

My Life

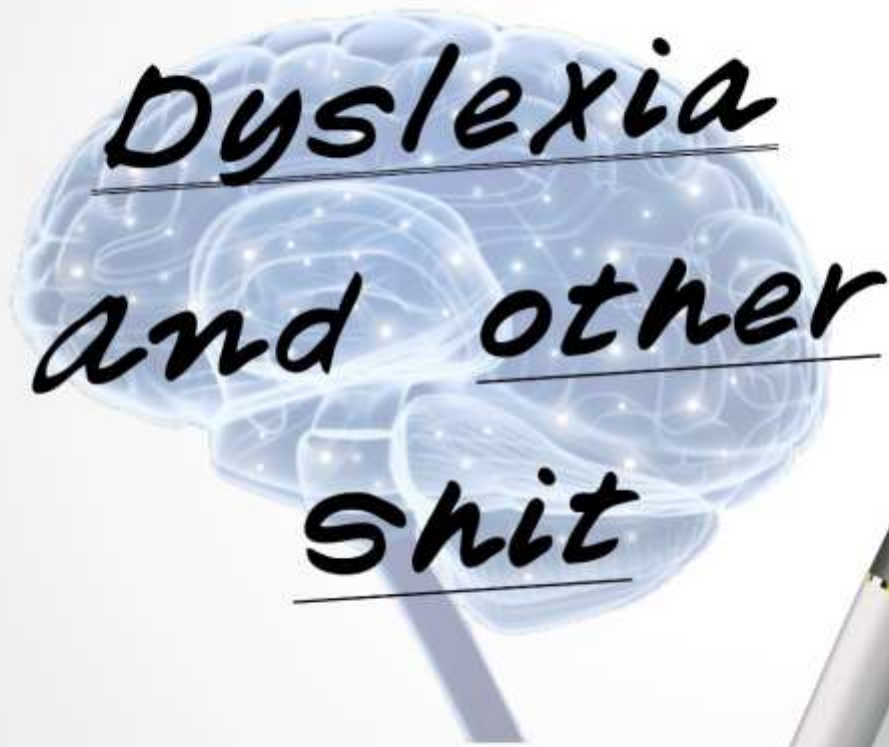
with

Dyslexia

and other

shit

Nicole Kiefer



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**Reminder: Please remember this is a reading sample of the book in its earlier stages, and not the finished version.**

# *My Life with Dyslexia and other Shit*

*By Nicole Kiefer*

# Introduction

This is the story of my life, or parts of it that made me the person I am today. This book is an example as well, a demonstration of how a dyslexic writes, which is why this book is not professionally edited. This book is written and edited by me alone, with no outside help at all, not even my family. Why? Because I want to demonstrate that the content of a story is the important part, not the spelling.

**Words spelled right, but out of context don't make a story, they make a dictionary. Words assembled with sense, smarts and imagination, but spelled wrong, still make a story.**

Of course I know that spelling is important and I don't want to belittle it, it norms our language, makes us able to communicate clearly without having to guess what the other person means, and it is a very important part in any language. Yet I often find that many people put too much weight into it, forgetting the content of the message they read completely, fully distracted and blinded by spelling errors. So this one has it all, the spelling errors, grammar mistakes, and punctuation hells. You don't like it, well to bad, because it is part of me, and I see no reason to be ashamed of who I am, and part of who I am is dyslexic.

Try to focus on the meaning, not the spelling. Actually, forget that there is such a thing, forget the existence of dictionaries, of writing rules, and become a renegade for just this one story.

I was born in 1979 in Germany, that's 36 years ago now. Like with every person there are highlights in everyone's life, and those points in time influenced

us in some way, making us the person we are today. Many more of those highlights will follow and influence and change me, I know that, but just like I did ten years ago, I feel like it's time to look back.

Getting older is not just a collection of years, but of experiences, and like our eyesight might change to worse in those years, our mind-sight will get sharper.

