

# Special Needs Special Life: 3 Keys to Conquer and Experience Peace while Parenting Special Needs Kids

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Written by Johanni Meiring.

## Dedication

Writing this book has been an enriching process and dream come true for me. I would like to thank the following people for your inspiration and support in this journey:

My Jesus for urging me and equipping me, and forming our lives with His hand

My husband for letting me get personal about our life, loving us and encouraging me

Our family for loving us through the good, bad, and ugly

My friends who has been cheering me on for so many years

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Charlene Vogel for the beautiful cover design

Special thanks to our children Johannes, Emma and Deronne, without you there would be no book

I love you so much!



# Bible references

Rom 8: 36-37, *NIV*

As it is written:

“For Your sake we face death all day long; we are considered as sheep to be slaughtered.

No, in all these things we are more than conquerors through Him who loved us.”

John 9: 1-3, *The Message*

Walking down the street, Jesus saw a man blind from birth. His disciples asked, “Rabbi, who sinned: this man or his parents, causing him to be born blind?” Jesus said, “You are asking the wrong question. If you are looking for someone to blame. There is no such cause-effect here. Look instead for what God can do.”

# Introduction

Dear Reader

Welcome to some very tender places in my heart.

Special needs parenting is not something you ever think about until it happens to you. It's like a Christmas gift you never desired, landing in your lap.

Yet, this package has your name on it and there is no doubt that it's yours.

Our parenting package was just as unexpected and confusing, but with this journey our lives changed in ways which is hard to explain. After 14 years of special needs parenting, I would like to share some experiences, lessons and encouragement which I pray will be of help to you.

There are no right or wrongs in this process called life, only choices. I believe that even in the moments of utmost confusion, there is grace for our special parenting choices.

In this book I share *three fundamental keys* that showed up while we, as a family, were storming through our reality.

May these words and thoughts help you know that you and your child will be okay.

**There is hope amid crises, confusion and pain.**

**SPECIAL NEEDS SPECIAL LIFE: 3 KEYS TO CONQUER AND  
EXPERIENCE PEACE WHILE PARENTING SPECIAL NEEDS  
KIDS**



# Chapter 1: Our Story

I decided to share our story with you, to connect with your heart. Your story differs from mine, but I know our hearts will relate. There is just something special about a conversation between friends who experienced the not-so-pleasant surprise that they turned out to be special needs parents.

Journey with me through my story of people living in an alternate reality. A parenting journey unexpected, not better or worse than what anyone else have experienced in this life.

Let's begin...

## **Our gift from God - Johannes**

After a long wait to fall pregnant my pregnancy was such a surprise and joy, so wonderful to announce in the early months of 2005!

I dreamt exciting dreams about our baby, and me being pregnant, at last. In all my thoughts about my future, I could not imagine any event being more significant than being happily married and having children. As idealistic and wonderful as those aspirations were, just as disillusioned did I feel when reality hit with my first wave of pregnancy nausea.

To be honest, it successfully killed the movie-like “I’m-having-a-baby-joy” quite quickly. I was still very excited about being pregnant but had to concentrate so hard on not throwing up everywhere, that I kind of missed the first three months of pregnancy. Gradually the nausea got a bit better. At the end of forty weeks I still cherished the thought of the magical moment of birth. My expectation of how labour was going to be, was the *grand finale* of my first pregnancy. I was going into labour drug-free, aiming for water birth...

Johannes' birth was not what I expected. It was traumatic, long and very painful. I was still in shock for a few days afterwards.

This disappointment was uniquely devastating to me in the season of my life when having my first baby had to be perfect. The best effort I could give. The magical motherhood dream I was yearning for.

Alternatively, I was introduced to the first bits of my new reality, changing my mind-set and setting off into dealing with so many unexpected moments and realities still awaiting us.

The absolute wonder of our first baby, was like many other parents' experience: just too realistic for comfort...

I clearly remember our first night at home after the birth of Johannes. He was screaming uncontrollably, and I was so angry, angry that no one ever told me that holding my precious new-born baby would feel so terribly out of sync. All those magazine pictures with smiling mothers with a sleeping baby on her shoulder came to mind, and once again I could not understand. I thought I had everything figured out. I prepared so diligently, tried to be so ready for this wonderful moment in our lives.

My eldest son's colic and constant hunger sent me through the turmoil of not having enough milk, and very rarely succeeding in keeping him content.

As months rolled by, he reached his milestones of development up until two years of age, as far as a mother of her first baby would notice. His speech was not very clear, but we understood him, so we didn't really notice the fact that his milestones weren't reached and developing completely as it should. The only serious, constant battle was sleep. *We Baby Wised* and *Baby Sensed* (these were popular baby books at the time) as much as we could but continued to just cope with social events and out of the routine situations.

We did not have the baby that would just fall asleep out of exhaustion, but the one who just woke up more and more the longer the day went on. I remember our nurse's comments at our check-up visits: "Is he very sensitive? Does he experience life very intensely?" I could answer a definite YES on both questions, but there was no discussion further than that.

