Down Syndrome
Australia

A guide for new parents

This document has been produced by
Down Syndrome Australia.

Down Syndrome Australia is the peak body for people with Down syndrome in Australia. Our purpose is to influence social and policy change, and provide a national profile and voice for people living with Down syndrome. We work collaboratively with the state and territory Down syndrome associations to achieve our mission. Our vision is an Australia where people living with Down syndrome are valued, reach their potential, and enjoy social and economic inclusion.

Acknowledgements

Thank you to all of the people working and volunteering at the state and territory associations who have contributed to the development of this booklet. The content of this booklet has been put together from the resources that the state and territory associations have developed over many years.

Editing, design and layout by Black Widow Design.

June 2018
Last reviewed:
November 2021

Funded by the
National Disability
Insurance Scheme (NDIS)

Contents

Introduction

Congratulations on the birth of your baby! You are probably experiencing some very mixed emotions and may have many questions. We hope that this booklet will help you and your family as you get to know your new baby.

All parenting has its moments. There are moments of great joy and there are moments of frustration. Parenting a child with Down syndrome is no different.

This booklet has been designed to help you learn and understand more about Down syndrome and to help you celebrate the many joyful experiences that you will have with your gorgeous new child.

Our intention is to provide you with a resource that can be used to answer some of the many questions you may have. We have also developed a shorter Frequently Asked Questions resource for new parents, which is available at **www.downsyndrome.org.au.** We suggest that you don't try to read this booklet from cover to cover in one go, unless you feel ready.

Right now, you probably want to know what Down syndrome means – not just about chromosomes and biology, but how it is going to affect your life. Most new parents ask questions like:

"What will life be like for my baby?"

"What can we do to help our baby reach his or her full potential?"

"What will life be like for our family?"

We can't tell you exactly what your life is going to be like, but we can tell you that the future for people with Down syndrome is brighter than it's ever been before. There are many positives on this journey that we hope you will uncover as your child grows and develops.

Within these pages we will talk about the biology because this knowledge will assist you as you navigate the medical system over the coming days and weeks. We've also included information about some of the support that is available and we have included information and advice for the essential job of looking after yourself.

Most importantly we hope this booklet reminds you that you are not alone. We hope you remember it has been put together by people who have been in your shoes.

Welcome to the world little one. Again congratulations to you, new parents. We hope you will allow us to share this journey with you.

Warm regards from the Down Syndrome Australia team.

Receiving a diagnosis of Down syndrome

Some people receive a diagnosis of Down syndrome during pregnancy, others receive it after the birth. Either way, this can be a challenging time. You may feel a wide range of emotions, including grief, shock or a fear of the unknown.

In the early days after diagnosis there are no right answers and there are no right responses. Everyone will respond in their own way. Giving everyone – including yourself – permission, and time, to respond in their own way will help.

You may have many questions. These might include:

- What will life be like?
- Will we cope?
- Will our relationship survive?
- Will my child be healthy?
- Will my other children be ok?
- What kind of future will my child have?

Having a baby with Down syndrome can result in a multitude of often conflicting feelings, including love, anger, disbelief, embarrassment, guilt, inadequacy, protectiveness, happiness, sadness and shock.

At this point, you may find it helpful to know that other people have been exactly where you are now. The following are quotes from parents of children with Down syndrome that offer a glimpse of the kind of responses other families have had.

"That wonderful feeling following childbirth – a mixture of emotions ranging from exhaustion to elation – a sense of accomplishment to have such a perfect, beautiful little bundle given to me. And then: 'Your baby has some problems – he has Down syndrome.' My body went into total overload.

First I took it minute by minute, then hour-by-hour and then day by day. I looked at Daniel and his vulnerability in that big wide world scared me. By the time I got to week by week, I realised Daniel was someone very, very special and that he had something to give that big world out there.

There have been some hurdles and there will be some more, but after one short year Daniel has given so many people so much joy."

