Alzheimer’s, a form of dementia in which protein fragments called amyloid clump together in plaques that damage brain tissue.

Image credit: Getty Images.
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Brain atrophy in Alzheimer’s
We have all come into a room sometimes and wondered —

I should fetch something, what was it?

My patients, they can close the door behind them, and they don’t know where they are heading, why, and sometimes they don’t even know who they really are.

Per Lundberg
Dementia nurse
Part 1: The disease

Trying to understand
About Alzheimer’s disease
I will not go into too much medical detail about the disease, however one thing is extremely important to know and to understand: Alzheimer’s disease affects the brain, it affects the brain so much so, that new information cannot be retained and old information gets lost.


Alzheimer’s disease, named after the doctor who first described it (Alois Alzheimer), is a physical disease that affects the brain. During the course of the disease, proteins build up in the brain to form structures called ‘plaques’ and ‘tangles.’ This leads to the loss of connections between nerve cells, and eventually to the death of nerve cells and loss of brain tissue. People with Alzheimer’s also have a shortage of some important chemicals in their brain. These chemical messengers help to transmit signals around the brain. When there is a shortage of them, the signals are not transmitted as effectively. Alzheimer’s is a progressive disease. This means that gradually, over time, more parts of the brain are damaged. As this happens, more symptoms develop. They also become more severe.

Alzheimer’s in context
In an ageing society, managing and providing care for people with dementia is one of the great challenges of today. Worldwide, 47.5 million people have dementia and there are 7.7 million new cases every year. The total number of people with dementia is projected to 75.6 million in 2030 and almost triple by 2050 to 135.5 million. Much of this increase is attributable to the rising numbers of people with dementia living in low- and middle-income countries. (WHO, 2015). These numbers do not include families and carers, who are also affected emotionally and economically by their condition (Prince et al, 2011).

My explorations
Much worthy research is being done in trying to defeat the disease, finding a cure and providing a higher quality of life in all stages of the disease. A lot of effort is being put into trying to keep patients at home longer, providing education and assistance for non-professional carers, creating empathy for patients in society at large.

In my artistic development project I have explored various opportunities in improving the situation for Alzheimer patients and their carers. My standpoint for all my explorations is that, from the patient’s perspective, we have to deal with what is there — there is no capacity for change, from a carer’s perspective however, there is a lot we can do to improve the situation.

The first opportunity is information. There is a common misconception that Alzheimer patients are simply a bit forgetful. Sadly it is much much worse then that. This gained awareness leads to the second opportunity — empathy. Once we can emphasise and understand Alzheimer patients, we should be able to help them better. The third opportunity was to embrace and work with what there is; the here and now. The fourth opportunity was about acceptance. How can we accept loss? And the last opportunity was to be in charge and regain some control by putting the decision about the time that remains in control of the patients.
From the beginning — oh — you start writing notes, ‘this I should remember’. And suddenly, there are notes everywhere.

Per Lundberg
Dementia nurse
I have seen a woman — I prepared the toothbrush, gave it to her, went away to fetch some diapers, when I came back she was standing in front of the mirror, brushing the teeth in the mirror. And she kept on doing it for ten minutes until I was able to put the toothbrush in her mouth instead.

Per Lundberg

Dementia nurse
Not knowing the limits of your own body, where it starts and where the end is. Upside down is very ... strange. When you are sitting on the chair, you can likewise put yourself on the floor. Beneath or behind.

Per Lundberg
Dementia nurse
Your perception changes. Climbing over lines on the floor. We used to have the same colour floor throughout the whole clinic. Then they redesigned it. Now we come out of the elevator and there is a big blue square, the first thing you see. All the patients stand there. Aha, the sea, for them it was something, water, or a hole. They walk round, or jump over.

Jumping can be problematic when you are old, or you are unsure about what is up or down.

Per Lundberg
Dementia nurse

Anish Kapoor
Descension
www.designboom.com
You get up in the middle of the night, you don’t know if its night or day, and perhaps you have paranoia, so you think the apartment or the house is full of guests, you have to get up and prepare some dinners. And then you stand all the night cooking.

Per Lundberg
Dementia nurse
They can get up twenty, thirty times a night, going to the toilet, because they don’t remember if they’ve been there or not. So when they get back to the bed, they have to turn around again and go to the toilet. This can go on for hours.

Per Lundberg
Dementia nurse
Memories are the key not to the past, but to the future.

Corrie ten Boom
*The Hiding Place*
If we imagine our memories to be a series of events happening over time. Good and bad events. We store these events and learn from them. In a new and unknown situation, we will consult our memories of previous events to advise us on our actions.

When confronted with a distressing situation, we will consult previous distressing events to inform us. Dementia patients will often find themselves in distressing and frightening situations. Where am I? Who is this? Am I supposed to know what you are asking me? This constantly launches patients back into previous distressing events. This is why one will often see ‘looping’ behaviour. The patient gets stuck in a series of memories or events that present themselves over and over again like a broken record.

I have learned much from the SPECAL method, as advocated by the Contented Dementia Trust. This is a controversial and counter-intuitive method that recommend to follow the “three golden rules”:

1. Don’t ask direct questions:
Avoid asking any direct question that requires the person with dementia to search for factual information that they may not remember. This only just confronts them with their disease which can be unnerving and scary. For example, the patient may have tidied up the house and now you can’t find certain items. “Where did you put my wallet?” seems like a normal question to ask, however, the patient probably doesn’t recall cleaning, certainly won’t recall your wallet or where it may be. A simple question like that may spiral out of control and cause paranoia, or aggression, or simply sadness. And you still won’t know where your wallet actually is!

2. Listen to the expert (the person with dementia) and learn from them:
Listen to the questions the person with dementia is asking, and consider very carefully what the best answer might be from their perspective rather than your own.

My mother kept asking where the dog was. I tried over and over again to explain that the dog had died. Then I went on a SPECAL course and decided to try saying that the dog was fast asleep. She sighed with relief. It was just a different answer, that’s all, but it made such a difference.

For people with dementia, feelings are more important than facts. It is crucial that the information they receive generates good feelings for them. Having a record of good feelings, yet not knowing why, is one thing. Having a record of negative, possibly traumatic feelings with no explanation as to why, is quite another. We owe it to the person with dementia to avoid leaving them with anxieties that they cannot, only moments later, explain. So we must search for the information and the language that is most acceptable to them. They will ask the same question over and over again, once you have found an acceptable answer to this question, you can also use it over and over again. In our case it was “where is Thijs?” (my dad), we found the acceptable answer to be “in the shed”, he was often found tinkering in the shed, and knowing that he was there provided comfort for my mother. It is remarkably hard though to tell these lies. It makes you feel like a terrible fraud.