When I wrote these things down the first time, I recounted them overshadowed with anger and frustration, and even so people praised my first version, reading over it again now, ten years later, I don't feel like I nailed it. That's why I decided to rewrite the book, I published then years ago in Germany. Actually it was pretty exactly ten years ago, when I received the email from the publisher, who would start my writing career. One of the many events that shaped the person I am today, and will be part of me for the rest of my life.

As you look back some moments in life are clearer than others, and some stuff our parents, friends, or just people around said still rings in our ears. Those are the things I want to focus on, but the times in-between are important to, yet more in a general way, so those I won't go into details. Yet I will have to interrupt my own story from time to time to give you the info you need to understand it, because there are a lot of health factors in my story, and sadly I belong to the kind of people who only get rare ones, or mostly.

# Before birth and early childhood

## *Miracle child or devils girl*

I start with a little explanation of where I came from, yes I know, the belly of my mom, obviously, but even my birth is a little bit more than just that.

My story begins before I was born, because I shouldn't have been born in the first place. My mother was born with Spina-Bifida, a birth defect, more specific, a neural tube defect. While in a normal embryonic development, the neural tube closes, in a case with spina-bifida it doesn't. Part of the neural tube doesn't close properly, which causes damages to the spinal cord and bones, often rendering the child paralyzed from birth. Now back in 1979 and before that, it was believed, at least in Germany, that if a woman was paralyzed, her Uterus and all those parts needed to conceive, were just as useless as her legs.

Surprise, they were wrong, and because they were I was conceived. Then they told my mother she could never give birth the normal way, and planned a caesarian section. Surprise, I didn't see the calendar and decided on an earlier appointment. So I was born the good old fashion way, and quick to boot.

It was the reason my parents called me their miracle child, and I get it now. I have my own children now, and have been through the worry that most mothers have, before the child is even born. Especially when there are several genetic mutations in the family, which could mess the child up. As a child or teenager, I simply was embarrassed when my parents called me that, and tried to flee every time it came up. But their thought of me being special, explains a lot, especially how

my mother held on to me when I was little. And then there is the fact that after all, I did have some "damage" when I was born. I have been born with clubbed feet, don't think I need to explain those, and Nail-Patella-Syndrome. Which is a genetic mutation, causing the fingernails to develop wrong, or not at all. In many cases only a portion of the nail develops, split apart by skin, making it look like two very little nails on a finger, or weirdly grown. I believe the bones underneath are affected as well, but aren't sure. Then the elbow joint is often deformed so the arm can't be stretched fully, the patella is often too small, deformed or none existent at all. Those are most prominent symptoms and how the doctor in the children's hospital diagnosed it. By doing so he also accidentally diagnosed my father, from whom I inherited that genetic mutation, only he had never known that it was that, and believed he had been in an accident as a child.

Well, that was a two for one for the nice doctor who took care of my clubbed feet. Sadly he didn't know or explain about all that came with NPS, like weak tooth enamel, dyslexia, kidney problems, glaucoma, nerve problems, Fibromyalgia and so much more that is either not certain or proven, to be part of it. Over the years, I learned that there is much more than what research could prove to NPS. As rare as it is supposed to be, there are a lot of people out there who have it, and work together and with their doctors to establish what part of NPS is, and what is not.

So that's the rundown of the medical conditions I was born with, yet since there is no treatment for NPS, I was only treated for the clubbed feet, which meant having both my lower legs in a cast for the first year of my life. My parent's had to take me to the children's hospital every week, to get the casts taken off and new ones put on. In addition, since I didn't let the weight of the casts stop me

and began to crawl and walk, as any child would, they had to take me often between the hospitals appointments, to my pediatrician to get the casts fixed.

(Sorry guys for being such a pain in the ass, but I guess I couldn't help myself. However I am grateful for the time, effort and mental stress you endured for me.)

