guide for Grandparents

Congratulations on the birth of your grandchild!

THE
SEPTEMBER
INSTITUTE

STICHTING Down syndroom

DSSA
Down Syndrome South Africa

Original edition
Een kleinkind met Downsyndroom-een gids voor opa's en oma's
Stichting Downsyndroom

This brochure, created for grandparents of children with Down syndrome in South Africa, is a collaborative effort between The September Institute and Down syndrome South Africa (DSSA)

INTRODUCTION

Congratulations on the arrival of your grandchild!

Your grandchild is truly unique, not only because they are your grandchild, but also because they have Down syndrome. In South Africa, approximately 500 babies with Down syndrome are born each year.

Given that your grandchild has Down syndrome, you may have additional questions. Many people are unfamiliar with Down syndrome until they are directly faced with it. This brochure is specifically designed for you, aiming to provide answers to many of your questions. If you have any unanswered questions, please don't hesitate to reach out to us. Seeking information not only benefits your child but also your grandchild.

Down syndrome presents a unique journey for you as a grandparent. It may bring forth a mix of emotions, from the joy of welcoming a new life to concerns about the Down syndrome diagnosis and the challenges your grandchild may encounter. You might be feeling a range of emotions, including confusion or anger. Each person's response is individual.

You may have concerns about your grandchild's well-being, your child and their partner's ability to cope, and what the future holds for them. These concerns are common among grandparents.

Many grandparents who have walked this path are eager to share their experiences and offer advice. While we can't take away the process of working through your emotions, we can provide you with valuable knowledge and insights from those who understand what you're going through.

COMMON CONCERNS GRANDPARENTS MIGHT HAVE

It is normal to worry when you receive unexpected news. Most individuals have not encountered Down syndrome before and have limited knowledge about it.

You may be asking yourself:

- Is my grandchild going to be okay?
- Can my child and their partner handle this responsibility?
- What kind of life will my grandchild have?

These concerns are common among grandparents, and you're not alone in feeling this way. The journey ahead may seem daunting, but there is a wealth of support and information available to help you navigate this new chapter.

> **“ Our son called to say our granddaughter was born. I went straight to the hospital. My daughter-in-law's parents were already there, and the atmosphere was heavy. But I immediately went to the baby. I didn't notice anything right away. I congratulated my daughter-in-law. She responded: ‘Don't you see anything?’ No, what should I see? ‘She has Down syndrome.’**

“ At the ultrasound, it turned out that the baby had a thickened nuchal fold. My daughter had an amniocentesis, and it was confirmed that the baby had Down syndrome. I never doubted the baby would come. My daughter has always worked with children with disabilities, so she knew a lot about it. Her reaction was: if this is it, it’s not so bad. In hindsight, we still feel the same way.

“ When my granddaughter was born with Down syndrome, the ground seemed to fall away from under my feet. Your world collapses. But you just keep going; no one has guarantees in life. Soon you learn not to worry about things that don’t (yet) exist. Enjoy the things that go well.

“ Our son called and said: ‘We have a son.’ I asked: ‘Is everything okay?’ ‘No,’ he said. Then the ground fell away from under our feet. ‘Everything is physically fine, but he has Down syndrome. I’m going to the hospital for further testing now.’ You’re shocked, but as soon as he’s in your arms, everything is over. He was so beautiful, but very floppy.

“ When my son called crying after Els was born, it broke your heart. We went to see them immediately. When we saw the baby, we fell in love right away. I don’t know what we exactly expected, but Els was such a beautiful child. It wasn’t as bad as we thought. My husband said when we got home: ‘What was I supposed to see? She looks very ordinary. You could see it a bit in her eyes and neck.’

RECOGNISING DOWN SYNDROME IN NEWBORNS

How can you tell if a newborn baby has Down Syndrome?

The answer isn't always straightforward. In some cases, it's immediately apparent, while in others, the signs may be less obvious.

Some of the typical features include:

- eyes that slant upwards;
- tiny folds covering the inner corners of the eyes (epicanthic folds);
- small white flecks on the iris (Brushfield spots);
- a small nose with a broad, flat bridge;
- a small mouth which makes the tongue appear large;
- small low set ears;
- a single crease on the palm of the hand;
- short hands and fingers;
- inclining pinkie;
- wide gap between the big toe and second toe; and
- a slightly flattened appearance of the back of the head.

