



# The experience of 'home' in dementia care

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## **'I am somewhere I am not supposed to be'**

You awaken in the early hours of the morning with a feeling of disorientation and strangeness. Shifting in your covers, you realise that the room that surrounds you is not your bedroom at home, but rather a communal dormitory with other sleeping bodies in beds mere feet from you. You are confused and frightened; moving to step a foot out of bed, an ear-piercing alarm suddenly shrieks through your head. The bodies around you stir awake, and turn towards you with irritation, telling you to 'stop it', to 'shut it off'. Another body opens the door of the room and bundles you back into bed. The alarm stops. After a while, confused, afraid, and inexplicably drowsy, you fall asleep again.

Wandering the hallways of this building later that day, you struggle to remember how you got here. Who are these other people? No-one will answer your questions. You touch your wrist where it hurts from earlier — a strange woman tried to remove your clothes and wrestle you into a bath so you struck out at her and demanded your privacy. Despite this intrusion, you surmise that you must be in a holiday home, and even talk to the others about how your family will be around shortly, only to hear them turn to one another and mutter 'delusions'. Saddened and confused, you sit down in a chair, and though others come to try to chat, you can't bring yourself to engage with anyone. You long for your own home — the pictures which hang on your wall, your green garden, the familiar scent of your own blankets, and the memories you've created there with your friends and family. Here, it is all unfamiliar.

## **When familiarity is lost**

As unreal as the above scenario may seem, it is one which is faced every day by many persons with dementia living in long-term care. Persons with dementia find themselves undergoing several transitions — not only does short-term memory decline in dementia, but general cognitive abilities, personality features and close relationships also change. As the disease progresses, families can no longer deal with the person with dementia living at home any longer, and many find themselves entering long-term care. This can be very difficult for both the person with dementia and their family, and can result in feelings of betrayal, loneliness and disorientation. Persons with dementia also often engage in what is called 'problematic behaviour', reacting to this upheaval in a number of ways:

- By constantly searching for exits, asking to leave, or trying to escape;
- By wandering around the residential home, seemingly aimless;
- By lashing out at caregivers, becoming physically aggressive;
- By refusing medication or food;
- By withdrawing from social interaction.

Much of this behaviour can be traced from the fact that these persons are displaced. They are no longer living at home, no longer living with their family. Instead, they are surrounded by strangers, often perceived as acting unusually, and carers, who carry out care activities with them that they may find intrusive and undignified. Moreover, these persons are living in a communal environment that, as illustrated by figure 1, is (by its very design) impersonal: carpeted floors are replaced by linoleum; thick, family-sewn quilts replaced by standard issue blankets; bathrooms accessorised by grab rails and hospital disinfectant. The impersonal nature and unfamiliarity of the environment leads to confusion and distress on the part of the person with dementia as they try to make sense of their environment and re-enact what they consider as 'home' in this unfamiliar setting.

## Displacement in home and identity

This research seeks to understand how persons with dementia create a sense of 'home' in long-term care settings, and by investigating how they remember their own homes in order to understand their aspirations of 'home'. Through this, I will be able to make recommendations concerning how we might be able to foster 'homeliness' in dementia care settings. By doing so, we can alleviate some of the difficulties faced by both carers and persons with dementia, and aid the quality of life and sense of independence of persons with dementia.



Figure 1: Interior of one of the dementia care settings featured in this research. Image: Kellie Morrissey.

Drawing from the work of Bachelard, who emphasised the sensory properties of 'home' in his 1958 book 'The Poetics of Space', this research places emphasis on the metaphor of the house as the 'home of memories.' Our memories, Bachelard writes, are sensory and deeply personal, and thus our memories of 'home' are constructed through our lived experience. Despite this degree of personalisation, 'home', to Bachelard, does not have to be a static place, as throughout our lives we move time and again, making each new dwelling place our 'home.' However, once we enter a nursing home, several things may stand in the way of our considering the place a home:

- The presence of unfamiliar others;
- The sense of being 'watched' at all times;
- The unfamiliarity and 'clinical' feel of the setting;
- The relative absence of choice and loss of autonomy.

It is true — we become attached to places throughout our lives; often so much so that these places and spaces become part of our identities. This so-called 'place identity' can be threatened by disruption to our living environment: think about how persons displaced by natural disasters are quickly labelled as 'victims', and how persons with dementia become 'patients' or 'residents'. Environmental psychologist Proshansky theorised that it is through our physical localisation that we learn many of our social roles — our roles in the home (daughter, mother), in the school (peer-group membership) and in the neighbourhood (ethnic group membership). Once persons are displaced and live in a dementia care setting, once their memories degrade and they are left with little stimulation, a lack of familiarity and a lack of remembrance of 'home' leads to a loss of a sense of self and purpose.

