

# Medical management of children with Down's syndrome

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Down's syndrome, trisomy 21, is the commonest autosomal trisomy, and the commonest identifiable cause of learning disability. The natural prevalence is around 1/600 live births. Prenatal diagnosis and termination of some affected pregnancies has led to a current incidence in the UK of around 0.9/1000 live births.<sup>1</sup> Whilst wider availability and uptake of prenatal diagnosis may decrease this further, a projected rise in maternal age may work in the opposite direction. It is difficult to predict how these factors will interact, but it is unlikely that incidence will reduce significantly in the near future.

Most people are familiar with the physical features of the syndrome and are aware that learning disability is almost inevitable. A wide range of health problems are also recognized as being associated with Down's syndrome. However, many people, including health professionals, have a view of the disorder that is outdated and pessimistic. The stereotype is of a person with severe learning difficulties, who remains totally dependent throughout a life blighted by ill health, who is likely to live in an institution, and to die in early adult life. The positive side given is that 'they are all good-natured, affectionate and love music'. Like all stereotypes, some of these characteristics are true of some people with Down's syndrome. However, just like the general population, there is enormous variability in appearance, personality and ability. Some enjoy very good health. Some young adults are able to live semi-independently and to work. Some are less able, but nevertheless live fulfilling lives and make a contribution to society.

Down's syndrome is a multi-system disorder, but the extent to which different systems are affected varies from person to person. In the past some treatable

conditions were thought to be 'part of the syndrome' and were left untreated. Today we hope that the health of children with Down's syndrome will be monitored as carefully as that of any child so that their progress is not hampered by additional secondary but preventable handicap.

This article covers all major and some less well known health problems. Inevitably it cannot be comprehensive, and less common problems are merely listed in Box 1. For further detail the reader is referred to 'Further reading' listed below.

## THE PAEDIATRICIAN'S ROLE

### At time of diagnosis

Usually, Down's syndrome will be suspected at birth or in the newborn period. If the diagnosis is made antenatally, the paediatrician may be an appropriate person to give information to the parents in order to help them reach a decision about continuing the pregnancy. If the diagnosis is made at birth or later, the paediatrician should be involved immediately in:

- Confirming the diagnosis
- Giving information to the parents
- Medical assessment.

A confident diagnosis can usually be made after examining the baby, and although it must be confirmed by chromosomal analysis, which most laboratories are able to process in 48–72 h, in general, parents prefer to be given the news as soon as possible, and this should not be delayed by waiting for test results. The importance of the time of disclosure and the way it is handled cannot be over-stressed.<sup>2–4</sup> This initial contact will influence the parents' adjustment and also their subsequent working relationships both with the paediatrician and with other

Correspondence to EM.

**Box 1** Specific medical problems that occur more frequently in people with Down's syndrome

#### Cardiac

Congenital malformations  
Cor pulmonale  
Acquired valvular dysfunction

#### Orthopaedic

Cervical spine instability  
Hip subluxation/dislocation  
Patellar instability  
Scoliosis  
Metatarsus varus  
Pes planus

#### ENT

Conductive hearing loss  
Sensorineural hearing loss  
Upper airway obstruction  
Chronic catarrh

#### Ophthalmic

Refractive errors  
Blepharitis  
Nasolacrimal obstruction  
Cataracts  
Glaucoma  
Nystagmus  
Squint  
Keratoconus

#### Gastrointestinal

Congenital malformations  
Feeding difficulties  
Gastro-oesophageal reflux  
Hirschprung's disease  
Coeliac disease

#### Endocrine

Growth retardation  
Hypothyroidism  
Hyperthyroidism  
Diabetes

#### Immunological

Immunodeficiency  
Autoimmune diseases, e.g.  
arthropathy, vitiligo, alopecia

#### Haematological

Transient neonatal  
myeloproliferative states  
Leukaemia  
Neonatal polycythaemia  
Neonatal thrombocytopenia

#### Dermatological

Dry skin  
Folliculitis  
Vitiligo  
Alopecia

#### Neuropsychiatric

Infantile spasms and other  
myoclonic epilepsies  
Autism  
Depressive illness  
Dementia (adults only)

