

share the journey - parent pack



footsteps
down syndrome ireland



share the journey - who are footsteps?

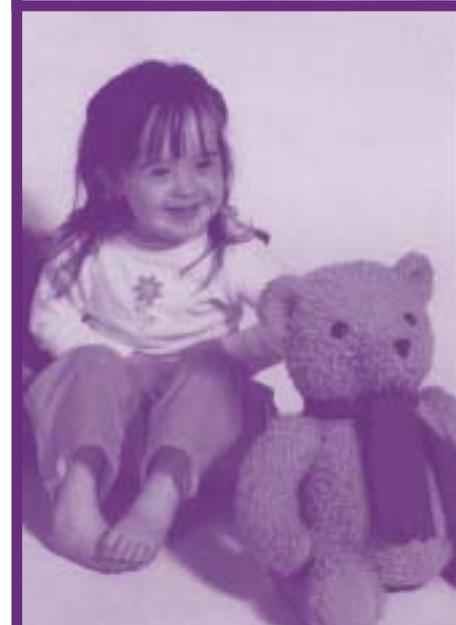
Footsteps is the name for the association Down Syndrome Ireland - the national organisation of parents and guardians of people with Down syndrome. We recognise that people with Down syndrome are no different to anybody else - they experience many great things and also face many challenges throughout their lives. However, as they may need a little extra help along the way, we aim to make their futures as bright and independent as possible by providing education, training, employment, support and friendship every step of the way.

On a personal level, you now have your own journey to make as Down syndrome becomes part of your everyday life. We are here to share that journey with you and provide you with all the information and support that you need along the way. This includes our help line **1890 374 374**, literature and resource library, counselling service, parents' groups, holidays and information centres.

Footsteps is committed to representing people with Down syndrome and their families by lobbying for improvements that are so urgently needed in early intervention, education, training, employment, medical, housing services and disability legislation so that people with Down syndrome may have brighter futures and the means to achieve their goals. Our National Resource Centre programme will provide expert advice and support in these areas and your baby will lead a more independent future because of your participation.

Through our 23 branch network nationwide, you can access thousands of other parents and families just like your own, who will have similar experiences and who will share in yours. You are very welcome to attend meetings in your local branch, which we hope you will find very useful. Most branches even provide social events/clubs, parent meetings, speech and language training and much more, so be sure you and your baby get out there and embrace life.

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congratulations on the birth of your new baby

The birth of a baby, whether your first child or fifth, is an exciting and happy time for the whole family. And you can rest assured that this occasion is no different. As you'll discover, the fact that your baby has Down syndrome is very much secondary to the fact that he/she is an individual. Your baby has the exact same needs as every other (which he/she, like all kids, will be sure to let you know about!) and will bring you all the same joy and happiness in the world.

There is a lot of misunderstanding about why a child may be born with Down syndrome. It is important you realise that the presence of the syndrome is not a result of anything that you did or didn't do. Down syndrome is a chromosomal condition - it cannot be controlled and it's not your fault.

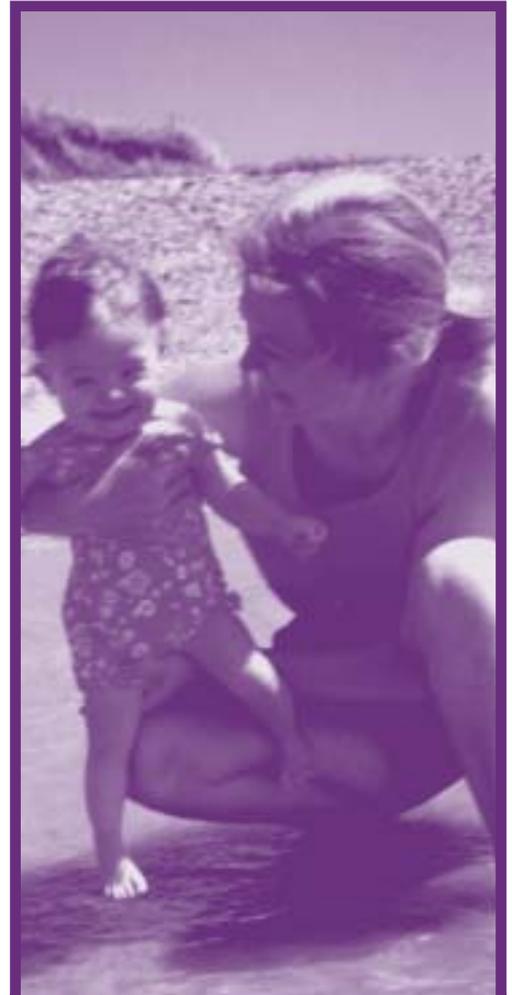
Whether a baby is born with a disability or not, it's a fact of life that some parents cope better than others in caring for their newborn. So try not to criticise yourself or be nervous - you're certainly not alone. In fact, there's an entire organisation of people just like yourself who are willing to share your experiences.

