INDUCTION PACK

COMMUNITY CHILD HEALTH

NORTHERN IRELAND MEDICAL AND DENTAL TRAINING AGENCY



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1. INTRODUCTION

Welcome to community paediatrics. We hope you enjoy your attachment with us. Working in Community Child Health can seem very different to acute paediatrics. You will be part of a team of different professionals and other agencies. You will also be expected to work independently under supervision and to organise some of your own timetable. A senior member of staff is always easily contactable for advice and support. This pack contains some information, which may help during your attachment and may be useful in your future career.

1.1. What is community paediatrics?

Community paediatrics is a diverse clinical specialty, which defies a single job description as most posts have evolved in response to local needs. It has been a separate specialty since the publication of the Court report in 1976 [1]. However, the role of doctors working in the community has also changed with much of the routine work in immunisation, child health surveillance and school health being taken over by nurses in primary care. Community paediatricians have been engaged in bringing leadership and consultant skills to vital fields for the health of children. These include specialist work in neurodisability, safeguarding, behavioural paediatrics and children's mental health, school health and in improving the public health of children. An essential part of the function is working in a multidisciplinary environment with children's nurses, therapists, teachers and social workers [2].

At the time of the Court report, there had already been notable improvements in the health of children in the UK. Although health improvements continue we face new challenges [2]:

- More can be done for infants and children who are very sick.
- There are more chronically disabled children, their disabilities are more severe, they are surviving longer and their parents have higher expectations.
- Emotional and behavioural problems are on the increase.
- Many children in the UK still live in poverty or are disadvantaged.
- Many children now receive much of their care at home or out of hospital.

In a paper in Archives of Disease in Childhood in 2002, Curtis and Waterston discussed the future of community paediatrics and proposed that "community paediatrics is not a specialty as such but a philosophy of delivery of child health care with the following principles: high accessibility; holistic vision; close working with parents; interagency care and teamwork; advocacy directed at the needs of all children; and above all a preventive orientation" [1]. It is these principles that should guide the development of community and hospital paediatrics as we face the challenges of today and the future.

References

- [1] Curtis, E and Waterston, T. *Community paediatrics and change*. Arch Dis Child 2002; **86**: 227-229.
- [2] Craft A, McClellan N, Sibert J. Strengthening the care of children in the community. A review of community child health in 2001. London: RCPCH, February 2002.

1.2. Our community

Northern Ireland is a region of the UK, which in the recent past was best known for the 'Troubles' and was characterised by political divide and civil unrest. However, it is as likely to be

known today for its unique culture, areas of outstanding natural beauty and its connection with the *Titanic*. Northern Ireland has a largely rural landscape with most of the population living in the east of the province, heavily concentrated in the urban area of Belfast.

In June 2010 there were an estimated 1.79 million people living in Northern Ireland, 21.2% of whom were children (aged under 16), reflecting a high birth rate compared to the rest of the United Kingdom. During 2010 just over 25,000 babies were born in Northern Ireland and just over 14,000 people died. It was projected that the Northern Ireland population reached 1.8 million during 2011 [1]. Although part of the UK, Northern Ireland has differences in its legal and political system. Devolution of many powers to the Northern Ireland Assembly took place on 2 December 1999. There is also cooperation with the government in the Republic of Ireland over some issues, notably health.

1.3. Structure of health care



There are five trusts in Northern Ireland, providing health and social care services to the Northern Ireland public. Services are provided locally and on a regional basis. Hospital paediatric services are mainly situated at RBHSC and in the Ulster, Craigavon Area, Antrim Area, Altnagelvin, Causeway, Daisy Hill and Erne hospitals [2].

1.4. Poverty

It is important to be aware of social and economic factors in our community which can have a significant impact on the health of children. In terms of child poverty, from 2006-09, 26% of children in Northern Ireland were living in low-income households (using the low-income threshold of the 60% of median income after deducting housing costs). Northern Ireland's 26% rate is slightly below the UK average of 31% and is lower than the other UK regions [3]. In comparison to Scotland, Northern Ireland has similar child poverty rates but a 'younger' population, with the result that children in poverty make up a bigger part of the Northern Ireland population. Research by the Department for Social Development found that the poverty rate was lower in Belfast than elsewhere but not significantly so (18% compared with 20% in other urban areas and 19% in rural areas). This masks a difference between the rural east and west, the poorest and richest parts of the province respectively [4]. Unemployment has long been a problem in Northern Ireland, but during the recession has risen more than in any other part of the UK [4].

1.5. Domestic violence, mental illness and substance misuse

As well as poverty, issues such as domestic violence, mental illness and substance misuse can have adverse effects on child health and increase the risk of abuse. Domestic violence accounts for 16% of all violent crime in Northern Ireland and there were 24,482 domestic incidents reported to the police in 2009/10. Women's Aid had 38,296 calls to their helpline in 2010/11 [5].

Northern Ireland has one of the highest incidences of mental illness in the developed world and a recent study by the University of Ulster found that the lifetime prevalence of any mental health disorder was 39.1%. There are high levels of post-traumatic stress disorder in the community, much of which is related to the sectarian conflict [6]. Substance abuse is also a problem in our society. In 2011, 284 people died directly as a result of alcohol misuse, an increase of around 40% on the loss of life recorded in 2001 [7]. In June 2010, the Health Minister stated that "alcohol misuse is one of the biggest public health issues facing Northern Ireland and its impact cannot be underestimated". He was commenting on a study, which had estimated the cost to society of alcohol misuse to Northern Ireland in 2008/09 as £679.8million [8].

1.6. Immigration

Another influence on Northern Ireland society has been immigration, which has increased in recent years due to new countries joining the European

Union, allowing more economic migration. Between 2004 and 2008 around 65,000 people moved to Northern Ireland from overseas, equivalent to 3.6% of the 2008 population. The Northern Ireland Statistics and Research Agency (NISRA) estimates that there around 30,000 people from the new EU accession states in Eastern Europe living in Northern Ireland representing around 2% of the population. The spread of these migrants across the province is far from uniform. In Dungannon, they comprise around 7% of the total population. Some 5,000 migrants live in Belfast, making up around 2% of the population, but one-sixth of the total EU immigrant population [4].

1.7. Disability and mortality statistics

In terms of child health, the infant death rate in Northern Ireland has markedly declined from 13.2 per 1000 live births in 1981 to 5.7 per 1000 live births in 2010. However this has remained the highest of all the UK regions and is above the UK average of 4.3 per 1000 live births in 2010. There is a marked difference in the rate of infant mortality across Northern Ireland, the rate in the most deprived fifth of areas (7 per 1,000 live births) being one third higher than the rate elsewhere (5 per 1,000). For childhood disability, a survey by NISRA in 2007 found that the proportion of children who have a disability in the community is 6%. The prevalence of disability amongst children living in households varies from a low of 5% in the east of Northern Ireland (Antrim, Ards, Ballymena, Banbridge, Craigavon, Down and Larne) to 8% within Belfast. The survey found that 4% of children were living with two or more disabilities; with chronic illness, learning disability and social or behaviour difficulties being the most prevalent [10]. Regarding child abuse, it is difficult to obtain accurate estimates of the extent in our society. As a proxy measure. between 2006 and 2011, the number of children on the Child Protection Register has increased by 46% (762), from 1,639 to 2,401, respectively. At 31st March 2011, there were 2,511 'looked after children', down by 4% (95) from 2010, but up 3% (75) since 2006 [11].

This summary is intended to give you some context for community paediatrics in Northern Ireland. However, there will be specific local issues and factors in the area where you are working. During your attachment, you should aim to develop your awareness of these by listening to families and meeting with a range of professionals and agencies in the community.

References

- [1] http://www.nisra.gov.uk/publications/default.asp10.htm
- [2] Health and Social Care Board. Gateway for health and social care in Northern Ireland. http://www.n-i.nhs.uk/index.php?link=trusts
- [3] Family Resources Survey. The Poverty Site, Guy Palmer. http://www.poverty.org.uk/index.htm
- [4] Monitoring poverty and social exclusion in Northern Ireland 2009. New Policy Institute, Joseph Rowntree Foundation, September 2009. Accessed http://www.poverty.org.uk/reports/ni%202009%20findings.pdf [5] Women's Aid
- [6] Bunting B, Murphy S, O'Neill, S and Ferry, F. Lifetime prevalence of

mental health disorders and delay in treatment following initial onset: evidence from the Northern Ireland Study of Health and Stress. Psychological Medicine 2011 pp 1-13.

[7] http://www.belfasttelegraph.co.uk/news/local-national/northern-ireland/united-bid-to-tackle-alcohol-abuse-16109307.html#ixzz1ttj0qvBv

[8] June 2010 News releases Northern Ireland Executive

[9] NISRA Vital Statistics

http://www.nisra.gov.uk/demography/default.asp2.htm

- [10] The Prevalence of Disability and Activity Limitations amongst adults and children living in private households in Northern Ireland. Northern Ireland Statistics and Research Agency, July 2007. Accessed http://www.nisra.gov.uk/publications/default.asp9.htm
- [11] Waugh, lain and Fitzpatrick, Manny (2012) Children Order Statistical Tables for Northern Ireland 2005/6 to 2010/11 Belfast: Northern Ireland, DHSSPS.

http://www.dhsspsni.gov.uk/children_order_trends_2011 - tabbfinal.pdf

2. PRACTICAL INFORMATION

2.1. The Community Child Health Team

The community child health team includes Consultant, Associate Specialist and Speciality Grade doctors, and colleagues from speech and language therapy, physiotherapy, occupational therapy, community children's nursing and school health. Specialist nurses for asthma, diabetes and epilepsy may also be



involved. The team may include a dietician, psychologist, orthoptist, dentist or music therapist. Direct involvement of social services in the team is variable but there is frequent contact. Reception and secretarial staff are important members of the team and will help you with many of the practical aspects of your work. Your Trust induction should provide you with contact details for the community child health team and a timetable of clinics and other activities.

2.2. Teaching

There will be regional training events relevant to community paediatrics organised by NIMDTA and BACCH NI. There should also be local community paediatric team meetings, which often include educational topics as well as clinical and business issues. Other teaching opportunities may be arranged locally, although discussing cases with a Consultant or other members of the team is always valuable for learning. Your base should have internet access, and books and journals that you can refer to. You should arrange to do some work-based assessments during your attachment. There will also be opportunities for audit and guideline development within your local team.

2.3. Patients

When seeing patients try to ensure you get the correct information from them with regard to their address, phone number, name of school, other professionals involved i.e. names, address etc. Please note that health visitors are only involved with children until they are school age, unless there is social services involvement - after this care passes to the school nurse.

2.4. Parental Responsibility and Consent

The Children (N.I.) Order 1995 and Family Law (N.I.) Act 2001 state who is a person with parental responsibility. Within Child Health Services, it is only such a person who can give consent, when necessary, for any assessment, treatment or care of a child under 18 who cannot or does not wish to consent for him/herself.

The law allows young people, who have clear understanding of what is involved, to consent to their own treatment/care. If the young person is aged 16 – 18, he/she can agree to being examined, treated or cared for in the same way that adults can. People providing health or social care do not then have to ask his/her parents for consent as well. If the young person is under 16,

he/she may still be able to give consent provided he/she is able to understand what is involved in the proposed treatment or care.

In all cases, it is only necessary for consent to be given by **one** person. That person may **either** be a person with parental responsibility **or** a young person who is deemed capable of fully understanding what is involved (considered competent). The young person's competency will be determined at the time of assessment, treatment or care.

Those who have Parental Responsibility

- 1. The child's mother.
- **2.** The child's father if married to the mother at the time of the child's conception or birth or if the father subsequently marries the mother at a later stage.
- **3.** The child's father if he is registered as the father on the child's birth certificate for children born on or after 15 April 2002.
- **4.** In some instances, parental responsibility is shared with the Health and Social Services Trust (Social Work Department) where a child is named in a Court Order.
- **5.** A legally appointed guardian appointed either by a Court or by parents with parental responsibility in the event of their own death.
- **6.** A person who has obtained a Residence Order for the child.

Usually foster parents, step-parents, civil partners of a parent, private foster carers and relatives do not have parental responsibility, unless they have acquired it through a Court Order.

If this is not the case then the parents still have parental responsibility **OR** parental responsibility may be shared with the Health and Social Services Trust.

Important An adult may only give consent for a child to receive an assessment, treatment or care if he/she has parental responsibility for that child. A young person under 18 may only consent to assessment, treatment or care for him/herself if he/she has sufficient understanding of what is involved (ie, is deemed 'competent').

