

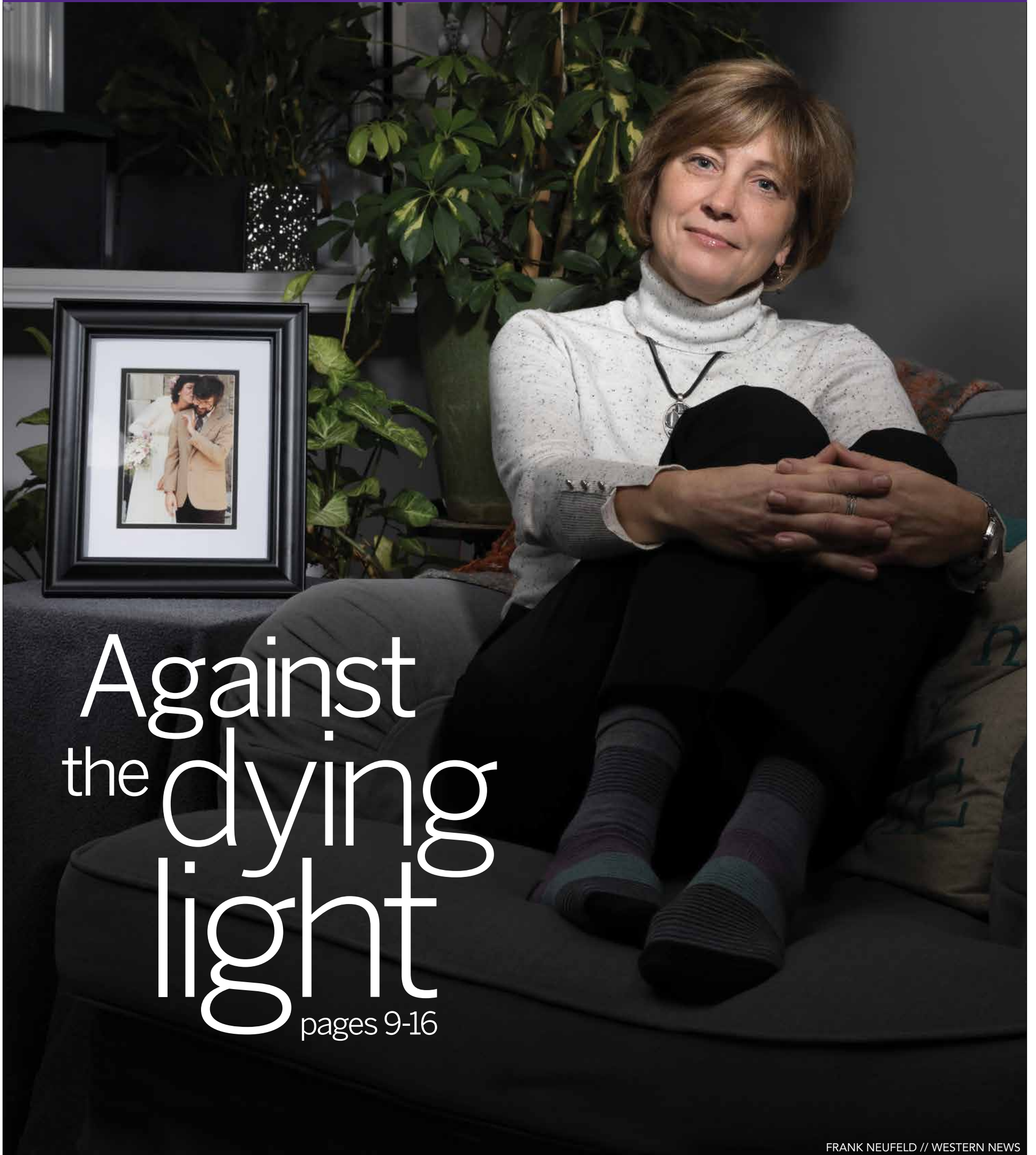
# WESTERN NEWS

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## Against the dying light

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# Louise lost the love of her life to Alzheimer's.

She's still fighting – and so are we.



BY JASON WINDERS

Death was a relief. Louise knows people have a hard time saying that. But it is the unspoken feeling that hangs in a room when two or more caregivers of Alzheimer's patients gather. We're not wired to admit to others we think that way. But when Gord's journey came to an end, after seven years, it was a relief - for Louise, for her family, for friends and colleagues and, most importantly, for Gord.

