Jo Failer

I Don‘t Think So: A Living Legacy

(OT: Ich denk nicht dran. Ein Vermächtnis zu Lebzeiten)

Sample Translation by Anette Pollner

PROLOGUE

I stood in the supermarket, staring at a pineapple. It wasn’t particularly ripe nor particularly beautiful. And it smelled like a tropical garbage bin at the end of the night shift. But it had attitude. While I was forgetting what I wanted, it sat there – upright, spiky, fully up to speed. A passing child looked up at me and said, loudly enough so I could hear it, and the elderly lady by the tomatoes could hear I, too: ‘Mummy, the man is talking to the fruit.’ The mother quickly dragged her child away, the elderly lady just lifted her head as if trying to check whether the fruit was talking back. Then she squeezed a tomato and the scene dissolved into vegetables and silence. Maybe I really did say something. Maybe: ‘You’re lucky. You don’t have to remember anything.’

Three metres along, the dairy aisle. A yogurt called Protein Dreams. Ingredients: milk, sugar, fruit preparation. I read it three times. In my head, it said: milk, air, the past. Trace elements of all that came before. I no longer knew what I needed. Even worse, I couldn’t make sense of anything here. Flickering thoughts. I only realised on the way back that I had scrunchies, window cleaner and vegan hemp chocolate in my basket. No dental floss. No plan. Just that feeling: I used to be someone who knew what he wanted.

Moments like this happen often. More and more often. The film is playing but you don't have a part in it. Maybe you used to be the main character. Or maybe you just were the props assistant. Doesn't matter. There's no script. And in the silence, the pineapple is looking at you.

I received my diagnosis at the age of fifty-one. Early-onset dementia.

Suddenly, a system malfunction popped up, in an impersonal tone: 'An error has occurred. Reset is hopeless.' A name that doesn't want to be recalled. A thought that turns a corner and disappears. A conversation that freezes mid-sentence. And in-between, a new kind of clarity. Raw. Unasked for. Like a mirror image looking at you before you are ready, whispering that your life is fading away.

My mind is not completely dark yet. Something is still going on. Sometimes it's a disco, sometimes a flickering light, sometimes the last remnants of a glow. Thoughts pop up like your exes at parties. Uninvited, shimmering, nervous and always just when the music is too loud.

Sometimes I'm sitting at the kitchen table, open my laptop and stare at the word 'Tuesday'. It's right there, at the top of my calendar, as if it knows more than I do. Maybe today is Monday. Maybe I was just brushing my teeth. Maybe I'm already late for something I forgot. The coffee is steaming, the lunch boxes are packed, someone calls 'Daddy!' and I'm alive. But my thoughts act like bad Wi-Fi, sometimes here, sometimes there, sometimes dialling the wrong number. Still, life is going on, right here at the kitchen table, among the Lego bricks and the password query.

This book is for everyone. For those who are directly affected, for their relatives, their friends, for strangers – and for those who used to think that Alzheimer's was a TV commercial for memory games. This book doesn't stick plaster on the wounds. It rips them off. Because this condition can’t be cured with lotus positions, green smoothies or curative claims from the drip chamber. There is no medical fairy dust. Alzheimer’s is not a drama with a happy end. It is a silent robbery inside your brain. That’s what I want to describe: how it feels when the annoying light bulb starts to flicker. When my mind goes quiet and my thoughts no longer jostle each other but are in chill-out mode. And sometimes, just sometimes, that’s almost outrageously wonderful. This new life is like chewing gum on the bottom of your shoe. It sticks, drags, bothers you and doesn’t go away by itself. I had to create my own project management strategy for this life. Rituals, structures, humour and a new world view.

And even the pineapple has its place. It is a silent symbol for my intention to preserve a certain lightness of being, as long as my brain will allow it. Sometimes the pineapple puts on sunglasses and kicks back, swinging its hips. Then I join it in the dance.