3. Don’t contradict.
Do not argue with the person with dementia about where in their memory they may be. They are increasingly likely to use intact memories from their pre-dementia past, in order to understand what is happening around them in the present. The rest of us need to avoid disturbing the sense they are making, and start where they are at. If they behave like the dentist’s waiting room is in fact the airport, you may as well join the ride and see where you are travelling to. This pleasant trip down memory lane won’t take long, and there is no harm not being aware of being at the dentist.
At home, it’s nothing that I recommend. Because it’s ... I have seen so many carers die before the sick.

Per Lundberg
Dementia nurse

The carer
With more and more incidences of the disease, patients tend to stay home for longer, putting much more stress on non-professional carers. Webmd.com states that about 5.4 million people in the United States have Alzheimer’s disease and other types of dementia, and 70 percent are cared for in the community by family members and friends.

Caring for an Alzheimer patient is a 24-hour job. The burden this puts on a carer is extreme. Not only there is seeing to basic needs, there is a constant fear for something going wrong, suddenly the home is a dangerous place to be. The toughest burden is the emotional load. Dealing with a loved-one who no longer is the person you know them to be can be intensely sad, frustrating and depressing. Understanding why the patient is different helps, getting support from family and friends who understand helps.
Everything is hard. Everything is so goddamn hard. Getting into bed is hard, getting out of bed is hard. You can reach out a helping hand. What is this hand? But you can’t say, you are doing it wrong, this is wrong, you are wrong.

Per Lundberg
Dementia nurse
Part 1: The disease

Empathy
Cognitive Design
The Cognitive Design course at Umeå Institute of Design (UID) 2016 was aimed at generating understanding on what it is like to have dementia, and by doing so, the hope was for people to be more lenient towards dementia patients and their carers. Students were asked to "Design an experience to foster empathy for dementia patients." This resulted in a small exhibition of experiences; walking in the footsteps of a dementia patient setting the table, following a recipe, using a keyboard and an illustrative experience of the disintegration of the mind.

During the duration of the six week course students were introduced to interaction and design principles and methods. They had a long conversation with Per Lundgren, dementia nurse for over 37 years. Per (aka Pelle) introduced them to the disease by very moving storytelling—many of his anecdotes are featured throughout this document. It was clear that the students themselves were unaware of the extreme and often bizarre expression Alzheimer’s disease can have. Encouraged not to try and fix dementia, but to help people understand what the disease does through designing experiences that put us in dementia’s shoes, they sought out users, interviewed patients and carers and prototyped.

Shown here are photographs of the experiences they designed. The experiences were exhibited in the atrium of UID and open to all. Considered the limited time the students had, as well as little or no prior design experience, they tackled the problem enthusiastically and managed to create meaningful experiences.
DISINTEGRATION
Antonina Koudriavtseva, Suthan Logeswaran, Svitri Magnusson

It is not uncommon for people suffering from dementia to have difficulties communicating and understanding the outside world and vice versa.

This experience is designed to illustrate these difficulties, and ultimately, attempts to induce associated feelings of this disintegration.
The purpose of this project is to show the difficulties of everyday life when things do not behave the way you are used to. Dementia changes the way you perceive your surroundings and this is a table where things are different from how they seem.
A common effect that dementia has on the human mind is the loss of memory related to procedures and tools. Our aim with this exhibit is to emulate how a person with dementia might feel when they can’t remember the purpose of an everyday object.
The goal of this project is to create empathy and understanding for the frustration of losing basic everyday abilities. The keyboard is a good device to use for exemplifying this. Virtually everyone uses a keyboard in their everyday life, yet few reflect on the amount of skill needed to operate one in an efficient manner. In our Stupid Keyboard we have tried to switch places of just enough keys to impair one’s typing. This would create a feeling of confusion, but doing so without breaking the illusion of a perfectly normal and harmless keyboard.
Part 2: The here & now

Sensuous dementia
Transformative Homes for Sensuous Dementia, part of the Design for Social Innovation course at Technical University Eindhoven with MA students Industrial Design.

Design house, February 23rd. 2016
Within the course Sensuous Dementia, Pernilla Glaser, Marije de Haas and Ambra Trotto work with the students for a day on the theme of “Cracking the Loop”.

The assignment that we had created was to design ways for a wise home to support, through sensorial influence, the interference/ manipulation/ hack of a specific looping in a domestic activity, resulting in an experiential prototype.

Dementia patients often enter a situation defined as looping, where they engage in a perpetual repetitions of thoughts and conversational fragments. How to hack them? Can we hack these loops and steer into a direction that is pleasant/non-frustrating for the patient and it is manageable for the carer.

The goal of the students’ work is to design systems for the home environment to respond in a way that will eventually result in an experience which mutates the course of looping. Such experiences will use sensorial triggers to gently hack loops into new ones, that might be more pleasant and sustainable for the carer and thus the patient. The experience has to be designed as a system that involves and uses the (interactive) qualities of the space.

Preparation
The day before the workshop, all coaches worked at a design session together. This session led to some insights which were used in the work with the students. A first person perspective to the assignment, supported us in understanding more about the following and to stress these points with the students:

Focus on the carer
As dementia patients are literally incapable of learning anything new, we encouraged the students to focus on the carers. Can we design handles for carers to gently take a dementia patient out of a negative loop, and place them in a positive loop? Can we design loops to evolve in order to create pleasant experiences for patient and carer — together? Can we design loops to help the carer to initiate functional loops (eating, washing, sleeping)?

Focus on the sensorial
Dementia patients’ sensory perception can be confused. Sensory input can easily be misinterpreted to create bizarre experiences. We encouraged the students to explore the senses within the context of a loop.

Focus on play
Our ideas of what a normal social interaction requires is put to the test when an adult (who might once have been the one who one telling us that it is inappropriate to put your tongue out or sing loud in public) starts to behave in an irrational way. To practice playing might be a useful survival-strategy and allow for surprising points of interaction.

Focus on the “surreal home” environment / making it weird for everybody
To explore the possibility that a designed environment can be an assistant in a sometimes very slow but relentless transformation where the inner space loses its capacity for linear logic. What if the walls started to shift and didn’t box you in as firmly long before your mind started to change how you perceive? What if the floor became a wave and the chair could put its arms around you and hold you when you felt anxious? The idea is to create a home that can allow caretaker and the patient to slowly adapt and embrace the constant transformation that the disease implies — together.
Steps:
We explored these areas in the following exercises

**Mood boards**
Students worked in groups to create a mood board focussed on one sense (of their choice). How can you explore a specific sense, how can the sense be transformed into a holistic experience?

