

Script – Presentation

I'd like to begin my presentation with a quote attributed to author Jack London in 1916, whose relevance will be self evident before too long.

I would rather be ashes than dust!

I would rather my spark should burn out in a brilliant blaze than it should be stifled by dry-rot

I would rather be a superb meteor, every atom of me in magnificent glow, than a sleepy and permanent planet.

The function of man is to live, not to exist

I shall not waste my days in trying to prolong them

I shall use my time

This project began as a growing concern regarding the ability of senior housing to provide a meaningful home for those suffering from cognitive disorders such as Alzheimer's disease. Taking the example of the thousands of rooms currently being built under the new model of Maison des Aînés here in Québec, it's expected that up to 80% of the clientele will suffer from mild to severe cognitive impairment. In part due to the lack of information being provided regarding the actual care being given in these new establishments, there is significant uncertainty regarding whether a patient suffering from advanced cognitive impairment will be able to last out their days in a stable environment, or whether they would be transferred any number of times between medical care homes. The homes that then house the last few months, weeks, or days of such patients' lives, usually a more traditional CHSLD or hospital, are often ill-equipped to face the specialized needs of this group. My grandmother, France Tellier, suffered such a fate. Over the last two years of her life, she was moved four times between institutions, each accompanied by major drops in cognitive ability characteristic of a traumatic change in environment. Over these two years, we lost her, and she lost herself. My grandmother was a proud and a strong woman, and that was not the fate she would have chosen for herself.

Thankfully, this choice may not be taken out of the hands of patients for much longer. Though delayed by the pandemic, it is expected that the laws surrounding medical in dying, or MAiD, as it is practiced here in Quebec will be widened to include patients diagnosed with mental illnesses and cognitive disorders. Just in this past week, the special commission and the College des Médecins have officially supported this measure and is recommending an amendment to the legislation as soon as possible. After receiving a positive diagnostic, and following a repeated process of application, a person would be able to choose a stage of their disease, following their own sense of personal dignity, at which they wished to receive MAiD.

With these concerns in mind, I wished to study how architecture and design could ensure that a proper final home be provided for patients in need of specialized spaces, specifically patients suffering from Alzheimer's disease, and regardless of whether the stay in this final home lasts years, months, or even mere hours.

These past four months, I've been able to study the relationship between the brain and its environment in order to design this last home for patients like my grandmother, an establishment which could provide them with ongoing care but also include purpose-built spaces for the administration of MAiD. This research, punctuated by interviews with professionals in Alzheimer's research, elder care design, sociology and palliative care, helped create a compendium of knowledge with which to move forward into design. With this knowledge, I had devised a course of action for this semester and project, and wished to design three specific prototypical spaces. The heart, or the bedroom, the seat of episodic memory and a link to the past; the hearth, or common room, a connection to contextual memory and to others; and finally, the Lily, the last room, creating one last memory for the patient, and a meaningful memory for the family and friends which may accompany the patient.

However, despite this detailed plan for my research project, I kept returning over and over to this last space, the Lily, as the seat of the most meaningful experience, as the one most likely to impact a patient and their family. I have thus spent the better part of this semester focusing on this space alone, letting the other two fall to the leaside for now. I've not decided to abandon the other two elements

altogether. My dedication for this subject is strong enough that I wish to pursue this research further, developing the design of the heart and hearth outside of academia in the coming year.

The idea of creating a room or pavilion specifically for this purpose may seem foreign without understanding the state of MAiD in Quebec. The regulations put in place by the government in 2015 create a burden on the doctor who approves a MAiD request, obligates them to follow the patient and even push the plunger for the final injection. In the words of a palliative care physician and MAiD advocate who I was lucky enough to lengthily discuss with, taking this burden is meant to lift one off the patient's shoulders. If their request is granted, they know that they will be accompanied along the entire process and to the very end, not left behind by problems of a flawed organisation. With this quality of the system here comes the reality that having MAiD administered at home is rarely used or requested, even if possible. Palliative care wings in hospitals are typically where the treatment currently takes place.

Over the course of these last ten weeks, I've come to see this space not as an integral part of a larger center, but rather as a pavilion, providing its users with the quiet and privacy they deserve. This space, in proximity to either a home or healthcare facility, would act as what twenty years ago may have been designated a chapel. I've also chosen a site, a site which could continue to serve for my post-academic research. I've chosen to propose this new centre to take over the former home of the Shriners Children's Hospital, a lot perched on Mount-Royal near the Montreal General Hospital. This building already contains many of the amenities required by a healthcare facility, and its surrounding land provides a natural setting so often requested by patients for their last moments. Its proximity to the General Hospital also has the implication that the Lily could cater to MAiD patients out of their palliative care.

My proposal for this modern sanctuary is based on the research from the first eight weeks of the semester, and architectural devices attempting to reduce the adverse symptoms of cognitive disorders such as anxiety and confusion. Some explanations regarding this research can be found in the document I've placed in the chat for your perusal. The Lily is intended to be a flexible space, used by residents during their stay as well as for their last few hours on earth. An assembly space, a concert hall, a space for prayer. Acting as a non-denominational chapel in the landscape it creates a private and contemplative space for

spiritual use. The tripartite arrangement of rooms allows for gentle transitions and a series of contrasts facilitating navigation and use, while providing more private spaces for care practitioners or medical personnel. A non-descript building from the outside, its interiors appear as carved out of the concrete as the dip in the rock. The Lily is set within the mountain, in a dip in the slope and surrounded by trees, using the natural features to protect and shelter. It uses its mass as a damper for light, sound, distraction, for overstimulation of a fragile brain. It's cardinal orientation also ensures that should a patient desire, the room can be flooded with light yet remain controlled, without removing the delight of direct sunlight through an oculus practiced in the roof. For the intended primary practice of this space, families and loved ones are invited to tailor the space to the life and journey of the patient, to call back memories perhaps lost or fuzzy, to incite positive feelings from a confused or anxious person. We can explore the space through their perspective, their life.

