Recovering "Home": Settling the Unsettled Mind

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of the requirements for the degree of

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Canada

"I always thought of myself as a house. I was always what I lived in.
It didn't need to be big. It didn't even need to be beautiful. It just needed to be mine.
I became what I was meant to be. I built myself a life.
I built myself a house."

- George Monroe (Life as a House, 2001, Film)

"Then close your eyes and tap your heels together three times. And think to yourself,
'There's no place like home.'"

- Glenda, Good Witch of the North (The Wizard of Oz, 1939, Film)

Abstract

The feeling of emotional and mental displacement through physical displacement is most evident during dramatic life changes for example, moving from one house to another. During this time the individual must rethink not only where they are, but also who they are. During the course of this discussion, the connection between individuals and their personal environment will be explored and the role of autobiographical memory in architectural design assessed.

The concepts of identity, memory and 'home' within the context of the retirement home and Long-Term Care facility will be researched and evaluated. These terms will be defined in relation to the importance of personal environments throughout our lives, concluding the discussion through what is often considered a 'final home;' the care facility.

Extending this to a design concept, this research will be used to explore the opportunity of a community church to become a tool for remembering and, through the appropriation of an existing building, a connection to past experiences and events within the area. The church will be used to physically bridge the gap between the 'family home' and the retirement home, through a community centre space open to the public. The design of Prospect United Care Home will embrace the sensorial and emotional experiences necessary, but lacking in present facilities.

This design concept will focus on dementia care and the benefits of gradually aging within the comfort of one retirement community, in order to settle the unsettled mind. This model favours permanency by allowing a long-term connection of person to place as they deal with an evolving illness. Memory loss challenges not only the individual dealing with the effects of their disease, but also their loved ones, and care providers. The design of retirement homes and long-term care facilities should embrace the emotional connections to environments of the past, present and future of everyone inhabiting the space. Only once the individual feels "at home" can the mind once again be settled and their identity continue to be defined.

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Finally, I want to say thank you to my husband, Robert for believing in me. You have been my support system, my partner and my friend for the entire journey. It's been quite the adventure so far, and I have loved every minute with you. This is only the beginning.

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Prologue

Pieces of Myself

I carry with me, pieces of myself. Small trinkets, nothing valuable, but each one of them gives me moment for reflection. No one would ever look at these parts of me and call them beautiful. To the rest of the world their insignificance would be cause for removal. No one would even acknowledge them as something worth reflecting on, but each of them shines a light on to who I am.

I can't tell you why I keep them with me, it's not really because I love them. It's more because they are so deeply tied to who I am that I can't breathe without them. I have them sorted, placed in a particular order, perfectly spaced so that they don't interfere with each other. Everything has its place. It comforts me to know that they are there. I know where to find them, and I know who I am.

Nothing is right; the world has completely changed. The familiarity of what I know and my current situation is at odds with one another. The noisy street, the constant buzz of conversation, and the unfamiliar smell of hot pavement, I am far from the familiar comforts of home. Everyone is hungry with excitement, the walls echo with their screams of laughter and tears of joy. Why am I the only one who seems so lost? It appears that in a sea of individuals one person can be drowned by their collective wave.

People bustling, passing me by. A few acknowledge my existence, but most do not. How can they, when even I don't know where I exist? I search, I see nothing familiar, and I look for the pieces of myself, something to connect me to what I know. Those pieces are scattered now, continually surprising me when I see them out of the corner of my eye.

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Some are packed up tight in boxes, piled in dark corners, others left strewn about for the rest of the world to see. I keep searching, hoping I will find some form of guidance. To completely abandon these pieces of myself, to move forward and shed their hold on me, would be to abandon who I am. Who am I without them?

In the middle of the night, when the world is thick with darkness and it seems that I am lost and found all at the same time, the pieces of myself come to life. Objects flash in the corner of my eye; reminding me they're still there, reflecting in the moonlight. I focus on the corner of the room; the glow of the moonlight splashes through the curtains, as each corner has been set like a stage for a new scene. I begin to rearrange my insignificant trinkets, giving them a new order and new life. The possibility of past and present merging becomes unmistakably clear as dawn fills the room.

Hope fills my lungs. As I breathe in the fresh, cool, crisp air and feel the warmth of the sun kiss my face before it dips behind the clouds. I am me again. Pieces of myself still call to me, peeking out from behind the shadows as the sun dances across the room. I know they are there; I am reminded in the morning light. But as the daytime comes and the wind brushes through the trees, the harsh light no longer blinds me. A soft light now sparkles through the curtains and comforts me as I think of home.

Introduction

One of the key issues of the 21st century is the growth in numbers of Alzheimer's Disease (AD) and dementia patients in an aging population. Increased demands will be placed on healthcare and gerontology care as a significant portion of the population in North America retires. According to the Alzheimer's Society of Canada, "[c]urrently, there are 500,000 Canadians living with Alzheimer's disease and related dementias, a number that within a generation could reach more than one million people across the country."¹ As this number rises, memory loss and its lifestyle challenges is becoming a more widely accepted and discussed issue with baby boomers and their children. While the stigma of a dementia diagnosis is still a difficult reality, the support community and its resources is widening across the country.

Designing for dementia has become a priority in healthcare settings, as an understanding for individualized attention is perceived as both desirable and necessary. 'Memory care units' (MCU) within

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Image 01 – Exterior, Colonel By: Retirement Living by Revera, Ottawa, Ontario.

Image 02 – Exterior, Peter D. Clark Long-Term Care Centre, Ottawa, Ontario.

long-term care Facilities (LTC) and Retirement Homes are growing in numbers, as the unique nature of these symptoms are embraced in a more focused design approach. Specialized ‘Memory Care’ retirement homes and communities built to support individuals and their families are being constructed in North American and worldwide. There have been many design methods, including; person-centered design², exploration of advanced way-finding techniques³, personal expression through interior design⁴, and creating home-like settings.⁵ Each of these has their advantages and has proven to advance our ability to care for those with cognitive impairment. However, what they seem to be lacking is an ability to individually support an individual’s personal and emotional connections to architecture and place, as it defines their memories and identities, as well as an understanding of what it means to be ‘at home’ within the dwelling.

...

Design has become very standardized in gerontology healthcare. Currently memory care units and Long-term care facilities are designed and operated much like a hospital. Long-term care has attempted to modernize, however, due to government restrictions in funding and lack of space, their ability to assist doesn’t reach as far as it could. Retirement homes attempt to bridge the gap between the family dwelling and the Long-term care facility by creating a more ‘home-like’ atmosphere, or even mimicing the qualities of a boutique hotel. They

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attempt to bring together the necessary medical services while allowing people to live in comfort and luxury. However, these facilities provide little opportunity for an individual to self-reflect and add their own personality to a space. This individualized attention to space is important to people, as they develop their identity throughout their life within and through their dwelling.

In the book, *The Psychology of Home*, Barrie Gunter discusses how the process of inhabitation is important for developing rich and lasting memories that help form our identities. He best summarizes this concept in the following quote; “[t]he meaning of our home is defined by the experiences and relationships we have enjoyed there. These include ongoing, permanent relationships as well as special events or occasions that we have celebrated with those close to us. The home is therefore a repository of memories — happy and sad — that define who we are.”⁶ Gunter’s definition of ‘home’ asks us to consider our individual relationships with architecture and reminds us that who we are is often defined by where we live and have lived.

The design of retirement homes and long-term care facilities could benefit from this concept of dwelling, as it is put forth by Gunter. For the purposes of this research, his writing reminds us that when considering the places we live, our dwelling serves as a canvas, filled with layers upon which we have built our identities. When we choose to, or are forced to move away from our dwelling we break the connection that we had with that space, and wipe clean the layers we built. When we

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move from the environments that make us feel settled; we need to be given the opportunity to create a space that will echo our emotions and personalities in order to find comfort and security again.

Emotional connections to our dwellings are so strongly tied to our habits, personalities and our identities that over time our houses become an extension of the mind and the body. 'Home' is a process of uncovering our emotional connections to space and understanding how we have come to mentally inhabit our dwelling. Once we have fully embraced the house as an extension of self, our relationship with it becomes richer. Similar to the skilled craftsman and his hammer, when you know your dwelling inside and out, it is no longer an object, but an extension of who you are as a person. In the essay, "The Role of Domestic Architecture in the Structuring of Memory," Tonya Davidson discusses the role of memory in identity and dwelling. The essay looks at how houses can remember and their role in our lives as we inhabit them.

Through this exploration, she discusses Bernard Jager's interpretation of displacement; "[w]e are seldom immediately at home in a new place, and we all need a period of apprenticeship with tools before they can become fully useful to us – before they can fully function as extensions of our body. Inhabitation always includes within itself a form of habitation. "To inhabit" refers to a kind of having (habere) that permits us a radical access to material objects and allows us to treat these objects as extensions of our own body."⁷ From this, we can posit that to inhabit the house means to treat it as an extension of the body

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Image 03 – Concept of 'Phantom Limb'

and mind. Over time, we make our mark on the spaces we use. We alter them, we shape them, and in many ways they shape us. Through the process of inhabiting space and developing our identities through it, emotional connections are formed with the architecture we dwell in. Our most cherished places become architectural extensions of the mind and body, as we grow to accept them as a part of our identities.

...

As discussed, and will be examined, the architectural extension of the body and mind can be thought of as an additional 'limb' that we inhabit, so that it becomes a part of us. When the connection is broken, due to a forced or voluntary move, the 'limb' is disconnected from the body and mind; leaving us feeling unsettled. In the place of the now missing extra 'limb' the individual can begin to feel the effects of a 'Phantom Limb.'⁸

In medicine, this phenomenon usually refers to people who have undergone either a medical or non-medical amputation procedure, and who still have the sensation that the limb is connected to the body. While most people with 'Phantom Limb Pain' or 'Phantom Limb Sensation' are amputees, many individuals who were born with missing limbs have also commented that this 'Phantom Limb Pain' haunts them throughout their lives.

This sensation is often both physically and mentally painful for individuals, as they attempt to reconcile the visual, mental and physical reality of their bodily disconnect. What will be explored in this research

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Image 04 – “Phantom House” - Judith Doyle

is how this feeling might be compared to the feeling experienced by a person who faces leaving their life-long dwelling. By examining the way that patients who are mourning the loss of their amputated limb can ‘heal’ their mind by training it to rethink the limb’s connection to its environment, we can reconsider how an individual mentally and physically connects to their dwelling and attempt to alleviate the stressful effects of dementia, such as short-term and long-term memory loss, as well as mood and behavioural changes. If we accept this proposition, then in order to restore the feeling of being whole again, a system of creating and reconnecting with our ‘Phantom Limb,’ or in this case, our ‘Phantom Home’ might help in a healing process, connecting to a new space and making it home.

...

Canadian artist and scholar, Judith Doyle, through systems of artistic narration and three-dimensional animation, proposed a solution for repairing the broken emotional and visual connection in architecture.⁹ She created images and videos that reconstructed the dwelling and overlaid it with emotional cues, like family photographs and sounds. However, while Doyle attempts to reconcile emotional states with visual images, what her research and three dimensional creation seems to lack is the bodily connection to memory and ‘home’ that can only be experienced through the merging of all the physical senses and a process of inhabitation with space over time.

Donato Bramante, a Renaissance architect (1444-1514),

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Image 05 – 'Santa Maria presso San Satiro'

Image 06 – Interior of Rideau Street Convent Church as exhibited at the National Gallery of Canada. Photo: Malak, NGC/ MBAC, 2001.

addressed the lack of tangible space to complete his church choir, by conceptualizing lost space. He presented a very different option for dealing with the idea of prosthetic memory. Bramante explores the ability to 'trick' the brain and the individual with his bas-relief trompe-l'oeil backcloth in the choir of a church through an intuitive understanding of the importance of combining the physical, visual and emotional connections.

Through the later exploration of both of these scholars' work, and the exceptional example found at the Rideau Street Convent Chapel in Ottawa, we will begin to piece together how architecture and the thoughtful use of space might be used to serve as the link between broken physical and emotional connections. This will be discussed in greater detail in Chapter Four of this thesis.

...

In Chapter Five, when we consider the goals of a memory care unit (MCU), this thesis will specifically explore the settling of the unsettled mind of the elderly individual with dementia. As we will discover, people with cognitive impairments see the world in their own way. As short-term memory fades and only long-term memory resides, it becomes evident that their present environment no longer matches their internal domain of understanding. Most often, they live in the past and do not have the resources to change the environment around them to match their mental state. A mentally healthy person can see the stagnation as well as the changes in their environment and anticipate their needs and

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Image 07 – Prospect United Church,
October 2011 - Prospect, Ontario, Canada.

desires for the future. An individual generally has the mental capacity to consciously reorder their spaces and objects to match their personalities and environmental needs. When living with dementia, there is an inability to anticipate needs and changing desires, which makes it very difficult on the family caregiver of the individual with dementia. They are living in a world of constantly shifting personalities and states of mind. In later stages of their diseases they are often living in what I believe could be termed, 'conflicting views of space and time.'

