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Designing for People with

Dementia



Architect and Professor of **Architectural Practice** at the Bartlett School of Architecture. University College London, Niall McLaughlin describes his research into dementia and Alzheimer's disease. He explains the thinking behind his practice's design for an Alzheimer's Respite Centre in Dublin, and his subsequent collaboration with fellow Bartlett Professor of Architecture and Experimental Practice Yeoryia Manolopoulou in the creation of an installation about these themes at the Venice Architecture Biennale.

Niall McLaughlin and Yeoryia Manolopoulou, Losing Myself, Venice Architecture Biennale, 2016

The drawing was created from 1,250 sheets of tracing paper, which were then digitally scanned. Each sheet contains a filmed animation of a hand that draws. It describes only those things that can be perceived by someone with dementia in a particular room at a particular time. The drawing hand is a stand-in for the perceiving mind, assembling a world from fragments of sensory evidence.

Alzheimer's disease is a progressive condition that erodes the ability of neurons in the brain to transmit signals to each other through synaptic connections. This is caused by an accumulation of proteins known as plaques and tangles. It has no single pathology, but its progress erodes higher synthetic cognitive functions first, before degrading established memories, language and eventually the basic process of bodily regulation. It progresses at different rates in each individual, and it is not curable. Each manifestation varies, but there is a common pattern to the progress of symptoms that was of interest to us. People lose their ability to navigate, remember and to situate themselves in a coherent setting.

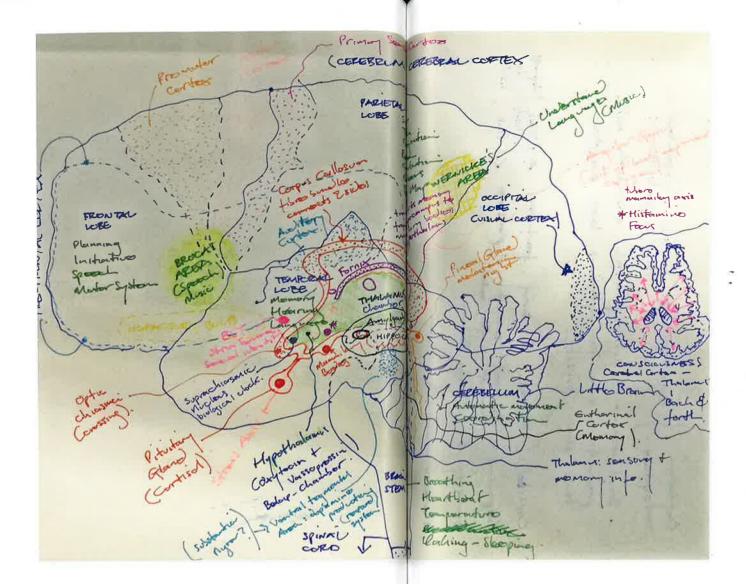
In 1999, Níall McLaughlin Architects was invited to design a respite centre in Dublin, for people with dementia. It was an unusual commission, because this kind of work is often given to architectural practices that claim specialism in the subject. In this case, our client, the Alzheimer's Society of Ireland, set us a challenge. They would teach us what they knew about dementia, and we would teach them what we knew about buildings. Together we would make the first specialist centre in the country. In their words, this case-study building could serve as an example in both its successes and its failures. This would inform future centres they hoped to build. We were encouraged to undertake as much research as we could and to use it to educate the client. It was an exceptional brief and it started a train of thinking that continued through two decades.

It took 10 years to raise funds and complete the building. During that time, we read everything we could about dementia and collated all of the available guidelines. We spent as much time as possible in the existing centre, an old converted primary school, talking to people with dementia and to caregivers, and watching the daily round of activities. When someone has dementia, it is not always possible to ask direct questions and expect equivalent answers. We tried a more open conversation in which a topic would be discussed informally and people could participate. I might say: 'I like this room here, it's not like my living room at home.' Then someone would start to talk about their own home. Often, 'home' would be somewhere else and long ago. For people with dementia, the twin anchors of time and place often slip. This was enlightening for us, and not confusing when we got used to it. We learnt about their deeply remembered experiences. If we can listen carefully to our clients and understand their world, then we can make new worlds for them. With dementia, this is especially difficult, as people are reporting back from a cognitive state that we can hardly begin to imagine.

