

Transcendental Tunes:

The use of familiar music together with digital jewellery as an alternative communication system that brings emotional connection between a patient living with Alzheimer's Disease and their Care Partners.

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Para Tani

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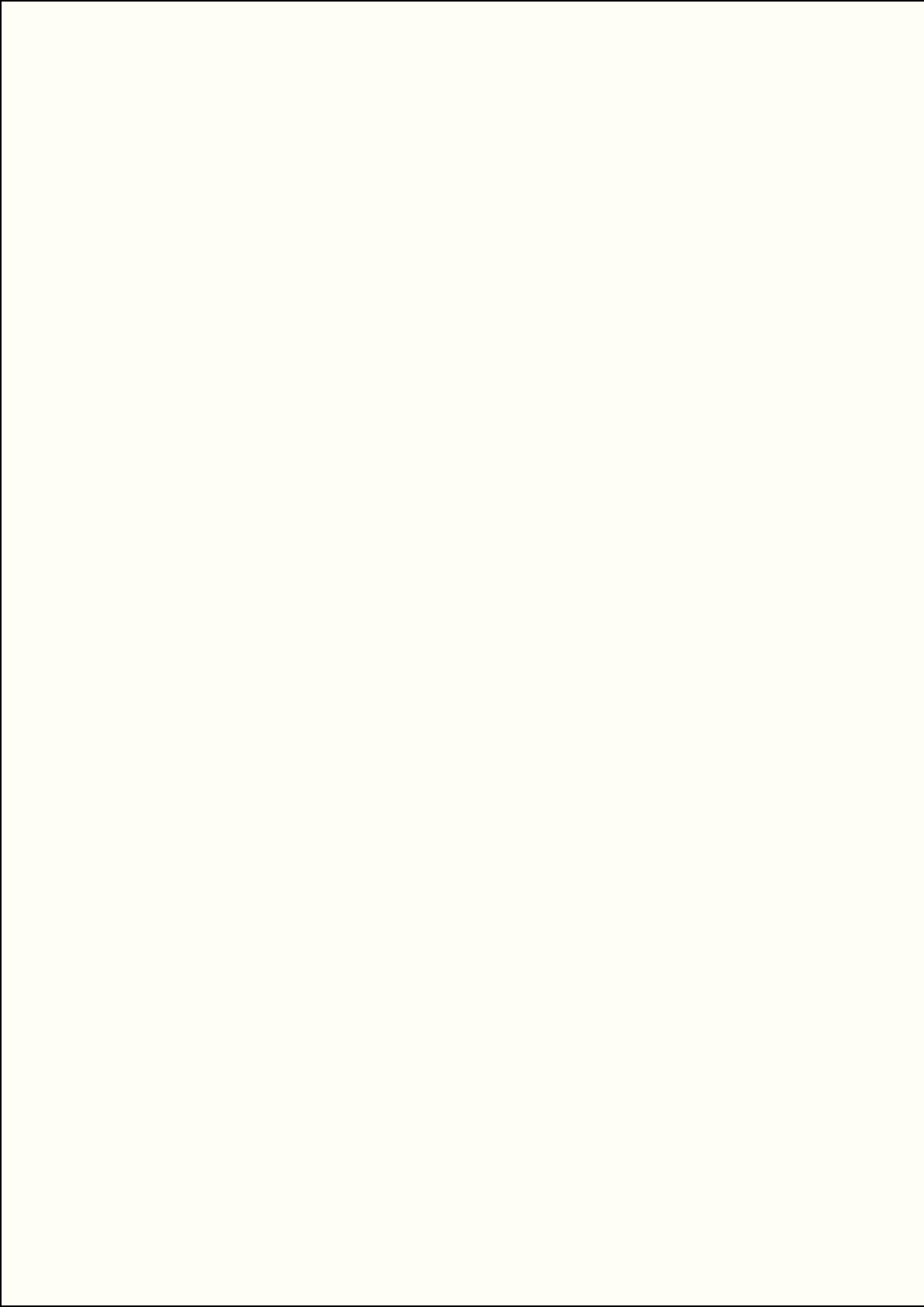
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Abstract

As life expectancy grows worldwide, so does the risk of suffering Alzheimer's disease (AD) because the rate of occurrence of the disease increases exponentially with age. Today around 18 million people suffer from Alzheimer's, and not only will the future population have a greater risk of developing the disease, but they will be more likely to become primary care takers of someone who does. Therefore, designers must look at the situation caused by AD and specifically the relationships between patients and the people surrounding them, like family, friends and caretakers, as there are many areas where they can help. Currently, the design world is creating solutions with an utilitarian approach, such as therapeutic toys or assistive technology, but those do not address what is really at hand. Designers are not making products that also provide dignity, sensibility and emotional aid between the care taker and the AD patient.

The question which I intend to answer in my thesis is: Can design tools that provide new ways of communication between the care partner and an AD patient be applied and become an emotional aid for them? Under the premise that people living with Alzheimer's don't lose their memories, but lose their capacity to reach them with normal stimuli, the design field can find tools to enhance existing stimuli for new ways of connection between care partners and Alzheimer's.

As recent studies show, the Medial Prefrontal Cortex (MPC), which is the part of the brain that works as a hub for familiar music, memories and emotions, is one of the last areas of the brain to atrophy over the course of the disease. This is why music elicits strong responses from people with Alzheimer's, to the point that they can evoke emotional-autobiographical memories. As this research is encouraging, we could take these reactions caused by music and reinterpret them as new ways of connection. This design thesis explores the relationship between music and Alzheimer's. By designing a system using familiar music with an emotional approach, this would provide those close to AD patients to explore a new method of a more meaningful, intimate communication that could change their perspective on new relationships between care partners and Alzheimer's patients.



1.0 Getting to Know Alzheimer's

“Never will I be three-fourths of a person, half of a person, nor 1/73 of a person. There has not, nor will there ever be a moment in my life when I’m not a complete Human Being. Please get this; it’s important to me, to those who love me, to those who are paid to care for me. It is important to our society. I am always me...”

-RICHARD TAYLOR, PATIENT LIVING WITH ALZHEIMER'S.

1.1-Introduction: The Case of Trini, Rosa and Carolina.

Witnessing the decay of someone with Alzheimer's disease (AD) is one of the most devastating processes one can ever experience. For care partners, patients lose their past, their history, their personality and eventually their lives. However, when caretakers understand that some of the patient's capabilities don't diminish over time, a door opens for creating new ways of communicating between them. This realization is crucial as maintaining a relationship between them may translate in better care for the patient and well being for all of those affected by the disease.

Yet, it is not easy to realize all this at first glance: being the primary care partner can also deteriorate them emotionally and physically. Rosa Elena and Carolina Sanchez Campos, know first hand the hardships of being primary caretakers of an Alzheimer's patient. Their mother has been diagnosed with AD ten years ago and they have been taking care of her ever since. Rosa Elena explains:

"WHEN THE DOCTOR DIAGNOSED MY MOM WITH ALZHEIMER'S, I DID NOT UNDERSTAND ENTIRELY ALL ITS IMPLICATIONS WHEN HE CALLED A VERY "DIFFICULT" DISEASE. AT THAT MOMENT I ONLY THOUGHT SHE WOULD FORGET A FEW SIMPLE THINGS SUCH AS DATES AND MEMORIES, BUT AS TIME PASSED BY, I REALIZED THAT ALZHEIMER'S WAS SOMETHING MUCH MORE SERIOUS THAN THAT. SOMETIMES I WOULD FIND MY MOTHER WEARING HER BLOUSE ON HER LEGS LIKE A SKIRT; TAKING 30 MINUTES TO PUT HER TROUSERS ON; OR BEING REALLY ANXIOUS WHEN NOT BEING ABLE TO FIND HER BELONGINGS. FOR EXAMPLE, SHE WOULD COMPLAIN SAYING THAT SOMEONE HAD TAKEN THEM. AND THOSE THINGS PUT ME IN A STATE OF SHOCK. I FELT PHYSICALLY PARALYSED AND I COULDN'T EVEN THINK IT THROUGH. EVENTUALLY MY MOM'S EPISODES BEGAN AFFECTING ME AS NO ONE WAS ABLE TO UNDERSTAND MY PROBLEMS. ONLY TO THINK ABOUT MY SITUATION WOULD MAKE ME CRY WITHOUT REALLY UNDERSTANDING WHY I WAS FEELING THAT WAY."

Through the last 10 years since their mother was diagnosed with Alzheimer's, Carolina and Rosa Helena experienced an emotional roller coaster that takes them back and forth from denial, anger and even bargaining:

"I started to tell God, that if he brings my mother back from Alzheimer's, I would do something in return" Helena explains. "I was willing to do a pilgrimage to La Villa (the most important centres of Catholic pilgrimage in Mexico). "But in the end you just give up; you accept the fact that this disease is irreversible and in my case, I accepted that my mother will eventually mentally fade. This process of acceptance is like climbing to a top of a mountain, sometimes you fall down in order to find yourself at the starting point, and you have to start climbing again".

On top of it, dealing with a family member with AD, makes family members to sacrifice their personal activities, changing their lives considerably. *"It took me 10*



*Trinidad Campos de Sanchez, circa 1989.
She is Rosa Helena's Mother.
Picture courtesy of the Sanchez Campos Family*

months to make the final decision of shutting down the wood workshop I had been running with my father". Helena, which happens to be an avid carpenter, explains, "Because, taking care of my mom was a full time activity, I realized that I needed to do these sacrifices. Sometimes I'll just open the door of the workshop and breath the smell of wood, just to close the door and cry." In the same time, by spending full time taking care of their mother, their husbands and kids also got affected: *"I couldn't go out anymore, or spend quality time with my kids and my husband, every time I was tired for cooking dinner and to spend time with them, although they wouldn't understand, they just felt jealous of my mother, they also wanted my attention".* Additionally, it was a problem for Rosa Helena and Carolina to make the rest of the family get involved in taking care of their mother. For the rest of their family, it was emotionally hard to help them, as they didn't want to face the burden. It seemed that they wanted to avoid the responsibility of taking care of her. It was difficult to negotiate who would spend time taking care of their mother.

However, helping her mother was not enough. The learning process made Rosa Helena want to share her experience and knowledge about the subject to other people in her situation. Together with her sister Carolina she founded "No Me Olvides A.C." -Spanish for "Don't Forget Me"- a civil organization based in Xalapa, Veracruz (Mexico). The organization has the objective of disseminating information on AD and creating help groups at the community level, connecting specialists and scientists with people that takes care of Alzheimer's patients.

Being Mexico a rather young population, AD is not as well known as in other developing countries like Europe and the United States. Carolina and Helena found



From left to right: Carolina, Trini and Rosa Helena, celebrating Trini's 91th Birthday, on April 30, 2010. Photo courtesy of the Sanchez Campos Family

themselves with few resources when not knowing how to provide care to their mother. *“This is one of the reasons Carolina and I started No Me Olvides, because when we began to deal with this problem, there was no one that could help us. So, we decided to help other people in the way we would have liked to get”*. For example, help was not even available from regular doctors and nurses as they didn't know much on Alzheimer's patients' care. Even nurses at the hospital thought that their mother was a stubborn old lady that behaved like a child, thus, treating her as one (Treating AD patients as spoiled children is useless, because a child may learn from punishment, but AD patients cannot). The lack of resources aggravated their situation. However, as they continued to learn from the disease and struggle with it every day, they only became stronger. Their civil organization succeeded in part because of their hardship. Today No Me Olvides A.C. has the support of several government organizations and Universities in Mexico, no to mention that the help groups they have helped to organize are continuously growing, becoming a large network of scientist volunteers and care partners, to talk about their experiences and knowledge of AD to the less experienced.