2.5. Investigations

If you have sent blood tests or arranged other investigations for patients, please put the correct child and Consultant details on the request forms. Request forms to medical genetics should include clinical details and signed consent from carers. If requesting an MRI, complete a request form with all the clinical details, an MRI checklist and a general anesthetic form if required. It is helpful if you can take responsibility for following up the results yourself and then discussing them with the Consultant and informing the GP and parents. It is important that this is done promptly and that results are filed in the patient's chart. If you are due to see a child at clinic and there are outstanding results, please attempt to find these before the clinic.

2.6. Dictation

After you see children at community clinics you dictate a letter to the referrer and send copies to the GP, health visitor and other relevant professionals. It is good practice to send a copy to parents and keep this in mind when you are using medical terms in the letter. It is important to ask parents if letters can be copied to various professionals and to inform them of the content, as they may wish for certain information not to be shared. The structure of a letter for a review patient is different to a new patient and



your Consultant can give you a proforma to use. Include feedback from other professionals in a letter from a multidisciplinary child development clinic. Some child development clinics provide a separate parent report. After you have finished your dictation, place your tape in an envelope with your name and the name and date of the clinic on it. Check with the secretaries as to where you should leave completed dictation. Dictation should be done promptly and please check your tray at least weekly to sign letters. If you need to keep charts in your tray, please leave a note/tracer in the filing system. If there is a waiting list for dictation to be typed and something needs done urgently please draw it to the attention of one of the secretaries.

2.7. Referrals

Children seen in community paediatrics often need referred to other professionals and agencies. Ask your Consultant and the secretaries about how this is done in your Trust. In some areas, referrals are done electronically. Referrals to educational psychology may require signed consent from a carer who has parental responsibility. Referrals to social services require you to complete a UNOCINI. You should include your reason for referral and can attach a separate letter. You do not need to complete the entire form but try to fill in as much as you can about the family structure and other professionals involved.

2.8. Guidelines

The following is a list of relevant National Guidelines. The guidelines can be accessed from the RCPCH site http://www.rcpch.ac.uk/child-health/standards-care/child-health-guidelines-and-standards/guidelines-endorsed-rcpch-subspe-1

NICE (http://guidance.nice.org.uk)

- ADHD: Diagnosis and management 2008 (CG72)
- When to suspect child maltreatment 2009 (CG89)
- Autism in children and young people 2011 (CG128)
- Chronic fatigue syndrome/Myalgic encephalomyelitis 2007 (CG53)
- Obesity 2006 (CG43)
- Promoting the quality of life of looked after children and young people 2010 (PH28)
- Depression in children and young people 2005 (CG28)

Scottish Intercollegiate Guidelines Network (SIGN) (http://www.sign.ac.uk/guidelines/published/index.html)

- 1. Management of Attention Deficit and Hyperkinetic disorders in children and young people 2009 (no.112)
- 2. Assessment, diagnosis and interventions for children and young people with autism spectrum disorders 2007 reviewed 2012 (no. 98)
- 3. Management of obesity 2010 (no.115)

RCPCH

- The physical signs of child sexual abuse 2008 (updated 2011)
- RCPCH Allergy Care Pathways 2011
- RCPCH evidence based guideline for the management of CFS/ME (chronic fatigue syndrome/myalgic encephalopathy) in children and young people 2004.

The Health and Social Care Trusts will have their own local guidelines, which are usually accessible on the Trust Intranet.

2.9. Leaflets

It is good practice to give families written information about their child's condition and about support organisations. Please familiarise yourself with the information leaflets available in your base. If you use the last leaflet or referral form please photocopy or print more and share any new material that you discover.

Written information in the form of factsheets and leaflets on specific conditions can usually be found on the relevant support organisation website. Contact a Family list contact details for support organisations for different conditions on their website www.cafamily.org.uk. Contact a Family also has a range of leaflets available on topics such as benefits, feeding, toileting, sleep and behaviour. ERIC (Education and Resources for Improving Childhood Continence) and the Continence Foundation of Australia have leaflets on all aspects of toileting. RCPSYCH have published a range of leaflets on mental health issues, behaviour and sleep difficulties in children and young people at http://www.rcpsych.ac.uk/mentalhealthinformation/childrenandyoungpeople.as
px.
The Medicines for Children programme by RCPCH has developed information leaflets for parents and children on medicines. These are available on the website, which also has videos for parents about how to administer medicines: http://www.medicinesforchildren.org.uk/.

2.10. Discharge policy

Discharge of patients from community child health clinics is ultimately the responsibility of the supervising consultant. Patients will be discharged when it is deemed that their needs have been met or when alternative arrangements have been made for their ongoing support. Check your local policy for discharging due to non-attendance. Children who do not attend may still

require follow-up, indeed repeated non-attendance at medical appointments may be an indicator of neglect. Discharge letters will be written formally to the child's GP and health visitor with copies sent to parents and other professionals involved. Patients who have child protection concerns or are on medications requiring medical supervision will not be discharged without Consultant overview and consideration given to ensuring patient safety.

2.11. Leave

All annual and study leave should be approved in advance by your Consultant supervisor. Please notify all the Community Paediatric Consultants of your on call and annual leave so that they can plan clinics. Certain clinics will need to be covered by junior staff and this may restrict how many trainees can be on leave or on-call at the same time. Please leave a mobile number and email address with the secretaries so that you can be contacted regarding



clinics. If there is a message book for junior staff, please check it regularly as messages may be left to contact parents.

4. **SAFEGUARDING**

During your time in community paediatrics you should familiarise yourself with the following publications and attend Safeguarding training, such as the Child Protection Recognition and Response in Child Protection (www.alsg.org/en/?q=en/cprr). There will be opportunities to attend case conferences and 'Looked after children' reviews. If you have any child protection concerns about a child that you have seen in clinic, you should discuss these with the Consultant and contact the Gateway team. A UNOCINI referral may need to be completed.

The Regional Child Protection Committee has replaced the four legacy Area Child Protection Committees. The key objective for the Regional CPC is to determine the strategy for safeguarding children and to develop and disseminate policies and procedures. There are five working groups, which have specific responsibilities for Trust Child Protection Panels, Policy & Procedures, Case Management Reviews, Education & Training and Communication & Audit. The Trust Child Protection Panels facilitate practice at a local level to support the RCPC. Further information is available at the RCPC website: www.rcpc.hscni.net/index.html

Reading:

(www.rcpc.hscni.net/Publications.html)



- Short guide to Policy and Procedures 2005
- Amendments to Policies and Procedures 2008
- http://www.core-info.cardiff.ac.uk/
- NICE guideline (Dec 2009): CG89 When to suspect child maltreatment: NICE guideline
- Promoting the Health of Looked After Children DH: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPublicationsPublicationsPublications
 SPolicyAndGuidance/DH 108501
- British Association for Adoption & Fostering website http://www.baaf.org.uk/

Useful RCPCH publications:

www.rcpch.ac.uk/Policy/Child-Protection/Child-Protection-Publications:

- Child Protection Reader: recognition and response in child protection (2007)
- Child Protection Confidentiality
- Safeguarding Children and Young People: roles and competences for Healthcare staff
- The Physical Signs of Child Sexual Abuse. An evidence-based review and guidance for best practice (2008)
- Fabricated or Induced Illness by Carers (FII): A Practical Guide for Paediatricians

4.1. Suggested Activities

- Identify the local Named and Designated Doctors (Lead Clinicians) for Safeguarding and shadow them.
- Attend the Regional Child Protection Committee or one of its subgroups, or attend a Trust Child Protection Panel with the Designated Doctor.
- Attend the Regional Child Protection Special Interest Group.
- Arrange a 'mini pupilage' with a local Judge (can be arranged through your Designated Doctor) to shadow and observe the court system.
- Participate in a project related to safeguarding e.g.review policies/protocols,
- develop new guidelines or audit an aspect of the safeguarding service
- Participate in Safeguarding training e.g. for the primary health care team,
 F2 or ST1-3, nurses, A&E or non-clinical staff
- Participate in a project related to adoption/LAC e.g. review policies/protocols, audit of how health care needs are being met
- Participate in local training sessions for foster carers
- Find out about the indications for and the process of a Case Management Review from the local Named or Designated Doctor, and if possible attend a meeting regarding a current CMR.

5. PUBLIC HEALTH

5.1. Child Health Surveillance

The existing Child Health Promotion Programme within Northern Ireland, introduced in 2006, is based on 'Health for All Children' (Hall and Elliman, 2002). Hall 4 promoted the gradual shift from a highly medical model of screening, to one with a greater emphasis on health promotion, primary prevention and active intervention for children at risk. The core programme is divided into 3 sections: health promotion, building relationships with families and health protection (screening, surveillance and immunisation). It includes:

Preschool 0-5

- Antenatal visit/contact
- Neonatal examination
- Newborn hearing screening
- Newborn blood spot screening
- Primary visit
- 8 week developmental review
- National immunisation programme and growth monitoring at 8 weeks, 3 months, 4 months, 12 months (immunisation only) and 4 years
- Developmental assessment at 2 years, focusing on language development
- School readiness assessment at 4 years

Primary

- School entry health assessment
- Vision screening
- Sweep hearing
- Growth monitoring
- P2-P7 targeted reviews

Post-primary

- Year 8 school entry health assessment
- Year 8-14 targeted reviews
- Year 11 school leaving immunizations

Health visitors, GPs and school nurses, deliver the child health programme. One important duty of the programme is to identify, assess and offer targeted support families with identifiable needs and vulnerable families. In May 2010, the Department of Health, Social services and Public Safety published 'Healthy Child, Healthy Future'. This is intended to strengthen and improve the existing programme.

Reading:

www.dhsspsni.gov.uk/healthychildhealthyfuture.pdf www.dhsspsni.gov.uk/guidance and principles of practice for professional staff health for all children.pdf

5.2. The UK Immunisation Programme (2011/12)



When to immunize	What vaccine is given	How it is given
Two months old	Diphtheria,tetanus, pertussis, polio and Hib Pneumococcal	One injection One injection
Three months old	Diphtheria, tetanus, pertussis, polio and Hib MenC	One injection One injection
Four months old	Diphtheria, tetanus, pertussis, polio and Hib MenC Pneumococcal	One injection One injection One injection
12 months old	Hib/MenC Measles, mumps and rubella (MMR) Pneumococcal	One injection One injection One injection
Three to five years old	Diphtheria, tetanus, pertussis, polio Measles, mumps and rubella	One injection One injection
Twelve – thirteen years old girls	HPV vaccine	Three injections
Fourteen to 18 years old	Tetanus, diphtheria, polio	One injection

BCG vaccination against TB is only offered to newborns with risk factors. A TB risk assessment is done in schools.

Childhood Immunisation Guidance notes for professionals 2011/2012. http://www.publichealth.hscni.net/sites/default/files/Childhood_ImmunisationFlick_Leaflet_2_3_0.pdf

5.3. Guidance on Infection Control in Schools

Reproduced from HPA leaflet:



Guidance on Infection Control In Schools and other Child Care Settings



Prevent the spread of infections by ensuring: routine immunisation, high standards of personal hygiene and practice, particularly hand washing, and maintaining a clean environment.

Please contact your local Health Protection Unit (HPU) on _____ if you would like any further advice or information.

Diarrhoea	Recommended period to be kept away from school,	Comments	
and Vomiting	nursery, or childminders		
illness#			
Diarrhoea and/or vomiting	48 hours from last episode of diarrhoea or vomiting (48hr rule applies).	Exclusion from swimming should be for 2 weeks following last episode of diarrhoea.	
E. coli 0157 VTEC	Exclusion is important for some children. Always consult with HPU.	Exclusion applies to young children and those who may find hygiene practices difficult to adhere to. Local HPU will advise Exclusion from swimming should be for 2 weeks following last episode of diarrhoea.	
Typhoid* [and paratyphoid*] (enteric fever)	Exclusion is important for some children. Always consult with HPU.	Exclusion applies to young children and those who may find hygiene practices difficult to adhere to. Local HPU will advise Exclusion from swimming should be for 2 weeks following last episode of diarrhoea.	
Shigella (Dysentery)	Exclusion may be necessary.	Exclusion (if required) applies to young children and those who may find hygiene practices difficult to adhere to. Local HPU will advise. Exclusion from swimming should be for 2 weeks following last episode of diarrhoea.	
Respiratory Inf	ections		
'Flu' (influenza)	Until recovered.	SEE: vulnerable children.	
Tuberculosis*	Always consult with HPU.	Not usually spread from children. Requires quite prolonged, close contact for spread.	
Whooping cough* (Pertussis)	Five days from commencing antibiotic treatment or 21 days from onset of illness if no antibiotic treatment.	Preventable by vaccination. After treatment non-infectious coughing may continue for many weeks. HPU will organise any contact tracing necessary.	