CHINESE WHISPERS

This is how it all began. Four or five years before my diagnosis. With interpretations. At first they said it was burnout, that trendy term for the exhausted. Too much travel, too many deadlines, too many nights with coffee as the pacesetter. My diary was full, my mind was empty. My life was structured by deadlines, not days. In airports, hotel rooms, production meetings. I was familiar with every breakfast buffet between Hamburg and Munich but not a single bird sound in the morning. Burnout sounded almost comforting, since it came with a programme. Fewer emails, more sleep, more breaks. So I travelled to Lake Tegernsee and occasionally deep into the mountains. Wellness retreats, candle light yoga, ginger water in bulbous glasses, a coach explaining in a warm voice that my diary was my worst enemy. I stood on my mat in the early morning mist, breathing in sync with soft flute tunes and thought: if my breath can heal me all by itself, why am I losing my words? Why am I looking for names like lost keys? Why do I need three attempts at one simple sentence?

Burnout, I learned, means ‘too much’ of everything. But what grew inside me was ‘too little’. A quiet retreat from mental functions I used to take for granted. I kept travelling into nature, I booked ‘time-outs’. People placed herbs on my forehead, murmured mantras, talked about internal balance. I nodded, breathed, counted. Everything was alright during the days I spent there. But it stopped the very next day. I bought a promise that everything would be normal again, like an insurance policy that never pays out.

Then the word ‘depression’ was introduced. No lifestyle label, no ginger. Harsh. Real. Eighteen weeks in-patient treatment at a clinic in the centre of Munich. Group meeting rooms with windows onto the lawn, conversations about feeling heavy, about exhaustion, about that hole in the middle of the day that swallows everything up. I was really down at that point and couldn’t see the light at the end of the tunnel for far too long. I only realised later that the doctors’ main task was to find the perfect antidepressants for me. And the consultant at the clinic succeeded. It was the only thing that helped me at the time.

Three years of antidepressants followed. They protected me and I could function again, at least outwardly. But in retrospect I know that it wasn’t the right treatment. At least not for me.

Because there was something that wouldn’t go away. A slight rattling, an internal aftershock. Like the shifting of tectonic plates underneath while the surface remained neat and well-ordered.

During that time, my son Linus said something that has stayed with me until today. We were sitting together, nothing special, a completely normal moment. And he said: ‘Daddy, I’ve never seen you cry. And you laugh very rarely.’ That broke my heart. He felt that something wasn’t quite right with me. He could sense my emotional armour. Because he was experiencing a father who was there and not there at the same time. I thought about it for a long time and eventually, in close consultation with my doctor, I decided to stop the antidepressants. Not irresponsibly. Not because I was rebelling against compliance. But because I wanted to feel my emotions again. Even at the risk that it would hurt. But what happened then was not relief. It was more like a gradual return of contours, of definition. Of tears. Of laughter. Of days that became tangible again. And the certainty that protection can sometimes help but at the expense of closeness.

My GPs, who I changed like wet nappies, called all this stress-related or psycho-vegetative. They used phrases like: ‘You’ve got to calm down, Mr Failer.’ Or: ‘That’s the ageing process, don’t worry.’ Many hear what you say but they’re not listening. Their eyes are glued to their monitors while their keyboards are clicking. Diagnosis by average. Then they print out a prescription or a referral for random medication or for conversations: ‘loss of focus’, ‘mental health issue’. No one says: ‘Maybe this is Alzheimer’s.’ You’re too young for that, too productive, too full of life.

The general public has a different view anyway. Alzheimer’s – in many people’s minds that’s a disease of forgetting, not of transformation. Old people. Blankets on their knees, the TV murmuring in the background. Not men with kids, projects, complicated love lives and a future. The picture is out of alignment, as if this disease has its fixed abode in the old people’s home, but not in the office.

