



New Parents Guide

Support and information as
you welcome your new baby





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Congratulations

Congratulations on the birth of your beautiful baby! We hope that you and your little one are doing well.

Finding out that your baby has Down syndrome may have been unexpected, and you might have questions about what the future will bring, or you may simply want to focus on getting to know your precious baby.

For some parents, being informed of the diagnosis prenatally gave them time to prepare and begin learning more about Down syndrome. If this was your experience, you might already have some knowledge and resources that can help guide you in the early days.

Whether you had time to process the information beforehand or this news has come as a surprise, there is no right or wrong way to feel.

Every parent's journey is different.

Some parents want lots of information straight away, while others prefer to take things one step at a time. The important thing is to move at your own pace.

Many parents say that it helps to focus on the present. Day by day, you will get to know your baby's unique personality, their likes and dislikes, and the little things that make them who they are.

Your baby is your baby first. While having Down syndrome may come with some additional needs, what matters most in these early days is the same as with any newborn: to be fed, changed, comforted and cuddled.

We know this can be a time of big emotions and adjustments. Some parents later say they wish they had spent more time simply enjoying their baby in those early days. That's why we encourage you to take things moment by moment.

There is extensive information online about Down syndrome, which can be helpful but sometimes overwhelming. This booklet, created by the team at Down Syndrome Ireland, offers clear, balanced, and up-to-date guidance to help you understand Down syndrome in a practical and supportive way.

We hope this booklet gives you reassurance and support as you welcome your baby into the world.



What is Down Syndrome?



Down syndrome is a genetic condition caused by the presence of an extra chromosome in a person's cells.

Chromosomes carry the instructions that make each of us unique, such as the colour of our eyes and hair or which family members we resemble.

Most people are born with 46 chromosomes, but babies with Down syndrome have 47. The extra chromosome affects chromosome 21, which is why Down syndrome is sometimes called Trisomy 21.

There is no single known cause of Down syndrome, and it can happen to anyone. Any parent can have a baby with Down syndrome.

Down syndrome is the most common chromosomal condition; there are approximately 9,000 people in Ireland with Down syndrome. In Ireland, one in every 444 babies are born with Down syndrome.

“ I had a prenatal diagnosis on my 12-week scan. We knew for a long time, and for so long, I just wanted her in my arms. There was just something about it, while I was pregnant, I just knew everything was going to be fine. I say it to parents all the time – once you have your baby, everything will be okay.

Sinéad, Aurora's mum

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Types of Down Syndrome

There are three types of Down syndrome, and they are all caused by the presence of extra genetic material on chromosome 21.

- **Trisomy 21.** This is the most common type, affecting about 95% of children with Down syndrome. It occurs when every cell in the body has an extra copy of chromosome 21.
- **Translocation Down syndrome.** This affects about 3–5% of children with Down syndrome. In this type, an extra copy of chromosome 21 attaches to another chromosome rather than being separate. In most cases, this happens by chance, but in a small number of cases, it may be inherited. If this is the case, parents may be offered genetic counselling.
- **Mosaic Down syndrome.** This is the rarest type, affecting about 1–2% of children. In this case, some cells have an extra copy of chromosome 21, while others do not. The number of affected cells varies from person to person.

After your baby is born, a blood sample will be taken and sent to the genetic laboratory at Children's Health Ireland to determine which type of Down syndrome your baby has. Many parents receive these results at their baby's six-week check-up as an outpatient.

How Down Syndrome Affects Development



Down syndrome affects each person differently. People with Down syndrome share some characteristic physical features, such as an upward slant to the eyes, low muscle tone, small nose and mouth, short stature, and a single deep crease across the centre of the palm. They also may have specific health challenges, which we'll discuss further in this booklet. All children with Down syndrome will have some level of intellectual disability, but this will vary from one child to another.

Because Down syndrome affects early development, children may take longer to reach milestones and will benefit from extra support. While it influences many aspects of their life, it does not define what they can achieve.