Other Features

- Unusual looseness of the joints;
- Poor muscle tone (hypotonia) making the baby feel and appear “floppy”;
- Loose skin folds at the back of the neck;
- Heart defects occur in about 50% of cases;
- Eye defects occur in about 60% of cases;
- Hearing defects may occur and can affect speech and language;
- Developmental delay (intellectual disability varies from mild to moderate).

Not every child with Down syndrome will have all these traits mentioned. Like all children, children with Down syndrome resemble their parents, e.g. hair and eye colour but they also have some of the typical features of Down syndrome. Furthermore, each person with Down syndrome is a unique individual and can vary in appearance, temperament and ability. It is also important to note that a person’s appearance has nothing to do with his intellectual ability. Therefore, a person, who has more of these above-mentioned characteristics, is not necessarily more intellectually impaired.

> “ **I was there for the delivery. I could see something was different, but no one talked about it, so I didn’t dare to bring it up. When the baby was two months old, he came to stay with us for a weekend. I discussed my suspicion with my husband. My other daughter-in-law then asked the parents if they saw anything unusual. That’s when things started to become clear.**

WHAT TO EXPECT IN THE EARLY DAYS

Babies with Down syndrome may sometimes face a challenging start in life. Common health challenges can include:

- Heart Problems
- Digestive Issues
- Feeding Difficulties
- Jaundice
- Cyanosis

These initial health concerns often cause more anxiety than the Down syndrome diagnosis itself. It's understandable to feel concerned if your grandchild is facing health challenges. Remember that your son/daughter may need extra support or space during this time. Ask how you can best assist them and truly listen to their needs.

> **“My daughter spent a lot of time in the hospital with the baby during the first year. My son-in-law was at home with the older child. I also went to the hospital, just to be there for my daughter. There’s not much more you can do. But it was nice that I could do this.**

THE ROAD AHEAD:

Extended Hospital Stay or Homeward Bound:

For many babies, these early challenges improve within a few weeks or months, allowing them to settle into life at home. However, for others, ongoing concerns with the heart, digestion, or respiratory system may mean frequent hospital visits and extended periods of care.

Instead of enjoying the joys of grandparenthood at home, you may find that hospital visits become a regular part of your routine. These times can be tough, but it's important to remember that many families go through similar experiences and find support in each other.

PROCESSING THE NEWS: BEFORE OR AFTER BIRTH

Whether grandparents know about the diagnosis before the baby's birth or not, the emotional journey of processing sadness, shock, or concern is similar.

For Those Who Didn't Know: Many express that they would have liked to have known in advance so they could prepare themselves and learn more about Down syndrome.

For Those Who Knew in Advance: Some find that knowing ahead of time led to increased worry, which sometimes cast a shadow over the pregnancy experience.

Regardless of when the news is received, each family member will process it in their own way. The important thing is to offer support and understanding, both to the parents and to each other.

> “ **In hindsight, it would have been helpful if we had known in advance. Son and daughter-in-law think so too. You want to be prepared and able to read up on it beforehand.**

> “ **My daughter called to say our grandson was born. In the hospital, my daughter asked: ‘Don't you see anything?’ We didn't see it. When I heard it, I thought immediately: ‘Oh, it will be okay.’ But grandpa cried all day. He was very sad about the worries our daughter would face.**

“ It wasn’t known during the pregnancy. No screening done, didn’t think about it. But also, what do you do with the result? It was a shock; my son was also extremely emotional. But he was also a first-time father. The shock wasn’t about our grandchild, but about our son and daughter-in-law. You don’t want this for your child. That was the first emotional thought. Then our concern shifted to the baby. She didn’t open her eyes for a long time, and we worried about that in the first weeks.

“ There are now three more grandchildren on the way. They don’t want to know if any of them have Down Syndrome; they’re welcome regardless.

“ After six months, Sanne had heart surgery, and then we saw that our daughter was very happy that Sanne had pulled through. We saw that our daughter and her husband were very attached to Sanne, and they started to accept it a bit. Now that Sanne is a year and a half, they still find it very difficult.

> “When Ollie was born and it was confirmed that he has Down syndrome I didn’t feel as though it was wrong because I know that this is what God has chosen for Ollie and that he has a plan for his life. Oliver is now 2 years 7 months old and he is such a blessing in our lives. He is a happy smiley little boy who loves to blow kisses, has a quirky sense of humour, loves books, stories, music and yoghurt. He is happy to wait his turn and loves to learn new things. God has blessed Ollie with 2 wonderful, loving, hands on parents and a proud big brother. I am his Granny and his teacher and I consider it a privilege to be both. I love you so much my Oliver Gary Noakes.

