From *I live a life like yours*
(*Jeg lever et liv som ligner deres*)
by Jan Grue

Published by Gyldendal Norsk Forlag AS, Oslo, 2018

Translated from the Norwegian by Alison McCullough

Please contact: Gyldendal Agency - foreignrights@gyldendal.no

From time to time I bump into people who knew me as a child, but who never expected to encounter me as an adult. Generally, common courtesy makes them hide their surprise at seeing me out in the world. An opening is required, a gap in the conversation that will give them the chance to say out loud what first crossed their minds upon seeing me: *So, you're still alive?*

My high school RE teacher told us a story. When her husband died, she cut off her long hair. Afterwards, as she sank into the bathtub, she had experienced a kind of purification. She was keen on rituals, and brought to her classes a gravity that I, a most serious fourteen-year-old, appreciated. I wanted to learn as much as possible – and felt that time was of the essence.

My RE teacher taught me the term *liminal phase*. It describes the most vulnerable part of a rite of passage, in which one exists between worlds. It is the phase during which a young person is no longer a child, but not yet an adult; when the dying have left the world of the living, but have not yet become one of our ancestors. It is in these phases that things can go drastically wrong, but it is also here that transformation takes place. We come into being through such phases. Without them, the world would fail to move forward.

I went from high school to college and on to university, and then met my old RE teacher again, at a conference. She had returned to higher education and written a master's thesis about Norse mythology and the Jotuns – about humankind's dark and dangerous shadows. I was a doctoral student in linguistics. I had started an in-depth work on rhetoric, examining how reality can be altered through language. She had written a history of mentalities, about ways of thinking we can no longer fathom. Our worlds had been brought back together, in a way.

My old RE teacher was not surprised that I was taking a PhD. My high school was situated just ten minutes' walk from the university library, where I would use my mother's membership card to borrow books about shamanism among the indigenous peoples of Siberia. I was well-acquainted with academia; it made sense, shaped my impressions. It promised a certain type of future, just as the first sentence of a book says something about how the story will play out.

My old teacher was surprised, however, at *how good I looked*. This was the other side of the future narrative – that which had nothing to do with my language, but with my body.

The expression makes me uncertain. *You look so good*. Indeed, why wouldn't I? I dress well. Over the course of several years I've learned about cut, about style. I purchased a tailored overcoat when I was eighteen years old. I like jackets with cuffs that can be unbuttoned; oxford shirts on which the yoke curves just so.

But that was not what she meant.

*

The underlying surprise at the fact that I'm alive first surfaces late in the evening. Or at least it did for the author I went to high school with. Two decades later, we were standing in the grand ballroom of the Hotel Bristol in Oslo. She said it with a combination of melancholy and reluctance, her eyes kind – how everyone had known it back then, that I wouldn't live very long.

This was something that everyone knew? *I* didn't know it. It certainly wasn't me who was the source of this notion, so where had it come from? She couldn't say. The idea was simply there, a shadow cast by nothing. The only substantial thing was my body. I used a wheelchair much of the time, but I also crossed the schoolyard on foot, walked outside at breaktimes and stood there in a circle with the other students. We talked about our teachers; we also talked about Joyce – it was that kind of school. I thought I was one among many. I was unaware I had an especially tragic aura.

I knew. I just didn't have the words to express it. I am attempting to find them now.

I am following a trajectory others might have followed. I live in the town where I grew up. I'm an academic, the child of two academics. I live a life like yours. I'm married to Ida, a woman who writes for a living, and we have a child. My son has my eyes, which are my mother's eyes; his face is reminiscent of childhood photographs of his grandfather. These are the threads that hold my life together. This is the tapestry, the tissue.

When I am recognised by someone who remembers the child I was, a rift occurs – a rupture. The image falters. For a brief moment the life I live is superseded by that which didn't happen; it slides past as a shadow to reveal blurred but familiar images, phantoms of the future that followed me into adulthood.

The recognition is followed by the same compliment – *you look so good* – and it is that word *so*, two letters at the centre of a polite remark, which carry the whole of it; what might have been, that which never came to pass.

Are you better now?

No, I say, my condition is more or less the same as before, as it was back then. I have the same wheelchair, I walk a little, my health is passable.