“ The feelings that you feel right now, are valid. I didn't know I was going to have a child with Down syndrome. You have an image and a perception in your head of what your baby will be like. It's okay to take some time to process that it's different. You then have to look at a new vision. You have to then think, I have a child with Down syndrome, what will that look like? For us, we have the most beautiful little girl. We couldn't ask for a better wee woman to be honest with you. I wouldn't change her for the world. ”

Gráinne, Grace's mum

Down syndrome is a lifelong condition, but with good healthcare, early intervention, and access to education, children with Down syndrome can thrive. Today, more than ever, children with Down syndrome are growing up with greater opportunities to learn, participate, and live fulfilling lives.

Advances in healthcare, education, and support services over the past few decades have made a big difference, and society's understanding of disability continues to improve. With the right support, children with Down syndrome can develop their independence and make their own choices about their future.

A child's growth is shaped by the love, encouragement, and opportunities they receive from their family and community. Like all children, children with Down syndrome thrive when they are supported, valued, and given high expectations at home and school.



How Can Down Syndrome Impact Health?

Babies and young children with Down syndrome have the same basic health needs as all children. They should attend routine check-ups and immunisations just like any other baby.

Some babies with Down syndrome are born without any health concerns, while others may have medical conditions that are more common in children with Down syndrome. Because of this, doctors recommend some additional health checks to ensure any concerns are identified early and managed appropriately.

Some newborns with Down syndrome may experience:

Low Muscle Tone (Hypotonia)

This can affect feeding and movement in the early months, but with time and support, babies gain strength and develop new skills.

Heart Conditions

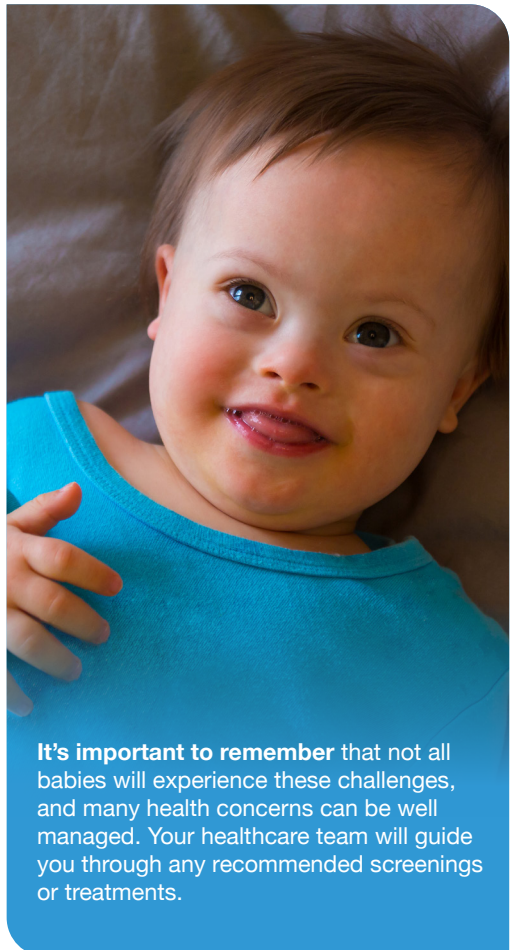
Some babies are born with congenital heart conditions, which vary in severity. If needed, these are closely monitored and managed by a specialist.

Feeding Difficulties

Some newborns may take a little longer to coordinate sucking and swallowing, but support from healthcare professionals can help.

Hearing and Vision Issues

Routine checks help identify concerns early so they can be addressed.



It's important to remember that not all babies will experience these challenges, and many health concerns can be well managed. Your healthcare team will guide you through any recommended screenings or treatments.

Medical Checks

After birth, your baby will need a number of routine screening tests. This can initially feel overwhelming but try to take it one step at a time. As time goes on, these appointments will become less frequent.