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Rashes/Skin	Recommended period to be kept away from school, nursery, or childminders	Comments
Athletes foot	None.	Athletes foot is not a serious condition. Treatment is recommended.
Chicken pox	5 days from onset of rash.	SEE: vulnerable children and female staff – pregnancy.
Cold sores, (herpes simplex)	None.	Avoid kissing and contact with the sores. Cold sores are generally a mild self-limiting disease.
German measles (rubella)*	5 days from onset of rash.	Preventable by immunisation (MMR x 2 doses). SEE: female staff - pregnancy.
Hand, foot & mouth	None.	Contact HPU if a large number of children are affected. Exclusion may be considered in some circumstances.
Impetigo	Until lesions are crusted or healed.	Antibiotic treatment by mouth may speed healing and reduction infectious period.
Measles*	5 days from onset of rash.	Preventable by vaccination (MMR x 2). SEE: vulnerable children and female staff – pregnancy.
Molluscum contagiosum	None.	A self limiting condition.
Ringworm	Until treatment commenced.	Treatment is important and is available from pharmacist. N.B. For ringworm of scalp treatment by GP is required. Also check and treat symptomatic pets.
Roseola (infantum)	None.	None.
Scabies	Child can return after first treatment.	Two treatments 1 week apart for cases. Contacts should have one treatment; include the entire household and any other very close contacts. If further information is required contact your local HPU.
Scarlet fever*	5 days after commencing antibiotics.	Antibiotic treatment recommended for the affected child.
Slapped cheek / fifth disease. Parvovirus B19	None.	SEE: vulnerable children and female staff – pregnancy.
Shingles	Exclude only if rash is weeping and cannot be covered.	Can cause chickenpox in those who are not immune i.e. have not had chicken pox. It is spread by very close contact and touch. If further information is required contact your local HPU. SEE: vulnerable children and female staff – pregnancy.
Warts and Verrucae	None.	Verrucae should be covered in swimming pools, gymnasiums and changing rooms.

Other infections

Conjunctivitis	None.	If an outbreak/cluster occurs consult HPU.
Diphtheria *	Exclusion is important. Always consult with HPU.	Preventable by vaccination. HPU will organise any contact tracing necessary.
Glandular fever	None.	About 50% of children get the disease before they are five and many adults also acquire the disease without being aware of it.

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Other	Recommended period to be kept away from school, nursery, or	Comments
infections	childminders	
Head lice	None.	Treatment is recommended only in cases where live lice have definitely been seen. Close contacts should be checked and treated if live lice are found. Regular detection (combing) should be carried out by parents.
Hepatitis A*	Exclusion may be necessary. Always consult with HPU.	Good personal and environmental hygiene will minimise any possible danger of spread of hepatitis A. SEE: cleaning up body fluid spills and PPE information below
Hepatitis B* and C*	None.	Hepatitis B and C are not infectious through casual contact. Good hygiene will minimise any possible danger of spread of both hepatitis B and C. SEE: cleaning up body fluid spills and PPE information below
HIV / AIDS	None.	HIV is not infectious through casual contact. There have been no recorded cases of spread within a school or nursery. Good hygiene will minimise any possible danger of spread of HIV. SEE: cleaning up body fluid spills and PPE information below
Meningococcal meningitis* / septicaemia*	Until recovered.	Meningitis C is preventable by vaccination. There is no reaso to exclude siblings and other close contacts of a case. The HPU will give advice on any action needed and identify contacts requiring antibiotics.
Meningitis* due to other bacteria	Until recovered.	Hib meningitis and pneumococcal meningitis are preventable by vaccination. There is no reason to exclude siblings and other close contacts of a case. Always contact the HPU who will give advice on any action needed and identify contacts requiring antibiotics.
Meningitis viral*	None.	Milder illness. There is no reason to exclude siblings and other close contacts of a case. Contact tracing is not required
MRSA	None.	Good hygiene, in particular hand washing and environmenta cleaning, are important to minimise any danger of spread. If further information is required contact your local HPU.
Mumps*	Five days from onset of swollen glands.	Preventable by vaccination. (MMR x 2 doses).
Threadworms	None.	Treatment is recommended for the child and household contacts.
Tonsillitis	None.	There are many causes, but most cases are due to viruses and do not need an antibiotic.

^{*} denotes a notifiable disease. It is a statutory requirement that Doctors report a notifiable disease to the proper officer of the Local Authority. In addition organisations may be required via locally agreed arrangements to inform their local HPU. Regulating bodies (e.g. Office for Standards in Education (OFSTED)/Commission for Social Care Inspection (CSCI)) may wish to be informed – please refer to local policy.

Outbreaks: if a school, nursery or childminder suspects an outbreak of infectious disease they should inform their Health Protection Unit (HPU). Advice can also be sought from the school health service.

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5.4. The impact of social and economic factors on children

 Socially graded inequalities are present prenatally and increase through early childhood. Maternal health, including stress, diet, drug, alcohol and tobacco use during pregnancy, has a significant influence on foetal and early brain development. The biological effects of birth weight on brain development interact with other influences associated with social position to influence



associated with social position to influence cognitive development. Lower birth weight, earlier gestation and being small for gestational age are associated with infant mortality [1].

- Children's life chances are heavily predicated by development in first 5 years of life. Most important factors are healthy pregnancy, maternal mental health, secure bonding, love and responsiveness along with clear boundaries (nurturing parenting), opportunities for social, cognitive, language, social and emotional development [2].
- Children from low income households are more likely to: suffer infant mortality, have preschool conduct and behaviour problems, experience bullying and take part in risky behaviour as teenagers and become poor



adults. They are less likely to do well at school or stay on after 16 years. It is not just the lack of income but a chaotic family life, lack of stability, upheaval and the focus on someone else's needs that affect children [2].

- Children face additional difficulties where there is drug/alcohol misuse, domestic violence, LAC, children who are young carers or who have a disabled parent [2].
- Bad housing conditions; including homelessness, temporary accommodation, overcrowding, insecurity, and housing in poor physical condition; constitute a risk to health. Children in bad housing are more likely to have mental health problems, to contract meningitis, have respiratory problems, experience long-term ill health and disability, experience slow growth and have delayed cognitive development [1].
- The impact of transport on health inequalities is most significant when looking at deaths from road traffic injuries. Children in the 10 per cent most deprived wards in England are four times more likely to be hit by a car than children in the 10 per cent least deprived wards [1].
- There is a social gradient in health the lower a person's social

position, the worse his or her health. Action should focus on reducing the gradient in health. Focusing solely on the most disadvantaged will not reduce health inequalities sufficiently. To reduce the steepness of the social gradient in health, actions must be universal, but with a scale and intensity that is proportionate to the level of disadvantage [1].

- Within the NHS, there has been a longstanding focus on acute services, and on access and waiting times. Less than 4 per cent of total NHS spending is targeted at prevention and this money does not have to be spent on reducing health inequalities. Both the universal aspects of policies and the increasing focus on those worse off are important. For example, social marketing campaigns are universal policies designed to improve health and change behaviours, but these are often poorly designed for reducing inequality [1]. Interventions are most effective if they help and support families in the early years [2].
- There has been a policy shift towards an 'Early Intervention' culture aimed at 0-3 years, as late intervention, when health, social and behavioural problems have become entrenched, is more costly and less effective [3].

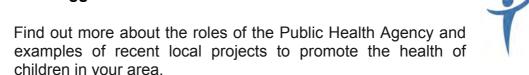


• Local health services should focus on antenatal education/preparation for parenthood and on social/emotional development for under-3s, but they also need to have a 0-18 approach, with remedial early intervention to break cycle of dysfunction from each generation [3].

References

- [1] The Marmot Review: Fair Society, Healthy Lives. Feb 2010
- [2] Field, F. The Foundation Years: preventing poor children becoming poor adults. The Report of the Independent Review of Poverty and Life Chances. Dec 2010.
- [3] Allen G. Early Intervention: The Next Steps. Jan 2011.

5.5. Suggested Activities



- Identify and work with your local immunisation lead/co-ordinator, attending local steering groups and participate in an immunisation initiatives
- Find out the local guidelines for neonatal BCG and Hep B vaccination

- Meet with your Trust Health Protection nurse/doctor to learn how they work
- Meet with your Trust Childhood Injury Prevention nurse/health visitor to learn how they work
- Provide and evaluate a session or talk to parents or non health staff about immunisation
- Observe a health visitor doing a child health surveillance visit
- Do an e-learning module on the Child Health Programme http://www.e-lfh.org.uk/projects/healthychild/index.html
- Find out about local initiatives to prevent childhood obesity
- Find out about how information is recorded on the Child Health System
- Read the Northern Ireland Children and Young People's plan at http://www.ofmdfmni.gov.uk/index/equality/children-young-people-strategy.htm
- Participate in service planning/development

6. <u>NEURODISABILITY</u>

6.1. Child Development

Much of the work in Community Child Health involves assessing children for possible developmental delay and disorders.

6.1.1. Influences on development

We are all well aware that it is not simply innate/genetic intelligence that is an important influence on a child's development. The environment in which they are living is of vital importance in determining a child's development and so it is essential to ask about family structure, housing, support for the parent(s) and parental wellbeing when assessing a child's development.

It is important to remember that children with disability may have development affected in areas other than those directly affected by the disability. For example, visually impaired children usually have delayed motor development and language development and children with language problems may have poor social development and difficulty learning to read.

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6.1.2. Typical Child Development

It is important to have an understanding of the typical pattern of child development in order to recognise the absence of typical development as well as atypical signs, and to know the significance of any delays.

Average developmental milestones

	Gross motor	Fine motor and vision	Hearing and language	Social
6 weeks	 Head level with body in ventral suspension 	• Fixes and follows	• Stills to sound	• Smiles
3 months	• Holds head at 90° in ventral suspension.	Holds object e.g. rattle placed in hand	• Turns to sound on level with ear	Laughs and squeals Hand regard
6 months	 No head lag Sits with support Up on forearms when placed prone 	 Reaches with Palmer grasp Transfers objects from hand to 	• Babbles	Works for toy May finger feed

	placed prone	hand to hand		
9 months	Crawls Sits steadily and pivots	 Pincer grasp Index finger approach Bangs 2 cubes 	 Can perform distraction hearing test (7-8 months). 2 syllable babble 	Waves bye byePlays pat a cakeIndicate wants
12 months	Pulls to standCruisesStands alone (briefly)Walks alone13 months	Puts block in cup Casting	One or two words	Imitates activitiesPlays ballObject permanence established
18 months	Walks well Runs	• Tower of 2- 4 cubes • Scribbles	• 6-12 words	Uses spoonHelps in houseSymbolic play
24 months	Kicks ballClimbs stairs2 feet per step	Tower of 6-7 cubesCircularscribble	 Joins 2 -3 words Knows 5-6 body parts Identifies 2 pictures 	• Removes a garment e.g. a sock
3 years	Throws overarmStands briefly on one footClimbs stairs1 foot per step	Tower of 9 cubesCopies a circleCuts with scissors	Talks in sentencesNames 4 pictures	Eats with fork and spoonPuts on clothingNames friend

Definitions of terms

Object permanence is the concept that things remain even though you cannot see them. When an object is dropped on the floor you look to see where it has gone. The first signs of it appear at 2-3 months of age when a child will briefly glance after an object that is removed from sight. The child then learns to search for a partially hidden object and by a year will search for an object that he has seen being completely covered by a cloth. It is an important concept to develop for emotional security and maturation, and also for language development.

Self-recognition is the ability of the child to see herself as a person, separate from others and to then develop self-evaluation. In the first 2 months of life

the baby probably sees herself as an integral part of her mother. By 8-12 months she will be aware of the effect she can have on other things (a subjective self). By 21-24 months this develops into a concept of an objective self as 'a girl', 'a child', recognising herself in the mirror or photograph, becoming proprietorial and wanting to do things 'for myself'. From 2 years the child will start to evaluate herself as a person, developing a sense of embarrassment, pride, shame.

Symbolic thought is the ability to recognise that something can stand for something else. For this, the child must be able to represent things internally when he can no longer see them. First evidence of this comes early in the second year of life with "deferred imitation" (imitating something seen previously). This leads on to symbolic play and then drawing. It is a vital precursor to language, since words are symbols for things.

Casting is throwing objects away as soon as they have been briefly inspected. Casting should have disappeared by 18 to 24 months.

Generalisation. Typically developing children can use previous experience to solve unfamiliar problems, such as recognising a cup as such even though it is a different colour and shape from their own. Children with learning disability often are unable to recognise an item such as hairbrush as such when presented to them in clinic even though they would recognise their own familiar hairbrush and be able to demonstrate its function at home.

