



Down
Syndrome
Ireland

National Leadership Local Support

New Parent Booklet



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CONGRATULATIONS ON THE BIRTH OF YOUR 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 will discover, the fact that your baby has Down syndrome is very much secondary to the fact that he or she is an individual. Your baby has the exact same needs as every other baby and like all children, he or she will be sure to let you know about these needs. This baby will also bring you all the same joy and happiness.

Being a parent of a new baby who has Down syndrome can be a traumatic experience for parents. Many will feel disappointed and possibly scared at the prospect of bringing up a child with an intellectual disability. They may also wonder if they have the strength and ability to do their best for their son/daughter. Some may worry about health issues, family life and about the effect of this condition on their child, family and each other.

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

All people with Down syndrome are unique individuals with talents and abilities. They are more like their families than anyone else. The only thing people with Down syndrome have in common is an extra copy of chromosome 21 in the cells in his/her body. Physically, people with Down syndrome may share similar characteristics but they also resemble their families. It is important for you to know that the presence or absence of these physical characteristics is of absolutely no relevance to your child's development.



FEELINGS AND EMOTIONS

People react in many different ways when told their baby has Down syndrome. Many people say the moment remains very clear in their minds and they remember it for a long time. They remember a feeling of overwhelming sadness and some feel protective towards their child.

Many parents describe a feeling of shock which affects them physically, emotionally and psychologically. Shock may make it difficult for you to understand everything that your doctor is telling you, so do not hesitate to ask questions when you feel ready. Don't be shy in asking to meet with the Doctor again either before you leave the hospital or at a later stage. It may be helpful to have a written list of questions to which you need answers.

Feelings of rejection are not unusual. The bond between a parent and child does not always happen suddenly – it is a process that continues to grow and develop throughout a child's life. As time passes most people realise that it was not the baby they were rejecting, but the condition of Down syndrome.

Do not assume that your partner experiences these feelings in the same way you do. We all react in an individual way and there is no right or wrong way. It may be difficult at times to support each other and sometimes a friend, family member or a parent who has had a similar experience to yours may be able to help.

Most parents report that as their child grows and develops they get to know the person and forget the label of Down syndrome. There may be times when feelings of sadness recur as you notice your baby is slower in reaching milestones than your friend's baby or other babies in your family. However, this happens less and less as your child develops.



WHATEVER THE RANGE OF EMOTIONS YOU ARE GOING THROUGH RIGHT NOW, YOU CAN BE SURE THAT MANY HAVE EXPERIENCED THEM BEFORE

DAD...

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.

MUM...

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. We talked about her future in a positive way and soon they began to see her ability too.

SISTER...

When my little brother was born, my Mum and Dad told me that he would be slow to walk and talk. Now he can do lots of things and I bring him out to play with my friends and their brothers and sisters, some of the time.

ADULT WITH DOWN SYNDROME...

The worst thing about having Down syndrome is having parents who fuss about me all the time. I know I have Down syndrome but it doesn't stop me doing anything. Sure it takes me a bit longer to learn things but people need to see past the Down syndrome and see the person.

TELLING BROTHERS AND SISTERS

Parents generally worry about the effect of this baby with Down syndrome on their family. Research tells us that the effect of Down syndrome on the family is far more positive than negative. As a parent you are the best person to decide how much information your children need.

Some parents report that children under six years take the news in their stride. Children over ten react in much the same way as parents and may need time to process their feelings.

Follow your child's lead. They will notice that you are sad and it is ok to tell them that the baby has Down syndrome and will take longer to learn things.

They should know the baby will always have Down syndrome and that *'you can't catch it'* as it happens in Mummy's tummy even before the baby is born.

They should know that Down syndrome is not anyone's fault, it just happens and is not an illness or a disease.

Parents often say that it is important to talk openly about Down syndrome rather than setting aside a day in the future to *"break the news"*. When everyday opportunities are taken to answer questions then worries are alleviated.

