

THE OLD KING IN HIS EXILE

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When I was six, my grandfather stopped recognising me. He lived in the house down the hill from ours, and because I cut through his orchard on the way to school, occasionally he threw a piece of wood at me, saying I had no business on his land. Sometimes, though, he liked to see me and would come over, calling me Helmut. That didn't mean anything to me either. My grandfather died. I forgot what had happened – until the illness started in my father.

In Russia there's a saying that nothing in life returns except our mistakes. And that they become worse in our old age. As my father had always been somewhat eccentric, we told ourselves that the slip-ups he started to make after his retirement were because he allowed himself to lose interest in his surroundings. It seemed typical of him. So for years we nagged, urging him to pull himself together.

Now I'm seized by a silent rage at all that wasted effort, because we were scolding the person instead of the disease. 'Please, don't let yourself go!' we said a

hundred times, and our father put up with us patiently, as if believing things are easiest if you resign yourself to them in good time. He didn't want to resist his forgetfulness and never used any memory aids. That way, he couldn't mistakenly think someone else had put a knot in his handkerchief as a reminder. Nor did he fight tooth and nail against his mental decline, and he didn't once try to broach the subject, although – with hindsight – he must have known it was serious by the mid-nineties at the latest. If he had said to one of his children, 'I'm sorry, my brain is letting me down,' everyone would have been able to deal with the situation better. As it was, for years there was a cat-and-mouse game where our father was a mouse, we were mice, and the disease was the cat.

That first nerve-wracking phase, marked by uncertainties and insecurities, is behind us. Although I still don't like to think about it, I now understand that there's a difference between giving up because you don't want to try and giving up because you know you're beaten. Our father accepted that he was beaten. Having arrived at that stage of life where his mental powers were on the wane, he staked everything on maintaining inner composure. Which, in the absence of effective medication, is also a practical solution for relatives who have to deal with this wretched illness.

In *The Curtain*, Milan Kundera writes: 'Faced with the unavoidable defeat we call life, the only thing left to us is the attempt to understand it.'



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I imagine dementia's intermediate phase, the phase my father is in, more or less like this: you're wrenched out of your sleep, you don't know where you are, everything whirls around you – countries, years, people. You try to get your bearings, but you can't. Everything continues to spin – the dead, the living, memories, dreamlike hallucinations, snatches of sentences that don't mean anything to you – and this condition doesn't change for the rest of the day.

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When I'm back home in Wolfurt, as I am only occasionally, since a number of us share the burden of care, I wake my father around nine. He lies under his blanket, in shock, but he's accustomed enough to people he doesn't know stepping into his bedroom that he doesn't complain.

'Wouldn't you like to get up?' I ask him in a friendly voice. And to inject a little optimism, I add, 'What a wonderful life we have.'

Sceptical, he struggles to his feet. 'You, perhaps,' he says.

I pass him his socks. He looks at the socks for a while with raised eyebrows and then asks, 'Where's the third one?'

I help him with dressing, to speed it up. He is willing to let me do it. Then I guide him down to the kitchen for breakfast. Afterwards I ask him to go and shave. He says,



with a wink, 'I'd have been better off staying at home. I won't be visiting you again in a hurry.'

I show him the way to the toilet. He sings, 'Oh dear, oh dear . . . oh dear, oh dear,' playing for time.

'If you shave, you'll look sharp,' I say.

He follows hesitantly. 'If you say so,' he murmurs. Looking in the mirror, he puts his hands on the hair sticking up on his head, pressing hard so that it actually stays down. He looks at himself again, declares, 'Almost like new!' and thanks me warmly with a smile.

He has started thanking me a lot. A few days ago, without any obvious reason, he said, 'I thank you most kindly in advance.'

I respond encouragingly to such utterances now. 'You're welcome,' I say, or 'Don't mention it,' or 'Happy to help.' In my experience affirmative answers, which give my father the feeling that everything is fine, are better than the probing questions I used to ask, which only embarrassed and unsettled him. None of us like to answer questions that, if understood at all, only make us aware of our own inadequacies.

At first, the process of adjusting was painful and draining. Parents seem, to their children, strong and able to stand up to life's unpleasant surprises, so we children are much harder on our parents for their increasingly visible weaknesses than we would be on other people. But over time I have settled into the new role pretty well. And I have learnt that you measure the life of someone affected by dementia differently.

