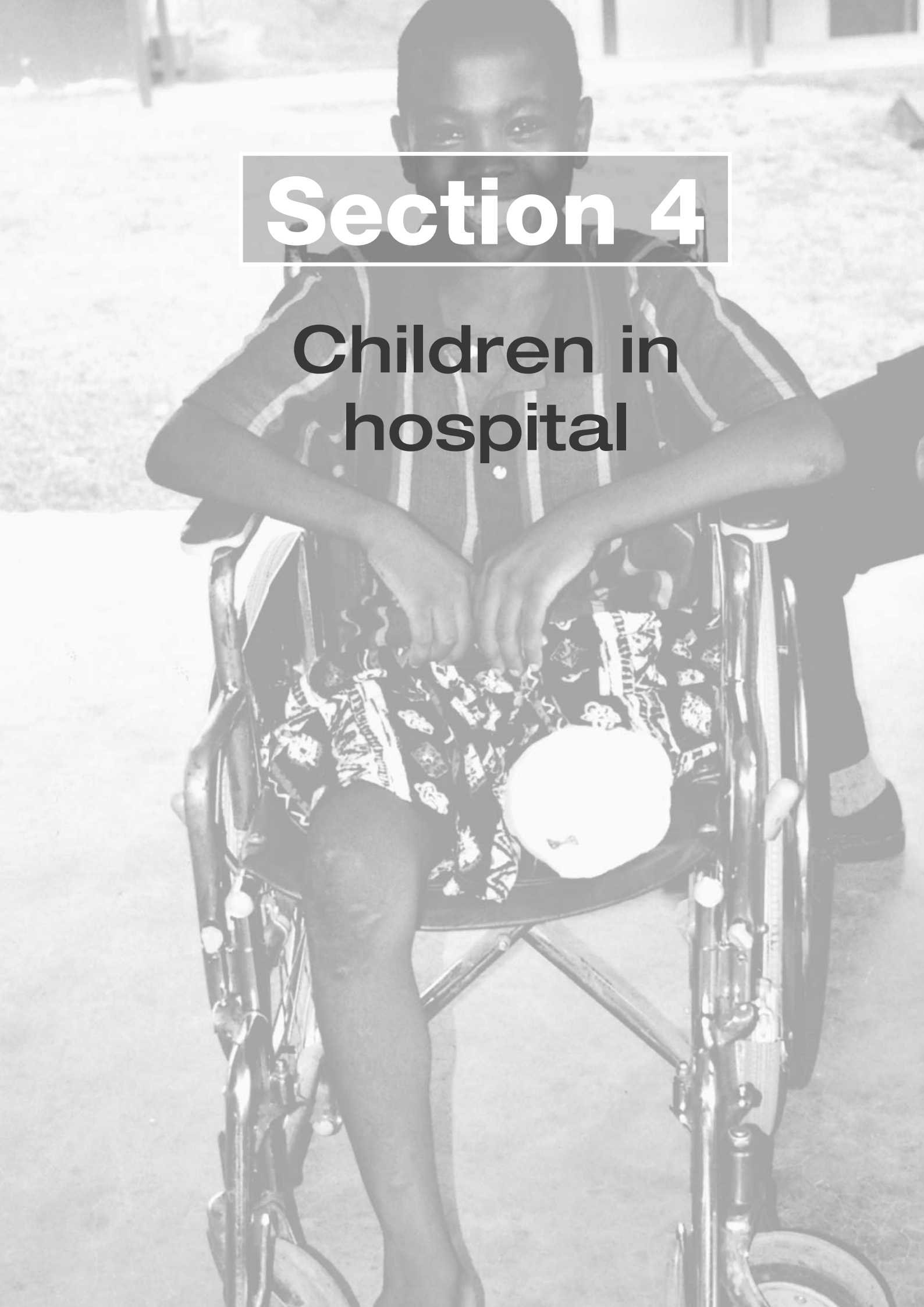

Section 4

Children in hospital

4.1 The differential diagnosis of common or serious presenting symptoms and signs in children

4.1.A The child with diarrhoea

There are several groups of causes of diarrhoea. For the management of acute and chronic diarrhoea, *see* Sections 5.12.A and 5.12.B.

Causes of diarrhoea

Infective

- Acute (< 14 days).
- Persistent (> 14 days).

Viruses, bacteria and parasites are the agents of infection.

Secondary diarrhoea

- Malnutrition.
- HIV.
- Disaccharide intolerance.
- Malaria.

Chronic (non-infectious)

- Food intolerance:
  - Milk protein, soy protein
  - Coeliac disease (gluten sensitivity)
  - Multiple food intolerances.
- Inflammation:
  - Crohn's disease
  - Ulcerative colitis.
- Pancreatic disease:
  - Cystic fibrosis
  - Shwachman syndrome (cyclic neutropenia).

Miscellaneous

- Non-specific 'toddler's diarrhoea'.
- Irritable bowel syndrome.
- Excessive intake of squash/fruit drinks.

