



Imid innur id-dar

I want to go home

The government recently published an evidence-based national strategy for dementia which recommends that all buildings should be designed in a dementia-friendly way. **Dr Claude Bajada** speaks to **Perit Alexia Mercieca** and **Dr Charles Scerri** to find out more.

What day is it? He cannot remember. It is awfully cold and rainy for summer. He cannot remember his brother's name. He is his closest friend. Each day is new and scary. It makes him sad. Why does everyone want to take him to new places? He wants to stay at home, it is familiar and comfortable. He has dementia. This is not a normal part of ageing, but it is a neurodegenerative disease, a progressive condition that affects the brain, slowly damaging it from within.

Memory loss is part of the condition that is dementia, but it is not the only symptom. People with dementia have problems with planning and organisation. They become confused when taken out of their usual

surroundings and find it difficult to control their emotions. It is a disease that can affect different aspects of brain function and is incurable.

Incurable does not mean untreatable. If doctors catch dementia at an early stage, medicines can slow its progression. But even with the best medication, disease progression is inevitable. How can our society ensure that a person with dementia can experience a good quality of life? Architect Alexia Mercieca, a researcher in the Faculty for the Built Environment (University of Malta), studies how building design can help people with dementia. Doing this requires a shift in the way we design and build structures.

'The typical care space in Malta is a corridor with rooms double banked on both sides, and a person will just walk up and down along it. ▶



3d renderings produced by Jonathan Avellino & Christopher Azzopardi

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It is a bit like having a hamster in a wheel going round in circles,' explains Mercieca. Places should be familiar and safe, where people with dementia can feel at home. This means understanding what the issues are and catering for them. '[One of the biggest] issues is wandering. We tend to think of this as 'misbehaving'. But wandering is essential to a person with dementia. So how can spaces be designed to actually allow those with dementia to wander safely? How can all the necessary safety features be integrated [and] camouflaged within a building, while still keeping it as close to 'home' as possible?'

In the 1998 film *The Truman Show*, Truman Burbank (Jim Carrey) lives in a made-up reality. Unknowingly, Burbank is the star of a reality television programme in which his entire life is

filmed by thousands of cameras. All the characters in his life are actors and even though he does not know it, he is leading a sheltered life, controlled by others. The audience sympathises with Burbank as he tries to break free from his manufactured life. But Carrey portrays a healthy middle-aged man who is in full possession of his cognitive functions. Now, what if we had to imagine that his character had dementia—would a sheltered environment be therapeutic for him?

Mercieca explains that the Netherlands have been experimenting with a similar concept for people with dementia. Just outside of Amsterdam, a nursing home called Hogewey caters for 152 patients with dementia. This is a speciality nursing home that includes a fully functioning village. There is a park, a supermarket, a restaurant, bar,

and a theatre. The only difference from other villages is that the members of staff are also the patient's carers. It is a sheltered environment that looks and feels like a village but is in actual fact a care facility.

Mercieca is excited to implement such a project in Malta. The first step is to provide a solid evidence base to support the idea. As part of her Ph.D. at the University of Edinburgh, she is studying the situation in the UK and in Malta. She is also investigating what was done elsewhere and is working to adapt best practice techniques to the local scenario, taking into consideration cultural shifts. The aim of the Ph.D. is to produce a set of guidelines to regulate dementia design in Malta. This fulfils one of the recommendations of the national strategy. Mercieca is ardent



Perit Alexia Mercieca.
Photo by Edward Duca

to underline that research shows there is 'less violence, less aggressiveness, less need for tranquillisers, and less medication [in adequately designed dementia-friendly accommodation].'

The government is backing Mercieca's project. In a statement to **THINK**, Parliamentary Secretary for Rights of Persons with Disability and Active Ageing Justyne Caruana, said that 'Mercieca's work 'would have a huge and positive impact especially on individuals with dementia and those who care for them. Dementia-friendly environments are essential in creating dementia-friendly communities where individuals and their caregivers are empowered to have aspirations and feel confident, knowing they can contribute to their communities, have more choice and control decisions that affect their lives. This would be of great benefit to society in general and is a cornerstone in eliminating stigma.' She stated that 'when new buildings are designed, they will take this approach from the very start,' taking into consideration the guidelines developed by Mercieca in her research. ➔

WHAT IS DEMENTIA?

Dementia is not a single disease. It is a word used to describe a group of neurodegenerative diseases that cause a global cognitive impairment. Many people think of dementia as a disease that causes memory loss but memory is not the only brain function that is affected in dementia. In fact, in some types of early dementia, memory is usually spared. People with dementia often have problems with thinking, planning, social skills, and language. As the condition progresses, it causes problems in the person's everyday life.

TYPES OF DEMENTIA

Alzheimer's Disease

The most common form of dementia. It is the condition that comes to mind to many people when they think of dementia. People with Alzheimer's Disease often start off noticing that their memory is getting worse. As the disease progresses, other brain functions become affected.

Vascular Dementia

Poor blood circulation to the brain causes small areas of the brain to die off, leading to dementia. The symptoms of vascular dementia depend very much on which areas of the brain are affected.

Lewy Body Dementia

This is a type of dementia that has a lot of symptoms in common with Parkinson's disease. Besides memory loss, patients with Lewy Body Dementia also shake, move slowly and they can also experience hallucinations.

Frontotemporal Dementia

This is an uncommon type of dementia. This is one of the strangest types of dementia because memory can be spared. People with this type of dementia can change their behaviour or they may stop understanding the meaning of words.



FACTS

- Dementia is not a normal part of ageing
- Malta has a National Dementia Strategy
- Alzheimer's disease is the most common type of dementia but it is not the only one
- Dementia Helpline: 1771 (24 hour service)
- Dementia Activity Centre: 2122 4461
- Dementia Memory Clinic: 2208 2000
- Malta Dementia Society: www.maltadementiasociety.org.mt

But Mercieca does not want to wait to complete her Ph.D. to make a difference. She wants her students to design a dementia-friendly space right away. She recently approached Parliamentary Secretary Caruana who immediately welcomed her idea. 'They were really excited about it and took it on. They gave us a garden at St Vincent de Paul [Residence] as a case study', notes Mercieca enthusiastically. 'One of [the students' proposals] was a reinterpretation of a typical Maltese village [adapted from the Hogewey concept], bringing together traditional elements in a

contemporary setting that aims to provide a familiar environment and is, most importantly, safe. In this space you would have a hairdresser, a little grocery shop, a post office. [They are] structures that allow the residents to perform simple activities but which are rituals, which are very important.'

The co-founder of the Malta Dementia Society, Dr Charles Scerri, is excited about these developments. 'Alexia is a godsend,' says Scerri, while lamenting that Malta's main problem is human resources. Despite this, he explains that Malta has made tremendous advances in the field of

dementia care. Ten years ago things were bleak. Families would try to hide the condition from society. Now, Malta is one of the few countries that has an evidence based National Dementia Strategy. The strategy even has a dementia-friendly version. 'We made a difference,' exclaims Scerri. Now, Malta must take up the challenge to go one step further to support cross disciplinary research into dementia and to create, evidence based, dementia-friendly environments like Hogewey. 'It will happen within the next five years,' says Scerri.

What day is it? He cannot remember. It is still cold outside but he is not sad. He lives in the new residence that has just opened. This is a dementia-friendly residence. The carers are his friends. He is about to go into the garden with them. He can also go to the little grocer shop. Their oranges are spectacular. At the end of the day he goes to bed. He likes his room. He is safe. He is home. **T**