what exactly is Down syndrome?

A syndrome is a name used for a collection of several features that usually occur together. The name Down syndrome comes from Dr. John Langdon Down, an English doctor who in 1866 first described the characteristic features of this syndrome. Almost 100 years later, Professor Lejeune (Paris 1959) discovered why our children share characteristics in appearance and have a degree of physical and learning disability. The reason is actually based in the make-up of chromosomes.

what is a chromosome?

Chromosomes are minute particles within the cells of our bodies. Very simply, they are the building blocks which determine our individual characteristics such as eye and hair colour. Chromosomes are normally grouped together in 23 pairs (46 in all), half of which come from the mother and half from the father. Most babies with Down syndrome have an extra number 21 chromosome, making 47 chromosomes in all. So our babies aren't so different - instead they're 'children with something extra who need something extra'.





The three forms of Down syndrome are called simple trisomy, translocation and mosaicism.

simple trisomy

About 95 percent of all people with Down syndrome have this particular form. Parents will have normal chromosomes, but their baby has three number 21 chromosomes, rather than the usual pair. This is an accidental occurrence that happens in the division of the cell. Although the birth of a child with Down syndrome is slightly more common among older parents, it can occur at any age.

translocation

As the name suggests, this means movement to another location, where a segment of number 21 chromosome actually breaks off and attaches to another chromosome. This is observed in about 4 percent of babies with Down syndrome and can take several forms. In all cases, the baby has a normal number of chromosomes, but has extra chromosomal material i.e. as well as the usual two number 21 chromosomes, the baby has an extra portion of number 21 chromosome attached to a normal chromosome. In about one third of these children either parent may carry a translocation but show no signs or symptoms. The mother's age is not an important factor in this type of Down syndrome.

mosaicism

In one percent of people with Down syndrome, body cells have a mosaic pattern. This means that there is an extra whole number 21 chromosome in only some of the body cells, the rest of the cells are normal/or have 46 chromosomes. As a result of this mixture, babies with a mosaic cell pattern may have less prominent physical features of the syndrome.



While statistics vary in other countries, in Ireland it is estimated that about one baby in every 600 born has Down syndrome. As yet, it is not known what causes Down syndrome.

Footsteps is a member of the European Down Syndrome Association which gives us access to the newest information coming on-stream, which we are committed to passing on to you.

share the journey - how Down syndrome is recognised

All people with Down syndrome are individuals with individual talents and abilities. They are more like their families than anyone else. The only thing people with Down syndrome have in common is the syndrome itself.

Physically, they may share some of the following characteristics to varying degrees. It is important you know that the presence or absence of these physical characteristics is of absolutely no relevance to your child's development.

One in two babies will have heart problems, which can vary from a simple murmur to a more severe condition. This is quite common and most heart problems will be diagnosed in the first three months of life and are treated medically or surgically if required;

Your baby's muscle tone **may be** less than in other babies which means that their head and neck will need extra support;

Your baby's birth weight **may be** less than that of other babies and their feet and hands may be smaller, broader and sometimes chubbier.

the bright future ahead

The quality of life of people with Down syndrome has improved immensely in the last thirty years. Just like the rest of us, they now enjoy longer life expectancy and can live happy, fulfilling and active lives as part of the community.