History

- Duration of symptoms.
- Nature of stool (e.g. fatty, floating, watery, with blood).
- Number per day.
- Dietary intake.
- Other accompanying symptoms.
- History of foreign travel.
- Possible food poisoning exposure.

Examination

- Chart growth/nutritional status.
- Document degree of dehydration.
- Look for fever, anaemia, lymphadenopathy, hepatosplenomegaly and finger clubbing.
- Look for signs of vitamin or mineral deficiency, oral ulcers and anal fissures.
- Look for candidiasis.

Investigations

TABLE 4.1.A.1 Investigations in the child with diarrhoea

Investigation	Looking for:
Stool Microscopy (warm stool for *Entamoeba histolytica*), white blood cell count (WBC), red blood cell count (RBC), ova, parasites Culture	Infection
Stool pH (< 5.5) Clinitest tablets or Benedict's solution	Lactose intolerance
Stool Fat globules	Pancreatic disease
Hydrogen breath test	Lactose intolerance
Blood culture (high temperature, rigors)	Septicaemia (e.g. *Salmonella*)
Urea, creatinine, electrolytes (if oliguria)	Haemolytic uraemic syndrome Hyponatraemia/ hypernatraemia
Full blood count	Hidden bleeding
Albumin	Chronic diarrhoea
X-ray of abdomen, ultrasound scan	Ileus, bowel perforation
Urine microscopy	Haemolytic uraemic syndrome

4.1.B The child with jaundice

Causes of jaundice

- Neonatal jaundice (*see* Section 3.4).
- Excess haemolysis (pre-hepatic):
  - sickle-cell disease (*see* Section 5.11.B)
  - thalassaemia (*see* Section 5.11.C)
  - hereditary spherocytosis (*see* Section 5.11.C)

  - malaria (*see* Section 6.3.A.d).
- Liver disease (*see* Sections 5.7.A and 5.7.B):
  - hepatocellular
  - obstruction to bile secretion
  - infective hepatitis
  - acute liver failure
  - chronic liver disease.

History
- Family history of hereditary haemoglobinopathy or liver disorder.
- Blood transfusion.
- Anorexia.
- Abdominal pain.
- Pruritus.
- Colour, nature and contents of stools and urine.

Examination
- Assess growth/nutritional state.
- Look for skin signs of chronic liver disease (e.g. spider naevi, clubbing, leuconychia, liver palms, scratches from pruritus).
- Assess liver and spleen (for enlargement and tenderness).
- Check for anaemia.
- Check for ascites.
- Look for frontal bossing or maxillary overgrowth (sickle-cell disease or thalassaemia).
- Observe colour of stool and urine.

Investigations

TABLE 4.1.B.1 Investigations in the child with jaundice

Investigation	Looking for:
Full blood count and film	Anaemia
Reticulocytes	Haemolysis
Haemoglobin electrophoresis	Sickle-cell disease and thalassaemia
Urine	Bilirubin and urobilinogen
Liver function tests: Liver transaminases	Bilirubin conjugated (liver disease or biliary obstruction) or unconjugated (haemolysis) Hepatitis
Serology	Identification of viral causes
Coagulation	Liver failure
Auto-antibodies	Chronic active hepatitis

4.1.C The child with lymphadenopathy

Common causes of generalised lymphadenopathy
- HIV infection.
- Infectious mononucleosis.
- Tuberculosis (TB).
- Leukaemia.
- Hodgkin's and non-Hodgkin's lymphoma.
- Cytomegalovirus (CMV), toxoplasmosis.
- African trypanosomiasis.

Infective causes of local lymphadenopathy
- Local skin (especially scalp) infections.
- Tuberculosis (TB), *see* Section 6.1.N.
- Environmental mycobacteria.
- Cat scratch disease.

History
- Known epidemiology of HIV and trypanosomiasis in the area.
- Contact with TB.
- Chronic ill health (e.g. malignancy, HIV, TB).
- Determine whether nodes are static or increasing in size.

Examination
- Chart growth and nutritional status.
- Check for fever.
- Check for liver or spleen enlargement.
- Check for purpura or anaemia.
- Check for *Candida* infection.
- Conjunctivitis, red cracked lips and persistent high fever, if present, suggest possible Kawasaki's disease.

TABLE 4.1.C.1 Investigations in the child with lymphadenopathy

Investigations	Looking for:
Full blood count	Atypical lymphocytes, leukaemic picture
Thick blood film	Trypanosomiasis
Bone marrow	Malignancy
HIV tests	HIV
Paul-Bunnell test	Infectious mononucleosis (positive 60%)
Erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP)	Infection, TB
Mantoux test	TB, environmental mycobacteria
Serology	Epstein–Barr virus, CMV, toxoplasmosis
Chest X-ray	TB, malignancy
Lymph node biopsy	Diagnostic (lymphomas, etc.)

4.1.D The child with abdominal pain

Note that this group includes adolescent girls who may be pregnant.

