



Parent Information Booklet

An information leaflet for new parents of
babies with Down syndrome

Down Syndrome Ireland
Kerry Branch

Contents

Introduction	1
Bonding and Telling Siblings	4
Parent Link	5
Toddler Group	6
Speech and Language Therapy	7
Occupational Therapy	8
Milestones	9
Deenagh Lodge	10
Entitlements	11
Contact Us	13



Congratulations!

The birth of a new baby is an exciting and happy time for new parents and the whole family. Being a parent of a new baby who has Down syndrome can come with feelings of worry and concern about health issues and family life, but like all other newborns, your baby has the same needs and will bring you the same joy and happiness.



Down syndrome – what is it?

Down syndrome is a genetic condition resulting from the presence of an extra chromosome in all or some of the baby's cells. Approximately one in every 550 live births is affected by Down syndrome. Down syndrome is slightly more commonly occurring in boys (around 15% more likely) than girls.

There are three types of Down syndrome:

1. Trisomy 21
 - 95% of individuals with Down syndrome
 - Extra number 21 chromosomes in every cell
2. Translocation
 - 3-5% of individuals with Down syndrome
 - Extra chromosome 21 attaches to another chromosome
3. Mosaicism
 - 1-2 % of individuals with Down syndrome
 - Some, but not all, cells have an extra chromosome 21

Blood tests are carried out to confirm the diagnosis of Down syndrome and to establish the type of Down syndrome that the child has.

The effects of the extra chromosome vary widely, and there is a broad range in abilities, development and behaviour among individuals with Down syndrome. Children with Down syndrome generally require additional time and support to reach developmental milestones. The level of support an individual needs as they grow up will differ from person to person.

Down syndrome Kerry

Down Syndrome Kerry provides support to people with Down syndrome and their families, and aims to help individuals with Down syndrome to gain fulfilment and independence. We provide Speech and Language Therapy, Occupational Therapy, and counselling services. We also organize parent and toddler groups, along with other social activities. While parent gatherings enable parents to meet and share experiences, toddler groups provide opportunities for infants and children of all ages to play and meet friends.



Bonding

Involve your baby in your daily routine. They will listen and respond to your voice and to the sounds around them as you bring them with you while completing tasks.

Encourage eye-contact by singing to your baby as you feed them.

Provide your baby with opportunities for playtime while lying on their tummy. This will encourage development of head control, and will lead to strengthening of neck and back muscles.



Telling Siblings

With the help of others, you can decide how much information to give your children. While children under six years often take the news positively, children over ten years often have similar reactions to their parents, and may benefit from time to process their feelings.

Children can be told that their sibling has Down syndrome and will take longer to learn new things. They can be told that this is nobody's fault, and it just happens. Parents often feel that it is important to talk openly about Down syndrome and to provide opportunities for children to ask questions.

Parent Link

Parent Link is a voluntary support and information service for new parents of babies with Down Syndrome in Kerry and the surrounding areas. The service is led by parents of children with Down Syndrome who are trained in Parent Link by Down Syndrome Ireland. As parents, they are familiar with the feelings and reactions of having a child with Down Syndrome in the family.

This is not a professional counselling service, but provides information on supports and resources available. Should you wish to contact Parent Link, they will provide time and a listening ear. Confidentiality is adhered to at all times. This service is provided free of charge and entirely on a voluntary basis, but we will try to respond to your call as quickly as possible. For more information, see the contact details below.

Contact details:

Rose Crowley: 086 1626937

Debbie Dillon: 087 8378982

Christabelle Looby: 086 0820839



Toddler Group

The Parent & Toddler group meet on the second Saturday morning in every month at 10:30am until 12pm in the Down Syndrome Kerry Office, Balloonagh Estate, Tralee. There are currently twelve parents who regularly attend the group with their children who range in age from 0 months up to 6 years. The group provides an opportunity for parents to meet up for a chat, and it is also a chance for the children to meet up with their friends. The Toddler Group organises different activities based on the children's interests such as art, music therapy and yoga.

The group provide each other with fantastic support, information and most of all friendship. The parents who attend the group have made friends that they will have for life.

The group is very open and welcoming. The parents encourage any new or existing members to come and join them.

For more information about the Toddler Group, contact Debbie on 087 8378982 or Christabelle on 086 0820839.

Speech and Language Therapy

The Kerry Branch of Down Syndrome Ireland makes Speech and Language Therapy sessions available to members. Therapy is on a fee for service basis, but service is not denied if payment is an issue. Arrangements can be made for Speech and Language Therapy service provision to any child with Down syndrome.

Long before babies understand and say words, they learn to take turns, develop eye-contact, and make sounds. Babies with Down syndrome may need extra time and extra repetition to develop their communication skills. Some children may also benefit from speech and language therapy to build on their communication skills.