**Play**
Playing is using all kinds of expressions, not just verbal. To communicate through looking such as in the exercise “come” when you give someone your place just by identifying that they are looking at you. And then you have to stare someone else down to get a new space yourself...

Playing together can be taking turns who will be the leader and who will be the follower without verbal agreements or exchanging wonderful invisible gifts that make you absolutely ecstatic. The magic of playing presides in the mutual agreement that everything is a wonderful opportunity to explore together, every handshake, sound, corner. There is no given to what is small or big, important or banal.

To play leader and follower with just your fingertips touching and as such joined together starting to explore staircases and hallways is to negotiate several spaces simultaneously. You are in the space between your bodies and in the surrounding space, trying out the boundaries of both.

**Exploring the building**
Students found opportunities within Designhuis to prototype their looping experience. Does the architecture itself invite for play? What interventions can we design to encourage/discourage a loop here? The day was carried out in the Designhuis in Eindhoven. The building was originally designed as a tribunal and has some interesting architectural characteristics, which mainly work on the tension between public and grand spaces vs. private and intimate spaces. Students were encouraged to use the qualities of the space, finding a location that would establish a dialogue with the interactive qualities of the loop that they had been previously exploring. Such dialogue could be based on a tension, a contrast or a specific resonance.

Designs were eventually influenced and embedded in the physical space and played with the affordances that such spaces provided. Students created prototypes within specific architectural constraints provided by the building where a carer and patient could engage, together, in a loop.

**Role playing as prototyping**
We explored role playing caretaker and person with different stages of dementia in the designed sketches the student had made. How would someone interpret a sofa with a small box that invites you to play with different materials or a track following the railing? It is important to let the role players first take on the space as they wish and the allow the designers, onlookers as well as the role players to share insights they got from the exercise.
Part 2: The here & now

The senses
The norm
Challenging the norm

Working with Pernilla Glaser was eye opening for me and the students. She made us challenge the norm in a series of exercises. It made me realise, once again, that the problem lies with the carer and not the patient. Alzheimer patients are unaware of ‘the norm’ and thus their behaviour may challenge this concept many times over. How we respond to this behaviour is important.

Pernilla started her session with a question:

You are walking to work — what is the smallest thing you can do to challenge the norm?

Pernilla says “Normal is the, often silent, agreement that we, without reflection, assign the role of compass. If you ask a group to change their way of greeting each other even in the slightest way, they will feel a massive change. Some will express it as liberation, others as a deep discomfort. The way we perceive each other and the environment is controlled by our normative thinking, and how that constructs what we expect of each other.

A way of accessing space, place and interaction can be to explore in the very intersection between holding onto, and letting go of control. This can be done, for example, through a collaborative exercise, where one is leading the other just by using the fingertips. That exercise can then be used to explore a place, thereby allowing you to be led by something else than your preconceived ideas.

Much like someone with dementia, who has lost their sense of the norm. Not knowing how to behave is not so much the problem — you cannot be burdened by what you don’t know — the way people respond to others who are not following the norm can be a bigger problem. A place where everything is possible can be scary, but it can also be a very allowing space, if we dare to enter it together.”

Have you thought about the question? Pernilla’s answer was “to look someone in the eye at the traffic lights”
Part 2: The here & now

Looping
People who have dementia often say or do the same thing over and over. They ask the same question and may repeat the same action, for perhaps hours at a time. These behaviours are common and are the source of frustration and stress for caregivers. When reading it like this, it does not seem so bad, however, it is more frustrating than you think.

I was looking after my mother for a week. My father, the primary caregiver, was on a very much needed holiday. My mother kept waking up in the night, looking for stuff, then wondering where dad was, then resulting in a loop of ‘why has he left me?’ in serious distress. This would go on in repetitive cycles of five minutes for hours. I was unable to stop her, change the subject or get her back to sleep — I was unable to do anything. After several nights of this (not to mention what would happen in the daytime), I was sleep deprived, cranky, sad, depressed and completely lost on what to do. At one point I considered drugging her with sleeping pills, punching her in the face, leaving, and worse. And this was just one week! How my dad managed for over ten years is beyond me.

Repetitive behaviours are due to the inability of the individual to retain information. They do not recall that they have just asked that question, nor do they recall the answer. They are also created by the stress, anxiety and fear that are produced due to this loss of memory. They are an expression and a release of frustration and anxiety.

The loss of an ability to focus in order to understand the information, store and recall it, also results in the lack of memory of an event. The part of the brain which enables a person to change to a new subject or activity may be damaged due to the dementia. If so, the person will be ‘stuck’ on one word, topic, or activity and be unable to stop repeating it over and over again, like a broken record.

We got the students to act out and visualise various loops (see next few pages). By acting out a loop, they grasped quite quickly what the mind fails to do with simply ‘knowing’. Repetition, even if it is a positive loop, can drive you mad!
Student visualisation of the loop. This group focussed on the sensory experience of food.
My Story Box

Lezhi Su

s145606

A mysterious box that helps the caregiver to transfer the patient’s attention from the older loop to a new loop or something that the patient needs to do.

Student visualisation of the loop. This group focussed on light and patterns.

Student visualisation of the loop. This group focussed on fidgeting.
Fascination
Joy
Amusement
Satisfaction
to experience an urge to explore, investigate, or to understand something
to take pleasure in some-thing or some desirable event
to enjoy the recent fulfil-ment of a need or desire
to enjoy a playful state of humor or entertainment

Positive Emotion
design stimuli to change the everyday loop into a positive experience

Student visualisation of the loop.
This group focussed on repetitive touch — walking along a railing.
Student visualisation of the loop. This group focussed on sound and music.
Part 2: The here & now

Designed experiences/
experiencing designs
Dear all,

We like to welcome you to the exhibition of the course “Transformative Homes for Sensuous Dementia”, which is developed by Master students of the department of Industrial Design at the Eindhoven University of Technology. The students worked the last eight weeks on developing new concepts triggering the sensorial skills of people with dementia and their care takers, in order to bring more structure, context, relaxation and connection in their lives. You can experience all four designs and are invited to discuss the rationale and implications of the designs with the students and each other.

When: Tuesday March 29, 14:00-18:00hr
(no fixed starting time, you can just walk in)
Where: Designhuis, Stadhuisplein 3, 5611 EM Eindhoven
How: Entrance is free. You will be guided in small groups through the exhibition.

More information: Caroline Hummels, c.c.m.hummels@tue.nl

On behalf of the entire coaching team I like to welcome you this Tuesday.