Joint attention is when an infant shows enjoyment by sharing an object or event with another person by looking back and forth between the two. Later, gestures and speech are used to engage another's attention simply to share experiences. The earliest stage of joint attention is responsive smiling which occurs by 8 weeks. By 8 months, a baby follows another's gaze. By 10-12 months, they can follow a point and at 12-14 months they begin to point. This is firstly done to request or show and can be accompanied by simple vocalisations. From 14-16 months, a child will point to comment and share things of interest and will integrate this with looking and emerging words.

Important points:

- Always begin by asking parents what their worries, if any, are. It is useful
 to ask about how the child being assessed compares with sibs if there are
 any.
- Make allowances for prematurity.
- A history of loss of skills i.e. regression should always be specifically sought and implies a progressive underlying cause for developmental delay.
- Late walking is more common in babies who have bottom shuffled and can be familial.
- Children not walking at 18 months have a 1 in 5 chance of having a significant problem so need to be looked at carefully
- Delayed gross motor development, (sitting and walking) is the least significant pointer to a general delay, but can be the most obvious and most worrying for the parents.

- A child presenting with language delay may have general delay unrecognised by the parents
- A boy with language delay may have Duchene Muscular Dystrophy
- Attention should be paid to persistence of immature patterns of play and behaviour as well as to failure to progress at the normal rate. For example, persistent hand regard, mouthing and casting (beyond the age of 12 months), is an important warning signal.

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6.1.3. Practical aspects of developmental assessment

Introduce yourself and ascertain who is with the child. Check contact details and professionals involved e.g. health visitor, social worker. It may be appropriate with some older children for them to play outside the room while you talk to their parents so that their parents are able to talk more freely. Begin by establishing what the parent(s) think about **why** the child has come for assessment. Was it the parents who were concerned or someone else, e.g. the Health Visitor or someone from school?

Some useful general questions are

- How does the child compare with other children of the same age?
- How much do you think the child is behind other children in development?
- Do you think the child is getting further behind as he/she gets older?
- Is the child losing the ability to do things he/she could do before?
- Is this what the child is like at home?
- Have I seen a fair picture of what the child can do?
- What do you think is the child's biggest problem?
- If the child could tell us, what would he/she say the biggest problem is?
- Is the child able to concentrate when interested in something?
- How does the child spend his /her time at home?
- Does the child pretend or show any imagination?

Observe the child closely during the consultation and make notes about how they move, play, communicate and interact. Watch very closely what they are doing when they think you're not looking, have a box of toys available and encourage them to play with them while you are talking to their parent(s).

Although there is a wide range of equipment that can be used to assist in the assessment of a child's development a small collection of carefully chosen items allows you to perform a more than adequate developmental assessment in most children. A set of 1-inch cubes, pencil and paper and a simple form board is a good starting point. A simple reading book may also be useful. With this small collection of toys you can gain quite a lot of information about what a child's developmental age is.

After your assessment, if you think there is a problem with a child's development it may be appropriate for you to refer to other professionals,

such as SLT, OT or physiotherapy. Where there is complex or severe disability multidisciplinary assessment should always be performed.

Physical Examination

Physical examination is an important part of a developmental assessment as it may identify a medical cause for developmental delay or an associated medical condition that may be affecting the child's development. Some general pointers for examinations are listed below:

- talk to the child at a developmentally appropriate level and explain what you are going to do to reassure child and parent
- begin by taking note of their general appearance.
- plot growth on a chart (use appropriate charts e.g. Downs).
- are the body proportions normal?
- are they dysmorphic? Look specifically at the eyes, ears, mouth, hands, feet. Who does the child look like in the family? (This may be reassuring in that the appearance is simply a family trait or it may mean that other family members have the same disorder). Family photographs can be useful here
- children will need to be fully undressed for a complete examination to be carried out; you will need to be sensitive about this and it can sometimes be achieved more successfully if you do it a bit at a time
- look for neurocutaneous features. You should have access to a Wood's light to look for depigmented patches
- do they have skeletal deformity; spinal abnormality, including pits/birthmarks over the spine, abnormal chest shape, limb abnormalities
- note the size, shape and symmetry of their head (e.g. microcephaly) and plot size on a chart
- from here you move onto the more specific examination features.
- thorough general examination; heart, lungs, abdomen (e.g. visceromegaly for storage disorders)
- more specific neurological examination. Think about power, tone, coordination and reflexes as well as cranial nerves.
- *Reproduced with permission from Sheffield Diploma in Paediatric Neurodisability, 2008

Reading:

Sharma A. *Developmental Examination: birth to 5 years*. Arch Dis Educ Pract Ed 2011; 96: 162-175.

Davie M. *Developmental Examination in the over 5s*. Arch Dis Educ Pract Ed 2012; 97:2–8.

Sheridan M. From Birth to Five Years. 1997. Routledge, London.

6.2. Cerebral Palsy

Cerebral palsy can be defined as a disorder of movement and/or posture and motor function due to a non-progressive interference/lesion of the developing brain. Causes can be classified as:

Prenatal

- Genetic
- Infection (CMV, rubella, chorioamnionitis)
- Toxins (drugs)
- Trauma
- Nutritional ("placental insufficiency")

Perinatal

- Prematurity (IVH/PVL)
- Infection (meningitis)
- Toxins (hyperbilirubinaemia)
- Perinatal asyphxia

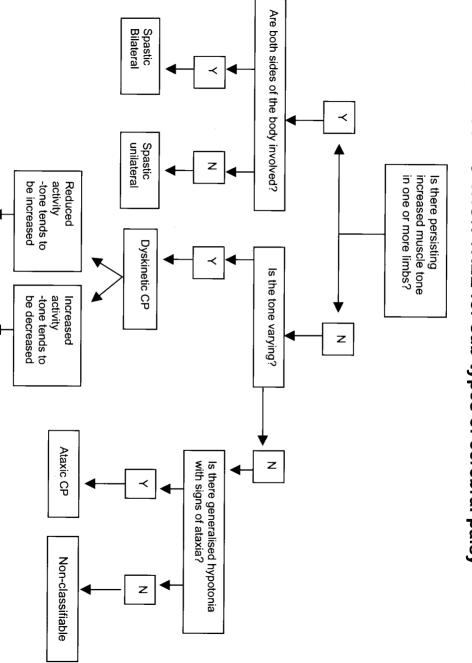
Postnatal

- Infection
- Vascular accidents
- Head injury
- Encephalopathy
- Anoxic event

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The Northern Ireland Cerebral Palsy Register (NICPR) is a confidential record of children and young people living with cerebral palsy within Northern Ireland. The prevalence of cerebral palsy in Northern Ireland is 2.2 per 1000 live births. Notification, assessment forms and an information leaflet for parents can be obtained from the NICPR website (http://www.qub.ac.uk/research-centres/nicpr/AboutUs/). The following classification tree is useful to describe cerebral palsy using the most recent terminology:

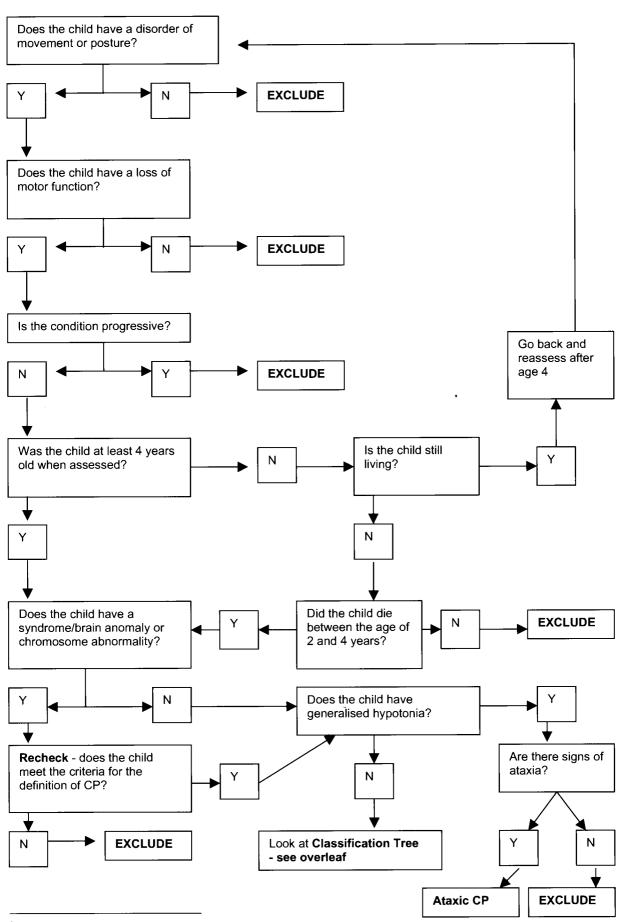
CLASSIFICATION TREE for sub-types of cerebral palsy



Dystonic CP

Choreo-Athetotic CP

DECISION TREE for identifying cerebral palsy¹



¹ SCPE Collaborative Group. Surveillance of cerebral palsy in Europe: A collaboration of cerebral palsy surveys and registers. *Dev Med Child Neuro*. 2000; 42:816-824

Definitions:

Tone – the resistance of a muscle to passive stretch

Spasticity – a velocity dependent increase in resistance to passive stretch. Usual associated features are clonus, increased deep tendon reflexes and extensor plantar responses. Increased tone is not necessarily constant.

Dyskinesia – varying tone e.g dystonia/choreoathetosis

Dystonia – abnormal sustained contractions of muscles resulting in unusual and abnormal posture, with reduced activity and increased tone, usually abolished in sleep

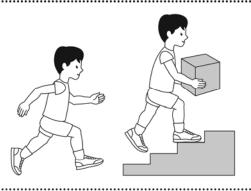
Choreoathetosis – jerky uncontrolled overshooting movements, some rotatory component, worse with stimulation and purposeful movement **Ataxia** – an abnormality in the smooth approach to an object with wide amplitude corrections during the movement. Gait is broad based and poorly coordinated.

6.2.1. The Gross Motor Function Classification System

This is a tool to describe the functional severity of cerebral palsy and is widely used in research. Children's functional level usually remains stable after 4 years of age. The full revised GMFCS for under 2 years to 18 years is available at http://www.canchild.ca/en/measures/gmfcs.asp

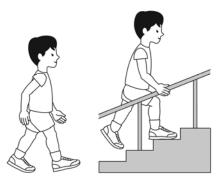
*reproduced with permission from Robert Palisano, Peter Rosenbaum, Doreen Bartlett, Michael Livingston, 2007 *CanChild* Centre for Childhood Disability Research, McMaster University.

GMFCS E & R Descriptors and Illustrations for Children between their 6th and 12th birthday



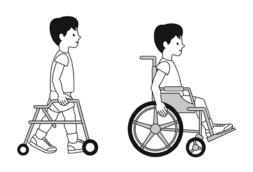
GMFCS Level I

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited



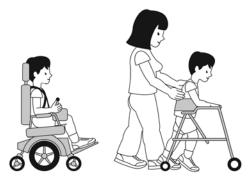
GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a handheld mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.



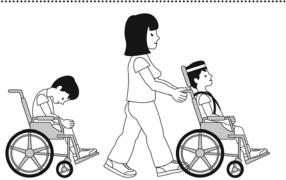
GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.



GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.



GMFCS Level V

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

6.2.2. Investigations

All children with cerebral palsy should have an MRI brain to investigate for an underlying cause and this will be abnormal in 90%. If the scan is normal the child could still have cerebral palsy but other diagnoses should be considered. Further investigations can be directed depending on the findings on MRI, e.g. investigations for neonatal stroke, genetics and congenital infection. When requesting an MRI, consider asking for imaging of the spine if the neurological findings are in the lower limbs and if there is any bladder/bowel dysfunction. Further investigations are important if there are no or few risk factors in the history to explain cerebral palsy or if there are unusual or unexpected associated features, e.g severe learning difficulties in hemiplegia. Any progression in symptoms should raise questions about the diagnosis and lead to investigations for other causes, e.g muscle disease, dystonia syndromes, metabolic disorders and tumours. All children should have assessments of their hearing and vision and professionals should be proactive in asking parents about seizures. A change in the child's functioning as they become older should also be investigated as it may be due to a general health problem, seizures, orthopaedic problem or a mental health issue.

6.2.3. Associated problems

Arising from the motor problems:

Feeding difficulties
Drooling and secretions
Chest infections
Bowel and bladder problems (incontinence, constipation)
Dislocated hips
Scoliosis
Osteopenia

Not directly arising but seen more frequently in children with cerebral palsy and may be related to underlying cause:

Visual impairment Hearing impairment Learning difficulties Dental problems Epilepsy

Psychological problems may be associated with any of the above.