I remember small, inconspicuous moments. Once at the supermarket checkout: ‘Your postcode, please.’ Five digits. Everyone knows them in their sleep, except me. Just a few seconds but long enough for the cashier to look at me with pity in her eyes. I could feel my hands trembling and my card slipping out of my fingers. It was nothing. And at the same time it was everything. Another time, in my job. A phone interview, meticulously prepared. I was talking to an oil millionaire from Texas about the myth of Porsche. The recording device was running, the voice on the other end was friendly, professional. My notes printed out neatly. And then – nothing. My first question had disappeared. Precisely worded and written down the day before, and now as if erased although it was there, in front of me, in black and white. I talked at random, improvised, delivered a story anyway. I was able to do that. But there was this cold spot inside me, whispering that something was missing. And this time, it wasn't just one word. So the search continued. I turned up in waiting rooms with magazines on heart health, joint pain and positive psychology. Nobody quite knew what they were looking for since the fog wasn't so dense yet. But I do remember one particular test. 'Memorise these three words: rose, ball, clock.' I repeated the words, nodded, smiled. Five minutes later I only remembered the clock. It was as if someone was wrapping my words in cotton wool inside my head before they disappeared. The doctor nodded, ticked a box, continued with his questions. I sensed that something was wrong, and also that he couldn't see it quite yet.

That was the beginning. And the first realisation: forgetting is not a condition, it's a process. Slow, precise, inexorable, like a hairline crack in the glass, barely visible but widening every day. No one named what was lurking between the tips for burnout and the treatment for depression. It wasn't just exhaustion and it wasn't just sadness. Words that escaped me. Appointments that fell out of my pocket. Routes that suddenly took a detour. I couldn't explain it at the time but I could feel that something was going on inside me that didn't fit into any mindfulness training. Looking back I recognise the outline of a shape. They called it burnout because I was working so much. They called it depression because my world was turning grey. But underneath, there was a disease that now has a name.

Later, when I was diagnosed, one sentence created a new pattern from all of it. 'Now you know why it was like that before.' Suddenly there was no either/or. What I had experienced, for years, as exhaustion, as darkness, as the constant running-up-against-limitations was no longer separate from the disease, it was part of it. I wasn't imagining it, it wasn't a personal failure. It was a slow sliding-off. My affect flattened, my energy became more sluggish. Decisions needed more effort than they should. What is instantly recognisable came a lot later. Words that just didn't come, thoughts that were slowing down. Small blackouts flaring up and dissipating again as if nothing had happened.

The experts say that affect and energy often change a long time before memory. I would put it a little differently. Something in the system no longer runs smoothly but there's no alarm yet. Only this niggling sense of something going wrong and nobody being able to say what.

FRIENDSHIP +

High summer in Munich. One of these days when the air itself seems tired. The sun hangs in the sky for far too long, the tarmac shimmers, everything is a little bit sticky. But in spite of that, I notice that there is movement. Not outside but inside me. After the time early on when it went very quiet around me, something seems to loosen up. Friends I haven't heard from for a long time contact me again. Only a few, but the right ones. Messages pop up. My phone rings, small signals arrive. Maybe because the word Alzheimer's has lost its first terror. Maybe because they now worry less about saying the wrong thing. Or because they've noticed that I'm still here. That I can answer. That I can laugh. That they can meet me without slipping into a different role. But maybe there's no special reason. Maybe it's just friendship.

Suddenly Dirk writes to me. 'We are here. If you would like to.' Nothing else is needed. A few days later we're sitting in a beer garden. Creaking benches, rustling chestnut trees, pork roast tasting, as always, a little bit of old times. Elke, Erich and Dirk, my old companions from Bodensee TV. People who remember the way I used to be before I started to lose myself. At the beginning, there's uproarious laughter. As in the past, when lightness of being was our standard mode. I can feel this slight burn behind my eyes, when you almost need to cry with joy. Then, in the middle of the meal, in the middle of a sentence, a quiet moment pops up. Elke looks at me. Not with curiosity, not with pity but properly, and asks: 'How are you really doing?' I tell her that I'm fighting but I'm also still laughing. That the blank gaps surprise me but don't defeat me. That I sometimes have go looking for myself but can still find myself. We don't have to dwell on it. A few honest words are enough. We wink at each other. We breathe.