“*Maisie had a heart defect when she was born and preparing for her surgery was incredibly exhausting. But after successful surgery, life became much easier. I was in awe of Maisie’s resilience and when things settled down, our lives became normal.*”

Emer, Maisie’s mum

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Weight and Length Plotting

All newborn babies are weighed at birth, and their length is plotted. Specific growth charts are available for children with Down syndrome. Your doctor and/or public health nurse will continue monitoring your child’s weight and height.



Blood Tests

A blood sample is taken at birth and sent to the genetics laboratory for karyotype testing. Karyotype testing is a chromosomal analysis that will tell us which type of Down syndrome your child has. Your doctor will inform you of the results, usually at your 6-week check-up. Your doctor may also carry out a full blood count (FBC). Routine blood samples are usually taken by your GP or paediatrician.



Hearing

All newborn babies undergo a hearing test as part of the National Newborn Hearing Screening Programme. Your child’s hearing will continue to be monitored by your local HSE audiology service.



Cardiac Testing

Due to an increased risk of cardiac issues, all newborns with Down syndrome should have the following tests, ideally before six weeks:

- **Echocardiogram (ECHO):** An ultrasound of the heart that examines the structure and the sound waves.
- **Electrocardiogram (ECG):** This test records the electrical activity of the heart.

If no cardiac condition is identified, your child will likely be discharged from cardiac services and will not need another check until their early teens.



Eyesight

Every newborn should have an eye exam to check for congenital cataracts, glaucoma, and other eye abnormalities. A recheck should take place with an ophthalmologist between six and ten months of age. Your child’s sight will continue to be monitored by an ophthalmologist.



Heel-Prick Test

Guthrie Testing (the heel-prick test) is carried out on all newborn babies and screens for six conditions. It is recommended that the test be done three to five days after birth. This may be done in the hospital before discharge or by your public health nurse. This is the first test to check the functioning of the thyroid gland, which will be checked again with routine blood tests.

Don’t hesitate to ask for clarification if you’re unsure about anything your doctor explains. You can also contact the Clinical Nurse Specialist for children with Down syndrome for additional health information.

Feeding Your Baby

Establishing feeding with your baby is an essential part of the early days. Many babies with Down syndrome can breastfeed successfully, while others may need additional support. Your maternity hospital team, including nurses and lactation consultants, will guide you through the process and help you find the best approach for you and your baby.

Breastfeeding offers many benefits, including essential nutrients and protection against illness. However, some babies may experience challenges such as a weaker suck or tiring easily. If breastfeeding is difficult, you can express milk and feed your baby using a bottle or tube with support from your healthcare team.

If breastfeeding or expressed breast milk is not an option or not your preferred choice, infant formula is a suitable alternative. In some cases, a dietitian may recommend a formula with higher nutrient content to support your baby's growth.

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I breastfed all of my children, and Grace was the best feeder. There is a misconception that a child with Down syndrome will struggle to breastfeed – that's not always the case. She is absolutely on the trajectory of her two sisters. She is fit, happy, healthy.

Gráinne, Grace's mum

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When to Seek Support with Feeding

Some babies with Down syndrome may need extra help with feeding. Speak to your healthcare team if your baby experiences:

- Difficulty coordinating sucking and swallowing
- Coughing, gagging, or breathing issues while feeding
- Prolonged feeding times (longer than 30-40 minutes)
- Frequent reflux or signs of discomfort during feeds
- Difficulty gaining weight or losing interest in feeding

If you have any concerns about your baby's feeding, don't hesitate to reach out for support. Your maternity hospital team is there to help you get feeding established in the early days. As you continue at home, your public health nurse and GP can offer further guidance, and our Clinical Nurse Specialist at Down Syndrome Ireland is also available to support you with any feeding questions or concerns.

Sharing the News

Telling Your Family and Friends

Sharing your baby's diagnosis with family and friends can bring up many emotions. There is no right or wrong way to do it, and it's okay to give yourself time to process before sharing the news.

Family and friends may need time to understand what Down syndrome means, and their reactions can vary. Your family may need some time to adjust to the news, just as you have.