It is also now the case whereby people with Down syndrome can be educated like everybody else. In fact many now rightly expect, and are well able for, an inclusive education and you should always encourage your child in their studies. In Ireland, dozens of young people with Down syndrome have already passed state examinations and reached other educational milestones.

Your child may also expect to work and live as part of their community, to form close friendships and achieve whatever personal goals they set themselves. Share their journey to independence with them and let them make you proud.



share the journey - share your own feelings

You may have had any number of reactions when you were first told that your baby has Down syndrome. It's possible that you experienced a sense of shock. Whether your reaction was positive or negative, it is not something you should dwell on or apologise for. Remember that you are an ordinary person reacting to an extraordinary situation.

At times of transition, we all experience the feeling of being stressed. We may also experience a wide variety of emotions. But rest assured that the feelings we generally think of as negative are a necessary part of the process of adjusting to a new situation.

Here we briefly describe some of the common feelings that parents have after hearing their baby has Down syndrome. Even if you have not experienced any of these emotions, it is possible that your partner or those around you may have, so you may find understanding and sharing them a help in supporting each other.

You may experience shock, which is mostly a physical reaction where you may feel yourself going cold or perspiring. Shock makes it impossible for you to take in what the doctor is telling you, so do not hesitate to ask questions when you feel ready to take in information.

You may feel a sense of disbelief but sometimes we find it necessary to shut our minds in order to cope with an unusual or frightening situation.

You may experience sorrow because, in some ways, you may feel like mourning the child you thought you were going to have, before you can fully rejoice at the birth of your new baby.

You may feel a strong sense of protectiveness. This is a natural instinctive response and is perfectly normal. However, be careful not to become so protective of your child that you do not allow him/her to develop to the best of his/her ability.

You may feel a sense of rejection but this may be experienced by any parent of their child, whether born with a disability or not. The bond between a parent and child does not happen suddenly – it is a process that continues to develop throughout childhood, so do not worry if this is your initial reaction.

People often feel angry when in a situation that they cannot change. It is a biological reaction and in a lot of situations actually gives us the energy to fight our way out of trouble.

Mothers may feel guilt as they have carried their child and worry that there is something they could have done to prevent this condition. If you are experiencing this emotion, please remember that the chromosomal error that causes Down syndrome happens at the moment of conception and your behaviour during pregnancy played no part. Also remember that just because your baby has Down syndrome does not make them a lesser person. They will bring you all the joy you dreamed of when you were pregnant.

Whether immediately or not, you will feel relief and happiness – labour is over and you have just brought a new person into this world. You'll experience all the joy and excitement that's associated with having a child and you will want to celebrate your newborn.



Once you get over your initial reactions and feelings, you will find yourself beginning to cope better with the situation you now find yourself in. Just take it one step at a time and let it happen naturally.

share the journey - share the feelings of others

Whatever the range of emotions you are going through right now, you can be sure that many have experienced them before. Here's just a few shared feelings from other parents to help put your mind at rest:

"We never tried to cover up the fact that our baby had Down syndrome. We found that often people coped better by us being open and showing off our baby."

Mother

"At the beginning when I looked at our baby, all I could see was Down syndrome. It was a terrific feeling the day I realised that I was no longer seeing 'Down syndrome'. I was seeing Sinead."

Dad

"When my little brother was born, my Mum and Dad told me that he would be slow to walk and talk and that we would have to help him a lot. Now he can do lots of things and I bring him out to play with my friends."