### **Creating privacy during transition**

Persons whose dementia is mild to moderate often suffer the most when they enter a long-term care setting — many remember their home and family and are distressed that they are now away from both. Others are not so sure of the details of their situation, but have the sense that they are now living somewhere that they are 'not supposed to be'. The transitions of these persons tend to be long and problematic, and as a result they may turn to wandering or aggressive behaviour in order to maintain their sense of self and make sense of their environment.

In order to adjust to communal living and to deal with the unfamiliarity of the environment, persons with dementia use what have been called 'resistance strategies' order to create a sense of privacy away from the 'gaze' of carers. These include:

- Chatting with others and selecting friends' groups within the care home;

- Selecting certain seating arrangements to facilitate 'hiding' from staff;
- Feigning sleep when not interested in a certain task or activity.

While much previous research on the topic of 'home' and dementia has focused on these 'resistance strategies', my research looks at the creative ways in which persons with dementia adapt the social and physical environment of long-term care in order to create a sense of 'home', resulting in increased familiarity and comfort within the environment. It also explores the ways in which people with dementia might like to experience 'home', and to understand what 'home' means to them.

## Methodology

My research is currently underway in two dementia care settings in the south of Ireland, which provide comparisons for each other — one a community hospital and the other a private dementia care home. My research uses ethnographic methodology — a type of research methodology which aims to give an 'inside view' of the culture and ways of living of groups of people – in order to understand the lived experience of residing in dementia care and how residents create a sense of 'home'. This is investigated via participant observation over the course of 18 months, and consists of a systematic process of taking field notes based around continuous involvement in the life and activities of the dementia care setting.

As well as observing and joining in in the life of the dementia care setting, unstructured, informal interviews and 'in-situ' conversation during creative activities allows me to bring the focus in tight to explore how persons with dementia would ideally like to experience a sense of 'home'.

Methodologically, this research also considers how persons with dementia might be fully involved in qualitative research as participants. To date, few studies have attempted to investigate the lived experience of persons with dementia in research, and instead have focused on caregiver accounts. This research investigates the experience of persons with dementia through creative methods (e.g., art and music workshops — some output from art workshops is seen in figure 2, above) which have been shown to aid persons with dementia to express emotions and help to retain cognitive ability.

## Findings

This research is currently ongoing; however, preliminary findings from this research are that persons with dementia create 'home' in dementia care in different ways:

- Through selecting seating arrangements in order to sit with friends;



Figure 2: Painting by participants during creative sessions. Image: Kellie Morrissey.

- Through inventing different scenarios explaining their situation — being served meals means that they are at a hotel, or in a café;
- Through domestic tasks — dusting windowsills and tidying up magazines;
- Through engaging in activities such as singing, dancing, watching favourite films and reminiscing;
- Through socialisation during time shared with others — sitting down to eat meals together;
- Through caring for each other — for example, reading the newspaper to another whose eyesight is poor;
- Through personalised objects and personalised environment — photos on the wall and family-made 'life storybooks';
- Through self-care and keeping up appearances — painting nails and curling hair.

Barriers to 'homeliness' have also been identified:

- Confusion over the identity of others in the care setting — staff and other residents;
- Being given medication and treated as a patient;
- The unfamiliar or clinical environment which lacks personalisation and causes confusion (due to layout issues or lack of signage);
- The behaviour of others — for example, the distress of one resident may cause another to become distressed;

- Locked doors, alarms and sensors which prohibit free movement through the care setting;
- 'Days out' — although therapeutic for most residents, the way in which they are handled can be problematic for others;
- Not being trusted or left alone with ceramic mugs or cutlery;
- Unmonitored television access can lead to distressing or generally unsuited/uninteresting material being seen;
- Having to conform to a certain schedule of eating, sleeping and socialising;
- Carer intervention in self-care and hygiene activities.

## **Implications and interventions**

The findings of this research have much to say on how daily life in a dementia care setting is experienced, with a particular focus on how persons with dementia experience and create instances of 'homeliness'. Further research will delineate the circumstances in which this sense of 'home' is experienced; through this understanding, we will be able to ameliorate the experience of dementia care settings in order to foster a sense of 'home'. This may be applied in carer/nurse training, in layout and activity planning for persons with dementia and in technological design. Applications of this research will lead to increased comfort, familiarity and independence, and a decrease in problematic behaviours and distress for persons with dementia.

With an ever-aging population and €1.69 billion spent on dementia care in Ireland each year, it is imperative that every area is investigated in order to alleviate not only the financial and societal burdens that the disease entails, but also to understand how the empowerment and high quality of life of persons with dementia can aid in promoting creativity, participation and independence. Through understanding and fostering 'homeliness' and familiarity in the care context, this research will do just that.

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