Causes of acute and chronic abdominal pain

- Idiopathic:
  - Irritable bowel syndrome (intermittent stool variability).
  - Migraine (headaches with photophobia).
- Psychogenic.
- Gastrointestinal:
  - Appendicitis (central pain moving to right lower abdomen).
  - Peptic ulcer (upper abdominal pain, vomiting, blood in vomit/melaena stool).
  - Gastroenteritis (contact history, watery and/or bloody diarrhoea).
  - Intussusception (redcurrant-jelly stool, spasms of pain, mass in left lower abdomen).
  - Oesophagitis (retrosternal pain).
  - Inflammatory bowel disease (loose bloody, mucousy stool, weight loss, systemically unwell).
  - Constipation (hard, painful infrequent stool).
  - Bowel obstruction (bile-stained vomiting, abdominal swelling).

TABLE 4.1.D.1 Investigations in the child with abdominal pain

Investigation	Looking for:	
Full blood count	Anaemia, eosinophilia, infection	
Erythrocyte sedimentation rate (ESR)/C-reactive protein (CRP)	Inflammation	
Urea, electrolytes	Renal disease	
Amylase	Pancreatitis	
Liver function tests	Liver dysfunction, hepatitis	
Urine stick test: blood, protein, glucose	Glomerulonephritis, nephritic syndrome, diabetes, urinary system calculi	
Urine microscopy for organisms, casts, culture	Infection, glomerulonephritis	
Stool, ova, cysts, parasites, white blood cell count (WBC) and red blood cell count (RBC)	Infestation, dysentery, inflammatory bowel disease	
Pregnancy test	*See* Section 2	
Ultrasound scan (abdomen and pelvis), X-ray (straight abdominal film)	Bowel obstruction, constipation, lead poisoning, ovarian cyst, pregnancy, calculi	
Barium studies and endoscopy	Peptic ulcer, inflammatory bowel disease	
Barium studies and endoscopy	Peptic ulcer, inflammatory bowel disease	
Differentiating between organic and non-organic (psychological) abdominal pain		
	Organic	*Non-organic*
Nature of pain	Day and night	Periodic, often peri-umbilical
History	Weight loss/reduced appetite Lack of energy Fever Change in bowel habit Urinary symptoms Intestinal symptoms Vomiting: • bile stained • continuous • blood Rectal bleeding	Migraine School and family problems Isolated vomiting, not bile stained
Examination	Appears ill Weight loss Distension Absent or accentuated bowel sounds Shock Abdominal mass: • constipation • other	Normal, thriving

  - Food intolerance (e.g. milk protein, gluten) (dietary history).
  - Meckel's diverticulum.
  - Henoch–Schönlein purpura (purpuric rash and/or arthropathy).
  - Sickle-cell disease (history, anaemia).
- Urinary tract:
  - Infection.
  - Calculi.
  - Hydronephrosis.
- Liver:
  - Hepatitis.
- Pancreas:
  - Inflammation (pancreatitis).
- Malignancy:
  - Lymphoma.
- Gynaecological:
  - Dysmenorrhoea.
  - Pelvic inflammatory disease.
  - Ovarian cyst.
- Pregnancy related (*see* Section 2).
- Respiratory:
  - Pneumonia/pleurisy.
- Trauma.
- Poisoning:
  - Lead.

4.1.E The child with anaemia

Anaemia, especially that due to iron deficiency, is very common in resource-limited communities. Anaemia can be caused by a combination of inadequate nutrition and recurrent infections, such as malaria. Intestinal parasites such as hookworm are important causes. Genetic disorders such as sickle-cell disease and thalassaemia should always be considered in relevant ethnic groups. Acute worsening of anaemia may present as heart failure in young children.

For children aged < 6 years, normal haemoglobin concentration is > 11.0 g/dL (haematocrit is > 33%), *see* Section 5.11.A.

- Moderate anaemia: haemoglobin concentration is 6–9.3 g/dL.
- Severe anaemia: haemoglobin concentration is ≤ 6 g/dL, severe pallor (palmar/conjunctival), may have heart failure; gallop rhythm, enlarged liver and pulmonary oedema (fine basal crepitations in the lungs).

Causes of anaemia

Decreased production

- Prematurity: at 6–8 weeks postpartum.
- Hypochromic: iron deficiency (diet, blood loss, chronic inflammation).
- Normochromic: chronic infection or inflammation:
  - nutritional: malnutrition, scurvy
  - infiltration: leukaemia, malignancy
  - metabolic: renal and liver disease.
- Megaloblastic:
  - folic acid deficiency: infection, coeliac disease, anticonvulsants, haemolysis
  - vitamin B_{12} deficiency: intestinal resections, Crohn's disease, vegan diet.
- Hypoplastic: sickle-cell crises, drugs (e.g. chloramphenicol), malignancy.