Babies who have Down syndrome may experience difficulties with feeding. They may have low muscle tone which could lead to problems such as difficulty moving onto spoon feeding and difficulty progressing to different food textures. If your baby is experiencing feeding problems, the speech and language therapy service is available to provide advice and intervention.

If you would like more information on communication or feeding, you can get in touch with Aileen Hannon, CORU registered Speech and Language Therapist SL030813, at 085 236 1418.



Occupational Therapy

Down Syndrome Kerry provides Occupational Therapy services to children with Down syndrome for all areas of Kerry.

Occupational Therapists seek to enable people to participate in everyday activities, from involvement in play to attending school. For infants and toddlers with Down syndrome, Occupational Therapy may help to develop their play skills, motor skills, feeding skills and attention. The Occupational Therapist can also provide intervention for sensory processing difficulties.

If your child is experiencing difficulties with gross motor skills such as sitting, walking and climbing, or fine motor skills such as holding an object or using a spoon, Occupational Therapy may provide support. An assessment can be carried out and treatment can be provided.

If you would like to make an appointment, contact Nita Desai on 087 694 0505 (Thursday/Friday), or Down Syndrome Kerry on 066 710 3804.



Milestones	Age range (months) Age can vary. Consult with your therapist.
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Gross motor skills (large movements)	
Holds head steady in sitting position	3-9
Sits alone	6-16
Stands alone	12-38
Walks alone	13-48

Fine motor skills (small movements) / eye hand co-ordination	
Follows object with eyes	1.5-8
Reaches out and grasps objects	4-11
Passes objects from hand to hand	6-12
Builds a tower of two 1" blocks	14-32
Copies a circle	36-60

Communication Skills	
Babbles "Dada", "Mama"	7-18
Responds to familiar words	10-18
First words spoken with meaning	13-36
Shows needs by gesture	12-30
Two word phrases	18-60

Personal & Social Skills	
Smiles when talked to	1.5-4
Feeds self with biscuit	6-14
Drinks from a cup	12-23
Dry by Day	18-50
Bowel Control	20-60

Adapted from Cunningham 1988 Down's Syndrome – An Introduction for Parents. Souvenir Press LTD. Human Horizon Series.

Deenagh Lodge

The tea room at Deenagh Lodge is a beautiful café in the gate lodge of Killarney National Park. Young adults from Down Syndrome Kerry train in hospitality at the café. At our tea room, we serve delicious coffee, tea, food and great company.



Entitlements

People living with a disability and their parents are entitled to assistance from the Irish State. These entitlements have varying rules for qualifying; some are means tested, while others are not.

Medical Card and GP Visit Only Card

Depending on means testing, your child may be entitled to a standard or GP-only medical card. In cases where the child is not entitled to a medical card, he/she is still entitled to the following:

- Public hospital services free of charge (no in-patient or out-patient short-stay charges)
- Prescribed drugs and medicines for specific long-term conditions free of charge (see Long Term Illness Book)

For more information on Medical and GP visit cards, visit www.hse.ie or www.citizensinformation.ie

Domiciliary Care Allowance

This monthly payment is made to the carer of a child with a disability who lives at home. The allowance is means tested, with the means test applying only to the income of the child and not that of his/her parents. To receive this payment, your child must have a disability, be aged under 16 years, live at home, and must require significantly more care than a child of the same age who does not have a disability. Applications should be submitted early as payment is generally not backdated.

Tax Credits

Some additional tax credits and allowances are available to individuals with disabilities and their carers. Tax

legislation often uses the term “incapacity” rather than “disability”.

Incapacitated Child tax Credit

Parents of children who have Down syndrome may claim the Incapacitated Child Tax Credit. In order to claim this tax credit, you will need a doctor’s certificate stating that your child has Down syndrome. You should write to your local tax office, providing the name and date of birth of your child. The credit can be given to the parent who is maintaining the child, or it can be divided between two parents in proportion to their contribution to the child’s maintenance.

For more information in relation to tax credits, visit www.revenue.ie.

Contact us

You may consider getting in touch with Down Syndrome Kerry to meet other parents who have been where you are now. You can also get in contact to avail of services such as Speech and Language Therapy and Occupational Therapy.

Down Syndrome Kerry Office

Balloonagh Estate,
Balloonagh,
Tralee,
Co. Kerry
<http://www.downsyndromekerry.ie/>
066 710 3804

Speech and Language Therapy

Aileen Hannon, CORU registered Speech and Language
Therapist SL030813, at 085 236 1418

Occupational Therapy

066 710 3804

Parent link

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Toddler group

Debbie Dillon 087 8378982
Christabelle Looby 086 0820839
Deenagh Lodge
086 819 7188

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Old Naas Road,

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Useful Websites

www.revenue.ie

www.welfare.ie

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

www.downsyndrome.ie

www.downsed.org

www.hanen.org

www.lamh.org

www.mosaicdownsyndrome.org