

# Little One

a little guide from  
parents who have  
gone before you



**The NZDSA would like to acknowledge and thank everyone  
who contributed to the development of this resource.**

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# Welcome

Welcome little one, with all that newborn gorgeousness that you bring!  
Big congratulations too for your parents for you are worth celebrating!

You've arrived with an extra tiny little chromosome. Maybe it was already known or perhaps this was unexpected. But this tiny chromosome may have your parents wondering what this means for you, their baby. So this booklet is about giving a little guide to this first season.

We want to reassure you that while you've come with a little extra, you're the same as all other babies. Feeding, sleeping and let's just say causing quite a few nappy changes! When it comes to parenting you - that's the essence of it - you're a beautiful baby!

There is so much to love about these precious days. The wonder of all the first experiences, the joy of the first smile, the first bath, counting your tiny fingers and toes and those gorgeous snuggles!

This journal will have space to record all these precious milestones that you will absolutely nail.

It's all going to be ok - in fact more than ok. These early days are for enjoying and celebrating you! And these days go by far too quickly. Keep your focus on today and don't let worry about future days cast shadows over the present. Because one thing is for sure, there is joy, love and laughter ahead more than anything else.

**It's a beautiful life!**

*Pip & Oscar*





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# A Little Encouragement

by Rachel Callander

*Welcome to the world, little one! In your lifetime, I believe that significant change will occur. It has already begun. As a human race we are learning more about the importance of diversity, the need for global tolerance and acceptance of difference. Your presence and unique character, is needed and loved.*

*Dear parent,*

Your child is far more than a diagnosis — Identity can't be diagnosed. Down syndrome is not an identity, it is simply a part of the whole. Your child is an amazing and intricate human being, with their own abilities, strengths, weaknesses and personality. The health space tends to focus on weaknesses — the areas that need treatment and support.

Your child has significant value, and you are their champion. You will see so much growth, development and achievement in your child. Others may not see these developments, but you can help them see. You can celebrate, advocate, and be proud of every milestone. Your child is a wonder, a teacher, a grower of acceptance, a vessel of diversity, an amazing human.

*Here's what the doctors don't know:*

They don't know your child — the strength of their spirit, the breadth of their courage and determination. Doctors don't know the depth of love your child will draw out from you and others, the impact they will have on the world, their unique personality.

What doctors do know, is how to help with medical issues. They can advise you when

you come up against health challenges, of which there may be some.

Let them help where they can, and release them from some of your expectations:

- They won't know everything. They don't have all the answers, even when they act like they do. They have a lot of information, but nobody has all the answers.
- They don't have the right to tell you what is best for your child. You will know what is best. Doctors can advise you well, but you get to decide.

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It's OK to grieve. Whenever unexpected news arrives, our hearts go through a grieving process for the loss of whatever we were expecting. It's natural, and it's healthy.

It's OK to fear. You may fear the future — the unknown, the discrimination, the conflict your child may encounter. You may fear for yourself — are you enough? Can you do this style of parenting?

Remember that every day is a new opportunity for you to grow. And we do our best growing in difficult times.

You are capable. You will grow and learn and stretch and bend and feel like you reach breaking point. You will experience hard times, but if you are open to it, you can also experience great joy.

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*Rachel Callander, is a TEDx presenter, speaker, trainer, award winning artist and the author of the Outstanding Book of the Year Award 2015 IPPY New York, Super Power Baby Project. This exceptional book celebrates the lives and abilities of children with chromosomal or genetic conditions, and was inspired by Rachel's late daughter Evvie, who was born with a very rare condition herself. In the two and a half years of Evvie's life, Rachel learnt a lot about the use of language in the health system, and has spent the subsequent years continuing to explore the impact and implications of how it is used by health professionals - To positive and negative effect. This book is Evvie's legacy, as is Rachel herself, and both have much to teach us about ourselves, and how we negotiate conflict, grief, hope, uniqueness, celebration, and a meaningful life.*

*"Always be on the lookout  
for the presence  
of wonder"*

E.B White



# About Down Syndrome



## A little extra care

Having a baby with Down syndrome means that there will be a few extra tests while in hospital and shortly after. It doesn't mean that your baby will necessarily have any of the conditions. It is just that there is a little more care and concern for your wee one.