PARENT OF A CHILD WITH DOWN SYNDROME

"The fear of the unknown is terrifying by its nature, and that was the position my wife and I found ourselves in that morning. Within half an hour of the news, our parents arrived to be first in line for cuddles with their latest grandchild. The nursing staff explained the situation to them and without a second's hesitation the message from our parents was loud and clear: 'So what? She is our granddaughter and we love her; we love you and that's all that matters."

PHILL WALL

As you will sense from these quotes, the feelings in the immediate days after diagnosis do not predict what life with your child will be like. Many parents worry about how a child with Down syndrome will affect their family. Of course, every family is different, but personal stories and research show that most families that have a child with Down syndrome are stable, successful and happy, and that their siblings often have greater compassion and empathy. In fact, some studies have shown that families of children with Down syndrome have lower rates of divorce than the national average. Families generally find their feet and include the needs of their child with Down syndrome with the needs of all family members. How this happens will be different for everyone, because each child and family is unique.

Getting the support you need

Your extended family and friends may need time to adjust to the news of the diagnosis. We've included some advice about sharing the news with them on pages 17 and 18, and there is also a separate information sheet you can give to them.

Hospital staff are there to help you. They will provide you with advice and ongoing care for any health needs your baby may have. There is general health information in this booklet and you will also receive a health booklet with more specific information about your baby's growth and development. Don't hesitate to ask for more information or advice from your health care professionals.

One source of support that you may like to consider – either now or further down the track – is talking to other parents of children with Down syndrome. No one else will understand what you are going through quite as well as they do. Of course your experience is unique, but these parents are very familiar with some of the twists and turns on the emotional rollercoaster that you are on now. The Down syndrome association in your state and territory are the experts on Down syndrome and they can support you or put you in touch with local volunteer families. Links to your local association can be found at the back of this booklet.

There is also a range of professional support services available, including speaking to a counsellor or mental health professional. You can ask your family doctor, the hospital staff or the Child and Health Services in your area to point you in the right direction. Your local Down syndrome association can also assist you to find the right services.

Remember to take time for yourself - go for a walk, read a book or go out for a catch up with a friend. This time is not a luxury; it is essential to your health and wellbeing which in turn is vital for your family.

What will life be like?

Every parent faces trepidation as they hold their newborn child and wonder what the future will be like. For parents of a child with Down syndrome, there may be a large degree of uncertainty. In the early days, many parents wonder what level of intellectual disability their child will have, and how this will affect their life.

It is important to remember that Down syndrome will not be the most important influence on how your child develops or lives their life. Instead, what happens after birth will be far more important. Just like all children it is the family, environmental, cultural and social factors that will shape a child's life. Just like all children your baby needs to be fed, cuddled, interacted with and most importantly, to be loved.

Your child's potential

Today, the future for children with Down syndrome is better than it has ever been before. Over the past 30 years or so, there have been big advances in health care, education and support services for people with Down syndrome, and a doubling of life expectancy in this period too. We've also seen huge shifts in the way the community views and treats people with disability. These days, people with Down syndrome can look forward to living long and fulfilling lives, with plenty of opportunities for making their own choices and living independently.

> **Know that your child will walk, will talk, will learn and will grow to be an important part of their community, I can't stress that enough.**
>
> PARENT OF A CHILD WITH DOWN SYNDROME

Your child with Down syndrome can and will learn. Sometimes we take children's development for granted. Children generally master skills like turning on a tap, learning to walk and remembering to say 'please'. Your child will also master these kinds of skills but may need more time and support to do so.

As adults, some people with Down syndrome require minimal assistance to lead an ordinary life in the community, while others may require more support. Each person is unique, and the way they develop and reach their potential will depend on the individual.

"I look back now at those first weeks and I am amazed at how my feelings have changed. In the beginning, I was devastated. I didn't think I could cope with having a child with Down syndrome – a child who would eventually become an adult with Down syndrome. I spent the first days in a trance. How could I grow to love my baby? I didn't really want him. I wanted another baby – the one I was expecting to have. But he was here and despite how I was feeling, he was just a baby and he needed me. I think the best advice I received was from a friend who pointed this out to me. 'He's a baby first – just go home and enjoy your baby.'