All the best,
Caroline Hummels
Jorge Alves Lino
Ambra Trotto
Marije de Haas
Pernilla Glaser
Sietske Klooster
Rens Brankaert
Jun Hu

For the time being
Jeroen Ablas, Joch Jansz,
Manon Junggeburt,
Mantas Palaima, Veerle Wijshoff
For the time being
Jeroen Ablas, Joch Jansz,
Manon Junggeburth,
Mantas Pulaima, Veerle Wijshoff
For the time being
Jeroen Ablas, Joch Jansz, Manon Junggeburth,
Mantas Palaima, Veerle Wijshoff

Caregiver:
Betty, why haven’t you finished your embroidery?

Betty:
It is really frustrating when you forget things, you know. Especially when I forget the things I love to do. Luckily I can save my routine in my personal cabinet so it simply reminds me. With the cabinet I had the opportunity to prepare myself for later. Building an environment that helps me remember the things that I treasure now, will ensure I can enjoy them for the rest of my life.

Verzorger:
Betty, waarom heb je je borduursel niet afgemaakt?

Betty:
Het is zo frustrerend om dingen te vergeten, weet je. Vooral wanneer ik dingen vergeet die ik leuk vind om te doen. Gelukkig kan ik objecten in mijn kast plaatsen die me herinneren aan deze dingen. Met de kast had ik de mogelijkheid om me voor te bereiden op later. Het bouwen van een omgeving dat me helpt te herinneren waarvan ik houd, gaat ervoor zorgen dat ik er de rest van mijn leven van kan genieten.
Warm place
Jacqueline Nanne, Joanne Pek, Lezhi Su, Sylvie Claes
Warm Place
Jacqueline Nanne, Joanne Pek, Lezhi Su, Sylvie Claes

I like the warmth. It’s comfortable. When it is warm I feel at home. Now I’m older, I feel the cold more easily, especially in my hands. It’s warm here. I can feel it. It’s nice here.

De warmte hier is fijn. Het voelt goed. Ik krijg er energie van. Ik voel dat ik het vaker koud heb nu ik ouder ben, vooral in mijn handen. Hier kan ik me opwarmen.
Richness of tea

Charlotte vd Sommen, Dominique Fürst, Martijn Imhoff, Pepijn Schnitzeler, Xihao Hu
The richness of tea

*Person with Dementia:*
What a big room.
Where am I?
(pauze)

I am in a living room, I think.

*Caregiver:*
Let’s make some tea.

*Person with Dementia:*
Tea ... I can make tea here?
What’s this in the table?
I can see a light.
Is that tea?
Perhaps I should take a seat.

*Person with Dementia:*
Wat een grote kamer.
Waar ben ik?
(korte pauze)
Volgens mij ben ik in de woonkamer.

*Verzorger:*
Kom, we gaan thee maken.

*Person with Dementia:*
Thee ... kan ik hier thee maken?
Wat staat er op tafel?
Ik zie wel iets met licht
Zou dat thee zijn?
Laat ik er maar gaan zitten.
Orchestra of the senses
Anqi Li, Fabienne van Leiden, Manon Barendse, Martijn Lammers, Wouter van Wal
Part 2: The here & now

Alzheimer’s playground
Through explorations with the students, the time with my colleagues, research and more research, I have concluded that it is better to work with what you have as opposed to strive towards an impossible goal.

In the case of Alzheimer's disease, it is pointless trying to regain brain function, memory of even personality traits. What we have left to work with is the Here and Now. Can we make the Here and Now a good place to be? If we try to imagine that Alzheimer patients really have no idea about the future, the past and who they even are. Would they miss this sense of time? Can you miss something that you don’t know? Perhaps not — perhaps not if we, the carers, don’t continually point out to them what they are missing. What if we, the carers, the healthy people, could be in the moment together with Alzheimer patients and experience the same sense of wonder and confusion. Might this bring us together? What if we “make it weird for everyone”?

We know Alzheimer patients’ sensory experience is confused. What if we confuse the sensory experience for the carers as well? Then carer and patient could have genuine experiences together as equals.

I was inspired by the Maggie’s centres — architecturally designed environments for terminally ill cancer patients.

http://www.archdaily.com/

Maggie’s Centres are the legacy of Margaret Keswick Jencks, who had the notion that cancer treatment environments and their results could be drastically improved through good design. Her vision was realized and continues to be realized today by numerous architects, including Frank Gehry, Zaha Hadid, and Snohetta — just to name a few.

Here follow some snippets from an article by Samuel Medina “Living with Cancer,” taking a closer look at the Maggie’s centre’s roots and its continued success through the aid of architects.

It was May 1993, and writer and designer Margaret Keswick Jencks sat in a windowless corridor of a small Scottish hospital, dreading what would come next. The prognosis was bad — her cancer had returned — but the waiting, and the waiting room, were draining. Over the next two years until her death, she returned several times for chemo drips. In such neglected, thoughtless spaces, she wrote, patients like herself were left to “wilt” under the desiccating glare of fluorescent lights.

Wouldn’t it be better to have a private, light-filled space in which to await the results of the next bout of tests, or from which to contemplate, in silence, the findings? If architecture could demoralize patients — could “contribute to extreme and mental enervation,” as Keswick Jencks observed — could it not also prove restorative?

This is the central idea behind the experiment Keswick Jencks, or “Maggie,” started with her husband, architectural historian and theorist Charles Jencks, more than two decades ago. Their mission — to provide free, global care for cancer patients through great architecture — has since expanded to encompass 17 building projects (“Maggie’s Centres”), many of them by celebrated architects like Zaha Hadid, Richard Rogers and Rem Koolhaas.

What if we invite great architects to design environments for Alzheimer patients? I have collected some images of architecture and art works that I feel would be fantastic places to visit with an Alzheimer patient (depending on stage of disease, mobility etc.). I would use these works as a starting point to brief an architect to design transformative spaces for ‘here & now’ experiences with Alzheimer patients.

The images chosen would represent the playground spaces — making it weird for everyone — not a full time solution for housing. Alzheimer patients get tired very quickly and would need calm and stimuli free spaces as well.
The Critical Resemblances House is designed to maximize certain aspects of the visitor's experience. Arakawa and Gins propose that “juggling, jumbling, and reshuffling the body with its fund of landing sites introduces a person to the process that constitutes being a person. To reverse destiny one must first re-enter destiny, re-positioning oneself within the destiny of being slated to live without ever knowing how and why. The re-entering of destiny must be highly calculated. The world and everything in it will have to be transformed into a site of reversible destiny.”
Site of reversible destiny
www.reversibledestiny.org
“The best way to get a handle on how a person is situated in the world is actually to construct one, a handle expressly made for the purpose.”

Arakawa and Madeline Gins
Architects of the Site of Reversible Destiny, Yoro Park, Japan

“Memory and body come together in the act of looking. I’m really interested in what happens to meaning in that process: as memory and body walk through, take the passage through any given work, something happens, something changes.”