My son and I had a very close relationship in those years. The television was a saving grace for us many times. He was absolutely captivated by a screen; it could stop any meltdown. However, once the television was on, he would also not get tired of it, and we realised that he got over stimulated and had to put it off to keep our routine for him.

### **Absolute faith - Emma**

Our daughter was born right on que just as planned, 20 months after our son. "O, the ignorant plans of young parents," bargaining on living life exactly as they mapped it out.

There was big excitement in our family about the first girl amongst all the babies. We were also cautious about her baby behaviour since having the experience of Johannes' colic, bets were on if she was going to scream or not.

Well, she didn't disappoint, there were screaming matches and very little peaceful nights. We thought: "These things happen, just accept that baby years will not be easy for you."

We now had two children still in nappies. Potty training just did not seem to want to happen for our boy and the "terrible two's" was truly terrible. Observing other kids and parents in our peer group, I started to realise that he was being disobedient many times in incidences which he knew was wrong, but it almost seemed as if he could not help himself. He would repeat the same behaviour over and over, without learning from consequences. It caused stress in our home, but once again this behav-

your was counted as personality traits, strong-willed ways etcetera. I can remember tiresome days, screaming hours and so many hours of feeling defeated. Who else's fault could it be but my own, and the ways of parenthood?

I distinctly remember one evening, Emma was about three months old, and I was taking a bath with one hand on my baby's crib next to me on the floor, to regain some sanity. By then I was in a serious sleep deprived and defeated state. Nothing seemed to help to calm her down. She was still screaming loudly and painfully as she's been doing for the last hour without resolve. The thought suddenly crossed my mind: "I wonder if she's not autistic?" – Autism – a frightening concept I read about for the first time in a magazine a few weeks earlier. I was shocked at my thought and rebuked myself for thinking such things about my beautiful daughter... still crying.

Life carried on after that moment. Emma was just being a baby, not really sleeping. But who slept in our house anymore anyway..?

She sat very strongly on five months and started eating solid foods. At the age of eight months I could remember my daughter making sounds to start talking, sounds like "mama"... she made these sounds for a very short space of time, and then it just stopped developing further. The sounds were replaced with crying and unhappiness increasing each month.

When Emma turned one year, we planned a special birthday party, and a dedication to her. That day I will never forget, she was so stressed and had an allergy attack. The whole day just felt like a complete disaster! I was so disappointed.

That same day we also prayed for our new baby that was already on the way...

I was experiencing one of many bittersweet moments of our family life.

*I felt completely out of control with Emma's behaviour and in total awe that I am going to be a mother of three children.*

## **Surprise! Freedom and Spirit Filled - Deronne**

Yes, you read correctly. I fell pregnant again when our daughter was nine months old. I could remember feeling a bit nauseous and tired for a week before we did the test, but being pregnant was the furthest thought from my mind. I still thought that *I don't fall pregnant easily* and therefore did not take any permanent precautions regarding birth control...haha. There was so much going on I just didn't think that I could get pregnant this soon after Emma. Well...I did!

As you can imagine our third pregnancy came as a big shock to us. Not planned, and a big challenge to wrap our minds around, taking into consideration our current state of survival. Our Deronne surprise was one of the most awesome experiences of my life. Just when I thought that I was at my complete end on what I had to give; God blessed us with a child which He knew would force me into surrendering to Him. My cup, and my arms literally overflowed with children.

Deronne has brought so much other perspectives to our lives. God had a very definite plan.

Time does not stand still, and we carried on.

After a few months I was very pregnant but still carrying my daughter around. She was clingy, insecure, non-communicative and unhappy most of the time. It was hard, but at that time we did not attach any serious value to her behaviour. I did notice some differences in my peer group and family's experiences in raising their children, but I accounted our experience to the uniqueness of our family. Small children start to become clingier when mommy is pregnant, right? I just attributed most of Emma's behaviour to that.

On 23 April 2009 Deronne was born. It was a very different experience from the other two births. I almost did a drug-free birth again due to the anaesthetist being late, but God was gracious to me, and the doctor arrived just in time. Just after he administered the epidural my blood pressure fell and I really thought I was *not going to wake up*, but sure enough I did wake up ready to push my baby out.

I must say the third time around you have a good idea of what is coming, and no unrealistic fairy tale expectations on having a baby in the house. Some peace came with that...

The first few quiet days with our new baby I felt so blessed. I literally had more children than I could carry. I always wanted more than two children and dreamt of a busy house with lots of people. Well, that is what I received.

*...Just with a few bells and whistles I did not expect.*

Even though Deronne was not a completely quiet baby, I experienced so many restful “magazine-mom-and-baby-moments” with him. I remembered feeling so surprised that there could be so many predictable moments in raising a child. Much less crisis management and calming down moments. Many more happy moments. There was so much relief.

### **Ever present guilt**

Even as I write this, there is a feeling of guilt. The guilt of having a different experience with one baby than with the other two. Guilt that somehow this experience could show up in my motherly relationship with each child.