As the afternoon fades away, Erich leans back, looks at me and says, calmly, almost casually: 'You have to write this down, man. Your life with Alzheimer's. People will be interested. It's important.'

At first he called me almost every day, then every week, asking after my writing. This book is the echo of that afternoon. I owe the inspiration to Erich. My former mentor during my first steps in TV. I told him then that one day I would host the national sports studio at ZDF TV. That was enough, he was convinced. Just as he was again that afternoon, convinced that this book had to exist.

But in my case, friendships of course also have their limitations, different from before. I’m just learning this. They don’t notice when my fridge is empty. They don’t see that appointments disappear and, on some days, my everyday routine collapses. Not because they’re not interested but because friendship can provide closeness, but not structure. It supports you emotionally but it doesn’t organise your life.

I’m meeting up with Daniel. We got know each other professionally because he also loves to tell stories. We haven’t known each other for long but we like each other a lot. It’s one of those relationships where you’re immediately on the same wavelength. We’re walking slowly through the English Garden Park in Munich. First he looks at the Monopteros temple, then he asks: ‘What’s it like, Alzheimer’s? I don’t have the faintest idea what that must feel like.’ I look at him and sense that he is serious, he really wants to know.

‘Imagine you’re taking a step because you want to go somewhere and as soon as you put one foot in front of the other, the reason for taking that step has disappeared. Thoughts break off. Plans evaporate between two movements. I’m just forgetting too much’, I say. Daniel shrugs. ‘I know what that’s like. I walk to the fridge, open it and then I don’t know any more what I wanted. Then I see the beer. And then I know it again.’ I laugh. ‘Cool’, I say. ‘Then you maybe have Alzheimer’s too.’ Pause. ‘Early stage’, I add. It’s a joke but with a small sting. Because he will remember again what he forgot. While I, sometimes, don’t.

A few days later I’m sitting with Sylvia in the cafe where they serve up that notorious chaos but also, according to my son, the ‘most wicked’ burgers. We’re sitting on a bench by the window. She’s a friend from my school days. I’ve always had a crush on her and even now our encounter is more than just a walk down memory lane. We’re laughing a lot, enjoying the moment.

‘Jo, I don’t really notice it at all’, she says, after the third latte. I chuckle and say: ‘Cool, then let’s swap for two weeks. You take my brain, I take yours. Then let’s talk about it again.’
Alzheimer’s happens inside you and in silence. It happens where no one can see it. I’m trying to explain that to her. And, by the way, she didn’t take me up on my swap offer. But even if it’s often difficult to explain to others what Alzheimer’s is like, these old friendships create something that isn’t possible elsewhere. They gift me a moment of light-heartedness, a moment when everything is back to the time when everything was easy. And maybe that’s why we keep meeting up.

Friends give me something deeper than everyday life. They give me identity, memory, humour. They know who I used to be, and they’re not terrified of the fact that I’m different now. I used to have many contacts, now I have connections. Honest. Direct. No more loops of politeness, no more surface maintenance. The people who stayed are truly interested in me. Not in a version of me but me. And that, of course, is also true the other way round.

The irony is that this is exactly the kind of progress I might well never have made without this disease. I’ve erased many contacts. Peoplewho I thought, for a long time, would be there when I needed them. My expectations. Hopeful but unfounded. If anything came from them, it was lack of understanding. Well-meaning phrases that hit all the wrong notes. ‘But you’re looking good.’ ‘It’s not that bad, really.’ Or the quick dismissive laughter when I get stuck.

I don’t hold it against them. Many just don’t know how to deal with something you can’t see. Or worse: many never tried to want to understand it.

