

# **“Apply your own oxygen mask first”**

## ***A parent’s perspective on caring for a child with complex needs***

Alja van Maanen – The Netherlands

Good morning! Hyvää huomenta!  
Welcome on board this Boeing 737.  
First, I would like to ask for your attention to the safety instructions. Hand luggage should be stowed under your seat. Smoking is prohibited and the use of mobile phones is not allowed at any time during this flight.  
The emergency exits are located there and there.  
In case of sudden loss of cabin pressure, oxygen masks will drop down from above your seat. Place the mask over your mouth and nose and keep breathing normally. If you are traveling with children, make sure that your own mask is on first before helping your child. Let me repeat this: If you are traveling with children, make sure that your own mask is on first before helping your child.



That’s what it is all about: first make sure that you are stable yourself and only then will you be able to help your child properly.

I have 3 daughters aged 13, 10 and 7. When the plane is experiencing severe turbulence, they will surely all need my help. But my youngest daughter, Nova, has complex care needs, she is more vulnerable.

She has Rett syndrome and therefore severe multiple disabilities. Her level of development is thought to be between 9 months and two years of age. Not only with heavy turbulence, but during this whole journey, she will be completely dependent on me. Her whole life. Probably my whole life. And this responsibility takes an incredible toll on me.

I am her legs, because she cannot walk. So I lift and carry her all day long. Out of bed, into her wheelchair, onto the floor to play, back into her chair, into the bath and back into bed.  
I keep her balanced, as she cannot sit properly by herself, her muscles are not strong enough to keep her stable. As she already has a considerable curve in her spine, she wears a brace 24 hours a day.  
I am her hands, as she can’t use them so well, they fiddle and rub all day long. So I hold her cup when she drinks.

I am her senses, as, for example, she doesn’t respond to pain stimuli, so we need to be alert that she doesn’t hurt herself.

I am her brains, as I think for her. I imagine whether she wants to play or sleep, or cuddle or eat or drink. But also what she wants to eat or drink and how much, and how much tube feed is necessary. And oops, sometimes it’s too much, well you only notice that when it’s too late.

I read her or I try to, always needing to be alert. Registering signs of her being tired or maybe that something more serious is going on.

And finally I am her voice, as she cannot use it herself. She communicates with her laughter or her tears and fortunately we mostly see smiles and hear happy sounds.

Her small world is slowly getting a little bit bigger. Two years ago she got her own speech device which she can control with her eyes. A new way of communicating that we are slowly adopting more and more. With which she can tell us things deliberately, so I don’t have to think for her, and with which she can hopefully take back a little control. At the moment, life just happens around her and to her, but I hope she can become more of an active participant in the future.

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I want to take you back to the moment we got the official confirmation that Nova had the right to long term care in Holland. Nova was only three years old then, a cute little toddler. With this right to long term care she could go more often to the special day care facility and it would not be necessary to fight for the required care year on year.

A piece of text from this official letter:

“Both physical and intellectual disabilities are evident. Your daughter is dependent on care and her level of dependency is expected to be permanent. She has severe limitations in moving and transferring. It is not expected that she will be able to take control of her own life, to structure her days and to live independently. As your daughter will need long term, intensive care this indication will remain valid indefinitely.”

Wow, that hit me hard. That made me realize at once what her and our future would look like.

To be able to give Nova oxygen, everything she needs for her life to be as happy and fulfilled as possible, I must be stable, I must make sure I put on my own oxygen mask first. But what if I fail, what if the responsibility takes too great a toll on me? What do I do as a parent? Then, I still take care of my children first, even if it is at my own expense. And then we are at a point, where I see myself, my husband and many other parents of children with severe multiple disabilities, reaching overload. Often functioning at the margins of our energy levels and sometimes way over the limits. And without help it is impossible to stay within those limits. Even though I quit paid employment a few years ago and I am at home during the week.

I myself and we as a family have less time and fewer opportunities for the ‘normal’ things we would like to do and the ‘normal’ chores we have to do, just like all the other people and families around us. There is less time for the other parts of me. I am not only Nova’s mother. Everyone in our family should be able to do what they like to do most. I would love to give all my children the attention they need. Attention for my husband, for each other as partners. Spend time with friends and family, go on holiday and work. Every mother and every family has to make compromises in the time available, but in our family these things are even more complicated and sometimes there is no room for anything else at all.

Arranging care for Nova and everything around it takes an enormous amount of time and energy. To make room for the other parts of me, I would love to share a part of the 24 hour care, with the day care facility, a host family where she can stay one day or weekend per month, a specially-trained home carer for an evening at the weekend. But a great deal needs to be done before you are ready to hand over care of your child like this.