A common issue among individuals living with this disease is their inability to recognize and identify with their family house and an overwhelming need to 'go home.' However, as will be discussed, this need to return to a lost 'home' is fueled more by a desire to return to a safer, more comforting mental state than a particular dwelling. Understanding the cognitive functions of the individual with dementia could lead to a smoother transition for them and a resettling of the mind through environmental cues in order to bring them 'home.'

...

This settling of the unsettled mind through the process of inhabitation and sensorial experiences that create personal memories and connections with architecture will attempt to develop a possible 'cure' for a 'Phantom Home' feeling, by creating a physical space that will bridge the gap between conflicting views of space and time, and help an individual to cope with the loss of their dwelling.

The design concept will attempt to reconcile the loss of the

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dwelling by bridging the gap between family house and retirement home. This will be done by incorporating within the design a rural church that has possibly remained a constant element throughout the life of the individual. For individuals who may not have resided in the area, the church aims to provide a sensory connection to their own past experiences and memories. The architectural intervention may begin to provide the emotional stability necessary to move from the life-long dwelling, to the new 'home environment.' This church could serve as the physical constant and mental transition between one 'home' to the next. Once the person has consciously inhabited their new house and feels physically and emotionally connected, they can begin to experience their loss as a 'Phantom Limb?'

(Endnotes)

1 Rising Tide: The Impact of Dementia on Canadian Society (Alzheimer Society Ottawa and Renfrew County, January 2010).

2 Margaret Calkins, Ph.D., (2011, May 25). Person-Centered Design in Healthcare: Building Connections, PowerPoint Lecture presented at the Environmental Design Research Association Annual Conference, Chicago, IL. (<http://www.ideasinstitute.org/pdfs/CombinedPresentations.pdf>)

3 John Zeisel, Ph.D., I'm Still Here: A New Philosophy of Alzheimer's Care. (New York: Avery, Penguin Group, 2010): 144.

4 Sandra Davis et. al., "Guiding design of dementia friendly environments in residential care settings," Dementia 2009: 192.

5 Davis, 194.

6 Barrie Gunter, Psychology of the Home. (London, Whurr Publishers, 2000): 17.

7 Tonya Davidson, "The Role of Domestic Architecture in the Structuring of Memory," Space and Culture Aug. 2009: 338.

8 Herta Flor, "Phantom Limb Pain: Characteristics, Causes and Treatment," The Lancet. Neurology Jul. 2002: 182.

9 Bittani, Matteo, "Game Art: Judith Doyle's "Phantom House" (2010)," (02 February 2011) Gamescenes. [04 December 2011]

< <http://www.gamescenes.org/2011/02/game-art-judith-doyles-phantom-house-2010.html>>.

Chapter One: Retirement Living

Getting Started

When faced with the diagnosis of dementia, many people, including their families, feel devastated and lost. The Alzheimer's Society of Canada acknowledges that, at present, there is no cure for Alzheimer's or other dementia related diseases. Because of this there can be a lot of mixed emotions about the future that begin to surface and it can feel as though one is being robbed of the opportunity to fully enjoy and experience everything life has to offer, as well as share those memories and experiences with their family and friends.

Due to the cognitive and physical difficulties that might result in later years because of dementia, families of an individual will often ultimately make many difficult life decisions, and care options. Depending on personal and family budgets and resources, choices will often be made on the quality, level and frequency of care provided while and individual lives out their later years. There are many decisions that need to be made when a loved one can no longer look after themselves, and

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in Canada, there are several options depending on lifestyle and budget.

Choosing the best care option that suits that person and their family will greatly reduce the stress that can follow a dementia diagnosis and help everyone feel more comfortable and safe. We will go on to discuss those options and the current government and community support systems in place within Ontario to help individuals and their families making these decisions choose the right home for them.

Understanding the Options

The first step in retirement living is choosing the right retirement home. Often, these buildings and communities are more upscale bachelor or one-bedroom apartments targeted at active senior living. Tenancy in a retirement home is regulated by the Tenant Protection Act, 1997, and the owner of the facility becomes your landlord. The Health Protection and Promotion Act regulate accommodations and meals within the facility.¹ In order to be considered a “care facility,” and not just an apartment building, they will also include nursing staff for those who require extra assistance, and commonly an on-call doctor. The government of Ontario, with the support of associations like the Ontario Retirement Communities Association (ORCA), introduced the *Retirement Homes Act, 2010* in order to regulate facilities province-wide. This new act was developed in order to properly manage individual levels of care among retirement homes, provide people with supportive and caring living environments, as well as help residents and their

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Image 01 – Dining Room, Colonel By: Retirement Living by Revera, Ottawa, Ontario.

Image 02 – Fitness Room, Colonel By: Retirement Living by Revera, Ottawa, Ontario.

Image 03 – Lounge, Colonel By: Retirement Living by Revera, Ottawa, Ontario.

families when making decisions about their care options.² Before this, the only option was through ORCA's voluntary membership and survey. ORCA still provides this optional membership to facilities and homes, boasting an exceptional level of service and maintenance standards for its adherents. Retirement homes can apply for admission, which, on observance of ORCA's strict set of professional operating standards, grants them select status in a commitment to quality and accountability to residents, staff and the public.³ ORCA's 78 measurable guidelines are extremely rigorous, and in order for facilities to become an accredited member they must comply with "100% of the standards at their first survey and at subsequent surveys to attain and maintain membership. Residences must be accredited every two years."⁴ These regulations help to assure current and future occupants, as well as their families, that their care home is of the highest standards of living.

An excellent example of an ORCA member, who adheres to and exceeds the standards, would be Colonel By Retirement Living by Revera, in Ottawa, Ontario. This retirement home is an exceptional example of modern retirement living. The building features upgraded amenity spaces, a fitness room, luxury dining room, and hotel-like lobbies and lounges. They pride themselves on offering "comfort and service that's second-to-none, with [...] beautifully appointed suites and 24-hour personalized support available."⁵ Apart from the obvious age specific clientele, it is not unlike walking into a downtown boutique hotel.

Colonel By Retirement includes "Enhanced Living" options as a

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Image 04 – Typical Resident Bedroom, Colonel By: Retirement Living by Revera, Ottawa, Ontario.

Image 05 – Typical Resident Bathroom, Colonel By: Retirement Living by Revera, Ottawa, Ontario.

part of their “Continuum of Care” philosophy⁶ for those residents that require more assistance with day-to-day tasks. In a private retirement home, such as this, those quality services and options come at a premium, as each person is treated individually and on an as needed basis. However, they do include a separate floor with a Memory Care Unit (MCU) that is staff supervised and on lock-down. Once again, these extras come at a cost, but the high quality of service and individual attention is what is being offered in the price. Residents are monitored using an electronic tracking system and silent alarm, and staff implement their “gentle persuasion program”⁷ to personally and suggestively, coax clients back to their floor, bedroom and/ or group activities. This method is used for the safety and comfort of the resident and the peace of mind of the family. Retirement homes, such as Colonel By Retirement, are designed to appeal to the active senior who doesn’t, as yet, require round the clock care, and who would like to continue living a more active and social lifestyle. However, for the peace of mind of the person and their family, they can be assured that by choosing a home that includes those “Enhanced Living” options, if something should happen they can receive the care and support they need in comfort without relocating.

There are other options available to the aging person. Many individuals will choose to live at home for as long as they can, especially if a spouse or partner is still present and/ or it is not financially or logistically feasible to move both people to a retirement community with more individualized care. The Ontario Association of Community Care

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Access Centres (OACCAC) connects people with their local Community Care Access Centre (CCAC) to find information on “stay[ing] in your own home longer by providing “Care in Your Home” and by coordinating “Care in Your Community,” including specialized support services.”⁸ This not-for-profit organization will assist clients with support services in their community so that they can “age in place,”⁹ but also provide information, assessment and transfer to government funded Long-Term Care (LTC) facilities from the individual’s home or retirement community.

In Canada, you cannot apply directly to LTC, each person is assessed by a CCAC Case Manager who reviews financial options, care needs and home preferences. When the resources provided by the retirement residence and Community Access Centre are no longer providing the appropriate level of care required, or the level of medical care needed exceeds a person’s financial resources, an individual can apply to be on the wait-list for LTC. Once you have been admitted into LTC, The Ministry of Health and Long-Term Care (MOHLTC) pays for the care required while residing there. However, it is mandatory that you pay for accommodation costs, which are standard across Ontario. More information about the standards and current rates in Ontario can be found on the CCAC website under “Eligibility and Admission.” There are government subsidies available to individuals who do not have enough annual income to support the cost of basic living in LTC.¹⁰ However, since Long-Term Care is a government-funded necessity, once an individual is offered a bed from the wait-list, they will not be turned away because

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Image 06 -- Lounge, Peter D. Clark Long-Term Care Home, Ottawa, Ontario.

Image 07 -- Dining Room, Peter D. Clark Long-Term Care Home, Ottawa, Ontario.

Image 08 -- Typical Semi-Private Resident Bedroom, Peter D. Clark Long-Term Care Home, Ottawa, Ontario.

they can't pay for accommodation.

A good example of a government funded Long-Term Care (LTC) Home can be found at Peter D. Clark Long Term Care Home in Ottawa, Ontario. Like all four of the Long-Term Care Homes in Ottawa, the "Homes for the Aged and Rest Homes Act, the standards of the Canadian Council of Health Service Accreditation and the policies of the City of Ottawa and the Ontario Ministry of Health and Long-Term Care" regulate this facility.¹¹ These regulating bodies set the standards for service, maintenance, medical care and design of LTC facilities. In 2009 the Ministry of Health and Long-Term Care (MOHLTC) produced a revised and more complete Long-Term Care Home Design Manual for all current and future facilities. The document includes options for retrofit standards to improve the quality of spaces for residents. The introduction of a new 'Resident Home Area (RHA)' in the original 1999 documents was developed to create smaller home-like units that people could relate to.¹² Peter D. Clark Long Term Care Home follows this design model and executes it with care. The community is comprised of a series of houses, with bungalows that contain Memory Care Units (MCU) for individuals with dementia. "The Bungalows were developed through extensive community consultation, and research led by the Alzheimer Society of Ottawa, to create a small residential-style dementia care facility."¹³ The buildings feature living rooms, fireplaces, access to gardens, dining rooms, family-style kitchens and private and semi-private bedrooms. These houses adhere to the RHA model and create

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Image 09 – Atrium/ Lounge, Peter D. Clark Long-Term Care Home, Ottawa, Ontario.

independent “living systems,” as outlined by the guidelines, but also include areas of the community that overlap in a “village-square,” with a reception area, an atrium, café and hair salon. All of these features give the staff, residents and their families, plenty of options and diversity in their setting and daily activities.

However, as previously discussed, those that are admitted to a government funded LTC home are often coming from a medical crisis, either through the hospital or their CCAC caseworker. They are often no longer allowed to live on their own, and are placed in an emergency situation. Very few of the residents who are admitted to Peter D. Clark Long-Term Care, or a similar LTC home, come from the waiting list process and are simply following the natural process of aging and retirement. As a result, while a facility such as Peter D. Clark LTC is highly advanced in both service and design, and an excellent resource for individuals facing a dementia diagnosis, its ability to support and assist from the outset of the disease is nominal.

In the end, when faced with the decisions surrounding early retirement and then the challenges in later stages of aging, like dementia, individuals must prepare for all levels of care. There are community programs available to assist with these decisions, and family support plays a large role in location and levels of care that can be provided. When making the decision on aging at home and choosing a retirement community, a person must consider what each has to offer. Certainly there are advantages and disadvantages to every option, but

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in either case, no one wants to find himself or herself relocated in a crisis situation with no say in the result of the new location. Where one chooses to live the later part of their life is extremely important and makes a difference in the cognitive and physical aging process. Taking advantage of every opportunity available is important so that one can enjoy and experience everything life has to offer, as well as share those memories with family and friends.

(Endnotes)

- 1 Canada, Ministry of Health and Long-Term Care, "Government Legislation and Monitoring," Senior's Care: Retirement Homes, 23 Nov. 2010, 02 Feb. 2012.
<http://www.health.gov.on.ca/english/public/program/ltc/14_retirement.html#4>.
- 2 Canada, Legislative Assembly of Ontario, Retirement Homes Act, (Toronto: Government of Ontario, 2010), <http://www.ontla.on.ca/web/bills/bills_detail.do?locale=en&BillID=2298&detailPage=bills_detail_the_bill&Intranet=>>.
- 3 Ontario Retirement Communities Association, "ORCA Accreditation – Why it Matters," Look for ORCA Accredited Residences, 2012, 02 Feb. 2012.
<<http://www.orcaretirement.com/public/master.php?page=res>>.
- 4 Ontario Retirement Communities Association, "About the ORCA Accreditation Program," Look for ORCA Accredited Residences, 2012, 02 Feb. 2012.
<<http://www.orcaretirement.com/public/master.php?page=res>>.
- 5 Colonel By Retirement Living by Bevera.
- 6 Colonel By Retirement Residence Promotional Brochure, November 2011).
- 7 Nancy Jutasi, Personal Interview, Colonel By Retirement Residence, 22 November 2011.
- 8 Community Care Access Centre, "What We Do," CCAC Web Site, 2001, 31 January 2012.
<<http://www.ccac-ont.ca/Content.aspx?EnterpriseID=15&LanguageID=1&MenuID=137>>
- 9 Centers for Disease Control and Prevention, "Healthy Places Terminology," CDC Home, 28 June 2010, 09 March 2012. <<http://www.cdc.gov/healthypaces/terminology.htm>>.
- 10 Community Care Access Centre, "Eligibility and Admission," CCAC Web Site, 2001, 31 January 2012.
<<http://www.ccac-ont.ca/Content.aspx?EnterpriseID=15&LanguageID=1&MenuID=23>>
- 11 City of Ottawa, "Administration, monitoring and reporting," Long-term care, 2011, 02 Feb. 2012.
<http://ottawa.ca/social_com/housing/seniors/long_term/index_en.html>.
- 12 Ministry of Health and Long-Term Care, Long-Term Care Home Design Manual, (Ontario: 2009): iii. – 5.
- 13 Peter D. Clark Long Term Care Information, (Peter D. Clark LTC, City of Ottawa, 29 Nov. 2011).