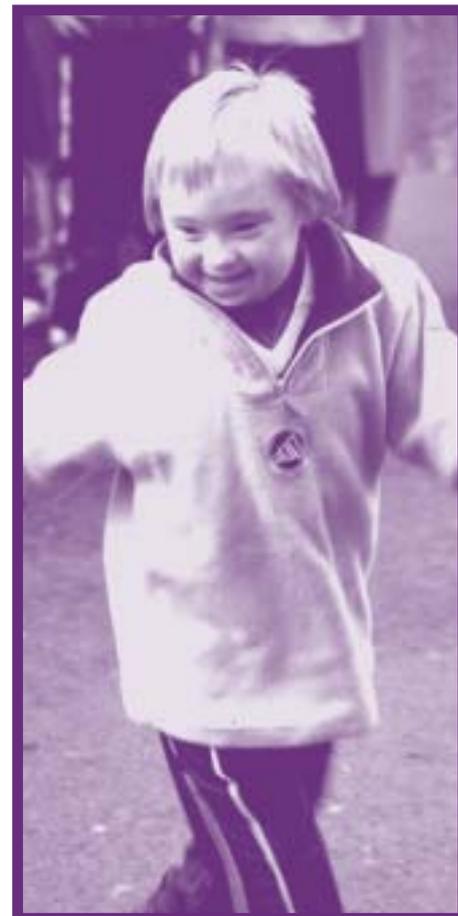
Sister

"I feel our family has learned a lot from one little boy. When I was growing up, I was never around children with special needs, so I didn't really know what to expect when he was born. After spending a small amount of time together, my fears disappeared. I am proud that my children are growing up with him and have a positive attitude towards children who are differently-abled. When they see someone with Down syndrome, they make their way to them and wave and say hello. My nephew has opened a door to greater understanding that we may never have had if he had not been given to us."

Aunt

"A baby with Down syndrome is wonderful. Respect them as they are and accept them for who they are. I am an individual first. Maybe he will grow up to play golf better than me!"

Person with Down syndrome



share the journey - stimulation and bonding

Never forget that your baby with Down syndrome has the same needs as any other newborn. Of course this involves the usual routine of feeding and changing, but we also recommend a huge dose of cuddles, hugs and a lot of love!

Stimulation, playing, touching, talking and smiling are so important in the development of every baby. By stimulating your child you will help them to become aware of you, the rest of the family, their surroundings and the day-to-day noises around your house and neighbourhood. But give your baby time to respond – on average, babies with Down syndrome take about nine seconds longer to react.

Smile at your baby. Like every other child, he/she wants to know that you love him/her. It will not only encourage and reassure him/her, but will make you feel much better too. Be affectionate with your baby – blow at all parts of his/her body. Tickle, rub and pat him/her as physical interaction will encourage bonding. Give him/her a daily massage with a light oil – it's great for the skin and sensory development.

Babies with Down syndrome tend to be quieter and cry less than other babies but this doesn't mean that you should leave your baby alone for too long. Involve them in your daily routine – they'll respond to the sound of your voice, the noise of the TV and the smell of cooking at teatime. Bring them from room to room with you, talking as you go.

Gently rock your baby in your arms – it's actually good for his/her balance. Always encourage, praise and cuddle him/her whenever you can.

Encourage eye contact by talking and singing to your baby while feeding them – this will help their development and is a good form of both stimulation and bonding. It's also helpful to put mobiles or chimes where baby can see and hear them.

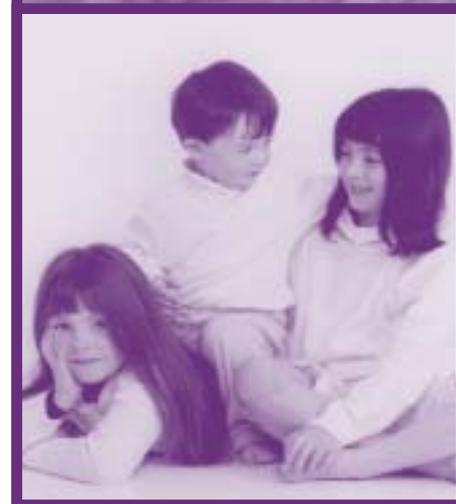
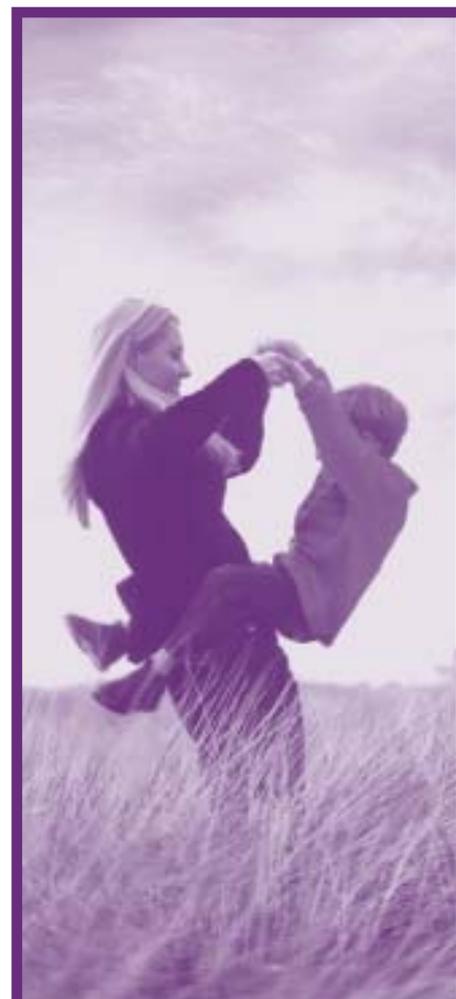
You should give your baby some playtime lying on his/her tummy everyday. This will encourage better head control and will contribute to stronger neck and back muscles in the future. It's always a good idea to give your baby the chance to experience different positions.