When I was a year old, my feet were operated, and it's funny but I actually have one memory of that time. Me laying on a cold table with a large square plate above me, a whirring sound that made me nervous and the room was cold. When I was younger I actually thought I had been kidnapped by aliens because of that memory. And in hard times, when I hated myself and my life, I had imagined that I had been like Superman, born on a different planet and one day my superpowers would show, and I would show the world how special I was. Of course neither was I kidnapped by aliens, nor born on a different planet, and sadly never developed superpowers either. What that memory is, is when they took x-rays of my patella and lower legs, to make sure there was nothing that hindered the operation. How sad is that... so simple and boring...

However that's the only clear memory I have of my early childhood, and I guess one of the fruit bearing grounds of my imagination.



# Before my first school day

## *What is death*

I know from my parents and later memories, that after the operation years of physiotherapy followed, and that I hated it. Yet all I recall of it are picking up marbles with my toes, walking in tip toes and playing with large bouncy balls. Another thing I have to thank my parents for, it's not easy to take a child to something it needs, but hates and fusses about. I might not remember it, but I'm sure I was a pain, simply because I still would be one, and because I went through the same thing with my own daughter.

However, I guess it was one of the reasons my parents didn't send me into kindergarten when I turned three, like most children were. (In Germany you start Kindergarten with three, but it is not mandatory and has nothing to do with school.) My mother always said when I asked her, that she didn't want a weekend child, but I think there was more to it. I think that since I was kind of a miracle, my parents were overprotective, and didn't want to let me go so very soon. Then they had to take me to physiotherapy once or twice a week, and I guess, not knowing much about NPS factored in as well. However I mostly grew up in the store my parents owned, where they sold school and photo supplies like cameras, flashes and those kind of things.

The store was on the ground floor but elevated, and had some steps at both entrances, which meant my dad had to pull my mom up and softly let her down, whenever we came or left. There was a large storage room, a bathroom, a kitchen, the office and of course the store itself, which again was a few steps down from

the office. My mom did mostly the office work, unable to get down into the store by herself. Nowadays I wonder why they chose that location in the first place.

Growing up in my parents business, left me sheltered from the world outside and socially unexperienced. I know my parents meant well, and had no harm in mind when they decided to raise me that way, until school would take me away from them often enough. It only proves that Hindsight is really 20/20, and years later you always know better. However, I met other children in the store, had a friend across the street and every summer, they send me to summer day-camp, to expose me to other children. Often when I was little my grandma would pick me up, take a walk with me or take me to the playground. On weekends I would visit with my grandma, who lived right above us, and she would take me to the zoo or other places, that were in the city and hard to reach for my mother. In my memory my grandma was a loving person, who showered me with attention and love, while my parents often worked, and even when I was with them, it felt like they had not much time.

My children most likely see it the same way. We adults are always busy, or at least seem as if we are, and our children see that more often, than when we take the time to be with them.

Anyway, according to my parents my grandma was not exactly the person I remember, because I didn't see or remember the other side of her. My grandma, like most mothers, was very protective, especially of my mom. I mean that woman went up against the school, to get my mother into a normal school with her handicap. Back then a child with handicap, any handicap, would usually be send to a special needs school. Not that those are bad, but they catered not just physically handicapped children, but mentally as well. Coming from a special needs school,

meant for most, that there was something wrong with the persons mental state, like slow learner, challenged with day to day tasks, and not many made a difference in their mind between physically challenged, and mentally challenged people. Getting my mom into a regular school, wasn't something easily done, or often to be seen in the 50s. However my grandma made sure my mother was placed in a normal class and had a normal education, and childhood. So I guess deep down she was a good woman, but she didn't like my dad at all. Being a mom myself, one that only wants the best for my daughter, I guess he just wasn't good enough in my grandma's eyes, and she handled it badly.

According to the tales I have been told, since I was old enough to understand them, (so only recently, like in the last ten years) my grandma made me almost hate my dad, and undermined my relationship to him.