The standard tests done are:

- A blood test called a Karyotype which looks at the chromosomes. This confirms whether your baby has Down syndrome and whether it is what is known as Trisomy 21, Translocation or Mosaicism.
- A blood test which gives a quicker result called a FISH test may also be ordered after birth if no previous chromosome test was conducted. This gives an initial indication that the baby has Down syndrome, but would need to be confirmed on the Karyotype test.
- At birth an Echocardiogram scan to check the heart.
- Newborn hearing test in the days after birth.
- Hearing test and Ear Nose and Throat Specialist review, at least once in the first year.
- Eye test after birth by ward doctors, then formal eye testing at 6-9 months.
- Blood test to check thyroid function. At birth and at 6 and 12 months, or more often if needed.
- Full blood count — blood test at birth, to check for an underlying blood condition.



# A little extra support

Early Intervention is professional assistance given to parents and their babies to support their growth and development. Depending on which New Zealand health board you are under, you will have some or all of the below specialists. They all come under what is known as the Child Development Team.

- Paediatric Doctor
- Speech Therapist
- Physiotherapist
- Occupational Therapist
- Wellcare Nurse

The team is there to support you and your child as your child grows and develops. They work alongside you to ensure that your child reaches their full potential. They provide assistance and help with any concerns that you might have, as well as help your baby reach their milestones. They predominantly do home visits, where they focus on gross and fine motor skills, feeding and communication.



## FAQs

### When were you told your child had Down syndrome?

*Pip – We found out that Oscar had Down syndrome within minutes of him being born. I had a C-section, so was still lying on the theatre table when the paediatrician told me that she thought it was likely that he showed signs of Down syndrome. At this point I hadn't even held him so I felt very detached from him at the time. I still remember the obstetrician leaning over after and saying to me that I had a beautiful baby boy who is strong and healthy. She was so right!!*

*Emily – We had a few indicators throughout the pregnancy with a high chance of 1 in 260 at the 12-week testing, along with a heart defect picked up at the 20-week anatomy scan. Although I knew it was highly likely I received confirmation with a phone call from my lovely midwife after she received the*

*results of our NIPT test. I was actually doing day-care pickup when she phoned and delivered the news so had our three other children in the car. In some ways it was a relief as the journey up to this point had felt quite long and anxiety of the unknown had really consumed me. I finally knew for sure and I could now move on and prepare.*

### How did you find breastfeeding?

*Paula – In those overwhelming early days I knew that this was one thing that I absolutely had to do. We had to work hard together. After a 4 month relentless cycle of breast feeding, expressing milk and NG tube feeds the tube finally came out – and Charlotte turned into the best little breast feeder ever! She stopped at 13 months. I couldn't have done this without my very supportive husband and a lot of support from our families. Top tip: we absolutely*



*could not have succeeded without using a nipple shield.*

*Zara – We were lucky that Essie fed really well, no different to my other babies.*

*Meaghan – I unfortunately wasn't able to breastfeed Olivia. She was very sleepy in the first few months and just fell asleep instantly. I expressed and bottled for the first few months. I do wish I kept trying as she got so much stronger after 3/4 months that I think we could of got there.*

## **NG (Nasogastric) Tube?**

*Paula – We had the NG tube for 4 months. It was a lot of work, but also reassuring that Charlotte was being well nourished. We did get out and about with the tube, and eventually felt OK doing a tube feed in public, despite many people staring. The tube was overwhelming at first, but our community nurse was lovely and helpful.*

*When we finally finished with the tube it felt amazing – like passing a really hard exam. And the best reward was that we could see Charlotte's beautiful face properly at last*

## **When did you start solids and how did it go?**

*Meaghan – We started solids around 6 months. Olivia took a little while to get used to the texture. The tumbleform chair from the CDT was super helpful with supporting her sitting so she could concentrate on swallowing. Around 8 months she just took off with her eating and hasn't looked back.*

*Alicia – I wanted to wait until he was 6 months old but he got very hungry at 5 months, he wasn't satisfied after breastfeeding alone. Julian had a poor swallow so was an aspiration risk so we had SLT input and kept him on thick*

*purée texture for longer than usual. Also I had to watch out for noisy breathing and swallowing difficulty when I fed him solids. Sips of water to help him swallow.*

*Pip – I started feeding Oscar solids at around 6 months. We started with puréed apple and baby cereal and he loved it! He was quickly onto eating toast and cruskits from then. Feeding has gone well in the sense that he likes all sorts of different textures. However, like his older brothers he is fussy. Definitely a family trait!*