Then I remember that my love for each one is so strong, stronger than any words that I can write down here. Looking in each little face, feeling each one’s skin as I bathed and cared for them can never be diminished

by any experience, no matter what we had to live through, or fight through.

*No amount of unexpected behaviours can dim the flame of parents' love for their children, even if the parents do get tired beyond what they think they can manage.*

## **The day we had to face the possibility of diagnosis**

I can remember this specific afternoon so clearly. It was over a weekend and we had a small, late afternoon get-together at my sister in law's house. Deronne, our baby, was almost three months old and we were still in "showing off the baby mode" to those who haven't seen him. It was a difficult afternoon for Emma, even though we haven't been there for long she just couldn't settle. The experience wasn't foreign to me and Gideon, we got used to her not sitting with any other people but us, and her being unhappy most of the time.

Obviously, family members started to notice that her behaviour was not improving, we just had so much going on that the only option was, survival. After all, who would think that there is something wrong with your child if she is a difficult toddler who just received a baby brother?

At some stage during our visit that afternoon Ebeth (my father in law's wife and heart friend to us all) just started asking and talking about the kids and how Emma is doing. Then, with all the courage she could muster up, she said that they have been worried for a while about Emma, and if we would not consider taking her for an evaluation at a therapist.

It took my breath away.

Even though I was very shocked at what this implied, I remember thinking at the same time: "Maybe all of this isn't just our fault. This chaotic sense of reality." We have been tired for a very long time and didn't really fight the idea.

That day our not-so-normal life started surfacing. I will forever be thankful to Ebeth who said those words. She was brave enough to talk where angels fear to tread. Without her suggestion, we would have lost lots of time in finding our way in helping our children.

*God sends angels along our paths, and more times than not they are the ones next to us.*

## Diagnosis

We started phoning around and finding out where to evaluate Emma.

This is such a common phrase to me now, but at that time evaluating her evoked so many emotions inside of me: “Is there something wrong? What could be wrong? What could they say? She is just a baby. Did I do something wrong? What do I do when there is something wrong?”

Even though I had all these thoughts, I never had an idea what the outcome would be. All I could think was:” I had a beautiful little girl, she’s just unhappy. She’s just unhappy. It would be great if *we could fix the... unhappy.*”

We secured her first evaluations with speech, occupational and physiotherapists who did the evaluation together. Waiting to go into the evaluation room was one of the hardest things I have ever done. While I was waiting, I just told myself “it’s going to be okay” but it’s almost as if I knew that it wasn’t.

All the evaluations were very thorough and sensitively done. I did not understand most of the feedback, but as they started explaining I realised that what they are saying is NOT GOOD. There is something wrong. Most of her development milestones were delayed, and they didn’t know why.

The initial feeling after receiving this news were numbing and shocking, but I remember my default mind set: “Run with the torch, I will save my child.” This mode just said: “Find out what’s wrong and fix it.”

After receiving the evaluation reports the therapists made an appointment with a resident specialist for diagnosis. The process of testing was daunting, but I WANTED TO KNOW, WE WANTED TO KNOW what was wrong with our child.

At the end of the appointment I was sitting shivering, waiting for the outcome. Then the specialist said these words: “The tests I have done is inconclusive, do you really want to know what is wrong?”

*I was shocked, perplexed and traumatised. What did she mean? How could she say that? I felt like I was falling, and she wants to know if I really want to know why? My child is not walking, talking or thinking the way she should, and I am not allowed to know why?*

To this day I still don’t understand what happened there. I walked out livid *carrying my torch* determined to find out what was going on. In “the torch mode” I was Googling frantically and questioning therapists till I’m sure they wanted to cry.

As I was gathering more and more information, I knew we had to explore the Autism Spectrum Disorder (ASD) possibility. It was daunting, but the only path that made sense. Emma was receiving therapy, but without specialist input we were not moving anywhere; every therapy session was a screaming match. I hated going there, if they started working with her, she was upset, when I left the room it was worse.

I then researched Autism in South Africa and found a specialist who specialised in the diagnosis of autistic children in our country. It was an expensive appointment, but worth it. Right..? We needed to help our child!

I was waiting in the car before our appointment with an expectation of clarity and answers. That day, Emma was as happy as can be. Can you believe it? We struggled moment by moment, day by day, but **THAT DAY** Emma did everything right. She was happy, and friendly, worked with the doctor during the test. The girl I saw on that mat was the one I wanted her so desperately to be every day.

I walked out with the comment that this doctor did not see Autism in the mix with Emma, and that she wished me the best of luck. This whole day seemed so backwards.... I was supposed to be rejoicing about the outcome, but once again I left her room perplexed. The Emma she saw was not the Emma I knew. This just left me helpless, once again.

I was not giving up; therapy sessions with Emma was very difficult and her difficulties didn't improve. I just knew I had to keep on searching. After a while, with the help of my heart friend, we could secure an appointment with a behavioural paediatrician.

That day I knew we were going to get an answer.

After testing Emma, the doctor was ready to give his very specific and concise diagnosis, but first he explained how ASD works and the typical behaviours associated with Autism. I was so relieved to be informed on how the behaviour of my child fit in with the diagnosis. This was a big part of what I was missing through our journey, just understanding my child's behaviour better.