As parents, we coordinate parts of care with a lot of professionals. For every piece of Nova there is a different expert. We deal with 15 different doctors, across three different hospitals in Holland. More than 10 caregivers and therapists who work with her daily in the care facility and in a normal primary school that she visits every Tuesday morning. If you don’t have the ‘helicopter view’ yourself and maintain the consistency required to coordinate all that is necessary between these caregivers, no one else will do it.

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In the meantime, our house has been extended on the ground floor, with a complete annex for Nova’s bath- and bedroom. The house gets fuller and fuller with special equipment. Imagine this in and around your house: a wheelchair, a wheelchair van, a wheelchair bicycle, an adjustable chair, an adjustable home care bed, a big bedbox in the living room, a standing frame, an adjustable shower bench, an adjustable washstand, a mobile lift, a tube feed pump, a mobile stander for the speech device. Every piece is necessary for the intensive level of care Nova requires and each must be completely adapted to meet her needs, now and as she grows and develops.

Much time is taken up in contacting all the different suppliers – to request the equipment, another adaptation, another repair.

Sometimes we receive a generic letter about a change of supplier for ‘your home care aid’. Yeah right, but which one of the 20 items?

Emotionally it’s tough, because living through it and accepting it will never stop. Time and again I feel sad and the feeling of loss is increasing, as the gap between my child and other children is getting bigger and bigger. She is growing into deficit. Every time we are confronted with milestones that Nova will never achieve or just little things connected to ‘what is not’ that can seize you suddenly. And sometimes you can handle that better than others.

Support and understanding from your family and friends is most important here I think. Contact with peers is also very helpful. Recognition makes me feel I’m not alone. A wealth of useful tips and experiences is what I find with them. Professional psychological support can sometimes be crucial, but not readily available. It can help a lot being able to talk to someone who is not closely involved in your family, but who does understand what is going on.

Every professional mainly treats one little piece of Nova. But for us, the holistic or ‘helicopter’ view is só important. What is the effect of the conversation that we have right now or the decision that we need to take, on Nova as a kid, and on our whole family? How do we feel about it? Do we keep an eye on the impact on Nova’s sisters?

As an example, I want to talk about the relation between me as a parent and the caregiver in the day care facility. To me, an equal relationship is very important. I want to be seen as the expert on my child. Which of the caregivers knows how my daughter responded to an investigation or therapy when she was little, through which I may now explain her behaviour? I am the only carer who has been and will be involved for years, 24 hours a day.

I’m also in control, at all times, so I appreciate it when the caregiver calls me to discuss when she wants to deviate from the agreements we have made. For example, if she wants to tube feed Nova more, because she doesn’t want to eat orally.

In turn, I acknowledge the caregiver in her professionalism and wide knowledge and experience of other children like my daughter. How often have I brought her into the care facility in the morning with a lot of questions in my head and even tears in my eyes? Such a relief when they listen to me and give some useful advice or plan a moment to sit down and discuss things further.

When we mutually respect each other’s position in this process, we do the best we can in caring for both Nova and me and our whole family. And I hope that when Nova is 25, whether she still lives at home or not, we will do this in the same way. Because, as her legal representative, I will still be as important in coordinating her care as I am now.

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I don’t know what it’s like here in Finland or in any other European country, but in Holland, financially-speaking, it seems to be well arranged. A lot of the ridiculously high costs for care, for care equipment and all the adaptations are reimbursed, but certainly not all. And it’s always very uncertain whether payment will actually be arranged in time, whether it will be at the expense of other allowances, etcetera. We had to make payments for our wheelchair van ourselves. In 2017 we were lucky as, unusually, our local authority paid for the extension built on our house. Yet this was only confirmed in writing two weeks before the work was finished. Others have to be content with insufficient solutions or even finance everything themselves.

As Nova is under the Dutch law for long term care, we are entitled to a personal budget that we can use to pay for most of the necessary care now. But the future is uncertain. Will the budget also be sufficient as more and more care becomes necessary? If Nova is able to join an education program in school? If Nova is 18 and legally an adult but still completely dependent? If she can no longer live in our home? If there is an emergency situation and we need more care immediately? Other parents’ experiences concern me at this point. Politicians seem to be slightly more aware of families like us now, so let’s hope this will lead to a better future.

The past years have felt like a flood that is continually growing, every time something new has arisen that we have had to deal with. And in spite of the great joy we also feel in having Nova, the situation for both now and the future has enormous consequences for our family.

And that’s why we need extra oxygen, a new oxygen tank regularly, please. Continuous support in all the areas I’ve mentioned, to be able to keep standing, this whole journey long. And although I have spoken about myself here, I also speak on behalf of my husband of course. Because I am grateful we can do this together. But without help, we will not be able to make it together.

Thank you.

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