#### Box 2

 The Down's Syndrome Association

The Down's Syndrome Association is a registered charity funded mainly from voluntary donations. Services offered include:

- Immediate help, support and advice on all aspects of the syndrome
- Specialist advisors in the following areas:
  - medical
  - speech and language
  - legal
  - welfare rights
  - education
- Information leaflets and videos on a range of topics suitable for parents, carers and professionals, including a medical information series
- Supporting research, including studentships

For further information contact  
Down's Syndrome Association  
155 Mitcham Rd, London SW17 9PG  
email: [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)  
<http://www.dsa-uk.com>

doctors. It is essential that the paediatrician is well informed and able to offer up-to-date, factual information on:

- The aetiology of Down's syndrome
- Development of children with Down's syndrome
- Immediate and future health concerns
- Local resources
- Long-term prognosis.

Parents should be given contact information for the Down's Syndrome Association (Box 2). Some, but not all, will appreciate being put in touch with another family with a child with Down's syndrome. Such introductions, however, should be arranged with care. Parents should be given a second opportunity to talk with the paediatrician and ask questions within the first few days. They should leave hospital knowing when they will next be seen, and who they can contact in the meantime should the need arise. The primary health care team should also be informed of the diagnosis.

### Neonatal medical assessment

It is essential that every newborn with Down's syndrome has a comprehensive medical assessment. Major gastrointestinal malformations will declare themselves clinically but evidence of cataract and congenital heart disease must be specifically sought. The latter may not be evident on initial clinical examination and appropriate investigative screening and ongoing surveillance must be initiated before discharge from hospital (see below). In districts where there is a neonatal auditory screening

programme, babies with Down's syndrome should be included.

### Ongoing medical management

All children with Down's syndrome should be offered regular medical review by a paediatrician throughout childhood. This may be a hospital, community, or developmental paediatrician depending on local service organization. In some areas, services are centred in a specific Down's syndrome clinic. Once children reach school age it may be most appropriate for their care to be coordinated by the school doctor.

The paediatrician should review the child's health and development and identify medical problems by a combination of history-taking, examination and screening tests, all directed at problems more likely to occur in Down's syndrome. A number of protocols and guidelines have been drawn up suggesting appropriate programmes.<sup>5-7</sup> The table of health checks is taken from the 2nd edition of the parent-held child health record (PCHR) insert for babies born with Down's syndrome<sup>8</sup> (see Table 1). It is based on the medical surveillance essentials for people with Down's syndrome developed by the UK Down's Syndrome Medical Interest Group.

The paediatrician will be just one of a number of health and non-health professionals working with the family. Others likely to be involved include:

- Primary health care team
- Other specialist doctors: cardiologist; ENT surgeon; ophthalmologist; orthopaedic surgeon, etc.
- Therapists: speech and language; physiotherapy; occupational therapy.
- Social worker
- Education: preschool teacher/portage worker; nursery and school staff; educational psychologist.

The paediatrician will need to refer to these other specialists and may also have an important role in coordinating the team.

### Transition to adult care

This is often a difficult area.<sup>6</sup> After years of regular paediatric supervision, there is no equivalent specialist service for adults. General practitioners are likely to be best placed to provide the ongoing service, but may not have the specialist knowledge. Psychiatrists with a special interest in learning disability are primarily concerned with mental health and social adjustment, and may not look at other health care needs. The paediatrician can help the process of transition prior to discharge by providing the general practitioner, the carers and the young person with a comprehensive report of any medical problems, previous health care and suggestions for ongoing care. Where the young person has

specific medical problems, the paediatrician should ensure that referral to appropriate adult specialists is made.