Increased haemolysis

- Haemoglobinopathies: sickle-cell disease, thalassaemia major.
- Non-immune: drugs, infection, hypersplenism, burns, haemolytic uraemic syndrome, disseminated intravascular coagulation, porphyria, snake venoms.
- Enzyme deficiency: drug-induced and spontaneous glucose-6-phosphate dehydrogenase (G6PD) deficiency, glutathione synthetase deficiency, pyruvate kinase deficiency.
- Immune: Rhesus and ABO incompatibility, autoimmune (e.g. reticuloses), *Mycoplasma* infection, systemic lupus erythematosus, drugs.
- Membrane defects: spherocytosis, elliptocytosis, stomatocytosis, erythropoietic porphyria, abetalipoproteinaemia.

Blood loss

- Perinatal:
  - placental and cord accidents
  - feto–maternal, twin-to-twin transfusions
  - birth injury (e.g. cephalhaematoma, sub-aponeurotic haemorrhage, severe bruising)
  - haemorrhagic disease of the newborn.
- Epistaxis.
- Trauma.
- Alimentary tract: haematemesis, rectal bleeding, hookworm.
- Blood clotting disorder (e.g. haemophilia, thrombocytopenia).
- Renal tract: haematuria.

History

- Symptoms of anaemia: lethargy, tiredness, shortness of breath on exertion, poor growth.
- Obvious blood loss: epistaxis, haematemesis, haematuria, blood in stools.
- Assess the diet (e.g. inadequate weaning diet).
- Steatorrhoea.
- Chronic infection, inflammation.
- Drugs: especially antibiotics, antimalarial drugs, anticonvulsants, analgesics, cytotoxic agents.

Examination

- Chart growth/nutritional state.
- Conjunctivae, nails and palms for pallor.
- Stomatitis.
- Jaundice.
- Bruising, lymphadenopathy or petechiae.
- Hepatosplenomegaly.
- Tachycardia, flow murmur, cardiac failure.

Investigations

TABLE 4.1.E.1 Investigations in the child with anaemia

Investigation	Looking for:
Full blood count	Haemoglobin concentration, white blood cell count, platelet count
Blood film	Red blood cell morphology, malaria, target cells, haemolysis
Haemoglobin electrophoresis	Sickle-cell disease, thalassaemia
Mean corpuscular volume (MCV), reticulocytes	Iron deficiency, haemolysis
Coombs' test	Haemolysis
Bone marrow	Leukaemia, malignant infiltration, aplasia
Bilirubin, liver function tests	Direct/indirect bilirubin
Urinalysis	Red blood cells, casts, bacteria, white blood cells, protein, culture
Serum ferritin	Iron stores
Barium meal/endoscopy	Inflammatory bowel disease
Platelets and clotting	Coagulation disorder
Stool microscopy, culture and occult blood	Hookworm (egg count), gastrointestinal blood loss

4.1.F The child who is vomiting

The history of the acute, recurrent or chronic nature of this symptom indicates the approach to the diagnosis.

Common causes (depending on age)

Infants

- Gastroenteritis.
- Gastro-oesophageal reflux (distinguish from possetting).
- Overfeeding.
- Bowel obstruction:
  - pyloric stenosis
  - intussusception
  - congenital bowel anomalies.
- Infection:
  - urinary tract in particular
  - meningitis
  - otitis media
  - pertussis.
- Poisoning:

Children

- Gastroenteritis.
- Appendicitis (with pain).
- Infection:
  - especially urinary tract
  - meningitis (including TB)
  - malaria.
- Bowel obstruction.
- Ingestion of drugs or poisons.
- Migraine.
- Pregnancy.
- Bulimia (but rarely does a child admit this).
- Raised intracranial pressure (RICP).
- Hypertension.
- Diabetic ketoacidosis.

History

- Accidental drug ingestion.
- Check whether it is vomiting, regurgitation or possetting (especially in an infant).
- Is it associated with coughing or a whoop?
- Is it projectile?
- Does it contain blood or bile?
- Is there any diarrhoea or constipation?
- Is there abdominal pain?
- Are there urinary or ear symptoms?
- Is there a family history of migraine?
- Are there difficulties in coordination during physical activity? Consider the possibility of a middle ear or brainstem problem.

Examination

- Does the child look ill?
- Is the child febrile? Is there neck stiffness, a full fontanelle and/or a rash?
- Measure the head circumference, especially in infants, and check fontanelles and sutures.
- Is the child dehydrated? Is there an odour?
- Assess growth and nutritional status.
- Examine vomit:
  - bile-stained vomit suggests bowel obstruction
  - blood (coffee grounds).
- Full examination (include blood pressure, fundoscopy and anorectal examination as indicated).
- Abdomen:
  - test feed for pyloric stenosis: swelling or visible peristalsis
  - tenderness or mass
  - check whether bowel sounds are present and, if so, what they are like.