Anish Kapoor
Leviathan
Anish Kapoor
Leviathan
http://www.metalocus.es/sites/default/files/file-images/ml_monumenta_2011_anish_kapoor_leviathan_06.png
Olafur Eliasson

*Weather*

everystockphoto. s3.amazonaws.com/
olafur_eliasson_
weather_1408983_o.jpg
James Turrell
Ganzfelds
1.bp.blogspot.com/_9spnkIQlRuc/TGSb7_dXJfi/AAAAAAAAA7c/Mb-
Cx0jr4E8E/s1600/bridgets_bardo_2.jpg
It was interesting reading the conceptual background of the pieces I’ve shown. The first two images on the Site of Reversible Destiny are based on a theory of “Procedural architecture”. Procedural architecture is defined in Architectural Body (2002). Understanding procedural architecture is be clarified by the notion of procedural knowing, i.e. the reduction of steps necessary to complete a routine, and making those steps a subroutine of that procedure. Walking, talking, and eating are examples of procedural knowing.

Procedural architecture brings into question an occupant’s procedures and steers him or her to examine the actions, or subroutines, he or she takes, thereby causing her to doubt herself long enough to find a way to reinvent herself.

It’s this reinvention that is interesting. I imagine this is what an Alzheimer patient is confronted with a lot, because they lose their “procedural knowing”. If we can create an environment where this is the norm, then this could reduce the stress of the not knowing, as it is the norm not to know.

This leads onto an opposite approach, the absence of visual information. In James Turell’s work, I find his “Ganzfeld” fascinating. Ganzfeld is German for “total field.” Gestalt psychologist Wolfgang Metzger coined the term in a 1930 article “Optische Untersuchungen am Ganzfeld” (“Optical studies in the ganzfeld”) published in Psychologische Forschung, in which he described a phenomenon he observed when subjects were made to experience an unstructured visual field. The absence of visual information can cause hallucinations. The brain fills in the absence with its own ideas. Whether this is particularly such a good idea for Alzheimer patients is questionable, however, in my personal experience of this artwork, it induces such a complete feeling of being immersed in colour, which, for me, was wonderful. No need to understand or know, just ‘being.’ Turrell himself says “My work has to do with perception—how we see and how we perceive.”

In a similar immersive vein, the work by Olafur Eliasson is interesting, particularly the work I’ve shown “Weather”. What was wonderful about this piece was how the viewers really immersed themselves in this piece. It was a moment away from the “norm” of daily life. People, especially in Britain, don’t normally lie on the floor in public spaces, or start doing yoga, dancing, talking to each other... It was wonderful to see how a work of art could transform our behaviour so completely.

Tate Britain says about this piece: “Eliasson’s impressive installation draws attention to the fundamental act of perceiving the world around us. But, like the weather, our perceptions are in a continual state of flux. The dynamic variations in the composition of the ephemeral elements of The Weather Project parallel the unpredictability of the weather outside, which despite the efforts and sabotage of humankind still remains beyond our control.”

Anish Kapoor equally creates grand experiences for the viewer. The artist considers that the purpose of his work is “to offer, through strictly physical means, a completely new emotional and philosophical experience.” he continues to say “I think there is no such thing as an innocent viewer. all viewing, all looking comes with complications, comes with previous histories, a more or less real past. Abstract art and sculpture in particular, has to deal with this idea that the viewer comes with his body, and of course memory. Memory and body come together in the act of looking. I’m really interested in what happens to meaning in that process: as memory and body walk through, take the passage through any given work, something happens, something changes.”

I think it’s fascinating how he talks about memory and the body coming together in the act of looking. Memory here could be interpreted as a much more abstract concept. Memory as experience, in the sense of the procedural knowing, the doing that your body does without having to think. The memory we are not aware of.
“Instead of squeezing people with dementia into complicated systems designed for people who can remember who the President is, we should find kinder, less judgmental ways to be with them. We, the lucky people who are yet to fail the memory test, will benefit too, by learning to make ourselves available to the physical, expressive and relational aspects of our own identities.”

by Charles Leadbeater

The disremembered

aeon.co/essays/if-your-memory-fails-are-you-still-the-same-person
Part 3: Accept & proceed

Rituals of Farewell
“All hope of maintaining a memory-based identity goes. Living with dementia then becomes a long process of mourning someone who is no longer there. But if we understand our identity as something held by relationships, expressed through feelings, reflected by our environment and enacted bodily, dementia instead becomes a daily puzzle to find common ground with people different from us.

Once the mind is invaded, all hope of maintaining a memory-based identity goes, and with that goes everything we value about the idea of independence and self-fulfilment. Living with dementia then becomes a long process of mourning someone who is no longer there. But if we understand our identity as something held by relationships, expressed through feelings, reflected by our environment and enacted bodily, dementia instead becomes a daily puzzle to find common ground with people different from us, and to find new, often non-verbal forms of communication and communion that make people feel good about themselves without necessarily knowing why.

Charles Leadbeater
The disremembered
aeon.co/essays/if-your-memory-fails-are-you-still-the-same-person
My mother was a sculptor and a collector. She collected many things, but her holy grail were rocks with holes. She collected many over the course of her life.

Being diagnosed with early onset Alzheimer’s was a curse. The disease she feared most. She had witnessed her own mother’s dying in this way. It hit her hard. It hit the family hard. She wished for a dignified death, to not have to experience, and for her family to witness, the undignified deterioration that is Alzheimer’s disease. We would have loved to be able to grant her this wish. Instead we all experienced her gradual and terrible decline.

My mother lost her sense of humour first. Then she lost the skill to learn new things. She lost her optimism. She lost her excellent problem solving abilities. She lost her beloved skill to read. She lost her disgust for milk. She lost her friends. She lost her kids. She lost her dignity. She lost herself.

Slowly and with much delay we learned to accept these losses. We had to deal with this grieving these losses over many years. Each rock symbolises a part of my mother we lost. Together we put her back together again, and can remember her as the beautiful being she was.
Using the phone
Brushing my teeth
Our holiday in Portugal
The cat
Peeling an apple
My sense of humour
My first born
The way home
Art
Poetry
Loving you
My disgust of milk
Loving you
Poetry
Art
Funeral rituals are in place to help those who remain understand and accept that their loved one is gone.

**What if there were different rituals for different departures?**

It has been studied that it’s easier to accept a loved-one’s death in the case of a prolonged illness — the death is not sudden, but expected. There has been a chance to say goodbye.

With sudden deaths, peaceful or violent, the grieving process is very different. Those who remain struggle much more with the loss. There are things left unsaid. There was no chance to say goodbye.