Chapter Two: Being 'At Home'

Identifying Home

"Home is [...] that for which one feels a sense of attachment, to which one 'belongs', and that has the appearance of the known and the familiar." — Jeff Malpas and Linn Miller ¹

Let us examine the quote and the concept of 'home' and its role in our lives. Our current definition can be seen to be lacking, in that we mistakenly attempt to define it in terms of a physical structure or three-dimensional local. 'Home' is defined by the Oxford English Dictionary as "a dwelling place; a person's house or abode; the fixed residence of a family or household; the seat of domestic life and interests. Also: a private house or residence considered merely as a building." Additionally, the dictionary defines 'home' as "the place where one lives or was brought up, with reference to the feelings of belonging, comfort, etc. associated with it."² This definition often leads to a comparison of 'house' and 'home.' A comparison that often leaves us fractured in our understanding of the potential reality of 'home.'

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'Home,' in many ways, begins to verge on the definition of identity. Our dwellings are interconnected with the significant events in our lives, the experiences that tend to form our vision of ourselves. Its role in our lives answers questions about human nature, both individually and socially. The reason the definition of 'home' is so widely discussed among individuals and scholars is quite simple. 'Home' is more than a physical structure, its definition is not fully encompassed by the definition assumed by 'house' or 'dwelling.' The phrase, 'at home' is much more complex than a physical state of being, it defines a process of thinking, and evolution of being, and a shifting state of mind.

...

The term 'house' is defined by the Oxford English Dictionary as "a building for habitation, and related senses." Additionally, "a building for human habitation, typically and historically one that is the ordinary place of residence of a family."³ This description of our dwelling spaces is what we mistakenly associate with the more intricate term, 'home.' The definitions assumed by such concepts as 'house,' 'dwelling,' 'shelter' and 'accommodation' are used to describe three dimensional spaces, and do not refer to the individual associations we make with place that are so important to our daily lives. Our individual descriptions of 'home' are supported by our personal memories of inhabitation and our sensory experiences linked to those places.

The experience of being 'at home' is almost always described as a feeling, and the emotions and memories connected to a space, that

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go along with it. When remembering our 'home' we consider the way the space makes us feel, including the comforts of the space, the treasured items that we chose to furnish our rooms, the people that live with us and make us feel welcome, and the daily experiences of living our lives in a space that we enjoy. Jeff Malpas and Linn Miller, focusing on ideas of selfhood the establishment of human identity through place, examine this theory in their essay, "Home and the Place of Memory," where they discuss the role that memory plays in our definition of 'home.'

"The ordinary places of our lives, together with the things contained within them, themselves function as places of memory – from the everyday memories, often in the form of routine and habit, that are given in the ordering of a house, a room, a drawer, or in the patterns of movement that are part of our daily activities, to the exceptional memories that we suddenly encounter when we find ourselves in a certain situation or locale and recall some fragment of our lives with an immediacy and vividness that may lead us to wonder how it could ever have been forgotten."⁴

When we examine this definition we can begin to consider how 'home' is linked to a particular state of mind, rather than a physical space. The meaning of 'home' is reflected in the patterns of our lives, the rituals of living and the constantly shifting memories and emotions over time. When we feel 'at home' in a space, we experience it much more intimately, making connections on a deep, personal level. Our emotions are developed from the experiences and events that take place in our houses and the patterns and routines we cultivate to organize our lives.

Reaching this state of mind can be difficult. To feel completely 'at home' within our dwelling and within ourselves is a process; one that

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can take a vast amount of time when the place we are asked to inhabit is lacking in personal space, memory triggers, and residential settings that are easily relatable. It becomes almost impossible to make the intimate, personal connections necessary to experiencing a sense of being 'at home.'

In order to reach this settled feeling of being 'at home,' we must continue to consider the research of Malpas and Miller. Their work explores the experience of belonging and the role that our dwellings play in containing the memories that form us.⁵ Their essay discusses the role that 'home' serves in orienting the individual between the past, present and future. For in order to develop a sense of self, one must stand in relation to the past, while facing themselves toward the future. The process of inhabitation within the dwelling will create a series of memories that will link the place to the person over time. These memories will be layered upon each other to create the version of ourselves we experience and understand. When considering the symptoms of dementia, an individual finds themselves 'trapped' in their past. Linear time is transformed, and they can find themselves understanding the past as the present, and as Malpas and Miller discuss, it is possible that the self could become "little more than a memory, and perhaps not even that."⁶ A rediscovery of the individual becomes so much more important as their memory constantly shifts. As we will explore, the person that friends and family once knew is not necessarily present anymore. However, as they are given the opportunity to rediscover themselves

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through space and time, they can learn to be emotionally present in whatever reality they currently inhabit. The orientation of the self to past, present and future becomes unsettled as the distinction between them blurs, but there is the chance to discover a new self in a new reality.

(Endnotes)

1 Jeff Malpas and Linn Miller, "Home and the Place of Memory," *Home and Space* Spring 2009: 34.

2 "home, n.1 and adj." Oxford English Dictionary, Online. December 2011, 10 March 2012.
<www.oed.com/view/Entry/87869>.

3 "house, n.1 and int." Oxford English Dictionary, Online. December 2011, 10 March 2012.
<www.oed.com/view/Entry/88886>.

4 Malpas, 39.

5 "Prof Jeff Malpas." University of Tasmania. 23 March 2012.

<<http://cms.its.utas.edu.au/arts/philosophy/pagedetails.asp?personId=2131>>.

6 Malpas, 42.

In[habit]ing the House

Turning a 'house' into a 'home' is a process of 'making place' over time. As individuals we transform 'space' into 'place' by gradually appropriating an undefined space that has the physical and geometrical attributes of a dwelling. Each person begins the process of inhabiting space and marking it with their identity the moment they enter. We arrange the environment in a way that comforts us and feels logical in its pattern of use. By adding our own selves to a place, by altering, inhabiting, and developing patterns of inhabitation we create a sense of 'home.' Mary Douglas in her essay, "The Idea of Home: A Kind of Space," describes familiarity and order as being the important elements in the sense of feeling 'at home;' "[In the 'home'] ... there has to be something regular about the appearance and reappearance of its furnishings."¹ Familiarity is developed from evolved layers of memory. As one spends a lifetime inhabiting their dwelling they use the familiar anchors found within it to organize their own minds and establish an identity.

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There must be something memorable about the space we inhabit. In order for us to feel welcome and comforted by our surroundings, we must know what to expect when we enter. As Malpas and Miller previously described, this familiarity and sense of order is what creates the foundation for our memories and our personal identities. If we consider these ideas, we can begin to accept a more evolved definition of 'home' that includes the importance we place on belonging and familiarity. Our identities are often formed around our habits and daily rituals as they take place within the dwelling. The memories that develop from these rituals are what begin to form our feeling of being 'at home.'

Familiarity, or an intuitive understanding of our immediate environment, is what most people would consider comfortable and reassuring. Our sense of 'home' is what often grounds us in the chaos of a rapidly changing world. When we leave 'home,' even for a short retreat, we generally consider the qualities of the new environment in relation to our dwelling.² Feeling at ease, and in-tune with our surroundings is often referred to as feeling 'at home.' This comfort level develops from the habitual use of our dwellings. Whether daily, weekly or even yearly routines, each event that takes place in the house contributes to the layering of memories and the growth of an identity.

When discussing the feeling of 'hominess' or being 'at home' there is connection with the process of moving in order to achieve this state of being. In the article, "Moving Homes: From House to Nursing Home and the (Un-)Canniness of Being at Home," authors Schillmeier

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and Heinlein discuss the “spatial and temporal practices and experiences that fabricate the (un-)canniness of what it means to be at home or not.”³ They observe that throughout human lifetime, emotions are heightened during events of great stress, especially including events surrounding moving. This is because the act of moving is in parallel with an act of emotional movement and displacement. The feeling of being ‘at home’ is an accomplishment, a state of mind to be achieved. When we move, either forced or voluntarily, there is an emotional upheaval as our relationships with space and items are forced to relocate or redefine their boundaries. However, as Schillmeier and Heinlein suggest, this relocation often results in a new understanding of personal identity.

“It is never only ‘things,’ the materials of extension, which are switched or reordered. What are simultaneously moved around are ‘attachments,’ that is, feelings of longing and belonging are affected by ‘keeping’ the relations that are created and sustained by our giving or not giving room to things. There is an ‘us-ness’ as well as a ‘there-ness’ to a sense of dwelling and this has implications for the meaning of home as well as for understandings of self and identity.”⁴

The items that we choose to surround ourselves with are carefully chosen reflections of us. As suggested, the very act of “keeping” items is a decision that we make to surround ourselves with objects that define us. How we order those items and then how we choose to reorder them later is also a conscious decision in defining our identities. When we choose to discard objects that no longer fulfill a need in our lives, place items into storage, or give a prominent place on the mantel to a favorite object, we make a statement about our

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connection to those items, how we want to associate ourselves with them, and how we want the world to see us through them. An individual who is struggling to find the missing connections to their past and their identities will seek to surround themselves with cherished objects. Many retirement homes and long-term care facilities will encourage families to bring along favourite objects to help with memory loss. When considering the design of personal spaces in dementia care, allowing for individuals to personalize their space with what they consider familiar objects could help them to more quickly identify with the environment. Additionally, as their memory changes, the ability to easily shift those objects around a space and change their environment could help them to adapt to a changing lifestyle and better reflect on who they are.

Through a process of inhabitation of the dwelling over time, one can find oneself again. The feeling of comfort can be lost when we move and the feeling of familiarity is gone, but over time and through daily rituals and routines the individual can once again sense the regularity of their space. By surrounding ourselves with cherished objects we attempt to create this familiar environment regardless of the space we are living in. There is a sense of order and nostalgia as certain objects continually appear in our physical and mental states. Hopefully, once embracing this need for the familiar, an individual can once again reestablish their connection with 'home.'

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(Endnotes)

1 Mary Douglas, "The Idea of Home: A Kind of Space," Social Research Spring 1991: 289.

2 Jeff Malpas and Linn Miller, "Home and the Place of Memory," Home and Space Spring 2009: 32.

3 Michal Schillmeier and Michael Heinlein, "Moving Homes: From House to Nursing Home and the (Un-) Canniness of Being at Home," Space and Culture May 2009: 218.

4 Schillmeier, 289.

Chapter Three: Living with Dementia

Towards a Possible Future

The population of Canada is aging rapidly and with that we can see a noticeable strain on our health care system as age related diseases such as dementia spread. The Baby-boomer population is entering retirement, with the first round having reached their senior years (65+) in 2011.¹ This poses a substantial problem as aging is an unchangeable risk factor for dementia and continues to be the most significant cause of disability among Canadians over the age of 65.² The increased demands that will be placed on Canadian health care, gerontology care and community resources, requires better design options, a focus on education and support, as well as the overall goal of continuum of care.

According to the Alzheimer Society of Canada, the term *dementia* “refers to a large class of disorders characterized by the progressive deterioration of thinking ability and memory as the brain becomes damaged.”³ One of the most familiar associations people will make with dementia is to use the term interchangeably with *Alzheimer’s disease*.

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Image 01 - 'Cousin Cliff' Holman and wife dealing with the later effects of Alzheimer's disease in HBO Documentary Film; *The Alzheimer's Project*.

However, it is just one form of the neurological disorder. Those who are diagnosed with the symptoms of dementia could be suffering from any number of diseases, including; Alzheimer's disease (the most common), "[Vascular Dementia, the second most common], Frontotemporal Dementia (including Pick's Disease), Lewy body Dementia, Creutzfeldt-Jakob Disease, and dementias that occur with chronic neurodegenerative conditions such as Parkinson's disease and Huntington's disease."⁴ These illnesses have a crippling effect on the individual and their families as they struggle to cope with a declining mental state and increasing medical needs. Its diagnosis can be a difficult reality to face.

Alzheimer's disease is the second most feared disease in America. It is second only to cancer.⁵ Much of the fear comes from a lack of education and what *The Alzheimer's Project*, a documentary series that highlights the experience of living with Alzheimer's, attempts to alter, a sense of hopelessness. The heart-rending image that society generally sees is the individual who has been slowly stripped of everything that makes them human. The definition provided by The Alzheimer Society of Canada shines a harsh light on its reality.

