

TIPS FOR *Health* PROFESSIONALS

Some useful tips for
conversations with
parents.





Breast feeding is valuable, but it can be a little more challenging so remember to check how the Mum is managing.

Here are some resources to help
verywellfamily.com/breastfeeding-a-child-with-down-syndrome-4160644

illi.org/breastfeeding-info/special-needs/



Ideas on how you can help our families as you are often the first professional person parents see when leaving hospitals.

- Do encourage them to join www.nzdsa.org.nz as the resources are free and there is a lot of useful information for them as well as support if required. They can also, if they wish, be put in touch with their local regional support group, many of which have social events and coffee groups for parents.
- Make longer appointment times so you have time to allow parents to ask questions and assist them where possible.
- Remind the parents that everything will be OK, they are doing a great job, and remember the baby is a baby first and foremost - do not put the Down syndrome first. Encourage them to take lots of photos and enjoy the time as the baby stage will go by very quickly. It is also OK to cry, be upset, breathe, and take time for themselves when they can and do not be afraid to ask for help. Also tell them NOT to use google for information as it is often very outdated or not useful.
- They may have a lot of information and resources given to them - ask if you can help them open and go through the information received. Often it can be too overwhelming for parents to do this.
- Ask if they need assistance to fill out the WINZ application form for child disability allowance if they have not completed it - <https://www.workandincome.govt.nz/documents/forms/child-disability-allowance-application.pdf>
- Ask if they need assistance to make initial appointments - e.g. paediatricians, therapists, doctors etc.
- Always use growth charts for babies and infants with Down syndrome Not the usual charts in the well child book. <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>



Always use milestone developmental charts for babies and infants with Down syndrome not the usual charts in the well child book as babies with Down syndrome will probably experience delays in some areas of their development. They will, however, achieve all the milestones just like other children but just on a different timeline. It will be more useful to look at the sequence of milestones achieved rather than the age the milestone is achieved.

Use this

	Milestone	Typical range	Range for child with Down syndrome
Gross motor	Sits alone	5-9 m	6-30 m
	Crawls	6-12 m	8-22 m
	Stands	8-17 m	1-3.25 y
	Walks alone	9-18 m	1-4 y
Language	First word	1-3 y	1-4 y
	Two-word phrases	15-32 m	2-7.5 y
Social/self help	Responsive smile	1-3 m	1.5-5 m
	Finger feeds	7-14 m	10-24 m
	Drinks from cup (unassisted)	9-17 m	12-32 m
	Uses spoon	12-20 m	13-39 m
	Bowel control	16-42 m	2-7 y
	Dresses self (unassisted)	3.25-5 y	3.5-8.5 y

Do not say

- Suffers from Down syndrome
- A Down's person
- Mentally handicapped
- Disease/illness/handicap
- Use Downs, Downsie as an abbreviation

Myth

- People with Down syndrome do not live very long

Myth

- Only older mothers have babies with Down syndrome

Myth

- People with Down syndrome cannot achieve normal life goals

Myth

- People with Down syndrome all look the same

Myth

- People with Down syndrome are always happy and affectionate

Do say

- Has Down syndrome
- Put the person first e.g. the child has Down syndrome – not a Down syndrome child
- Learning disability or intellectual disability
- Condition
- DS (if necessary)

Fact

- Today, people with Down syndrome can look forward to a long life given the right medical attention, many living well into their 70s

Fact

- Although older mothers have a higher individual chance of having a baby with Down syndrome, more are born to younger mothers, reflecting the higher birth rate in this age group

Fact

- With the right support they can. Most people with Down syndrome learn to walk and talk and many attend mainstream schools, passing exams, getting jobs, having relationships, and living full, semi-independent adult lives

Fact

- A person with Down syndrome will always look more like his or her close family. There are however certain physical characteristics that can occur and some people with Down syndrome can have all or some of them

Fact

- We are all individuals and people with Down syndrome are no different to anyone else in their character traits and varying moods. Just like the rest of our community, some will be social, some will be quiet, some will be physical, others more academic and they are definitely NOT always happy. People with Down syndrome will be just as grumpy as all of us when things don't go their way

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NZDSA
resources

Want to know more?

The NZ Down Syndrome website can provide more information and link you to many more articles and organisations.

www.nzdsa.org.nz



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This resource was produced by The New Zealand Down Syndrome Association

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