At a sibling course one young boy of nine years suggested that knowing what is happening is much better than imagining what might be happening. *"If parents say nothing then the children might think they had done something to cause it."*



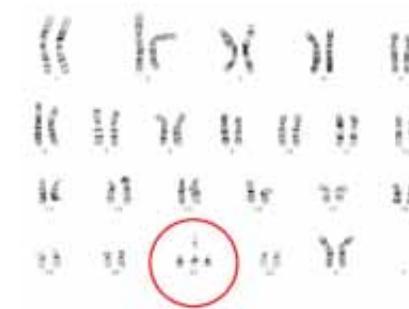
DOWN SYNDROME

Down syndrome occurs when there is one extra copy of chromosome 21 in cells in the body. Down syndrome is one of the most common congenital chromosomal abnormalities and it is named after the person who first described it. Dr. John Langdon Down was a doctor in London and in 1866, he was the first person to accurately describe the syndrome which today bears his name. In 1959 Professor Jerome Lejeune a doctor of genetics in Paris first identified the extra chromosome as being the cause of Down syndrome.

What is a syndrome?

A syndrome is a collection of several symptoms and signs that usually occur together.

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 total), half of which come from the mother and half from the father. Most babies with Down syndrome have an extra copy of chromosome number 21, making 47 chromosomes in total.



TYPES OF DOWN SYNDROME

There are three types of Down syndrome

- Trisomy 21 (95%) extra number 21 chromosomes in every cell.
- Translocation (3-5%) extra chromosome 21 is attached to another chromosome in every cell.
- Mosaic (1-2 %) mixture of cells, some with an extra chromosome 21 and some normal cells.

Each baby is an individual and this is no different for the baby who has Down syndrome. Your baby will have his/her own personality and many family features and characteristics. He/she will be more like his/her family than like any other person with Down syndrome.



QUESTION TIME

How do we know which form of Down syndrome our child has?

When a child is born with Down syndrome, or if Down syndrome is suspected, a chromosomal analysis is carried out (by blood tests) to confirm the diagnosis and determine the type of Down syndrome the child has.

Did I do anything to cause Down syndrome?

Down syndrome is never anyone's fault. It just happens.

Is Down syndrome hereditary?

A very small percentage of all translocation trisomies are inherited. Approximately 1/100 cases of Down syndrome may be inherited. Parents whose child has this type of chromosomal abnormality should seek genetic counselling.

Can Down syndrome be cured?

Down syndrome is a lifelong condition and cannot be cured.

Do all babies with Down syndrome have a heart condition?

Approximately 47% of children with Down syndrome will have a heart condition.

Do all babies with Down syndrome have medical problems?

Having Down syndrome does not guarantee any medical condition. Most children with Down syndrome are healthy and active and will benefit from a variety of opportunities just like the other children in the family. However, children with Down syndrome have a higher incidence of some treatable health problems.



A BRIGHT FUTURE AHEAD

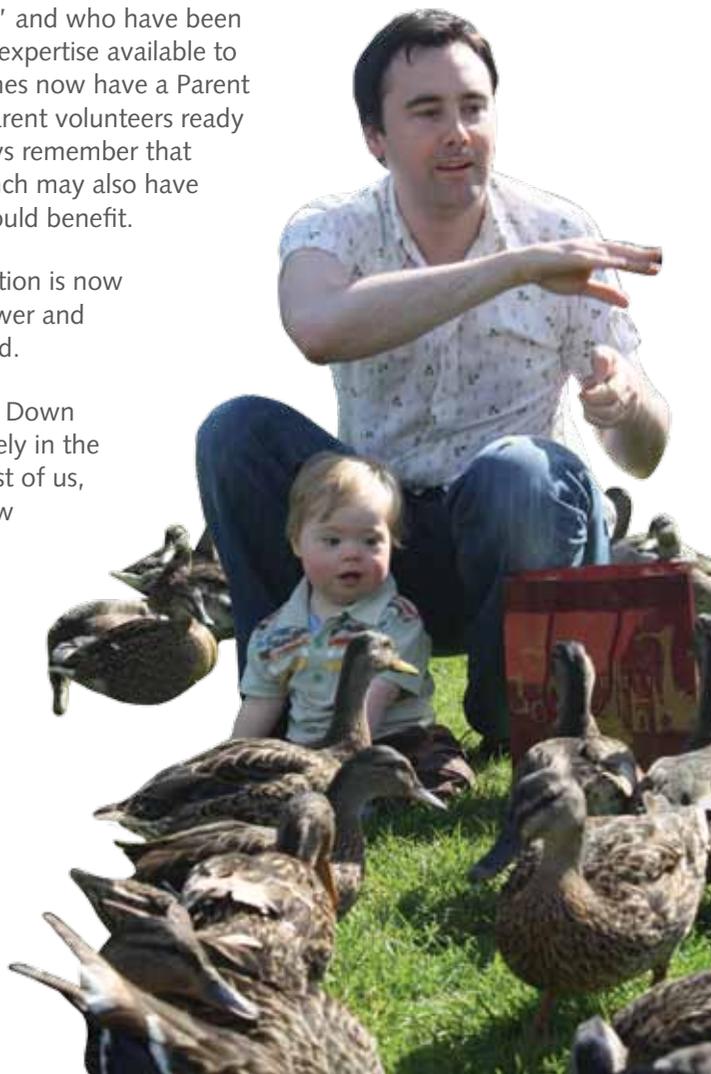
Never forget that your baby with Down syndrome has the same needs as any other newborn. Of course this involves the usual routine of feeding and changing, along with all the kisses and cuddles. Stimulation, playing, handling, talking and smiling are so important in the development of every baby. This is no different for your baby with Down syndrome. Enjoy this time as you would with any baby.