Investigations

TABLE 4.1.F Investigations in the child who is vomiting

Investigation	Looking for:
Urine microscopy	Urinary tract infection
Full blood count	Infection
Thick film	Malaria
Urea and electrolytes	Pre-renal or renal failure, pyloric stenosis
Blood culture	Infection
Lumbar puncture	Meningitis
Stool microscopy and culture	Ova, cysts, parasites, bacteria and viruses
Liver function tests	Hepatitis
Abdominal ultrasound	Masses, obstruction, free fluid
Straight abdominal X-ray/chest X-ray	Bowel obstruction, free air
Barium studies and/or endoscopy	Specific diagnosis
Pregnancy test	Pregnancy
Mantoux test	TB, meningitis
Brain imaging	Raised intracranial pressure

4.1.G The child with a rash

Causes of a rash

Macular rash

- Viral infections such as measles, sometimes meningococcal infection.
- Juvenile rheumatoid arthritis.
- Erythema marginatum: rheumatic fever.

Papular (vesicles, pustules) or bullae (blisters of various sizes)

- Chickenpox.
- Herpes simplex.
- Impetigo.
- Scabies.

Purpuric, petechial, ecchymosis

- Meningococcal disease.
- Henoch–Schönlein purpura.
- Dengue fever.
- Thrombocytopenia.

Desquamation with or without mucosal involvement

- Scalded skin syndrome.
- Toxic epidermal necrolysis.
- Kawasaki disease.
- Post-scarlet fever.
- Post-toxic shock syndrome.
- Stevens–Johnson syndrome.
- Epidermolysis bullosa.

Erythema multiforme

- Allergic reaction to drug or infection.
- Stevens–Johnson syndrome if very severe (then with bullae and mucous membrane redness).

TABLE 4.1.G.1 Investigations in the child with a rash

Investigation	Looking for:
Full blood count, erythrocyte sedimentation rate (ESR), C-reactive protein (CRP)	Systemic bacterial infection (e.g. meningococcal disease) Kawasaki disease Thrombocytopenia
Blood culture	Bacterial infection
Skin swab	Bacterial infection
Skin scraping	Scabies
Throat swab and antistreptolysin O titre (ASOT)	Streptococcal infection
Urinalysis (red blood cell count, casts, protein)	Nephritis (e.g. Henoch–Schönlein purpura) or connective tissue disorders
Skin biopsy	Epidermolysis bullosa
Auto-antibodies	Connective tissue disorders

Erythema nodosum
Lesions begin as flat, firm, hot, red, painful lumps approximately 2.5 cm across. Within a few days they may become purplish, then over several weeks fade to a brownish, flat patch. Erythema nodosum is most common on the shins, but it may also occur on other areas of the body (buttocks, calves, ankles, thighs, and arms).

- Streptococcal disease.
- TB.
- Connective tissue disorders.
- Sarcoidosis.
- Drugs.

4.1.H The child with failure to thrive

Approach to failure to thrive

- Failure to thrive is due to inadequate delivery of nutrients to developing tissues.
- It is usually manifested by failure to gain weight as expected.
- In extreme circumstances, height (length) and head circumference may be affected. Plot the mid-parental height.
- The majority of cases are related to gastrointestinal disorders: poor intake/malabsorption.
- Observe feeding, mother's interaction, child's behaviour, vomiting, diarrhoea and weight gain before embarking on investigations.
- Investigations should take place when a likely system and/or disorder has been identified.
- Always remember the possibility of child abuse.
- See relevant sections on gastroenterology, chronic infections, organ failure, hyperimmune disorder.

Failure to thrive: gastrointestinal disorders

- Oropharynx: cleft palate.
- Oesophagus: incoordination of swallowing (e.g. cerebral palsy).
- Stomach:
  - Gastro-oesophageal reflux
  - Pyloric stenosis.
- Digestion:
  - Pancreas: cystic fibrosis
  - Liver: cirrhosis.
- Small gut disorders:
  - Milk protein intolerance
  - Coeliac disease
  - Carbohydrate malabsorption
  - Protein-losing enteropathy
  - Short gut syndrome
  - Crohn's disease.
- Large gut disorders:
  - Ulcerative colitis
  - Crohn's disease
  - Hirschsprung's disease.

Causes of failure to thrive

TABLE 4.1.H.1 Mechanisms of failure to thrive

Mechanism	Systems involved:
Inadequate intake	Anorexia Breastfeeding failure Feeding mismanagement Swallowing disorders
Loss	Vomiting Diarrhoea Malabsorption
Structural dysfunction of organs	Brain (cerebral palsy, learning difficulties) Respiratory Cardiac Urinary tract Gastrointestinal tract
Increased requirement for nutrients or metabolites	Infection Connective tissue disorders Immune disorders
Failure of end-organ response	Metabolic (e.g. amino acid disorders, organic acid disorders) Endocrine (e.g. thyroid disorder) Malignancy Chromosomal abnormalities
Emotional and/or psychological	Parental problem: • Neglect • Abuse • Family dysfunction Child problem: • Feeding/behaviour disorders • Anorexia nervosa • Bulimia

4.1.I The child with fits, faints and apparent life-threatening events (ALTEs)

Common causes of fits, faints and ALTEs

- Febrile convulsions.
- Epileptic seizures.
- Hypoglycaemia.
- Infantile apnoea/hypoxaemic events.
- Premature birth.
- Respiratory infection (e.g. bronchiolitis, pertussis).
- Sleep-related upper airway obstruction (*see* Section 5.1.D).
- Vaso-vagal episodes (simple faints).
- Cardiac arrhythmias.
- Cyanotic breath-holding.
- White breath-holding (reflex anoxic seizures).