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6.2.4. Management

The importance of how the diagnosis of cerebral palsy is shared with parents cannot be overemphasized. Good



practice is outlined in the 'Right from the Start' template published by SCOPE in 1997. Management is holistic and multidisciplinary, involving physiotherapy, occupational therapy and speech and language therapy. Equipment for positioning, mobility aids and orthotics are used. There are medical and surgical options for the management of spasticity and dystonia. Children may also require orthopaedic surgery for associated problems. Paediatricians are particularly involved in the management of feeding difficulties, nutrition, chest infections and epilepsy. They also may be involved in liaising with other professionals, with education services and in directing families to sources of support and information.

Reading

Scope. Right from the Start Template. 2003, available to download at http://www.scope.org.uk/help-and-information/publications/right-start-template Krigger K. Cerebral Palsy: An Overview. American Family Physician 2006; 73(1):91-100.

Lundy C. Treating complex movement disorders in children with cerebral palsy. Ulster Med J 2009;78(3):157-163.

6.3. Autistic Spectrum Disorders

6.3.1. ASD History

In the early 1940s both Leo Kanner and Hans Asperger, used these terms in their publications (independently of each other), describing children with the characteristics we recognise



today as being autistic; and hence the label autism was born. Kanner, an Austrian psychiatrist based in America, was the first to identify autism as a distinct neurological condition, in 1943, although he could not specify a cause. In 1944, Asperger, a Viennese paediatrician, published a doctoral thesis using the term autistic in his study of four boys. Kanner's description was of children with severe autism, with the conclusion that it was a disastrous condition to have. Asperger's description was of more able children, and he felt that there might be some positive features to autism which could lead to great achievements as an adult. For thirty years, Kanner's description became the most widely recognised. Lorna Wing first used the term Asperger's syndrome in a paper published in 1981. Unfortunately, Asperger died in 1980, and never knew that a few years later a condition named after him would become well known worldwide.

6.3.2. Prevalence

- 1990s 3-6 per 1000 children (Gilberg, Wing studies)
- 2006 1 in 100 (Baird et al. Lancet 368:210-5)
- 2011 minimum prevalence 1% of childhood population (NICE)

 Estimated 200 new cases in NI each year with 1/3 of referrals given a diagnosis (ASD strategic action plan consultation Northern Ireland)

Increasing prevalence?

- Variable diagnostic criteria
- Overlap with other related conditions such as ADHD, severe learning difficulties
- Increases in awareness of autism and other spectrum disorders
- Differences in methodology
- New causative factors and real increase in rates?

6.3.3. Causation

- Primary 95% (genetic predisposition but exact cause unknown)
- Secondary 5%
- Chromosomal disorders, genetic syndromes
- Neurological (Pre, peri and postnatal CNS insult or infection, structural brain abnormalities, severe epilepsy)
- Metabolic (PKU)
- Environmental factors (maternal Sodium Valproate, fetal alcohol syndrome)

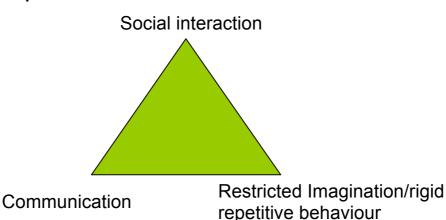
6.3.4. What is ASD?

A pervasive developmental disorder defined by the presence of abnormal and/or impaired development that is manifest before the age of 3 years, and by the characteristic type of abnormal functioning in all



three areas of social interaction, communication, and restricted, repetitive behaviour.

Triad of Impairments



Usually there is no prior period of unequivocally normal development but, if there is, abnormalities become apparent before the age of 3 years. There are always qualitative impairments in reciprocal social interaction. These take the form of an inadequate appreciation of socio-emotional cues, as shown by a lack of responses to other people's emotions and/or a lack of modulation of behaviour according to social context; poor use of social signals and a weak integration of social, emotional, and communicative behaviours; and, especially, a lack of socio-emotional reciprocity. Similarly, qualitative impairments in communications are universal. These take the form of a lack of social usage of whatever language skills are present; impairment in makebelieve and social imitative play; poor synchrony and lack of reciprocity in conversational interchange; poor flexibility in language expression and a relative lack of creativity and fantasy in thought processes; lack of emotional response to other people's verbal and nonverbal overtures; impaired use of variations in cadence or emphasis to reflect communicative modulation; and a similar lack of accompanying gesture to provide emphasis or aid meaning in spoken communication.

The condition is also characterised by restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities. These take the form of a tendency to impose rigidity and routine on a wide range of aspects of day-to day functioning; this usually applies to novel activities as well as to familiar habits and play patterns. In early childhood particularly, there may be specific attachment to unusual, typically non-soft objects. The children may insist on the performance of particular routines in rituals of a nonfunctional character; there may be stereotyped preoccupations with interests such as dates, routes or timetables; often there are motor stereotypies; a specific interest in nonfunctional elements of objects (such as their smell or feel) is common; and there may be a resistance to changes in routine or in details of the personal environment (such as the movement of ornaments or furniture in the family home).

In addition to these specific diagnostic features, it is frequent for children with autism to show a range of other nonspecific problems such as fear/phobias, sleeping and eating disturbances, temper tantrums, and aggression. Selfinjury (e.g. by wrist-biting) is fairly common, especially when there is associated severe learning difficulties. Most individuals with autism lack spontaneity, initiative, and creativity in the organisation of their leisure time and have difficulty applying conceptualisations in decision-making in work (even when the tasks themselves are well within their capacity). The specific manifestation of deficits characteristic of autism change as the children grow older, but the deficits continue into and through adult life with a broadly similar pattern of problems in socialisation, communication, and interest patterns. Developmental abnormalities must have been present in the first 3 years for the diagnosis to be made, but the syndrome can be diagnosed in all age groups. All levels of IQ can occur in association with autism, but there are significant learning difficulties in some three-quarters of cases.

*Reproduced from National Autistic Society 'What is autism?'

6.3.5. Early warning signs

Preschool

- Delay or absence spoken language
- Impairment in non-verbal communication
- Lack of initiation of interaction
- Looks through people not aware of others
- Not responsive to other's feelings/facial expressions
- Does not show interest in peers
- Lack of imaginative play
- Lack of turn taking
- Routines, rituals rigid, repetitive eg strong attachment to objects
- Mannerisms
- Unusual sensory responses

School age

Communication impairments

- Abnormal language development
- Unusual intonation, pedantic unusual vocabulary, mixing up he/she, referring to self as 'you', echolalia, jargon
- Cannot make inferences, literal interpretations
- Limited use of language for communication, only specific topics, impairment of social rules in communication eg turn taking, making inferences

Social impairments

- Can present as behaviour difficulties, hyperactive etc
- More obvious with peers than parents, quality of friendships
- Inability to join in or inappropriate attempts to join in with peers eg aggressive, disruptive
- Lack of awareness of 'classroom norms'
- Easily overwhelmed by social situations/stimulation
- Difficulty transitioning
- Fails to relate normally to adults too intense/no response

Imagination impairments

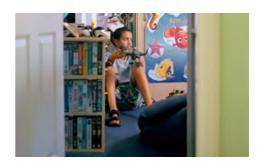
- Lack of flexible cooperative imaginative play and creativity
- Difficulty with unstructured situations and cannot cope with change
- Routines, rituals, mannerisms, restricted diet, sensory issues
- Development of interests -

Stage 1 Parts of objects

Stage 2 Category of objects (typical and eccentric), may pretend to be the object. Often transport, animals and electronics

Stage 3 Complex or abstract interests such as periods of history, geography





Stage 4 Interest in a person, fantasy literature and may have multiple interests

*adapted from http://www.sign.ac.uk/pdf/sign98.pdf pg 10 and 11, see also NICE 2011 Guideline pg 45 -50.

6.3.6. Co-morbidities

- Learning Disability
- Sleep disorders
- Anxiety
- Affective disorders depression/bipolar
- ADHD
- Self-injurious behaviour
- Schizophrenia
- Anti-social behaviour
- Obsessive Compulsive Disorder

6.3.7. Diagnosis

- ICD 10 criteria, DSM-IV criteria
- Co-morbid diagnoses
- Individual profiling strengths, weaknesses
- Standard tools ADI-R, ADOS
- Multidisciplinary, multiagency, multisite assessment
- Possible IQ testing

6.3.8. Management

- Making diagnosis first step
- Information
- Intervention- family support, medical, developmental, psychological, social, education

Functional behaviour analysis

- Indicating need for help/attention
- Escaping from stressful situation or activity
- Obtaining a desired object
- Protesting against unwanted events or activities
- Obtaining stimulation

Improving communication

- Important to pitch level of program to child's cognitive and linguistic developmental level.
- Ensure words and concepts relevant to child
- Examples of interventions PECS, TEACCH
- Improve others' communication ie reduce use of metaphors, sarcasm, irony, slang etc





Social skills training

- Social stories, visual schedules
- Support from teachers, pupils, befriending schemes
- Obsessions gradual change unless dangerous, clear rules, environmental modification

Sensory integration programme – OT

6.3.9. Voluntary Organisations

- National Autistic Society
- Autism NI (PAPA)





6.3.10. Guidelines

- SIGN. Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders, July 2007. http://www.sign.ac.uk/pdf/sign98.pdf
- Regional Autistic Spectrum Disorder Network for Northern Ireland (RASDN). Six Steps of Autism Care. Health and Social Care Board, October 2011.
- DHSSPS. Autism spectrum disorder (ASD) Strategic Action Plan 2008/09 – 2010/11. Northern Ireland Department of Health, Social Services and Public Safety, 2009. http://www.dhsspsni.gov.uk/asd-strategic-action-plan.pdf
- NICE. Autism in children and young people 2011 (CG128) http://guidance.nice.org.uk

6.4. Learning disability

ICD-10 defines learning disability as "a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period contributing to the overall level of intelligence i.e. cognitive, motor and social abilities."

ICD-10 categorises it as mild (IQ 50-69), moderate (IQ35-49), severe (IQ 20-34) and profound (IQ <20). In practice in the UK, people often use: Mild/moderate (IQ 50<70) and Severe (IQ <50). The prevalence in developed countries of SLD is 3.8/1000 and MLD 5/1000.

The children with learning disability who present to paediatrics usually have global developmental delay. Features on history and examination may suggest an underlying cause, e.g.

Genetic abnormalities: Family history, dysmorphism, malformations **Metabolic defect**: failure to thrive, hypotonia, consanguinuity, recurrent unexplained illness (especially anorexia and vomiting), loss of skills, coarse

facies, ocular abnormalities, macro or microcephaly, family history of unexplained illness or death

Brain malformation: abnormal skull, focal deficit, loss of skills, micro or macrocephaly, seizures, visual abnormality.

If there is progressive loss of skills it is important to consider: hydrocephalus, poorly controlled epilepsy, a metabolic disorder/neurodegenerative disorder, Rett's disease, infection or a vascular problem. True regression can be hard to ascertain, because development is taking place at the same time. All children and particularly those with a learning disability will sometimes learn something new and then appear to forget it for a while.

Management involves input from therapists to promote the child's development and medical management of any associated health problems. It is important to direct parents to sources of support and to give advice about areas such as behaviour, toileting and sleep. There may be local support groups (e.g. Mencap) or a National Society if a specific diagnosis has been made. Education clearly has a major role where there are learning difficulties. It is important that the Education Department is notified about the child as soon as it is clear that there will be learning difficulties when the child starts school.

*Reproduced with permission from Sheffield Diploma in Paediatric Neurodisability, 2008

Reading:

McDonald L et al. Investigation of global developmental delay. *Arch Dis Child* 2006; **91**:701-705 http://adc.bmj.com/cgi/content/full/91/8/701#T2.

6.5. Down's syndrome

The prevalence of Down's syndrome in Northern Ireland has been estimated as 1 in 575 live births [1]. This is higher than the UK prevalence of 1 in 1000 live births [2]. Down's syndrome is



the most common autosomal trisomy and the most common cause of severe learning difficulties. Certain health problems are more common in Down's syndrome and guidelines for medical surveillance have been produced by the Down's Syndrome Medical Interest Group. Further useful information is on their website http://www.dsmig.org.uk/. Children should have their growth plotted on Down's syndrome specific growth charts. The Down's Syndrome Association has local support groups for parents http://www.downs-syndrome.org.uk/.