Your baby will notice you, the rest of the family, their surroundings and the day-to-day noises around your house and neighbourhood. Give your baby time to respond – on average, babies with Down syndrome take about nine seconds longer to react than typically developing babies. Otherwise treat your baby just like you treated your other children. Be confident about your feelings, trust your instincts, you'll know what to do.

Access and visit your local 'Early Intervention Services' and find out what they have on offer. You might consider making contact with your local branch of Down Syndrome Ireland to meet with other parents who "know the systems" and who have been where you are now. Avail of the expertise available to you and the family. Many branches now have a Parent Link group. This is a group of parent volunteers ready to assist and support you. Always remember that you are not alone. The local branch may also have services from which your child could benefit.

Expert researched based information is now available for all parents to empower and enable them to support their child.

The quality of life of people with Down syndrome has improved immensely in the last twenty years. Just like the rest of us, people with Down syndrome now enjoy a longer healthy life expectancy which results in living a happy, fulfilling and active life. Your child will continue to learn throughout his/her life.



“

The first priority for parents is to maintain normal family life. 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.

Sue Buckley and Ben Sacks, 2001

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STIMULATION AND BONDING

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 your baby, 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 your baby as physical interaction will encourage bonding. Massage your baby with a light oil - this is great both for the skin and sensory development.

Involve your baby in your daily routine - they'll respond to the sound of your voice, the noise of the television and the smell of cooking at teatime. Bring your baby from room to room with you, talking as you go.

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

Encourage eye-contact by talking and singing to your baby while feeding - this will help your baby's development and is a good form of both stimulation and bonding. It is 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 is always a good idea to give your baby the chance to experience different positions.

Last but not least, 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.

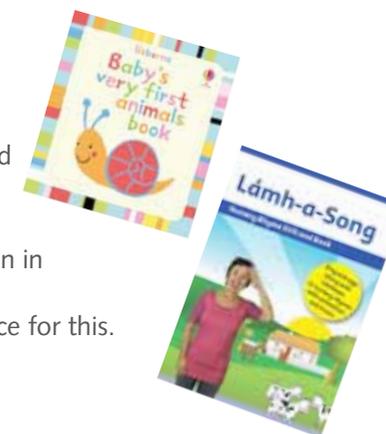
Children with Down syndrome are visual learners. This means that they learn better through their eyes. They find it easier to learn to talk if words are signed as well as spoken. Your speech and language therapist will inform you of Hanen programmes and Lámh courses to assist you.

At five years of age, many children with Down syndrome can achieve some of the same developmental targets as their peers. Most will be walking, toilet trained and able to feed and dress with minimal help.



SOME TIPS:

- When your baby gets older read to him/her. 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. The Lámh-a-song DVD is a wonderful resource for this.
- Talk to your baby in simple sentences.
- Label the things in the baby's immediate environment, pointing to and labelling the objects that you have in the bedroom, kitchen and around the house.