I can remember one incident, it has been stuck in my mind ever since. My mother was in the hospital with decubitus ulcers<sup>1</sup>, from sitting in the wheelchair. A very common problem with paralyzed people. My dad had to work at the store, and so my grandma took care of me over the day. She distanced me from my dad, I guess with simple things, like making me go to bed before he came home, waking me and taking me up to her apartment, before he left. Taking me to visit my mom, while my dad was working, so I saw her, but felt abandoned by my dad. She told me that my dad was evil and bad for my mother, and who knows what else that I don't remember. However I do remember that one evening, my dad came home from work and came to pick me up upstairs, to get me ready for bed. I didn't want to go with

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<sup>1</sup> Pressure ulcers, also known as pressure sores, bedsores and decubitus ulcers, are localized injuries to the skin and/or underlying tissue that usually occur over a bony prominence as a result of pressure, or pressure in combination with shear and/or friction.

him, didn't want to be with him and stay. He of course wanted me to come downstairs, and sleep in my own bed. When I refused and screamed at him, he just picked me up, and took me downstairs. I can still feel the hate when I remember that evening, I was so filled with it, and yet it had no reason, no real trigger, but it was rushing through me like rapids. When in our own apartment I told him that I hated him, and that he was the devil, evil in persona, and the reason for all bad things that happened to my mother and me. Well, what four year old would come to such conclusions?

My parents knew it was my grandmas doing, while I only loved that woman more with each passing day. I believed her, and it not only put a strain on my relationship to my father, but also to my mother, who I resented for being with him.

Why am I telling you this? Because it was the basis of many things that would go wrong later, but it took me years as an adult to puzzle the connection together, and lots of reading of psychology books.

My grandmother placed a chasm between me and my parents, one that was invisible to me, and my grandmother was the only bridge. One that vanished from one day to the next, at least that's how it felt to me, when I was only five years old.

I can't recall her being sick for long, before the hospital, or at all before the last time I saw her. I know of course that couldn't have happened from one day to the next, and maybe deep down in my memory that time is buried, but it won't surface. I know that I was excited to go to school soon, that I talked a lot to her about how great it would be, when she would see me that first day of school. I

wanted her to take me there, to be at my side when I got placed into first grade. In my mind, it would be her hand holding mine, she who would take that first picture of me as a school girl, and it was her I would show my first good grade to. I was excited to go to school, to learn and get to read and write, and do math. I wanted to know it all, be able to do all the things my parents and her were capable of doing, and wanted to know more than they did. That's what I remember of the time before the hospital.

Then she was in the hospital. She must have been there a while already, but I can't recall how long. My parents took me, my aunt was there as well if I recall it right, but my focus and my bleeding five year old heart, was on my grandma. Only she didn't look like my grandma, not really. She was thin, gaunt really, her eyes were dim, not a sign of the sparkle they usually held. It smelled in the room, and I know I plucked my nose with my fingers. I didn't know it was the stench of death that I smelled, a mix of cleaner, antiseptic, feces, vomit and blood. I smelled death on my grandmother, and I saw death stare back at me from her face, deep down I think my child's mind knew it. Or maybe it was the way my parents and aunt talked to her, that made me feel like I already lost her.

I saw the pain in her eyes, and it scared me, but I didn't cry, it felt wrong to cry. I guess my parents thought I took it well because I didn't break out in tears, when in reality I was screaming inside for someone to explain to me why I felt like this, why seeing the person I loved so much, hurt so much. However I didn't trust my parents to understand, it was part of the rift my grandmother had created. I didn't trust my parents, as a child in the age of five should have. I didn't think they could fix it. Well they couldn't have, nobody can fix death, but that didn't matter. It was the last time I saw my grandmother, and her face was

burned into my mind for all my life that day. Overshadowing the way she looked healthy for many years to come. For years whenever I remembered her, I only saw the pain, and heard her last words to me, as if spoken from far away. "Don't trust your dad, he will only disappoint you, he does not love you child."

I guess not even close to death could she accept that my mother loved a man she considered unworthy of her daughter. She placed a very big wall of mistrust and hatred between me and my parents that day, one that would be a problem throughout most of my life. She, the woman I loved so much, became my root pain.