## SPECIFIC MEDICAL PROBLEMS

### Cardiovascular problems

Forty to sixty percent of babies with Down's syndrome have congenital heart disease. Of these, around 50% have an atrio-ventricular septal defect (AVSD). Other abnormalities include Fallot's tetralogy and various combinations of ventricular and atrial septal defects. It is important to establish the cardiac status of all babies with the syndrome in the first few weeks of life, as irreversible pulmonary vascular disease occurs earlier and more frequently than in children without Down's syndrome. Clinical examination alone is not sufficient. Some babies, even those with significant defects, will have no signs or symptoms in the first weeks of life.<sup>11</sup>

Assessment should ideally include an echocardiogram in the first few weeks. This should be carried out by an operator skilled in the diagnosis of such lesions. If echocardiography is not available, ECG, chest X-ray and examination by an experienced paediatrician at birth and again at 6 weeks should pick up nearly all significant defects.

Babies with heart defects should be referred to a paediatric cardiologist for consideration of surgery as early as possible. In the recent past, many children with Down's syndrome were not offered surgery. The complex nature of some of the abnormalities that occur in Down's syndrome does mean that surgery may be difficult or impossible, and for some lesions operative morbidity and mortality are high. Currently, however, the operative survival for uncomplicated AVSD is around 90–95% in major centres in the UK. The decision as to whether or not to operate should be based on the nature of the heart condition, not the coexisting learning disability.

Children without congenital heart lesions can develop heart disease at a later age. This may be secondary to upper airway obstruction (see below), or, in adolescence or early adult life, the onset of primary valvular dysfunction.<sup>12</sup> The possibility of acquired heart disease should therefore be borne in mind at medical reviews, and echocardiogram in early adult life should be considered. Parents and carers of all children with heart lesions should be given verbal and written information about infective carditis preventative measures. In potential risk situations, if cardiac status is unknown, preventive prophylactic measures should be started.

### Orthopaedic problems

#### *Cervical spine instability*

Laxity of the transverse ligament of C1 or dysplasias of C1/C2 can predispose to dislocation/subluxation of the

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**Table 1** Down's syndrome — suggested schedule of health checks, taken from PCHR insert for babies with Down's syndrome (2nd edition).<sup>8</sup>

The following are suggested ages for health checks. Check at any other time if there are parental or other concerns

|  | <b>Birth to<br/>6 weeks</b>  | <b>6–10 months</b>                                      | <b>12 months</b>                         | <b>18 months<br/>to 2½ years</b>  | <b>3–3½ years</b>                        | <b>4–4½<br/>years</b>                                |
|--|--|---|--|---|--|--|
| 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. (see page 9 onwards). 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   |  |  |
| <b>From age 5 to 19 years</b>  |  |   |  |   |  |  |
| 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.  |   |  |   |  |  |

atlantoaxial joint with potentially catastrophic sequelae. Previously, this led to recommendations for X-ray screening and selective restriction of sporting activities. It is now clear that there are no screening procedures that predict those at risk; in particular, cervical spine X-rays are not informative. Both the Department of Health and the American Academy of Pediatrics have withdrawn previous recommendations about radiological screening.<sup>13,14</sup> Although the risks may have been overstated, there is no doubt that a few people with

Down's syndrome do incur acute and sometimes catastrophic damage to the cervical spinal cord.<sup>15</sup> Risk of injury from specific sporting activities seems minimal. Most dislocations occur in the course of everyday activity, medical treatment or coincidentally whilst participating in sport. Neurological symptoms usually precede incidents of major trauma.

Current advice, therefore, is that radiological screening is not indicated and sporting activities should not be restricted in those with no clinical signs. However,

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particular care should be taken when manipulating the head and neck of an unconscious child, e.g. during anaesthesia or following a road traffic accident, and all carers and clinicians should be aware of warning signs. These include:

- Abnormal head posture
- Restricted neck movement
- Neck pain
- Altered gait
- Deteriorating manipulative skills
- Deterioration in bladder or bowel control.

Any child with such symptoms should be referred to a specialist orthopaedic or neurosurgeon for further investigation. Treatment options include decompression by traction and spinal fusion.

### Other orthopaedic problems

Hypotonia, ligamentous laxity and skeletal dysplasias may predispose to other orthopaedic problems. These include patellar instability, scoliosis, subluxation/dislocation of the hips, pes planus and metatarsus varus. Intervention will be necessary if there is pain, limited function or risk of structural damage. Surgery will sometimes be necessary. Many children benefit from shoe inserts and some may need specialist footwear.