References

[1] L Devlin, P J Morrison. Mosaic Down's syndrome prevalence in a complete population study. Arch Dis Child 2004;89:1177-1178
[2] Morris J. The National Down Syndrome Cytogenetic Register for England and Wales: 2010 Annual Report, Dec 2011.

DOWN SYNDROME - SUGGESTED SCHEDULE OF HEALTH CHECKS

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

	Rirth - 6 weeks	Special checks	Preschool chacks	School age
		under 2 years		
Thyroid blood tests	Newborn routine heel prick - blood spot	From age 1 year thyroid fun of either	From age 1 year thyroid function should be discussed annually using results of either	nually using results
	test '	 Annual fingerprick TSH test OR 	t OR	
		 2 yearly thyroid blood tests 	2 yearly thyroid blood tests, including thyroid antibodies	
Eye checks	Newborn routine check	Age 18-24 months:	Age 4 years:	Repeat vision test every
,	including congenital	Formal eye and vision	Formal eye and vision	2 years, or more
	cataract check	examination including	examination including	frequently if
		check for squint, and	check for squint.	recommended by
		refraction for long or	Refraction and	optometrist or
		or short sight	assessment of near and	ophthalmologist
			acuity	
	Visual behaviour to be monitor	Visual behaviour to be monitored at every review particularly in first year	rly in first year	
Hearing	Universal newborn	Full audiological review	Annual audiological	2 yearly audiological
checks	hearing screen	by 10 months including hearing test and impedance check	review as before	review or more frequently if recommended
Growth monitoring	Length, weight and head circumference should be checked frequently and plotted on Down syndrome	umference should be ed on Down syndrome	Height and weight should be checked and plotted on Down syndrome growth charts at least annually	checked and plotted harts at least annually
	growth charts		while growing. (BMI checked if concern regarding overweight)	rding overweight)
Heart checks	By age 6 weeks, formal heart assessment including	At all ages low threshold for reviewing heart status if signs or symptoms develop	r reviewing heart status if	From adolescence onwards as part of routine
	Echocardiogram	-		health checks listen to heart for signs of acquired heart disease
Breathing checks	Enquire at every review for uneven breathing during the Low threshold for further testing using sleep studies	Enquire at every review for uneven breathing during sleep and poor quality sleep. Low threshold for further testing using sleep studies	p and poor quality sleep.	
Blood checks	Newborn blood test to check for abnormal blood	If blood film is abnormal in first 6 weeks, follow up or repeat blood testing may be necessary until age 5	rst 6 weeks, follow up or necessary until age 5	

Detailed recommendations for Medical Surveillance Essentials for children with Down syndrome can be found at www.dsmig.org.uk

6.6. Developmental Coordination Disorder

This can be considered in the group of developmental disorders known as specific learning difficulties (e.g dyslexia) where the child has significantly more difficulty than their peers in one area and this is not due to general learning difficulties. The difficulties need to significantly interfere with daily activities or academic progress for a diagnosis to be given. DCD may be diagnosed in a child with learning difficulties if their motor impairment is out of keeping with their general ability. DCD can present in a variety of ways depending on the age of the child, though most children do not present until school age. There is a mixture of gross and fine motor problems. Some children will present with associated problems, such as language disorder or reading and writing difficulties. Others present with secondary problems. These are some of the commonest ways of presenting:

Gross motor problems

Awkward gait, ungainly running
Falling a lot
Bumping into things
Poor balance
Poor balancing on one leg, inability to hop
Slow (or failure) learning to ride a bike
Difficulty learning to swim
Poor at catching, throwing, batting a ball



Fine motor problems

Difficulty dressing (clothes on the wrong way round, wrong order, difficulty with buttons and zips)

Feeding messy; difficulty using a knife and fork Poor at building with bricks, jigsaws, drawing Poor pencil control for writing Difficulty using scissors, rulers

Secondary problems

Behaviour problems Poor self esteem School failure

When a child first presents at the clinic a general paediatric and neurological assessment will be needed, particularly to exclude other causes of the problem. Assessments specifically for DCD will be best carried out by the OT but it is useful for the paediatrician to be able to carry out some initial screening. Note how the child undresses/dresses; watch writing/drawing, threading beads, winding a bobbin and cutting out; heel-toe walking, hopping, standing on one leg, hand tapping, diadochokinesis and standing with arms extended. Look for persistence of movement e.g. sticking the tongue, can the child leave it there. Look for associated movements when walking on the lateral sides of the feet (Fog test). The Movement Assessment Battery for Children (Movement ABC) is probably the test most commonly used.

Management involves explanation of the condition to the child, parents and teacher. Specific advice can be given to help tasks such as writing and dressing. It is important to help the child's self esteem. Specific treatment approaches used by OT and physiotherapy include the sensory integration and perceptual motor approach.

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6.7. Communication Disorders

It is important when thinking about communication disorders that we understand the different skills necessary for communication:

- Listening and attention
- Symbolic understanding
- Comprehension
- Expressive speech
- Phonology
- Oromotor skills
- Grammar/syntax
- Semantics
- Pragmatics
- Non-verbal communication



Different communication disorders can be thought of under the following presentations:

Disorders affecting speech production

Neurological problems such as cerebral palsy, structural problems such as cleft lip and palate, dysfluency (stammering), elective (or selective) mutism.

Specific language impairments

This term is used for children who have isolated language impairment and encompasses delayed and disordered language development. However studies show that children with "specific" language impairment have a high incidence of other neurodevelopmental disorders. Prevalence is about 5-7% and children with severe persisting difficulties probably comprise about 1%. Although management is predominantly by SLT, paediatricians have a role in identifying and addressing any possible causes of the problem (e.g. hearing loss, submucous cleft, ASD) and any associated difficulties. Secondary problems can include behaviour and literacy difficulties.

Types of language impairments:

- expressive language delay
- phonological-syntactic difficulties difficulty producing sounds accurately and to learn grammatical constructions
- articulatory dyspraxia this may be associated with feeding difficulties
- word finding difficulties
- semantic-pragmatic difficulties social use of language

- comprehension difficulties this is likely to be linked with an expressive difficulty
- auditory processing disorder.

Children who stop talking

- Usually associated with loss of other skills such in degenerative disorders
- Psychosocial social disorders have to be considered
- Acquired receptive aphasia (Landau-Kleffner syndrome)

Impaired language and social interaction

Autistic Spectrum Disorders

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Reading:



Public Health Agency. Healthy Child healthy future: Speech and Language therapy for children. Jan 2011 (gives developmental stages and referral quidelines and useful leaflets for parents)

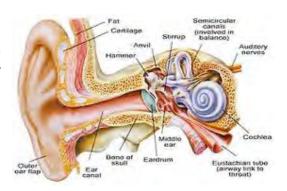
http://www.publichealth.hscni.net/publications/healthy-child-healthy-future-speech-and-language-therapy-children

6.8. Sensory Impairment

Community paediatricians may see children who have sensory impairment because of associated developmental problems, e.g. a significant proportion (perhaps 30%) of children with deafness have other disabilities such as visual disability, impairment, cerebral palsy. Community paediatricians may have a role in identifying a possible underlying cause. Some are directly involved in audiology clinics. Sometimes sensory impairment may not be detected until the child presents with a secondary problem and so vision and hearing should be considered in all children with developmental problems or disability. Community paediatricians may also be asked to provide medical advice to education for a child with sensory impairment.

6.8.1. Hearing impairment

In conductive hearing loss the conduction of sound through the outer or middle ear is impaired. This can be caused by atresia of the external canal in isolation, but this is often associated with abnormality of the pinna e.g. Goldenhar syndrome, or the middle ear e.g. Treacher Collins. Otitis media



with effusion (fluid in the middle ear cavity) is an important cause of middle

ear deafness or, much more rarely, a congenital abnormality of the ossicles such as fused malleus and incus, stapes fixation. Otosclerosis is a cause of progressive conductive loss but rarely occurs in childhood. In sensorineural deafness the outer or middle ear may be functioning normally, but there is a defect in either the cochlea, auditory nerve or auditory cortex. There are many genetic disorders that affect different parts of the cochlea. Congenital infections, measles and mumps, ototoxic drugs also affect the cochlea. Meningitis affects the cochlea and possibly the VIIIth nerve. Severe perinatal anoxia and prematurity may cause cochlea damage, nerve damage or central deafness (at the cochlear nuclei), but this is unlikely in the absence of other neurological impairments. Trauma may damage the cochlea or nerve. Hyperbilirubinaemia damages the cochlear nuclei. Deafness attributable to an abnormality of the auditory cortex is very rare.

6.8.2. Hearing assessment

Relevant questions include:

How does your child react to sounds at home?

Is there a family history of deafness since birth (or early in life)?

Are the child's parents related to each other?

Were there any problems during your pregnancy or soon after your child's birth?

What sort of speech sounds is your child making?

Do they enjoy the sound of their own voice?

On examination, look for:

level of development, attention span, communication; the ears for any signs of congenital abnormality; signs of glue ear; dysmorphism suggesting a syndrome (abnormal skull, iris colour, hair colour, other dysmorphic features) and other disabilities.

AGE OF CHILD (developmental age)	Preferred test(s)
0 - 3 months	TEAOE, ERA
3 - 6 months	TEOAE, ERA, modified
	distraction test
6 - 18 months	Distraction test, ERA
12 - 30 months	VRA, ERA
24 - 36 months	Cooperative test (e.g. few toys
	Toy Test, performance test), ERA
36 months +	Performance test, Word
	discrimination test (Toy Test or
	pre-recorded Toy Test), pure
	tone audiometry with unmasked
	bone conduction, ERA
48 months +	Pure tone audiometry with bone
	conduction and masking where
	necessary, word discrimination
	test, speech in noise testing

TEOAE – Transient Evoked Otoacoustic Emissions.

ERA – Electrical Response Audiometry (sometimes known as Brain Stem Evoked Responses)

VRA – Visual Reinforcement Audiometry

If you are able to visit a specialist audiology clinic you may be able to meet some of the team who are involved with children who have severe hearing impairment. This team may include a Consultant in audiological medicine/ENT surgeon, audiologist, hearing aid technician, specialist speech therapist, specialist teacher for the deaf, educational audiologist and specialist social worker.

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6.8.3. Visual Impairment

By 29 weeks of gestation the pupil responds to light. Between 26 and 30 weeks of gestation babies will react with dislike to a bright light. The foveal area of the retina is immature at birth and reaches mature levels



at about 4 years of age. Myelination of the optic nerve continues after birth up to about 2 years. By 2 weeks a baby will show a preference for looking at mothers face even without any other sensory clues. Young babies will respond to bright colours and will differentiate colour. Babies will follow with their eyes at birth and by 3 months will follow 180°. The ability to accommodate increases over the first 2 months; infants are naturally hypermetropic and overcome this by accommodation. Eye movements are poorly coordinated at birth. Binocular vision develops by about 4-6 months; if not developed by this age it may fail to develop. Development of vision is closely related to the rest of development, particularly fine motor development e.g. reaching for objects requires not only a certain degree of acuity but also depth perception.

It is not possible to test visual acuity with precision in babies but there are techniques that will give approximations to standard testing techniques. Objective testing of visual acuity by visual evoked potentials reaches adult values by 6-8 months but on functional testing (preferential looking) adult equivalents are reached by approximately 3 years. There may continue to be some plasticity of vision up to 10 years.

Refractive errors, strabismus and amblyopia are the commonest visual problems in children. Refractive errors are seen in 10% throughout childhood and strabismus and amblyopia in 4% and 3-5% respectively. They are even commoner in children with other disabilities, occurring in up to 50%. Medical definitions of visual impairment are usually used within



the framework of "best corrected visual acuity" so most children with refractive errors are not classified as visually impaired. There are about 2000 children in

the UK who are registered blind and 2,500 partially sighted, but it is known that registration is incomplete. An "educationally blind" child will need to use non-sighted methods including Braille as an education method. Partially sighted children will have significant residual vision and will use print, low vision aids and also often a mixture of Braille and print.

6.8.4. Causes of visual impairment

Group 1—obvious	Group 2—mass	Group 3—eyes look
external abnormality	behind the lens	normal but visual
of the eyes		behaviour is abnormal
Cataract	Retrolental fibroplasia	Refractive error
Corneal opacity	Retinoblastoma	Retinal degenerations
Microphthalmos	Norrie's disease	Optic atrophy
Cryptophthalmos	Toxocara	Optic nerve hypoplasia
Glaucoma		Coloboma
Anterior chamber		Congenital infections
cleavage syndrome		Cortical blindness
Albinism		Delayed visual
Nystagmus		maturation
Oculomotor apraxia		
Aniridia		

6.8.5. Visual assessment

Relevant questions include:

Do you think she sees normally? Why/why not?