I know Rosa Elena and Carolina since I was born because they are my mother's first cousins. On December 2009 I was visiting my parents in Xalapa. In Christmas Eve, my mother asked me if I could join her to pay a visit to my Aunt Trini, Rosa Elena's Mother. I knew that my great-aunt had Alzheimer's, but to be honest I never processed it in my mind. I knew that AD was a disease that makes people forget facts, places and unrecognized family members and friends, but I never realized how much people around AD patients could be emotionally affected. After listen-

ing to Rosa Elena and Carolina's accounts on their emotional wear down in taking care of their mother (and, contemplating her decay), I realized the huge importance -for both the world and myself- to explore the therapeutic side for the patient, and more importantly, the emotional side from the point of view of the family. I thought I could help them carry their emotional burden using design tools, as unconventionally as it sounds!

My research focus is to create new connections between both parts -patient and care taker- using some of the physical capabilities that stay longer over the course of the disease. More specifically, the creation of stimulating musical artefacts for the Alzheimer's, triggered by objects that provides a personal meaning for the people involved with the patient (caretakers and families) that gives them a sense of unity and involvement with this situation. The objective of this collection of artefacts is to be able to reminisce emotional-autobiographical memories in patients, providing an alternative way of communication.

Before I explain the actual design, I provide a background of Alzheimer's in the following section (1.2), detailing its causes and main symptoms, but most importantly, evidence on the fact that AD patients do not forget - but fail to recognize- their loved ones. In addition on how to reach this kind of emotional-autobiographical memories, that can be used for triggering memories of their loved ones, with the right kind of stimulus, more specifically, familiar music.

1.2- Alzheimer's Disease: Misconceptions and Opportunities.

It is well known that Alzheimer's provokes on the patient memory loss on recent learned information, like names, dates or find words to describe the patient context; makes patients confused with time and space and; provokes changes on patient's mood and personality. However there are several misconceptions of how the disease affects the affected person.

One of the inaccurate beliefs of the disease is that people living with Alzheimer's forgets their beloved ones such as a computer files that has been permanently deleted. The incredible good news is that this belief is false. The patient stops recognizing their relatives, not remembering them. The real challenge for patients is creating a connection between the person they have in front of them and the memory of that person. However, with the right sensor stimulation, one can help patients reach the emotional-autobiographical memories and direct them to a person (i.e. a family member), creating a communication bridge between them. This fact opens the doors for many opportunities, but before going deeper into that, it is appropriate to provide an overview of the disease below.

The Alzheimer's Association defines AD as: *"a progressive and fatal brain disease witch destroys brain cells, causing memory loss and problems with thinking and behaviour, severe enough to affect work, lifelong hobbies or social life"* (Alzheimer's Association, 2010, WEB). Note that the "progressive and fatal" aspect this is the part that Rosa Helena failed to recognize at her mother's diagnose stage: AD is irreversible, because the brain tissue is damaged fiscally. To this day, a cure is inexistent.

Scientists attribute Alzheimer's disease to two abnormal brain structures called amyloidal plaques and neurofibrillary tangles. A brain with Alzheimer's disease accumulates amyloidal plaques (protein fragments) between the neurons, which in a normal condition they are easily dissolved and eliminated by the human body. However when the brain looses the ability of dissolving them a chain reaction is generated in which the plaques influence the way neurons' protein are folded. The disorderly ways in which protein fold are called neurofibrillary tangles. To understand this better, imagine that a normal way of "folding" protein looks like an origami sculpture, and that the disorderly way (the neurofibrillary tangles) looks like a chaotic crumble of paper. The abnormal folding deteriorate the brain cells, creating brain tissue loss, therefore making the brain shrink from the outside to the inside, eliciting different ways of cognitive decay (*figure 1.1*). The way the plaques start invading the brain differ from patient to patient, making it really hard for Physicians to predict how the patient will be affected in the future.

Today is almost impossible to diagnose Alzheimer's Disease with a normal biological test (e.g a blood sample). Nonetheless physicians rely on the symptoms which Alzheimer's causes in order to determine that a patient suffers from the condition¹ Only when the brain is analysed by a forensic procedure, doctors can witness the sig-

¹ At the appendix of this thesis one can find a more detail list of the 10 signs of Alzheimer's.

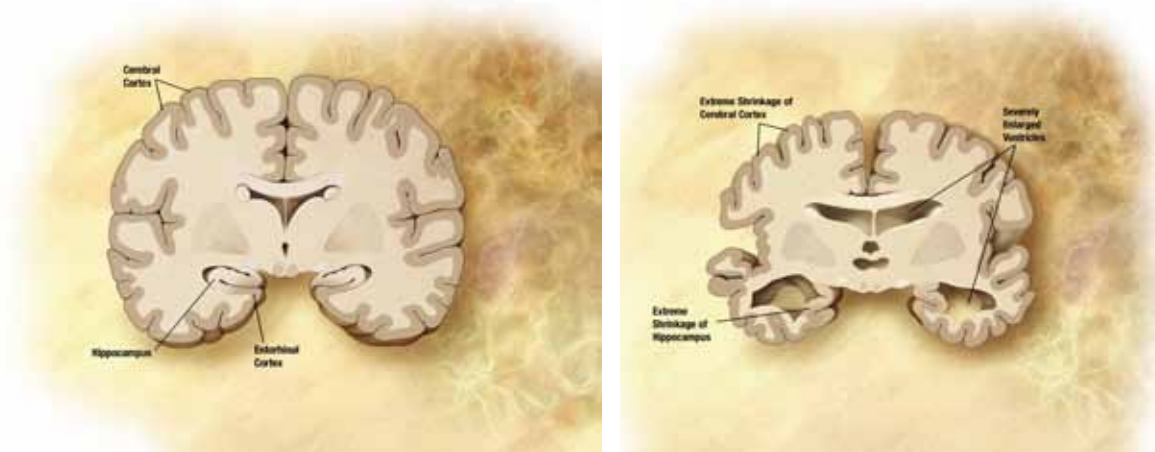


Figure 1.1: Comparison between a normal brain and an Alzheimer's brain, based on Medicine for People! publication, by Douwe Rienstra, MD at Port Townsend, Washington.

nificant loss of brain volume and finally confirm that a person suffered from Alzheimer's. It is likely that in the end of the course of the disease, a brain affected by AD could lose up to 40% of its weight. Even so, it could take at least 10 years for this to happen. This means that during most of the process, patients living with Alzheimer's can still reach most of their hard wired memories until the end.

The human brain contains up to 100 billion neurons (as much as the same number of stars on the solar system). When people are diagnosed with Alzheimer's, this person could be living with 90 billion active brain cells, and through the years, this number can be reduced to 80 billion or 70 billion. Those cells hold memories and other abilities that can stay intact for a large period of time (Zeisel, 2010) ².

As suggested before, the common conception of Alzheimer's disease is that patients suffer from memory loss. In the surface, patients seem to forget things that could challenge the way they lived previously. It is true that people living with AD have a difficult time trying to access memories about what to do in specific situations, like have a normal conversation during a social gathering or follow a food recipe. Still, recalling names or performing a series of complex tasks are really a tiny part of their memories. As John Zeisel (2010) argues, there are other kind of memories, emotional (times of joy, excitement, compassion); autobiographical (life period memories like childhood, school or teenage years); and story memories (how I met my wife/husband, when I saw my first movie, fairy tales) that provide the opportunity for communication and understanding (2010)². For this project the emotional and autobiographical memories are the ones that are more relevant, since these are

²At the appendix of this thesis one can find a more detail list of Memories not lost during the Alzheimer's process

the types of memories that can be triggered using i.e. music that the patient knew before. On the following sections (3.0) I will dive in more detail on how to use music as a communication tool for people living with Alzheimer's.

Nevertheless, for people implementing new ways that connect them to their AD beloved ones is not as easy as it sounds. People like Rosa Helena go through an emotional process that affects them, even more the patients. In the next chapter I will dive on how difficult is for the care partners to accept the fact that a patient is losing cognitive abilities and we will start looking at new ways on how a caretaker can still communicate with them.

1.3- It Hurts: Living in an “AD Situation”

For the new comer, stepping in on taking care of someone with Alzheimer's, the whole idea of the condition can be rather negative and overwhelming. In one hand, some believe that when people are diagnosed with Alzheimer's, they have no future, condemning them to a death sentence. Care takers forget that this condition could last ten to fifteen years, making it a life span that constitutes a future for the person living with it. If we add up the challenges that caretakers face on how to communicate with the patient, the scenario is rather a gloomy one.

However, a different approach can be taken that places care takers in a favourable position onto how to deal with a new AD situation. For example, taking on John Zeisel's example (2010): when addressing a person with Alzheimer's saying: *“Hi, Mom, remember me?”* we put a test to the patient's memory and it can be upsetting. This is likely to elicit an anxious response, such as: *“No, who are you?”* What Zeisel suggest is having a more tender and human approach: holding the person's hand in yours, putting her face at your level, looking at her directly in the eye, and say, *“Hi Mom, I'm your son José. We have wonderful times together, and I love you very much.”* Zeisel says that such an introduction is more likely to elicit a smile and the response *“Oh, Jose, it's so nice to see you”* (p. 20). This exemplifies how I approach the idea of the “AD condition” and inspires me on how to address new ways of helping the caretaker.

Nonetheless, as I mentioned earlier, this is easier said than done. Caretakers go through a lot in the AD situation's process.

For the care partner (another way to say “caretaker” inspired by Zeisel that personally, it's more engaging and meaningful), and especially when family-related to an AD patient, it's extremely painful to witness the disease's implications in the beloved one. Remember the case of Rosa Helena and Carolina, when they mentioned anguish and sadness in accepting their mother's new condition. A feeling of grief is experienced along the whole process which can provoke to the care taker mental, physical, social or emotional reactions. These reactions go from sleeping problems, changes in appetite, physical problems or illness (National Cancer Institute, 2010, WEB).

The relationship with the diseased person, the situation surrounding the disease and the person's attachment with the patient are factors that could depend on how the care partner could endure the situation. For Alzheimer's specifically, the mourning process stretches out for several years draining patients and families physically and emotionally.

When Rosa Helena talked about her AD situation's process as “climbing a mountain”, she was actually going through different phases of grief. Denial, anger, guilt, sadness and finally acceptance can be seen as stages of grief. However they don't happen neatly in this particularly order.² As Rosa Helena and Carolina's, care partners find themselves shifting back and forth from those stages.

