

1. Opinions



Old age, dependency and mobility

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Yann Castanier

For the release of the book “Je vous regarde disparaître” [I'm Watching You Disappear], which chronicles fifteen years of my grandparents' life affected by Alzheimer's disease, the Mobile Lives Forum asked me to talk about the mobility struggles that my family encountered in the face of old age.

It is more than just a personal journey. This has become a story shared by many. Faced with an aging population, families experience these intimate moments that become wider public issues. It is important to understand how we adapt to the different stages through which our loved ones go as they near the end of their lives. It is also important to highlight the challenges and sometimes the missing solutions to problems that at first may seem solely logistical but which inevitably impact the quality of family life.

While it is possible to study a subject through statistics, a personal story brings the human element to the forefront, reminding us of emotional considerations that lie beyond the technical ones.

As soon as we lose our independence, the space around us contracts. This shrinking of the environment can be gradual or abrupt, a slow slide towards less autonomy or a sudden transition into disability. My grandfather's decline was slow, my grandmother's rapid. In both cases, their whole lives had to be readjusted. Being together was no longer a given. New ways of living together had to be found and there were many obstacles. At each step of the way into the depths of old age, new pitfalls arose that had to be managed, to the point where seeing each other was no longer easy.

Together, in the same place

Grandpa stayed “at home” with Grandma for a long time. He lived in Pau, in a fairly spacious house, with a garden that he took care of. He was active, pruning trees, mowing the lawn, tinkering in his two garages, doing the shopping. My grandparents used to ride their bicycles around where they lived and they would drive their car when they came to see us in Sète for the holidays. Then the disease came. Everyday life took a hit.

At first, it was little things - feeling disoriented, losing objects - but they could still get around independently. Grandpa still went shopping at the mall by himself. But then, on a few occasions, he couldn't find his way home. My grandmother had never had a driver's license – it was different for their generation - so she had to go with him. That's how dependence began: she had to be there for everyday tasks.

One day, as Grandpa was driving us home from doing the shopping, my sister and I in the back seat, we heard a loud cry from Grandma: “Roger!”. The car was shaking, its wheels rolling on dirt and gravel. My grandfather had taken a wrong turn and suddenly entered a construction site that he didn't recognise. Driving had become dangerous for him and for others. A request to remove his license was filed at the local authority. Grandpa and Grandma became carless.

Their habits changed. My grandmother started walking to the local convenience store to do the shopping with a shopping trolley. Or she would take a taxi to the mall. This taxi would become central to her life. Meanwhile, Grandpa gradually lost his autonomy. His footsteps got slower, like whispers on the ground, and so the places we could take him became fewer. Space continued to contract.

But, tirelessly, Grandma accompanied him, including on vacation to Sète, to see my family. One day, at the beach, Grandma stepped away for a moment from their towels and when she came back, Grandpa was gone, vanished. We looked for him for a long time, until eventually we called the police to report him missing. He was found at 9 pm in swim shorts and a shirt, holding a pack of peaches even though he had no money. We never found out what happened. He didn't remember a thing.

After that episode, Grandma didn't let Grandpa out of her sight. She always brought him with us to activities, like going to the cinema even though he couldn't remember the movie by the time it was over. Even walking at such a slow pace became difficult. And so the space around him contracted even more, confining him to the house. It was exhausting. Going down steps from the bedroom to the living room, small shuffles to get from the kitchen to the living room, getting him out of bed when he couldn't manage this independently anymore. They were locked inside. Grandma couldn't manage anymore.

Together, out of sight

Grandpa went to a nursing home. By now his disease had progressed so much that I'm not even sure he noticed the change. This time, space expanded. Distance settled in. The Morlaas nursing home was seventeen kilometres from my grandparents' home. Grandma, married but now home alone, “without a license” and “without a car”, took the taxi to see my Grandpa. At first, she went there once or twice a week, so often that the taxi driver sometimes declined payment when he took her shopping or came to pick me up at the train station. The cost of seeing each other became a real issue. But there was also fatigue, and the visits became fewer and farther between. Distance became time. In the last few months, she only went to see him every ten days.