Finally, it was over. Gord, a University of Guelph professor, stopped eating in mid-May. Louise, a Western Biology professor, knew it wouldn't be much longer. On June 1, she remained at his long-term care bedside until late evening. After a call from her daughter checking on her whereabouts, Louise headed home for the night. She had been there only a few hours when the call came. Gord had died.

Still only months removed from that day, people ask if she is grieving terribly. She smiles politely and wonders how you explain to them you have been grieving for seven years.

There is a whole side of Alzheimer's nobody wants to talk about. Louise saw it, lived it. And is it ugly. But she has embraced telling her family's story to the world. "Until we talk about that side, people who are faced with a diagnosis, or their caregivers, seem to think 'Oh, well, they'll just start to forget.' No. It is way more," she said.

It has been hard not to let this journey define her. However, she developed inner strengths she didn't know she had. It has been empowering in many ways, enlightening in others, and profoundly sad. To see a brilliant mind in his prime chiseled down slowly - every day a loss - was the most painful thing she has ever endured.

Soon after Gord's death, the family held a celebration of life at the Jet Aircraft Museum in London. It was a perfect place.

Born in Saskatoon, Gord spent his early years in London while his father attended Western. The family eventually settled in Lethbridge, Alta., where Gord was a member of the local Air Cadet squadron. After earning his Honours BSc in Zoology in 1968 from Western, he spent four years in the Canadian Air Force.

Those who gathered for his celebration shared numerous stories, tears and laughs. Louise is still proud of both their girls, who wanted to take part. It was difficult. But how could it not be? Not only had they just lost their Dad, but they had been losing him for some time, during their most formative years. Emily, 21, stood up and told stories about her father. Annie, 16, spoke a bit, but wanted to play her ukulele and sing. Mom knew she could get through it. These kids loved theatre; performance offered them solace. And their Dad did so love watching them on stage - what harm in one more performance for him? Can you imagine the tears when Annie strummed and sang *I Will Follow You Into the Dark*?

**Some of the things she saw she'll never forget.** You repeat a mantra in Alzheimer's caregiver classes: It's not the person; it's the disease. It's not the person; it's the disease. It's not the person; it's the disease. But that is hard to keep in mind because there they are - the person you have known for nearly a lifetime, right in front of you, doing things you could not imagine them doing.

Louise kept Gord as socially active for as long as possible. Often he would just sit among the crowd. But he was out. Occasionally, his manners went out the window and created awkward moments - that was part of it.

Then isolation came. Friends disappeared. Louise knows it was fear of what Gord might do. Or fear of seeing a man their age struggling with the disease. But she is still disappointed.

Today, Louise credits the staff of Harris House and McGarrell Place for the kind, compassionate care they provided for Gord. She also recognizes the support of the Aging Brain Clinic at Parkwood Institute and the Alzheimer Society of London & Middlesex. That village it takes to raise a child also

helps a lot at life's end.

In January 2013, Gord moved into assisted living. Louise could no longer manage. The disease progressed. His behaviour became more and more of an issue. He wandered. He became confused. Even faced a bout or two of violence. No idea why. Strange damn disease.

In July 2013, Gord moved into long-term care. He was unusual there - young, no medications, otherwise healthy. Louise visited daily. The Girls had trouble seeing him in that state - they didn't know if that person in the chair was their Dad or not. Mom gave them permission not to. It was so hard to explain to adults. What do you say to kids?

Gord always knew Louise. He may not have said 'Louise' or 'my wife.' But he knew they were connected. He hugged. Took her hand. Relaxed as much as he could. She made the handyman in her life what she called a "toddler board" to tinker with - chains to slide, locks to click, plugs to connect, doors to open and close. He always loved tinkering. That board gave him joy now.

She doesn't remember the last fully coherent conversation they had. Maybe that is best. She does remember little things, moments in time. But life moved too quickly after the diagnosis.

She cannot help but think they could have known sooner. Maybe had a bit more time to make memories. When Gord's medical records were transferred from his family doctor to the Aging Brain Clinic, Louise discovered there were some signs of atrophy years earlier in that CAT scan after the car crash. Part of Louise wonders if he hid that information because he didn't want her to worry - or he didn't want to face what was to come. What are we going to tell The Girls?

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**Their daughters were 14 and 9 when their father was diagnosed.** Gord and Louise had stopped for coffee on the way back from the doctor where they had received the news. Louise was shaking - she needed a break. And Gord was done driving. He spoke first.