While he was explaining how the spectrum works and the typical behaviour children present, I mentioned that my eldest son also displayed many of those behavioural traits. Those strange behaviours I couldn't explain suddenly had an explanation.

On 2 October 2009, one day before Emma's second birthday, she was diagnosed with Autism. The doctor also sent us to do evaluations on Johannes for clarity on his development.

I'll never forget that day, just after we received diagnosis for Emma. My husband and I went to a restaurant close to the doctor's rooms. We sat together but didn't really know what to say, it was as if somebody punched us in the gut. Emma was sitting on one of the rides that just goes around and round, it made her very happy.

### **It was the start of our journey on the Autism ride.**

I remembered crying about the diagnosis that same afternoon when a friend came to check in if I was all right. *Almost the way you visit people when someone has died.* The hardest was to try to explain what the doctor said, verbalising the typical prognosis for Autistic kids made me feel powerless and lost.

We did the evaluations for Johannes and it was clear that there were certain specific delayed milestones for him. He had to receive speech and occupational therapy on a regular basis and was prescribed scheduled medication for behavioural improvement. He was diagnosed with ADHD.

In one month's time we received two diagnoses for two of our kids.

One of the phrases that helped me through was: "It can only get better from here", but these words did not solve all of our uncertainties and fears.

As with any tragedy, life does not stop, so we carried on from then just trying the next best thing on this very foreign journey.

### **There you have it...**

Our story up until diagnosis, in a nutshell. The emphasis is on nutshell. There are so many details which I have not included. There are also many people in different seasons who have been on this journey with us for years. They loved and supported us while even we weren't sure what to

do. The support from friends and family which braved this journey with us carried us and is still such a relief in our lives!

When it comes to support, I often find so much value with the simple act of grace. In the midst of our difficult times, when people handled us with grace, it gave us the courage to go on.

The days and months after diagnosis were challenging. Is challenging still. Our lives do not reflect the typical difficulties of parenting or day-to-day-routines. It's more complicated, but uniquely ours...

God had a specific design for us in mind. This design keeps us on our toes and on our knees all at once. Is it good? Not always. Is it bad? Not necessarily.

Would I change things if I could? Earlier in my life I would answer a definite YES, but now as I share my heart, I know that I would be a different person if Autism and ADHD did not come our way. The changes these challenges caused in me could not be done any other way, and I have peace in that.

I am very thankful to God that He decided to focus on my character in this special way.

# Conquer

The definition of the word **Conquer** (*Merriam-Webster.com*): *To gain mastery over or win by overcoming obstacles or opposition.*

*“Dear believer, after experiencing the terrible valley of suffering, did you depart with the spoils? When you were struck with an injury and you thought you have lost everything, did you trust in God to the point that you came out richer than you were before?”*

*Being “more than a conqueror” means taking the spoils from the enemy and appropriating them for yourself. What your enemy had planned to use for your defeat, you can confiscate for your own use.”*

*– Streams in the Desert by LB Cowman, 1997*

## Chapter 2: Three Keys to Conquer in Your Special Parenting Journey

If you are a special needs parent your reality has been shaken as ours were.

How can I claim that it is possible to live a fulfilling life in the face of so many trials and challenges? Dear reader, I write these words because I have experienced it to be true. I really want you to know that your life is deeply meaningful. You have not been left behind or forgotten.

**Important Note:** Let us not confuse a **fulfilling life** with a **comfortable life** that would simply not be true. These keys are meant to be tools to help you open the way to living significantly. To find your life *which towers above survival and will open secrets in dark places which will astound you.*

Get ready to take back your life with hope and excitement!

### **Key Number One: Letting go of the dance with denial**

We must start here, denial, so ever present in our lives. Often, we hang on to this emotion so much that it can even feel like a long-lost friend.

The psychological definition of trauma is “damage to the psyche that occurs as a result of a distressing event or an overwhelming amount of stress that exceeds the ability of the individual to cope and integrate the emotions involved.” (Amy Kee, 8 July 2018 – from psychcentral.com)

One truth which I have realised over and over again through our process of diagnosis and journeying with other special needs parents is this:

**On that day when diagnosis is received... you are also diagnosed, not only your child.**

Think about it. Our children are mostly not in a season in their lives or even capable of understanding the words, meaning or consequences of the diagnosis. You receive the blow and you have to process it and take responsibility for the consequences it may bring.

Special needs parents experience trauma in diagnosis of their children, but as in many traumatic situations it goes untreated and you must walk out of the doctor's rooms with shock and helplessness. Then, while you are still bleeding, you must move forward in this state together with the huge responsibility of your child's future on your shoulders.

Most of the time the parent doesn't even know what exactly happened, and how they got to be in this situation but move forward they must.

These words by Amy Kee struck a nerve. It is exactly how I felt after diagnosis.