### Ear, nose and throat problems

#### *Hearing*

Over 50% of children with Down's syndrome have hearing loss. This is most commonly due to glue ear, but a minority have sensorineural deafness. The latter becomes more prevalent with age. The natural history of glue ear differs from the general population. The condition often persists into adolescence and adult life. The glue is unusually tenacious. The benefit of grommet operations may be short-lived and frequent repeats necessary. Narrow ear canals make grommet insertion more difficult. Grommets do have their place in management, but perhaps should not be the first treatment option. Medical management with long-term, low dose antibiotics or orally administered decongestants are of unproven efficacy, but may be worth trying. For many children, the best option will be hearing aids. These are most likely to be accepted and useful if fitted by a specialist paediatric service, supported by specialist teachers for hearing-impaired children.

As for all children, one of the most important factors in managing hearing loss is the recognition that there is a problem. Unrecognized, it is a significant cause of secondary handicap. All people with Down's syndrome should have regular audiological surveillance throughout life. In areas where there is a neonatal screening programme, children with Down's syndrome should be

included. All should have audiological review between 6 and 10 months of age. This will usually need to be done by a specialist audiology service, partly because many children will not be developmentally ready for routine distraction testing at 7–8 months and also because more detailed assessment including otoscopy and impedance testing should be done. After this, preschool children should have their hearing reviewed annually and older children at least biennially.

#### *Upper airway obstruction*

People with Down's syndrome are particularly prone to partial upper airway obstruction and obstructive sleep apnoea.<sup>16</sup> Narrow airways and tongue hypotonia are common contributory factors. The condition may lead to growth retardation, poor developmental progress, tiredness and lethargy. Significant hypoxia and cor pulmonale can result. Sleep disturbance, snoring, drooling and swallowing difficulties may be diagnostic pointers. Symptoms are likely to worsen around age 2 or 3 as lymphoid tissue becomes relatively large in a restricted pharyngeal space. Some children require adenotonsillectomy. The paediatrician should consider the possibility of upper airway obstruction in all children with Down's syndrome, and ask specific questions in history-taking.

### Catarrh

Many children with Down's syndrome have persistent mucopurulent nasal discharge. In addition to predisposing to glue ear, this may make the child feel constantly below par. It reduces social acceptability and may interfere with sleeping and eating. For children who are unable to effectively blow their noses, mechanical decongesters may help. Oral and nasal decongestants can be useful. Some children benefit from low dose, long-term antibiotics. Some improve markedly on a milk-free diet.

### Ophthalmological problems

Ophthalmological problems, including congenital cataracts, nystagmus, squint, glaucoma, keratoconus, blepharitis and blocked nasolacrimal ducts, are over-represented in Down's syndrome.<sup>17</sup> Refractive errors, including hypermetropia, occur in approximately 70%, and if uncorrected, constitute a significant cause of secondary handicap. The possibility of ophthalmic problems should be considered at every review, starting with the routine neonatal examination where a check should be made for congenital cataracts. After this, the paediatrician should monitor visual behaviour by observation and parental history. If any abnormality is suspected, the child should be referred to an ophthalmologist. Even where there are no concerns, referral for full ophthalmic assessment, including refraction, fundoscopy and

orthoptic testing, should be made in the second year of life. Vision should continue to be checked at least every 2 years throughout life. This can be done by a school nurse or high street optician once the child is developmentally ready to cooperate with standard vision testing. More serious ophthalmic problems such as glaucoma or keratoconus will be picked up either because the child has pain, red eye or because of changing vision.