¹ At the appendix of this thesis one can find a more detail list of Memories not lost during the Alzheimer's process

My aim in writing this thesis is making Design to step in as a tool to help care takers –such as my cousins- for obtaining aid through the emotional “activities” or “processes” described below. I take again the example of Rosa Helena and Carolina to describe each step of the process.

a. An embracing act when a relative is being diagnosed:

Providing an embracing act by creating new positive rituals of embracing the disease helps the family and the patient to genuinely do something for issuing the problem; providing not only acceptance, but opening new doors of understanding of what they are going through. Remember when Trini was diagnosed with AD, it was hard for Rosa Elena and Carolina to envision what lay ahead, worsening their overall situation.

b. The involvement of the other members of the family:

My cousins had a hard time making other members of the family in getting involved, as they also didn't understand or didn't face the issue. Again, this made Rosa Helena and Carolina's AD situation more difficult. Making the rest of the family to get involved since the early stage can make care takers feel that they are not alone.

c. Helping the emotional burden of witnessing the decay of the patient living with Alzheimer's disease.

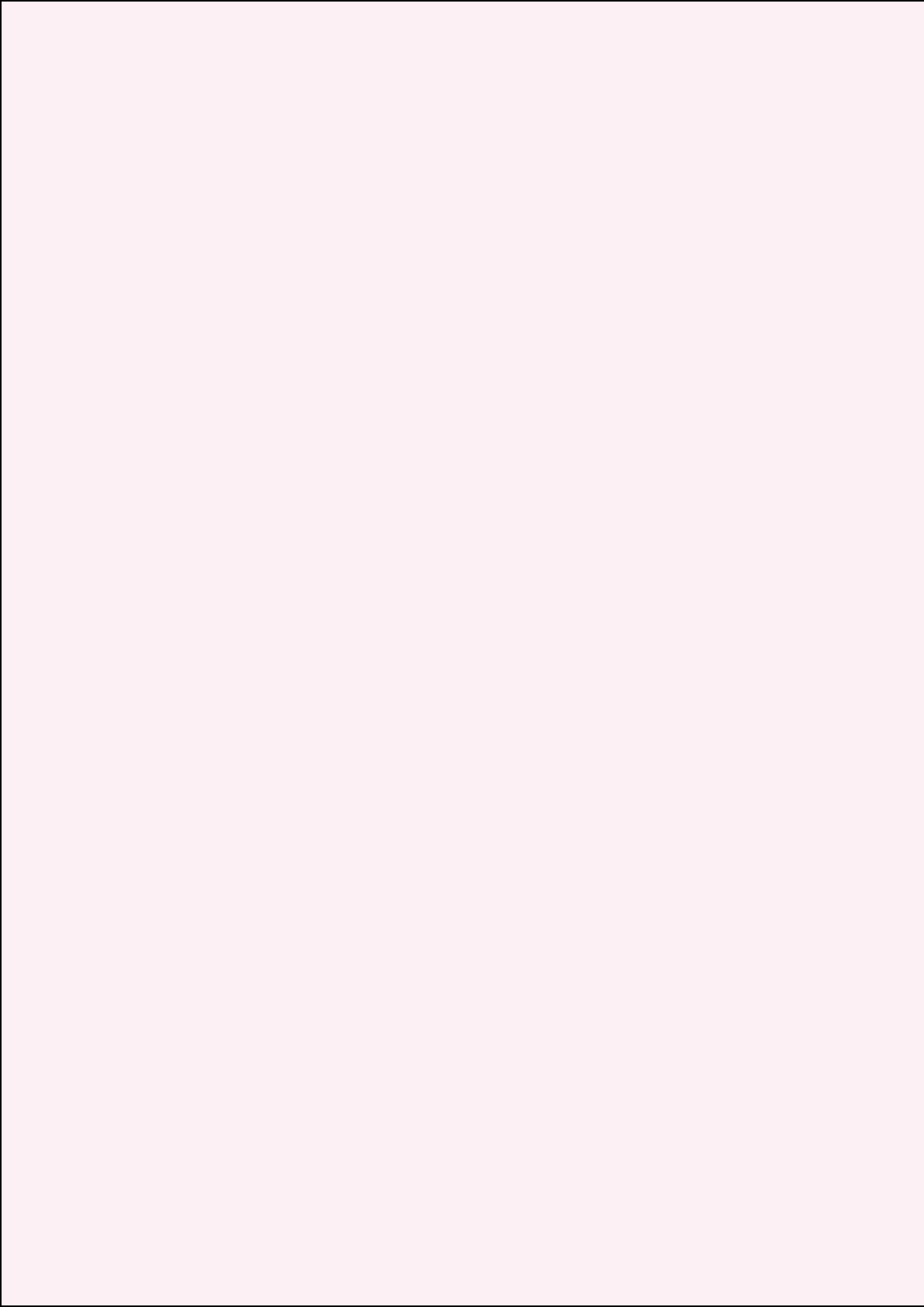
Going back into the “chain of losses” that Rosa Helena and Carolina experienced by taking care of their mother, one can imagine that this is one of the most gruelling parts to go through the course of the disease. This can make for the care partner difficult to understand that some abilities and capabilities of the beloved one living with AD are not gone, and can be used and reached. Making care partners understand that there are still some ways that they can communicate, can bring a big emotional aid and a new understanding of what the patient is going through.

Having provided an overall picture of the grieving AD situation for care takers, my thesis' research focuses on finding answers to the following two questions:

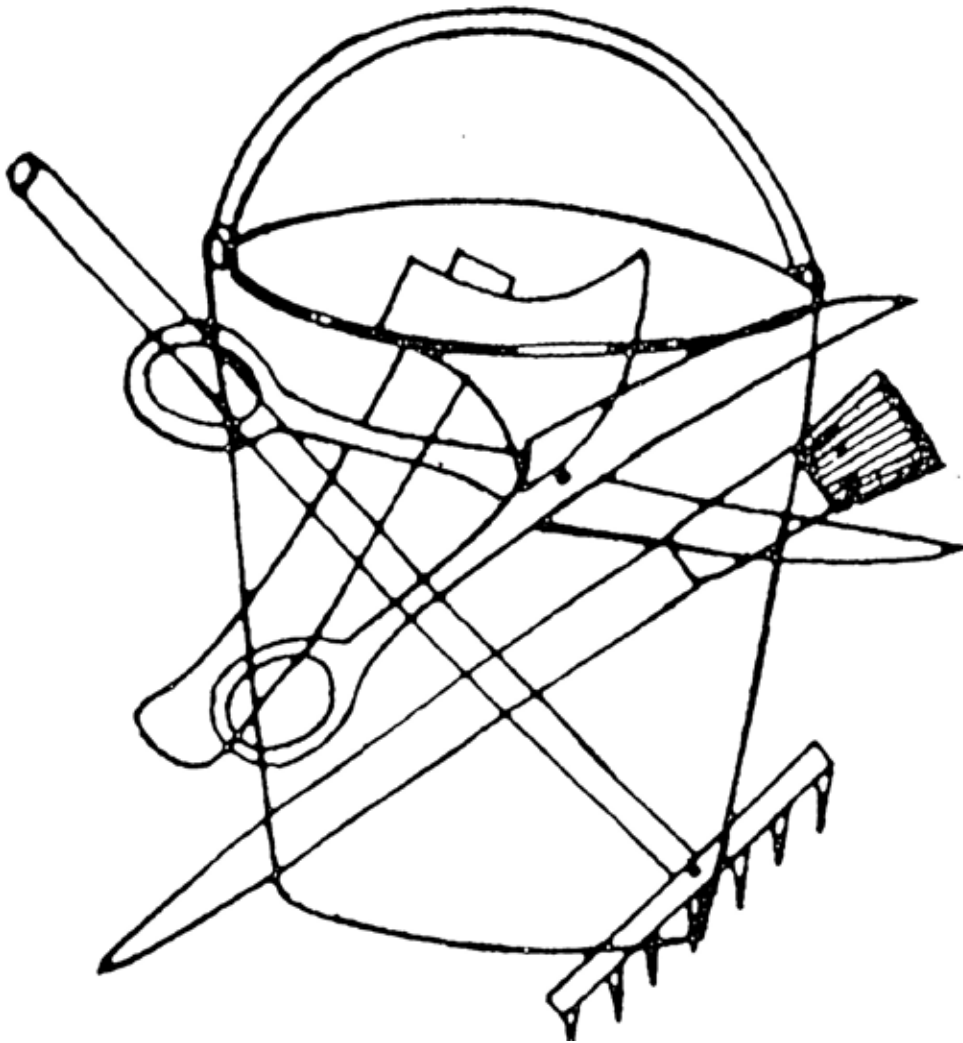
-Which tools can be designed to help family members of AD patients to make their emotional challenges more bearable?

-What physical stimulation in the AD patient lasts the most during the course of the disease that can be used as an alternative channel of communication?

In the next section (2.0) I will discuss all the factors when it comes to design something for an Alzheimer's patient, followed by how to use music as the channel for new ways of communication.



2.-Design Tools for Alzheimer's and their Care Partners



Images like these are used by psychologist to help diagnose Alzheimer's, since people living with this kind of dementia, their perception can change. Some people with Alzheimer's could not recognize the different objects in the image. For them is just an abstract image.

2.1-Design Challenges in an AD Situation.

Designing objects and systems for people with Alzheimer's is completely different than designing objects for people without the condition. For AD patients, it changes the way they perceive their surroundings. Colour, contrast, visual perception of motion or sense of touch can be different from a person not living with this disease. These are factors that a designer must keep in mind when it comes to design process when they face this challenge.

However, the most important factor that a designer has to understand is that for a person with AD it is extremely difficult to learn interactions with new objects. For an AD patient, uncommon artefacts can confuse them and in some cases, it can make them anxious, as when they are confronted with something strange to them. I will analyse this factor further down.

When it comes to visual perceptions as when the floor presents a high colour contrast, such as a dark carpet placed over a clean floor, patients misunderstand them as if there is a hole on the surface, and they would not walk over it. Another example, they could not recognize objects drawn only by their outlines, making some intricate graphic icons, signs or illustrations difficult for them to understand. Therefore when a person has AD, the capability of visual abstraction also changes.

These factors can provoke in an AD patient different unexpected behaviours and generalizing behaviours of an Alzheimer's patient becomes impossible. As Psychologist Riët Daniëls, at The Landrijt Center for Specialized Care and Treatment in Eindhoven (NL), explained in an interview :

"IN THE ALZHEIMER POPULATION, TWO PEOPLE WITH ALZHEIMER ARE NOT COMPARABLE. SO IS VERY DIFFICULT [TO ASSIMILATE THE BEHAVIOUR OF TWO PATIENTS]. YOU CAN SEE THAT ON AVERAGE PEOPLE HAVE THE SAME COGNITIVE PROBLEMS, BUT ONE PERSON CAN HAVE HUGE RESTLESSNESS, THE OTHER CAN TAKE HIS CLOTHES OFF. EVERY CASE IS DIFFERENT YOU HAVE TO LOOK AT THE PERSON, WE HAVE TO KNOW THE HISTORY, WHICH IS IMPORTANT, BECAUSE WE DON'T KNOW EXACTLY WHAT IS GOING TO HAPPEN WITH THEIR LIFE. WHO IS THIS PERSON, WHAT HE ALWAYS LIKED, WHAT ARE HIS PREFERENCES."