"The view through trauma-tinted lenses is one of constant fear. It makes the world seem a frightening and dangerous place where no one can be trusted." (Amy Kee, 8 July 2018 – psychcentral.com)

There is a range of possible responses to trauma. We are not all the same and each one of us react to life in different ways. Our emotions and reactions just make so much more sense if we understand what is happening to us on a psychological level.

Naturally a person who experience trauma has two psychological experiences they face: The Grief Process and Post Traumatic Stress Disorder (PTSD). Please note that grieving and experiencing Post Traumatic Stress Disorder are not results of being weak! They are simply very natural and understandable human reactions to trauma.

**The grief process has five stages:**

1. Denial - this can't be happening.

2. Anger - why did this have to happen?
3. Bargaining - I promise I'll never ask for another thing if only you will...
4. Depression - a gloom that comes from having to adjust to reality so quickly.
5. Acceptance.



(Source: The 5 Stages of Grief & Loss by Julie Axelrod, 20 Nov 2019- psychcentral.com)

### **The main symptoms of PTSD are:**

- **Re-living the traumatic event** through distressing, unwanted memories, vivid nightmares and/or flashbacks. This can also include feeling very upset or having intense physical reactions such as heart palpitations or being unable to breathe when reminded of the traumatic event.
- **Avoiding reminders of the traumatic event**, including activities, places, people, thoughts or feelings that bring back memories of the trauma.
- **Negative thoughts and feelings** such as fear, anger, guilt, or feeling flat or numb a lot of the time. A person might blame themselves or others for what happened during or after the traumatic event, feel cut-off from friends and family, or lose

interest in day-to-day activities.

- **Feeling wound-up.** This might mean having trouble sleeping or concentrating, feeling angry or irritable, taking risks, being easily startled, and/or being constantly on the lookout for danger.
- It is not unusual for people with PTSD to **experience other mental health problems** as well, like depression<sup>1</sup> or anxiety<sup>2</sup>. Some people may develop a habit of using alcohol or drugs<sup>3</sup> as a way of coping.

(Source: Effects of Trauma – PTSD - phoenixaustralia.org)

Without running the risk of getting too “psychological” on you I want to urge you to take note of the fact that when you go through trauma that one or all of these symptoms might be your reality at some stage or you may be experiencing some of these symptoms even now. Our special needs parenting experience made me realise that if I knew that I was in a process of grief, I might not have stayed stuck in denial for as long as I did.

Denial has its purpose, it kept me from falling apart many times. Denial can help us for a short period of time, to come to terms with reality without shutting down or detaching ourselves from our lives out of shock.

But... when we stay in denial too long it can cause us to make wrong decisions for our kids at crucial times of their treatment. We are then reacting out of fear and disillusionment rather than common sense. We can simply be better parents when we are not in denial. I must warn you that denial can disguise itself in many ways. We have different ways to not face

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1. <https://www.phoenixaustralia.org/recovery/effects-of-trauma/depression>

2. <https://www.phoenixaustralia.org/recovery/effects-of-trauma/anxiety>

3. <https://www.phoenixaustralia.org/recovery/effects-of-trauma/alcohol-and-substance-use>

reality, but if that survival skill is wearing you down and stealing life from you, chances are that you are still dancing with denial.

Acceptance feels light and joyful not heavy and without hope. Imagine living with a feeling of peace, even joy, about your current circumstances. Imagine waking up in the morning without the burden of being responsible for developing, or changing your child, but only for loving them for who they are. You are allowed to have that life.

When I finally reached acceptance (not complete acceptance - but most of time), the weight which was lifted from my shoulders was extremely significant. Suddenly my eyes were opened to a new kind of reality with hope and peace.

Moving from denial to acceptance is not quick or easy. It is a process, with all those stages as discussed above, which has to run its full course. You need time to grieve properly.

It is the first step to taking charge of your new life.

Embrace the process, don't fight it.

### **Key Number Two: Accepting that you cannot fix your child**

If anyone gave me this advice when my babies were small, I would be downright angry! Surely, I do play a big role in my child's journey to a better life?

Every parent plays a tremendous role in their children's lives, and this is just as true for special needs parents. Reality is just that our first reaction is usually: "Okay so it's broken, let's fix it". But it would help us more to first come to terms with the extent of the damage. That is just an approach which is very painful, and much harder to do.

In those early days after diagnosis, almost immediately after, I started doing what we all do: I picked up my torch and started running. Firstly, trying to find out what the doctor meant when he used those diagnostic terms, and then how I can find more treatments and remedies to help my children. I could not accept that this was the be all and end all of our story.

Obviously, our specialist had a treatment plan. I was just not going to sit around and wait for this prognosis to happen to us; I was going to try to fix it. I was going to do something to make this whole thing just be better or less painful in some way. I wanted this bad dream to end, and the only way I knew how, was to do more. By being busy I didn't have to think about the diagnosis or really deal with it.

In the centre of this denial cycle of mine a lot was done, and I mean a lot. BUT...I was also on the verge of a breakdown on any given day. Nobody really dared to ask how I was doing. I guess they did not know how to respond if I told them how I felt. (When you are a special needs parent, without even knowing, your life intimidates people. They don't know how to help). All I knew was that I had to survive, and I just kept going.