Lastly, be sure to make your child curious as to what's going on. Make noise nearby, where you can't be seen, so that baby will become curious and want to get up to see what you're doing. This may encourage improved muscle tone.

Read to your baby. Use simple books that contain one picture and one or two words on each page.

Sing nursery rhymes, helping your baby to join in with the simple hand movements.

Talk to your baby in simple sentences. Label the things in the baby's immediate environment, pointing out and labelling the objects that you have in the bedroom, kitchen or house.



share the journey - what to ask your doctor

Your doctor will be more than happy to answer any medical queries that you may have and will make sure that your baby is as healthy as possible. To do this, they will carry out a comprehensive medical assessment as this is very important for your newborn child. This assessment will include height, weight, head circumference, a blood sample for Karyotype and any other investigations that may be appropriate.

During the first six weeks of your baby's life, tests carried out still include:

- Heart assessment (to rule out congenital heart disease)
- Heel prick (normal routine metabolic screen for Phenylketonuria (PKU), Hypothyroidism, Maple Syrup Urine Disease (MSUD), Galactosaemia and Homocystinuria)
- Eyes examination (to rule out cataract)

A primary health team will be informed of your child's diagnosis to make sure your child receives the best possible care. In hospitals where there is a hearing screening programme for newborns, your baby should also be included. In addition, you may meet with a social worker and physiotherapist while still in hospital, or this may be arranged within the first six-week period after your baby is born.

When you're ready to leave the hospital, make sure you know when you will next be seen and who you can contact in the meantime if the need arises. Always pick up the phone with any queries you have – there are lots of people willing to support you on your journey.

Your paediatrician is just one of a number of these health and non-health professionals who will support your child and family. Other specialist doctors may include those who look after the heart, hearing, vision and joints, if the need arises. Therapists may include those who will look after muscle tone, feeding and language development. All of these professionals will help you make sure that your baby gets the best possible start in life.



share the journey - suggested schedule of health checks

	<i>growth</i>	<i>heart</i>	<i>thyroid</i>	<i>sight</i>	<i>hearing</i>
<i>Birth - 6 Weeks</i>	Height/weight/head circumference on Down syndrome Specific Growth Charts	ECG + Chest X-ray (birth and 6 weeks) or Echocardiogram 0-6 weeks	Routine Guthrie test	Eye Examination, exclude cataract and glaucoma	Neonatal screening where available
<i>6-10 Months</i>	Growth assessment as above at each routine visit			Visual behaviour, exclude squint	Full audiological review (Otoscopy, impedance, hearing thresholds)
<i>12 Months</i>	Growth assessment as above at each routine visit	Dental advice	Full thyroid function tests or TSH (Guthrie) yearly when available	Visual behaviour, exclude squint	
<i>18-24 Months</i>	Growth (height/weight) as above		Full thyroid function tests or TSH (Guthrie) yearly when available	Ophthalmological examination incl. Orthoptic screening, refraction and fundal examination	Full audiological review as above
<i>3-3½ Years</i>	Growth (height/weight) as above		TSH (Guthrie) yearly when available		Full audiological review as above
<i>4-4½ Years</i>	Growth (height/weight) as above		Full thyroid function tests or TSH (Guthrie) yearly when available	Ophthalmological examination as above	Full audiological review as above