As I learned more about Down syndrome, I realised that things weren't as bad as I'd initially thought. Kids with Down syndrome did have a future and life could actually go on. Bit by bit, I became involved with his progress and I didn't have time to feel sorry for myself.

As I look at my beautiful grown up son today, I can't believe I ever felt that way about him. He has filled my life with so much joy and has opened so many doors to me. I am grateful I managed to get through those first weeks of anguish and that I allowed myself to love him. Now I couldn't be without him."

PARENT OF A CHILD WITH DOWN SYNDROME

What about the other children?

Introducing a new brother or sister to an older sibling can be challenging at the best of times. Having a baby with Down syndrome may add to the challenges. As much as you can, keep in touch with the needs of your other children during the first intense weeks of life with your new baby.

Research shows that there can be many positive aspects to having a brother or sister with disability. These benefits include greater maturity, responsibility, self-confidence, independence and patience. Children who have a sibling with a disability can also be more altruistic, open to humanitarian ideals and have a closer relationship with their family.

In order to help your children adjust and thrive within your family, you can:

- Talk to them and encourage them to openly express their feelings.
- Give them responsibilities that are appropriate for their age and maturity level.
- Provide them with choices and include them in decision-making, valuing their opinions.
- Give them information about Down syndrome. Answer questions to the best of your ability, and, if you don't know the answers, search for them together.

Your local Down syndrome association will have resources you can use that may help you with your other children. There are also many family events and activities throughout the year that will allow your children to meet other siblings of a child with Down syndrome. Sharing these kinds of experiences with people who are in a similar situation can be a great source of support for all members of the family.

Telling your other children about Down syndrome

The best method for telling your other children about a Down syndrome diagnosis will depend on their age, so we’ve included some age-appropriate suggestions below. No matter what the age of your child, keep your information honest, realistic, factual and positive. Words like, “Baby has Down syndrome, which means he may take longer to learn some things and need help sometimes are a good way to start. Try to avoid words such as ‘disease’ or ‘affected with’ as they bring negative connotations.

Children under two

It is not necessary to explain to children under two years that their new baby brother or sister has Down syndrome. But you don’t have to feel like you should avoid mentioning Down syndrome altogether. Let the term become part of your family’s vocabulary over time.

Children who are two to four years old

With very young children, it’s a good idea to keep your language simple and use terms that they will understand. You can use picture books to make this process easier. Ask your local Down syndrome association for some examples.

Many pre-school children don’t understand the implications of what they are being told. Usually, they don’t need to have anything explained to them. They will ask their own questions in time, often around four to five years of age.

You may decide to discuss Down syndrome with your child before he or she starts school. This way, your child will be more confident if their friends at school ask any questions.

Children who are five and older

Older children will be able to take in more information and will be able to get used to words like 'disability' or maybe even 'chromosome'.

Try to achieve a balance between providing information without over-emphasising difference or allowing it to become a key part of the new baby's identity.

You could say that the new baby has far more in common with you and your other children than they have differences. You can acknowledge the disability and the differences associated with it, but explain that Down syndrome is only one part of who the baby is.

While Down syndrome will affect the way the baby develops, it won't determine who she will be as she grows up. Talk together about the strengths each of you have and the things you are not so good at, or are still learning about. Remind children that each person is unique and that there is no one right way to be, and that part of growing up is learning to appreciate and respect all sorts of differences in people.

Explain that Down syndrome is nobody's fault. It just happens in some people.

Avoid passing on unhelpful and out-dated stereotypes or creating an overall impression of limitations. Reassure your children that the new baby can be expected to do and learn the same things as them – it may just take longer and they may need extra help for some things.

Make the most of opportunities to discuss disability and Down syndrome as they come up in everyday conversation. Chatting about things as they come up, not simply setting aside time for specific discussions, sends the message to kids that this is all just part of everyday life. It also opens the door for them to ask questions as they feel the need.

What about family and friends?

You may need time alone to absorb information about Down syndrome before you are ready to answer any questions your friends and family have. If you want to, you can ask the hospital to divert calls and visitors until you are ready but don't be afraid to share your emotions with close friends and family – they will want to help you.