WHAT TO ASK YOUR DOCTOR

Having Down syndrome does not guarantee any medical conditions or health problems. Most children with Down syndrome are healthy and active and will benefit from a variety of opportunities just like the other children in the family. However, it is well recognised that as a group they have a higher incidence of treatable medical disorders.

As a new parent it may be helpful to read the health chart for medical checkups. Some children may only ever have one health problem whilst others may have more; therefore it is advisable to read, only, about the issues that concern your child rather than the whole booklet. Parents need to link with their healthcare professional to ensure that all health screening tests are carried out regularly every year as outlined in the medical guidelines.

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 will include:

- Heart assessment (to rule out congenital heart disease)
- Heel prick (normal routine metabolic screen for Phenylketonuria (PKU))
- Hypothyroidism
- Eye examination

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 who should inform you of any entitlements such as tax allowance or health benefits to which your child is entitled.

A physiotherapist may give you a programme of exercises to help your baby's muscle tone if this is required. These exercises can be carried out at nappy-changing time and should take no more than a few minutes at this stage of the baby's life.

When you are 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 including Down Syndrome Ireland.

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 and vision, 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.



DOWN SYNDROME - MEDICAL MANAGEMENT GUIDELINES

Suggested schedule of health checks taken from guidelines

	GROWTH	HEART	THYROID	SIGHT	HEARING
BIRTH 6 WKS	Length/weight/head circumference - Plot on Down Syndrome Specific Growth Charts*	Clinical examination ECG + Chest X-ray Birth & 6 wks OR Clinical examination ECG + Echocardiogram Birth & 6 wks	Routine Guthrie test	Eye Examination, exclude cataract & glaucoma	Neonatal screening where available
6-10 Months	Growth assessment as above at each routine visit*			Visual behaviour exclude squint	Full audiological review [Otoscopy, Impedance, Hearing thresholds]
12 Months	Growth assessment as above at each routine visit*	Dental Advice	Full Throid function tests OR TSH [Guthrie] yearly when available	Visual behaviour exclude squint	
18-24 Months	Growth [height/weight] above*	Dental Advice & examination of teeth	Full Throid function tests OR TSH [Guthrie] yearly when available	Ophthalmological examination including Orthoptic screening, refraction & fundal examination	Full audiological review as above
3-3^{1/2} Years	Growth [height/weight] assessment as above*	Dental Advice & examination of teeth	Full Throid function tests OR TSH [Guthrie] yearly when available		Full audiological review as above
4-4^{1/2} Years	Growth [height/weight] assessment as above*	Dental Advice & examination of teeth	Full Throid function tests OR TSH [Guthrie] yearly when available	Ophthalmological examination as above.	Full audiological review as above

* Encourage a healthy lifestyle [healthy eating & regular exercise] at all times, from age 5 -19 yrs.

PAEDIATRIC MEDICAL REVIEW ANNUALLY

Cardiology	Echo in early adult to rule out mitral valve prolapse
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 annual fingerprick TSH, when appropriate structures, personnel and funding are in place

Professor Hilary MCV Hoey & Joan Murphy RSCN MSc Paediatrics
Department of Paediatrics, University of Dublin, Trinity College at the National Children's Hospital, AMNCH, Tallaght, Dublin 24

DOWN SYNDROME - CHILD DEVELOPMENT

This table gives an outline of the usual development of children with Down syndrome. Just as with all children there is a great deal of individual variation in the age at which the different skills develop. In the table we show the usual range for some milestones. A few children will have additional health problems which may slow their development. However, all will continue to grow at their own pace. You can use the table to find out if your child has a particular difficulty in any area which may require extra help