"Alzheimer's disease [AD], the most common form of dementia (approximately 63 per cent), is a progressive, degenerative and fatal brain disease. In this disease, cell to cell connections in the brain are lost and brain cells eventually die."⁶

The effects of Alzheimer's disease and age related dementias can be extremely terrifying since over the course of a decade-long illness the individual loses the ability to recognize their surroundings, their

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loved ones, and eventually themselves. Unlike any other progressive terminal illness, dementia targets the brain and functionality of memory. This can make even an early diagnosis seem like the individual is already gone, leaving the family and even the person to undergo primary grief.

It is often difficult to detect the early signs of dementia. “Symptoms commonly include loss of short-term and long-term memory, judgment and reasoning, as well as changes in mood, behavior and the ability to communicate.”⁷ These symptoms are often confused with normal signs of aging; however, it is not normal for seniors to progressively lose cognitive function to the point of personality changes and an inability to function in daily life. These are serious indicators of a progressively fatal neurological illness.

A diagnosis of dementia can be a shock for the individual as well as their family. A flood of mixed emotions, including sadness, fear and grief can follow. At present there are no medical cures for Alzheimer’s or other related dementias. However, excellent research is being done on therapies and treatments that could slow the progression of their disease, prevent early onset and help people live a more fulfilling life once diagnosed. John Zeisel’s self-help book, *I’m Still Here: A New Philosophy of Alzheimer’s Care*, paints a more positive picture for the future of individuals living with a dementia diagnosis.

“A person living with Alzheimer’s is first “a person” and only then someone with a disease. The way the world sees Alzheimer’s today is that a person is almost totally lost once he or she receives an Alzheimer’s diagnosis – lost both to themselves and to those who love

them. An Alzheimer's diagnosis is seen as an Alzheimer's "sentence." But this just isn't so. Throughout the more than decade-long progress of the disease, the person is crying out, "I'm still here." We all need to start hearing that cry before it fades away completely."⁸

It is important to treat all people living with dementia just so, as people. As Zeisel, president and co-founder of the Harthstone Alzheimer's Family Foundation and Harthstone Alzheimer's Care Ltd. points out, the diagnosis can be arduous enough without family, friends and caregivers giving up. He proposes a number of treatment options that can be applied to daily life and can help ease the burden. Some of his techniques include, connecting through visual art, music and drama, designing dementia appropriate living spaces, and building better avenues of communication between caregivers, family and patients. He stresses that we must focus positively on the person that is still present and what they are still able to accomplish and enjoy. As was previously discussed, allowing the individual to embrace who they are in the present, regardless of their ability to recall the past, can help them to feel more 'at home' within their environment and within themselves. While their life may not be what it was before, there is still the opportunity to discover new talents and new joys.

Worldwide and in Canada, more research and education has been implemented on both a national and community level. The Alzheimer's Society of Canada has begun to recognize and research dementia related issues within the health care system. Their executive summary from 2010, *Rising Tide: The Impact of Dementia on Canadian*

Society, outlines the key issues that are currently burdening our society. The report states that without any intervention from government or other changes, the number of new dementia cases per year will rise from 103,700 in 2008 to 257,800 in 2038. This is a projected growth of 2.5 times greater.⁹ Their mission is to provide the studies and the resources needed to create a national plan for Canada that will curb this growth.

This plan brings hope to the future of those diagnosed with Alzheimer's disease and other forms of dementia in Canada. Greater strides in education, community support and health care can be made with a better understanding of where we currently lie, and what we need to achieve. The Alzheimer's Society of Canada's primary emphasis is on reducing the stress that will be placed on our current health care system by developing preventative measures, creating better education and support systems and focusing on individualized patient care. "Education and the development of stage-specific coping skills, both for the person with dementia and their caregivers, are important aspects of effective care plans."¹⁰ In the design of a dementia care facility it may be important to include a more community driven resource centre. As we will see later, including necessary services for families and the community could help to support a better understanding of dementia. By providing better training and support for the caregivers and families, more continuous and well-rounded care can be delivered to create a more manageable treatment plan and lifestyle for individuals with dementia.

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(Endnotes)

- 1 Alzheimer Society of Canada, Rising Tide: The Impact of Dementia on Canadian Society Executive Summary (Canada, 2010): 10.
- 2 Alzheimer Society of Canada, 2.
- 3 Alzheimer Society of Canada, 3.
- 4 Alzheimer Society of Canada, 3.
- 5 The Alzheimer's Project: The Memory Loss Tapes, Dir. Shari Cookson. HBO Documentary Films, 2009.
- 6 Alzheimer Society of Canada, 3.
- 7 Alzheimer Society of Canada, 3.
- 8 John Zeisel, Ph.D., I'm Still Here: A New Philosophy of Alzheimer's Care, New York: Penguin Group (2009) 7.
- 9 Alzheimer Society of Canada, 6.
- 10 Alzheimer Society of Canada, 3.

Conflicting Elements

If we follow this accepted literature, we will note that dementia is a progressive neurological illness that affects brain function and memory. This results in changes in cognitive function, short and long-term memory loss, mood and behavioural changes, as well as a loss in the ability to communicate. Alzheimer's disease, the most common dementia related illness, affects everyone differently, as no two brains are alike. However, research has shown that no matter the individual, its development will be a rapid and harsh mental and physical decline, with no medical cure at present.

Our brains process information in a rational and sequential order to determine the most relevant and imperative knowledge needed for the future. The senses accept everything from the world around us. Information is then processed and analyzed by the different areas of the brain, including the hippocampus region, which has been found to be an essential element in the formation of new memories. In the

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Image 02 - General view of how information is processed at the level of the brain.

Image 03 - Distinction of Long-term memory into five systems.

final stages of memory processing, information is compared against previous knowledge and linked with similar information to be stored in either a *semantic* knowledge base (Learning facts, which you are able to repeat without recourse to their original context. General Knowledge.) or *episodic* information (Consciously remembered episodes, usually biographical, emotional, directly associated with their contexts).¹ It is the collection of these functions that make up what we call our identities and personalities. During the progression of Alzheimer's disease, each of these memory functions is affected at different stages.

Research presented by the Alzheimer's Association has shown that the earliest stages of Alzheimer's (usually undetectable) begin up to 20 years before diagnosis. Over the course of the illness, nerve cells gradually die and brain tissue shrinks. In an Alzheimer's brain the cortex gradually shrivels up, the hippocampus region (an area of the cortex that plays a key role in the formation of new memories) shrinks immensely, and ventricles (fluid-filled spaces within the brain) grow larger.² At the start, *plaques and tangles* begin to form in brain areas involved in learning and memory, as well as thinking and planning, such as the hippocampus. "Plaques form when protein pieces called beta-amyloid clump together. [...] The small clumps may block cell-to-cell signaling at synapses."³ "Tangles are insoluble twisted fibers found inside the brain's nerve cells. In Alzheimer's disease the tau protein, [forming part of the construction,] is abnormal and the microtubule structures collapse."⁴ This results in the required nutrients no longer being able to move from

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Image 04 - Early Stages of Alzheimer's disease.

Image 05 - Mild to moderate Stages of Alzheimer's disease.

Image 06 - Advanced Stages of Alzheimer's disease.

one part of the nerve cell to another. Over time, the brain tissue shrinks as nerve cells die.

Generally, individuals are diagnosed during the mild to moderate stages, which lasts between 2 to 10 years. Plaques and tangles grow and spread to sections of the brain involved in speaking and understanding communication as well as personal spatial relationships. During this time, changes in behaviour as well as the decreasing ability to recognize friends and family begin to be noticed.⁵

The most severe stages of the disease, where little to no cognitive function exists, will burden the individual for between 1 to 5 years.⁶ "In advanced Alzheimer's disease, most of the cortex is seriously damaged. The brain shrinks dramatically due to widespread cell death."⁷ An individual's cognitive and physical ability to care for himself or herself is greatly diminished; their life span during this time is prominently dependent on age and other health conditions. As a result this stage of the illness is the most difficult for family and friends, as the individual they have come to know and love seems unrecognizable.

...

Dementia gradually dissolves the identity of the individual that loved ones remember. However, this trait of the illness is even more difficult for the individual. Loss of short-term memory leads to confusion and frustration as present external surroundings no longer match internal reality. As dementia develops, people often become more agitated and depressed as they struggle with everyday tasks and memories. They are

increasingly aware of older associations and memories being quite clear and seemingly recent. Long-term memory begins to take prominence in the mind, and families and caregivers will start to notice that individuals are frequently transported to another period in their lives, with many people believing, as we will come to see, they are once again a child in their parent's house.

The stories and recollections that are shared during the course of the illness are rich in emotional connections and vivid detail. People will be able to account for distant, minute events as though they happened yesterday. These stories are extremely important for caregivers and families to encourage positive communication in individuals. Habib Chaudhury discusses the importance of using these personal narratives as a tool for reflection and engagement. Some of them have been shared in in his book, *Remembering Home: Rediscovering the Self in Dementia*, where individuals have carefully recounted their personal memories with the help of caregivers and family, in relation to their dwellings. Used as a therapy technique, he advises people to use the act of remembering as a tool for situating oneself within their own reality. "By enabling caregivers to engage the individual's remaining memories, cognitive abilities, and —more important — emotions, home stories provide a key medium for relating to the individual's reality. Memories of the physical home become the means to connect to and help meet the individual's need to be 'at home,' to be psychologically secure and comforted."⁸ Chaudhury records a number of personal accounts revolving around

attachment to 'home.' One such story came from a woman named Helena who, when asked by the city to move out of her house, could not accept the idea of being separated from her dwelling. As a result, she made a deal with the city to sell them the land and she would be able to move the house to another site.⁹ Her actions are just one example of the strong emotional bond that people form with their house, and how it often becomes engrained in our self-identity. As short-term memory fades, it is important to understand and acknowledge what to the individual is a current emotional connection they feel they have lost in their relationship to 'home.' Using memories and emotions as a therapy technique to engage can help caregivers understand the needs and emotional responses of the individual seeking to 'return home.'

The conflict between the internal and external reality is extremely challenging to live with. Individuals exist in constantly shifting realities that test their emotional and mental states. According to Chaudhury, "the contrast between an institutional context and the places remembered from one's past becomes particularly salient for persons with dementia. [...] The more enduring characteristics of self-identity are threatened by losses of physical and cognitive abilities and losses of places to which one was attached, creating a sense of self that is in turmoil."¹⁰ What their families, friends and caregivers see is the struggle that they face each day with attempting to reconcile what they understand and remember with what their loved ones, doctors and the world are trying to tell them. During the course of the decade-long

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illness, the brain is rapidly shrinking as cells die and plaques and tangles invade the memory centres. While Alzheimer's affects people differently, the predictable nature of the disease helps us to expect, in some ways, how the individual will experience their surroundings at different stages.

The medical treatments required by its symptoms are just the beginning, as the emotional support necessary is immeasurable. Across Canada and worldwide there is a movement toward more individualized and person-centered care. People with dementia need to be valued, and treated with respect, dignity, and compassion.¹¹ Research, education and community services continue to grow in Canada, however as the rate of Alzheimer's and age related dementia's rises, greater strain is placed on health care services. "In Canada, services related to dementia care and available treatments are unevenly distributed and frequently lack coordination. Even where available, such treatments are often not standardized and there is little continuity of care."¹² This means a greater focus should be employed on educating caregivers and facilities on the realities of living with this progressive and changing disease. Providing more holistic care to individuals with dementia may come from helping caregivers to understand the shifting states of reality and help to reconcile living in conflicting views of space and time.

LIVING WITH DEMENTIA

(Endnotes)

- 1 Hans J. Markowitsch & Harald Welzer, The Development of Autobiographical Memory (New York: Psychology Press, 2010) 66-74.
- 2 Alzheimer's Association, "Brain Tour: 9. More brain changes," alz.org, 2001, 26 February 2012. <http://www.alz.org/braintour/healthy_vs_alzheimers.asp>.
- 3 Alzheimer's Association, "Brain Tour: 11. More about Plaques," alz.org, 2001, 26 February 2012. <http://www.alz.org/braintour/healthy_vs_alzheimers.asp>.
- 4 American Health Assistance Foundation, "How the Brain and Nerve Cells Change During Alzheimer's Disease," ahaf.org, 10 January 2012, 26 February 2012. <<http://www.ahaf.org/alzheimers/about/understanding/brain-nerve-cells.html>>.
- 5 Alzheimer's Association, "Brain Tour: 15. Mild to moderate Alzheimer's," alz.org, 2001, 26 February 2012. <http://www.alz.org/braintour/healthy_vs_alzheimers.asp>.
- 6 Alzheimer's Association, "Brain Tour: 13. Progression Through the Brain," alz.org, 2001, 26 February 2012. <http://www.alz.org/braintour/healthy_vs_alzheimers.asp>.
- 7 Alzheimer's Association, "Brain Tour: 16. Severe Alzheimer's disease," alz.org, 2001, 26 February 2012. <http://www.alz.org/braintour/healthy_vs_alzheimers.asp>.
- 8 Habib Chaudhury, Remembering Home: Rediscovering the Self in Dementia (Baltimore: The John Hopkins University Press, 2008) 104.
- 9 Chaudhury, 41.
- 10 Chaudhury, 5.
- 11 Chaudhury, 2.
- 12 Alzheimer Society of Canada, Rising Tide: The Impact of Dementia on Canadian Society. Executive Summary (Canada, 2010) 3.