How to tell family and friends

Some new parents decide to tell their family and friends about the diagnosis when they announce the news of the baby's arrival. You may find that, the longer the news is delayed, the harder it is to mention. Some parents tell their friends and family through phone calls and visits, while others send a letter or use social media. We've provided a sample letter on the next page to give you some inspiration about the language you could use.

Family and friends are often confused and unsure about how they should react to the news that your baby has Down syndrome. They will take their cue from you. If you are upbeat and matter-of-fact, they will be too.

At a time when you need all your strength, it can be overwhelming having to tell everyone of your baby's diagnosis. You might consider asking a close friend or family member to do this for you. They can tell everyone how you and the baby are doing, and answer any questions. Dealing with just one person is much easier than dealing with all of your friends and family members at once.

Remember that your child has Down syndrome, it is not who he or she is.

The birth announcement

Dear friends and family,

We are delighted to announce the arrival of Thomas, born on Thursday 1 July at the Royal Women's Hospital. Sarah and Nicholas are very happy to be a big sister and big brother.

Thomas was born with Down syndrome. This means that he has an extra copy of chromosome 21. Chromosomes are the parts of our cells that contain all the genetic information our bodies need to grow and develop. We are still learning about Down syndrome ourselves so we probably won't be able to answer all of your questions at the moment.

We are happy and proud parents and we would like you to see him as we do. He is, quite simply, our beautiful baby boy. We wanted to give you time to adjust to the news, so you won't feel the need to have an immediate response. We hope you will feel the same as we do.

We'd also like for you to treat him just like any other baby. Congratulate us on our new addition to the family, and wish us well as you always had intended to do.

We would like to encourage you to call us, and come to see Thomas. He sleeps, eats, cries and needs his nappy changed, just like every other baby! Please feel free to come and give him a cuddle.

So, what's next?

Hopefully now you are moving from living minute-by-minute toward hour-by-hour, or even day-by-day. No doubt you are busy caring for a new baby, with all the demands of feeding, bathing and settling your child.

We hope that you can take the time to enjoy these precious early moments with your newborn. And we hope that you are finding time to take care of yourself as well.

The following sections of this booklet are all very practical. They include information about what Down syndrome is, feeding your child and what you can do to support your child's development.

You are embarking on a remarkable journey. But please remember you are not alone as you take your first steps – there are many people around you to share the journey with you.

What is Down syndrome anyway?

Down syndrome is a genetic condition. It is not an illness or disease.

Our bodies are made up of millions of cells. In each cell there are 46 chromosomes. Down syndrome is caused when there is an extra chromosome. People with Down syndrome have 47 chromosomes in their cells instead of 46.

What are chromosomes?

Chromosomes are structures that contain the genetic information people need to grow and develop. They are present in all the cells in our bodies.

Each chromosome is made up of DNA, which contains encoded genetic instructions (genes) for the development of all the structures and functions in the body. Every chromosome contains thousands of genes. Our development is controlled precisely by our genes, so that if a person has either too much or too little chromosomal material this can have a significant effect on their development.

Each cell in the human body usually contains 46 chromosomes arranged in 23 pairs, which are labelled 1-23. For example, the 23rd pair are the so-called ‘sex chromosomes’ that determine whether a baby is a boy or a girl. In people with Down syndrome, an extra copy of chromosome 21 is present.

Types of Down syndrome

There are three types of Down syndrome, which can be identified by a blood test, usually taken after birth.

1. Trisomy 21

Ninety-five per cent of people with Down syndrome have Trisomy 21. In this type of Down syndrome, every cell in the body has an extra chromosome 21.

2. Translocation Down syndrome

Three to four per cent of people with Down syndrome have translocation Down syndrome. In this type of Down syndrome, a partial chromosome 21 attaches itself to another chromosome. This variation does not significantly change the impact of the condition. Sometimes, translocation Down syndrome is hereditary, so parents will usually be advised to have blood tests and genetic counselling.

3. Mosaic Down syndrome

One to two per cent of people with Down syndrome have mosaic Down syndrome. In this type of Down syndrome, which occurs after conception, only some cells have the extra chromosome 21. The rest of the cells have the usual genetic composition. Sometimes this means that fewer characteristics may be expressed, and possibly to a lesser degree.