## Growth

Short stature is a characteristic feature of Down's syndrome. Mean adult height is 145 cm (4'8") for females and 157 cm (4'11") for males. New centile charts for Children with Down's syndrome based on data from the UK and Republic of Ireland are now available.<sup>18</sup> Children with Down's syndrome do not generally suffer from classical growth hormone deficiency, and the cause of the growth retardation is not known. However, poor growth may be an indicator of congenital heart disease, upper airway obstruction, coeliac disease, hypothyroidism, and other conditions that are more common in the syndrome. Children with Down's syndrome should therefore be weighed and measured regularly, and measurements plotted on Down's specific charts. Any significant deviation from these centiles should lead to detailed assessment. The Down's syndrome specific charts, suggest that in older children with Down's syndrome, obesity is the norm. However, obesity is not an inevitable consequence of the syndrome. Weight for height should be plotted on BMI charts (included on UK Down's Growth Charts). Excessive weight gain should be thoroughly assessed and advice on exercise and nutrition offered where appropriate.

## Sexual development

Parents often ask questions about sexual development. By and large this proceeds as in the general population, and most adolescents cope well with the demands of puberty. There are, however, small variations. Some boys have small genitalia. Subfertility occurs in both sexes but more so amongst men. There are many reports of women with Down's syndrome having children. There is a 50:50 risk of Down's syndrome in a pregnancy where one parent has the syndrome.

## Thyroid dysfunction

Thyroid dysfunction, commonly hypothyroidism, is more prevalent in people with Down's syndrome at all ages.<sup>19</sup> The prevalence increases with age. Uncompensated hypothyroidism is found in around 10% of the school age population. Signs and symptoms may not be obvious and if present may be dismissed as being part of the

syndrome. Diagnosis on clinical grounds is therefore not reliable and biochemical screening is essential. In the UK, all babies are screened for hypothyroidism. For children with Down's syndrome each district should have a policy for thyroid screening thereafter. This should include either estimation of T4, TSH, and thyroid autoantibodies in venous blood at least every 2 years or annual dried blood spot TSH measurement (Guthrie) using fingerprick blood.<sup>20</sup> Transient changes in TFTs may occur. Mildly raised TSH or the presence of autoantibodies with normal T4 and no clinical evidence of hypothyroidism does not usually warrant treatment. However, these children have a high risk of developing clinical disease and more frequent testing is essential. Though less common, hyperthyroidism is also more frequently seen in Down's syndrome. The paediatrician should always bear in mind the frequency of thyroid dysfunction and have a low threshold of suspicion at all times.

## Gastrointestinal problems

Ten percent of children with Down's syndrome have congenital malformations, including atresia of the jejunum, duodenum, oesophagus and anus, annular pancreas, and exomphalos. These may be picked up on antenatal scan, or present in the neonatal period. There are less severe forms, e.g. anal or duodenal stenosis, where symptoms are milder and may go unrecognized for some time. Children with Down's syndrome should not be denied treatment for surgically correctable conditions on the grounds that they have Down's syndrome.

Also more common in Down's syndrome are coeliac disease (around 4%) and Hirschsprung's disease (around 2%). It is important to consider these in the differential diagnosis of constipation, diarrhoea and poor growth. Many infants with Down's syndrome will have feeding difficulties.<sup>21</sup> This is often due to oral motor dysfunction, but gastro-oesophageal reflux is also common and can play a part. Appropriate management of these in infancy may prevent eating problems later on.

## CONCLUSION

Anyone undertaking a medical literature search on Down's syndrome will find that much current research focuses on prenatal diagnosis with the aim of terminating all affected pregnancies. Also, over the years, there have been numerous fashions involving unconventional treatments. Thus the main focus seems to be on what we cannot yet (or may not want to) do and on treatments of unproven efficacy. However, a great deal is known about a wide range of treatable medical problems that occur more frequently in people with Down's syndrome. At present, the most significant benefit that medicine has to offer children with Down's syndrome is to offer quality

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screening and assessment specific to their needs, and the same opportunities for medical treatment as the rest of the population.

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## Additional resources:

Down's Syndrome Medical Interest Group (DSMIG(UK)) and Down's Syndrome Medical Information Services (DSMIS)  
 Children's Centre, City Hospital Campus, Nottingham NG5 1PB  
 Tel 0115 9627658 ext 45667. Fax 0115 9627915.  
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