> “I found it difficult to say at first and often cried. Now, after a few months, it’s better. Everyone was very positive, and I received nice cards. That helped a lot. There was really only one response that wasn’t so nice, but that was because the person didn’t know what to say.*

> “I always immediately mention that my grandson has Down syndrome. I need to say it; otherwise, it seems like I’m hiding it. It’s a part of him, and I’m proud of it. Jaimy is simply my grandson with Ds, just as Mara is my granddaughter with a beautiful head of curls.

Be prepared for stereotypical reactions from others, such as:

“They are so sweet.”

“Maybe it will get better.”

“Maybe he doesn’t have it too badly.”

“Why did they let him be born? That shouldn’t happen anymore these days.”

(In SA some cultures believe that having a child with a disability means you did something wrong)

These reactions often come from ignorance.
Try to find an answer for yourself.

NAVIGATING THE COMPLEX ROLE OF BEING A GRANDPARENT

A Unique Dual Role

Becoming a grandparent is a treasured milestone, especially as you welcome a beloved grandchild. However, when that grandchild has a disability like Down syndrome, it can bring unexpected uncertainties and mixed emotions. You may feel sadness not only for your grandchild but also for your own child, who now faces a different path in life with more challenges than you ever wished for them. This layered experience of joy and worry is both unique and deeply personal.

Managing Reactions from Others

Many grandparents who have been in your shoes encourage openness about your grandchild's Down syndrome. Clearly communicating your needs and expectations with friends and family can ease the journey. Let others know how to respond to the news—whether they should give you space to process or congratulate you on the new arrival. Establishing a supportive environment can help ease this transition.

Adjusting Future Expectations

We all hold dreams and hopes for our children and grandchildren. When your grandchild has Down syndrome, you may find yourself re-envisioning these expectations. While the future may look different from what you initially imagined, there are countless opportunities for love, growth, and joy ahead.

Even though you might want to know much more about it, we can't tell you exactly what your grandchild will or won't be able to do later. We can only provide a general picture, but it’s important to remember that each child is unique. “Before birth, you wish for her to have a beautiful life. Now we also wish for her to have as independent a life as possible. But we know that it's always a waiting game to see what will work.”

Your grandchild has physical features of Down syndrome. You can see it in the nose, the eyes, perhaps the hands. But it's good to know that your grandchild mostly resembles their parents. You will recognize personality traits of them in your grandchild. For these children, what their environment teaches them is crucial.

> **“ You also have to accept what he can and cannot do. And not constantly think: ‘Can he walk yet, can he do this, can he do that?’ It will come as it comes.**

> **“ My prayers were that God’s will would be done and that he would be with our Son, Daughter in law, Ollie’s older brother Benjamin and the greater extended family as we waited for Oliver’s birth and that he would be with Ollie as he grows and give his parents wisdom and guidance.**

Down Syndrome (Trisomy 21):

UNDERSTANDING THE BASICS

What Causes Down Syndrome?

Down syndrome, also known as trisomy 21, occurs when a fetus has three copies of chromosome 21 instead of the usual two. Despite extensive research, scientists still don’t know why this happens. It is a random event, a matter of pure chance.

There is no factor that causes Down syndrome—it's not due to the mother or father, diet, lifestyle, or living conditions. This has all been thoroughly investigated, and currently, no known cause has been identified.

Who Can Have a Child with Down Syndrome?

Down syndrome can occur in mothers of any age. While the chances increase as the mother gets older, younger mothers can also have a child with Down syndrome, even though the likelihood is lower.

> “ **Don’t be fooled, they understand a lot. If you have more patience, you’ll notice that too. It comes in more slowly.**

Future Generations and Family Members

If your grandchild has Down syndrome, it does not increase the chance that their siblings or future family members will have children with Down syndrome. It's important to remember that this condition is purely a matter of genetics, not influenced by actions, behaviours, or beliefs.