When you feel ready to start seeing family and friends, try to keep the focus on your baby and these special early moments. You might share that you are taking things one step at a time while enjoying getting to know your beautiful baby.

“

Grace is thriving because of the family that she is in and her sisters, and the people around her. People will say silly things but just let them. It's not a reflection of you or your little girl or boy.

Gráinne, Grace's mum

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“

I can genuinely say our lives are all the better for having Maisie. Her siblings adore her and we have so much fun together.

Emer, Maisie's mum

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Talking to Brothers and Sisters

It's usually best if you, as the parent, talk to your other children about their new sibling with Down syndrome. You know them best and can determine the right time and amount of information based on their age and understanding.

You don't need to wait for a specific moment or have a formal conversation. Talking about it naturally as part of everyday life is often the most effective way to share the news.

As you speak about Down syndrome, your children will look to you for guidance. If you focus on your baby as a unique individual rather than just their diagnosis, they will too.

Emotional Wellbeing

The first days and weeks after having a baby are full of emotions. Alongside the joy, you may experience a mix of feelings such as uncertainty, love, fear, sadness, or an overwhelming sense of protection for your baby.

Every parent processes this experience in their own way. There is no right or wrong way to feel. It takes time to adjust, and all emotions are valid.

If the diagnosis was unexpected, you may feel shocked or in disbelief. Some parents describe feeling numb or struggling to take in everything the doctors and health professionals say. If this happens, it can help to schedule a follow-up meeting with a list of questions to understand your baby's needs better.

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Get ready for a wonderful adventure! When we first received the Down syndrome diagnosis, my father-in-law said that you will never have a more loving child. He was right, Ruairí seems to sense more than any other child I've ever met. When I might be a bit down, he will arrive over with his big smile, infectious laugh and a hug to help out. Don't worry about the what ifs, love the child and care for them as you would any other child.

Colin, Ruairí's dad

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It's natural to have many questions, such as:

- How will Down syndrome affect my baby's development?
- What does this diagnosis mean for me as a parent?
- How will this affect the rest of my family?
- What can I do to help my baby reach their potential?
- What will my child be like as they grow up?

Take things one step at a time. Be patient with yourself and allow yourself the space to process your emotions. Over time, as you get to know your baby, you will gain confidence and find your own way forward.



Bonding with Your Baby

In these early days, you may experience mixed emotions as you adjust to the news. Tiredness and big feelings can sometimes make bonding with your baby difficult. That's okay. Take it one step at a time.

Right now, the most important thing is focusing on feeding, cuddles, and closeness. Newborns need to feel safe, loved and secure.

Bonding is the foundation for your baby's emotional development.

When a baby feels secure and connected, they develop a strong sense of trust in the world. This trust helps them feel safe enough to explore, learn, and build relationships as they grow.



If you're feeling overwhelmed, here are some simple ways to nurture your bond with your baby:

- Spend time holding and cuddling your baby
- Comfort them when they need it
- Smile, talk, and sing to your baby
- Respond to their sounds, coos, and cries
- Make eye contact and let them watch your face
- Keep them close so they can hear your voice and feel your presence
- Ensure they are warm, fed, and feel safe

There is no perfect way to bond. What's most important is that your baby feels your love and presence. Just be there for your baby, holding them close and responding to their needs, as this helps build a strong and loving connection.

Self-Care

It's important that parents look after themselves. Welcoming a new baby brings many changes, and it's natural to feel tired, emotional, and even overwhelmed at times.

Every parent adjusts differently, and you may find that your needs and feelings are not always the same as your partner's, and that is ok.

Taking care of yourselves as you navigate this new journey, also helps you care for your baby.