## Damage to Spatial Perception

To understand the basic processes that underlie our perceptions of navigation and situation, we spoke to neuroscientists and neuropsychologists at University College London. We met Kate Jeffery and Hugo Spiers who both explore the functions of dedicated cells that are implicated in navigation. We spoke to Sebastian Crutch, who works with posterior cortical atrophy, a form of dementia that degrades visual perception.

Our sense of our own situation in time and space has its origin in sensory information that enters the cranium,



Niall McLaughlin,
Regions of the Brain,
London,
2015

This felt-tip-pen sketch from McLaughlin's notebook is an attempt to hold together the complex anatomy of the brain and to understand how different regions care for various aspects of perception and cognition. through apertures such as the eyes and ears, in the form of tiny electrical and chemical signals passing along chains of neurons. The first level of processing takes place in the primary sensory cortices, which deal with light, sound, smell, touch, acceleration, movement and balance. This information is originally dispersed in separate parts of the brain. Then, groups of neurons encode progressively more complex levels of input by reinforcing synaptic connections, allowing signals to cascade through specialised interconnected clusters producing information. As the signals stream down into deeper levels of the brain, they are associated into groups and sets that interact to identify entities in the outside world.

To establish coherence, these information streams are captured and held in a matrix, allowing the brain to position them in relation to each other in both time and relative proximity. The neurons that deal with this task are not immediately connected to an external sensory environment. They process already coded data and integrate it. This is the function of a part of the brain known as the hippocampus. Sets of specialised cells create this spatio-temporal matrix, which acts like a net that allows the multitude of encoded data-streams to place packets of information in relation to each other and generate the perception of a legible scene, set at a particular time. Kate Jeffery elegantly describes the hippocampus as a 'stage set'.

I picture the hippocampus, and associated functions in the entorhinal cortex and the retrosplenial cortex, as a nexus of incoming and outgoing streams. While they receive and place data from the outside, they also appear to send sets of integrated perceptions to the outer cortices of the brain where they are laid down as long-term memories. This seems to be the place where our sense of space and our conception of past and future are held together under the aegis of episodic memory.

These beautiful processes at the centre of our perception hold time and space together, showing that they are inextricably linked. We cannot remember without having a scene to place our memories into. The faculty of storing information in time and knowing our location in space is the same thing. We might call it the sense of being situated. Everything we think we are flows out from this source. It is here that dementia does its worst work. The pathology of the disease begins with and progresses from the sites of these higher synthetic functions, working towards the outer cortices where our older memories reside. I can't say what it is like to have dementia, but I imagine it is like finding that all the bits of your world begin to slip apart and won't make sense in relation to each other. The centre can no longer hold them together and so they drift as unfathomable fragments.