"I see now that there are enormous differences between children with Down syndrome. Our granddaughter has a truly unique personality. She has limitations, but she can also do a lot. She is a child of your children and thus resembles her parents. I didn't realize that so much. She's 10 years old now and we enjoy her. She has a good sense of humor (from her parents) and you can laugh a lot with her. On the other hand, she can be very stubborn about what she wants. We have to work hard to find a satisfying solution for both sides. There are also moments of frustration because she can't do something. That's sometimes difficult for her and for us because we want her to be happy. But a life without frustrations is not possible for any child. She also really enjoys company and good food. She says thank you to her parents for the delicious chicken sticks or asks us if we like it too, and we find that so funny! Our other grandchildren don't do that. Wende lives a normal childhood, goes to school, does horse riding, biking (tricycle), dancing, and swimming. She has loving parents and I see a happy child."

IS DOWN SYNDROME HEREDITY?

This question often arises, though it may not be an immediate concern. For almost everyone, the answer is "no"—Down syndrome is typically not hereditary.

An Exception: Translocation Down Syndrome

In rare cases, Down syndrome can be hereditary. This occurs if chromosome 21, which is small, is "stuck" to a larger chromosome, like chromosome 18. If one parent has this attachment (a translocation), there's a higher chance of having a child with Down syndrome.

Here's how it works:

- Each egg or sperm cell normally has single copies of each chromosome.
- When chromosome 21 is attached to another chromosome, it may go unnoticed during cell division, leading to an extra chromosome 21 in the new cell.
- This results in the child having three copies of chromosome 21, causing Down syndrome.

When Parents Already Know:

If translocation was the cause of Down syndrome in your grandchild, this is typically identified in the chromosome analysis that confirmed the diagnosis, so the parents are usually already aware.

> “ **I was very afraid that Down syndrome would always be in the foreground. But after a few weeks, it went to the background; she was simply our granddaughter. I also often had conversations with my son: not everything is Down syndrome, behavior is also just part of a baby. It's actually not much different. But of course, you still need to do something about Down syndrome.**

MOSAICISM

What is Mosaic Down Syndrome?

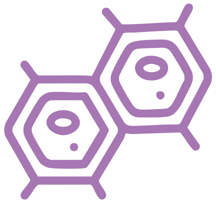
Very occasionally, chromosome testing reveals that the child has a mosaic form of Down syndrome. The child does not have trisomy 21 in all cells but only in a portion of the cells. This occurs because there were not three chromosome 21s in the first cell division but only several cell divisions later. Research indicates what percentage of cells has trisomy 21 and which do not. The child may have fewer Down syndrome characteristics. How this manifests varies by child. It depends on which cells have trisomy 21 and which do not. Because the diversity is so great and there are not many children with mosaicism, there is no specific information that precisely describes your grandchild with mosaicism.

How is Mosaic Down Syndrome Diagnosed?

Genetic testing can determine the percentage of cells that have trisomy 21 and those that do not. The characteristics of Down syndrome may be less pronounced in children with mosaicism, though this varies greatly from child to child.

What This Means for Your Grandchild

Because mosaicism can affect each child differently, it’s hard to predict exactly how it will manifest. The specific traits and development depend on which cells have trisomy 21 and which do not. Due to the diversity and rarity of mosaicism, there isn’t detailed information that will precisely describe your grandchild's unique experience.



“ I often hear: ‘They are such sweet children.’ Then I say: According to me and statistics, that is no different from other children.

“ From the first time I was told that Oliver was born with Down syndrome. I did not quite understand what it was. But when I saw a picture of him with his parents taken in hospital my heart was filled with love. I prayed daily for his recovery. And I thank God today for Oliver he has brought so much love into my life. Every little step he takes and every smile brings me so much pleasure my love for him is unmeasurable.

“ When I heard that the baby may have Down syndrome, we were all feeling a little sad as we didn't know much about it. When Oliver was born and we heard he was struggling to breathe, the diagnosis didn't matter and the first time I laid eyes on him, I realized I would not change him for another baby in this world. He is the light in our family and we can't get enough of him! We are grateful for who he is and all the joy he brings in our lives.

“ I wasn’t shocked and that I didn’t have negative feelings towards the news. When my son first told me that the Doctor wanted them to go for more blood tests to check for Down syndrome, I told her that we would pray. As a Christian, I believe that God is Sovereign, he is our Creator and that in the Bible it says that he knits us together in our mother’s wombs.

HOW DOES THE EXTRA CHROMOSOME AFFECT AN INDIVIDUAL?