Diagram 1: Typical female karyotype

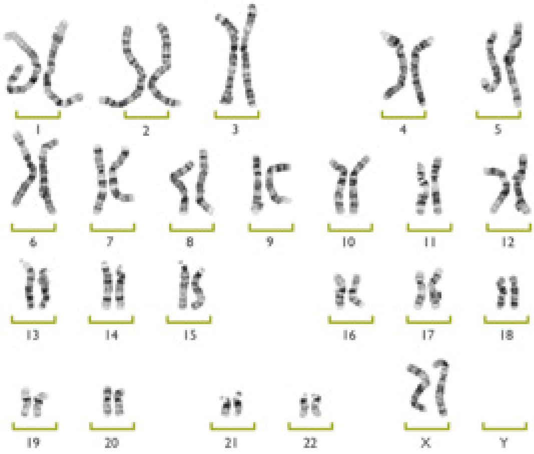
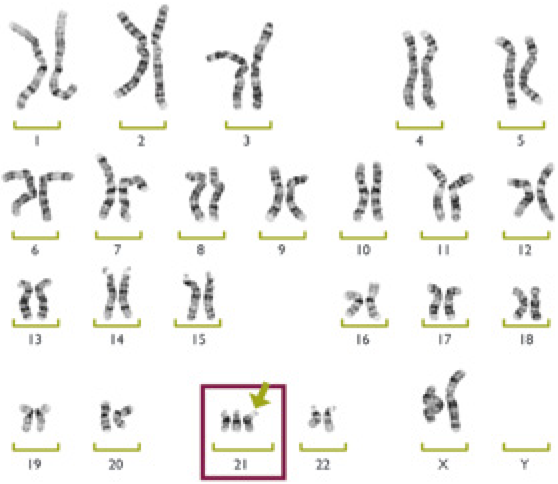


Diagram 2: T21 female karyotype



Are there any cures?

Although we know how Down syndrome occurs, we do not yet know why it happens. Down syndrome occurs at conception, across all ethnic and social groups and to parents of all ages. It is nobody's fault. There is no cure and it does not go away. However, we do know that people with Down syndrome who receive good health care, early intervention into their development and quality education go on to have a better quality of life.

Down syndrome is the most common chromosome disorder. About one of every 1,100 babies born in Australia will have Down syndrome. Down syndrome is not a new condition – it has been recorded throughout history.

All people with Down syndrome have:

- Some characteristic physical features, such as an upward slant to the eyes.
- Some health and development challenges.
- Some level of intellectual disability.

But because no two people are alike, each of these things will vary from one person to another.

What impact can Down syndrome have on health?

Many babies with Down syndrome are born without any health problems at all. However, some newborns with Down syndrome may experience some health complications, such as:

- low muscle tone
- a heart defect
- digestive or feeding issues.

Some babies and children with Down syndrome may present with other health concerns such as:

- respiratory issues
- vision problems
- hearing difficulties.

If your baby has a particular health concern, you will need to seek more specific and detailed information. Please talk to your health care professional about any of these medical matters, and ask for information as you need it.

Your baby's health record

Along with this booklet, you should also have received information on health and development as a companion resource to the baby book provided by your health department, sometimes known as your baby book or clinic book. The insert contains growth charts, a developmental milestone chart and a recommended health check schedule, designed specifically for children with Down syndrome. If you haven't received it, please contact your local Down syndrome association.

Choosing a paediatrician

It is important that your child's health is monitored especially through the early years. Development of speech and learning can be affected by hearing, thyroid function, vision and heart conditions.

The most important thing to remember when choosing a paediatrician, is to find a doctor who is willing to learn about Down syndrome and collaborate with you, the parent, to ensure your baby's healthcare needs are met. One of the best ways to find a paediatrician who knows about Down syndrome is to ask other parents of children with Down syndrome. Also remember: you have choice – if you are not happy with your current paediatrician, there are others around.

Feeding your baby

Although many babies with Down syndrome will quickly learn to breastfeed, some will take longer and need more help to get the hang of it.