"What do you think? This isn't good."

"No, you're right. This isn't good."

"Do you think it's Alzheimer's?"

"Well, the doctor didn't say, but I am guessing so. We'll have to go to the family doctor for a diagnosis."

Gord paused. Louise remembers that moment - remembers his look - vividly. "This is going to be so hard for you, Emily and Annie. You need to do the right things, make the right decisions to move forward in life."

To this day, Louise thanks him for those words. It was the kindest, most generous thing he had ever done - and to have done it facing his darkest hour is incomprehensible. When it came time to make tough decisions - how to manage the family, when to move him into care - there was no guilt. Louise knew she had his permission.

Both knew what was coming. It wouldn't be pretty. The symptoms of Alzheimer's disease worsen over time, although the rate at which the disease progresses varies. On average, a person with Alzheimer's lives four to eight years after diagnosis, but can live as long as 20 years, depending on other factors.

Once diagnosed, a person may function independently. He or she may still drive, work and be part of social activities. Despite this, the person may feel as if he or she is having memory lapses, such as forgetting familiar words or the location of everyday objects.

Looking back, Gord ticked off almost all the common difficulties signaling Alzheimer's:

- Problems coming up with the right word or name;
- Trouble remembering names when introduced to new people;
- Challenges performing tasks in social or work settings;
- Forgetting material that one has just read; or
- Increasing trouble with planning or organizing.



LOUISE // CONTINUED FROM PAGE 11

Gord didn't want The Girls to know right away. A pre-teen and teen were already dealing with a lot; Dad didn't want to further burden them. "When the time comes, I'll tell them," he said. Problem was, when the time came, he couldn't tell them.

Soon after the diagnosis, he stepped away from work. It was like a weight had been lifted. A little of his "old self" surfaced in that moment. Relief. He didn't even want to clean out his office. Louise headed in and took care of it for him. She discovered an office impeccably ordered. An organized man already, this was next level – even the paper clips were lined up as straight as soldiers during inspection.

"Jeez, Gord, your office was really organized."

"Doing that was easier than working."

Ever the scientist, Gord remained so until the end. He embraced clinical trials, even left his brain behind for others to understand.

Louise quietly let those closest to him know. Family. Friends. His grad students. His colleagues at the Great Lakes Fisheries Commission. She didn't want his legacy to be seen through the lens of his last few years.

Louise cared for Gord at home, along with working and raising the family. It was all so much.

If your family is starting this journey, Louise wants you to understand one thing – you cannot do it alone. The journey can be lonely, exhausting. People think "I have to be the one. I promised them I would take care of them." Societal pressure will say you need to keep the patient at home for as long as possible – but for whom, Louise asks. Guilt and pride get in the way of everything – especially logic.

As soon as you get that diagnosis, reach out for help. If you don't have family, find other ways. It's too big for anyone, Louise stresses.

When Gord was first diagnosed, the first question out of people's mouth was always, "Does he know who you are?" Louise laughs at that today. If only that was the only thing he didn't know.

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**In 2008, Gord and Louise were heading to the airport to catch a flight.** Gord had forgotten his passport in his office. As the couple headed to Guelph to pick it up, their car sideswiped a FedEx truck just down the street from their London home. Louise has no memory of the incident to this day. Gord, who was driving at the time of the crash, was shaken – he had no idea why he would have made that turn, at that time, in that way. It was a complete lack of judgment that came from nowhere.

Always mindful his mother had dementia, he visited his family doctor. Luckily, he told Louise, the doctor said his memory tests were fine, as was a CAT scan they performed on him.

Beyond the crash, there were other incidents. Today, Louise seamlessly links them together to paint the picture of a man in slow decline. But, in the moment, nobody was connecting them. Why would they? With Gord only in his early 60s, Louise wasn't thinking Alzheimer's. That was an old-person's disease. He was a man of the mind, still active physically, socially, intellectually.

But today, she can list off the moments.

First thing he lost was words. Couldn't find them. It was maddening – "you know, the guy who flies the plane. You know what he's called."

Louise remembers hanging shelves in their home and can still see Gord, always a handy guy, holding an anchor and a screw, unable to process what each one did. "These aren't going to work. We can't use these," he told her. He was trying to put the anchor into the screw. She found it "weird."