Merging Elements

A more advanced ability to care for individuals with dementia could be accomplished through the design of a holistic retirement community that strives to educate about the realities of dementia as well as treat the symptoms. In the design concept we will see the integration of community services aimed at education with the facility services required for an individual seeking treatment at any stage of their dementia related disease. According to the Alzheimer's Society of Canada, the current services available to individuals with dementia and their families are greatly lacking. There is a need for facilities and community services that assist individuals from onset of diagnosis through their entire journey with dementia. This will provide more individualized care and better emotional and medical support for patients and their families.

While living with the effects of Alzheimer's disease and other age-related dementias, individuals are living in a world of constantly shifting realities. As their brain physically changes, so too does their

mental state and ability to recognize current surroundings. Caregivers will often comment on how an individual more and more frequently will slip in and out of the present as the disease progresses.

As realities change, people will begin to make the statement, “I want to go home.” This is a common issue among people living with dementia. However, according to Rydel Long Term Care Planning, “this question doesn’t really concern the physical aspect of going home but more a longing to revert to a time when the person with AD felt safe. Try to imagine how worrisome it must be to constantly feel that you’re surrounded by unfamiliar people who appear to know everything about you.”¹ Could their desire to ‘go home’ be seen more as a desire to return to a state of feeling reassured, comfortable and ‘at home?’

By providing a continuum of care model, where individuals with dementia could progress through their illness in one location, somewhere they feel secure and the freedom to be themselves, they might eventually achieve a feeling of being ‘at home’ within the retirement community. Dementia, and especially Alzheimer’s disease, makes it increasingly difficult to retrieve more recent memories and associations. Designing spaces that are easily recognizable and intuitive, no matter the stage of the disease, will help an individual to feel more comfortable in their surroundings. As we encounter space and objects, our brains will unconsciously attempt to find “landmarks” and cues in order to assess where to go, how to act and what to do.² We also

instinctively know how to navigate our way from our dwelling to the office, or even from the bedroom to the bathroom. This architectural important and instinctive nature is called *way-finding*. It is defined by John Zeisel as “the mental and physical act of navigating through an environment [...]. [F]or more people [it] is an unconscious process that uses procedural memory learning as a critical part of the process. In other words, if we take the same route over and over, it becomes second nature to us. The same is true for those with Alzheimer’s, so the more clear and dominant a path is and the more multisensory cues indicate the pathway, the easier way-finding will be.”³ Designing spaces that help individuals to better understand the use of space and find their way, could promote independence and self-assurance, while reducing agitation and depression.

A retirement community that combines advanced way-finding design techniques and sensory cues to help people understand and navigate their surroundings would promote a safer and more independent lifestyle. Keeping this in mind, helping individuals to navigate their way through shifting views of space and time could also help them to feel more secure in their environment regardless of the mental state they are currently residing in. Designing sensory and memory cues that would resonate with individuals through all stages and all periods of time might allow them to feel more ‘at home’ in that community.

LIVING WITH DEMENTIA

(Endnotes)

1 Christine Lever, "Dad wants to go home," (19 January 2012) Bydel Long Term Care Planning. [2012]

2 Esther M. Sternberg, M.D., Healing Spaces: The Science of Place and Well-Being.

(United States: Belknap Press, 2009) 133.

3 John Zeisel, I'm Still Here: A New Philosophy of Alzheimer's Care. (New York: The Penguin Group, 2009) 144.

Chapter Four: Prosthetic Memory and the Phantom Home

[Re]constructing Memory

“Memories are central to our identity - to our sense of who we are and what we might become [...], whether those memories come from lived experience or whether they are prosthetic seems to make very little difference. Either way, we use them to construct narratives for ourselves, visions for our future.” – Alison Landsburg ¹

If we accept the following statement and research that has been presented we can begin to discover the potential that is held in reimagining our past. Memories are the foundation to who we are as individuals. However, as reality changes and the past becomes the present, an individual experiencing the effects of dementia could find the opportunity to redefine who they are. ‘Prosthetic memories’ do not come from an individual’s actual life, but are implanted memories that are claimed as one’s own. These memories are then used in the construction of their self-identity and become indecipherable from the reality of their lives. If we can understand how we identify with artificial

memories and why we hold on to them, perhaps we can begin to see how these connections can be used to heal and build new relationships during dramatic life changes.

In *Prosthetic Memory: Total Recall and Blade Runner*, Alison Landsberg, a professor of history and art history and scholar in memory studies, takes us through the two films and speaks about the futuristic way in which they approach the idea of 'prosthetic memory'; "memories which do not come from a person's lived experience in any strict sense. These are implanted memories, and the unsettled boundaries between real and simulated ones are frequently accompanied by another disruption: of the human body, its flesh,[...]"² It is the vivid nature of 'prosthetic memories' that motivate the central characters in the films to take action, regardless of the fact that they are not actually 'lived experiences.' The lines between what is 'real' and what is 'prosthetic' have become completely blurred for these individuals. Landsberg proposes that this distinction between lived memories and prosthetic memories in fact does not matter in the case of the present and the future decisions of the individual. What she determines is that these 'prosthetic memories' simply offer the characters a course of action to live by a way to deal with the present and future realities they will have to face.

"Surprisingly enough, memories are less about validating or authenticating the past than they are about organizing the present and constructing strategies with which one might imagine a livable future."³

Image 01 – Sydney Opera House

Our past is only a tool that helps us to face our future. Our actions and emotions are not tied to life events, but in fact to emotional connections. Our ability to remember changes and expands throughout our lives. In the process, we are able to recreate past experiences using “fresh nuances and insights. [...] All self-interpretations are dynamic and in evolution.”⁴ Habib Chaudhury explores the complexity of a blurred past and present while dealing with dementia. Through therapies geared toward recollection and prompts, also called “reminiscentia,”⁵ individuals can be guided through their personal life narratives in their own words. Caregivers are taught to use prompts while discussing the past in order to help individuals remember emotional connections to places, events and people. “A photograph is a wonderful thing. It allows us to pause, reflect, wonder, and remember. It helps us stand outside the flow of time because of its “stillness.””⁶ Chaudhury explains how photographs and cherished personal items are excellent visual cues that can be used to help shape a person’s current identity, regardless of whether or not those imparted life stories were actual lived events. By creating an environment that allows the individual to embrace the prosthetic experience as their own, we can alter the individual’s perception of time and space in the present and future.

Often these therapy techniques are conducted in a safe, quiet environment, free from distraction and outside influences. The creation of spaces, which allow an individual the opportunity to embrace ‘prosthetic memories,’ stories that are not their actual lived experience,

Image 02 – Shimon Attie, Joachimstrasse 11a, 1933, 1992. (Writing on the Wall), Young, James E.

must engage all of the senses. Photographs are used by caregivers to spark the imagination and memory of an individual who has difficulty placing themselves within the confines of time and space. However, a successful architectural concept could provide the opportunity to engage an individual more profoundly than just an image. Juhani Pallasmaa, a contemporary Finnish architect and architectural theorist whose work focuses on the importance of sensorial experience and tactility in architecture, explores this idea in his book, *The Eyes of the Skin: Architecture and the Senses*.

“An architectural work is not experienced as a collection of isolated visual pictures, but in its fully embodied material and spiritual presence. A work of architecture incorporates and infuses both physical and mental structures. The visual frontality of the architectural drawing is lost in the real experience of architecture. Good architecture offers shapes and surfaces moulded for the pleasurable touch of the eye.”⁷

Pallasmaa discusses how the body and the city (through architecture) are interconnected. Essentially, the individual experiencing the space and the space itself are one. This is a result of experiencing the space through all of the senses over an undetermined space of time. An individual remembers a place because it has affected our bodies and our senses, and we have made enough of a personal association. If we understand and accept Pallasmaa’s description of the environment and the senses, we could start to imagine an identity inclusive of ‘prosthetic memories.’ An individual could find it easier to believe in the ‘prosthetic memory’ if they have another sensorial experience with which to connect

it to. Being in a space that stimulates memory through the senses might help someone to feel more emotionally connected to the memory, even if they never experienced it. It can be considered that in order to assume the identity of 'prosthetic memories' without hesitation, it should be faced as an entire mind-body experience.

'Prosthetic memories,' while not usually being faced as a mind-body experience, play an integral role in the development of our society. Alison Landsberg, proposes that on a cultural scale, mass media and technology, based on their history of blurring the lines between real and unreal, are already an ideal arena for the production and circulation of prosthetic memories. Over the years they have continued to produce images that flood society and integrate themselves into our lives. We watch films and see pictures that become so engrained in our thoughts that they become 'prosthetic memories,' occurrences that we have never lived, but emotional connections so vivid that we feel we have experienced these events and places personally. These 'prosthetic memories,' provided by mass media, alter our thoughts and feelings. They change our thinking, and eventually our actions in the future. The fact that they do not 'belong' to us does not appear to change the strength of our emotional connection to them.

In a simple example, think of the images we consider being the iconic examples of foreign countries. Take the image of the Sydney Opera House. What do we imagine when we think of this place? What do we feel? These photos, provided by mass media, are typical examples

of how we remember certain countries. Through cultural perceptions, stories, movies, and other forms of sensory and social stimulation, we often form 'prosthetic memories' about these places. When examining this image, do emotional connections or associations with this place surface? Do feelings of reminiscence take place? Can a dialogue about the place be formed? People will sometimes feel as though they already have a personal connection with the place, even if they have never actually experienced it.

Landsberg discusses our desire as a society to experience historical events and places as they happened for ourselves. There is an obligation to develop strategies for experiencing our cultural and collective past.⁸ For, once we have experienced the reality, we have the opportunity to alter our perception of the event and place. The emotional connection that was linked to our 'prosthetic memory' is given the chance to evolve as we experience the present. Because we experience a place through all the senses and occurrences tend to trigger emotional connections, the real events and memories will usually override the prosthetic ones. As our memories and identities evolve, our perception of a particular place will alter. Our emotional connection with a place changes over time as events and experiences shape us, and our identity changes.

Another example of attempting to alter our emotional connection with a place comes from artist Shimon Attie. Between 1991 and 1996 he embarked on a project entitled, *Sites Unseen*, utilizing

photographic images to “literally [bathe] the sites [in] a now invisible Jewish past.”⁹ The purpose of this project stemmed from his belief that “memory of a site’s past does not emanate from within a place but is more likely the projection of the mind’s eye onto a given site. Without the historical consciousness of visitors, these sites remain essentially indifferent to their pasts, altogether amnesiac. They “know” only what we know, “remember” only what we remember.”¹⁰ He hoped, that by projecting these images of a forgotten past on to the walls of the city, those who encountered them would forever associate these images with this place, creating for themselves a ‘prosthetic memory.’ Individuals who experienced these sites during the time of Attie’s installation would share a collective memory that was very real and very much a part of their lived experience. Attie’s hope was that once this project finished, the images would forever haunt the sites, as they resided in the minds of the people who experienced the installation and remained as a collective ‘prosthetic memory.’

From these examples we can suggest that, as futuristic as ‘prosthetic memory’ seems, it does exist and we do in fact create emotional connections to places where we have never been as well as connections to places using experiences we have never lived. Landsberg identifies both these ideas in regards to the mass media’s creation and integration of ‘prosthetic memory’ in our lives on a cultural scale. Individually, integrating ‘prosthetic memories’ into our identities can be much more complex. It requires a deeper level of commitment and

belief from the person, as we are asking them to build a very intimate connection with an object or place.

'Prosthetic memory' in relation to the dwelling could serve as tool during the moving process and inhabitation of a new house. When moving to a new house the familiar spaces and feelings are disturbed. In order to feel a sense of comfort and of being 'at home' again, once must journey through the process of rituals and routines. If a sense of familiarity could be brought to the individual during this transition period, then perhaps feelings of security and well-being could be established more easily.

(Endnotes)

1 Alison Landsburg, "Prosthetic Memory: Total Recall and Blade Runner." Body and Society Vol. 1 no. 3-4 (1995) 186.

2 Landsburg, 175.

3 Landsburg, 176.

4 Habib Chaudury, Remembering Home: Rediscovering the Self in Dementia. (Baltimore: The John Hopkins University Press, 2008) 5.

5 Chaudury, 77.

6 Chaudury, 77.

7 Juhani Pallasmaa, The Eyes of the Skin: Architecture and the Senses. (England: John Wiley & Sons Ltd., 2005) 44.

8 Landsburg, 178.

9 James E. Young, "Sites Unseen: Shimon Attie's Acts of Remembrance, 1991-1996." At Memory's Edge. (New Haven: Yale University Press, 2000) 64.