All babies, including those with Down syndrome, are born with the instinctive knowledge and ability to get themselves to their mother's breast and to attach themselves correctly, with their mother's support. Spending one-on-one, skin-to-skin time with your baby when you are learning to put her to the breast will help to allow these 'baby-led attachment' instincts to work. It's also a lovely way to develop bonding between mother and baby.

The exercise of breastfeeding itself will improve your baby's muscle tone, and can help with speech and tongue control in the future and as with all babies, breast milk assists their immune system. As your baby gets stronger and learns to breastfeed more effectively, she will be able to drink more milk.

It is important that you make sure your baby is getting enough milk. Signs that she is getting enough milk include:

- lots of very wet nappies each day
- soft, unformed bowel motions
- good skin tone
- some growth in weight, head circumference and length.

If you are worried about any of these signs, please talk to your healthcare professional straight away.

If you are having difficulty learning to breastfeed, we encourage you to employ the services of a skilled lactation consultant, or contact your local breastfeeding association. You can also express and bottle feed with breast milk, while your baby learns to feed. Remember that many mothers and babies need extra help to breastfeed.

The Australian Breastfeeding Association (ABA) has an information booklet called *Breastfeeding: Your baby with Down syndrome*. This is available from **www.breastfeeding.asn.au** and Down syndrome associations.

Some babies with Down syndrome are not able to breastfeed. Don't worry if you find breastfeeding is not suitable for your baby. Sometimes low muscle tone causes difficulties with sucking or a medical problem may mean your baby is in hospital and the condition may make it difficult for her to breastfeed.

Bottle-feeding is a rewarding experience for mother and baby, especially if you remember the following key points

- Feeding is a time to really enjoy being close to your baby.
- Make sure you and your baby are comfortable as this makes feeding easier.
- Hold your baby in a semi-reclining position to help strengthen head control (the same as if you were breastfeeding your child)
- Make sure the baby can see your face, so you can make eye contact, smile and talk to your baby while you are feeding.
- Seek advice on the best formula, bottle and teats for your baby from your local health professional. It may take a while to find just the right ones for your baby.
- Stay on 'formula' milk for the first year.

- Introduce semi-solids slowly, as advised by your child and family health service.
- Never add food, sugar, or salt to baby's bottle.
- Trust your instincts!

Many fathers, grandparents and older siblings, agree that bottle-feeding is great as it means they too can experience this special time with the baby. Of course it is important that the baby is introduced slowly to different 'helpers'.

Early communication

Babies often stop sucking for short rests during feeding. This is one way babies learn that communication is a two-way process. Make sure you talk to your baby if he stops sucking and give him a moment to gurgle, smile or wriggle in reply before he is encouraged to return to the bottle or breast.

It is important to encourage awareness of his mouth and face. This will strengthen baby's muscles, for both eating and speech development later on.

You can do this by:

- Gently guiding his hands to his mouth.
- Encourage exploration of different objects and textures.
- Massage gums with your little finger.
- Play games like 'pat-a-cake' around the lips and mouth.

Early intervention

All young children go through rapid and significant changes during the first three years of life. During these early years, children achieve the basic skills that lay the foundation for future progress. Children with Down syndrome typically face delays in certain areas of development, so early intervention is beneficial in helping them reach their developmental milestones. Early intervention can begin any time after birth, but the sooner it starts, the better.

It is good to know what to expect from early childhood intervention services before you start using them, so you can have realistic expectations of the services, be able to make informed choices, and will know when services are doing well or falling short.

What is early intervention?

The most common early intervention services for babies with Down syndrome are physiotherapy, speech therapy and occupational therapy. There may sometimes be other professionals involved. Early childhood intervention services are designed to enhance the way infants and toddlers develop. However, it is important to remember that children develop through their family relationships, so most learning will occur within the family between visits to professionals, not during the sessions. The main goal of early childhood intervention services is to help you understand and meet the developmental needs of your child. The services provide information, encouragement, support and advice on supporting development.

How can early intervention benefit your baby?