AREA OF DEVELOPMENT	MILESTONES	AGE RANGE		For you to record the age at which your child acquires these skills
		Down Syndrome	Other Children	
Gross motor skills [moving around]	Holds head steady in sitting position Sits alone Stands alone Walks alone	3-9m 6-16m 12-38m 13-48m	1-4m 5-9m 9-16m 9-17m	
Fine motor skills and eye hand co-ordination	Follows object with eyes Reaches out and grasps objects Passes objects from hand to hand Builds a tower of two 1" blocks Copies a circle	1.5m-8m 4-11m 6-12m 14-32m 36-60m	1-3m 2-6m 4-8m 10-19m 24-40m	
Communication Skills	Babbles "Dada", "Mama" Responds to familiar words First words spoken with meaning Shows needs by gesture Two word phrases	7-18m 10-18m 13-36m 12-30m 18-60m	5-14m 5-14m 10-23m 11-19m 15-32m	
Personal & Social Skills	Smiles when talked to Feeds self with biscuit Drinks from a cup Dry by Day Bowel Control	1.5-4m 6-14m 12-23m 18-50m 20-60m	1-2m 4-10m 9-17m 14-36m 16-48m	

Down's syndrome insert DSMIG © 2000

Adapted with permission from Cunningham 1988 Down's Syndrome - An introduction for Parents. Souvenir Press Ltd. Human Horizon Series.

ENTITLEMENTS

People living with a disability and their parents/carers/guardians are entitled to some level of assistance from the Irish State. The qualifying rules are different for each entitlement and for each HSE area; some are means tested, others are not.

Medical Card / GP Visit Only Card

Your child may be entitled to a standard or a “doctor only” medical card if your family income is below a certain level.

It is possible to get an individual medical card for your child if he/she has particular medical expenses but the exact basis on which this is decided is not clear. If your child does not qualify for a medical card or a “doctor only” medical card, he/she is nevertheless entitled to the following:

- Free public hospital services; no in-patient or out-patient short-stay charges are levied if your child has one of the specific long-term conditions as per the Long Term Illness Book or if referred from child/school health clinics
- Free prescribed drugs and medicines for specific long-term conditions (see Long Term Illness Book)

The Health Service Executive's (HSE) complete guide to Medical and GP visit cards available at: www.hse.ie

Domiciliary Care Allowance

The Domiciliary Care Allowance is a non-statutory monthly means tested payment made to the carer of a child with a disability who lives at home. The means test applies to the income of the child and not that of his/her parents. In order to qualify, your child must have a disability, be aged under 16, live at home and must need substantially more constant care and attention than a child of the same age who does not have a disability. It is important to apply for this early as generally it is not backdated.

The assessment of whether or not your child needs more constant care and attention is made by the HSE. They look at the degree of additional care and attention needed by the child rather than the type of disability involved. There are no particular disabilities specified. Children with Down syndrome usually qualify for this allowance.

TAX CREDITS

There are some extra tax credits and allowances which are available to people with disabilities and their carers. Generally the tax legislation uses the term “incapacity” rather than “disability”.

Incapacitated Child Tax Credit

There are no tax credits or allowances in respect of children generally but there is a tax credit available to parents or guardians in respect of incapacitated children. You may claim the Incapacitated Child Tax Credit if you have a child who has Down syndrome. If you are claiming this credit for the first time you should write to your local tax office advising the name and date of birth of your child. You should have a doctor's certificate which states your child has Down syndrome. The credit is given to the parent who is maintaining the child or it may be divided between two parents in proportion to their contribution to the child's maintenance. The child's income, if any, is not taken into account.

You can find more information on the tax revenue website.





National Leadership Local Support

DSI comprises a professionally staffed national office and twenty-five local branches servicing and supporting our members across the country.

LOCAL BRANCHES

The local branches are run on a voluntary basis by our members and offer a range of services, activities and supports. Branches are funded through donations and local fundraising. Each branch is unique in the type and range of services they offer. Samples of services include speech & language therapy, early development groups, literacy classes and drama classes. For more information on your local branch see www.downsyndrome.ie

THE NATIONAL RESOURCE TEAM Expertise and Understanding

The national resource team at DSI provide specialist support in the areas of early development, education, counselling, health, speech and language therapy and independence to our members and the professional community connected by Down syndrome.

PARENT LINK

Parent Link is a voluntary support and information service for parents of new babies with Down syndrome. It is a service run entirely on a voluntary basis by parents who are familiar with the feelings and reactions associated with having a child with Down syndrome in the family. Parent link parents will provide time, confidentiality and a listening ear for new parents. Parent link parents receive training in communication skills from DSI's national resource team. For a contact in your local area please phone the national office on **01 4266500**.