Consider Mary, whose life was punctuated and marked by the gatherings of her numerous family, by Christmas dinners and spring weddings, by weekends at the lake and ski outings. She was surrounded by those she loved and who loved her in every cherished but fading memory, in every photograph covering nearly every surface of her bedroom at the home. She often got visitors. Though she may no longer recognize all of them, especially the tiny ones, she knew they meant her good and enjoyed the company and the walks outside, the bingo in the bright hall. When her family started recognizing the signs, and the caregivers contacted the doctor, all they told her was of the big party they were planning for her. When the time came, her partner came to get her, and together they went up the path behind the centre, taking their time to take in the late spring flowers, the smell of the earth, the wind in the trees. Suddenly cut off from the world as they entered a building she didn't quite recognize, she could smell the lilies on the table, hear gentle music. As she made her way down the gentle curve of the corridor, she could begin to hear the laughter of children and chattering of their parents, the scraping of chairs. When she arrived in the main hall, bright in the cloudy morning light, her whole family was there to welcome her, with a long table for them to have lunch together, a few couches. They ate, and laughed, and sang like in her memories and in the photographs. She played with the young ones, few of which she could name, but glad to see them

running around. Her caretakers were there too, near the end, giving her a last glass, for celebration, with everyone she loved close around her, gentle smiles on their faces.

Consider Philippe, who had never had children but whose life was no less loving thanks to a dutiful husband and plenty of caring friends. Philippe and his husband had filled their lives with concerts, travel, adventures of any kind. Philippe had gotten his diagnosis early, and with the medication, he was able to remain active for several years. When the symptoms became more than could be safely handled at home, Philippe moved to the centre, and his husband got an apartment on Cote des Neiges so he could come see him daily, so Philippe could still see their dog, and have meals together. His husband organized small concerts in the nearby chapel, for the benefit of all the residents, their families, their caretakers, live music by student musicians who merely wanted to play. But then again, the time came, and the symptoms had gotten worse. Philippe had made explicit requests at the time of the MAiD application. If he didn't outlive his husband, he wanted him and him alone to accompany him with their dog, and he had requested that a cellist come play for them. None of this he specifically remembered of course. But his husband did, and his doctor made the arrangements. Going up that same path, Philippe looked to the city, struggling to recognize all the buildings. Were there always this many? It was silent upon entering the Lily. They walked gently through the corridor, into the tall space, muted without any furniture. He could vaguely remember music in this space, but none was playing now. He enjoyed the warmth as they passed below the large skylight, on the way out into the clearing. Out on the patio, a young woman was at the cello, playing absentmindedly one of Bach's cello suites. They sat down on the couch together, their dog at their feet, and the young cellist began playing Elgar's cello concerto. Philippe couldn't have named it, but he could feel it raise the hair on his neck, the long-forgotten joy of the sensuous notes of the strings. Before the cellist began the third movement, a lady in the white coat came to give them some tea, his with milk and his husbands black, as they had always taken it. The cellist began playing the third movement, then the fourth and last, notes fading away in his husband's arms.

Consider France, whose life was defined by her strength of character, by her undying love for her family and their own families, by the fierce pride she felt of them, and of herself. She had not had the

chance of an early diagnosis, and the medication could only give her some time before symptoms made her forget those she loved, what they'd accomplished, what she'd accomplished. She would not let herself knowingly become a burden to others, or waste her days trying to prolong them. She would stay home until it became impossible, but no more. She had made a passion for walking, discovered abroad with her then fiancé, and had continued to be a regular patron of Mount-Royal Park throughout her life. When the time came to take the drive to the former Shriners, she may not remember the name of the street, or what used to inhabit that odd white and red building, but she knew the mountain, the smell of the trees, the songs of the birds and the vibrant fall colours as she made her way up the winding path with her husband, her children. She knew the place from what felt like long ago but couldn't remember why they had come. She was calm, however, with those she loved around her, enjoying the crisp autumn air as they gently ascended over the city behind her. The muted room at the entrance of the building allowed for rest, before they descended to the hall, where the curtains were pulled, but a couch and a few chairs were set where the sun made a bright circle on the floor. She recognized the music that played softly, not taking note of the words, sitting in the sun and chatting with her family. She enjoyed hearing them speak between themselves. An attendant brought them some coffee, giving her her cup specifically before retiring behind a wooden screen. She drank it, her husband's hand in hers, enjoying the sunlight, the music, the trees through the skylight...

The Lily has the power of affirming these narratives. Its main goal is to provide peace to patients, so often confused and anxious, and to their families, for whom the loss, even if predictable, can still be terrible. It wants to help create a few last good memories for the patients and their loved ones, memories often robbed by the circumstances of the current system. It creates a new home for joyful memories: a place for a peaceful death. It is a journey, a modern gateway in the face of the greatest common denominator.

Thank you.