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If my father wants to say thank you, let him say thank you, even if there's no obvious reason, and if he wants to complain, let him complain, whether or not his judgment is corroborated by the world of facts. He has no world beyond his dementia. As part of his family, I can only hope to remove some of the situation's bitterness by allowing a sick man his muddled reality.

As my father can no longer cross the bridge into my world, I have to go over to his. There, within the limits of his own mental state, beyond the wider society based on objectivity and linear goals, he is still an impressive man, and although not always very sensible by common standards, somehow brilliant.

A cat wandered through the garden. My father remarked, 'I used to have cats. Well, me and some other people. You could say I had a *pawtial* share.'

Once, when I asked him how he was, he answered, 'No wonders, but signs.'

And then there were phrases plucked out of the blue, unreal as words from a dream: 'Life doesn't get any easier without problems.'

The wit and wisdom of August Geiger. The only shame is that language is slowly draining out of him, that breathtaking sentences are becoming rarer and rarer. To think what's lost – that hurts. It's as if I were watching my father bleed to death in slow motion. Life slowly seeps out of him, drop by drop. A person's personality trickles out, drop by drop. It's still intact, the feeling that this is my father, the man who helped bring me up.

But the moments when I no longer recognise the father I once had are becoming more frequent, especially in the evenings.

Evening gives a taste of what mornings will soon bring, for with night comes fear. That is when, restless and helpless, my father wanders around like an old king in his exile. Everything he sees is frightening, everything sways, is unstable, threatens to dissolve in the next instant. And nothing feels like home.

I've been sitting for a while in the kitchen, typing up notes on my laptop. The television is on in the living room and my father, hearing voices coming from there, tiptoes across the floorboards, listens and murmurs to himself a number of times, 'None of my business.'

He then comes into the kitchen and pretends to watch me as I write. But, glancing to the side, I notice he needs help.

'Wouldn't you like to watch some TV?' I ask.

'Why bother?'

'Well, it would be fun.'

'I'd rather go home.'

'You are home.'

'Where are we?'

I give his house number and the street.

'All right, but I was never here much.'

'You built the house in the late fifties and you've lived here ever since.'

He makes a face. He's not satisfied with this information. He scratches his neck.

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‘I believe you, conditionally. And now I want to go home.’

I look at him. Although he is trying to hide his confusion, you can see how difficult it is for him. He’s jumpy. Sweat glistens on his forehead. The sight of this man on the verge of panic shakes me.

His terrifying homeless feeling is a symptom of the illness. I can best explain it to myself like this: because of their inner disintegration, people with dementia no longer feel secure and so they long for a place where they will feel secure again. Yet since their confusion cannot be shaken off anywhere, however familiar the place, even in their own beds they aren’t at home.

To echo Marcel Proust: the true paradises are those we have lost. A change of location doesn’t help, except as a distraction, and singing serves that purpose just as well, if not better. Singing is more fun. People with dementia love to sing. Singing is emotional – a home outside the tangible world.

It’s often said that people with dementia are like small children. Almost all the writing on the subject makes use of the metaphor, which is annoying, because it’s impossible for an adult to *regress* to childhood, while it’s in a child’s nature to *progress*. A child develops new abilities; someone affected by dementia loses theirs. When you spend time with children, you gain a keen eye for every step forward; with dementia, for every loss. The truth is that age gives nothing back. It’s

a helter-skelter downward slide and one of our greatest worries is that old age can last too long.

I turn the CD player on. My sister Helga bought a collection of classic folk songs for such occasions, such as ‘Hoch auf dem gelben Wagen’ and ‘Zogen einst fünf wilde Schwäne’. Often the trick works. We warble away for half an hour. He gets so wrapped up in the singing that I have to laugh. My father starts laughing, too, and as it happens to be time for bed, I seize the moment and steer him towards his bedroom. He is now in good spirits, although with no better sense of time, space, or what’s going on. At the moment that doesn’t bother him.

‘Not to win, but to endure is all,’ I think, and from this day on I’m at least as exhausted as my father. I tell him what he has to do, until he is wearing his pyjamas. He slips under the covers all by himself and says, ‘So long as I have a place to sleep.’

He looks around, lifts a hand, and greets someone whom only he can see. ‘It’s liveable,’ he comments. ‘Actually, it’s pretty nice.’

How are you, Dad?

Well, actually, I'm fine. But 'fine' in quotation marks, because I'm in no position to judge.

Do you ever think about the passing of time?

Time passing? I don't actually mind whether it passes quickly or slowly. I'm not hard to please with these things.