But you look better?

Memory can play many tricks on us; it goes hand in hand with our expectations. The past is not that which happened, it is that which we are talking about now.

Shouldn't you be dead?

I have exceeded expectations – outstandingly – with no allies other than my body, which has lived its life on its own terms. My body is unaware of the diagnosis it was given; the kind of prognosis it received. And that is a good thing.

Never tell me the odds, as Han Solo once said.

This is me, as an adult. This is me, as a father. This is my son. He has my eyes, but not my diagnosis. He is also, in more ways than one, the result of that which did not happen.

*

Into the unknown: we do not know where we are going.
We're sailing in a leaky boat; we know that we are dying animals.
We dream of Byzantium, bail out what we can, sailing onwards, together.
We are Argonauts, astronauts, adventurers, explorers. This is our journey.

*

Towards the end of sixth form, in my early twenties, I lived through film.

I went to the Cinemateket cinema in Dronningens gate, be it summer or winter. On a Sunday evening once a month there would be a surprise screening; nobody knew which film would be shown until the lights went down. I stood in the queue with my friends. Press screenings were scheduled during the mornings; I would sit by myself in the half-empty theatre.

I watched my way through history from the silent movie era onwards; wanted to know who all the central directors were, what was important.

Eventually, I came to Wim Wenders. In *Wings of Desire*, Bruno Ganz plays an angel (sporting a dark, tattered overcoat and ponytail) who wanders around the city. Nobody sees him, but he observes, listens. He places an invisible hand on a shoulder; he is present. The screenplay was written by Peter Handke, but I didn't realise this at the time. An old, blind man named *Homer* is mentioned in the credits, but again I failed to notice this back then.

What I took from the movie was this: the angel becomes a person. He falls in love, but it is both simpler and more complicated than that. He steps out of perpetuity and into the moment. The ancient Greeks had two words for time: *chronos*, the cosmic order, and *kairos*, the here and now – it is in *kairos* that we live and in *kairos* that the angel falls. He desires all that can be found there, that is found *here* – all the sounds and smells and tastes. A cup of coffee, a cigarette (it goes with the overcoat and ponytail; angels who are affixed to film are always already trapped in time).

The angel asks, and he receives. He becomes a person. Now he is mortal. And I understood: this is true.

*

Ida and I are in California, about to leave for Hawaii. We are as far west as it is possible to get in the world, but we are about to go even further. Five hours by plane out into the middle of the Pacific Ocean, to the group of islands located furthest from all others. There are

skyscrapers and busy streets there, but on our approach it will be night, and so the lights and the great, dark expanses of extinct volcanoes will be all that we see.

We have plenty of time to spend together here in California. I take time to read books about where we are and where we're going. I tell Ida about what I'm reading; we tell each other about the books we read. We want to hear each other's opinion, but also want to hear ourselves recount our own. Every new book is an exploration, and by telling each other about them we strengthen the feeling of having covered a certain distance, of breaking new ground.

We will not settle down here; we know that. In just under a month we'll be in San Francisco; our return tickets have been sent to us by email. Hawaii is an unprecedented luxury before we return home; a gesture I'm making on this first long journey we are making together. But I also have printed copies of our return tickets in my bag, because I like the assurance this provides me.

Our expedition is comfortingly delimited, but when we get home, we will have to decide. We have been together for around six months and have reached a kind of turning point. We have spent more nights together than apart; Ida has left more and more of her belongings at my apartment. We are in the process of becoming interwoven. If we don't move in together when we get home there will be no way back – only forwards, separately. We can choose. There are no coercive circumstances. We are free to do as we wish.

*

I have a literary character flaw: I do not want to explain too much. I don't want to reveal my sources. It's an idiotic attitude, but I have a hard time changing it. They're something I don't want to give up, something I don't want to have to explain. I have no desire to be easily accessible; I want to be understood intuitively, and these are two very different things.

Sometimes I fancy that I have a somewhat aristocratic attitude to life. In Honolulu, Ida and I walk past the Royal Hawaiian Hotel with its coral pink walls, in the middle of Waikiki Beach, where Joan Didion often stayed and where no room costs less than five thousand kroner per night. I have the strong sense that we should have stayed there, enveloped in luxury, on this our first trip together. Since we have found each other it seems unreasonable that we should need to think of practical matters – what something costs; whether or not it is wheelchair accessible.