Children and adults with Down syndrome often experience a range of unique developmental characteristics and challenges:

- They may take longer to reach milestones
- Different skills may develop at different rates; a child may learn to walk sooner but take longer to speak, or vice versa.
- Skills often require many repetitions to master.
- Skills learned in one situation may not easily apply to another.
- Repetition is essential, as skills can fade without consistent reinforcement.
- They may understand more than they can easily express.
- Responses to questions or prompts can take a little longer. Giving them time to respond encourages interaction.
- In babies especially, reactions are often small—like a brief finger movement or a soft sound. Observing carefully helps identify their unique ways of responding.
- They may concentrate on one thing at a time and have difficulty focusing on multiple things simultaneously.
- The child will usually become toilet trained, but possibly later than others.
- About 60% of babies with Down syndrome are born with heart issues, and digestive concerns are also more common.
- Persons with Down syndrome have a strong visual memory.
- Persons with Down syndrome usually have low muscle tone.

WHAT KIND OF LIFE WILL THE CHILD LEAD?

Over time, families find a rhythm that feels relatively ordinary. Meals are shared, everyone goes to school, and family routines form. However, families may need to take extra steps in certain situations. For example, finding babysitters may require someone older and more experienced than a teenager. When the child visits others, it's important to consider safety and make sure any special needs are understood by the caregivers.

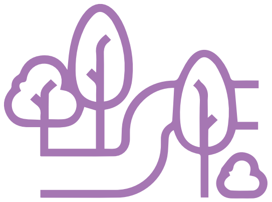
Eventually, questions about the child's future will arise, such as where they will live, who will assist with daily needs, and what level of support will be required. While it's certain that some level of support will be necessary, the specifics vary widely. Much like with any child, the future cannot be precisely predicted.

Future Expectations

Many adults with Down syndrome lead fulfilling lives, with levels of independence varying according to individual needs:

- Some adults live independently with support, work in full time, part-time or volunteer roles, and have an active social life.
- Others live in supported housing, use specialized transport, and enjoy chosen day activities with friends.
- Some adults with more complex needs may rely on comprehensive, ongoing care.

It is difficult to predict which path any child with Down syndrome will follow. However, one of the most effective ways to create opportunities is through Early Intervention, which provides vital support in the early years to help maximise potential.



THE IMPORTANCE OF EARLY INTERVENTION

for Babies and Children with Down Syndrome

Early intervention is crucial for babies and children with Down syndrome as it helps build a strong foundation for learning and development. This support, which can begin within the first months of life, provides targeted therapies and guidance to address key developmental areas, including motor skills, communication, and social interactions.

Early intervention services are tailored to each child's needs and may include speech and language therapy, physiotherapy, occupational therapy, and educational support. Engaging in early intervention helps children with Down syndrome develop essential skills at their own pace, supports school readiness, and promotes greater independence in daily life.

Furthermore, early intervention also empowers families by providing them with knowledge, strategies, and resources, fostering a more supportive environment for their child's growth. Research shows that early intervention can significantly improve long-term outcomes, enabling children with Down syndrome to achieve their full potential in childhood and beyond.

CONTRIBUTION OF GRANDPARENTS TO PARENTING

Here are experiences from grandparents of almost adult grandchildren with Down syndrome.

A grandmother with an 18-year-old grandson:
“In the past, I felt sorry for people with Down syndrome. Now I don’t at all. He’s just my grandchild; he’s part of the family. Fortunately, children are now well cared for. Koen also wants to look nice. We made sure he kept his tongue in his mouth. We did it together; it took a long time but succeeded. He still doesn’t speak well. This makes him socially withdrawn because he finds it difficult that not everyone understands him.”

“You can really teach them anything. He should also follow the normal rules. He can learn them, so you should also teach them to him.”

“Just treat people with Down syndrome like everyone else because they want to participate. Treat them like any other child so they don’t feel different. They’ll feel different on their own. Respect them and let them experience everything, for example in a G-team.”

A grandfather of a 15-year-old granddaughter:
“*We had a tandem. On that tandem, we had a child seat, first in front and later in the back so Ella could ride with us. We were quite a sight.”*

Grandmother about a 16-year-old granddaughter:
“It’s going well with her now. She doesn’t have a very high level. She hardly speaks, except when it’s about ice cream. She learns everything by doing it a lot, especially if it’s something she’s interested in. We are very involved in her growing up. We want that too.”