Does she look at your face?

Does she watch as you walk away?

What sort of things can she see?

Recognising faces (not voices)

Does she look at toys/pictures?

Does she hold objects close to her eyes?

Does she feel for objects?

Have you seen either eye turning in or out?

Is there a family history of eye problems?

Are there other disabilities?

On examination, look for:

Eyes: size (microphthalmos, macrophthalmos), iris coloboma, any other anatomical abnormality of the eye or lids

Abnormal eye movements (Roving nystagmus, jerking)

Corneal reflections in all positions of gaze and cover test

Look for head tilt/abnormal gaze, which can be due to field defects or squint.

Look for screwing up of the eyes due to photophobia

Assess visual fields and ophthalmoscopy.

6.8.6. Functional visual assessment

These behaviours all depend on developmental age:

• Observe if the child gazes at light or the window (usually children with

- very low vision, except in early infancy—when this is commonly seen)
- Observe the child's response to sound and if they localise the sound, which is often impaired with severely visually impaired children
- Observe eye poking or rubbing, which occurs in severely visually impaired children, usually with retinal disorders; as it produces stimulation of the retina (self stimulation).
- In an older child observe if the child brings his head down close to a book or a table of if he brings an object close to his eyes
- Observe whether a child uses a tactile or visual search for lost objects or to explore toys
- Observe the child's mobility, particularly in an unfamiliar environment, particularly changes of surfaces where there is change in depth, steps, doorway etc
- What objects can a child identify near or in the distance
- Use books to observe the way the child looks at a picture do they hold books up close. What type of pictures can child identify near and in the distance.

Tests of visual function include preferential looking, Logmar chart, visual evoked responses and electroretinogram.

The team involved in the management of children with severe visual impairment includes a teacher for the visually impaired, ophthalmologist, Community Paediatrician and therapists, orthoptist, optometrist, educational Psychologist and specialist social worker.

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Reading:



Sonksen P and Stiff B. **Show me what my friends can see: a developmental guide for parents of babies**, London, Dept Neurology and Developmental Paediatrics, Wolfson Centre, 1991. A booklet for parents of a child newly diagnosed as being visually impaired. Can be downloaded from http://www.gosh.nhs.uk/EasySiteWeb/GatewayLink.aspx?alld=81645

6.9. The School Health Service

The School Health Service has overall responsibility for the health of all school children, which it fulfills by the surveillance and immunisation programme. The service aims to identify children with special educational needs as early as possible and refer them to the Education and Library Boards. It also has a specific responsibility for children with special needs in school, especially if these



are caused or affected by their medical condition. For these children the school health service should ensure proper management of the condition so

far as it directly influences the child's learning and/or social development. It should also ensure that parents, and with their consent teachers, are aware of the presence of such disorders and of their significance for the child's education. The following resources provide useful guidance in this area:

- DENI. Supporting pupils with medication needs, Feb 2008.
- http://www.deni.gov.uk/support with medical needs.pdf
- Northern Ireland Assembly. Research and Information Service briefing note. Administration of medication to pupils, July 2011
- http://www.niassembly.gov.uk/Documents/RalSe/Publications/2011/Education/8711.pdf
- DHSSPS/DENI. Guidelines for management of anaphylaxis in educational establishments.
- http://www.dhsspsni.gov.uk/anaphylaxis_doc-2.pdf

The School Health Service should also advise the Education Board about any special medical needs a child with special educational needs might have. This is done by way of the Statementing Procedure. The Education Board reviews any child who has a Statement of Special Educational Need annually and the School Doctor may be asked for advice. At 14 years the Statementing assessment procedure is redone and the School will require a medical. At this medical assessment the doctor should, in consultation with the parent and if appropriate the child, decide if the child should be considered disabled and referred to Social Services for assessment when they leave school, under the Disabled Persons Act. This assessment should form part of the transition plan for the young person. The School Health Service works closely with other agencies within Health & Social Services and outside of it.

6.9.1. Special Educational Needs

Code of Practice (on the identification and assessment of special educational needs)

Stage 1: Teacher completes a Record of Concern. Support by the class teacher.

Stage 2: SENCO and class teacher draw up an Individual Education Plan:

- Sets targets to be achieved and a date for a review to check progress
- Usually involves support given by special needs teachers within school.

Stage 3: Outside advice / support is requested e.g. specialist teaching, educational psychology.

Stage 4: Statutory Assessment Procedure underway.

Stage 5: Statutory Assessment has been completed and Statement of Special Educational Needs has been produced.

6.9.2. Statutory Assessment Procedure

- 1. Education and Library Board has to be requested to consider initiating Statutory Assessment.
- 2. Education and Library Board will write to parent to confirm agreement that it is undertaken.

- 3. Education and Library Board will request Advice:
- Parental
- Educational
- Psychological
- Medical
- (Social Services)
- 4. Assessment takes place and Advice submitted.
- 5. Draft Statement sent to parents for approval:
- Details the learning difficulties and disabilities as identified during the assessment.
- Describes the special help the child should get to meet the needs as identified.
- Describes any non-educational needs the child has (such as transport to school).

Parents are given 15 days for consideration and to name school.

- 6. Final Statement includes the name of the school and all advices submitted are attached to it. Whole process should take no longer than 18 weeks.
- 7. Annual Review of Statement 14+ Review.

Education support for Northern Ireland has useful advice and resources and covers all five boards http://www.education-support.org.uk/parents/special-education/

6.10. Suggested activities

- Attend a multidisciplinary feeding clinic/feeding assessment for children with feeding issues to understand role of SALT, dietician and medical investigation
- Attend with an occupational therapist for a seating assessment
- Attend the ASD diagnostic clinic to observe an assessment
- Observe a Griffith's assessment
- Find out about local support groups for children with neurodisability, e.g. ASD, Down's syndrome
- Visit a local special school
- Ascertain what local mental health services are available for children with learning disabilities and attend a specialist clinic or team meeting.
- Attend a neonatal follow up clinic
- Attend a genetics clinic either at a tertiary centre or outreach clinics in peripheral centres
- Attend a Specialist Neurology clinic e.g. Epilepsy, Spina Bifida, Neuromuscular or Spasticity clinic, Neuroradiology meeting.
- · Attend an orthopaedic clinic and find out about orthotics
- Meet with an educational psychologist to find out about their role and observe an assessment
- Write Medical Advice for a Statement of Educational Needs
- Gain a deeper understanding of the management of medical conditions in school e.g. by conducting an audit of medicines management, providing clinical advice for relevant guidelines e.g. anaphylaxis.

- Understand the role of different hearing and vision tests, including the ages at which there might be used
- Meet a Peripetetic Teacher for Hearing and Visual Impairment
- Link with a paediatric ophthalmologist to observe some clinics for disabled children including orthoptic clinics and Low Vision Aids Clinic
- Attend an audiology clinic
- Visit a special school or unit for children with sensory impairment to understand what services they provide.

7. BEHAVIOURAL PAEDIATRICS

7.1. Common behaviour problems in children

Up to 28% of problems seen in a general paediatric outpatient clinic area are due to emotional and behavioural difficulties. Most of children's behaviour is learned and the behaviour depends on culture. Assessment of behaviour problems must answer the question "Is the behaviour appropriate for children of this **age** and this **family**?"

Use the ABC to define the problem:

Antecedents- what leads up to the problem Behaviour- what actually happens Consequences- what happens then (secondary gains?).

Behaviour patterns may take time to change, which is not surprising considering that the behaviour may have taken months to develop.

Discipline

At 18 months, the child begins to experience discipline when he/she is faced with growing numbers of rules, regulations, and expectations within the family. Positive reinforcement is generally much more effective than negative reinforcement in modifying behaviour.

Guidelines for disciplining children

12-30 months- techniques that are direct, clear and immediate, and that produce a moderate amount of anxiety without unduly frightening or angering the child.

20-24 months on- clear and simple explanations of the reasons for punishment should be given, without elaboration.

Older children- techniques that diminish anxiety and emphasise the verbal control of behaviour through attention to general rules, appeals to reason and common sense, and other cognitively oriented techniques.

Incentive schemes

Most commonly used is STAR CHART

To be effective:

- establish exactly with parent and child what has to be done to gain a star
- agree how stars and chart are going to be kept
- clarify whether stars can be cashed in for tangible rewards
- look at ways scheme could go wrong and make a contingency plan
- specify how programme should be reviewed
- agree what constitutes ultimate success it need not be cure.

Time out (from Positive Social Reinforcement)



- is a form of ignoring
- only works for behaviour problems which are maintained by attention
- in conjunction, need more attention for desired behaviour
- ignore or remove the child for bad behaviour
- use 1-2-3- rule:
- 1. child told to stop bad behaviour
- 2. if doesn't stop, child warned he/she will have to go to time out
- 3. continued misbehaviour, child put to time out.
- put child in boring, safe room, eg. hall, for 1 minute/year of age
- behaviour may get worse before it gets better, therefore persevere
- apology not required once out of time out
- do not release child at height of tantrum.

Attachment

Normal children show separation anxiety at the age of 7-9 months, i.e. important step in evolution of attachment behaviour, and means that child has begun to recognise their separateness from and dependence upon the carer. After a few months they will have a better understanding of their permanence, and separation anxiety will disappear.

Masturbation

- 1/3 of mother of 1 year old children have reported some form of genital manipulation
- between 2-5 years of age, 1/2 of boys and 1/3 of girls are observed to be involved in some sort of genital handling
- Parents should ignore the behaviour, rather than punishing it.

Exhibitionism

Exhibitionistic and voyeuristic activities (including undressing games, such as 'doctors and nurses') are common among pre-school children. By 5-7 years, children develop an increasing sense of modesty.

Toilet training

It is neither uncommon nor harmful for toilet training to be achieved as late as the 3rd year. Nightime bladder control is attained by 90% of 5 year olds and 95% of 10 year olds. Up to 1% of adults continue to wet the bed. Soiling:

Take history- never toilet trained, constipation with overflow, severe psychological disturbance, developmental delay? Examine

Treatment- explanation / demystification, disimpaction, maintenance - laxatives/diet/star chart (reward defecation in the toilet not clean pants), may need admission for disimpaction/retraining? refer to child psychiatry.

Negativism

Between 2 and 4 years, some degree of negativism (refusal to sleep, eat or conform) is a normal part of the development of the child's individual personality.

Sleep problems

10-20% of pre-school children have sleep problems of one kind or another.

Difficulty settling:

Take a good history- if necessary keep a diary of sleep patterns

Treatment- set a bedtime, establish bedtime routine (warning that bedtime approaching, bath, pyjamas, story etc)

Graded stages of change to desired pattern will work better than sudden change - e.g. if the child gets up, put back to bed, go and check in 5 mins, and continue until child asleep. Gradually, increase time. Parents should be warned that the behaviour may initially get worse.

Sedatives- in a desperate situation they are sometimes employed, but should only be used short term (e.g. 1 week Vallergan) and for no longer than 2 weeks.

Waking at night:

Most children wake during the night, often more than once, but it becomes a problem for only a few families

Take a history

Treatment- again try a graded approach e.g. settle child in his/her own bed, return in 5 minutes to check, continue till child is asleep, than gradually increase times. If child has difficulty settling as well as waking during the night, deal with the settling problem first.

Eating problems

Take a history - what is the main concern - nutrition or discipline? What happens at a typical meal - if necessary keep a diary Plot growth on a chart and reassure parent Give guidelines for setting scene for desired mealtimes:

- no eating between meals
- no fuss over the meal even if child doesn't eat
- set time for meal to continue before food removed
- routine mealtimes e.g. sitting down with rest of family
- avoid too many drinks before and during meal.

About the ages of 2-3 years, children begin to develop a need for some autonomy, a sense of wanting and being able to do things their own way. They do not, however, have the full range of motor and social skills to be successful. Frustration and much anger may result. Common manifestations of anger are crying and screaming, breath-holding spells, temper tantrums, and physical aggression against objects or people.

Breath holding

Fairly common in first 2 years of life (up to 5% of all children). Crying stops and then about 5 seconds later child goes blue and may lose consciousness for a few seconds - such children have no increased risk of seizure disorders later on. The condition is benign.