I don't know how much time passed between the visit and her funeral, which is my next memory, but it wasn't long. I know that she wasted away quickly and died in less than a month altogether. I know that one day everyone around me was suddenly sad, crying and sobbing, especially my mom. They told me that grandma was gone, and that she would rest in heaven and never come back. I was five, my understanding of death limited, and I didn't really understand how she could be gone. I believed they hid her, had send her away because I loved her more than my parents.

Of course I didn't tell my parents what I thought, after all I couldn't trust them, according to my grandmother, especially not my father. If I would tell my mom, she would only tell him, so I couldn't trust her either. If I had told them, they might have handled things differently. But I didn't, and they haven't.

When the day of the funeral came, my parents decided to leave me at my friend's house, and go there on their own. I wanted to go there, wanted to see that my grandma was gone, that she was dead, even as I didn't really understand what that was. My friend, same age as me, had lost her grandma a while earlier. She

explained to me that dead was when the people you loved laid in a box not moving, breathing or being really there. That their soul had left and there was nothing but a shell left of them. Of course having never seen "the box" or "the shell" I imagined it quite literally and thought she was kidding. Yet it didn't change that I wanted to be there with my parents, because they had said they were going to say good bye to her, and I wanted to say good bye too.

My friend lived across the street from our store, and I sat at the kitchen window, watching my parents as they left for the funeral, all dressed in black and my mother crying. It was then that I cried as well, only that one time and not for long, but I cried and sobbed as I watched them leave.

I don't remember them coming back, or even the next few months. Maybe I was in shock, maybe there was nothing memorable happening in that time. However, that day when they left me behind, to say good bye to the woman I loved so much, only widened the rift my grandma had created, and reaffirmed the walls of mistrust and hatred, towards my father. Of course I didn't know it back then, or could have done anything against it. Today, I even believe that my parents couldn't have done anything at that point to change it, my grandma had done a great job in messing me up. Even knowing it today, I can't bring myself to be mad at her for it, which only shows how deeply rooted she was, and still is in my soul.

Having lost her however, didn't dim my excitement for school, if anything it deepened it because going to school would get me out of the house one day, and away from my parents. Not that I did think it that clearly, or had a plan or something worked out, man I only was six by then. I was more thinking like this...

School, growing up, looking for where my grandma went because of my parents... I was pretty messed up I guess... But it had me more excited about school than ever, and the months after my sixed birthday, where filled with imaginings of how school would be like.

I can specifically remember the summer before school started. As I said earlier, my parents send me to summer day-camp each year, and that one was no exception. I wanted to know everything about school, it seemed logical to me that older children who went to school, would be able to tell me about it. That's why I spent those three weeks in summer day-camp, as the biggest annoyance the older kids could encounter. No child that looked older than me, teenager or even caretaker, was save from my questions about school. The things they told me, only made me want to start school sooner, I couldn't wait for it. The only damper was, that my grandma wouldn't be there as I had imagined, another point I hated my parents for, I guess. None of my hatred or dislike and distrust was consciously, it was all just there, when it would hinder me the most, and do the most damage to my young life.

However school finally approached, and my first day of school was imminent, a day I had waited excitedly for.

Before I go on, I want to give you a short summary of my mindset in the age of six. Just to make things easier to understand. In my mind there was no difference between an able-body person, and one with a disability. Because of my parents, I had gotten to know several people with disabilities with my six years,



blind people, some with amputated limbs, Down syndrome, or deaf people were nothing strange, or different to me.

Since my contact to other kids was limited, I had no social skills to speak off. But since I got along with the kids that came into the store just fine, I couldn't imagine not getting along with anyone. I was showered with love by anyone I knew, and couldn't imagine it being different when going to school. I was sure the other kids would love me, the teachers be proud of me, and anyone who saw me would instantly like me. Yea well... as I said... I was messed up already...

So with those things in mind, let's move on to my time in school.