Most children are expected to achieve milestones at certain stages, calculated in terms of weeks, months or years. Because of the challenges associated with Down syndrome, your baby may experience delays in some areas. You can expect your baby to achieve the same milestones as other children, but this will be on her timeframe. As development is so individual, babies with Down syndrome will also have different timeframes from each other.

There are specific milestones in each of the areas of development:

- cognitive development – the way we learn and think
- gross motor and fine motor development – the way we move our bodies
- communication and language
- social and emotional development
- problem solving skills.

What types of early intervention can you expect to use?

Because every baby and family is different, early intervention support must be tailored to meet different needs and circumstances. Early childhood intervention teams usually work with parents to develop a plan to guide the work of the team. Sometimes the team may have a 'key worker' who is the point of contact for the whole team.

Each type of early intervention therapy addresses specific aspects of your baby's development.

Physiotherapy

Physiotherapists focus on helping children develop gross motor skills such as rolling, sitting, crawling and walking.

For example, during the first three to four months of life, most babies without Down syndrome are expected to gain head control and the ability to pull to a sitting position (with help) with no head lags and enough strength in the upper body to stay in an upright position. Babies with Down syndrome may have low tone and take longer to achieve this milestone, so a physiotherapist can show you exercises that you can do with your baby to help them get there.

Gradually, your baby will become able to explore his surroundings, to reach and grasp toys, to turn his head in order to follow a moving object with his eyes, to roll over and to crawl in pursuit of a desired object – all of these behaviours depend on gross motor as well as fine motor development. These physical, interactive activities help your baby understand and master his environment, and also help him to learn, communicate and develop social skills.

Speech therapy

Speech therapy is another important part of early intervention. Speech therapists (sometimes called speech pathologists) help to develop early communication and understanding. There are many pre-speech and pre-language skills that must be acquired before your baby says his first words. These include:

- the ability to imitate and echo sounds
- turn-taking skills – learned through games such as 'peek-a-boo'
- visual skills – looking at the person who is speaking and visually following objects
- auditory skills – listening to music and speech for lengthening periods of time, or listening to speech sounds
- tactile skills – learning about touch, exploring objects in the mouth
- oral motor skills – using the tongue, moving lips
- cognitive skills – understanding more about his environment and ability to make things happen.

A speech therapist can help with these and other skills, including breastfeeding and eating solid foods, which can help strengthen your baby's jaw and facial muscles to help their future communication skills.

Occupational therapy

Occupational therapists help children develop their independence skills. When your child is an infant, the therapist will focus on developing his fine motor skills. This will include activities such as opening and closing things, picking up and releasing toys of various sizes and shapes, stacking and building, manipulating knobs and buttons, experimenting with crayons and so on. Occupational therapists also help children to learn to feed and dress themselves, and teach skills for playing and interacting with other children.

What should you expect from early intervention services?

Early intervention services should be family-centred. This means that parents are respected as the experts on their child's needs and family circumstances. Your early childhood intervention team should:

- See you as real partners in your child's early intervention support.
- Support you as decision makers regarding your child's therapy services.
- Make sure you get all the information you need to make decisions.
- Make sure you have real and meaningful early intervention options.
- Help you develop your skills and confidence to meet your child's needs.

What should you guard against?

There are a couple of common misconceptions about early childhood intervention services that it's important to understand in order to get the most from your services:

- that professionals will do all the work
- that professionals have all the answers.

It's natural for parents, especially new parents, to expect the professionals to be the ones working with their child, and to be the ones with all the answers. However, therapists and other professionals only spend a very small amount of time directly with your child. And, while they may be experts in child development generally, they don't know each child as well as the parents do, and they don't know initially what strategies will work best for that child and family. The best approach, leading to the best outcomes for your child, is for professionals and parents to pool their knowledge and expertise and work together.

The National Disability Insurance Scheme (NDIS)

The NDIS provides tailored, specialist support to children who will benefit from early intervention. Children with Down syndrome who are under the age of seven are eligible for early intervention supports under the NDIS, if they meet Australian residency requirements.