“Koen comes to stay with us on weekends and every vacation. We really enjoy that. The activities adjust accordingly. Now grandpa and Koen go to the pub together. With grandpa on the tandem.”

SUPPORTING YOUR CHILD AND SON-IN-LAW/ DAUGHTER-IN-LAW

Families with a child who has Down syndrome often need additional support for everyday activities. Between visits to hospitals, doctors, and therapists, daily routines can be time-consuming. If there are siblings, extra babysitting may be required, and even without other children, new parents may benefit from extra help as they adjust.

> “ **Don’t think too much ahead; it’s easy to fall into the worrying mode. You tend to make big leaps forward. I forced myself not to do that. No, don’t worry, it always turns out differently. It’s just practice, when thoughts run away with you, practice stopping. Wait patiently, you only know what’s happening now. Enjoy how he is now.**

USE PERSON-FIRST LANGUAGE

Person-first language is important because it places the focus on the individual, rather than defining them by a diagnosis or disability. For example, instead of saying “Down syndrome child,” we say “child with Down syndrome.” This approach respects the individuality and humanity of each person, acknowledging that they are much more than their condition.

Using person-first language promotes dignity, reduces stigma, and encourages others to see the person first, with their unique qualities, strengths, and potential. It fosters inclusivity and reminds us that each individual’s identity is not defined by any single characteristic.
In short, person-first language emphasises respect, empathy, and understanding.

IN THE BEGINNING

The arrival of a child with Down syndrome can change life's expectations overnight. Some parents process this adjustment quickly, while others take longer. For some, feelings of sadness about the diagnosis may linger. It's important to remember that these feelings do not lessen the love they have for their child.

As a grandparent, you play an important role in this process, offering empathy, understanding, and support as your child and their partner navigate the early days of parenthood and come to

"You can offer to be there. When my daughter first saw the little one in the bath, she started crying very hard. I was just there. Sometimes she'd say, 'I can't handle this.' I told her: 'You don't have to do this alone, we will always be there for him.'"

"My daughter later said that I did help her with the processing. I actually felt that I could have done more for her. We were so busy with the baby: making sure he drank well, undergoing tests, that I could have wrapped my arm around her a bit more often."

"Mom and dad were very positive and open from the start. They immediately went for it. That helped us a lot with the processing. Grandpa did intervene at the beginning when mom was overly worried about illnesses, etc. No one was allowed near the little guy when he was a bit sick. Grandpa told them it was exaggerated and that they didn't worry like that with the first two children."

"My son doesn't want to talk about it. It is what it is, and we love her, he says. Everything is fine otherwise. The mother goes with the child to physiotherapy and the health clinic and is more confronted with it. I give advice and help her with perspective."

CHILDCARE

Most children with Down syndrome can attend regular childcare settings, where inclusion is the best practice. Being in a mainstream environment supports social and developmental growth by encouraging interactions with peers, building friendships, and providing a sense of belonging.

However, some children may face additional challenges. Feeding issues, particularly if tube feeding is required, or a combination of health concerns, may mean they need extra support. Children with Down syndrome may also be more vulnerable to illnesses, becoming tired more quickly, or needing additional time to recover. As a result, they may need to stay home more often.

Grandparents can play a vital role in these times by helping with childcare and supporting their grandchild's needs. Many grandparents are regularly involved in their grandchild’s care, taking on responsibilities such as attending physiotherapy or speech therapy appointments. By sharing these caregiving roles, grandparents allow parents the time and space to focus on the broader aspects of parenting and planning for their child’s future.

“Yuan can’t just be left somewhere. If there needs to be babysitting, we do it; we babysit a lot. But it’s also very important that parents can also spend time together, as they are in the caregiving role 24 hours a day.”

> “ **Mara needs a lot of attention. I really enjoy spending time with her. I appreciate her simplicity and purity. It’s an advantage to be a grandmother; you’ve already had small children and are now much more patient.**

BABYSITTING

All parents of small babies are initially wary of babysitters, whether they are friends or acquaintances. For parents of a child with Down syndrome, this barrier is often even higher, and usually for good reason. Their child needs extra care. Not always physically, but often emotionally. Think of tantrums, not being potty trained at a later age, or running away behavior. These issues usually resolve over time, but at certain ages, they can be significant. Parents will only feel comfortable leaving if the babysitter is trusted, and that's something you can offer.