### The Architectural Plan

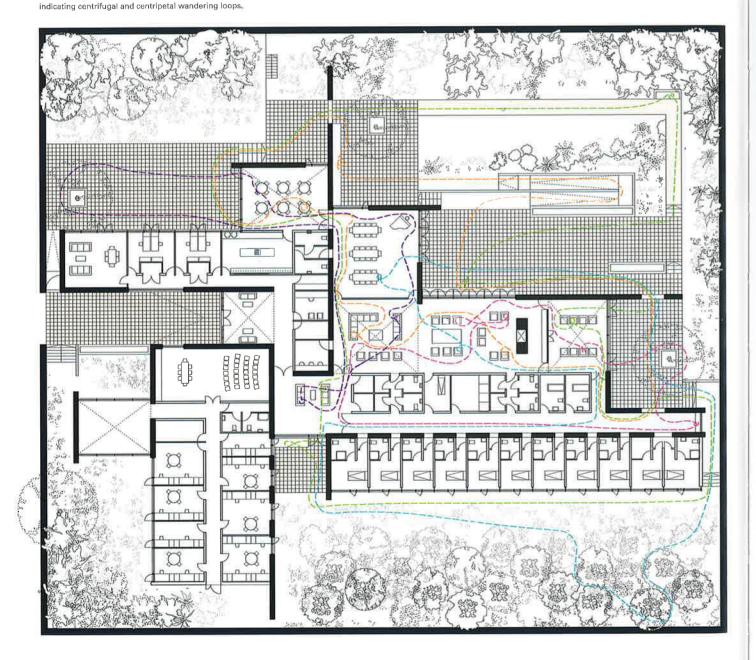
As part of our research we collected a suite of drawings and paintings by Paul Klee. These seemed to represent the dilemma of the individual negotiating space, using memory and projection to navigate. It made us think that the ability to conceive of space and to situate yourself within it is learnt from earliest childhood. A newborn may not know that she is not her mother; she must first become aware of her independent body with its own boundaries, and then the space that opens up between her body and that of her mother. This is a place of intimacy. As this child moves out to negotiate the room, the house and the family, she is socialised. At the same time, she acquires a spatial understanding of the world that extends out beyond her. Little by little she becomes aware of the somatic space of her own bounded form. She learns about her capacity for action, and how that can be measured against the openness that she is beginning to explore. This openness is not innocent or empty. It is thick with social and psychological meanings; of taboos, permissions and desires. We think the acquisition of our own spatial sense is equivalent to the learning of language. It is not simply that it describes the world, but that the world can only be understood through it. It is the medium of experience and therefore the cornerstone of the self. If, in later life, dementia causes the gradual deterioration of our ability to navigate and remember, it must also erode our concept of who we are in our deepest identity.

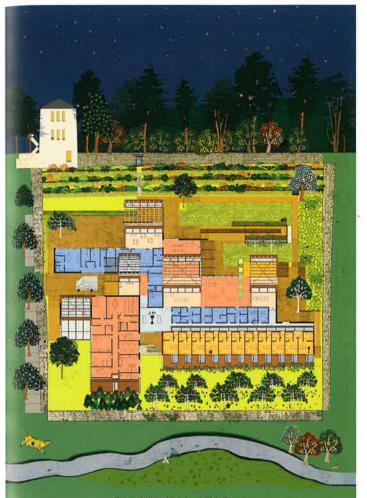
We thought about the experience of dementia as a continuous present tense. You are unable to remember where you have been and therefore cannot project where you might go. We wondered what it might be like to experience the world as an ongoing unfolding, held between empty expanses on each side. The sense of the past moving into the future must dissolve. The intuition of sequence, of one event or place following another, would collapse. Some architectural plans seem to address this predicament. The memory of Luis Barragán's house in Mexico City (Casa Luis Barragán, 1948) allowed us to think of passing through a succession of rooms, each one linked to a different garden until, eventually, you return to the room you first came from. So too

Níall McLaughlin Architects, Alzheimer's Respite Centre, Dublin, 2009

Miniature drawing showing the new building set within the walls of an old kitchen garden, The spaces between the building and the old walls create a sequence of new orchards, courts and gardens.

Plan of the building showing a sequence of rooms opening out into different gardens, each associated with times of day and a variety of smells, textures and colours, The drawing is overlaid by dotted lines





Rudolf Schindler's Kings Road House (Schindler-Chace House, West Hollywood, Los Angeles, 1921) and Mies van der Rohe's unbuilt Brick Country House (1924). They allow that same apprehension of moving through an unfolding progression of spaces. Dementia is often characterised by continuous wandering and open searching. We conceived of a plan where you might ramble away from the lively central social spaces to other rooms, looking out onto different gardens, but your journey would eventually bring you back to the space where you started out. This was the basis of the building that we designed. It was set in an old stone-walled garden. Within it, we placed a timber building that created a suite of smaller gardens, each receiving light at different times of day. Every garden had a room looking on to it and you could meander through these rooms in an open circuit.