Looking back I am tempted to feel that this was the season I had to go through to help my children, but in my heart of hearts I know that my children and I might have gained more if I was not that broken in that season. Years went past from which a lot of detail is missing from my mind, I was too traumatised to just love my babies. They had to be better and more normal. It was a heavy load to carry.

Despite the ways I could have parented better, the journey was still our unique process which we travelled through and learnt from. Mercifully my eyes did start to open as they grew up. Gradually I realised that I will be losing out on my and my children's lives if I did not stop trying to play God, determining their every step to push them towards "normality."

Once I started to tell myself that things are as they are, that it's okay to have special needs children it was as if a curtain was lifted. So many of the provision for their needs started to seamlessly fall into place. This happened as I accepted, surrendered to God's plan for us, and decided to find joy in our everyday lives.

Surrender did not mean healing of their conditions, but healing of my pain and loss. I was starting to heal, and it influenced everyone around me. I would not change that experience for anything.

Everything special needs parents do for their children have an extreme impact on their lives. You know where there is help needed and what options needs to be tried out. Just remember you are not a healer. God is the only one who heals.

You are a parent; it is so important to just be the parent with the love for your child at the centre of that.

*A beautiful transformation happens when all preconceived ideas and idealistic goals are set aside, and we can just accept each other and love each other for who we are. Your child needs that acceptance from you.*

### **Key Number Three: Taking back your life for everybody's sake**

There is one universal truth: Parents doubt themselves. Thousands of parents look for parenting advice wherever they can find it. They feel guilty, not good enough and overwhelmed. If you talk to a friend and he or she feels unsure about parenting for some reason, it's usually quite easy to encourage them and help them to not feel hopeless as a parent. Now turn the focus and try to encourage yourself for being a good parent. Well that's a whole different story. We usually have a fundamental flaw in our parenting mind-set and that is GUILT.

While other parents carry the load of feeling guilty about day-to-day parenting, we carry the load of wondering how we could have contributed to our children having a special need, disability or condition. Then we add the day-to-day guilt of not doing enough to help our children.

None of these guilt trips are helpful. You can fight those voices who are shouting accusations in your ears. Guilt only drag us down and make life too heavy to bear and prevents you from experiencing joy. I have personally not met one special needs parent who is not doing their uttermost best to help their child, speak good words to yourself.

All the negative self-talk does is to keep us in a defeated state...

*“When you’re in survival mode, you’re just trying to get through the day. Survival mode means there’s no long-term or medium-term plan. It’s all about getting through the next 24 hours... When you’re stuck in survival mode, you feel like you’ll never dig yourself out of the hole.”*

(Source: Lee Rosen, 8<sup>4</sup> Signs you’re in Survival Mode – How to escape, Roseninstitute.com)

Survival mode can stay the way of living for us. It can become such a default mind-set that we might even feel a bit guilty if we are not feeling as if we’re drowning.

Survival mode has a way to transfer anxiety to our children, they are so tuned in on us that they cannot escape the helpless anxiety we are prone to experience daily.

I want to propose another approach to you. An approach which is in your reach, and can change everything for you, for the better.

## **My proposition?**

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4. <https://roseninstitute.com/8-signs-youre-survival-mode-step-escaping/>

- **Surrender your fears to God**

The only way to “reset” things and try to live a lighter life is to surrender. We cannot surrender this load to anyone. The only One who can truly carry this load is the Author of our lives. He understands the meaning of your life, He has the answers to your questions.

- **Remember the time before kids**

Often, once we become parents, it is so easy to forget who we truly are. Children are such an intimate part of our make-up that we get consumed with our parental life. We lose parts of our identity and forget how we lived life before kids. Have you tried to remember who you were before kids? It might seem that everything has changed including your identity, but that is not true.

- **Get to know yourself deeply and find out what gives you joy**

Only a selective few take the opportunity to get to know themselves better. Usually a personal or emotional crisis forces someone to re-examine thoughts and personalities, and their reactions to situations. We all can dig deeper these days. Life coaching, counselling and support structures are readily available to assist us in growing our emotional intelligence. That investment in yourself can change everything for you.

- **Give yourself permission to love life despite your challenges**

We all have serious issues to deal with, the beauty of life and the silly things around, help us cope through them better. Give yourself permission to wake up with a song in your heart,

counting the good things in your life. There are so many good things if we can focus on counting them and appreciating them.

- **Reach out to support**

You may feel very isolated and alone in your journey, I can assure you that you are not alone. There might not be a family with the same conditions around the corner but keep on asking around and somewhere you will find someone who understands what you are going through. Do not refuse help if people offer their resources, find a way to enjoy the support. It's good for you and for them. For more information about PARENT REALITY (Our support group which supports parents with special needs kids) read the insert at the end of the book.

All these proposed actions will take definite intention from your part. Each one of them is also a process by itself. It is my hope that I will be able to provide further content to help you navigate through them. But for now, keep them in your heart and address them in any way possible.