In the case of Alzheimer’s disease, biologically, the patient may take a long time to die, however, we have to accept the loss of their identity during this biological process. Again there is no chance for goodbye. This is particularly hard to accept and understand, as the biological individual is still around.

Could we help the carers for dementia patients by designing rituals of farewell for memories or skills lost?

There is a wealth of rituals out there, there are spectacular cultural differences between how people ritualise death.

The Torojan people of Indonesia keep the diseased amongst their midst. For Torajans, the death of the body isn’t the abrupt, final, severing event of the West. Instead, death is just one step in a long, gradually unfolding process. Late loved ones are tended at home for weeks, months, or even years after death.

For Torajans death is just another step in the process of being alive. Dead and alive people are not disconnected but separated.

The New Orleans jazz funeral is one of the prototypical images of New Orleans, Louisiana: the boisterous, jazz-tinged funeral procession. fuses West African, French and African-American traditions. Funerals in New Orleans strike a unique balance between joy and grief as mourners are lead by a marching band. The band plays sorrowful tunes at first, but once the body is buried, they shift to an upbeat note. Cathartic dancing is generally a part of the event, to commemorate the life of the deceased.

When a loved one dies in Aboriginal society in Australia’s Northern Territory, elaborate rituals begin. First, a smoking ceremony is held in the loved one’s living area to drive away their spirit. Next a feast is held, with mourners painted ochre as they partake in food and dance. The body is traditionally placed atop a platform and covered in leaves as it is left to decompose.

As part of this project I collaborated with artist Bert. Bert designs rituals for any occasion, often to do with her own life, but also for clients and specific occasions. Together we decided it would be an interesting turn to commercialise death and death rituals. Designing bespoke ritual solutions for those that remain after a loved one has died. A service design project where the agency would deal with issues that remain when people die; financial issues, dividing belongings, settling family feuds, dealing with grief, legacy pieces — the lot. By making death yet another service, we hope to normalise death. Death happens to us all, there is no need for such stigma, and perhaps we could also reduce the fear for death this way.

This project is ongoing, but in this document I specifically want to focus on dying of Alzheimer’s disease. It is incredibly hard, as a carer, to witness the slow decay, and the ongoing series of small deaths of your loved one. In my personal case it is interesting to reflect, now that my mother is dead, the path that my grief has taken. I found it hard, but along the course of my mother’s illness I clearly learned to accept the small losses, one by one, until really there was nothing left. The final departure therefore was not so painful anymore. There was a sense of relief, and an opportunity to celebrate what was good about my mother’s life.
Shifts in nature and culture affect us daily but without spiritual vision and ritual structure we lose the capacity to handle death and embrace life fully. Instead we build walls of denial to hold off terror and confusion.

Without rituals of loss and renewal we lack the capacity to experience sorrow and joy – essential human feelings.

My work explores creating modern rites of passage that are based on universal symbolism of our collective unconscious.
There are different ways to deal with grief and loss. Some of the grief-stricken remain depressed for long periods of time — most people move on. They eventually settle into their old routines or develop new ones.

Sixty percent of mourners show no symptoms of grief one month following a loss. Some even overcome grief within days. Psychologists who study these questions note that there is no single factor that predicts who copes well and who does not. Many variables, from your personality to your social world to your levels of stress before the loss, play distinct roles.

A new study, however, suggests differently. Researchers Michael I. Norton and Francesca Gino at Harvard Business School studied how people cope with extreme loss. In the study, published in February 2014 in the Journal of Experimental Psychology, they found that those who overcome their grief more quickly all have something in common. Following the loss, they performed what the researchers refer to as “rituals”.

These rituals were not the public displays of bereavement such as funerals, wearing black for a certain period of time, or religious customs. They were very private and personal rituals. Of their 76 test subjects only 15 percent of the described rituals had a social element (and just 5 percent were religious). By far, most of the rituals people did were personal and performed alone.

One woman whose husband died still washes his car each week, as he had done when he was alive. Another woman who lost her mother would “play the song by Natalie Cole ‘I miss you like crazy’ and cry every time I heard it and thought of my mom.” A man whose wife passed away wrote: “In these fifteen years I have been going to hairdressers to cut my hair every first Saturday of the month as we used to do together.”

These private rituals sound quite emotional. One would expect that performing them would make mourners more depressed by reminding them of who and what they have lost. But that’s not what happens, as Norton and Gino discovered in a follow-up study.

In their next study, Norton and Gino invited 247 people into their lab to reflect on the death of a loved one or the end of a relationship. To induce grief in the subjects, the social psychologists asked them to write in detail about the loss and describe the emotions and thoughts they experienced at the time it occurred. Then, the researchers divided the group in two: a ritual and a no-ritual condition. Those in the first condition were asked to write about a ritual they performed following the loss. Here, as in the previous study, many people reported private, personal, and emotionally-moving rituals that connected them to the memory of their lost loves in a deep and powerful way.

After the writing exercise was over, the researchers measured the grief of the participants in both conditions. As one would expect, people in both groups became sad doing the exercise, but the people who wrote about rituals were less sad. They reported significantly less grief than those who did not write about rituals.

Public mourning rituals have a clear purpose. By gathering together social bonds get strengthened. Private rituals do no such thing. They seem to serve no practical function.

When Norton and Gino probed deeper into the emotional and mental lives of their research subjects, they found that rituals help people overcome grief by counteracting the turbulence and chaos that follows loss. Rituals, which are deliberately-controlled gestures, trigger a very specific feeling in mourners — the feeling of being in control of their lives. After people did a ritual or wrote about doing one, they were more likely to report thinking that “things were in check” and less likely to feel “helpless,” “powerless,” and “out of control.” By performing their own private rituals, the bereaved can regain their footing in a world that has become a little emptier than it was before.
“People think it’s just forgetting your keys, she says. Or the words for things. But there are the personality changes. The mood swings. The hostility and even violence. Even from the gentlest person in the world. You lose the person you love. And you are left with the shell... And you are expected to go on loving them even when they are no longer there. You are supposed to be loyal. It’s not that other people expect it. It’s that you expect it of yourself. And you long for it to be over soon.”

Alice LaPlante
*Turn of Mind*
Part 4: The end game

Designing Death
As much as I try to come up with solutions to make the time Alzheimer patients have before they die worth living, I can’t help but feel depressed. From my experience witnessing the course of this disease, if it was up to me, I would do what I could to avoid it at all cost. It would seem I am not the only one who feels this way. In an emotional guest post on Harvard’s law blog, Professor of Law, Norman L. Cantor makes a strong personal case on how he will avoid the ‘Ravages of Extreme Dementia.’ Having experienced the course of this disease with a close friend, he argues why he will do whatever it takes to avoid experiencing this himself: “My own preference, at least after a definitive diagnosis of Alzheimer’s is received, is never to reach the mentally debilitated stage when I am no longer in charge of my fate. Rather, I plan to engineer my self-deliverance (to use a euphemism for suicide as is appropriate to someone stricken with a fatal affliction accelerating their own demise) while still competent to do so. This will be my course as long as no reliable therapies are available.”