The first time I went to Hawaii I travelled there with student friends. Four of us shared a room, and my strongest memory from the trip is that I tried not to fall in the shower, to walk extremely carefully from the shower to the bedroom in a squeaky pair of Crocs. I remember that I went there with a wheelchair that I could only propel a few metres under my own steam, so when the others went out – to talk a walk, to go swimming in the sea – I was forced to wait patiently, in the room or the run-down hotel restaurant. The air that streamed through the building, constructed as a pavilion with unclear boundaries as to inside and out, was mild as an embrace. It was like nothing I had ever experienced.

The aristocratic element consists in not having to explain oneself. It is to write, as Joan Didion does of California and Hawaii, as if one has always belonged, as if one knows all there is to know, as if history and the world are just as self-evident as if they were one's own, an *objet*

d'art owned by one's family for as long as one can remember. Or, as Stephen Fry says Unity Mitford once remarked to him: *Of course, you never knew Hitler, did you?*

Ida and I are travelling together; we are newly in love and together falling in love with the places we visit. Many of them are places I have visited before and I want to tell Ida everything I already know so that she, too, can know what I know; I also want to stay silent, not say anything, so that we might discover everything together. Abstractions tell us nothing – old references tell us nothing unless we can feel their true physical weight. The word must become flesh. We must find out who we are in the world; what the world is to us.

*

This book is about *becoming a person*. For a time this was my working title, because the angel that becomes a person, that of Wim Wenders and Peter Handke, has long stood on my shoulder.

It was, however, a title I had to give up, because it does not belong to me – it belongs to the poet Mark O'Brien. He was worthy of giving his autobiography the title *How I Became a Human Being* in a different way to me, and I must give him precedence.

If anyone is my Jungian shadow, it's O'Brien. I am weak, but he was weaker. I weigh fifty-five kilos, he weighed half that. My muscles are small, his were barely visible. My big, electric wheelchair gives me a freedom he never knew; he was too vulnerable, too fragile.

The angel from *Wings of Desire* becomes a person by stepping *down* and *in*. He moves from black and white into colour, and when he injures himself in the fall, the first colour he sees is that of his own red human blood.

For O'Brien it was different – in his autobiography he becomes a person by stepping *up* and *out*, although the movement from the monochrome to the colourful is the same for him; the same longing for sensuality, for bodily presence.

As for myself, I'm not sure. Is my own story about descending or ascending? Or is it about stepping into myself – about realising that I always already *was* a person? I am not completely comfortable with O'Brien's title; I'll let him keep it. I know his demons, but they are not mine.

Nevertheless, while O'Brien was alive we had many things in common – one of which is an intimate relationship with machines. An understanding of bodily boundaries and bodily rhythms beyond the norm.

O'Brien wrote poetry. I write prose. I write using a keyboard and the words flow, I work quickly. My greatest challenge is that the foreign words flow too freely, too maniacally, losing their anchor points in my body. I need a foreign word, *logorrhoea*, to describe this condition.

O'Brien did not suffer from *logorrhoea*. His challenges were quite the opposite of mine. When one is unable to control a keyboard – when one has such weakened respiratory function that one spends much of one's life in an iron lung – it is necessary to turn to poetry, where the words are few and the meaning condensed; where a well-expressed thought can contain a

whole world. This is what I am aiming for, in the way that we might strive for that which comes least naturally to us.

The Man in the Iron Lung by Mark O'Brien

I scream
The body electric,
This yellow, metal, pulsing cylinder
Whooshing all day, all night
In its repetitive dumb mechanical rhythm.
Rudely, it inserts itself in the map of my body,
Which my midnight mind,
Dream-drenched cartographer of terra incognita,
Draws upon the dark parchment of sleep.
I scream
In my body electric;
A dream snake bites my left leg.
Indignant, I shake the gods by their abrupt shoulders,
Demanding to know how such a vile slitherer
Could enter my serene metal shell.
The snake is punished with death,
The specialty of the gods.
Clamp-jawed still in my leg,
It must be removed;
The dream of the snake
Must be removed,
While I am restored
By Consciousness, that cruelest of gods,
In metal hard reluctance
To my limited, awkward, déclassé
Body electric,
As it whispers promises of health,
Whooshes beautiful lies of invulnerability,
Sighs sibilantly, seraphically, relentlessly:
It is me,
It is me.