Then work started stressing him out. Every spring, for 30 years, Gord took his lab team into the field to work. But one spring, he was anxious about it. "This is all so complicated," he told Louise. He started spending hours and hours labouring over lectures he had given for years – ones where a quick glance at his yellowed notes would have more than sufficed. He canceled lectures for odd reasons, like a conflicting appointment he made to put his snow tires on.

Gord was not the absent-minded professor type. This was all so not him.

His department chair began to notice, as well. She was kind and compassionate about raising the issues, but as student complaints about Gord's clarity and repetitiveness mounted, she finally brought the issue up. "My chair is concerned about my driving. She wants me to go see a doctor because of my driving," he finally told Louise.

The couple went to the workplace occupational



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safety doctor – his chair had sent along a list of concerns. They were raw, honest. Gord read them. "Yeah. A bit harsh, but probably true," he said. He was flat. No emotion. This reaction didn't surprise Louise. Always a fighter for his point of view, Gord had grown more and more apathetic. And then the appointment progressed – and the couple's life changed forever.

Gord couldn't spell 'world' backwards.

Or subtract seven from 100.

Or draw a clock face that read 10 minutes 'til 2.

That clock face. It still gets Louise. That was the moment it all became clear.

"Oh my god."

•••

**Nobody was paying attention when they met.**

Louise Milligan was a McMaster University undergrad working in a Biology lab. She was young, nervous and afraid to make a mistake. She worked on a project alongside David Gordon McDonald – known to most as Gord – who was a postdoctoral scholar in that same lab.

When they met, Gord had already spent four years in the Canadian Air Force, then earned his masters and PhD in Biology from the University of Calgary. He was 13 years older than Louise. But that didn't matter – she was drawn to his sense of humour, his kindness. Together, they were the smartest people in most rooms.

Gord was eventually hired by the Department of Biology at McMaster as an Assistant Professor in 1980. By then, Louise was a PhD student. They continued dating and married in 1983, settling first in Dundas, Ont., then Paris, Ont., and, finally, in London, Ont., in 2002.

As a professor and a student working in the same lab, they were discreet with their relationship, even after they married. So much so, they had been married two or three years before the professor in the office next to Gord's asked if the two of them were "dating or something."

Their careers grew, almost in parallel.

In 2002, Gord left McMaster to take up a position at the University of Guelph, as professor, in the Partnership for Ecosystem Research and Management program, joint with the Great Lakes Fisheries Commission. He focused his energies on developing lamprey management strategies in an effort to protect the Great Lakes fisheries. He was passionate about teaching and research. He was happiest when tinkering in the lab, helping students design and build various pieces of equipment to measure everything from lamprey swimming behaviour to the blood chemistry of blue mussels.

In 1988, Louise joined the former department of Zoology (now Biology) at Western. She worked with and trained dozens of talented undergraduate students and taught courses ranging from first-year Biology, to second-year Animal Physiology, to fourth-year seminars, as well as Political Biology, Marine Biology field courses and thesis courses. Since 2006, she has taken on more of an administrative role as Associate Dean (Administration) for the Faculty of Science. She enjoys that role as it offers opportunities to engage with the many talented colleagues in Science and across the university.

In life, as in work, Louise says she lucked out. The couple had a lot of common interests. When they went on joint sabbatical, they spent 24/7 together. It would not be every couple's idea of perfection. But for Gord and Louise, it was. They worked all day in the lab together, then went back to their apartment in the evening where they bounced ideas or untangled problems. They traveled. They lived life.

It was 14 years before they had their first child, Emily. Gord was a father at 50. He was not sure about fatherhood at such an advanced age. But he loved every minute. A few years later, they had a second daughter, Annie.

He took great pleasure in watching The Girls' soccer games, Original Kids Theatre performances and engaging them in lively discussions around the dinner table. Everything was fair game starting when The Girls were little – reviewing what happened in everyone's day, then advancing to bigger issues as they matured, like books, movies, politics, and school, especially their science classes where Gord couldn't help himself from correcting their teachers. And bedtime stories – that was Gord's time to perform.

By such wonderful chance, Louise and Gord had found a true partnership in work and life.

A lifetime of memories awaited them. ❧

# Five memories and a funeral

BY JUAN LUIS SUÁREZ

**First Memory: He Knows First**

I am on the phone (or was it Skype?) with him and I am longing for the words of acknowledgement and the praise, also for the soft criticism that my father used with each of my publications. They were part of a ritual in which he would receive the book, read it, comment it with his friends at the tapas bar before lunch, show it off at his cultural association in the afternoon, and share it with my already retired high school teachers and mentors. It was a ritual of old age, of small towns and rural regions, a ritual of living through your children those things that you will never experience yourself.