History

- Cyanosed:
  - Occurs with infant apnoea
  - Some febrile convulsions/epileptic seizures.
- Extreme pallor:
  - Vasovagal
  - Cardiac arrhythmia.
- Trauma/illness related (especially to head): white breath-holding.
- Emotional upset: cyanotic breath-holding.
- Snoring/inspiratory stridor during sleep, often with chest recession and restlessness: sleep-related upper airway obstruction (*see* Section 5.1.D).
- Exercise related: cardiac arrhythmia (*see* Section 5.4.C).
- Drug abuse.
- Fabricated or induced illness (*see* Section 7.6).
- Convulsions (*see* Sections 5.16.D and 5.16.E).
- Preterm infant in first few weeks (*see* Section 3.4).
- Respiratory illness.
- Diabetes/starvation (*see* Section 5.8.A).

Examination

- Growth and nutritional status.
- Signs of respiratory infection.
- Signs of anaemia (associated with cyanotic breath-holding and infant apnoea).
- Signs of fever.
- Neurological examination (to exclude or identify neurological abnormalities).
- History of breath-holding (*see* Section 5.16.I).
- Signs of cardiac disorder.
- Blood pressure lying and standing, for vasovagal episodes.
- Mouth and throat for enlarged tonsils or retrograde/small mandible for predisposition to sleep-related airway obstruction (the latter is also common in sickle-cell disease and Down's syndrome).

Investigations

TABLE 4.1.I.1 Investigations in the child with fits, faints and ALTEs

Investigation	Looking for:
Full blood count	Anaemia, infection
Blood glucose concentration	Hypoglycaemia
Haemoglobin electrophoresis	Sickle-cell disease
ECG	Wolf–Parkinson–White syndrome and long QT syndrome Structural lesion of heart
Oxygen saturation during sleep	Low baseline SaO_2 predisposes to infant apnoea/hypoxaemic events Should be > 94% (at sea level) (*see* Section 9, Appendix) Especially common in preterm infants and infants aged < 6 months with respiratory infection
Video (if available) during sleep (parents can do this with a mobile phone)	Sleep-related upper airway obstruction
EEG and video during episode	Epileptic cause
Chest X-ray	Lung disease in infantile apnoea/hypoxaemic events

4.1.J The child with generalised oedema

The major differential diagnosis relates to the presence or absence of hypoalbuminaemia.

Common pathophysiology

- Heart failure:
  - Jugular vein pressure increased, liver enlarged, triple rhythm, murmurs, basal lung crepitations.
  - Cardiovascular disorders.
  - Severe anaemia.
- Acute glomerulonephritis.
- Low serum albumin:
  - Nephrotic syndrome.
  - Liver disorders.
  - Protein-losing enteropathy (e.g. malabsorption, intestinal lymphangiectasia).
  - Malnutrition.
- Increased vascular permeability:
  - Anaphylaxis (history).
  - Shock.
- Over-hydration (particularly excessive IV solutions such as 5% dextrose).

History

- Shortness of breath, chest pain (pericarditis).
- Blood in urine (nephritis).
- Facial swelling (nephrotic syndrome or acute glomerulonephritis, anaphylaxis).
- Nutritional history (malnutrition).
- Gastrointestinal symptoms (protein-losing enteropathy).
- Exposure to allergen or sting (anaphylaxis).
- Excess and/or inappropriate IV fluids.

Examination

- Chart growth and nutritional status, and look for features of kwashiorkor and vitamin deficiencies.
- Cardiovascular system, including blood pressure.
- Rash with or without wheeze/stridor (anaphylaxis).
- Widespread purpuric rash/very ill patient (meningococcal septicaemia).
- Jaundice or other signs of liver disease.
- Anaemia and lymphadenopathy.
- Enlarged liver and/or spleen.
- Ascites (especially nephrotic syndrome). Ascites may be transudate (e.g. nephrotic syndrome) or inflammatory (e.g. TB, peritonitis). Abdominal malignancy may cause ascites and obstructive oedema of the lower limbs.

