



PCHR insert for babies born with Down's syndrome

Second Edition, October 2000

The following pages are extracted from an additional insert available for your baby's Personal Child Health Record book (the Red Book). They have been produced by the UK Down's Syndrome Medical Interest Group. They are for babies who are born with Down's syndrome and give additional information which will help you maintain the health and well being of your child.



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Babies and young children with Down's syndrome have just the same needs as any child. You should follow all the advice in the PCHR. Take your baby for routine child health checks in the usual way. Make sure he/she has the usual immunisations. You will find information about this in the immunisations section in the PCHR. In addition it may be appropriate for some children with Down's syndrome to have additional immunisations. You can discuss this with your paediatrician.

There is no such thing as a typical child with Down's syndrome. Children with the syndrome are as different from each other as are all children. However, by and large, their development is slower than that of most children. The next page gives the usual developmental progress of children with the syndrome. By understanding what is usual for a child with Down's syndrome you will be able to recognise any additional problems at an early stage. If your PCHR has pages on which to record developmental 'firsts' you can use these in just the same way as for any child.

It is not possible in this small booklet to cover all topics relevant to your child's health and well being. Your local healthcare team, or one of the agencies listed on page 5 will be able to provide more information.

If you would like to read more about the syndrome we recommend:

'Down Syndrome: The Facts' by Mark Selikowitz.

Published Oxford University Press 1997.

Price £8.99 ISBN 019 262662 0.

Child development

This table gives an outline of the usual development of children with Down's 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 develop at their own pace. You can use the table to find out if your child has particular difficulty in any area which may require extra help.

| Area of development | Milestone | Age range | | For you to record the age at which your child acquires these skills |
|--|---------------------------------------|-----------------|----------------|---|
| | | Down's syndrome | Other children | |
| Gross motor skills (moving around) | Holds head steady in sitting position | 3-9m | 1-4m | |
| | Sits alone | 6-16m | 5-9m | |
| | Stands alone | 12-38m | 9-16m | |
| | Walks alone | 13-48m | 9-17m | |
| Fine motor skills and eye hand coordination | Follows object with eyes | 1.5-8m | 1-3m | |
| | Reaches out and grasps objects | 4-11m | 2-6m | |
| | Passes objects from hand to hand | 6-12m | 4-8m | |
| | Builds a tower of two 1" cubes | 14-32m | 10-19m | |
| | Copies a circle | 36-60m | 24-40m | |
| Communication skills | Babbles "DaDa", "Mama" | 7-18m | 5-14m | |
| | Responds to familiar words | 10-18m | 5-14m | |
| | First words spoken with meaning | 13-36m | 10-23m | |
| | Shows needs by gesture | 14-30m | 11-19m | |
| | Two word phrases | 18-60m | 15-32m | |
| Personal and social skills | Smiles when talked to | 1.5-4m | 1-2m | |
| | Feeds self with biscuit | 6-14m | 4-10m | |
| | Drinks from cup | 12-23m | 9-17m | |
| | Dry by day | 18-50m | 14-36m | |
| | Bowel control | 20-60m | 16-48m | |

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

Down's syndrome insert © DSMIG 2000

Health problems

Children with Down's syndrome do not on the whole have health problems which are different from those which can affect any child. Some have very good health whilst some seem to have more than their fair share of illness. Because some problems occur more often among those with the syndrome all should have some extra health checks so that if there is a problem it can be identified and treated as quickly as possible.

Heart problems

About half of all children with Down's syndrome are born with some sort of heart problem but less than one in five have a serious problem. It is important however to identify any serious problems in the first 2 months because early treatment may be needed. If the checks we recommend are carried out nearly all serious problems can be identified before a child is six weeks old. If these checks are done and your child is given a clean bill of health then he/she is very unlikely to develop a heart problem during childhood.

Vision and hearing problems

Children with Down's syndrome are particularly likely to develop hearing problems and long or short sight. It is very important to identify these early on because they can easily be treated. If not treated they can affect your child's developmental progress.

Thyroid problems

The thyroid gland is more often underactive in children with Down's syndrome than in other children. If this happens your child's development will slow down unless treatment is given. Treatment is simple and effective. Regular blood tests need to be done to see if this sort of problem is developing.

Child Health Checks

You will find information about Child Health Checks in the main part of your PCHR. Your child should be included in just the same way as other children in your area. We also advise a few extra tests or checks for children with Down's syndrome.

The next page tells you in the first column what sort of health checks (thyroid, growth, eyes, hearing, heart) are needed. The other six columns tell you at what age these should be carried out. We give details about the actual tests or procedures which we advise. Your GP or Health Visitor will be able to explain these to you.

Different areas organise their child health services in different ways so the schedule will not always be followed precisely. However if you think that your child has missed out on one of these checks take this book along to your GP or Health Visitor or Paediatrician and ask if you can have it carried out.