So, which approach can we take when designing new objects for an AD patient? What Dr. Daniëls suggest is that, we have to look at the objects from the past. When a person with AD faces a new object, if it does not look familiar, they would not recognize it. An example that Dr. Daniëls pointed to me is that her patients, after developing Alzheimer's, they cannot recognize The Senseo Coffee Maker (a futuristic looking machine for brewing coffee, very popular in The Netherlands), but they can recognize a more familiar and older coffee machines (*figure 2.1*). The same happens



*Figure 2.1: The Senseo Coffee Machine.
futuristic looking machine for brewing coffee, very popular in The Netherlands*

with musical artefacts. A person with Alzheimer's cannot recognize a CD player or an iPod as an artefact that provides music (*figure 2.2*). Dr. Daniëls uses old radios from the 50's or 60's because they are more recognizable for them.

For people with Alzheimer's, most recent objects lose their meaning. Going back to Rosa Helena's story, she explained to me, that her mom would take the remote control of the T.V. and use it as a coffee steer. Her Mom being part of a generation where T.V. were not as common as today, she didn't assimilate enough the memory of what a T.V. remote would look like and what it is for. Although she was able to use the T.V. remote when she didn't have the condition, eventually, she lost its meaning of the apparatus, not being able to connect the idea of the object and what the remote control was used for.

Also there is a possibility that traditional garments cannot be used for every AD patient. Rosa Helena also explained that when her mom got a more advanced stage of dementia, and she could not dress by herself, she would prefer using more comfortable, baggy clothes. Traditional clothing would be extremely uncomfortable for her. This happens because my aunt's brain could not filter all secondary stimulus that was not part of the context, a common condition for people suffering with Alzheimer's. As a result, Trini would try to take them off. Thus, Rosa Helena started using clothes with Velcro, so when her mother would tear them apart, the clothes would not get damaged. Apparently, when an object over-stimulates a person living with Alzheimer's, they will want to take it off, making it extremely difficult for patients to wear non-familiar objects. Dr. Daniëls mention that patients in her clinic



Figure 2.2: A vintage radio is more recognizable as a sound providing artefact than a modern-looking iPod on it's portable speakers.

would feel extremely uncomfortable using hearing aid ear pieces, and they would take them off, consequently, losing the gadget. When I asked Dr. Daniëls about using headphones, she mentioned that compared to newer generations, the old population of today are not used to wear headphones, although when we become old, we wouldn't have problems using them, since we are more familiar to this device. This means that by taking this approach, what would work for a patient today, might not work for a patient ten or twenty years from now.

When it comes to design for the people living with AD, a designer must look at these factors, like their different perception and their both, past and present context, that they lived through the years, with and without Alzheimer's. Although, personally I would also add another factor: The care partner, which apart of being part of the patient context, could also be involved in the usage of the object about to be designed. And this brings the question:

Do the object meant to assist a patient can also help the caretaker emotionally? Can a product help both sides of the whole Alzheimer's journey?

Nevertheless, the design and the art world have addressed Alzheimer's before, with different approaches. In the next chapter I will analyze some of these projects and objects.

2.2- Current Approaches on Design for Alzheimer Patients.

Alzheimer's is a commercial niche when it comes to product design. One can find numerous products on the Internet or off-the-shelf. This is probably as a result of the huge needs for both patients and caretakers to simplify their lives.

When analysing some of the products that already exist for people with Alzheimer's, different conceptual approaches are found. The most common objects are those that provide them with cognitive stimulation, such as puzzles, board games and toys (*figure 2.3*). Most of these products are not designed for Alzheimer's specifically, but for children, although, their characteristics (colour, texture and safety) could be suitable for people with AD. Don't get me wrong. I'm not questioning the functionality of this kind of products, by using toys or other artefacts, I wonder how the care taker will assimilate the fact that their own beloved one appears to have a regression to their childhood by using these kind of products.

Another batch of products that could be found off-the-shelf, are monitoring products, like sensor alarms that trigger when the patient goes out of the room, or GPS systems that bring the exact location of the person while wandering (*figure 2.4*). This kind of objects mostly issue utilitarian necessities, but at the same time, they appear to shout the disabilities of the patient using them, by giving a sense of control and surveillance on someone with Alzheimer's.

The art world also has made its contribution for people with dementia. Artist Ivonne Drögel Wendel together with Lino Hellings, created "De Coupé", an artistic installation on De Bieslandhof, a nursing home in Delft (NL). In this installation people with dementia can sit on a space that resembles a real train compartment where the windows project a video of a typical Dutch landscape, passing by (*figure 2.5*). "Travelling is a pleasant state of 'doing nothing'. In a train compartment one can withdraw into oneself and give oneself over to contemplation without being bored (Wendel, 2008, WEB)" The installation works extremely good for patients, they enjoy their time "passing by" on the train compartment and they feel relaxed, giving them "the right to do nothing". This project although is a nice inspiration on relaxing the person with dementia, in my view has a lack of emotional support for the rest of the people involved with the patient. It may look like the whole installation is tricking the patient into a circumstance that does not exist, sedating the patient into a limbo that resembles a context that is not there.

Another approach is using technological tools and media. An example is Microsoft's SenseCam (*figure 2.6*), a sort of black box-looking device functioning as both digital camera and sound recorder, capturing different circumstances and creating a "summary" of the resulting content by picking crucial images, and reviewing them periodically to awaken and strengthen the memory of the event. (Bihattacharjee, 2010). By using digital pictures as a memory aid, The SenseCam promises that it will not only benefit patients, but also family and friends by "avoiding the routine of re-

peating conversations over and over”. This device has the size of a hand’s palm and the patient has to wear it as a pendant around the neck. Although the technological approach can be quite impressive, the real question is how the patient will react to it as the black boxed object could confuse him or bother-him while it is hanging from their neck

These examples (and others), show a lack of an emotional approach. Most of these projects do not address the dignity of the patient, but point to the helplessness (and annoyingness) of the patient. The devices send to the caretaker strong signals of a misconceiving reality that ignores the patient’s full capacity. Additionally, creating objects that try to force the patient into a world conceived for people not living with the disease and merely trying to adapt to an suitable context that is not worthy environment for an AD patient is the wrong approach:

What if a different environment for AD patients was created? A place or situation where the patient feels comfortable and where biased and negative signals were not sent to the care partner?



Figure 2.3: Toys like the Spinoza Talking Teddy Bear can be effective for therapy, but questions how the item is helping the care partner emotionally.



Figure 2.4: The Keruve 2010 is a system where the Track station (shown here) tracks down the GPS device embed in a wrist watch, that the patient uses.



Figure 2.5: Ivonne Drögel Wendel & Lino Helling's "De Coupé", Installation, where people enjoying "the right to do nothing"



Figure 2.5: Microsoft's Sence Cam, that picks crucial images, and reviews them periodically to awaken and strengthen the memory of the event.

2.3-Fulfilling an Emotional need of the Care Partner using Jewelry as Assistive Technology.

When we talk about design and emotions, the field of design has been mostly focusing on customer needs concerning functionality and utility (Khalid, 2006). Most design research on emotions and design, covers more the relationship between the object and the person using it, the pleasure it creates and the satisfaction it brings to the user.

Although, the emotional relationship between the user and an object can go beyond user satisfaction: objects can become more than material possessions. As Norman indicates, “We take pride in them, not necessarily because we are showing off our wealth or status, but because of the meanings they bring to our lives (2004, pp.6)”. We become affective with our personal artefacts when a meaning is created by a number subjective experiences with in different situations that we live around them. Objects can work as reminders of past memories or an expression of one’s “self” (Norman, 2004).

However, when it is required to fulfil a more transcendental emotional need beyond the user-object relationship, as this thesis intends, the designer can choose from different categories of objects that not only pursue on functionality, but also can build a personal meaning of connection with others. With the care partner in mind, this specific thesis, evokes the jewellery as category of objects that is centred on meaningful relationships between people and experiences. As Olivier and Wallace suggest:

“JEWELLERY IS AN INTIMATE FORM OF OBJECT. THIS ARISES FIRSTLY THROUGH A LITERAL CONNECTION OR RELATIONSHIP WITH THE BODY. JEWELLERY IS MEANT TO BE IMAGINED ON, OR IN AN RELATIONSHIP WITH, A BODY. EVEN WHEN NOT WORN, OR WHEN CONSIDERED UNWEARABLE, AN INTIMATE CONTEXT REMAINS. SECONDLY, JEWELLERY HAS AN INTIMATE HUMAN-RELATIONAL CONTEXT; IT IS OFTEN SITUATED IN A RELATIONSHIP OR AS A LOCUS FOR FEELINGS RELATING TO PERSONALLY SIGNIFICANT PEOPLE, EVENTS, OR PARTS OF OUR HISTORIES. EXAMPLES OF THIS IN TRADITIONAL JEWELLERY INCLUDE A WEDDING RING, A LOCKET ACTING AS A MEMENTO, OR A PIECE OF HEIRLOOM JEWELLERY THAT WE PERHAPS NEVER WEAR, BUT THAT NEVERTHELESS HAS AN INTIMATE ASSOCIATION WITH THE PREVIOUS OWNER, EVENTS WHEN THEY WORE THE JEWELLERY, AND OUT FEELINGS TOWARDS THEM (2008, PP. 207)”

For Wallace, a contemporary jeweller and digital artist, jewellery can act to play a role within what we each consider personally meaningful for us in our lives, in an emotional context, and how the expression of fragments of this can be enriched through the integration of digital technologies (Culture Lab Newcastle, 2010)³. Her



Figure 2.7: Standard RFID Tag. The Antenna is normally moulded as a coil-shaped circuit. With designer's ingenuity, an RFID antenna can be designed in aesthetically way.

inspiring approach by adding digital technology into them, opens a door for jewellery as the carrier of specific information, augmenting the object into not only as a symbol of connection with other people, but also as a medium for new ways of communication. Therefore, looking at jewellery as assistive technology⁴, as the monitoring systems revised before (GPS tracking systems or the motion sensor alarms), the piece can become a double utilitarian object where the assistance can bring emotional aid on a more sensitive way.

This mention, by using jewellery as a medium for stimulation (using digital media, e.g. digital music) suitable to evoke a new dialog between the partner and the patient (more on that later), jewellery becomes more than a meaningful ornamental object, but also the platform where new ways of connections can be achieved. This means that jewellery (intended for the caretaker) has to react with another artifact designed for the Alzheimer's patient. By providing another object (with the specific requirements pointed out by Dr. Daniëls), that could provide the musical stimulation, complements the communication system. Analyzing the elements of communication technology, we can assign each element where the caretaker, using the specific piece of digital jewellery works as the sender; the object who reads the signal works as a receiver; the music becomes the message and the reaction of the person with AD provides the notification: the acknowledgment that information has been sent or received (Oliver and Wallace, 2008).

In addition, creating digital jewellery is an invitation for the designer to re-think how a technological artifact can be conceived. Dunne, debates that "the electronic

⁴ The term 'assistive technology' refers to 'any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed' (Royal Commission on Long Term Care 1999).