This time there was no comment, no commendation, no criticism. There was no reading. I am not able to concentrate and I need to read a page several times to barely grasp what I read, and then I forget it all. Said the man described by his friends as the person with the most extraordinary memory they ever met. He knew something was wrong.



SUÁREZ

**Second Memory: The Living Room**

Dad is doing just fine. Most of the time he keeps me company in the living room, says mom. And what does he do there? He watches TV!

My father never watched TV in his life. He didn't like it, unless they were giving a classic Hollywood movie "from his youth." He would spend most of the time in his library, reading, listening to music, organizing the world, later learning to use the Internet. He would go to the living room for meals and family meetings. Not even soccer fancied his interest.

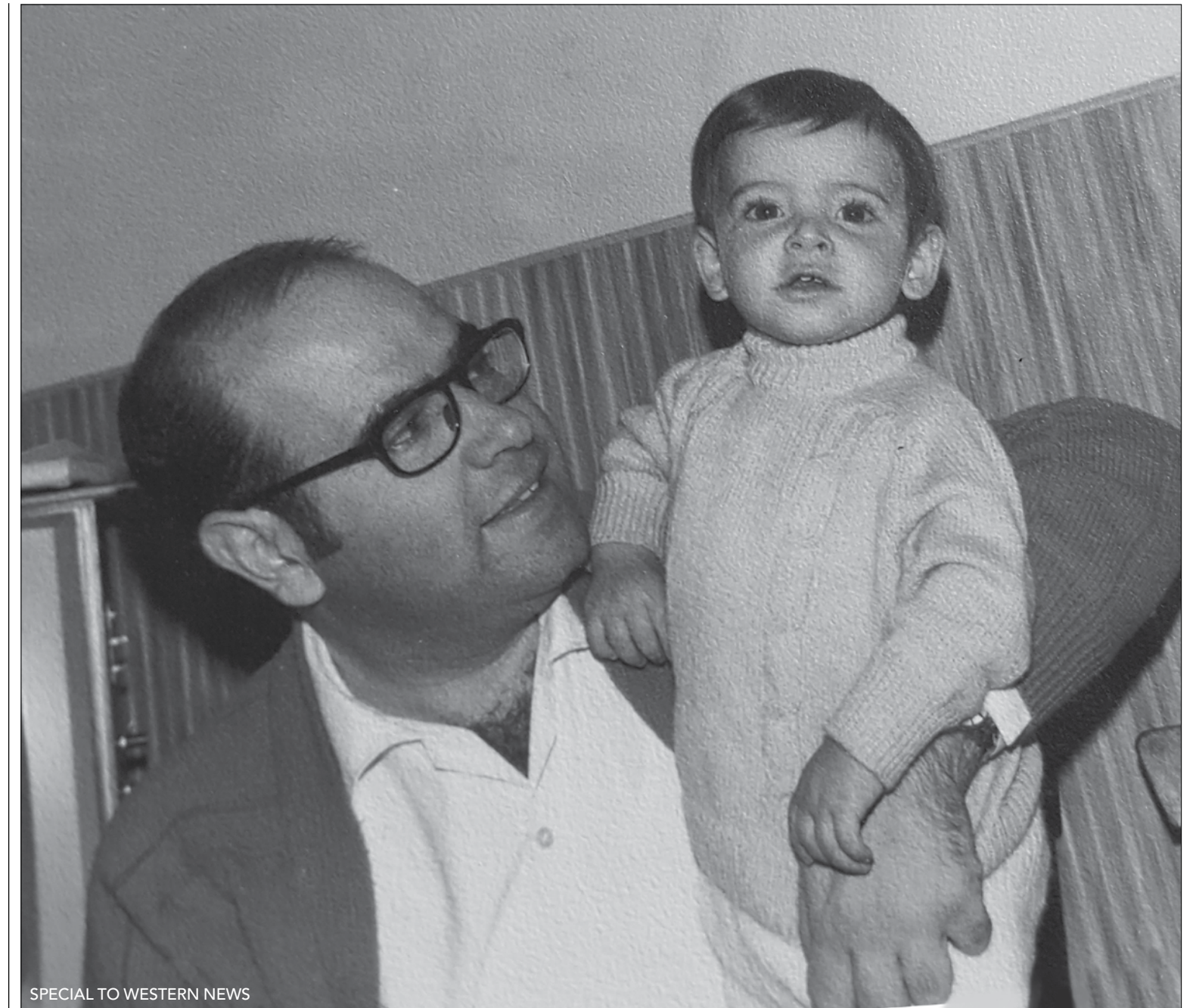
There was a period at the beginning of his illness that he was aware of the process he was undergoing. He was aware that he was losing his memory and all control over his own life, over the small habits and routines that one spends his own life building up.