The clean-up was painful but also liberating. We only claimed we were close. Those that remain are the ones that don’t make promises but are there. Not every day. But it’s enough.

Friendship + is friendship plus sticking around. Plus endurance. Plus honesty.

And then there's another kind of closeness that I wouldn't call friendship because it follows different rules but it is incredibly valuable. When you're meeting others with Alzheimer's', you sit together and listen. No one explains the disease, it's just part of the atmosphere. In the dementia support groups, it's not about the origin or the future, it's about the present. The here and now. About what's possible in this moment. Conversations take a different course. They're more direct, explicit, less decorated. Everyone is allowed to complain when they're feeling unwell. Things are allowed to be expressed without having to be immediately pinned down, mollified or dissolved. It creates a closeness that doesn't crop up very often outside. It doesn't replace friendship but it works. It offers relief. It takes away from the pressure to constantly keep up or translate yourself. No one asks how bad it is or how long you're still going to cope. No one says 'You'll be fine'. Maybe what's so special is that you're not being held here but you can let yourself be held. It's a familiar, reliable place. And I've befriended it.

I DON'T THINK SO

Two experiences with my children stay present in my mind all the time. I've already described them in this book. They are a kind of visual anticipation for when I'm losing my lightness of being in this serious condition. They don't explain or resolve anything. They only show me that I'm here. Now. In my life. My children are in my life. My children and me. It's the only thing that counts.

Linus came up from his bedroom. He stopped in front of me as I was drinking my cappuccino, looked at me and asked: 'Daddy, why do we have oat milk if there are no oat cows?' I didn't have an answer. Now I often think back to that question. It’s a symbol for something I could never imagine. To have Alzheimer’s. An absurd construct, suddenly inserted into the shelves of your life. It used to be a statistic, a headline, somebody’s else’s problem. Now it is suddenly your bar code. A thin pattern of black lines that identifies you under a scanner. As real as an invented herd of creatures that trample through your brain at night and leave traces that nobody can wipe away. And then there was Carlotta at our last shared family holiday on Lake Garda. I was sitting on a chair, half awake, half asleep. Carlotta stood next to me and painted a red heart onto my arm. Carefully. And waterproof, just in case. ‘So you’ll never forget me’, she said. That heart stays. Forever.

One word has had a special meaning for me for some time now: self-efficacy. It sounds a little esoteric, as if coming round the corner in sandals and with a flip chart, ready to start a workshop. For me however this weird bundle of a word is no longer a concept but a survival tool. A small Swiss Army knife for every day. Particularly when my mind looks like a removal box labelled ‘Caution – Empty’. I understand. I’m not what I’m losing but what I’m doing. That’s what I hold onto every morning. I am the only one who can get me out of this mess. When I wake up and my mind feels like an unfurnished flat, I could just stay in bed. Pull the blanket over my head. Mute my phone. Pause the world. But I do get up. I walk into the kitchen, switch on the coffee machine, listen to the hum of the grinder. Then I watch my espresso trickle into the cup, a thin, dark jet that agglomerates at the bottom into a small universe of crema. In this moment I think: I did that. I made something happen. It’s only coffee and at the same time it’s proof that I can still press buttons, that cause and effect haven’t completely decoupled yet in my life.

Something similar happens when I’m writing. Sometimes it’s just one sentence, sometimes it’s three, sometimes it’s one word that I’m scribbling on a piece of paper while the water is still running in the bathroom. Sometimes I read it the next day and don’t have the faintest recollection of when I wrote it. But I recognise myself in it.

This book doesn’t prove that you can stop Alzheimer’s. That would be nonsense. And I’m far too good at research to delude myself. This book proves that the disease doesn’t silence me. That I’m still the co-author of my own story. For myself. For my children. For everyone who wants to avoid a chair circle with herbal tea and prefers to live a genuine life.