10 Young, 62.

Sensing the Phantom

As previously discussed, we can now realize the individual's relationship with dwelling as a physical, mental and emotional connection. Through a process of inhabitation he or she can find himself or herself developing the foundation of their identity within their space. When the connection with the 'home' is broken and comfort and security of being 'at home' is completely shifted, an individual can be left feeling unsettled. The memory of the 'home' that was lost during transition still exists in the mind of the individual. Once they have settled into the routines and habits of the dwelling and become 'at home,' the house has become an extension of the mind and body. However, an identity crisis and unsettling of the mind can occur when the individual is faced with the practice of moving from their lifetime dwelling.

In the following chapter, we will examine how the feelings associated with physical displacement could be compared to the feelings associated with physical amputation. Amputation of a limb from the body

can take years (if at all) to heal and to cope with. Individuals who lose a limb generally do so under severe circumstances, and many people find that the amputated member leaves a 'phantom limb' sensation or pain in its absence. Even people who were born with missing limbs claim to have the same sensations associated with 'phantom limbs.' A 'phantom limb' refers to "an arm or leg that lingers indefinitely in the minds of patients long after it has been lost in an accident or removed by a surgeon."¹ Over the past decade, this definition has expanded to include additional parts of the body; breasts, penis, tongue and eyes. Individuals afflicted with this symptom after amputation were originally thought to be insane, that these sensations were all in the mind. However, Indian scientist, V.S. Ramachandran was intrigued by the abnormal nature of these symptoms and the phenomenon of the 'phantom limb' sensations. He believed that these individuals were not imagining these feelings, but that the neurons in their brains were continually sending them information that contradicted their present 'body image.' This term refers to the individual's "internal constructed ensemble of experiences – the internal image and the memory of one's body in space and time. To create and maintain this body image at any given instant, your parietal lobes combine information from many sources: the muscles, joints, eyes and motor command centers."²

When each of these factors combine, the correct information is sent to the brain and the limb that needs to move, does so. If mind and body is working in harmony, the individual is able to understand their

Image 03 – “The Mirror Box Theory”

body image internally and externally. When just one of these elements doesn't work, either the proper visual feedback isn't being given, the muscles and joints aren't signaling to the brain (because they are no longer there), or the wiring in the brain has been remapped, we see symptoms of paralysis, mental confusion, and in this case; 'Phantom Limb Pain (PLP).' Decidedly, for Ramachandran, the answer to this scientific dilemma was to develop a cure for these sensations and 'PLP.'

Through a process of scientific and creative decision-making, what Ramachandran developed was the Mirror Box. This tool became a therapy technique for individuals suffering from 'phantom limb' sensations and 'PLP.' The Mirror Box is a simple box with two mirrors in the centre. "The patient places the good limb into one side and the stump into the other. The patient then looks into the mirror on the side with [the] good limb and makes "mirror symmetric" movements, as a symphony conductor might, or as we do when we clap our hands. Because the subject is seeing the reflected image of the good hand moving, it appears as if the phantom limb is also moving. Through the use of this artificial visual feedback it becomes possible for the patient to "move" the phantom limb, and to unclench it from potentially painful positions."³ Ramachandran, through a series of experiments with open-minded patients, discovered that by using the inexpensive, simple, mirrored box that he constructed himself, those that practiced with it on a daily bases eventually rid themselves of their 'PLP.' Many of the individuals actually lost all their sensations altogether. He had discovered

an important link between our 'body image' and the visual feedback we give our brains.

This discovery goes further by suggesting a link to our understanding of how we store images in our minds and then relate that to reality. Ramachandran refers to this as the psychological term; Hebbian link when he describes a physical act of movement. "These occasions must have created a memory link in your brain between the motor command to clench and the unmistakable sensation of "nails digging," so you can readily summon up this image in your mind."⁴ Once we receive that information from our palm that we are digging in too hard, we have a pain reaction and will stop clenching. People that no longer possess the limb no longer have the physical and visual feedback of the limb to tell their brain they are clenching too hard. Thus, one theory in the study of 'PLP' suggests that individuals who suffer from this symptom would benefit from the mirror box therapy in order to 'trick' the brain into believing they can unclench the missing hand.

What this discovery opens up is the notion that calculated visual feedback and alternative therapies have the potential to 'heal' the mind and remap what was broken in the amputation of the limb. Ramachandran discovered a way to 'trick' the brain into remapping the present 'body image.' In many ways, this theory of a conflicting 'body image' in space and time could be applied to individuals with dementia. They are currently living in conflicting views of space and time, and what they see in front of them does not match their current state of mind.

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We will examine how this definition could be applied to architecture and dwelling in order to remap the present 'home image' and restore a sense of connection to place.

(Endnotes)

1 V.S. Ramachandran, Phantoms in the Brain. (New York: Harper Publishers, 1998) 22.

2 Ramachandran, 44.

3 Wikimedia Foundation, Inc., "Mirror Box," (04 November 2011) [Wikipedia.org](http://en.wikipedia.org/wiki/Mirror_box). [04 December 2011] <http://en.wikipedia.org/wiki/Mirror_box>.

4 Ramachandran, 54.

Image 04 – Judith Doyle, 'Phantom House'

Finding the Phantom

Scholars and architects, Judith Doyle, Donato Bramante and the National Art Gallery of Canada, have explored the process of remapping the broken emotional and visual connections with space that an individual can feel when displaced. Their projects each identify a need to redefine a space that has either been lost or was incomplete. Judith Doyle, a Canadian artist, demonstrates how virtual reality allows us the ability to create and recreate spaces that may only exist in our imaginations. This technology permits us the opportunity to construct spaces from personal or collective memory. Renaissance architect, Donato Bramante's artistic representation of an incomplete church choir convinces the viewer of what does not exist in three-dimensional form. The National Gallery of Canada exhibits an even more ambitious undertaking of a similar idea. The deconstruction, storage and reconstruction of the Rideau Street Convent Chapel is an example of a community's desire to hold on to their collective memory. Each of these projects is a tool for remapping and

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Image 05 — Donato Bramante, 'Santa Maria presso San Satiro'

Image 06 — 'Santa Maria presso San Satiro,' CMU 4th Year Studio, <<http://cmuarch2013.wordpress.com/2009/03/28/lecture-notes-preston-scott-cohen/>>.

repairing the fractured emotional and visual connection lost when we are displaced from our most cherished places.

Judith Doyle's 'Phantom House,' designed in an online video game called Second Life, was her attempt to 'mirror' her childhood house in an effort to construct something that she could mentally return to whenever necessary during the mourning process. Her research in conjunction with Baycrest in Toronto, Ontario, a centre primarily for memory research in the elderly, helped her to actualize this project.¹ Currently, there is no research published that talks about Doyle's project as a therapy for others dealing with the loss of their family or 'home.' Her design was intended simply as an artistic personal endeavor, meant to help her deal with the physical and emotional loss of her parents and family house. However, her attempt to reconstruct the 'home' virtually even on a personal scale is an example of how important the process of mourning the dwelling in the advent of a major life change can be.

Between 1482-86, in Santa Maria presso di San Satiro in Milan, Donato Bramante explored the art of 'tricking' the brain into conceptualizing missing space. His addition of a bas relieved trompe-l'oeil backcloth in the choir of the church due to forced site restrictions fools the eye into thinking that the space extends much farther than it does in reality.² This visual illusion was created not only to materialize the vision of Bramante, but also to fulfill the psychological and emotional expectations of the people visiting. Without the addition of the trompe-l'oeil in the choir, the space would appear unfinished, unbalanced, and

Image 07 – Interior of Rideau Street Convent Church as exhibited at the National Gallery of Canada. Photo: Malak, NGC/ MBAC, 2001.

Image 08 – Interior of Rideau Street Convent Church - 1907

it would differ greatly from the expected church designs of the time. There was a level of expectation that needed to be met in the design of religious spaces during Bramante's era. An unbalanced and 'broken' nave would not have been adequate. Similar to the technique of the 'mirror box,' by recreating what was lost or correcting a 'body image' through a visual connection, the beholder's expectations of the space are met and emotional connections are satisfied.

An elaborate and emotionally stirring recreation of lost space can be seen in the National Gallery of Canada's Rideau Street Convent Church exhibition. This striking historical interior was originally a part of the 1888 Rideau Street Chapel designed by priest-architect, Georges Bouillon. With a long history of serving the Ottawa community in a religious and educational context, (In 1925, after its use as a convent, Bruyere College was founded) community groups and the museum worked together to save the church when it was slated for demolition. The church interior was eventually dismantled, and the rest of the building demolished. The National Gallery purchased the deconstructed pieces of the church interior in 1973, and stored them in an Ottawa warehouse for 15 years. Eventually, with the help of funding, space allowance and volunteers, over a period of four years the Rideau Street Convent Chapel interior was reconstructed inside the National Gallery and unveiled in May 1988, just shy of its 100th anniversary. This enormous undertaking is an example of a community's need to reconstruct a lost place. The restoration team's goal was to "mirror the last existing state of the

Image 09 – Reconstruction of Rideau Street Convent Chapel inside the National Gallery of Canada - 1984 - 88.

interior before demolition.”³ The reconstruction within the walls of the gallery is an accurate installation of the historical architectural elements, including all the necessary reproductions in order to complete the visual scene.

By entering the reconstructed space, visitors are given the opportunity to adopt the ‘prosthetic memory’ of the exhibit as their own. The interior space is meant to transport the individual through time and space to experience the emotional connection with this unique place that so many people were inclined to protect. A variety of musical, dance and theatre productions have taken place in the church exhibit since its original opening. One distinctive sound art installation by artist, Janet Cardiff was erected in 2001 and currently remains. Her installation seeks to sculpt the air around through a hauntingly beautiful musical performance by the Salisbury Cathedral Choir. Upon experiencing this exhibit, it becomes obvious that, while striking, the architectural elements of the space feel hollow and without life. What awakens the senses and brings the space to life is the shared experience of the individuals who are rendered motionless in their need to listen to and fully experience Cardiff’s sound installation. The performance combines with the space to provide the missing sensory information required by the mind and body to completely accept this space as a personal ‘prosthetic memory.’ The exhibit excels at physically reconstructing a lost visual and tangible connection with a building. However, it is the sculpting of sound within the exhibit that transcends time and transforms the space into a sculptor

of memory, prosthetic and personally experienced alike.

When considering these examples: Doyle's 'Phantom House,' Bramante's Santa Maria presso di San Satiro, and The Rideau Street Convent Chapel, the question that reoccurs is whether or not a purely visual manipulation fully satisfies the healing process of the Mirror Box phenomenon when considering memory. In order to be completely convinced of the 'prosthetic memory' being imparted, so that one's present and future actions would be altered, a complete use of all the senses would be necessary. It is possible that in Bramante's case, the optical extension of the choir could satisfy the viewer because the church is complete in every other form. The other senses are engaged with the sights, sounds, smells and textures of the religious setting. Therefore, an extension of the space, while necessary to reinforce the overall design of the church as a whole, doesn't need to provide its own additional sensory information to be convincing as its own entity, the sensory information necessary to be believable, is provided. The Rideau Street Convent Chapel can be seen as the most successful of these projects. This is a reconstruction of an entire space that, through the installation of sound art, includes the sensory information needed to assist the individual in the formation of a 'prosthetic memory.' Without the installation by Cardiff however, the chapel can be seen as a technically accurate architectural reconstruction that lacks the ability to construct a new 'prosthetic memory' for the viewer. Doyle's attempt at a virtual recreation of her childhood 'home' identifies how important it is

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to properly mourn for and disconnect from our houses, so as not to be left with the need to heal the 'phantom home.' However, its disconnect on a tangible level could still leave the majority of individuals searching for a way to reconnect and heal.

These artists and scholars have each developed a way in which to deal with a contradicted image. They have used 'prosthetic memory' to construct and tell a story of what is not in existence. Memories are central to our identities; however, whether those memories are from lived experience or 'prosthetic' really makes no difference to the way we see the future. Once we have accepted this theory, we can begin to understand our past and our memories as plastic and flexible. Our memories are tools that can be used to construct a new future; change the tools and you can change the way you see the future.

(Endnotes)

1 Bittani, Matteo, "Game Art: Judith Doyle's "Phantom House" (2010)," (02 February 2011) Gamescenes. [04 December 2011]

< <http://www.gamescenes.org/2011/02/game-art-judith-doyle-phantom-house-2010.html>>.

2 Visual Arts Cork, "Donato Bramante," visual-arts-cork.com. [04 December 2011]

< <http://www.visual-arts-cork.com/old-masters/donato-bramante.htm>>.

3 National Gallery of Canada, "The Rideau Street Convent Chapel: Restoration," gallery.ca. [14 March 2012]
<http://cybermuseum.gallery.ca/cybermuseum/showcases/chapel/index_e.jsp>.

Chapter Five: Settling the Unsettled Mind

Designing for Dementia

If we accept the idea that our memories are the foundation to our identities and that their presence gives us direction when considering our thoughts and actions for the present and future, then we can begin to accept the concept of a flexible past and changing identity. The image that we have of ourselves is based on the experiences and emotions that we have faced throughout our lives, and the dwelling is often the backdrop to those occasions. As we have discussed, this is why after years of inhabitation within the house, an individual feels so emotionally attached and their identity so intertwined.