Advice from other parents includes:

- **Take things one day at a time.** Focus on today and enjoy getting to know your baby rather than thinking too far ahead.
- **Talk about your feelings.** This is a significant change in your life; you and your partner may experience different emotions. It's important to talk to each other openly and honestly. If you are parenting alone, reach out to family and friends for support.
- **Accept help.** Don't hesitate to ask for or accept support from family and friends at this time. They can help with cooking meals, doing chores, or simply offering a listening ear.
- **Look after your basic needs.** It's normal to feel tired and overwhelmed, but try to eat well, rest when you can, and get enough sleep. Sleep deprivation can make everything feel harder, so taking care of yourself is not just good for you; it's good for your baby, too.
- **Find support.** Many parents say that joining a parent group was one of the best things they did. Connecting with others who understand your experience can help you feel less alone and learn from other parents' experiences.

Take things one step at a time. Be patient with yourself and allow yourself the space to process your emotions. Over time, as you get to know your baby, you will gain confidence and find your own way forward.

If you're struggling, please reach out for help. Talk to someone you know and trust. Your local Public Health Nurse/GP can advise you on supports and counselling available in your area.



Early Intervention



“ *The most powerful influence on the progress of a baby with Down syndrome is to be loved, wanted and absorbed into the everyday life of the family and of the community. Specific teaching and therapies will definitely help but must be kept in perspective and not allowed to create stress and anxiety for families.*

Prof. Sue Buckley & Ben Sacks.

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The First Years of Life and Early Intervention

The early years are a crucial time for your child’s development. During this stage, they begin building essential skills in movement, communication, learning, play, social interaction, and independence. These early experiences build the foundation for future learning.

Although children with Down syndrome may take longer to reach certain milestones, early intervention provides essential strategies to guide their development and help them succeed.

Early intervention is about creating a supportive environment that helps your child learn in everyday life.

What is Early Intervention?

Early intervention is an umbrella term that includes activities, therapies, and strategies designed to support your child’s development. These interventions are most effective when built into everyday routines in familiar environments like home and preschool.

Children naturally learn through daily routines, interactions and play. They learn best when they’re having fun and following their curiosity. That’s why early intervention should fit naturally into their environment and routines, making learning enjoyable and engaging.

It’s important to remember that early intervention isn’t just about therapy sessions. As a parent, you play the most important role in your child’s development. By using simple strategies during daily routines and play, you create natural opportunities for your child to learn and thrive.

Early intervention professionals will work closely with you to monitor your child's progress and provide individualised guidance. You know your child best; professionals bring expertise in child development and Down syndrome. Working together in partnership will allow you to build a foundation of support for your child.

Early intervention professionals can also collaborate with educators and teachers to make sure that support continues in preschool and school.

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I would say, connect at a very early stage to Down Syndrome Ireland, connect with groups of other parents of children with Down syndrome. It's about the connection, advice and support from people who get it. Don't be afraid to ask for services, have a voice. You are a voice for your child.

Gráinne, Grace's mum

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Some of the professionals you may work with include:

Early Intervention Specialist (EIS)

Early intervention specialists help support children's overall development, working with families to incorporate learning, communication, play, and social skills into daily routines.

Occupational Therapist (OT)

Occupational therapists can help you learn how to support your child in everyday tasks like dressing, feeding, and playing, promoting independence.

Speech and Language Therapist (SLT)

Speech and language therapists focus on supporting the development of communication skills, including speech, listening, and comprehension. A specialised SLT can also help children with feeding and swallowing difficulties.

Physiotherapist (PT)

Physiotherapists work to support children's physical skills, helping them with movement, strength, balance, and coordination.

Not all children will need support from every professional listed here. This guide is to help you understand their roles so you can access the right support if needed.

How to Access Early Intervention Services

Children with Down syndrome are supported through the Children's Disability Network Teams (CDNTs), which provide early intervention services across Ireland. Your maternity hospital will refer you to your local CDNT, and the team will contact you directly.

It's important to know that while all families should have access to these services, waiting times can vary across regions, and some areas currently have longer waiting lists.

Down Syndrome Ireland and our local branches offer a range of support services for new families. You are welcome to contact our Early Intervention Specialist for information or guidance. You can also join one of our monthly baby groups, available in Dublin, online, or in some local branches. These groups offer early support, the chance to meet other families, and practical ideas to help you support your baby's development.