*

How I Became a Human Being was published posthumously in 2003, but O'Brien completed the work. He died in 1999, on the United States' Constitution Day. I often think about him because he lived in Berkeley, and although six years passed between his death and my first visit to the city, many people who knew him still lived there; it was an environment in which many like him had lived, had died fairly young. It was an environment made up of activists and academics, of family, of friends. All of them knew something of vulnerability.

When I was about to move to Berkeley – when I had lost the right to a place to live and was running out of time – they were the ones who tried to help me. Most of all Sue, my academic sponsor, a professor of English literature who, when I finally met her face to face, reminded

me of a Buddhist monk or yogi. She was a widow; her husband had been in Vietnam and exposed to the herbicide Agent Orange. Sue had a warmth and existence I came across many times in California. Eventually, I began to think of it as the life one strives for when one remembers that time is scarce, for all of us.

Joan Didion wrote that *a place belongs forever to whoever claims it hardest, remembers it most obsessively, wrenches it from itself, shapes it, renders it, loves it so radically that he remakes it in his own image*. I cannot do this for California, for it does not belong to me in this way. Instead it is the opposite – *I* now belong to California, or at least my conception of California, that which I have created for myself.

*

Mark O'Brien weighed around half of what I weigh, I who was so small and thin, such a *delicate* child. I measured my movements in metres; he measured his in millimetres. His childhood and youth consisted of the hospital, the nursing home, other institutions. No friends, no self-determination, nothing – not before he had grown up, practically speaking, and fought his way to a place at the university.

The differences between us drive me away from the title of his autobiography. I was always already a person. He was sent away from his family so early, as he was among the last of the children born in 1955 who contracted polio to die of the disease, in 1999. He lived alone for so many years.

Until I was ten, we – my parents, my sister and I – lived in a red house in Lyder Sagens gate in Oslo. Every summer we took a trip to a small cabin, also painted red, on the island of Nøtterøy in Vestfold. I was thirteen years old before I first went to a summer camp with other children who had *something wrong with them*, before I spent so much as a week within an institutional framework.

And yet.

There is a moment, a form of recognition. A sensation of loneliness, a feeling of being a body that nobody wants to know about – oneself least of all. So we look each other in the eyes, Mark O'Brien and I – even though we do it reluctantly, even though we each would rather avoid the other's gaze.

*

There is something else: the question of time. The unlived life has no extent, no dimensions. I am haunted by what might have been, by that which didn't happen. But do I really have any firmer foothold in the life I have lived?

I might proceed chronologically, arrange the events in order. It seems reasonable, gives the impression of structure and predictable progression – that which happened was that which had to happen – but this is a reconstruction, a rationalisation, an illusion. The past seems to hang on the wall like the Bayeux Tapestry, but it is a projected image, a game in light and shadow that originates in my memory. It exists *now*, as I write, so that the incidents of the past also exist *now*, such as I remember them, as I write. I am writing forth a me that no longer exists.

I am also attempting to reconcile the memories of my childhood, which was happy and protected, with the awareness also contained within these memories – that I was different, and that there were constant hostile impulses, discomfort, reluctance.

I ask my parents, and they say, 'to us you were always just Jan.'

We have had this conversation many times. This time we are sitting around the coffee table in the living room of my parents' house, the house in Villaveien where we moved when I was ten and my sister was seven. It is a light room in a functionalist villa, with corner windows that let in the light. Through them I can see the ramp that extends from the veranda down into the garden. In the old house, the red Swiss-style building in Lyder Sagens gate, we lived on the first floor. There was a short flight of stairs leading up to the main door and a longer one up to our apartment. My parents decided we would have to move. In the new house, they built a bedroom and a bathroom on the ground floor, for me.

