups are often cared for together in larger homes.

In Hogewey, Holland, staff have developed the concept so that people with dementia live together in a village dedicated to minimising their disability and maximising their quality of life. Hogewey village is situated on the outskirts of Weesp, a small, traditional Dutch town, which is 20 minutes south east of Amsterdam.

The village occupies a four-acre site and from the outside looks much like the neighbouring two-storey, terraced dwellings, although built almost to the margins of the land and with larger windows. The village cost £17 million to build, which was funded by the Dutch government and charitable organisations. The fees of £4,300 a month are usually funded by health insurance with means-tested contributions.

Half of the village is open space. As in Weesp, there is a pavement café, a restaurant, theatre, supermarket and hairdressing salon. The 152 residents, who are diagnosed with severe dementia, live in 23 small homes in groups of six to eight. They have their own bedrooms and share kitchens, bathrooms and living areas. Staffing in each home consists of one qualified nurse supported by two or more care assistants.

Hogewey has received considerable media attention (Fernandes 2012, Hans 2012). Descriptions of the village have focused on it as a utopian, if illusory, environment designed to lead residents to believe they are living in a version of the past, where hairdressers, gardeners and shop assistants play their roles until required to provide nursing care. Newspaper accounts (Fernandes 2012, Henley 2012) have mentioned the film, ‘The Truman Show’, referencing the protagonist’s situation as the dupe surrounded by manipulators in an artificial world.

It was difficult to imagine how the environment could work. For example, we wondered:
- How each cohort’s environment would reflect their individual histories.
- How the environment would need to be refurbished periodically to match the tastes of each subsequent cohort.
- How tastes in décor and music tend to be individual and not appropriate for group living.
- The effect on residents if they ‘suddenly realised’ and could not make sense of the illusion and lost trust in others.
- People with dementia often perceive themselves to be younger than their actual age, which could lead to difficulty in reconciling meeting grandchildren with their perceived roles as younger or middle-aged people.

Hogewey seemed to be a physical embodiment of a ‘therapeutic lie’ in which professionals make an untrue statement justified by a happier outcome, for example, ‘your husband’s at work, he’ll be back later’. We half feared the village would be a ‘reminiscence world’ inhabited by kindly actors with a paternalistic approach to their clients.

The nature and practical workings of the village sparked our imaginations and we decided to visit if a chance arose. The opportunity came on an English speakers’ open day in March 2013.

The lifestyle
Hogewey’s architecture supports everyday life. It promotes activity, engagement and conversations in an environment that is safe. It feels normal. However, the physical and social environments are carefully thought out and developed to achieve this effect.

Each resident, supported by their family, completes a questionnaire that is designed to elicit their cultural values, beliefs and norms. They then live with others who are identified as having a similar lifestyle, characterised more by their outlook on the world than by superficial factors, such as whether they prefer lampshades or chandeliers, although these are recognised too. Each home or apartment is built, decorated and furnished to reflect residents’ previous lifestyles, and staff and residents.
interact in this environment, thus reinforcing the sense of self in a natural-seeming context.

There are seven lifestyles reflecting elements of Dutch society: cultural, urban, homely, Indonesian, spiritual, rustic and upper class. Each home is different; the ‘homely’ group has a larger kitchen area and more traditional sturdy furniture. The staff joked with residents as they peeled potatoes for dinner together. In this home we were shown a smoking room that had been converted into a workshop. In the gooise or Dutch upper-class residence there was a smaller kitchen, as this group may have had servants – a role now played by carers. Here the furniture was elegant and appeared expensive. Bedrooms were institutionalised in appearance with just a few personal items and bathrooms large and clinical, demonstrating the value given to group living and reminding us of residents’ personal care needs.

The atmosphere in each home was also different; we were told that the ‘urban’ or cosmopolitan home may be more jovial than the gooise home. Each home exists independently and functions as a unit, so food is brought from the local supermarket and meals are prepared at home. Alternatively, residents can eat out at the café or restaurant. Family can join them as the restaurant is open to the public.

Choice is important, and people’s lifestyles reflect their previous habits. The two Indonesian homes were located at far ends of the village as this group enjoy walking so can take a stroll to visit each other. The idea of membership is important in Hogewey as it creates a feeling of belonging or ‘being in the right place’. The ‘homely’ residents may attend a baking group, while the gooise listen to classical music in a drawing room.

Outside each home people have their own sitting and garden area. The ‘homely’ group also had a garden shed equipped with a broom and spade as they might have previously enjoyed gardening. Social groups that reflect residents’ interests are offered, so people are encouraged to move around the different parts of the village to join in whatever is going on or to take part in various clubs and activities. A large group of well-supported volunteers work alongside qualified staff to support these social activities. Through relationships and activities, residents are enabled to live their lives as they wish, reinforcing their individual and social identities.

**Personhood and culture**

Kitwood’s (1997) influential concept of ‘personhood’ as ‘a standing or status that is bestowed on one human being, by others, in the context of relationship and social being’ has been the cornerstone of the person-centred care movement in the UK and beyond since the 1990s (Baldwin and Capstick 2007). Kitwood’s work integrates central aspects of a person’s experience of dementia, such as personality, biography, health, neurological damage and social psychology.

The emphasis on social psychology clarifies the importance of meeting service users’ social and emotional needs – identity, occupation, love, comfort, attachment and inclusion – through every person-centred interaction, while avoiding the damaging alternative in which people are excluded and demeaned, which Kitwood called ‘malignant social psychology’. In ‘bestowing’ personhood, social relationships are highlighted as the essential feature of high quality care. However, Kitwood’s work has been interpreted in literature and practice (Adams 2008) with emphasis on one-to-one relationships rather than the group or cultural relationships that may be inferred from the term ‘social being’.