# The Building in Use

The building was completed in 2009. In the decade that it took to build it, the client changed from a voluntary group to a professional cohort, managed by the regional health authority. The change in approach was evident. The building was managed more formally with a much clearer designation between staff and clients. The glamorous little room at the centre of the plan, designed as a hairdressing salon, was converted into a nurses' station. The contemplative prayer room, looking into a secluded court, was shut off and re-designated as a staff training room. The gardens were progressively closed off to avoid accidents. With fewer volunteers, the staff were less able to monitor the space, and doors were locked to prevent wandering. When I revisited the building, I sensed that the ethos had changed subtly from spiritual welfare to physical safety. I brought my plans and observations to Lesley Palmer, Chief Architect at the Dementia Services Development Centre, University of Stirling. She thought that what we had designed could have worked well, but needed a certain style of management, where individual autonomy is valued differently in relation to risk.



The building is made from a collection of timber lanterns set within old garden walls, creating a sequence of courts, orchards and lawns all linked together.

My reflection on this experience is that a building does not have agency in its own right. Instead, the role of this building is to frame the activities of those people who are being cared for and for those involved in caring. The difference between cared-for and caring seemed less obvious with the voluntary group as our client. The roles were more rigid in the professional cohort and were clearly divided into passive and active roles. If the nature of the caring community changes and the building remains the same, a disjunction emerges. This gap then enlarges as the managers of the building perceive that it is not serving their immediate goals. They make small alterations, and each change enhances the disjunction and fixes it into the building.

The building is still, at its heart, a daisy chain of high bright rooms looking onto gardens. The environment seems to have a positive impact on anxiety, orientation and wellbeing. On my last visit I had a touching conversation with a woman who was wandering around following the walls of a room. I asked where she was going and she said she was looking for the stairs. Since there are no stairs, I asked why that was. 'All my things are upstairs,' she replied. In the uncertain world of dementia, our carefully conceived building was already haunted by other places, charged with their own intense and personal meanings.