In the following design concept we will explore the opportunity that a new dementia centre has to bring a community together and educate people on the realities, both positive and negative, of life with memory loss. The Alzheimer Society of Canada has expressed that greater strides in education, community support and health care can be made with a better understanding of where we currently lie, and what

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we need to achieve. Their primary emphasis is on reducing the stress that will be placed on our current health care system by developing preventative measures, creating better education and support systems and focusing on individualized patient care. A community centre is included in the realization of this design concept. The goal of the centre is to provide a space for education, retreat and support, not only for families and individuals currently facing a dementia diagnosis, but to also to allow everyone the opportunity to break down the stigma of dementia they may hold. The more knowledge and understanding people have about Alzheimer's disease and other age related dementia's, hopefully the less fear and stress there will be for the individuals who are trying to cope with their new lifestyle.

Greater emphasis on education for families and individuals may help to ease people into their changing life. However, more focus on educating caregivers and facilities could also help to make the transition easier on patients. In the design concept has stressed the importance of creating a holistic care environment. Through discussion with various dementia facilities in the Ottawa area, it was noted that there is an issue with asking people to move from one centre to another based on care requirements. As was previously discussed, if we accept the idea that moving from one dwelling to another is stressful, especially for an individual with dementia, then we may accept that over the course of the disease one wouldn't want to move based on care needs. The transition would create another stressful event. Because of this, we will

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see the merging of a community centre and day-away program area, a retirement home, and a long-term care facility in the design concept. By combining all of these functions, an individual could, if they wanted, face their disease at every stage through the stability of this dementia centre. When their reality is constantly shifting, they would hopefully find some comfort and consistency in calling this place 'home.'

Another essential element in designing this comfortable and consistent environment is creating easily recognizable and intuitive "landmarks" inside and outside the building, referred to as designing for way-finding. As we have considered, the brain seeks out the familiar and the obvious in order to determine where to go, how to act and what to do in a space. There are general "landmarks" that we understand, including signage, pathways and roads, doorways, houses, schools, and many more. There are also "landmarks" telling us how to behave when we enter a space that are essential cues for people with dementia, including; table and chairs for a dining room, bed in the bedroom, toilet and sink in the washroom, and television and couch in the living room. These can of course be expanded to including formal and informal living spaces, but more generally these cues tell us how each space is designed to be used. Dementia, and especially Alzheimer's disease, makes it increasingly difficult to make these associations. It becomes increasingly important to design spaces that are easily recognizable and intuitive, regardless of the stage of the disease. This will help an individual to feel more comfortable in their present surroundings. The following design

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incorporates several levels of “landmarks” for individuals at different stages. Various parts of the building focus the attention of the individual towards important elements, such as the historical Prospect United Church. These elements are integrated to help them make decisions about where they would like to go and what they would like to do as they navigate through the building.

It is generally understood that way-finding and navigational abilities diminish with the progression of Alzheimer’s disease and other age related dementias. It becomes increasingly difficult to retrieve more recent memories of events, people and spaces, as short-term memory fades and long-term memory becomes more vivid. If we accept the previously introduced concept of the ‘phantom home,’ then we can assume that an individual who is experiencing the symptoms of dementia is also dealing with conflicting views of space and time. Similar to the notion behind Ramachandran’s ‘phantom limb’ therapy, the visual feedback an individual is receiving when they experience a space, does not match the internal reality they personally know and believe. The idea behind implementing ‘prosthetic memories,’ as introduced by Landsberg, might provide a supportive bridge for individuals between this visual and emotional disconnect they are experiencing when transitioning from their lifelong dwelling to the dementia centre. We have discussed how Doyle, Bramante and the National Gallery have all attempted to develop a way in which to deal with a contradicted image. They have used ‘prosthetic memory’ to tell a story about something that doesn’t currently exist.

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Their projects give people the opportunity to experience a space that otherwise wouldn't be possible, and develop a 'prosthetic memory.'

In the following design concept the use of an existing architectural element, the rural church, will serve as the memory 'springboard' in the overall design of the retirement community. This space will be used as the element that bridges the gap between family dwelling and retirement home, as well as between community and retirement. Individuals living in the community for the greater part of their lives should recognize the building as an iconic structure, and hopefully also personally identify with it. Its presence is meant to help an individual bring to life memories of past experiences that might not have happened in this specific location, as provide the sensory stimulation necessary to imagine some collective memories that could have taken place in this space but were not a personal lived experience. It is the hope that facing these memories would help to bring people together as community and allow them the comfort and security of a familiar environment.

Image 01 - Prospect, Ontario.

Constructing the Past

“Our buggy was always the first in the shed... we wandered through the churchyard... hunting for raspberries behind the shed. When we heard the organ begin to play we went in, and sat in the back seats on the men's side. Later, after singing and reading the lesson verse about, we went up to the boy's class, held in the side seats facing the pulpit... and watched the Bible class in the gallery, or the hornets as they came out of the stovepipe holes in the front walls of the church.” – Excerpt from a Letter about Prospect United Church¹

Prospect United Church, in Prospect, Ontario has a long history within the Lanark County community as an icon of social and religious significance. The Kidd Family, who offered up much of the history of this building, is a prominent and historical family within the community who has taken it upon themselves to preserve the story of the church. “There is a long standing known history with this building that is quite special to the community. There has been at least four generations baptized in that church. It has been know to [the Kidd] family for a long time.”² There is a strong community memory, and as we can see here,

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Image 02 – Prospect United Church,
October 2011 - Prospect, Ontario, Canada.

Image 03 – Prospect United Church,
October 2011 - Prospect, Ontario, Canada.

for many a personal relationship, that is tied to this building. This rich memory is what I propose, makes it an ideal site for the realization of a new dementia care facility that will bring a new life and a new memory to the building and the site.

The property where the church currently sits was first a cemetery plot, donated by William Kerfoot of Lanark County. Tombstones that are still legible on the site date back as far as 1821.³ The history of Prospect United Church documents that the original church building was a long structure erected across the road from the present site. It is stated that; “[w]hen the Prospect Methodist Church (its original name) was rebuilt of stone in 1847, the site was relocated to the north side of the Fourth Concession Line.”⁴ On its current site, the historical church is surrounded by modern farmland, houses and rolling countryside. Richmond road, where it fronts, is a typical country thoroughfare that indirectly connects the greater Ottawa area with the town of Carleton Place. This connection allows for easy access of medical care from Carleton Place and District Memorial Hospital, as well as additional services from the advanced medical care found in Ottawa, Ontario. Its proximity to required services and community needs is adequate, as the site also provides a secluded rural atmosphere that would promote relaxation, inner focus and healing. From the research explored and the documented site visits, we can see that most memory care units and dementia care facilities are located within city centres. The design of this dementia centre would be geared toward seniors already living within

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Image 04 – Prospect United Church,
August 2004. One of the final church services.

the community of Prospect and Lanark County, so allowing them the opportunity to remain outside the city, and hopefully offering them an easier transition between dwellings.

After the church congregation disbanded on December 31, 2004 the Beckwith Township purchased the church and its surrounding land in order to preserve the history of the community.⁵ “When the township took over, there wasn’t enough land for a severance. With the graveyard still there, people wanted to keep the building,” however, to date there has been no official use for the building or the property.⁶ It was noted that there have been a couple of weddings in the church since 2004, but the only real event that takes place annually is a fundraiser to raise money for the maintenance of the structure. This lack of programming for the church provides an excellent opportunity to reimagine the building and the site for a new purpose. This place used to be the social hub of the neighbourhood, bringing people together for far more than just religious services. Individuals might not only identify with this building because of its historical significance and community memory, but through its new use, they have the opportunity to develop a new experience and memory of the site that touches on the past and embraces the future.

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(Endnotes)

1 Leona Kidd, A Leisurely and Religious Sunday (Excerpt from a Letter), Prospect United Church History as recorded members of congregation, distributed by Kidd Family. (23 January 2012).

2 Leona and John Kidd, Personal Interview, 23 January 2012.

3 Leona Kidd, Prospect Methodist Cemetery, *Prospect United Church History as recorded members of congregation, distributed by Kidd Family*. (23 January 2012).

4 Leona Kidd, The Methodist Stone Church at Prospect, *Prospect United Church History as recorded members of congregation, distributed by Kidd Family*. (23 January 2012).

5 "Prospect United Church -- a Brief History," Ashton-Munster Pastor Charge, (07 March 2012) <http://apc.royalyorkers.com/apc_home.html>.

6 Leona and John Kidd, Personal Interview, 23 January 2012.

Image 05 – Prospect United Care Home.
View from Richmond Road.

Image 06 – Prospect United Care Home.
Overall Floor Plan. - NTS

Prospect United Care Home

The following concept touches on the design and sensory issues that have been previously outlined by this thesis. The building as a whole is designed to function as a community, with each section functioning both independently, and as a whole when required. The private and public areas of the building are positioned in order to promote independence and privacy, while allowing for active socialization. The goal of the design is to promote feelings of community and freedom, while providing the safety and comfort necessary for individuals living with dementia.

Community Centre:

The Education and Community Centre of Prospect United Care Home can be found in the Southern part of the facility. This space is designed to support the proper education of dementia and its lifestyle to patients, their loved ones and the community. The historical church is included in the design, and is used for a variety of purposes, including

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Image 07 – Prospect United Care Home.
Community Centre/ Old Church.

Image 08– Prospect United Care Home.
South-West Elevation, Main Entrance.

Image 09– Prospect United Care Home.
Journey through Main Entrance and Community
Space. Image of Window View to Prospect
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Image 10– Prospect United Care Home.
Community Centre Space/ View of Church
Courtyard.

Image 11 – Prospect United Care Home.
Community Space - NTS

religious services, community gatherings, choirs, and the facility's other group activities and therapy sessions. The 'town centre' area, adjacent to the church, includes all the necessary support functions for a long-term care home and retirement community. Incorporated here is, a hair salon and barbershop, a small restaurant and cafe, a 'general store' (which can also be transformed into another group activity room when necessary), and a doctor's office. The doctor's office allows individuals to leave their private dwelling space in order to visit a doctor, dentist or other professional, allowing those who would like it, the opportunity to keep their personal space separate from other standard community functions. The Education and Community Centre allows families and friends to visit residents in a safe environment separate from their private 'home.'

Retirement Home:

Residents that arrive at Prospect United Care Home in the mild to moderate stages of Alzheimer's disease or other forms of dementia are given the opportunity to move into one of the gender specific retirement homes. Each of the houses can accommodate up to six adults, with the two dwellings working together as one 'retirement community.' These homes are designed for individuals, who are looking to maintain a more independent lifestyle, allowing them private bedrooms and washrooms, and a more family dwelling centred layout. The bedrooms are not wheelchair accessible, as they are designed for people that don't require

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Image 12 — Prospect United Care Home.
Retirement Home - NTS

Image 13 — Prospect United Care Home.
Long-Term Care Home - NTS

Image 14 — Prospect United Care Home.
Interior of Long-Term Care Home.
Entrance to Meditation Garden/ Main Space.

Image 15 — Prospect United Care Home.
Interior of Long-Term Care Home.
Lounge Space/ View to Garden.

as much help with daily physical tasks. This helps to keep costs lower, as less staff are required. This space gives residents the support that they require while they adjust to their changing lifestyle. The open concept living, dining, and kitchen space not only provides proper sightlines throughout the house, but also allows for staff to work with the residents and help with their daily needs, while giving individuals the chance to feel 'at home' within their space.

Long-Term Care Home:

The Long-Term Care Facility of Prospect United Care Home is designed for individuals experiencing moderate to advanced stages of Alzheimer's disease or other dementias. This area is on lock-down from the rest of the facility, and is designed for individuals who require constant supervision and assistance. Emphasis was placed on helping residents to focus on personal healing, reflection and meditation. Common spaces are designed to promote feelings of comfort and security. There are obvious sightlines between the living, dining and kitchen spaces. Several washrooms are located in the main spaces as well to help remind residents who might have trouble with these daily tasks. The bedrooms are a mix of single and double rooms. This allows individuals who would like the company, as well as lower costs, to choose a room that fits their needs. The main space includes an enclosed meditation courtyard that allows residents the opportunity to experience the gardens year-round. This is a safe space, which can be seen from the second floor administration

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Image 16 – Central Garden Courtyard within Retirement Community space.

Image 17 – Interior Meditation Garden within Long-Term Care Home.

Image 18 – Prospect United Care Home. Longitudinal Section - NTS.

Image 19 – Prospect United Care Home. Exterior View.

Image 20 – Prospect United Care Home. Exterior View.

area as well as the main space, so that staff can always keep an eye on residents. The walls around the courtyard also provide a 'way-finding' guide for residents that they can follow to find the main spaces as well as their bedroom, no matter where they are in the building. Rest stops along the way allow individuals to pause and relax as well as experience the courtyard gardens and farmlands outside.

Way Finding:

The overall floor plan of the entire building is broken down into three distinct areas, the long-term care centre, the retirement community and the community centre. The overall space is designed as a community, connecting three distinct spaces with interior walkways that allow residents to freely move within the building, while still enjoying views to the exterior. The large walkways allow for obvious sightlines throughout the building, which give residents the opportunity to always see their destination, and where they currently are. This makes 'way-finding' much easier for the residents, as they don't need to rely on signage or other visual cues in order to make their way through the building.