In short, do not believe the lie that your life has been taken away from you when, in fact, it is as it always should have been. Your destiny has always been to have a mind-blowingly, powerful, significant and different life, which few people get to live.

My friend asked me this question right in the beginning of our journey... "Who wants boring children anyway?" After a few years I can answer: "Not me, definitely not me!"

Without simplifying your experience in any way, I want to encourage you to not lose a big part of your life in trying to fix, understand or deny your special needs journey. This experience can enrich and grow you. I lost precious time, don't do the same...

My friend, give yourself permission to dream, to be honest and love your life!

We are all only granted one life, live yours!

**These are the three keys** which I wish I could get a grasp on throughout our journey. I really believe that an understanding of my grieving process would have saved me and my kids from so much emotional chaos.

But...I will never regret our journey because it led me to you.

These keys can serve as tools in saving you from unnecessary emotional camping in places which leaves you numb and fearful.

Let's take your special life back.

## Chapter 3: A Few Words on Faith and Your Child's Condition

It is almost impossible to deal with diagnosis of any kind and not bring God into the picture. It's in these situations, that our helplessness gets highlighted, and our acknowledgement of an Almighty Hand is the next step.

We ask why, we fight, and we pray. Miracles do happen, but chances are that you are reading this book because your miracle hasn't come. Just know your experience does not prove that God does not exist, that He does not love you or even that you will not see a miracle for your child. It just means that we live in a broken world and your child is affected by it, as are all of us in some way or the other.

While Jesus was on earth, he healed some people, but not everyone, even Paul struggled with a thorn in his flesh till the time of his death.

God's thoughts are higher than ours, and His hand is very securely stretched over you and your child. He said that in this world we will have trouble. Well, then I presume this is our trouble. He also follows by saying: "...But take heart! I have overcome the world." He is not leaving you to deal with this alone. He wants you to overcome with Him, and to overcome does not just mean to win the battle, but to also take the spoils.

In your journey there are ample spoils for you to grab on to. Reach out to the character, patience, faith and surrender which you can take hold of and wear it around your neck.

God works everything to the good for those who love Him!

And He is doing that for you even now.

I would like to share a blog post with you where I wrote down the clear insight given to me in my process of finding a reason for our children's challenges:

### **If I can just find the reason**

*(Written: 9 June 2015)*

That is the first thing you do when you receive diagnosis, you look for the reason. Who, or what is to blame for this terrible name given to our confusion? "It will make me feel better, if I know the reason I can cope better." But will we, cope better? Will our load be lifted with the reason for this pain? Will this untrodden path be easier to walk?

Walking down the street, Jesus saw a man blind from birth. His disciples asked, "Rabbi, who sinned: this man or his parents, causing him to be born blind?" Jesus said, "You are asking the wrong question. If you are looking for someone to blame. There is no such cause-effect here. Look instead for what God can do." (John 9: 1-3, *The Message*)

As I understand it, Jesus says no. "No, don't do that to yourself. Trust God for your life, see what He will do." If He will heal, if He will minister, if He will restore, if He will humble, it is all up to Him. But we must trust and look for what He is doing.

Face it. We cannot change the diagnoses. We cannot manipulate God into doing anything. But we can pray and trust, we can worship and find rest in Him.

We can spend our lives trying to identify the cause, the root, where it all began, and the source of this brokenness. And then when we find it, what then? Will we be free? No, we could just add grief, disappointment and most probably bitterness to our lives. All feelings we can do without.

Whether you know the cause and accepted or don't know and desperately want to know why. God advises us to look to Him. To draw near to Life.

“Before I formed you in the womb, I knew you before you were born I set you apart....” (Jer 1:5, *NIV*)

When a friend reminded me of God who forms us in the womb, I suddenly, with great surprise, realised that since the diagnoses I did not believe that He formed them purposefully this way. That somewhere, in this forming process there was a “glitch”. How unproductive to try and fix something I think God overlooked. How impossible. What a heavy burden.

To cope with the news I threw myself into every, and anyway to help fix whatever went wrong. Here I could cope and not fall into a pit of despair. We therapised, medicated, dietised and whatever else I could find to do. Any parent does this, when your child cries, you fix it. You change the nappy, give medicine, rock them, or kiss them. We are programmed this way we take care of our children. Do not get me wrong, all of treatments contributed to my children's development and the overall place they are functioning in today.

After four years I just realised, as if for the first time, God made them this way. It isn't just a temporary setback; they are unique and set apart. Their *way of doing* may look and sound different, but their life purpose will be carried out gloriously on this earth. And Gideon and I have the privilege to share the journey.

The blind man was healed, and nothing would ever be the same for him again. He testified, and praised God. He met his Maker in an unthinkable wonderful way. Through him people saw what Jesus could do. BUT if he was not blind, he was not part of this great uproar, this undeniable miracle...

(Source: [www.johannimeiring.com](http://www.johannimeiring.com)<sup>1</sup>, If I can just find the reason, post-date: 17 May 2020)

### **A prayer for you and your child**

Sometimes situations and circumstances actively influence our loss of faith in such a way that we feel as if it is impossible to gain faith again. Logic and past experiences overwhelm all the childlike faith we ever had.