He became scared. This is one of the worst things of the illness, the fear that it instills in the person that suffers it, in their family and friends. No matter how old you are, seeing fear in your dad's eyes produces an inextricable pain in your soul. That fear will come back later.

**Third Memory: A Patient**

Dad has turned into a patient. This is a relief for the family. The mode changes and now the goal is to look after him. There is sense of mission, although they don't realize how hard this mission will be. A young therapist comes home a few times a week and they do writing and math exercises. He has become docile.

He has been officially diagnosed with this or the other. The family doctor seems to have limited knowledge on the subject and it is not clear when one disease ends and the other starts. The psychiatrist seems to know a bit



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more and at least she is able to regulate the medications to prevent the outbursts.

The truce has not lasted. I am told that he easily becomes agitated, irascible, violent against objects and obstacles. He does not sleep steady and he doesn't others sleep either. Mom and daughter are worried that he will flee the home, so they don't sleep, don't rest, and even worse, they don't know what to do. In spite of the intense love and care, they feel guilty. They are exhausted. Is there a humane way to treat a loved one who is disappearing in front of you?

**Fourth Memory: The residence**

An afternoon, mom answers the phone. The owner of the repair garage calls to say that dad has walked out the five kilometres to his place and has started yelling at him, accusing the man of stealing his car: Where is it? Where did you hide it? Give it back! At that point, his car has been parked for several months as he is not fit to drive anymore. The garage owner knew about my dad's illness (good thing about small places) and he was telling my mom not to worry, and just pick him up.

The episodes of rage, at home and on the street, become more frequent. He tries to escape home, he spends all the money he has in anything he sees, he gets lost. Sometimes he comes back. One day that I was visiting we took a stroll. A man walks by and says "Hi," and I take the opportunity to ask dad who the man is. He is not able to produce the name, but in his now deficient speech he tells me all his background. I feel some hope. I am wrong.

The situation is not bearable anymore and the family decides that he needs to go to a residence. There are no openings in town and the closest one is located in a village 20 km away. Mom is old and she doesn't drive anymore; my sister and my brother work. My younger brother and I live away; we have an excuse. But them: How many times a week should they visit? For how long? Should they feel relieved or guilty? Fear and pain have definitely transferred to the family.

The first time I visit I feel it: the residence is ... a residence.

**Fifth Memory. Welcoming and farewell**

When will I go back home? Dad

barely speaks anymore, but when he does he only asks one question. He wants to go back home. We lie to him every single time. As soon as you get a bit better with the new treatment. He will not improve.

He is a child now. We lie to him, although I suspect that he realizes. He recognizes mom and all of us, he recognizes his grandchildren, but not other close people. He communicates through his eyes, although they are losing their brightness. He does not move well and is extremely thin.

When visit times come to an end, he does not want to go back into the closed quarters of the patients. Family members cannot cross those doors unless they have a special permit. The pain arises every single time when he stops at the doors, looks back to us and seems to say: I don't want to be here, why don't you take me home? I cannot stand his eyes. I cannot say goodbye.

For 20 years, since the first time I left for university, no matter the time of day or night, dad would drive me to the station, we would have a coffee together and he would stand on the platform to say goodbye until the bus were out of sight. Every time

seems liked it could be the last. When I returned for sporadic visits, he was always there, waiting on the platform as though he never left. Now he is the one leaving through those doors.

**A Funeral**

It is late in a fall afternoon and I feel happy. I am working with my students in my new lab. The cell phone rings, I get out and very quietly I hear my sister saying it. Dad has passed away. ("Papá ha fallecido.") She does not say "died." She uses the formal and artificial "fallecer" because fathers don't die – they just can't. Or we cannot afford that they do.

They want to go through the funeral fast so I will not be able to make it in time. I just know that he will not be waiting at the station.

The narrator of *One Hundred Years of Solitude* says that a good old age is but the result of an honest deal with one's own loneliness. Seeing the way my father went I wonder: Will time remember its end of the deal? ❧

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