In a qualitative study of older people with dementia and their thoughts on dying by Goodman et al (2013), there are a few cases where patients, already strongly affected by cognitive decline, state “what is the point of it all, I like to be useful (...).” In this study it was found that people often appreciated the care they were receiving, and the moment-to-moment living wasn’t bad, it however did seem there was no longer a purpose to their lives. The study concludes (amongst other things): “The systematic introduction of advance care planning (ACP) for people with dementia can reduce the incidence of inappropriate life prolonging treatments, involve family members in decision making and improve overall delivery of end-of-life care (Detering et al., 2010).”

After finishing this project I will start a PhD “Designing Death; a dignified end-of-life plan for Alzheimer patients.” In my research I will focus on supporting patients to make a very considered design for their death after receiving a diagnosis, while their cognitive functioning is still in place (like in Norman Cantor’s heartfelt blog post).

In a small study I conducted among my friends (33 people), with a demographic of western 40-50 year olds, well-educated, active participants of society, I found that 94% of them had considered their own death, and 76% had quite clear ideas how they would like to die. Only 21% were afraid of death, but 64% were afraid of the process of dying. 70% of this group was most afraid of a death to do with losing mental abilities.

Being in control of your own death seems a timely subject. Design company IDEO is currently running a design challenge about the end-of-life experience. This challenge was not particularly aimed at dying from Alzheimer’s disease, there were a large number of cases that dealt with Alzheimer’s specifically.

Interestingly, out of all the 361 submissions in the Inspiration phase of the IDEO Challenge, 50 where to do with Euthanasia being an essential human right, 77 where about planning death, 92 where about making talking about death socially acceptable, 69 where about rituals, 47 where about leaving legacies, 6 where specifically about using new media for legacies and 20 where about location and facilities.

There were 303 ideas submitted in the Ideas phase, here the picture shifts. Only 11 ideas were submitted about euthanasia, 60 about planning death, 64 about socially acceptability and communication, 49 about rituals, 61 about legacies, 31 about facilities, 19 about education and 10 about medical support.

One thing this tells me is that talking about euthanasia is a lot easier than designing for it! What seems like a logical proposition; the essential human right to be in control of your own death, becomes a lot more complex when you have to decide time, place and manner. Parameters shift and ideals change when facing death. What seems unacceptable while being healthy, may become bearable when facing death. What seem like unshifting principles of acceptability can change as you age, have a family, when other people are intertwined in such decisions.
- Have not thought about how to die
- Quickly or while asleep (unaware)
- Painless
- With loved ones
- Outdoors
- Saying goodbye
- Designing my own way
- Old and contented

Afraid of losing mental abilities
Afraid of losing physical abilities
Can’t choose fate
I want some control in the process of my own dying
Let nature run it’s course
I want to be able to manage my suffering
I want to design my own death

Afraid
Not afraid

DEATH
DYING
How might we reimagine the end-of-life experience for ourselves and our loved ones?

How it works
At OpenIDEO, people from all corners of the world collaboratively tackle some of the toughest global issues.

The challenge process
A challenge is a three to five month collaborative process that focuses our attention on the topic and creates a space for community members to contribute and build off each other. This approach is modeled on IDEO’s design thinking methodology.

Research: It all starts with an invitation for you and others around the world to share inspirations, stories, tools and successful examples on the challenge topic.

Ideas: Based on learnings from the Research phase, the OpenIDEO community shares new, wild or existing ideas and collaboratively refines them.

Refinement: We then focus on testing ideas with end users.

Feedback: This is when the OpenIDEO community shares comments and suggestions for next steps.

Top ideas: Working closely with the challenge sponsor, the OpenIDEO team chooses a set of top ideas based on their potential for impact, level of engagement and relevance to the challenge topic and evaluation criteria.

Impact: This is where you can share learnings, find collaborators and share updates on how ideas are evolving.

Submitted research and ideas
I decided to participate in the challenge by submitting some of my research and ideas. As this challenge goes beyond my primary focus of research, dementia, I will aim to put a dementia filter on my learnings from this challenge. As Alzheimer’s is a terminal illness, any thought about dying is relevant, however much of the discussion was not necessary relevant to Alzheimer patients as it would require sound cognitive functioning at the terminal stages.

Rituals of Farewell
I propose a bespoke ritual, designed for the patient and carers, to accept loss as it occurs within the duration of the disease. Accepting memories and skills lost will help the carer be less frustrated with the diminishing loved one in front of him, which will put less of a burden on the patient, to know or be who she once was.

Dignified end-of-life plan for Alzheimer patients
Could a dignified death be an option for those diagnosed with a disease that will diminish cognitive functioning?

Rituals and legacy
Can rituals and legacy pieces find a place in our landscape?

Death plan
If we make birth plans, why not make death plans too?
Dignified end-of-life plan for Alzheimer patients

Could a dignified death be an option for those diagnosed with a disease that will diminish cognitive functioning?

Euthanasia is legal in some countries; in the case of a terminal illness and the patient themselves being able to make the decision to die.

But what if the suffering that is taking place is caused by loss of cognitive functioning? In this case euthanasia is no longer an option.

I am wondering if there is a way that we could design a decision making support system to help plan a good death for dementia patients.

What if the next step of the ‘quantified self’ is the ‘qualified self’?

- Could we design a system to help assess (personal) life quality?
- Could this system help patients as well as professional and non-professional carers make life-and-death decisions?

What if we can set and measure our own parameters that define our personal quality of life? Could we base life-and-death decisions on these parameters being met?

This idea was then expanded upon by Jim Rosenberg, an IDEO Community Activator, here follows an edited version of his idea:

This concept is for any individual. It reimagines the end of life as something that we are aware of each day as we live, using approaches from the quantified self to help you set values-based goals and track the values-based and emotional health of your choices day by day.

It’s easy to lose the forest of life for the trees of living. Bills to pay, dripping sinks to fix, dinner to cook, startups to invent, kids to get to bed, and on and on. How can we stay more aware of the big picture of life as we are living? How can we better follow our deepest values each day, as though we were truly present with the fact that we are all impermanent and life will end?

The Quantified Impermanent Self (QIS) extends the idea of wearables like FitBit to help us track our “path to the end of life.” Wearables and connected apps, like FitBit and Nike +, help you set goals, measure activity, and understand feedback so you can change your behaviors. Generally speaking they are focused on the physical and the well-prescribed: sports activity, posture, nutrition, medication regimes, and cognitive behavioral therapy interventions such as reducing alcohol use. The QIS uses the same model but measures how well your moment to moment choices fit your values and long-term desires for your life.