In these moments of faithlessness God has always reminded me that as true as His healing power is, just as true is the fact that His ways are higher than my ways. Often the answer to questions has not been me insisting that God heal my children, but rather that my eyes be opened to see what He sees.

Lauren Daigle sings these words in one of her songs: “If You don’t move the mountains I want You to move, I will trust, I will trust in You”.

Faith and acceptance don’t necessarily have to function in opposition but could bring unspeakable rest and expectation all at once.

“Not either ... or, but both and more” – Nico Liebenberg

The following prayer pressed on my heart as I was listening to sermons about faith and prosperity. Not prosperity in the sense of love of money, but the abundant life He promises us.

May it give you words and hope in those times you do not know what to pray anymore, especially in those times when your faith is gone.

### **Special Needs Parent Prayer:**

*(The spaces provided is for your child’s name)*

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1. <http://www.johannimeiring.com/>

*Father,*

*Help me see what You see when you look at (\_\_\_\_\_) so that my way of looking at him/her will not limit his/her life purpose in any way. Help me to not lose hope and faith for any miracle you want to grant us at any time, as a result of his/her condition. For nothing is impossible with God (Luke 1:37).*

*Your servant David confirms in Psalm 139: 13-14 that You created (\_\_\_\_\_) 's inmost being and You knit him/her together in my/ my wife's womb. We praise You because (\_\_\_\_\_) is fearfully and wonderfully made. Your works are wonderful and I know that full well. You also say in John 10:10 that the thief comes to steal, kill and destroy, but You have come that we and our child may have life to the full.*

*Lord, grant (\_\_\_\_\_), and us, life to the full, and nothing less.*

*May Your will be done in our house on earth, as it is in heaven.*

*In the name of Jesus we pray all these things*

*Amen*

## Chapter 4: The Hope in Your Chaos

Making sense of difficult situations is draining. We think and reason, we talk and disagree but none of these actions leave us feeling better or more hopeful. There is no logical answer to chaos. We live in a broken world. Period.

How did I discover hope in our hard journey? Through love. Loving God and loving our children. You can make all the plans in the world but love for your child is what pulls you through at the end of the day.

Since we received diagnoses our children have grown. They have experienced breakthroughs and we have been living a special life. Special needs children do develop, they grow up in their own timeframe.

Hope and peace became part of our lives when we re-drew the blueprint from how our kids *should be TO who they really are*. Therapy helps, medication helps, and medical practitioners help. In our case all these avenues helped us build the unique path our kids and we would walk in.

With the Grace of God both kids have fully developed speech, have good cognitive functioning and shows love and affection towards those around them. All these things were my biggest fears of lack in their functioning, and they did not realise.

Today we celebrate uniqueness and walk with our special needs banner with pride. If you can't beat them join them....right?

Today I would like to assure you that you will be OKAY! This trial will not break you, it will grow deep, deep places within you.

Take heart dear parent, with God you can conquer this.

You are not alone!

## Closing Words

Isn't it amazing how easy it is to connect with someone who understands your journey? You feel safe and understood.

I realize that some of the issues in this book might have you thinking without specific resolve. I have found that discussion and reflections in a safe space often help us to arrive further along the journey of acceptance.

I would love to continue this journey with you through life coaching.

It was my privilege to spend time with you through the pages of this book.

My prayer is that you will start to heal one step at a time and grow into your destiny without hesitation or shame.

Keep fighting for your child but most of all love your life with all its richness.

You are destined for greatness!

All my love

Johanni xx

# The Parent Reality Community



Parent Reality is a support group for parents with special needs children. The group was founded in October 2014 with the purpose to:

- Create a safe space for parents,
- connect parents with each other and
- create platforms for sharing helpful information.

In the early days of our diagnosis I had such a need to speak to other parents living a similar journey but could never find those parents. Today Parent Reality teaches me day after day how these parents can help each other to heal and walk through their special needs lives.

Contact me if you would like to join our special tribe!

We have various platforms where you can find us.

<https://www.parentreality.co.za>

<https://www.facebook.com/parentreality>

[https://web.facebook.com/groups/269563743502833/learning\\_content/](https://web.facebook.com/groups/269563743502833/learning_content/)

<https://www.instagram.com/parentrealitysupportgroup>

Contact me at [johanni@parentreality.co.za](mailto:johanni@parentreality.co.za) to be added on our WhatsApp Group





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## About the Author

**Johanni Meiring** is a Special Needs Parent, Life Coach and Co-Founder of Parent Reality. She completed her training with Balance4Coaches (Course creator Nico Liebenberg) in 2014. Johanni also holds a degree in BCOMM (Marketing Management) from the University of Pretoria. Professionally she has experience in business communication, marketing and overall small business management. Johanni has a deep passion to serve and support Special Needs Parents.

Follow her blog on [www.johannimeiring.com](http://www.johannimeiring.com) for more written pieces on life topics and information about life coaching.

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