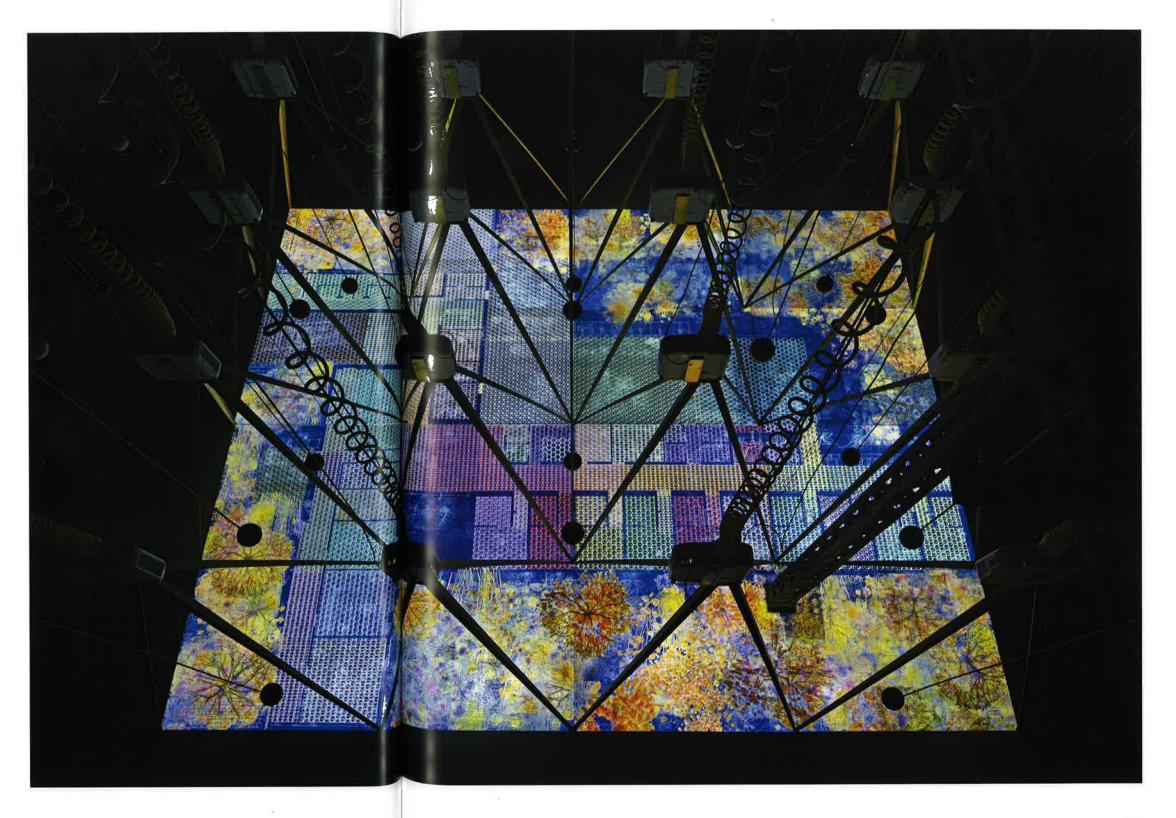
### The Plan Revisited

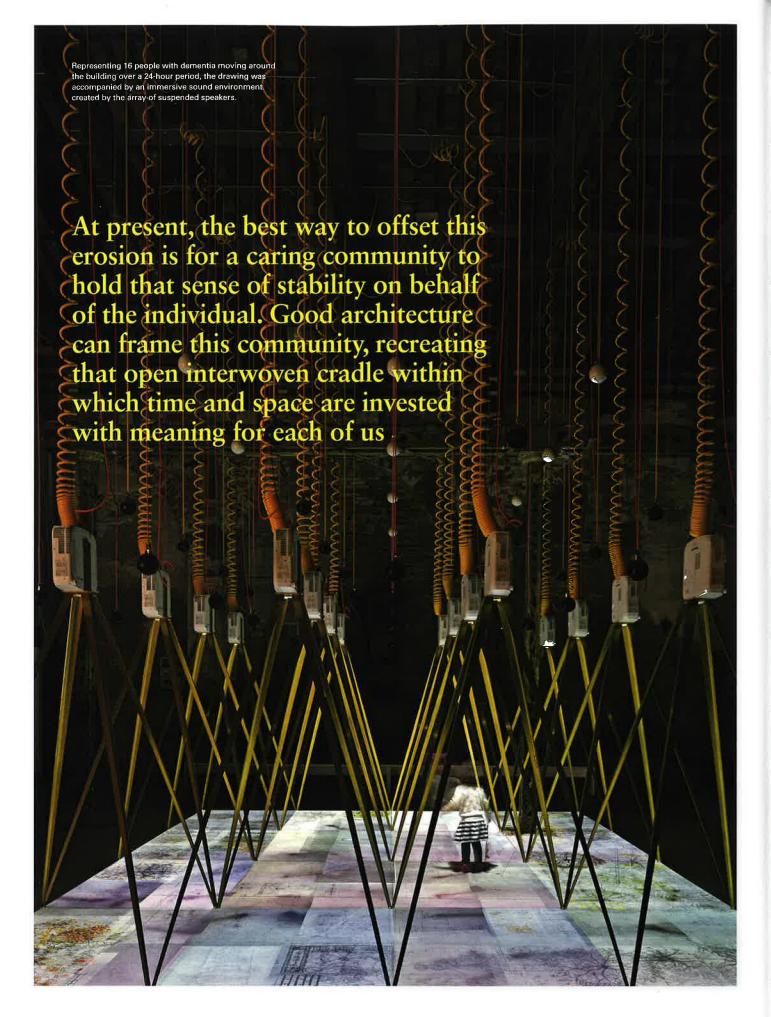
In collaboration with the architect Yeoryia Manolopoulou, we made a drawing of the building for the Irish Pavilion at the 2016 Venice Architecture Biennale. *Losing Myself* represented the plan of the building as it might be experienced by different people with dementia. A typical plan shows a horizontal cut through all of the building all at once: each room is simultaneously visible. With dementia, this conception of the building becomes impossible. You might only be able to apprehend fragments of the whole, based upon immediate perception.