People in care homes in the UK have opportunities to take part in similar therapeutic and social activities to those in Hogewey. ‘Singing for the brain’, reminiscence therapy, having their hair done, playing bingo and so on are offered in many care environments. However, these are additionally arranged, often by someone who is brought in, rather than springing naturally from the momentum of everyday life. Not everyone likes bingo or enjoys the music of Val Doonican.

Cognitively intact people in care homes can feel lonely (Age UK 2011, Alzheimer’s Society 2013). Perhaps this loneliness is related to a sense of social alienation that exists despite current concepts of good practice being based around meeting perceived emotional needs. The questions we ask when planning care reflect our focus on needs and risk rather than seeking to identify ‘who is this person?’ or ‘how do they live?’. Normal life involves an element of uncertainty, yet in the UK care planning for people with dementia aims for risk avoidance at the expense of emotional wellbeing and a person-centred approach (Clarke et al 2011).

Hofstede’s (2013) work on cultural values allowed us to compare UK culture with that of the Netherlands. The largest difference between the two was in the masculinity/feminity dimension, where results showed that Dutch priorities were about quality of life as opposed to British emphasis.
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on professional success. In attitudes to risk, the Dutch were more averse to uncertainty.

These results could be interpreted in different ways, but perhaps having explored the Hogewey alternative and become certain of its positive impact on quality of life, the Dutch response was to feel confident in developing the service. The question ‘how do they live?’ answered through the questionnaires completed by residents and families, reflects the importance of social identity in an individualistic society, a value we have in common and one illustrated in Kitwood’s (1997) ‘personhood’ concept.

Everyday life
Staff at Hogewey describe how residents are busy and active, and we were able to witness this. People with severe dementia, most of whom had little verbal language and poor orientation, contributed to running their households while enjoying culturally congruent activities with people with whom they felt comfortable, mutually reinforcing roles and identities.

There was minimal use of medication, including antipsychotics, and people remained active, living at Hogewey until the end of their life. We did not see reminiscence materials, rather people were occupied in everyday activities. In enacting the lifestyle, residents and staff make it real. Integrating the social and person-centred models offers an opportunity to acknowledge people as interdependent members of cultural groups where, paradoxically, individual identity is more naturally and consistently sustained.

The design that supports this starts from knowing the people, their approach to life, cultural and personal values and how these would be acted out in living a normal life. The physical environment was created to reflect and promote this, from the inside out, thus creating an appropriate environment rather than expecting people who have limited capacity to adapt to their surroundings. The environment becomes enabling so that people with severe dementia can carry out roles and activities that we in the UK do not associate with the levels of functioning of people in the later stages of disease.

The Hogewey environment is a deliberate and artificial creation, yet it does not feel deceitful. We were left with the impression not of ‘therapeutic lying’, but of a real, culturally congruent community verified by people living their lives. So, for example, we might have expected to find items from the past in the shop such as old-fashioned soap powders, but instead it was a normal functioning supermarket.

In essence we all construct our lives and lifestyles through the decisions we make over our lifetimes. This feels natural because we take it for granted, and people with dementia living at Hogewey can feel this too. People are naturally orientated to reality, because reality has orientated itself to them. Their emotions are validated – but this is automatically so because they are rooted in the truth of their current experiences.

The Hogewey initiative demonstrates that people with dementia can be valued, maintaining their status in society. They have freedom to choose to listen to classical or traditional music, to stay at home with others or walk about freely, to go to a posh restaurant or a café.

The truism that dementia is no respecter of status is proved false – it is others’ responses that make this so. There is no need for dementia to be seen as a social leveller or to result in a one-size-fits-all approach to care. The knowledge that people with dementia can continue to be themselves in their immediate and wider society, when provided with an enabling physical and social environment, leaves us with the responsibility to bring about changes in the services we offer.

Applying the model in the UK
The dementia-friendly communities initiative (Department of Health 2012) acknowledges the centrality of being a member of a community, the interdependence of local people and the need for everyone to be dementia aware, sensitive and supportive so that people with the disease can live well. This remains the case as dementia progresses. Ideally, creative and committed funding initiatives will allow us to develop our own sensitively designed living spaces where people with dementia can live in freedom and safety, contributing to their households and community.

Disseminating information about the Hogewey approach might even inspire like-minded people approaching retirement age and interested parties to commit to combining financial resources to promote community-living environments where those who develop dementia are supported and included as we all would wish.

In the meantime we can learn from the Dutch example and adapt existing environments to reflect some of the concepts that are applied successfully.
at Hogewey. It would be possible to make culturally congruent group living a reality, for example, by analysing people’s social values and enabling similar people to live together in small group zones, decorated appropriately, in care homes.

At Hogewey, local people are invited in and in the UK we could aim to invite people into care environments and reintegrate people with dementia in local communities.

Well-supported volunteers, integrated into teams, could take on the role of supportive friends rather than clinically orientated problem-solvers and accompany people with dementia to the shops and chosen activities, according to their wishes and previous lifestyles.

Conclusion
In Germany, Switzerland and Japan there are plans to create similar environments to Hogewey. Whether we also adopt the model or make use of principles we can adapt, it is time to reclaim the ‘social’ in Kitwood’s definition and apply this in groups as well as in one-to-one relationships. An environment that facilitates ‘normal life’ is made up of sensitively designed buildings inhabited by people in social relationships. The investment in this approach is repaid in the opportunities for people in later stages of dementia to truly ‘live well’ and in the message of hope that sends about our wider cultural values and the implications for the future of dementia care.

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