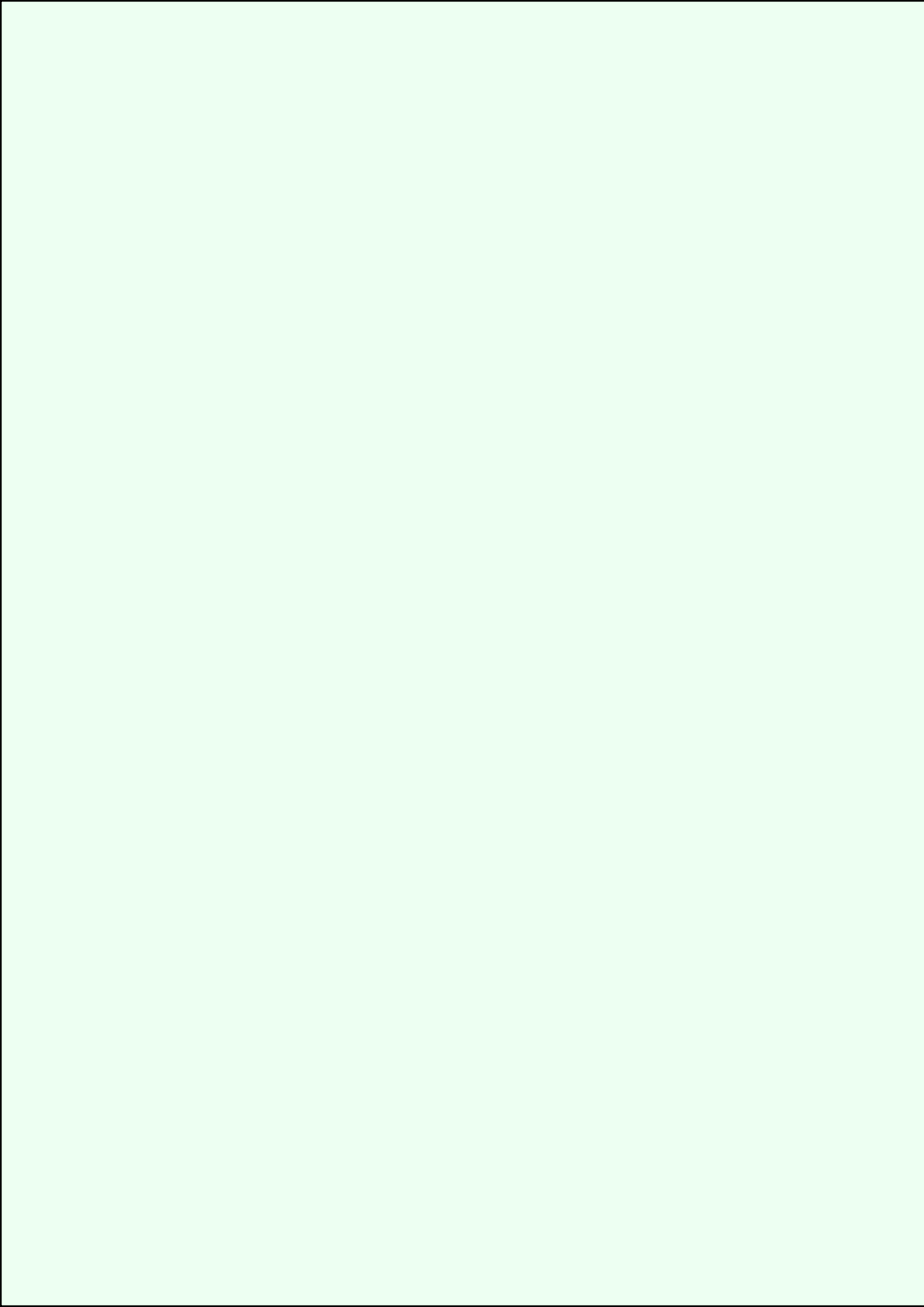
object occupies a strange place in the world, closer to washing powder and cough mixture than to furniture and architecture, and is subject to the same linguistic discipline as all package design (2005 pp.1)”. Instead of using design to create a “package” for guts and circuits, but we aesthetically intervene the technology from its core, as if we also design the way how circuitry looks like, we will no longer need to hide it with a package, instead, we will frame its beauty.

Let’s take the RFID⁵ tag as an example (*figure 2.7*). It’s antenna that is used to send the radio signal with the identification code, it is normally molded as a coil-shaped circuit. With designer’s ingenuity, the antenna can be designed aesthetically as a pictogram. Then, the RFID tag which is used to electronically identify products, life stock or other goods, emerges physically as a symbol, using its electronic components to carry a visual message.

On top of it, designing an RFID tag as jewellery, with all the layers of meaning and significance for the care partner, it becomes the perfect medium for triggering the stimulus that evokes the emotional autobiographical memories needed for the alternate way of connection that this project is looking for.

Finally it is time to unveil the fact that this project will be using familiar music as stimulation for the AD patient. In the next section, I will analyze why music is the chosen way of stimulation and why it can be used as the longest lasting mode of communication between the care partner and the AD patient.

⁵ RFID or Radio frequency identification is a technology that relies on tagging objects in order to identify them. An RFID reader sends a short-range radio signal, which is picked up by an RFID tag. The tag then transmits back a short string of data. Depending on the size and sensitivity of the reader’s antenna and the strength of the transmission, the tag can be several feet away from the reader, enclosed in a book, box, or item of clothing (Igoe, 2007).



3.-Alzheimer's and Music

“As soon as we hear a song that we haven't heard since a particular time in our lives, the flood gates of memory open and we're immersed in memories... a key unlocking all the experiences associated with the memory for the song, its time and place.”

-DANIEL LEVITIN, FORMER MUSIC PRODUCER TURNED INTO NEUROSCIENTIST

3.1-The Power of Music:

There is a very special relationship between music and the Alzheimer's brain. Whenever music is played to AD patients, almost, without exceptions, they will react in a very positive way, specially with songs they once knew. Oliver Sacks mention that: "musical perception, musical sensibility, musical emotion, and musical memory can survive long after other forms of memory have disappeared (2007, pp. 337)" In addition that music has the power of bringing emotional-autobiographical memories on the patients, we could use music as longest lasting way of communication between the Patient and the Caretaker.

This musical reactions provokes a sense of reconnection with reality in the caretaker's point of view. As Rosa Helena mention me later on: "*My sister Carolina plays my mother old music from Jalisco, the region in Mexico where my she comes from. She starts to sing along and it looks like she enjoys it a big deal. For us, it seems that when she listen to her music, she remembers all the experiences that this kind of music evokes to her*" A reaction that makes Carolina and Rosa Helena feel like the personality of her mother comes back from the fogginess of Alzheimer's.

There have been formal studies of the persistence of musical powers in advanced Alzheimer's, like the work of Professor Lola Cuddy at the University of Kingston (Canada). She did an extensive research of the effects of music and Alzheimer's patients, finding that one of her subjects, a 84-year old woman with an advanced stage of this particular dementia, showed to be spared for music recognition (*figure 3.1*). Like my great-aunt, she responded by familiar music by singing along, and often continue to sing after the stimulus was over. When the subject was stimulated with familiar music, played with wrong notes, the old lady will react with surprise, laughter, a frown or an exclamation, like "Oh Dear!" (2005).⁶In addition to that, when she was stimulated with music from an specific period of her life, she would vividly remember places and names, and she would reckon people from that period of her life. These kind of effects given by music can bring some sort of emotional comfort to the care partners and families.

Oliver Sacks also describes a similar case, but from the care partner point of view. Writer Mary Ellen Geist, contacted Sacks about her father living with Alzheimer's, explaining the relationship with music and her dad:

"THE PLAQUE HAS APPARENTLY INVADED A LARGE AMOUNT OF HIS BRAIN, AND HE CAN'T REMEMBER MUCH OF ANYTHING ABOUT HIS LIFE. HOWEVER, HE REMEMBERS THE BARITONE PART TO ALMOST EVERY SONG HE HAS EVER SUNG. HE PERFORMED WITH A TWELVE-MAN A CAPPELLA SINGING GROUP FOR ALMOST FORTY YEARS...MUSIC IS ONE OF THE ONLY THINGS THAT KEEP HIM GROUNDED IN THIS THIS WORLD. HE HAS NO IDEA WHAT HE DID FOR A LIVING, WHERE HE IS LIVING NOW, OR WHAT HE DID TEN MINUTES AGO. ALMOST EVERY MEMORY IS GONE. EXCEPT FOR THE MUSIC[...](2007, PP. 338-339)".



Figure 3.1: Professor Lola Cuddy (right) with her patient, with an advanced stage of this particular dementia, showed to be spared for music recognition

Why familiar music has this ability to trigger all of these emotional responses? Neuroscientist and former music producer Daniel Levitin thinks that we remember music better when it has an emotional meaning. The amygdala and neurotransmitters in the brain “tag” this emotional charged musical memories as something important, making them more difficult to forget, even for an Alzheimer’s patient (2006). Ziesel, in the other hand, argues that responding and performing music is hard wired in the human brains. He points out that: “narrative music expressing strong emotions, is likely to have predated language as form of communication (2010, pp.54)”

Emotion plays a key role on why the Alzheimer’s brain can remember familiar music. And as Petr Janata, a cognitive psychologist at the University of California (USA) discovered, it also has to do where in the brain the stimulation is being processed. He was able to identify that the Medial Prefrontal Cortex (*figure 3.2*), the part of the brain that defines the “self” in all of us, is also the region that connects autobiographical memories, emotions and music (Janata, 2009). This hub for familiar music and emotions also is one of the parts of the brain that stays intact longer during the Alzheimer’s disease, causing memory for familiar music being retain longer than other kind of memories on an AD patient.

Apart of evoking emotional-autobiographical memories, music also has therapeutic advantages for the AD patients. When people living with Alzheimer’s are exposed to music, they behave more relaxed, it diminished depression and increases sleeping. A study at the School of Medicine in the University of Miami (USA) confirm