> “
>
> **THEY ARE SO TIRED. YOU ONLY HAVE TO SAY SOMETHING AND THEN IT GOES WRONG. IT'S LIKE WALKING ON EGGSHELLS.**

CHALLENGES CAN ARISE

Because many grandparents are closely involved with the family, they also know a lot. This can sometimes cause tension.

“We’ve always been very close. That has remained the same. I sometimes think, ‘Should they really do that?’ For example, they arranged a sleepover place for him. I think, ‘Is that really necessary?’ But it turned out to be okay. I never voiced my thoughts because it’s their child and their choice. And in hindsight, they always turn out to be right.”

“You become closer to your own child because you’re more involved. As a result, you see more of their lives. More than might be good. We solved this by offering a listening ear, but we always made sure not to criticize. You hear more, but it’s their life. You share it, but you shouldn’t be overbearing.”

> **“You see more than usual; you shouldn’t comment on it. My husband is better at that; we often talk about it. We are involved, and that is also requested of us, but there is still a limit.”**

DOWN SYNDROME IN SOCIETY

Many people worry about the place of children and adults with Down syndrome in society. How are they perceived? What about their opportunities? What kind of care can the children and their parents expect? Where should they live?

HOW TO HANDLE REACTIONS FROM OTHERS

Reactions to Down syndrome vary greatly. Some people encounter a lot of positive feedback, while others face some negative reactions. Especially when the baby is newly born, Down syndrome often becomes a topic of conversation when you actually just want to talk about your grandchild. Not everyone knows a lot about Down syndrome. Sometimes people still have outdated views.

YOUR OTHER GRANDCHILDREN

Sometimes grandparents tell us that they also have a role towards other grandchildren. Grandchildren often dare to ask more questions about Down syndrome to grandma than to their own parents. Grandparents have the role of explaining things. The questions may be about what Down syndrome means and about the future.

“

THE MOST REACTIONS WERE POSITIVE. ESPECIALLY IN THE FAMILY, IT WAS EASILY OVERLOOKED. IT WAS ACTUALLY A BIT IGNORED. I FOUND THAT A BIT DIFFICULT.

OPPORTUNITIES IN SOCIETY

More and more children with Down syndrome are attending regular primary schools. Research shows that children with Down syndrome learn more language and math skills in mainstream settings than at special schools. It's good that there is a choice between regular and special education. This way, parents can decide where their child will thrive best. It's important to consider the child's wishes and the options for extra support, whether paid or voluntary.

"I still encounter situations where mothers remove their child from the slide when I show up with Bonne. Then I say, 'He's not contagious or anything; he just has an extra chromosome.'"

"Parents and grandparents are often asked: did you know beforehand? That question also carries a judgment."

"We were also asked this question. There are tests available, with the underlying assumption that these children shouldn't be born. You have to justify yourself. That's not pleasant. My response: 'You're the umpteenth person to ask that. You can test, but what do you do with the result?'"

"My biggest concern is acceptance. You notice that other children sometimes look at him strangely, that he stands alone. A cousin says, as soon as someone looks at him a bit weirdly: 'He's ours!' It's amazing how children notice and handle that."

"He has been fully accepted into the family, both in Suriname and in the Netherlands. In Suriname, Down syndrome is viewed differently. Children are often hidden away there. In our family, fortunately not; there is a lot of love and warmth. They all adore Nick. It's important to remove the taboo around Down syndrome. Open the doors and remove that taboo."

COMMON MYTHS VS FACTS ABOUT DOWN SYNDROME

Myth: People with Down syndrome have a short life expectancy.

- **Fact:** Advances in medical care have greatly increased life expectancy for people with Down syndrome. Many live into their 50s, 60s, and beyond.

Myth: Down syndrome is a rare condition.

- **Fact:** Down syndrome is one of the most common chromosomal conditions, occurring in approximately 1 in every 700 births worldwide.

Myth: People with Down syndrome are always happy and affectionate.

- **Fact:** People with Down syndrome experience the full range of emotions, just like anyone else. They can feel happiness, sadness, anger, and frustration.

Myth: Children with Down syndrome cannot attend mainstream schools.

- **Fact:** Many children with Down syndrome attend mainstream schools, where they can thrive with the appropriate support. Inclusion in regular education settings often benefits their social and cognitive development.

Myth: Down syndrome is hereditary and runs in families
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- **Fact:** Most cases of Down syndrome are not inherited. It usually occurs as a random genetic event during the formation of reproductive cells.