Investigations

TABLE 4.1.J.1 Investigations in the child with generalised oedema

Investigation	Looking for:
Full blood count	Anaemia
Urinalysis: • Dipstix: protein, blood Bilirubin Microscopy: red blood cell count, casts	Nephrotic syndrome, nephritis Liver disease Nephritis
Stool	Hookworm
Serum albumin	Low albumin levels
Imaging: abdominal ultrasound	Hepatosplenomegaly Malignancy Ascites (transudate/inflammation)
Echocardiogram	Cardiac disorders
Ascitic fluid Colour: clear, cloudy, bloody, chylous Cells: white blood cell count, malignant cells Protein: < 25 grams/litre transudate > 25 grams/litre exudate Ziehl–Neelsen stain Culture:	 Inflammation (e.g. from TB) Infection, malignancy TB TB/general

4.1.K The child with headaches

- Headaches are common in children.
- They should be taken seriously if they persist.
- Their prevalence increases with age.

Acute headache

Common causes of acute headache include the following:

- Febrile illness.
- Meningitis/encephalitis.
- Acute sinusitis: pain and tenderness (elicited by gentle percussion) over the maxilla; there is usually a history of preceding upper respiratory tract infection and a postnasal discharge may be present.
- Head injury.
- Raised intracranial pressure.
- Intracranial haemorrhage (severe sudden headache, with rapid loss of consciousness).
- Migraine.

A careful history and physical examination will usually reveal the cause.

Raised intracranial pressure (RICP)

- Headache may be sudden or gradual in onset, often occipital in location and becomes progressively more severe.
- Made worse by lying down (in contrast to migraine and tension headache, which are relieved by lying down), by coughing, stooping and straining, and may wake the child from sleep.
- Worse in the morning and often associated with nausea and vomiting.
- Other signs of raised intracranial pressure may be present, such as impaired consciousness, bilateral abducens sixth nerve palsies (false localising sign) and, when severe, bradycardia and hypertension.
- Papilloedema is a late sign.
- Localising neurological signs may be present, depending on the site of the lesion. Ataxia suggests a posterior fossa tumour; cranial nerve palsies suggest a brainstem lesion; visual field defect suggests a craniopharyngioma; unequal pupils suggest a supratentorial lesion such as subdural haematoma.
- In endemic areas, cerebral malaria and neurocysticercosis are important causes.

Benign intracranial hypertension

- Raised intracranial hypertension without any space-occupying lesion or obstruction of the CSF.
- Can be caused by drugs (corticosteroids, especially during withdrawal, ampicillin, nalidixic acid) and sagittal sinus thrombosis.
- Most without cause, especially in young adolescent girls.

Recurrent or chronic headaches

Two common causes are anxiety (tension) and migraine.

Tension headache

- This affects around 10% of schoolchildren.
- Typically the headache is symmetrical and described as hurting or aching over the cranial vault.
- The headache develops gradually and is not associated with other symptoms.
- It is induced by stress (e.g. due to school examinations, assignments, etc.) and can coexist with migraine in the same child.
- It may be caused by isometric contraction of the head and neck muscles in anxious children.

Migraine

See Section 5.16.J.

Conversion (hysterical) headache

- Headache can be a conversion symptom used by the child to gain attention.
- The initial headache may have been due to an organic cause (e.g. febrile illness), but its persistence and recurrence are due to psychological factors.

Management of headaches

See also Section 5.16.A relating to an acute onset of headache.

- A detailed history and a careful full examination should be undertaken in order to rule out serious underlying causes.
- Investigations are rarely needed.
- X-ray of the sinuses will confirm sinusitis and CSF examination will confirm meningitis/encephalitis.
- A CT scan of the brain is essential if raised intracranial pressure is suspected or if there are localising neurological signs.
- Treatment is directed at the underlying cause and at pain relief.
- Benign intracranial hypertension can be alleviated with corticosteroids (dexamethasone 0.6 mg/kg/day in two divided doses) and/or acetazolamide (8 mg/kg 8-hourly, increasing to a maximum of 32 mg/kg/day) and repeated lumbar puncture.
- For tension and conversion headaches, counselling and stress management are important.

Relief of pain

For most headaches, simple analgesics alone or combined with non-steroidal anti-inflammatory drugs (NSAIDs) will suffice (e.g. paracetamol with or without ibuprofen). Remember that frequent or recurrent use of analgesics can **cause** headaches.

4.1.L The child with respiratory distress

Presenting features

- Tachypnoea.
- Increased effort of breathing: tracheal tug, inter/subcostal recession.
- Poor feeding, sleep disturbance.
- Grunting.
- Unable to speak in sentences.
- Positioning: sitting up/forward, neck extension, splinting chest.
- Tachycardia.
- Altered mental state: agitation (hypoxaemia)/drowsiness (hypercapnia).
- Pallor/cyanosis (late sign).