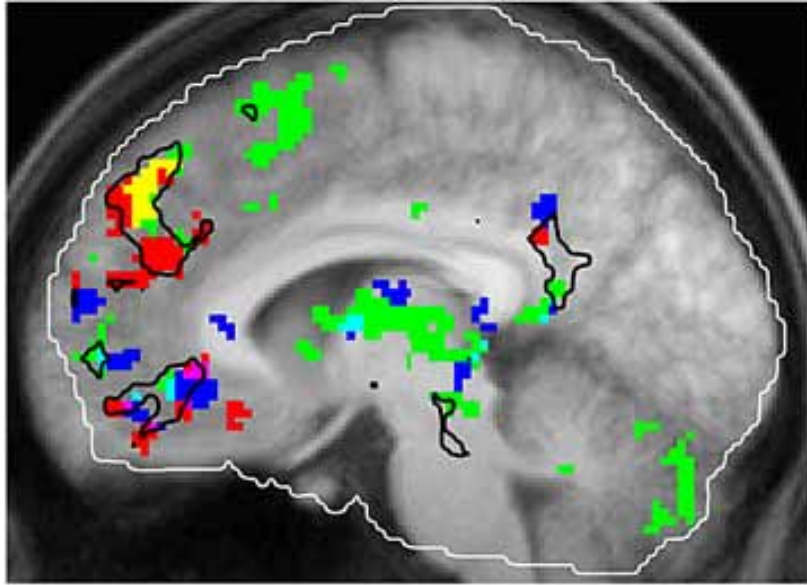
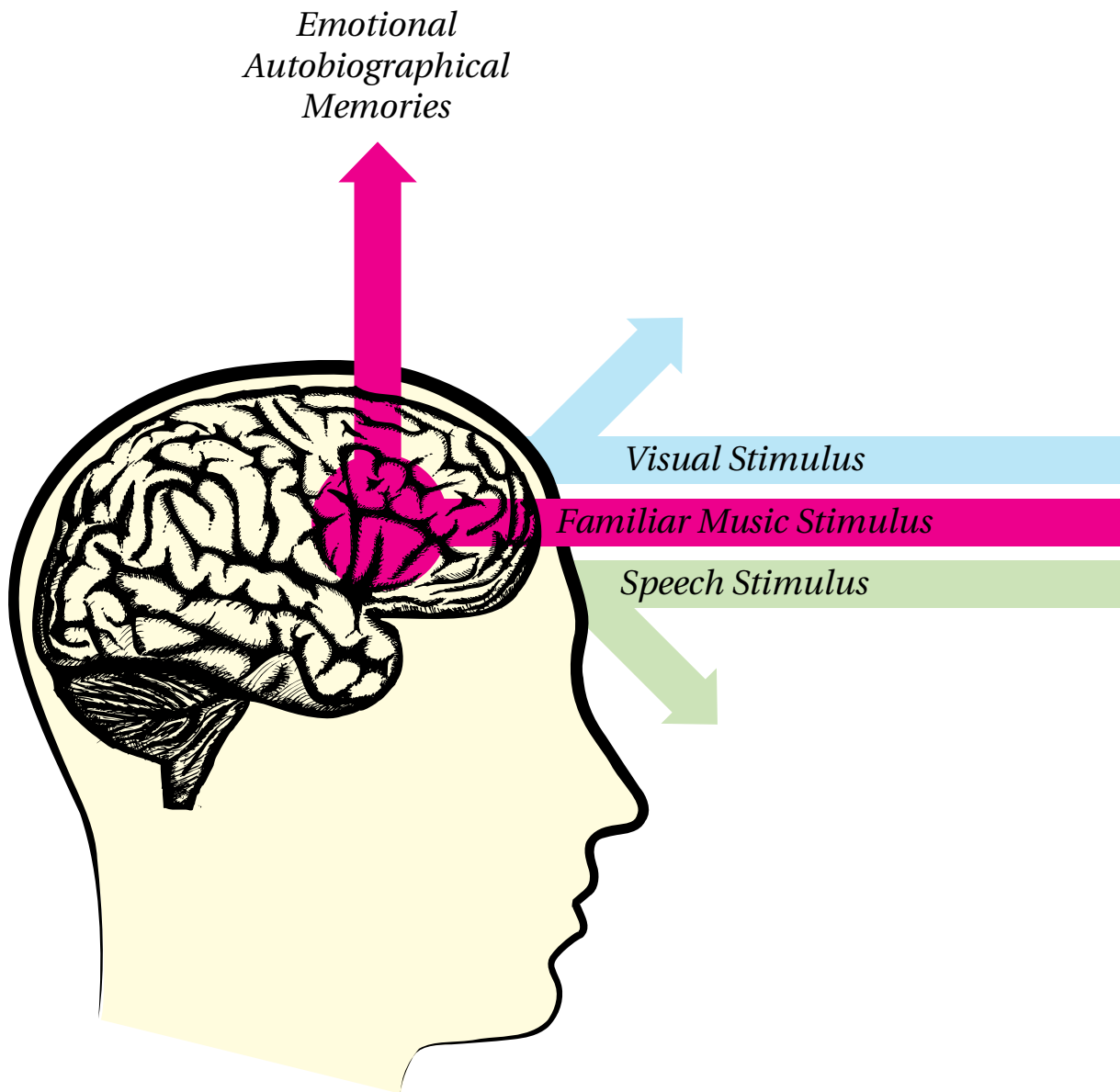


Figure 3.2: The region of the brain marked in red and outlined, indicates where the Medial Prefrontal Cortex is. This is the part of the brain that works like a hub between familiar music, and emotional-autobiographical memories.

that music increases levels of serum melatonin, a natural hormone who functions as a synchronizer for the biological clock, but also contributes to patients to behave more calm and relax (Kumar et.al. 1999).

The ubiquity and antiquity of music has been always percent as a human activity in every recorded human culture (Levitin, 2006). Perhaps this explain why music is so important for human society, specially for the people living with Alzheimer's. However, we have to ask ourselves, how powerful is the power of music on an AD patient, and most importantly, what it's the role that music should play on a communication system. In the next chapter we will analyse how can we use music on the Alzheimer's context.



On an advanced stage of Alzheimer's, familiar music can be the only kind of stimulus that can evoke emotional autobiographical memories.

3.2.- *Real Capabilities of Music on the Alzheimer's Brain.*

Considering all the positive reactions that music evokes on a patient with AD, can be extremely encouraging and one may be seduced to use music beyond its actual capabilities, looking for other positive reactions that are not achievable. One of these misinterpretations is that music could be used to make the patient learn new information. Looking back at the case of Mary Ellen Geist, Sacks recalls that she had the idea to use music as embed information, inspired on her father's ability of recall songs. As Sacks explains:

"GIVEN HER FATHER'S POWERFUL MUSICAL MEMORY, MARY ELLEN ASKED, "WHY CAN'T WE USE THIS MUSICAL MEMORY AS AN OPENING...EMBED SHOPPING LIST, INFORMATION ABOUT HIMSELF, IN HIS SONGS?" I SAID THIS WOULD NOT WORK. MARY ELLEN HAD, IN FACT, FOUND THIS OUT ALREADY FOR HERSELF. "WHY COULDN'T WE SING HIM HIS LIFE STORY?" SHE HAD WRITTEN IN HER JOURNAL IN 2005. "OR THE DIRECTIONS FROM ONE ROOM TO THE NEXT? I'VE TRIED-IT DOESN'T WORK" (2007, PP.341)8.

For Sacks, "there cannot be a carryover from performance and procedural memory to explicit memory or usable knowledge" ("2007, pp.342). The study by Andrea Halpern, a Cognitive Psychologist at Bucknell University (USA), also confirms this. Her research showed that Alzheimer's patients could recognize famous patriotic tunes, nursing songs and other cultural-famous tunes. However, when the subjects were stimulated by novel tunes, although they were quite similar to the original ones, the patients would not recognize them (Halpern et al. 2005)⁹. When I contacted Andrea Halpern early this year, she further mentioned to me that the main cognitive problem in AD is that patients have a great deal of trouble with new learning, even with "paired associate learning", which is pairing an object, word or subject in our case, with the idea it represents. This means that it is extremely difficult using arbitrary music, jingles or chimes for learning, let's say, the way back from the supermarket, or following a musical cooking recipe, in an Alzheimer's context.

We know that musical memory stays for longer and it has the reaction of evoking memories with people with Alzheimer's. So it is almost inevitable to bring these questions:

-Can these memories triggered by familiar music, could be linked to other actors? Could we use this stimulation to making someone living with Alzheimer's recognize their loved ones?

Even though all the cases mentioned in the previous chapter, could make us think this is possible for music, in the scientific world there is not enough information to confirm this. When I asked Petr Janata (the researcher who identified the part of the brain that connects music with autobiographical-emotional memories), about if a person with AD could associate semantic content with music he answered the following:

THAT'S A GREAT QUESTION, AND I DON'T KNOW THE ANSWER TO THAT. I WOULD LIKE TO KNOW THE ANSWER, BUT IT IS A VERY DIFFICULT THING TO TRY TO GET AT. INDIVIDUALS, SPECIALLY IN SEVERE STAGES OF THE DISEASE CAN'T ARTICULATE WHAT THEY ARE THINKING. SO IT IS VERY DIFFICULT TO REALLY KNOW WHAT ITS BEING EVOKED IN THEIR MINDS. I EXPECT THAT IT IS MORE THAN JUST MEMORY THROUGH THE MUSIC ITSELF, CLEARLY THERE IS SOME EMOTIONAL COMPONENT ALSO, BUT PROBABLY GOES BEYOND THE MUSIC AND THE EMOTIONS. IN PRINCIPLE, ONE COULD TRY FIGURE OUT WHAT THE CONTENT OF THE MEMORY ARE WITH ALZHEIMER'S INDIVIDUALS WHO HAVEN'T PROGRESS AS FAR IN THE DISEASE, SO ITS STILL SOME COGNITIVE IMPEDIMENT OR EARLY STAGES OF ALZHEIMER'S. THAT'S SOMETHING THAT HAS TO BE DONE [AS A SCIENTIFIC STUDY]. THERE HAVEN'T REALLY BEEN ANY COGNITIVE PSYCHOLOGIST WHO HAD BEEN STUDYING THIS ISSUE. LOLA CUDDY, FOR EXAMPLE, EVEN SHE HAS MOSTLY BEEN LOOKING AT ASPECTS OF THE MUSICAL MEMORY ITSELF, RATHER THAN MEMORIES THAT MIGHT BEEN ASSOCIATED WITH THE MUSIC. SO ESSENTIALLY IS STILL AN OPEN QUESTION AS TO HOW MUCH MEMORY THERE IS OR THE SEMANTIC CONTENT IF YOU WILL, THE PEOPLE, PLACES, OBJECTS, THINGS LIKE THAT.

What for Janata is an open question, for this thesis is an opportunity to explore the possibilities of using familiar music as an alternative way of communication that could bring emotional aid for the care partner.

Reflecting upon John Zeisel's example mentioned before, on how is better to have a dialogue with a loved one living with AD, what this project intends is not shouting to the patient: "Can you recognize me? But telling in a more sensitive, intimate way "it is me, we have wonderful times together and I love you" by using familiar music instead of words. Perhaps with this kind of stimulation one can reach emotional memories that cannot be expressed with words. Perhaps by doing this, the care patient will realize that there is still much of the personality of their beloved one, he just need to find the right way to connect to it. Perhaps this can evolve as a new relationship between the both sides.



4.-Transcendental Tunes.

4.1.-Designing alternative way of meaningful communication between the Care Parter and an Alzheimer's Patient

Design can touch more than one emotional fibre of what a specific object represents, not necessarily with an utilitarian function, but a meaningful one. Objects like Jayne Wallace's "Blossom", a piece of jewellery, where "is not a piece made to be worn as accessory, as denoted by the purposeful manner in which the piece is worn; it is a piece to wear when you have the time to reflect and contemplate the experiences, meanings and human relationships it reflects" (Oliver and Wallace, 2008, pp.211). This piece of digital jewellery explores the connection between the owner of the piece, (Ana, a woman born in England with a Greek heritage) her family, and Cyprus, where the family comes from.

If we could take Wallace work as an inspiration and juxtapose it to assistive technologies have to offer, we could reach a new way of designing objects within the context of Alzheimer's or other disabilities, that also contemplates the family or people living around them, with dignity, sensibility and emotions. In order to reach this, we must have different variables in mind, as I explain in this chapter.