Temper tantrums

Common - peak age around 2.5 years. A distinction is to be made between temper outbursts and full-blown temper tantrums. In the former, the child is angry, but still has some control over dealings and can at times respond to a calm approach on the part of the parents who accept the anger. When the stage of temper tantrum is reached, the



child no longer has either control or an observing ego, except that he/she remains aware that the frustrating parent is still in scope. In this latter case, no form of verbalisation will control the child's behaviour. It is then important for the parent to separate physically from the child. Parents can sometimes divert their children to other activities before they reach the point of loss of control, or help them to isolate themselves voluntarily until they feel better. It is important not to demean the child or make fun of his/her angry state. Children need to know that angry feelings are normal, but that control of excessive anger is an important, part of growing up and being mature. Tantrums in public places can be very embarrassing for parents. They should try and avoid the tantrum in the first place by distracting the child or maybe offering a reward if there is no tantrum. It is very important that the behaviour is not reinforced and the parents do not give in.

Defiance and oppositional behaviour

These are related to the child's learning how to express aggression. It is to some extent normal in the older toddler, as an effort to achieve a sense of autonomy or individuality. This oppositional behaviour should be accepted by the parents so long as it does not go beyond the parents' own limits. A technique for dealing with children who have strong oppositional feelings is to give them choices, both or all of the choices being ones that the parents can accept. This gives the child the feeling that he/she has some options, with the knowledge also that the parents are still in the background able to keep things from getting out of control. If a child becomes irrational or extremely angry, parents may have the child go to his/her room, or leave the child and become busy in some other part of the house.

Aggression

Aggression is a problem of both normal development and of psychosocial disturbance. The child of 2-5 years may show aggressive outbursts ranging from temper tantrums and screaming to hurting other or destroying furniture. In these situations aggressive behaviour frequently arises out of frustration. Usually such aggressive behaviour in 2-3 year olds is directed toward the parents in response to demands for performance or compliance, or as a response to frustration of the wishes or intent of the child. By 4-5 years such behaviour is more likely to be directed at siblings or peers. Verbal aggression increases between the ages of 2 and 4 years, and after the age of 3 years revenge and retaliation become more prominent as determinants of aggression. Frustration and aggression are closely associated. When a child suddenly, and for no apparent reason, without injury or thwarting, has a sudden outburst of temper and aggressiveness, temporal lobe epilepsy is a possibility. Therefore, a good history, including the A-B-C is essential.

Treatment- bad behaviour should be labelled so the child is clear about what is unacceptable. Alternative acceptable behaviours should be identified and rewarded. If necessary, time out may be used for unacceptable behaviour.

Crying

Crying in infants is common in the first 3-6 months of life. It commonly occurs in the evening. First exclude organic disease - history, examination, and development and reassure parent. The baby should be picked up and comforted in a calm and gentle manner (e.g. walk around with baby in baby sling). Once the child is 3 months old, it may suffice to prop him/her up so he/she can see the interesting environment around him/her.

Hyperactivity

It is difficult among 2-4 year old children to identify those who will develop hyperactivity from those who are simply active, boisterous and gregarious. To assess the term "hyperactive", a full description of the behaviour is needed - this will clarify the expectations of the parents



and reveal their level of tolerance. "Normal" active children learn during the pre-school period to master motor output and to maintain attention and concentration. Children with "true" hyperactivity are relentlessly active and have ceaseless tireless movements, sleep very little and have a very short attention span, even for television. They tend to be impulsive, disruptive and intrusive. For the normal but active child, common causes such as lack of appropriate stimulation should be remedied. Sedentary tasks should be provided and acceptable behaviour rewarded. Other causes include developmental delay (school aged children may need assessment by the educational psychologist to exclude learning difficulties), and unreasonable expectations of the parents. There is no evidence that food additives are a common cause of hyperactivity in children. Children with true hyperactivity or other emotional problems manifesting as hyperactivity should be assessed further for ADHD or ASD.

Nightmares

Occur during REM sleep and are common in 3-4 year olds. They are not associated with emotional problems.

Night terrors

Occur mainly in children over 5 years old. The child screams out, is often sweating and appears terrified but difficult to wake. There is no memory of the event the next day and usually he/she falls back to sleep within a few minutes. Occurs in stage 4 (deep) sleep - i.e. usually before midnight and is not associated with emotional problems. Parents need reassurance about normality and self-limiting nature of the condition.

Treatment - wake the child 15 minutes before the event usually occurs - this changes the sleep pattern (i.e. anticipatory waking).

Sleepwalking

Occur in stage 4 sleep. Children can harm themselves, therefore ensure

doors locked etc. Do not wake while sleepwalking. Treatment - wake 15 minutes before usually start to change sleep pattern.

Reading:



Dr Christopher Green books

New Toddler Taming: A Parents' Guide to the First Four Years
Babies - A Parent's Guide To Surviving (And Enjoying!) Baby's First Year
Beyond Todderdom - Keeping Five to Twelve Year Olds on the Rails

The Incredible Years, Carolyn Webster Stratton
The Incredible Years

7.2. ADHD

Attention deficit hyperactivity disorder (ADHD) is a common, chronic condition that affects around 5% of children in the UK. Affected children have inattention, hyperactivity and impulsivity that is greater than expected for a child of their age, sex and cognitive ability. Around 1% of school age children fulfill the ICD-10 criteria for hyperkinetic disorder.

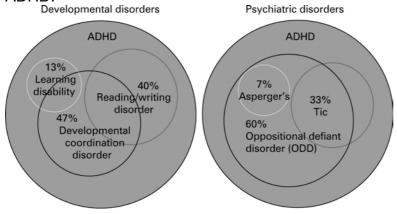
ADHD may seriously affect the individual and their family. In Europe carers often delay seeking help for years after suspecting their child has difficulties (from a mean age of 5.2 years when concern is first felt, to a mean age of 7.6 years when help is sought). When they do contact professionals it may take years for a child with ADHD to be recognised and treated (mean age at diagnosis 9.1 years).

When a child or young person presents with attentional difficulties and hyperactive/impulsive behaviour, it is vital that a careful assessment is undertaken. This should include a full history, relevant physical examination, collection of information from other sources (especially the school) and appropriate questionnaires. All other possible causes of inattention and comorbid conditions should be considered.

As stated in the NICE Technology Appraisal updated in March 2006, "drug treatment should only be initiated by an appropriately qualified healthcare professional with expertise in ADHD and should be based on a comprehensive assessment and diagnosis". General practitioners may perform continued prescribing and monitoring of drug therapy, under shared care arrangements. If a diagnosis of ADHD is confirmed, all relevant treatment options should be considered. The degree of impairment suffered by the child is the most important factor when deciding upon appropriate management.

Psychoeducation, behavioural management training for parents and teachers, individual input for the child or young person and other educational or social support should be used when relevant.

The majority of children and young people with ADHD have one or more comorbid or coexistent conditions (fig 1). Appropriate input for these comorbid conditions must not be forgotten. NICE is currently considering further guidelines on the assessment, diagnosis and multimodal management of ADHD.



Comorbidity in ADHD in Swedish school age children. Mood and anxiety disorders are not included

Figure 1

Prior to initiating medication, all children should be physically examined to ensure blood pressure is normal and that the child has no apparent cardiac or growth problems. Neurological examination is important to exclude other possible causes of ADHD symptoms and to consider possible comorbidities. A family medical history, asking particularly about cardiac problems, epilepsy and mental health problems, is also essential to guide the choice of medication.

7.2.1. Medication for ADHD

Drug treatment for ADHD is not a new option. The first reports of the positive effects of treating hyperactive children with stimulant medication were recorded in 1937. In the 1960s controlled trials of methylphenidate supported its use. Only in the last few years, however, have there been several useful



licensed alternative medication treatment options to consider: immediate release methylphenidate (Ritalin, Equasym, Medikinet), sustained release methylphenidate (Concerta XL, Equasym XL, Medikinet XL), dexamfetamine (Dexedrine) and atomoxetine (Strattera) are those most commonly used.

The usual starting dose of methylphenidate is 5 mg one to three times daily. The dose is increased weekly or fortnightly by 5–10 mg in the daily dose until a good effect is seen or side effects occur. The maximum daily-recommended dose of immediate release methylphenidate is 60 mg. A single dose of this formulation begins to act about half an hour after ingestion (depending on absorption) and has an effect lasting between 2 and 5 h. The appetite suppression most children experience means that medication should be given

with or just before food. As medication "wears off", some children experience a striking rebound of symptoms, which may cause problems at school before lunch, on the way home from school, at teatime or before bed.

Methylphenidate is available in modified-release formulations giving extended action enabling once-daily dosing to be used. This is important in negating the need to administer a dose at school, thus reducing stigma for the child, avoiding the need for storing the medication in school and arranging for staff to administer it, and decreasing the possibility of drug diversion in school. Concerta XL is an osmotic release tablet with an outer coating of immediate release methylphenidate. The morning dose may have some effect for up to 12 h. Equasym XL is a capsule containing beads which release methylphenidate over approximately 8 h. Medikinet XL is an alternative capsule formulation with approximately an 8 h action, with around 50% of the dosage available "immediately". There is some evidence that sustained release preparations provide better control of ADHD with fewer "swings" in symptoms and fewer side effects. Once daily dosing may also increase compliance.

Dexamfetamine is also a CNS stimulant. It is currently licensed for use in children over 3 years old. Treatment is initiated at 2.5 mg daily for children aged 3–5 years and at 5–10 mg daily for children over 6 years of age. The usual maximum daily dose is 20 mg.

Atomoxetine (Straterra) was licensed in the UK in 2004 for the treatment of ADHD in children, adolescents and adults who had a positive response to treatment with atomoxetine in adolescence. Atomoxetine should be commenced at a dose of 0.5mg/kg body weight increasing to 1.2 mg/kg after 1 week. There is some evidence that some children have a greater improvement in quality of life as measured by the Child Health Questionnaire on 1.8 mg/kg/day. Maximal effect takes around 8 weeks and builds gradually.

7.2.2. Possible side effects of stimulant medications

Very common (>10%)

Insomnia

Emotional lability

Reduced appetite and poor growth

Common (1–10%)

Headache

Dizziness

GI symptoms

Increased blood pressure

Tachycardia/arrhythmia/palpitations

Rare (<1%)

Increased tic frequency

Psychosis

Seizures

Liver toxicity

The most common problem is appetite suppression, which may result in sub-optimal growth. It is important to recommend the child has breakfast before taking morning medication and if using immediate release methylphenidate lunch should be eaten with the midday dose and tea before the third dose. Long-term growth should be monitored carefully. When children have a very positive response to treatment but grow poorly, the input of a dietician can be very helpful. About 20% of children with ADHD have sleep difficulties at the time of diagnosis. It is also important to exclude sleep difficulties as the cause of the "ADHD" symptoms. Stimulant medication may increase sleep difficulties, especially if given later than teatime. For some children, paradoxically, sleep is improved and this may be secondary to a calm evening.

The most common side effects of Atomoxetine are gastrointestinal symptoms such as nausea or stomachache. This may be reduced by taking the medication with food and by using twice daily dosing. The American Food and Drugs Administration undertook a review of atomoxetine as a part of their review of increased risks of suicide in children taking SSRIs. There is evidence of increased suicide risk in young people with ADHD. Treatment may result in increased awareness of the individual's difficulties and the mood of children and young people in early treatment should be sensitively monitored. The Committee on Safety of Medicines (CSM) has advised that patients and their carers should be informed about the risk and told to report clinical worsening, suicidal thoughts or behaviour, irritability, agitation or depression.

7.2.3. Co-morbid conditions

Research trials often exclude children with general learning disability and ADHD. Given the huge benefits for children with learning disability if they can concentrate more and be less hyperactive, further trials and collation of clinical experience is needed. Problems of inattention and hyperactivity affect one half of the individuals with autistic spectrum disorder. Care must be taken to ensure that inattention and hyperactivity are not manifestations of core autism symptoms, as this requires different management. The prescribing of psychotropic agents to individuals with autistic disorder is increasing, but the evidence base is limited, with some exceptions, to uncontrolled studies and more research is needed. Substantial benefit in reducing inattention and hyperactivity is reported with atypical antipsychotics such as risperidone, but weight gain and sedation are common and sometimes unacceptable side effects. Moderate benefit maybe derived from methylphenidate or atomoxetine for children with autism spectrum disorder (ASD) and symptoms of ADHD.

*Reproduced from Harpin V. Medication options when treating children and adolescents with ADHD: interpreting the NICE guidance 2006 *Arch of Dis in Child - Educ and Pract* 2008;93:58-65.

7.3. Suggested activities

 Find out about local services for children with behavioural difficulties and the referral pathway



- Attend clinical sessions or consultations with the local CAMHS team
- Ascertain what local mental health services are available for children with learning disabilities and attend specialist clinics or team meetings
- Attend a local CAMHS referral meeting
- Find out about local services (Trust or voluntary sector) that provide counseling or family support
- Visit local organisations/services working with young people who abuse drugs, alcohol