With the QIS app you would use a guided assessment to identify your values and set goals for the most important expressions of those values in life. This assessment would be based on existing work from psychology, spirituality, and research on the reflections of those at the end of life (such as the five things people say most often at the end). Then, rather than adding sensors to your body to track activity, heart rate, etc. the QIS would add sensors to your digital life — your email, social media feeds, calendar, etc. Perhaps it could even add sensors to your physical life by listening to your conversations or watching you via a smartphone or wearable. The QIS artificial intelligence / machine learning system would assess and provide feedback on how your daily decisions and use of time track to the values and expressions you hold most dear. At the end of the day you could look at how many moments you spent teaching, or discovering something new, or paying attention to your wife, or helping a neighbor — whichever expressions of a value-based life you defined in your assessment and goals. The QIS could take advantage of the best practices in wearables and behavior change. There could be a gamified interface for those who want challenges, levels, badges and the like. There could be social connectivity to share with your community or other people around the world working on expressing the same values in their lives. There could be periodic reflection and resetting of goals. And so on.
How does this reimagine the end of life experience? First, a life lived more fully from deep values and with awareness is a life that will allow for a much more peaceful and accepting end of life, for the person who is dying and for his or her community. Second, the QIS opens a space for talking about planning for the end of life and exploring questions about death and dying. It would be natural in the assessment and in periodic reviews to ask questions about mortality. How would you feel about your life today if you were to die now? How do you want to leave your family at the end of your life — are you doing the things that are most important to you to make that outcome happen? And the QIS could track preparations (e.g. life insurance, advance directive, conversation with your family about your plans, etc.) as part of its assessment of your behavior.

The language we use around death is a big part of the overall challenge. All of the language in this post — the Quantified Impermanent Self, the path to the end of life, etc. — is about the end of life experience and impermanence. For this post I wanted to be more explicit with the language. In practice I imagine we would talk about the tool and the experience differently to open the door to more people e.g. helping you “live to your values.” We could then ask questions that use awareness of death to help people make better decisions about life.

Another challenge is how we make a tool like this available and effective for the broadest community. It needs to be designed to add value to the lives of people in different economic situations, with different degrees of control over their work and how their days are spent, and who come from very different value systems.
“Memory is identity....You are what you have done; what you have done is in your memory; what you remember defines who you are; when you forget your life you cease to be, even before your death.”

Julian Barnes
Nothing to Be Frightened Of
Can not save file
Not enough memory

Restart Resume
Beyond Dementia
Working within the limitations of Dementia opens up new ways of thinking, borne out of necessity. Many people, designers and non-designers alike are coming up with solutions of dealing with this disease on a daily basis. I observed that (design) solutions often strive to an Ideal. They strive to achieve future situation that is better than the current one. This is a noble goal. However, often I see that this future perfect situation is within the mind of the designer. It is the vision of the one designing this ideal solution that decides the situation to be better. In the case of Alzheimer’s disease this would be to strive for a pre-disease situation. One where the patient retains their memories and has capabilities of a healthy person. This is an unattainable goal, and one, I strongly believe, does not actually improve the wellbeing of the patient.

In design education we try to avoid designer ego solutions with user studies, participatory design and other methods of generating empathy for the target audience. In the case of Alzheimer’s disease these methods don’t work – as discussed at length at the DementiaLab event in Essen, September 2016. Patients with cognitive problems make bad participants. Successful design collaborations were in one-on-one situations. Patients responded well to the attention they received from the designers, they responded well to doing things together. The designers admitted that once the design was finished, the designed artefact was less successful than anticipated during the collaboration.

In relation to Dementia specific designing this leads me to two conclusions
1) Working together in the Here and Now with patients is a success.
2) Designing solutions / designed artifacts for Alzheimer patients is more successful in pleasing the designer and/or the carer

I think these conclusions can be scaled up and provide good ways of working outside of the realm of Dementia.

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**Designing for and in the Here and Now**

As I have been engaged with the subject matter of Dementia, I also became a parent to a gorgeous baby boy. It turned out my son has a developmental delay, he doesn’t communicate verbally. It is unclear why this is as yet, one preliminary diagnosis is that he would be on the Autism Spectrum. Bringing up my son has taught me many things, the primary one being patience. Patience to take things as they come. We may have many ideals and ideas on a potential future, but these don’t always play out. It is really important to make the best of what you have got. And what a wonderful thing we have got! Realising this and working within limitations has expanded my thinking enormously. My ideals aren’t shared by everybody. Some people are horrified by social situations. Some people forget who they are and where they have come from. Is it then important we force them to enjoy social engagements? Is it important that people know their past? What if we make the situation we share the best possible situation it can be? What if we make the situation equal, where we, the designers, and the people we design for, play equal parts, where we can learn from each other?

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**Integrated designers in Industry**

Trying to scale up this thinking, “designing for and in the here and now to improve a given situation”, leads me to believe that the role of designers should structurally change. Traditionally a designer gets hired for a set problem, fixes it, and leaves. I feel this no longer applies. Problems evolve, situations evolve and sadly designers aren’t going to be able to come in and fix stuff far into the future. Designers should be part of any team, to continually assess, evolve and provide solutions that can be flexible. One case study I continually refer to is that of a friend of mine, Chris Gruijters: he is a designer embedded in a Dutch correctional facility. He has intimate knowledge of the prison system, in a Patricia Moore empathetic design style he has been a prisoner, a guard, and now he is a full time design employee in the prison. Embedded in the system he provides solutions for communication, transportation, furniture and more.
Images

Images not credited belong to the author. Other images used, in order of appearance:

Getty Images, Alzheimer’s, a form of dementia in which protein fragments called amyloid clump together in plaques that damage brain tissue

www.loadingdocs.net/gina/

Notes everywhere

Anish Kapoor, Descension
www.designboom.com

TUe, MA Industrial Design, “Transformative Homes for Sensuous Dementia” part of the “Design for Social Innovation” course.

For the time being: Jeroen Ablas, Joch Jansz, Manon Junggeburt, Mantas Palaima, Veerle Wijshoff

Orchestra of Senses:
Anqi Li, Fabienne van Leiden, Manon Barendse, Martijn Lammers, Wouter Wal

The Richness of Tea: Charlotte vd Sommen, Dominique Fürst, Martijn Imhoff, Pepijn Schnitzeler, Xihao Hu

Warm Place: Jacqueline Nanne, Joanne Pek, Lezhi Su, Sylvie Claes

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Site of Reversible destiny

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