When designing a communication system between the care partner and the Alzheimer's patient, this project invites to define each role for the people using it. This is because the two actors have different cognitive abilities and therefore, each user will have a different experience while engaging the stimulation that the system provides. It is necessary to assign the caretaker the role of the tangible user, (the carrier of the object with a personal meaning and significance for this connection), because the care partner has the ability to read the object, learn its function and understand the symbolic meaning of the jewellery piece that has been designed for him or her. Conversely, the Alzheimer's patient becomes the user for which the physicality of the object is not as relevant as the emotional experience that the electronic artefact provides, (i.e. the musical stimulation) consequently the object in place needs to be designed with using a different approach. Let me explain the two user roles more deeply.

Looking back at the three main emotional needs identified in the case study of Rosa Helena and Carolina, (which are, embracing act when a family member is diagnosed, involvement of the family and an emotional aid when witnessing the mental decay of the patient), the challenge of this thesis project is to create a system where new rituals are suggested using meaningful electronic objects and musical stimulation. This systems consist on a collection of digital jewellery that the family will use, first, as a symbol for both embracing the new situation and involvement of the family. Second, this artefact will also function as a carrier for a non verbal message that will bring new ways of connection between the care partner and the patient. And third, the message, which is familiar music for the patient, will bring stimulation on ways that can bring emotional comfort to the care partner.

For this to be possible, each care partner in the family must choose a meaningful



Figure 4.1: Jayne Wallace's "Blossom" Jewelry could not be designed to be worn as an accessory, but worn when the user has time to reflect and contemplate the experiences, meanings and human relationships.

song that connects him or her to the patient, a familiar song that both, the care partner and the patient know and that represent their relation emotionally. This works as a first step of the ritual to embrace the new situation, where the whole emotional process of choosing a "Transcendental Tune" not only represents the connection, but also the message that can be received by the patient in the most extended part of the Alzheimer's process. This act of embracement functions as an initiation ritual that can bring strength for facing the Alzheimer's situation.

The pieces of digital jewellery, intended only for the care partner, will carry the chosen song electronically, using RFID technology. This will give the jewel another layer of personal significance, where not only the jewel becomes a symbol of a connection between two people, but also the medium where this connection starts to develop.

As the digital jewel triggers the musical stimulation, and the song starts to fade in with in the proximity of the patient, as he or she will recall that specific special song, memories related with this specific song and the carrier of the digital jewel will be evoked on the patient. The acknowledgement of the song becomes the respond of a nonverbal "Hi! It is me. We spend wonderful times together and I love you".

In addition, the main function for these pieces of jewellery is not for being worn as an everyday accessory, but more as a ceremonial heirloom, where is intended to be used when the care partner wants to fully connect with the patient. This kind of nonverbal but meaningful communication will to establish a new dialogue that invites the care partner to be conscious on the fact that the patient still has some ca-

¹² Enzo Mazini, professor of Design at the Politecnico de Milano, Marco Susani, an interaction and strategic designer and John Thackara, held the Info-Eco at the Dutch Design Institute in 1995, where explored the boundaries of phisicality needs versus digital information.

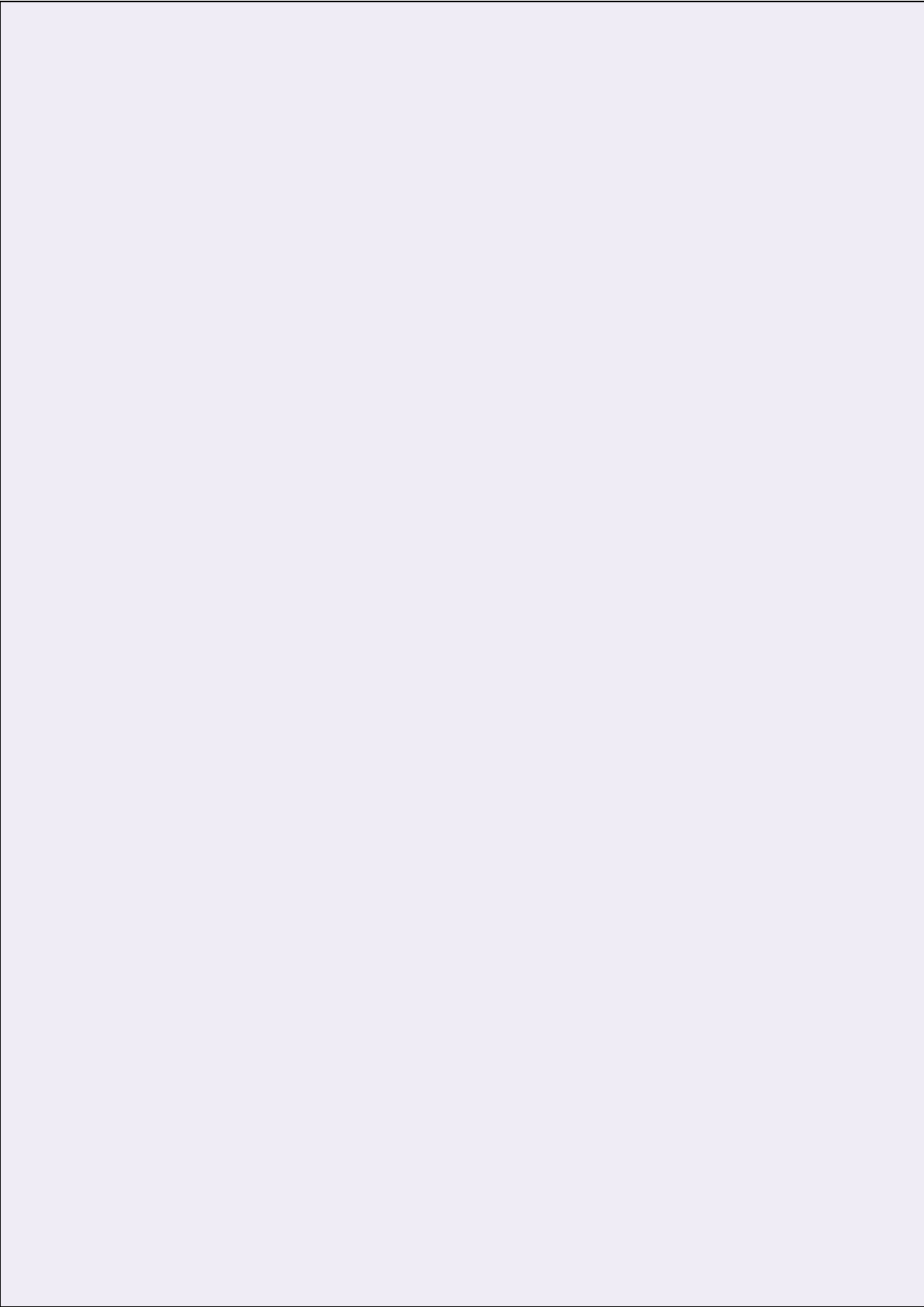
pabilities for further connection.

In the contrary, for the AD patient it is more important what the stimulation of the electronic artefact can provide, instead of the physicality of it. While Manzini, Susani and Thakara once explored the relevance of the experience provided by an electronic artefact, rather than the object, electronic technology can provide services currently offered through discrete objects. We can see the stimulation as how electronic information could satisfy needs normally fulfilled materially (Dunne, 2005). When we talk about a discreet object, we have to have the AD patient in mind, in terms of the way the shape and feel of this object can fit in the AD context. I decided to take the inspiration of an old radio, using materials like wood and fabric, since at the period in time I'm evoking, the radio was resembling more a piece of furniture (the 1940's to the end 1950's), than a futuristic electronic object (from the 1960's until today). By this, I will ensure that the patient recognizes the object as a music-providing device, making him or her less anxious when he or she understands that the music is coming from the RFID reader.

But one has to be careful to keep a balance between materiality versus the dematerialization of information technology. As this project request, the artefact which reads the digital jewellery is also used in a certain way by the caretaker, which has to be also contemplated. More specifically, the artefact has to send a message to the care partner that the device is activated when the RFID reader –in the shape of a vintage radio- has to speak to the care partner as well in terms of interaction. As the piece of jewellery is been read by the object, it also needs to show in its interface (as quiet and discreet as possible), only able for the care partner to read. In this way, both objects, the jewel and the reader will have a dialogue where the message that gives the stimulus (music) is the result of an electronic conversation that elicit the emotional connection between our two actors.



For the Care Partner, the physicality of the object is more important than the stimulus provided by it. For the patient living with Alzheimer's, it is the total opposite.



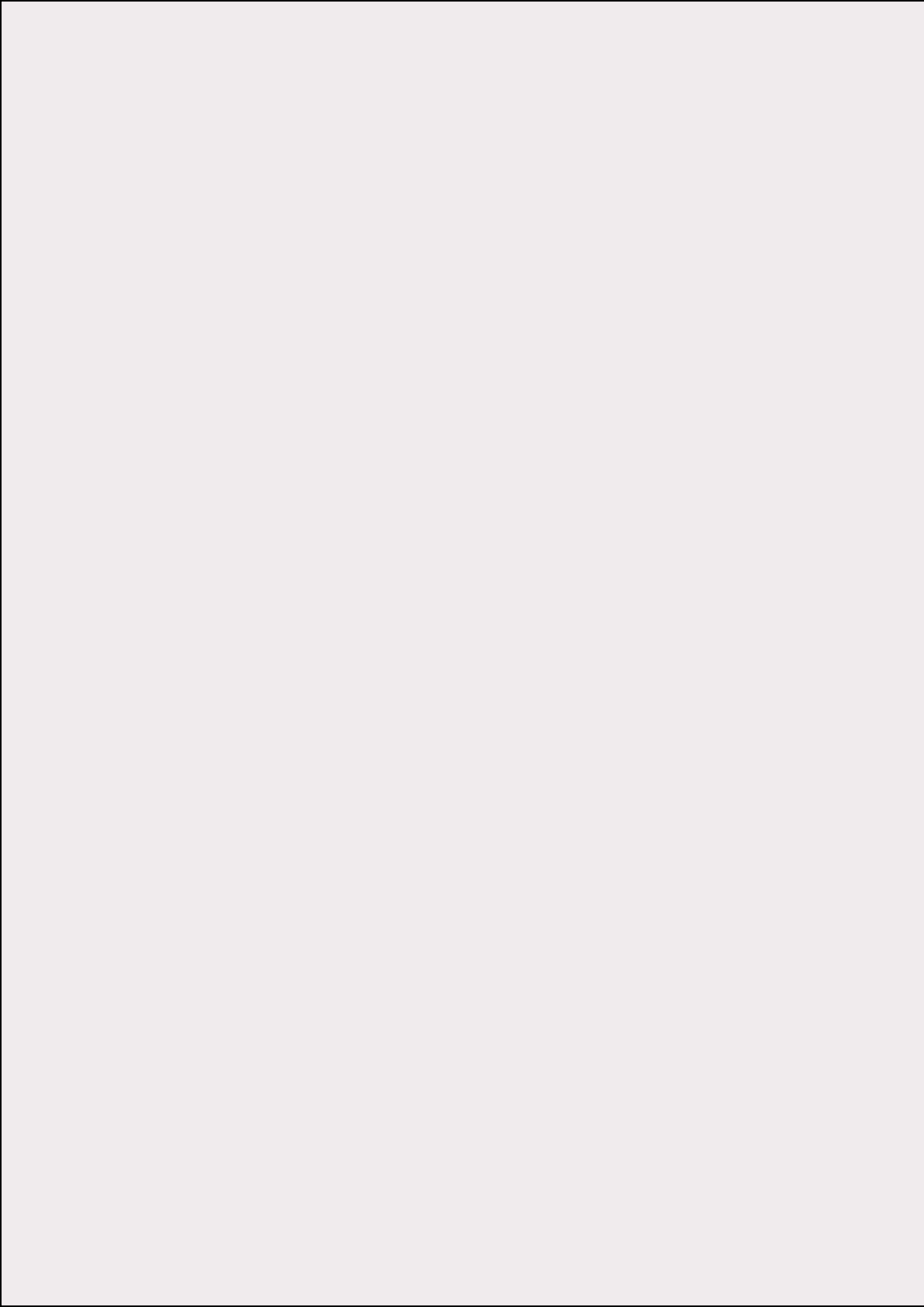
5.-Conclusion

Designing for the Alzheimer's situation, with the goal of bringing new ways of communication for emotional purposes, is a challenge where the expected result can come up intangible. In one hand we have the subjective approach like the one of John Ziesel, who that he invites the care partner to look at alternative ways of connection through the responses of different stimuli and understanding the new reality where the patient lives. In the other hand we have the scientific world that even if it acknowledges that familiar music can evoke emotional-autobiographical memories, still takes the semantic content with caution, since the scientist find hard to prove what kind of memories are being evoked in an Alzheimer's brain (or any brain for what that matters, since nobody has found a way to figure what a person really thinks).