Suggested schedule of health checks

| The following are suggested ages for health checks. Check at any other time if there are parental or other concerns | | | | | | |
|---|--|---|--|---|--|--|
| | Birth to 6 weeks | 6 - 10 months | 12 months | 18 months to 2 1/2 years | 3-3 1/2 years | 4-4 1/2 years |
| Thyroid blood tests | Routine Guthrie test | | Thyroid blood tests including antibodies | | Thyroid blood tests including antibodies | |
| | If your area has introduced fingerprick blood tests these should be done every year. | | | | | |
| Growth monitoring | Length and weight should be checked frequently and plotted on Down's syndrome growth charts. Head circumference should be checked at each routine medical check. | | | Length and weight should be checked at least annually and plotted on Down's syndrome growth charts. | | |
| Eye check | Visual behaviour. Check for congenital cataract | Visual behaviour. Check for squint | Visual behaviour. Check for squint | Orthoptic examination, refraction and ophthalmic examination | | Visual acuity, refraction and ophthalmic examination |
| Hearing check | Neonatal screening, if locally available | Full audiological review (Hearing, impedance, otoscopy) | Full audiological review (Hearing, impedance, otoscopy) annually | | | |
| Heart check and other advice | Echocardiogram 0-6 weeks or chest X Ray & ECG at birth and 6 weeks | | | dental advice | | |

| FROM AGE 5 TO 19 YEARS | |
|--------------------------|---|
| Paediatric review | Annually |
| Hearing | 2 yearly audiological review (as above) |
| Vision / Orthoptic check | 2 yearly |
| Thyroid blood tests | At age 5 years, then either 2 yearly venous surveillance or annual fingerprick. |

Detailed recommendations for Medical Surveillance Essentials for children with Down's syndrome are available. For further information contact your local community paediatrician.

Feeding

Many babies with Down's syndrome feed just as well as other babies but there are also quite a few who have difficulties, particularly in the first few weeks.

The most common problems are:

- that the baby falls asleep soon after starting feeding so doesn't take enough.
- that the baby may have a weak suck.
- that the coordination of sucking, breathing and swallowing has not yet matured so that baby gets tired and distressed and again he/she ends up not getting enough milk.

These problems usually get better after the first few weeks but can be very worrying for parents at the time. If your baby does have these problems you can help by feeding little and often until feeding settles down to normal.

If you have decided to breast feed your baby before he/she was born don't change your mind just because he/she has Down's syndrome. Most mothers who want to, do breast feed their babies successfully although efficient breast feeding may take longer to establish. If your baby has the early feeding problems mentioned above you may find it helpful to express breast milk for a time until breast feeding can be established. This has the additional advantage of allowing you to measure the amount of feed that your baby is taking. You can then go back to breast feeding as soon as your baby is mature enough to cope. Your health visitor or breast feeding expert will be able to advise you about this.

A few children with Down's syndrome have difficulties with feeding at later stages of development - for instance when moving on to solids. If this happens your Health Visitor will be able to advise and you may need more specialist help from a Speech & Language Therapist.

Remember though, **many babies and children with Down's syndrome feed just as well as other children.**

Sources of help and advice

Down's Syndrome Association (DSA)

155 Mitcham Road, London SW17 9PG.
Tel: 020 8682 4001 Fax: 020 8682 4012
Email: info@downs-syndrome.org.uk
<http://www.dsa-uk.com/>
(Regional offices in Wales, Midlands and N. Ireland)

Scottish Down's Syndrome Association (SDSA)

158/160 Balgreen Road,
Edinburgh EH11 3AU.
Tel: 0131 313 4225 Fax: 0131 313 4285
Email: info@sdsa.demon.co.uk
<http://www.sdsa.org.uk>

Down's Syndrome Ireland

30 Mary Street, Dublin 1.
Tel: (00353) 1 8730999
Fax: (00353) 1 8731064
Email: dsi@eircom.net
<http://www.downsyndrome.ie>

Down's Heart Group

(advice and support for families of children with heart problems)
17 Cantilupe Close. Eaton Bray.
Dunstable, Beds. LU6 2EA.
Tel: 01525 220379 Fax: 01525 221553
Email: Downs_Heart_Group@msn.com
<http://www.downs-heart.downsnet.org/>

The Family Fund Trust

(to ease stress on families with disabled children)
P.O. Box 50, York YO1 2ZX.
Tel: 01904 621115 Fax: 01904 652625
Email: info@familyfundtrust.org.uk
<http://www.familyfundtrust.org.uk>

Down's Syndrome Medical Interest Group (DSMIG UK)

(network of doctors and nurses with a specialist interest in Down's syndrome)
Children's Centre, City Hospital Campus.
Nottingham, NG5 1PB.
Tel: 0115 962 7658 Ext 45667
Fax: 0115 962 7915
Email: info@dsmig.org.uk
<http://www.dsmig.org.uk>

Down's Syndrome Medical Information Services (DSMIS)

(an information service for healthcare professionals run by DSMIG - contact as above)

The Down Syndrome Educational Trust (DownsEd)

(advancing the development of children with Down's syndrome worldwide)
The Sarah Duffen Centre,
Belmont Street, Southsea,
Portsmouth, Hants. PO5 1NA.
Tel: 023 928 24261 Fax: 023 928 24265
Email: enquiries@downsed.org
<http://www.downsed.org/>

MENCAP

(advocacy and practical support for people with learning disabilities)
123 Golden Lane, London EC1Y 0RT.
Tel: 020 7696 5503/5593
Fax: 020 7608 3254
Email: info@mencap.org.uk
<http://www.mencap.org.uk>

ENABLE

(advocacy and practical support for people with learning disabilities in Scotland)
6th Floor, 7 Buchanan Street,
Glasgow, G1 3HL.
Tel: 0141 226 4541 (this number tends to be used for the family freephone service, and callers are put through)
Fax: 0141 204 4398
Email: enable@enable.org.uk

Local services:

There may be a local group of the DSA in your area. DSA head office will provide information.

Child health care is provided in most areas through the community paediatric services and child development centres (CDCs). Your GP and/or health visitor will be able to tell you how to get in touch.

Your local social services department will also be able to give information about local provision. You will find their number in the phone book.

For information about obtaining further copies of this insert contact:

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