The process for families to access NDIS early childhood services is found on the NDIS website. For more information visit **www.ndis.gov.au**

You can also search for an Early Childhood Partner on the NDIS website **www.ndis.gov.au/contact/locations**

Checklist for support

Here's a checklist of the practical, financial, health and other support that is available to you and your family.

1. Contact the Down syndrome association closest to you

The contact details for our associations are on page 38 of this resource. You can also visit our website at **www.downsyndrome.org.au** to find links to each of the state and territory associations. Membership with these associations will provide you with a range of benefits and support throughout your child's life – from the early days with a new baby through to school and beyond. Each association has a range of events, activities and training sessions you can attend throughout the year, along with plenty of useful resources and friendly people who can share your experiences.

2. Make contact with your local child and family health service

Most areas will have a local child and family health service, sometimes called the maternal and child health nurse. The staff in this service will be able to support you with information and advice relating to the general health and development of children from birth to five years. They can conduct regular routine health and development checks and can also provide you with lactation consultant support, or put you in touch with a lactation consultant in your area. In addition to a local GP, many families find it useful to see a paediatrician regularly, to monitor health and development and to offer referral to any relevant specialists.

3. Submit an application to Centrelink for the Carer Allowance

As a parent of a child with Down syndrome, you may be entitled to a monthly allowance and Health Care Card for your child until she turns 16. A claim form and further information is available from your local Centrelink office or from their website at **www.humanservices.gov.au.** You can call them on **13 27 17**.

Please know that you are not depriving others by claiming an allowance that you are entitled to.

4. Seek out early intervention support

As we have described, early intervention plays an important part in the development of children with Down syndrome. A range of services is available from birth to six years of age, including physical therapies and speech and language therapy. Note that these services vary from state to state. Your local Down syndrome association will be able to provide information about the services that are available in your area. You may also want to speak with your paediatrician and other parents about services in your area.

5. Enquire about government programs, particularly the NDIS

There is a range of government programs to support people with disability, like the National Disability Insurance Scheme.

You may be able to access early intervention funding that is available for children with disabilities like Down syndrome, who are under seven years of age.

Find out more about Early Childhood Early Intervention on the NDIS website: **https://www.ndis.gov.au/understanding/families-and-carers/early-childhood-approach**

Find an Early Childhood partner in your area:
www.ndis.gov.au/Contact/locations

You can also contact your local Down syndrome organisation for information and support about applying for NDIS.

Remember, you are not alone

There is a Down syndrome association in each state and territory. You can contact these associations for support and advice. We are here to help you. Our associations are made up of parents, just like you, and we also have a range of professionals and people with Down syndrome who work or volunteer with us. We'd love to get to know you and be part of your journey through parenthood. Please contact us on the details below or call 1300 881 935, to be automatically connected to your closest association.

Associations

National: 1300 881 935

New South Wales

Down Syndrome NSW
T: 1300 881 935
E: admin@dsansw.org.au
W: www.downsyndrome.org.au/nsw

Victoria

Down Syndrome Victoria
T: (03) 9486 9600
Toll Free 1300 658 873
E: info@dsav.asn.au
W: www.downsyndrome.org.au/vic

Queensland

Down Syndrome Queensland
T: (07) 3356 6655
E: office@downsyndromeqld.org.au
W: www.downsyndrome.org.au/qld

South Australia

Information Service South Australia (Down Syndrome Australia)
T: 1300 344 954
E: infoSA@downsyndrome.org.au
W: www.downsyndrome.org.au/sa

Western Australia

Down Syndrome WA
T: (08) 6253 4752
E: admin@downsyndromewa.org.au
W: www.downsyndrome.org.au/wa

Tasmania

Down Syndrome Tasmania Inc.
T: 1300 592 050
E: info@downsyndrometasmania.org.au
W: www.downsyndrome.org.au/tas

Northern Territory

Down Syndrome Association NT
T: (08) 8985 6222
W: www.downsyndroment.com.au

Australian Capital Territory

ACT Down Syndrome Association Inc.
T: (02) 6290 0656
E: admin@actdsa.org.au
W: www.downsyndrome.org.au/act

downsyndrome.org.au

Down Syndrome
Australia