Starting Early Intervention at Home



Parents often feel anxious to start early intervention at home and wonder when to begin.

The process can start soon after birth. You can begin simple activities once you're back home and feeling more settled.

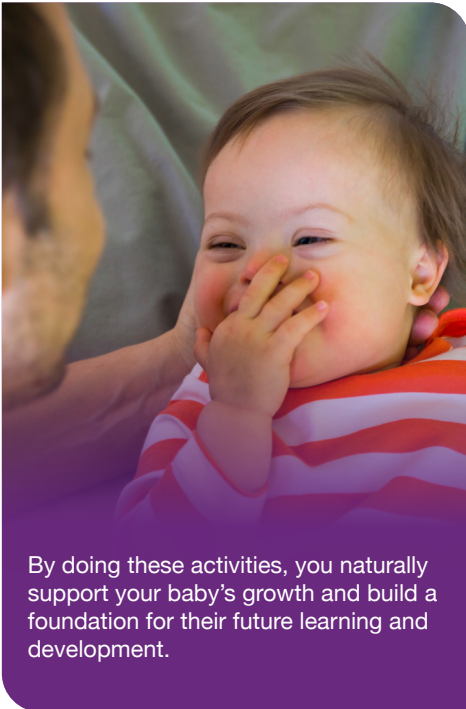
Many parents aren't sure where to start and are eager to engage with services. But while you're waiting for services to begin, be assured that you can already support your baby's development.

Early intervention often includes simple, traditional play activities that naturally stimulate key areas of development. These activities have been passed down through generations because they are effective in supporting a child's growth at each stage. When you meet early intervention professionals, you'll see that they often use these natural play activities to support your baby's development.

So even while you wait for formal early intervention, activities such as singing to your baby, rocking them, talking to them, or encouraging exploration on a baby gym are all beneficial to your child's growth. Once you meet early intervention professionals, they will provide individualised guidance tailored to your baby's needs.

Here are some simple activities you can try with your baby, along with ways they can support your baby's development in the first few months.

The most important thing is to follow your baby's cues and focus on activities they enjoy. Watch how your baby responds. If they seem relaxed, smile, or look interested, that's a good sign they are enjoying it. If they turn away, become unsettled, or start crying, it might be time to pause and try something different. Every baby is different, and finding what works for your little one helps make these moments positive and enjoyable for both of you.



By doing these activities, you naturally support your baby's growth and build a foundation for their future learning and development.

- **Baby Massage:** Gently massaging your baby helps them become more aware of their body, which is essential for motor skills like rolling, reaching, and crawling. It also promotes bonding and early communication through touch, encouraging your baby to smile and focus on your voice.
- **Sing to Your Baby:** Singing to your baby develops their listening skills and teaches them to pay attention to sounds. It also introduces them to the rhythm and melody of speech, which forms the foundation of language development. Responding to your baby's coos or babbles helps encourage communication.
- **Gentle Tickles and Rocking:** Tickling and rocking your baby are enjoyable ways to bond and help your baby start communicating through their reactions. These activities lay the foundation for early communication skills.
- **Shake Rattles and Show Toys:** Shaking a rattle or showing your baby different toys helps them practice tracking objects with their eyes and ears, which are the first steps toward more complex physical skills like reaching and moving. It also keeps them engaged and excited about interacting with their surroundings.
- **Textured Baby Blankets and Play Gyms:** Allowing your baby to explore different textures with their hands or watch toys move around helps build hand-eye coordination and teaches them to grab, hold, and release objects. These skills are crucial for later independence, like feeding themselves.
- **Tummy Time:** Tummy time is essential for strengthening your baby's neck and back muscles, which are needed for head control and later skills like rolling, sitting, and crawling. It's especially important for babies with Down syndrome, as it helps with challenges related to muscle tone and supports physical development. Always make sure tummy time is done only when your baby is awake and that they are supervised at all times.
- **Read to Your Baby:** Even though your baby won't understand words yet, reading aloud helps with bonding and language development. Your baby will enjoy hearing your voice, looking at pictures, and feeling the textures of the book. This encourages listening skills and cognitive development.