The ramp in Villaveien is made of metal. I remember many incidents from this ramp – stumbling and falling on it and grazing my knee; learning to steer the wheelchair up it and turn around on the platform at the top. I remember both walking and wheeling around the garden at breakneck speed, the most important thing being to get underneath the bushes where the last of the ripened raspberries still hung.

For many years I found it difficult to believe what my parents said. I trusted that they meant it, that to them *I* was simply *me*, but at the same time I remember the photograph in which the three of us stand leaning on the railing of the ramp. It was taken a year after we moved into the house, and was featured in an article in the *Aftenposten* newspaper about rights that cannot be honoured, about battles that must be fought over and over again. It is a picture taken in protest at that which is wrong and unjust. Something I also understood back then – the ravages of the storm of injustice.

Then my own son was born, and countless notions about who he might be, regarding what I had expected, collapsed into the real child like a miracle of quantum physics. *Now* I believed my parents – after I had become a father and seen that a child is both oneself and, of course, entirely itself.

I look at the photograph once more, thinking of Ida, of who we have become together. I now see one thing in this facsimile from the *Aftenposten* in 1992 – I see a united front. Against what – against the world? There is something not present in this image, something we are glaring at through the lens of the photographer's camera, and this *something* has, if not a name, then a language and a presence. Ida and I know this *something*, as a couple and as a family, and every day we strain to keep it from our door; to keep it from the house where we live as a family. It is a storm and it is polluted air; it is whispering and accusatory voices. Even though they are not within me, I can hear them and understand them, can speak like them. Are they not a part of me then, since I know them so well?

*

In the book *Time Travel: A History*, James Gleick explains that the basic problem of both time travel and memory is the same: entropy. We lay layer upon layer, and when we think we are digging down to something older, something more authentic, something purer, we only

introduce further complications. We do not become children again, and we know just as little of what it is to be a child as we know about life in the 1400s.

We cannot *travel* through time. That would require a starting point and a destination that exists independently of us, a past that is, quite literally, another country. This is *chronos*, cosmic time. But that is not where we are. We are surrounded by the moment and take it with us. We cannot escape the eternal 'now', where the future becomes the past. We live in *kairos*. In the same way, memory is something that plays out and lives within us; it is not a kind of copy cast from the mould of a *then*. Every time a relive a memory I change it, ever so slightly, because each time I relive it I add a new stroke of the brush.

I am rewriting the manuscript yet again. My language changes imperceptibly, so the manuscript becomes another even if I think it continues to remain the same; an authentic reflection of myself.

Ida and I have become a couple, got married, had a child. I write as our son, who has turned one year old, sleeps outside in his pram below the veranda roof as the rain pours down. Ida sits beside me practicing the piano – Ingrid Bjørnov's book of classics, songs for children and movie themes. The storm is outside.

I am attempting to reconstruct who I was before all this, but that person has already become a stranger to me. I am thirty-six; I have a memory of being eighteen years old. I can reconstruct it, but this is an active act, an act with a purpose. Ida hesitantly starts to play 'Somewhere Over the Rainbow', over and over again. I could not have imagined this moment when I was eighteen – not only would I have dismissed it as sentimental, but I would have been reluctant to look at it. It would have struck me as too intimate, too overwhelming.

The written word is stable in a way that memory is not. A proverb from one of the oldest written cultures states that *the weakest ink is more powerful than the strongest memory*. George Orwell believed that keeping a diary was among the best habits a person could have. It enforces intellectual honesty. One is not only forced to remember all the times one was wrong, but also all the times one was right – but for the wrong reasons. The diary is an amendment to the truth of the moment, which always alters in line with what is opportune. In *Nineteen Eighty-Four*, Winston's first and decisive act of resistance is to write down something that has happened.

I was never good at keeping a diary, but a kind of journal was kept for me. The voices I recognise, but which are not *me*, are here in writing and far easier to access than what I might have been thinking many years ago. They are also therefore much more powerful in their way – they possess a kind of dusty, totemic power.

This journal takes the form of a good metre-long shelf's worth of papers; my parents gave them to me. Perhaps it was only by chance that I took charge of these papers after Alexander was born, but it was appropriate nonetheless. I will always be my parents' son, but now I too am a parent, and have taken on their habits. When Ida and I were sure that we were going to have a child together, I made a 'prenatal' ring binder. As we neared the due date, I made a 'birth' ring binder. I'm used to collecting and collating documents; it is to leave a trail of breadcrumbs, to pull a red thread after oneself. It is to refuse to get lost; to demand the truth.