## **What was your must have item for your baby?**

*Meaghan – Our must haves in the first few months: love to dream swaddle, snot sucker (nasal aspirator), baby carrier (front pack).*

*Zara – A front pack! Mostly due to the fact Essie is my third child so we had to be on the go most of the time. She also loved being propped up in the baby bouncer/recliner so she could see what was going on.*

## **What can I expect my baby to be like?**

*Paula – Just like any other baby – but somehow so much more special. I still think about Charlotte's Down syndrome about 50 times a day... but mostly I am SO grateful for the wonderful gift we have been given of a beautiful girl who loves hugs and kisses and food. Your baby will be beautiful and amazing and look right*

*into your soul with beautiful eyes.*

*Emily – Your baby will be beautiful just like any other baby that needs to be loved, fed and cared for. I was amazed at how 'normal' everything felt. I don't know what I expected, but I kept thinking how different it would be to our other children, that we wouldn't go to cafés as often or on holiday as much (selfish I know) but she sure loves a café and a trip away, we celebrate so much with her. You will see traits of family members; Sadie looked so much like her brother when she was born. I imagined I would only see her 'Down syndrome' and find it difficult to bond with her but it was quite the opposite.*

*Zara – Essie is special to so many people. Something about her presence is beautiful and brings out the best in everyone she meets. She was a very content and smiley baby; she slept well and loved the faces of her brothers more than any toy. You will also find great delight in getting to know your darling little baby.*

## **How do I tell family and friends?**

*Zara – We took the approach of telling everyone straight away and assuring them that she was doing really well, was totally gorgeous and we couldn't be more in love, everyone seemed to follow our lead and be really positive in response. We constantly have to be aware that the outcomes and reality for people with T21 has changed dramatically in recent years, so some people have outdated ideas that can feel offensive, even when they are not intended to be.*



*Emily – There is absolutely no pressure to share the news before you have to, just when you are ready. Remember this isn't bad news, it's just different to what you expected and you may need a while to process and adjust to your new normal and that is more than ok. I shared with my family and close friends straight away via a text message because I found it difficult to talk about it without tearing up but as time went on I found it much easier to talk about. Remember you have a beautiful baby on the way that will be loved and adored by everyone around you. Sadie is such a light to our family and touches everyone she meets in the loveliest way, it's her special gift.*

*Pip – I found the best way at the start was to be open and upfront. But actually, be true to yourself and how you're feeling. There's no right or wrong way of sharing with family and friends and it will differ depending on the person. To the rest of*

*the world, it was this is Oscar; yes he is one of four boys! Don't think you have to introduce your little one as he/she has Down syndrome.*

### **Is there anything I need to watch out for?**

*Paula – There are lots of complications that can happen with any little one – so I think if something doesn't feel right, just get your baby checked out. Never feel like you are being a burden for making yet another trip to the doctor or hospital. All new parents have foggy memories – so if you didn't understand something, or just can't remember – ask again.*

*Meaghan – Not so much things to watch out for but advise to always trust your motherly instincts.*

*I wouldn't change  
you for the world...*



*but I would change  
the world for you.*

Anon



# Milestones

Capturing those first moments

**My first smile**

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**I slept through the night**

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**I rolled over**

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**I giggled for the first time**

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**I'm eating solids**

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**I'm sitting by myself**

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**I'm crawling**

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**I'm standing**

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**My first tooth**

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**My first word**

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**I took my first steps**

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# These are a few of my favourite things

**My favourite song**

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**My favourite book**

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**My favourite toy**

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**My favourite food**

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## Connect with us

- **Find us on the web** [www.nzdsa.org.nz](http://www.nzdsa.org.nz)
- **Find us on Facebook** - T21 Mums NZ – our Facebook page, NZ Mums of Kids with T21 - A private group for mums with babies with T21
- **Find us on Instagram** - T21mumsnz
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## A gift for you

The NZDSA would like to gift you a year's full membership.

Please contact us [neo@nzdsa.org.nz](mailto:neo@nzdsa.org.nz)  
0800 693 724



# notes

*Love doesn't  
count chromosomes*



## notes



# notes

Normality is  
a paved road.  
It's comfortable  
to walk  
but no flowers  
grow on it.

Van Gogh



*The NZDSA is a family whānau organisation*

**Our mission is to work alongside families, whānau and carers to support and empower people with Down syndrome to realise their potential and aspirations through all life stages and within all communities.**

We also have a child or family member with Down syndrome and we'd love to hear from you.

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