Entitlements

Navigating entitlements can feel overwhelming, but these supports help ease financial pressures and ensure your child gets the necessary care. Below are key benefits available to families of children with additional needs.

Your maternity hospital will help you apply for these entitlements before discharge.

Domiciliary Care Allowance



The Domiciliary Care Allowance is a monthly payment for parents of children who need extra care beyond what is typical for their age. This allowance is not means-tested, meaning your income does not affect eligibility. You must apply through the Department of Social Protection, providing evidence of your child's additional care needs. We recommend applying as soon as possible, as this can help you access other supports more quickly.

Medical Card



Once approved for the Domiciliary Care Allowance, you can apply for a Medical Card for your child. This card covers GP visits, hospital care, prescription medications, and other essential healthcare services at no cost. This is particularly important for children who may need frequent medical appointments and specialist care.

Carer's Support Grant



Families receiving the Domiciliary Care Allowance automatically receive the Carer's Support Grant, an annual payment made each June. No separate application is required.

Incapacitated Child Tax Credit



The Incapacitated Child Tax Credit is available to parents of children with disabilities, including Down syndrome, who are paying tax as employees or self-employed individuals. While the name may sound misleading, it is simply the official term used for this tax relief. We strongly encourage families to apply, as it can help reduce tax payments.

Other entitlements available to you include:

Carer's Benefit



A financial support programme for parents who leave full-time work to care for a child with additional needs. Eligibility depends on your social insurance contributions (PRSI). Payments can be received for up to two years.

Carer's Leave



Allows employees to take a temporary leave from work to provide full-time care. You can take leave for 13 to 104 weeks, but it is unpaid. Your job will be kept open during this time. You may also be eligible for Carer's Benefit or Carer's Allowance, but this is not required to take leave.

Carer's Allowance



This is a means-tested weekly payment for individuals providing full-time care to someone due to age, disability, or illness.

For more information on entitlements, visit Downsyndrome.ie

First Steps: Checklist

Many parents share how overwhelming it can feel initially, with so much new information to process.

To help you through this time, we've put together four essential first steps to help you access the services and support you and your child's needs.

Maternity hospitals provide good support in completing these steps, so be sure to liaise with the referral nurse to ensure everything is taken care of.

Check off each item as you go to make sure important referrals and applications are completed.

Referral to Paediatrician or GP. Make sure your referral to your local paediatrician or GP for your child's medical check-ups and ongoing health monitoring is completed.

Referral to Local CDNT. Ensure your referral to your local Children's Network Disability Team (CDNT) is completed.

Domiciliary Care Allowance Application. Fill out and send the application for Domiciliary Care Allowance to help support your child's care needs.

Incapacitated Child Tax Credit Application. Apply for the Incapacitated Child Tax Credit to receive tax relief for your child's care.

Recommended:

Become a member of Down Syndrome Ireland. Join Down Syndrome Ireland to access support and resources from your local branch. To become a member, sign up at Downsyndrome.ie

Down Syndrome Ireland

Down Syndrome Ireland is the national charity supporting individuals with Down syndrome and their families. We have a National Office in Dublin and 25 branches across the country offering local support.

Becoming a member helps you connect with other families and gives you access to up-to-date information, local services, and national supports.

How We Can Help Right Now

- If you have any questions or need support, please get in touch at info@downsyndrome.ie
- Our Nurse Specialist can help with health or medical queries.
- Our Early Intervention Specialist can guide you on available services and how to support your baby's early development.
- You can join a Parent and Baby Group, where you'll meet other families, get practical information, and support your child's development.
- Our local branches offer connection and support through parent-to-parent networks and events.

These early days can feel like a big adjustment. Take things one day at a time. With the right support, you'll feel more confident, more informed, and ready to enjoy this special time with your baby.

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