NEW PARENTS' CONFERENCE

DSI's national resource team host an annual new parents' conference. During the residential weekend new parents are helped by speakers who are experts in the world of Down syndrome. They receive information and have time for discussion on such topics as their feelings, health concerns, speech and language therapy, family life and interaction and communication skills. Please contact Annette at the National Office for further details on any of our services.

- A Lo-call help line is available Monday to Friday from 9.30 am to 5.00 pm (**1890 374 374**) or email info@downsyndrome.ie
- Our website is www.downsyndrome.ie
- Local branch contact details available from the website or from Annette in the National Office.

LIST OF HELPFUL CONTACTS

Down Syndrome Ireland

Citylink Business Park,
Old Naas Road,
Dublin 12.
T 1890 374 374, (01) 4266500
F (01) 4266501
E info@downsyndrome.ie
www.downsyndrome.ie

Office of the Revenue Commissioners

Central Repayments Office,
Freepost,
Coolshannagh,
Monaghan,
T 047-38010
F 047-82782
www.revenue.ie

Child Benefit Information

www.welfare.ie

Guide to Entitlements and Supports

<http://www.crc.ie/documents/ChildrenEntitlements2008.pdf>

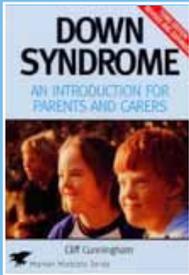
Social Welfare Office

Social Welfare Services Office,
Department of Social, Community
and Family Affairs,
Ballinalee Road,
Longford.

Websites

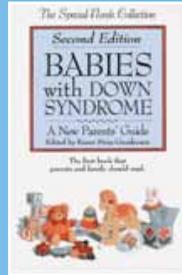
www.downsyndrome.ie
www.downsed.org
www.hanen.org
www.lamh.org
www.mosaicdownsyndrome.org

RECOMMENDED READING



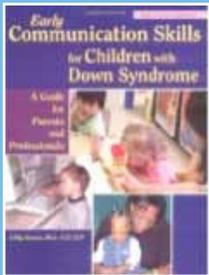
**Down Syndrome
An Introduction for
Parents & Carers**

Cliff Cunningham



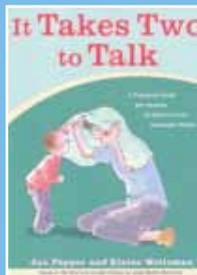
**Babies with
Down Syndrome**

Karen Stray-Gendersen



**Early Communication
Skills for Children
Down Syndrome**

Libby Kumin



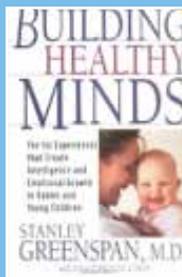
It Takes Two to Talk

Jan Pepper
& Elaine Weitzman



A Minor Adjustment

Andy Merriman



**Building
Healthy Minds**

Stanley Greenspan M.D.



This booklet was written and compiled by **May Gannon**, Down Syndrome Ireland.
[Counsellor, Psychotherapist and Dramatherapist]

May is the Director of Down Syndrome Ireland's National Resource Team and provides therapy and education for parents, family members who have Down syndrome, siblings and extended family members.

May is the founder and director of the nationwide Parent Link support service. May lectures and provides information for trainee mid-wives and trainee neo-natal nurses and is consulted by schools and universities nationwide.

She is available to talk to any parent who feels in need of counselling, support or just a listening ear. You can contact May on **087 960 7939** or through the switchboard at the National Office on **01 4266500**

ACKNOWLEDGEMENTS

Gráinne Murphy, National Resource Team, Down Syndrome Ireland

Dr. Joan Murphy (Phd), Health Specialist

Annette O' Neill, Down Syndrome Ireland

Pat Clarke, Chief Executive, Down Syndrome Ireland

Clare Leonard, President, Down Syndrome Ireland

Printed thanks to the fundraising efforts of the staff at Ulster Bank Finance Team.



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www.downsyndrome.ie