Among the papers I received from my parents are medical records, clinical descriptions, discharge summaries from hospital admissions; copies of letters sent to municipal and governmental bodies, travel agents and suppliers of medical aids.

Reading these papers, as trivial and disintegrating as they are, still feels like diving into ice-cold water. It is of little use to know that the deep pool lies there, glimpsed out of the corner of an eye, before one day suddenly stripping off all one's clothes and taking the plunge. This is a trajectory other than that which I remember following. It is a different life to the one I remember living. This is unsurprising, as it was my parents who read the letters and responded to them; they were not addressed to me, they were about me. But I hardly recognise myself in the *me* that is their subject, and the timeline they portray does not lead to the life I live now. The life outlined in these papers is a much more pitiful life, perhaps a shorter life, and one with little joy in it regardless. Yet this horizon of expectation was just as complete.

Common to all the papers is that they attempt to hold someone accountable, someone who refuses to take responsibility. The travel agency who promised to transport a wheelchair and then forgot or failed to follow through on their assurances. The hospital that failed to follow up, the governmental bodies who failed to follow their own rules. Institutions and organisations have long memories, but only when it suits them. Otherwise they live, and justify their refusals, in the now.

The papers depict two full-time jobs, performed over many years, from when the first ambiguous signs of my muscle disease began to reveal themselves until I reached the end of my teens. Naturally, the paperwork did not end there, but by that time I had started to take on much of the work myself; had started to act as my own secretary and case worker, my own post office and national archives.

Among the papers is the following:

Clinical note, 12.06.1984

Healthy three-year-old boy, dark blond with brown eyes, attractive and well-proportioned, krasil *[sic; should probably be* grasil*, meaning slight, delicate] with a generally slender body type, relatively weakly developed musculature but good posture.*
[...]
He seems to have developed early in terms of fine-motor skills, language and intellect.
He showed little interest in lifting his head, turning, attempting to crawl, etc. and has never crawled. However, he sat unsupported at the usual age and could almost walk as early as at 10.5 months, but walked very unsteadily and constantly fell flat on his face until he was two years old.
He has difficulty navigating stairs and lifts his left leg first every time. His balance seems to be getting poorer. He also struggles to climb.

This is not the beginning, but the beginning is not documented in writing. The beginning must have been a feeling, a sense of something not being as it should. *I* was *me*, but I was also a child who *constantly fell flat on his face*, and the worry that accompanies this cannot be easily explained away.

I visit my parents at their home, my childhood home. We cover the coffee table with ring binders and cassettes, and leaf through brochures, sheets of paper, member magazines from the *Association of Muscular Diseases*. My parents tell me, as they have told me before, how difficult it was to know. The papers exist, but for my parents the two or three-year-old boy is also a memory – he no longer exists – and for them, too, the memory of him is overwritten by the six-year-old boy, the ten-year-old boy, the 36-year-old man who is writing this.

We are palimpsests. We are manuscripts on which the text has been crossed out and written over, crossed out and written over. Everything fades, everything leaves a trace.

My mother visits me at the office; she's brought the papers with her in three plastic bags. We leaf through them once more, then I put them on a shelf. We talk as if remembering a war.

There was always something, wasn't there?
There was always something, all the time.

These papers are the gaze from outside, the gaze belonging to medicine, the physiotherapists, the education system, the municipal council, the district, the legal system, the travel agencies. It is the gaze that regards me as cargo, a logistical problem.

I read over the papers again. And though the text is stable – the same words remain on the pages as in 1984, the year I was three and received my first diagnosis – I am different. As Jacques Derrida points out, the reader changes, and therefore the text changes, too.

A sign outside the housing co-op where Ida, Alexander and I live, a sign also from the mid-1980s when the building was erected, states that vehicles are not permitted to drive into the rear courtyard. The exception is for the transportation of two things – goods and persons with disabilities. *The transporting of goods, the transporting of persons with disabilities*. These are words that bear re-reading, some decades after they were first affixed to a sign.

*