From age 5 years to 19 years

Paediatric review Annually

Hearing 2 yearly audiological review as above

Vision 2 yearly ophthalmological examination including refraction and fundal examination

Thyroid 2 yearly from 5 years (venous) or fingerprick TSH annually

Professor Hilary MCV Hoey

Joan Murphy RSCN MSc Paediatrics

share the journey - support along the way

Always remember that you are not alone. In addition to Footsteps, there are many other people that will offer you support and you should be aware of all your benefits and entitlements, the majority of which are listed here. For more information, please feel free to contact us.

people/places

Service Provider – Service Providers vary from region to region, however they will look after newborns and their parents. Your paediatrician will advise your service provider, who will make arrangements to meet you over the next few weeks. If you haven't been contacted, ask your local Footsteps branch who your service provider is.

Your Public Health Nurse – All new mums get a visit from the public health nurse. She can give you general advice on your baby's health and information on other services.

Social Work Department at your Maternity Unit.

Don't forget that you can always contact Footsteps for additional support and information.

possible benefits and entitlements

Domiciliary Care Allowance – apply to your local health board;

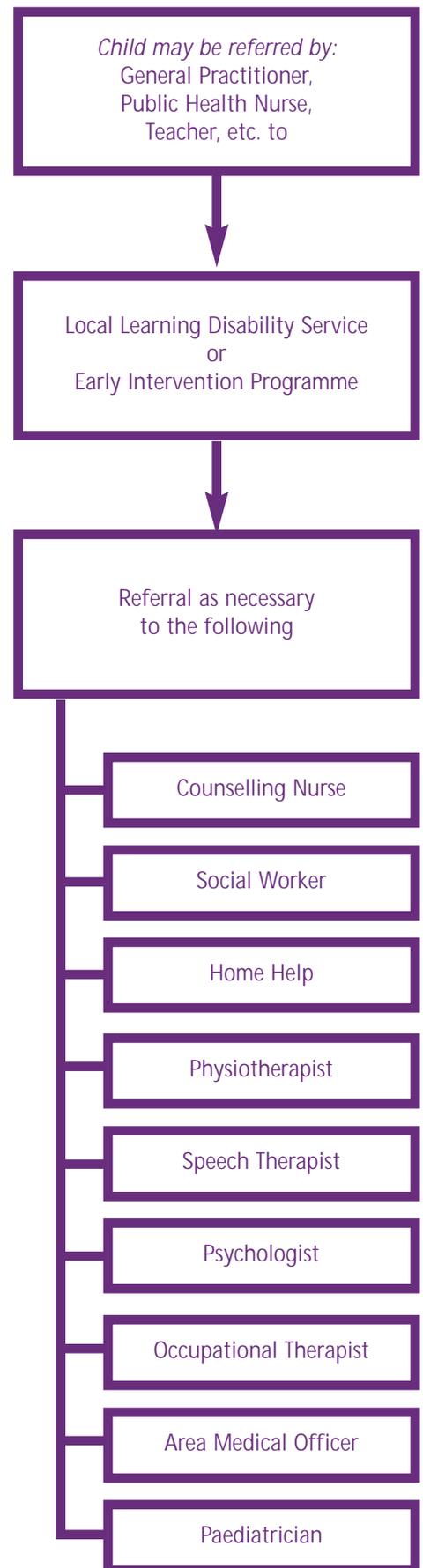
Carer's Allowance – apply to Carer's Allowance Payments, Social Welfare Services Office, Department of Social, Community and Family Affairs, Ballinalee Road, Longford;

Respite Care Grant – this is automatically received by those collecting either of the above benefits;

Long-term Illness Card – apply to your local health board;

Tax Free Allowances – details can be obtained from your tax office;

Other Payments – obtain booklet entitled "Entitlements for People with Disabilities" from Comhairle.





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