At the nursing home, Grandpa lost the ability to walk. He was taken out to the park in a wheelchair. At first, Grandma could push him, but as she got older, she lost the strength needed for these little excursions. I continued taking him out as much as possible when I visited. But Grandpa's space eventually shrunk even more, to only a few corridors. He passed away in 2010.

Alone at home

Grandma lived alone in Pau for five years. Without a driving license, and given her dwindling ability to walk, her life became confined to four streets: that of her home, the cemetery where Grandpa was buried, opposite the house, the supermarket at the end of the neighbourhood and the bank facing the supermarket. Grandma had long since stopped cycling to the shop, but now she stopped pulling her shopping trolley and instead pushed an empty wheelchair where she could put the groceries as well as sit down. Sometimes she still called the taxi to go to the supermarket. She remained independent like this for five years, but she didn't come to see us in the South anymore. Taking the train was too complicated and too strenuous. So we would go and see Grandma. We were lucky to be able to drive and have the resources to travel regularly.

Then Grandma fell for the first time. Luckily, caring neighbours found her. It wasn't particularly serious. She was able to return home. The whole neighbourhood started watching out for her, making up for our geographical distance. They did bits of shopping for her, such as buying an electric stove after there was a gas accident and the firefighters came. Then Grandma fell a second time. It was more serious.

She fractured her hip and her wrist. She was never able to walk again. She had to use a wheelchair and was under constant supervision, 24/7. She was put in a convalescent care home, but the doctors diagnosed her with frontotemporal dementia, a disease similar to Alzheimer's. It became clear that she would have to be put into a retirement home permanently. But we could not leave her alone, 420 kilometres from my mother's home. We had to bring her closer to Sète and therefore move her away from her own home. Distance. Separation. Heartbreak.

In a nursing home, far from home

Her house had to be sold and emptied. We had to get organised. Nobody lived in Pau anymore. The real estate agency, the notary, the moving truck. The banalities of liquidating a life are nonetheless violent. Grandma entered a nursing home in Frontignan, where her family had fled the war. Coincidentally, she spent her remaining days opposite the school where she spent part of her childhood. But this didn't make it any sweeter for her. She kept complaining, saying that she wanted to go home. Losing her territorial roots added to her confusion. As she became completely dependent and suffering from dementia, my mother was still able to see her two or three times a week, which helped to maintain links. She recognised her until she died, but she gradually forgot who I was.





At first, my mom was able to get her in the car and transfer her to the wheelchair. Then, that also became impossible. Outings were then organised by the Group for the Integration of Physically Handicapped People (GIHP, Groupement pour l'Insertion des personnes Handicapés Physiques). With their adapted vans, this association picks up people at the nursing home and takes them to medical appointments, to see their families or simply for a trip out. All you need to do is book the service over the phone and the service is free. This made travel much easier for my mother who did not have a car that was adapted to my grandmother's wheelchair. We used this service up until her final Christmas, shortly before her passing.

Then Grandma also passed away. The distance between where she died and the cemetery led to a ceremony in two stages: first a cremation in Sète and then a burial alongside Grandpa in Pau. I was unable to attend this funeral, which took place a week later, as I had returned to work. The distance. Always. Between us.

This story, both in this leaflet and in the book you have in your hands, is far from unique. In just a few pages, it is a summary of what thousands of families go through. Maintaining links with the elderly is essential and this means giving them as much autonomy as possible, for as long as possible, being able to see them regularly, accompanying them on outings and then visiting them in their nursing homes. Mobility services make it possible to maintain a family bond that is essential to support old age.

The book: *Je vous regarde disparaître*, Par Yann Castanier, Revelatœur, 2023.

Personnal website of Yann Castanier <https://yanncastanier.com/reportages/papy-mamie-et-alzheimer-2/>

Mobility

For the Mobile Lives Forum, mobility is understood as the process of how individuals travel across distances in order to deploy through time and space the activities that make up their lifestyles. These travel practices are embedded in socio-technical systems, produced by transport and communication industries and techniques, and by normative discourses on these practices, with considerable social, environmental and spatial impacts.

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