Myth: People with Down syndrome are unable to work or live independently.

- **Fact:** Many people with Down syndrome hold jobs, live semi-independently, and participate actively in their communities. With the right support, they can lead fulfilling lives.

Myth: Only older parents have children with Down syndrome.

- **Fact:** Although the likelihood of having a child with Down syndrome increases with maternal age, the majority of babies with Down syndrome are born to mothers under 35, simply because younger women have more babies overall.

Myth: People with Down syndrome cannot form meaningful relationships.

- **Fact:** People with Down syndrome often form deep, meaningful friendships and relationships and may even marry or have long-term partners.

Myth: All individuals with Down syndrome have severe intellectual disabilities.

- **Fact:** There is a wide range of abilities among individuals with Down syndrome, and many can develop strong skills in communication, academics, and employment.

Myth: People with Down syndrome do not feel pain as others do.

- **Fact:** People with Down syndrome have the same capacity to feel pain and discomfort as anyone else, although they may sometimes have different ways of expressing it.

AND NOW WHAT?

We hope that you've found the experiences of many grandparents who went before you helpful. You may still have questions that haven't been addressed here, or you might want more depth on a topic. You can visit our website or give us a call. We hope you enjoy spending time with your grandchild. As one grandmother aptly put it:

> **“You can hardly call Down syndrome positive, but it has brought a lot of positivity into my life.**

FINALLY...

The following grandparents contributed to this brochure:
Without them, we couldn’t have created this booklet.
Many thanks to them.

Nannie Arends,
Josee and Henk Hijstek,
Marcel and Jacky Verduijn,
Mr. and Mrs. Ossel,
Clasien Henkes,
Fransje Grisnich,
Janny Lagerweij,
Lucie Verhaar,
Jan and Henny Root,
Lia Blom,
Lisette van der Hoeven,
Erna and Kees Tekke,
Nellie Rijneveld,
Diny Smeenk,
Hans and Heleen Boot,
Jannie and Johan van Veenendaal,
Piet de Kreij,
Marlies Goossens,
Fam. Luijben,
Yvonne Heere,
Huub van Amelsvoort,
Henk and Wiepie de Geeter,
Mrs. A willemsen,
Lydia Tangerman,
Jan and Deeltje Boxma,
Tonny Ritsema,
Guus and Jeanne Vos,
Marja Kusters,
Mrs. Veenenboer,
Mrs. de Cock,
Josephina Watson,
Mr. and Mrs. Verzijl

And many thanks to Geke Drost who supported the interviews.

DEFINITIONS:

Cyanosis: a condition where the skin, lips, or nail beds appear bluish or purplish due to a lack of oxygen in the blood. This occurs when there is insufficient oxygen being delivered to the tissues, often caused by respiratory or circulatory problems. Cyanosis can be a sign of an underlying medical issue that needs immediate attention.

Juandice: a common condition in newborns where the skin and eyes take on a yellow tint due to the accumulation of bilirubin in the blood. Bilirubin is a yellow pigment produced when the body breaks down red blood cells. Normally, the liver processes bilirubin and sends it to the intestines for elimination. However, in newborns, the liver is not as efficient as in adults, leading to a quicker buildup of bilirubin. Jaundice affects about 60% of full-term babies and 80% of premature babies. It's usually mild and clears up on its own within two weeks.

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> OUR VIEW HAS DEFINITELY CHANGED. THEY HAVE VALUE IN SOCIETY. IT’S NICE THAT THERE ARE OPPORTUNITIES TO INTEGRATE. YOU SEE THAT OTHERS REACT DIFFERENTLY WHEN YOU HAVE COME INTO CONTACT WITH IT. EVERYONE REACTS DIFFERENTLY. SOME DON’T NOTICE IT, OTHERS FIND IT STRANGE.

JOIN OUR COMMUNITY

Become Part of Our Support Network

By joining *The September Institute*, you'll have access to our community, resources, and expert advice. We offer online programs, one-on-one consultations, and group support that will help you navigate your journey with confidence.

CONTACT US

We're Here for You

If you have any questions or need guidance, don't hesitate to reach out to us. At *The September Institute*, we offer resources, expert advice, and a network of families and professionals who are here to support you and your child.

Visit us at www.septemberinstitute.org or contact us at:

Email: info@septemberinstitute.org