This thesis acknowledges these two sides of the story, and rescues the reaction of what familiar music elicited on the Alzheimer patient, as a way of reconnecting with the care partner, witch is powerful enough for the last to give an emotional assistance.

In addition to that, creating the rituals, as in choosing the familiar music and carry the digital jewel that triggers the tune, creates a meaning of embracing the Alzheimer's situation for the care partner, through what the digital jewel represents. Design is intended to help us make our everyday life easier, but the Designer, specially when we discuss about covering this kind of issues, also has to be careful not to take the functionality to such a level that it covers the emotional side of the artefact, bringing it to a level that could be counterproductive in terms of shouting the disabilities of the patient. As we have seen before, the Designer can be seduced into creating something extremely functional and ignoring the emotional needs that people could, as we seen through this thesis. Therefore it is encouraged for the designer, when an emotional need is being identified, the solution must have an emotional design approach.

The subjectivity of an emotional design approach could bring a sort of intangibility of the final result, but in the same time, emotions are intended to be subjective. When it comes to design for an emotional need, the object created has to have also this intangible side as the need itself.



Appendix

10 Signs of Alzheimer's Based on The Alzheimer Association.

1.-Memory Loss that disrupts daily life:

Memory loss is the most familiar symptom, specially forgetting recently learned information. Patient forgets important dates and events, asks for the same information over and over and relays on memory aids.

2.-Challenges in planning or solving problems:

Another sign is when people experience changes in their ability to develop and follow a plan or work with numbers. Like having challenges in planning or solving problems like balancing a checkbook, following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things that they did before.

3.-Difficulty completing familiar tasks at home, at work or at leisure:

People with Alzheimer's often find it hard to complete daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favourite game.

4.-Confusion with time or place:

AD patients can lose track of dates, seasons and the passage of time. They may have trouble understanding something if its not happening immediately. Sometimes they may forget where they are or how they got there.

5.-Trouble understanding visual images and spatial relationships.

For some people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining colour or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not realize they are the person in the mirror.

6.-New problems with words in speaking or writing.

People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (like calling a "watch" a "hand-clock").

7.-Misplacing things and losing the ability to retrace steps.

A person with Alzheimer's disease may put things in unusual places. They may lose

things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time.

8.-Decreased or poor judgment.

People with Alzheimer's may experience changes in judgment or decision-making. For example, they may use poor judgement when dealing with money, living large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean.

9.-Withdrawal from work or social activities.

A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favourite sports team or remembering how to complete a favourite hobby. They may also avoid being social because of the changes they have experienced.

10.-Changes in mood and personality.

The mood and personalities of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zones.

The Grief Process Based on The Analysis Provided by the Alzheimer's Association.

Denial

- Hoping that the person is not ill.
- Expecting the person to get better.
- Convincing yourself that the person hasn't changed.
- Attempting to normalize problematic behaviours.
-

Anger

- Being frustrated with the person.
- Resenting the demands of care giving.
- Resenting family members who cannot or will not help provide care.
- Feeling abandoned and resenting it.

Guilt

- Wondering if you did something to cause the illness.
- Regretting your actions after the diagnosis.
- Feeling bad because you're still able to enjoy life.
- Feeling that you've failed. For example, when you can't care for your loved one at home.
- Having negative thoughts about the person or wishing that he or she would go away or die.
- Regretting things about your relationship before the diagnosis.
- Having unrealistic expectations of yourself, with thoughts such as: "I should have done..." "I must do everything for him or her." "I must visit him or her every day."

Sadness

- Feeling despair or depression.
- Withdrawing from social activities.
- Withholding your emotions.

Acceptance

- Finding personal meaning in caring for someone who is terminally ill.
- Seeing how the grieving process affects your life.
- Appreciating the personal growth that comes from surviving loss.

Memories Still there, Based on John Zeisel:

Sense Memories:

- Smell/Fragrance Memories
- Touch Memories
- Visual Memories
- Body Memories
- Music Memories
- Taste Memories
- Sound Memories
- Proprioceptive Memories

Emotional Memories:

- Times of Joy
- Sad Memories
- Fear Memory
- Pain Memory
- Love Memories
- Excitement
- Regret
- Shock
- Compassion

Body Memories:

- Having a Baby
- Riding a bicycle
- Throwing a ball
- Putting a golf ball
- Dancing the fox-trot
- Breaking a leg
- Carrying a heavy load

Skill Memories:

- Cooking
- Dancing
- Drawing
- Knitting
- Bowling
- Sewing
- Digging

Hard Wired Memories:

- The Sun
- Smiles
- Fireplace

Art Memory

- Paintings
- Poetry
- Music
- Sculpture
- Dance

Environmental Memory:

- Colour
- Place
- Object
- Texture
- Environmental mood memory
- Spatial Memory

Autobiographical Memories

- Life Period memories (childhood, school, teenage years)
- Type of events-hunting, going to the beach, chopping firewood
- Special event memories
- Family Memories-my wedding, my son's college graduation

Song Memories:

- Popular tunes
- Religious hymns
- Children's songs
- Military music
- Dance music

Story Memories

- How I met my wife/husband
- When I was a child-that time of life

- Childhood events
- When I saw my first movie
- Fairy Tales

Collective Memories-Major

Events Experienced:

- World War II
- D Day
- The Coronation of Elizabeth II
- The assassination of President Kennedy
- The fall of the Berlin Wall
- The death of Diana, Prince of Wales
- 9/11

Social Norms Memory:

- How to be polite to others at dinner
- How to greet someone coming to visit
- How to behave at holiday parties
- How to behave at religious ceremonies
- How to behave at a wedding
- Just how to say Hello

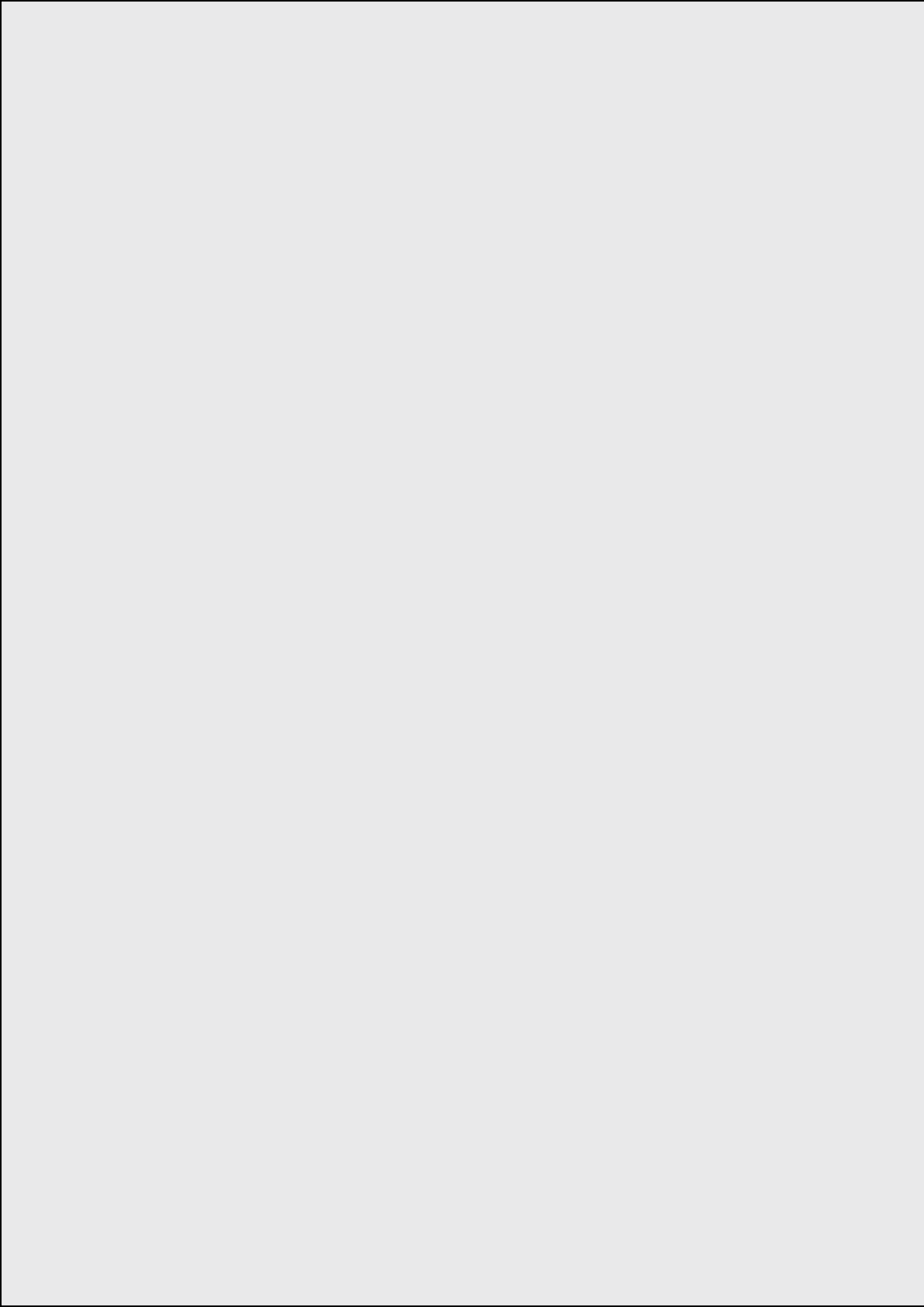
Tip-of-the-tongue

Memory

- Names you know you can't recall without a cue
- Habit Memory (Learning)
- Eating with Chopsticks
- Putting eyeglasses in the same spot every night
- Setting a table the same way every time

Types of Memory that are more compromised than those above:

- Cognitive Map/way finding Memory
- Factual (Learned) Memory
- Complex Sequence Memory
- Message Memory



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