The walk-ways or halls connecting each of retirement homes, long-term care centre and community centre, are designed to allow residents the feeling of openness. When considering how to create an entire community under one roof that would allow individuals the freedom to explore different aspects of the building and reimagine its spaces

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Image 21 – Prospect United Care Home.
Canopy Structure Light Study, 9:00am.

Image 22 – Prospect United Care Home.
Canopy Structure Light Study, 12:00 noon.

Image 23 – Prospect United Care Home.
Canopy Structure Light Study, 3:00pm.

Image 24 – Prospect United Care Home.
Canopy Structure Light Study, 7:00pm.

as they needed, it was determined that the design of the connecting halls needed to be grand enough to support the emotional need to go outdoors even if that person wasn't able to do so physically. The roof structure in the hallways around the retirement homes incorporates a roof canopy that mimics the light patterns found on the forest floors from leaves in tree canopies. The patterns traced along the floor are meant to help residents who might have trouble with telling time, as they watch the light move. It is also designed to eliminate the emotional associations that can be found with stepping out of one's dwelling and into another hallway. By changing the architectural setting and atmosphere, residents are given the opportunity to reimagine the space, and hopefully they are triggered to consider this part of the building as more of a community space, and outdoor area.

Looking past the hallway, retirement home residents are also looking straight into the garden courtyard, which is open to the elements. Individuals are able to use the continuous wall around the garden as a guide to find their dwelling as well as the entrance to the community centre when necessary. The walkways are designed to cue individuals to consider this space as an outdoor area and community space, the halls are large enough to provide ample walking space for residents, staff and families to enjoy exploring the centre, while allowing for areas of rest and relaxation.

There are several opportunities for views out towards the farmlands around the site that might provide some residents the visual

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stimulation needed to recall personal memories of country life. This visual stimulation also allows residents to keep track of the changing seasons, time of day and weather, a challenging notion for individuals with dementia.

Way-finding cues have been included in areas of the building that are particularly important for residents to explore, notably accessing the Community Centre. Views along the path, windows with direct views of Prospect United Church, were carefully planned in order to ensure that residents would be able to find their destination, as well as give their brains a stimulating path to be explored. As individuals progress in their disease, their cognitive ability does decline rapidly, but providing stimulating environments could help to keep individuals interested in their space and enjoying their life longer.

Prospect United Care Home stresses the importance of creating a supportive and appropriate continuum of care environment. The overall building is designed to support feelings of security and comfort while allowing residents the freedom to explore their community. There is an emphasis on allowing for individual private space, as well as several levels of public and community space. This gives residents choice and the possibility to create a more 'home-like' environment at every stage of their disease.

Concluding Thoughts

The design concept for Prospect United Care Home attempts to reconcile the loss of the personal dwelling by bridging the gap between lifelong family house and retirement home. The incorporation of the historic Prospect United Church allows individuals the possibility of recalling personal events and memories, through whole body sensory stimulation. For those who have experienced the church as a resident of the community throughout their lives, it could serve as the physical constant and mental transition between one 'home' to the next.

If we follow the research presented, we can begin to understand the complexity of designing a dwelling space for individuals living with dementia. The changing nature of the symptoms, and a person's own personal experience combine to define a very unique set of design requirements. The facility that must be developed in order to provide an appropriate 'continuum of care' for the individual must consider all the changing needs of each person living there.

CONCLUDING THOUGHTS

This design may not answer the question of 'home' for everyone. The building attempts to provide individuals with another alternative, a care option that is currently not available in Canada, and attempts to answer some of the questions not being asked by current care providers. Prospect United Care Home might be best suited for a single person, who has been diagnosed within early stages of dementia. They are seeking a facility that can not only give them the support and care needed for their disease as they progress, but also for their emotional and social connections.

Prospect United Care Home, as a whole, is only one answer to the increased demands being placed on the Canadian healthcare system. As the number of Alzheimer's disease and dementia patients rises in North America many options will need to be presented. However, what this design concept does is offer one answer to the 'continuum of care' philosophy, and the community outreach, that is so desperately needed in current dementia care facilities.

The research presented is the beginning of a lifetime pursuit. In order to provide a more accurate assessment of the design concept, further research and case studies would need to be explored. Further consultation with social workers and psychologists trained in the challenges of life with dementia, would also allow for a more accurate evaluation of the overall design. Their input would also allow for further exploration of the specific benefits of using the historical church to create the physical and mental bridge between 'home' spaces.

Epilogue

Assembled Self

assembled, *adj.*

Gathered into one place or company; put together.

- Oxford English Dictionary, Online.¹

I want to go back. I need go back. I am having trouble recalling even the smallest details. What colour was her dress? How tall was that tree? What did the carpet feel like under-foot?

As I shuffle through dog-eared photographs and fuzzy memories, waves of calm, sadness, excitement and hope flood over me. These feelings hit me like a summer rain, just tiny drips at first, followed by a sudden down-pour. I let it strike me.

I awake, the sun is dancing across my face, kissing my cheeks. Photographs are scattered across the floor and the breeze makes them flutter and shift even more. My hand still clasps one image, we are gathered around the table, the dim light illuminating one of our many late night conversations. Everything is still as they pose for the camera. I can see her dress. I can see the tree, I can feel the carpet.

I remember.

¹ "assembled, adj." Oxford English Dictionary, Online. 09 May 2012, March 2012.
<<http://www.oed.com/view/Entry/11789>>

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Image 01 - Exterior, Colonel By Retirement Home - Photo credit: Revera Living, http://www.reveraliving.com/Revera/media/Revera/Overview%20Page%20Images/Colonel%20By/Exterior_overview.jpg?width=330

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Photo credit: Brynne Campbell

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Photo Credit: Brynne Campbell

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Photo credit: Ashton-Munster Pastor Charge, http://apc.royalyorkers.com/apc_home.html

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1/32" = 1'0"

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 $1/32" = 1'0"$

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 1/32" = 1'0"

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Bibliography

"About the ORCA Accreditation Program." Look for ORCA Accredited Residences. 2012. Ontario Retirement Communities Association. 02 Feb. 2012 <<http://www.orcaretirement.com/public/master.php?page=res>>.

"Administration, monitoring and reporting." Long-term care. 2011. City of Ottawa. 02 Feb. 2012 <http://ottawa.ca/social_com/housing/seniors/long_term/index_en.html>.

Alzheimer's Project, The: The Memory Loss Tapes. Dir. Shari Cookson. HBO Documentary Films, 2009.

Alzheimer's Society of Canada. Rising Tide: The Impact of Dementia on Canadian Society. Canada: Alzheimer Society Ottawa and Renfrew County, January 2010.

"assembled, adj." Oxford English Dictionary, Online. Oxford University Press. 10 Mar. 2012. <www.oed.com/view/Entry/11789>.

Bachelard, Gaston. The Poetics of Space. Boston: Beacon Press, 1958.

"Brain Tour." alz.org. 2001. Alzheimer's Association. 26 February 2012 <http://www.alz.org/braintour/3_main_parts.asp>.

Canada, Legislative Assembly of Ontario, Retirement Homes Act (Toronto: Government of Ontario, 2010), <http://www.ontla.on.ca/web/bills/bills_detail.do?locale=en&BillID=2298&detailPage=bills_detail_the_bill&Intranet=>>.

Calkins, Margaret, PhD. Person-Centered Design in Healthcare: Building Connections. PowerPoint Lecture presented at the Environmental Design Research Association Annual Conference. Chicago, IL. 25 May 2011. <<http://www.ideasinstitute.org/pdfs/CombinedPresentations.pdf>>.

Charron, Lise. Kinsway Arms St. Joseph Manor. Personal Interview. 01 October 2011.

BIBLIOGRAPHY

Chaudhury, Habib. Remembering Home: Rediscovering the Self in Dementia. Baltimore: The John Hopkins University Press, 2008.

Colonel By Retirement Living by Revera.

Colonel By Retirement Residence Promotional Brochure. November 2011.

Davidson, Tonya. "The Role of Domestic Architecture in the Structuring of Memory." Space and Culture Vol. 12 no. 3 August 2009: 332-342.

Davis, Sandra et. al. "Guiding design of dementia friendly environments in residential care settings." Dementia Vol 8 no. 2 May 2009: 185-203.

De Witt, Lorna, et al. "Living on the threshold: The spatial experience of living alone with dementia." Dementia Vol 8 no. 2 May 2009: 263-291.

Douglas, Mary. "The Idea of Home: A Kind of Space."
Social Research, Vol.58, No.1 Spring 1991: 288-307.

"Eligibility and Admission." CCAC Web Site. 2001. Community Care Access Centre. 31 Jan. 2012 <<http://www.ccac-ont.ca/Content.aspx?EnterpriseID=15&LanguageID=1&MenuID=23>>.

Engel, Susan. Context is Everything: The Nature of Memory. New York: W.H. Freeman and Company, 2000.

Flor, Herta. "Phantom Limb Pain: Characteristics, Causes and Treatment." The Lancet, Neurology Vol 1 July 2002: 182-189.

Gallagher, Winifred. House Thinking: A Room by Room Look at How we Live. New York: Harper Collins Publishers, 2006.

Gallagher, Winifred. The Power of Place. New York: Harper Perennial, 1994.

"Government Legislation and Monitoring." Senior's Care: Retirement Homes. 23 Nov. 2010. Ministry of Health and Long-Term Care. 02 Feb. 2012 <http://www.health.gov.on.ca/english/public/program/ltc/14_retirement.html#4>.

Gunter, Barrie. Psychology of the Home. London: Whurr Publishers, 2000.

BIBLIOGRAPHY

"home, n.1 and adj." Oxford English Dictionary Online. Oxford University Press.
10 Mar. 2012 <www.oed.com/view/Entry/87869>.

"How the Brain and Nerve Cells Change During Alzheimer's Disease." ahaf.org. 10 January 2012. American Health Assistance Foundation. 26 February 2012
<<http://www.ahaf.org/alzheimers/about/understanding/brain-nerve-cells.html>>.

"house, n.1 and int." Oxford English Dictionary Online. Oxford University Press.
10 Mar. 2012 <www.oed.com/view/Entry/88886>.

Jutasi, Nancy. Colonel By Retirement Living by Revera. Personal Interview.
22 November 2011.

Kelsey, Susan, et al. "Transitioning Dementia Residents from Assisted Living to Memory Care Units: A Pilot Study." American Journal of Alzheimer's Disease & Other Dementias Vol. 23 no. 4 August/ September 2008: 355-362.

Kidd, John and Leona. Personal Interview. 23 January 2012.

Knickman, James R. and Emily K. Snell, "The 2030 Problem: Caring for Aging Baby Boomers." Health Services Research Vol. 34 no. 4 August 2002: 849-884.

Lamont, Kelly. "Mirror Box Therapy – Seeing is Believing." Explore Vol. 7 no. 6 November/ December 2011: 369-372.

Malpas, Jeff and Linn Miller. "Home and the Place of Memory."
Home and Space Vol. 4, Iss. 2 Spring 2009: 29-47.

Markowitsch, Hans J. & Harald Welzer, The Development of Autobiographical Memory. New York: Psychology Press, 2010.

Meyers, Robin. Richmond Care Home. Personal Interview. 23 January 2012.

Ministry of Health and Long-Term Care, Long-Term Care Home Design Manual. Ontario: Ministry of Health and Long-Term Care, 2009.

"ORCA Accreditation – Why it Matters." Look for ORCA Accredited Residences. 2012. Ontario Retirement Communities Association. 02 Feb. 2012
<<http://www.orcaretirement.com/public/master.php?page=res>>.

BIBLIOGRAPHY

Peter D. Clark Long Term Care. Personal Interview. 29 November 2011.

Peter D. Clark Long Term Care, Information Handout, 29 Nov. 2011.

Rowles, Graham D. and Habib Chaudhury, ed, Home and Identity in Late Life. New York: Springer Publishing Company, 2005.

Schillmeier, Michal and Michael Heinlein. "Moving Homes: From House to Nursing Home and the (Un-)Canniness of Being at Home." Space and Culture Vol.12 No.2 May 2009: 218-231.

Sternberg, Esther M., M.D., Healing Spaces: The Science of Place and Well-Being. Cambridge: Harvard University Press, 2009.

Van Hoof, J., MSc., et al. "Environmental Interventions and the Design of Homes for Older Adults With Dementia: An Overview." American Journal of Alzheimer's Disease & Other Dementias Vol. 25 no. 3 February 2010: 202-232.

Van Hoof, J. and Helianthe S. M. Kort, "Supportive living environments: A first concept of dwelling designed for older adults." Dementia Vol. 8 no. 2 May 2009: 293-316.

Wornoff, Nancy. New Orchard Lodge. Personal Interview. 23 November 2011.

"What We Do." CCAC Web Site. 2001. Community Care Access Centre. 31 Jan. 2012 <<http://www.ccac-ont.ca/Content.aspx?EnterpriseID=15&LanguageID=1&MenuID=137>>.

Yates, Frances A. The Art of Memory. Chicago: The University of Chicago Press, 1966.

Zeisel, John, Ph.D. I'm Still Here: A New Philosophy of Alzheimer's Care. New York: Avery, Penguin Group, 2010.