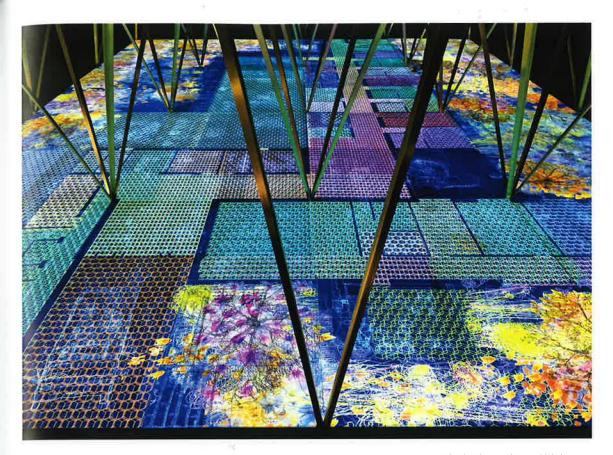
Niall McLaughlin and Yeoryia Manolopoulou, Losing Myself, Venice Architecture Biennale, 2016.

Losing Myself is a redrawing of the plan of the Alzheimer's Respite Centre in Dublin from the perspective of people with dementia, projected onto the floor of an old factory building in Venice's Arsenale by an array of projectors resting on brass legs. All of the data was streamed down cables from the ceiling. The circular dots are suspended speakers.

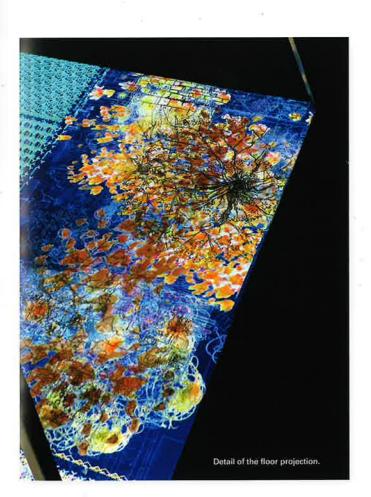
Losing Myself represented the plan of the building as it might be experienced by different people with dementia. A typical plan shows a horizontal cut through all of the building all at once: each room is simultaneously visible







above: The drawing overlays multiple layers of perception, including the changes in the day and the seasons, individual fragments of perception and the deep activity of grid cells and place cells in the brain.



The drawing was assembled by overlaying the imagined experiences of 16 people who use the centre – each one was represented by one of a team of 16 draughtspeople. They worked together to make a new plan in which they only drew what would be apparent to someone with dementia at any particular time. That perception changes as they move around the building through a 24-hour cycle. It contrasted the comprehensive, allocentric properties of a typical plan with the fragmented and necessarily egocentric perceptions of individuals who are moving through the spaces, but unable to hold the pieces together.

The process of making this drawing allowed us to reflect on what we had learned about dementia and about buildings over the 17-year period since the building was commissioned. Our apprehension that we inhabit luminous places, that hold their identity within the flow of time and the extension of space, is created by showers of charges cascading through clusters of neurons in the darkened interior of the cranium.

With dementia, biochemical changes to the connections within these clusters erode the comprehension of a stable self, situated in a coherent place. At present, the best way to offset this erosion is for a caring community to hold that sense of stability on behalf of the individual. Good architecture can frame this community, recreating that open interwoven cradle within which time and space are invested with meaning for each of us.  $\varpi$ 

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