

Prologue

Having an autistic child is one of the most life changing conditions you can ever imagine. That's how it was for us anyway. When our son was born, autism was not a diagnosis that was generally known, not the way it is today. None of us had ever heard the word autism before. But now it was the reality for our little family, at the beginning of our adult lives.

Our own model was also a long way from the “ideal” family with an autistic child. We had lots of love but no routines, instead we were youthfully spontaneous. Decided the days as they came, all according to the weather and what was going on as young ones do, with the friends we had around us. We have always had many friends and liked to be where the action was, in the city, the beach, barbecue evenings or just chilling. Our neighbours used to say that if we weren't away, we had guests, it was always one or the other. In addition, we were at the beginning of our adult life and started a company that grew, we also wanted to invest in that direction.

We had a lot going on that required our focus and attention, things that are completely normal at the beginning of any adult's life. We also wanted a house, so after a few years we were on track to the future with a house, car and a growing business. The future looked bright in that sense.

Of course, it was challenging, a track and a goal in life that required both time and great effort. If we had an autistic child today, all this would be settled, but not then. Life hadn't made us who we are yet. We were young and still "on the way".

Add to that the immaturity, there is no way around when life experience hasn't caught up yet. Yes, a lot in our life happened in those early days that made us both focused and spontaneous, young as we were, curious as we were, poor and hard working as we were.

Many couples go their separate ways when they have an autistic child, but now looking back at more than 30 years of marriage, we can probably say that our son's autism has never been a reason for us to separate. Of course, things have happened over the years that could have been a cause, they happen to any couple – but never this. Our fights, we fought them together with common goals, the time we used, we used together, always together. The joint decision was made right from the start and made us invincible. We and his wonderful big brother along with Nico, were invincible.

Invincible, but vulnerable. Could our life with family, work and recreation really work together with autism? And what happened to us when we couldn't allow our child an independent adult life of his own? What does life become like when the human qualities needed in a relationship do not work, such as learning ability, adaptability, social codes and communication? Could we be the ones who invested everything to give our son the best possible life, not only as a

child, but also as a youth and an adult? Is invincibility without end? Or would autism be the invincible? Did we really stand a chance?

We achieved spontaneity together with structure by using our own inexperience. Our life hadn't settled down yet and it would not go on without him, never. Instead, it would be spontaneously structured, an expression that does not exist. We dare to say that our son has had and still has a good life. Our decision to never stop fighting for him, made his life at all stages as good as it could be, with his limitations.

We must also be able to say that it has been a huge struggle, not only in terms of our responsibility as parents, but also our responsibility for an autistic person completely without communication. Also, an eternal struggle against the authorities for his rights, a fight that will apparently never end. Constantly in today's society there is the threat that his opportunities will be drastically changed due to a political decision or for "efficiency" with society's resources. An aspiration that we are constantly reminded of affects the weak ones. But our son has never been weak, he has always had us. Our story should also include this fight — the fight for the voice of a mute human being.

You have probably heard stories of parents when they first suspected that something was wrong with their child, the investigation process, then finally being told that the child was autistic. And then life changes, with intensive training and everyday life constantly adapted to the child's needs. But what happens after that? How did we move forward in life together when autism wanted us to stay in the same place?

What we had to change in life, when Nico was diagnosed and really from the time he was born, changed drastically several times during his upbringing. It wasn't just getting started and then everything went on automatically, right on track. Oh no, it was just the opposite. We were on track but many times it felt like the train was coming straight at us.

We started well, paid attention to what we were taught, and pretty quickly we learned the codes of autism. But what we thought was a manual that would work in further life, just as upbringing has a certain developmental manual for a child's different ages, turned out to be something completely different. There were no manuals for his development and needs. They did not follow a natural progression up through the ages. We learned that the hard way, on a path without end.

Over the years, it has also been quite transformative to first have a child, then a youth, then an adult with the same restrictions. Every part of life has been like starting a new chapter, especially the development from youth to adult. Adult autism should almost be a diagnosis of its own, not because it differs from a child's diagnosis, but because the problems become so much bigger with age and so much more difficult to solve. A child can be physically managed and controlled, but you can't do that with an adult individual. What to others may seem like an anxious or difficult child, becomes completely different if you put the same behaviour in an adult body.

A child is given upbringing and guidance in life, which changes continuously with age. The upbringing of an autistic

child is something else again, not "only" based on upbringing, but also on strategies and routines. It is also based on other things that have nothing to do with upbringing or feelings at all but must be there for everyday life to work. This is all truer now that Nico has grown up. Everyday life is not governed by ingenuity or a forward moving drift in life that other young people experience, but by routines, routines and routines. Not meaningless routines but things with content, a life of content, a content that we as parents constantly must invent and reinvent and also figure out. Otherwise, it will be just meaningless routines. Yes, in addition to living our own lives, we also had to "live" his life.

Beyond all this, we must never forget that the most important thing for us was love. Not routines or understanding or adaptation to his disability, but that he would feel loved and needed. We showed him very clearly how happy we were for every bit of progress he made. We wanted him to understand how we felt about him, that we loved him deeply. That's probably what he's been told most in his life: "We love you".

But all of this comes later. Let me start where it all started, on a Saturday in the month of May 30 years ago. A normal day, it seemed, but this Saturday our lives would change forever. The life we had hoped for would never be. We just didn't know it then.