But ‘I don’t think so’ also has a flipside. It’s the mean, quiet variant that has to do with forgetting. For me, the feeling is first, the loss comes later. A strange silence in my mind before I know what it swallowed up. Like a room that is suddenly too large. You notice the empty space before you see which chair is missing. And then I’m standing there, not necessarily lost, not dramatically confused, more as if someone briefly stopped the film and forgot to let me know. I know something is missing before I can name what it was. What is brutal, for me, is not the moment of forgetting but that tiny vibration just before, a sort of internal frost. No drama, no dizziness, just a brief rift in continuity. ‘Something is about to happen.’ And then it happens. I rarely lose the world but I’m increasingly losing my access to it. I’m right in the middle, quite lucid, and at the same time I know: right now a part of me is missing here.

In the past, I would have called this an existential crisis of meaning. But now I know that it is a neurodegenerative process that can’t be stopped. The medical profession calls it a memory disorder, a disorder of episodic recollection, the ability to retain new information. I call it ‘this damn hole my noun is disappearing into right now.’ It’s not that I suddenly don’t know any more where I live. It’s more as if my mind is increasingly removing the context. And yes, that’s brutal. Not for the statistics. For me. And this is exactly where the flipside of ‘I don’t think so’ starts. The side that doesn’t lose me but pulls me together. That tells me: you are more than the gaps. Reducing myself to the role of a patient whose life revolves around his health insurance number? I don’t think so. Making my disease the main character in my life while the rest disappears offstage? I don’t think so.

When I’m sitting at my kitchen table at night, when the wooden beams creak underneath me and the lamp above me throws a soft yellow light onto the table, my life sometimes feels like a prop. Used, misplaced, but still clearly part of the scene. The cup in front of me is half empty, its content is half cold but it is there. A small, mundane monument to the fact that I made it up to here. And then the thoughts suddenly arrive, uninvited. What if, one day, the names of my children disappear into this hole?

What if, one day, I listen to their voices like beautiful, foreign melodies? What if I, who used to have such a good memory, in both my professional and private life, will one day no longer be able to remember that I used to be the man who sat at the kitchen table and wrote about self-efficacy?

That’s the moment when I hold my breath. When it gets very still inside me. And I speak right into this silence. I say: ‘I don’t think so.’ At first my voice was very quiet, almost shy, as if I needed to get used to my own courage. Then a little more assertive. I don’t mean to say that I can magically make the future go away. I’m not crazy, I know where this disease usually ends up. I’ve read the studies, I’ve seen the progression charts, I’ve chewed the statistics like rubbery candy. ‘I don’t think so’ doesn’t mean ‘it won’t happen to me’. It means ‘I won’t let my time until then be stolen’. Viewing my days merely like drop-down menus: carefree, exhausting, overwhelming? I don’t think so. Letting go of my humour because it apparently doesn’t seem to fit a serious diagnosis? I don’t think so. I’ve worked on it for a long time. It stays.

There are moments when I lose track right in the middle of a sentence and can only see the face of the person in front of me. I would have covered that up before, made a joke, changed the subject. Today I just say: ‘Just a moment, my mind is recharging.’ My humour. It dissolves the tension, others exhale, so do I. And it is exactly in these kinds of micro-scenes that something happens, something not mentioned in the medical textbooks. I notice that the person in front of me doesn’t just see me as someone who is sick but as a person with a weird but functioning sharp-witted mind. That’s self-efficacy. The everyday version.

I’m thinking about my children. Their laughter, ringing through my flat as if it’s raining confetti. Their remarks like ‘Daddy, you’re sometimes like a phone running low on charge, but you’re still working.’ That hurts and comforts me at the same time. I love their honesty. It’s ruthless. It’s worth its weight in gold. When my daughter said she wanted to become a doctor ‘so that she can fix me’, it’s not an empty phrase. It’s her plan. I responded with ‘well hurry up then’ and hoped that these words would stay in my mind long enough so that we could laugh about it later. The laughter happened. So far, her plan has worked.