Causes

TABLE 4.1.L Causes of respiratory distress

Common cause	Findings on examination
Upper airway obstruction	Stridor, hoarse voice, drooling, sitting up, head held forward
Inhaled foreign body	Suggestive history, tracheal deviation, unilateral hyper-expansion on chest X-ray
Asthma	Hyper-expansion, wheeze, reduced air entry, reduced peak flow, hypoxaemic (SaO_2 < 94% at sea level)
Bronchiolitis	Inspiratory crackles, wheeze, hypoxaemic (SaO_2 < 94% at sea level)
Pneumonia	Fever, grunting, pleuritic or abdominal pain, signs of consolidation or effusion. Clubbing indicates chronic disease (e.g. bronchiectasis)
Tuberculosis	Contact history, lymphadenopathy, fever, weight loss
Pneumothorax	Unilateral hyper-resonance on percussion, tracheal deviation, apex displacement
Cystic fibrosis	Recurrent respiratory infections, failure to thrive, fat malabsorption, family history
Heart failure/pulmonary oedema	Sweaty, gallop rhythm, hepatomegaly, heart murmurs, basal lung crepitations, raised jugular venous pressure (JVP)
Sickle-cell disease/acute chest syndrome	Hypoxaemia (SaO_2 < 94% at sea level), chest pain

Investigations

TABLE 4.1.L.2 Investigations in the child with respiratory distress

Investigation	Looking for:
Oxygen saturation (pulse oximeter)	Hypoxaemia < 94% at sea level
Chest X-ray	Lung disorder
ECG, echocardiogram	Heart disorder
Mantoux	TB
Erythrocyte sedimentation rate (ESR), C-reactive protein (CRP)	Inflammation
Full blood count	Infection
Haemoglobin electrophoresis	Sickle-cell disease
Bronchoscopy	Foreign body
Sweat test or DNA analysis	Cystic fibrosis

4.1.M The child with pyrexia (fever) of unknown origin (PUO)

Definition

Pyrexia of unknown origin (PUO) is defined as a minimum temperature of at least 38.3°C for 1–3 weeks with at least 1 week of hospital investigation. It is very important to determine whether fever is continuous or recurrent by plotting it on a chart (*see* Section 9, Appendix).

Baseline investigations

- Full blood count and film.
- Erythrocyte sedimentation rate (ESR)/C-reactive protein (CRP).
- Blood cultures.
- Thick film and/or rapid diagnostic test (RDT) for malaria (endemic areas/recent foreign travel).
- Mantoux test.
- Epstein–Barr and other viral serology.
- Urine microscopy/culture.
- Chest X-ray.
- Lumbar puncture (if meningeal signs are present).

TABLE 4.1.M.1 Relatively common causes of pyrexia of unknown origin in children

	Cause	Specific investigation
Bacterial infection	Tuberculosis	Chest X-ray, tuberculin skin test, lumbar puncture
	Campylobacter	Stool culture
	Typhoid	Blood and stool culture; serology, but unreliable. Clinical signs
	Brucellosis	Serology
	Cat scratch disease	Lymph node biopsy
	Rheumatic fever	Throat swab, anti-streptolysin O titre (ASOT)
Localised infection	Hidden abscess	Abdominal ultrasound scan
	Bacterial endocarditis	Blood cultures, echocardiogram
	Osteomyelitis	X-ray, bone scan
	Pyelonephritis	Urine microscopy and culture
	Cholangitis	Abdominal ultrasound scan
Spirochaete infection	*Borrelia*	Serology
	Syphilis	Serology
	Leptospirosis	Serology blood and urine culture
Viral infection	HIV	Serology
	Epstein–Barr virus	Serology, Paul-Bunnell test, blood film; atypical lymphocytes
Chlamydia infection	*Psittacosis*	Serology
Rickettsial infection	Q fever	Serology
Fungal infection	Histoplasmosis	Serology and culture
Parasitic infection	Giardiasis	Fresh stool microscopy
	Malaria	Blood film, rapid diagnostic test
	Trypanosomiasis	Thick blood film
	Toxoplasmosis	Serology
	Toxocariasis	Serology, blood eosinophil count
	Leishmaniasis	Serology, bone marrow
Connective tissue disorder	Juvenile idiopathic arthritis	Auto-antibodies
	Systemic lupus erythematosus	Auto-antibodies
Neoplasia	Lymphoma	Node biopsy
	Leukaemia	Blood film/bone marrow
	Neuroblastoma	Urinary VMA
	Wilms' tumour	Ultrasound or CT scan
Miscellaneous	Kawasaki disease	Erythrocyte sedimentation rate (ESR), platelets, clinical findings
	Inflammatory bowel disease	Barium studies/endoscopy
	Fabricated illness	Surveillance

4.2 Caring for children and young people in hospital

4.2.A Nursing sick children

BOX 4.2.A.1 Key points

- Children are not 'small adults'.
- Good basic care is essential and may reduce the need for further intervention.
- Have a system for allocation of nurses to patients. Any system is better than no system.
- Keep the sickest children in the place where they can be seen most easily.
- Provide information for children and their families and involve them in decision making. This reduces anxiety, improves their compliance and will make your care more effective.
- Empower the parents to provide care. This is better for the child and will help you.

Introduction

The spectrum of professional nursing care is vast, and ranges from the challenges of meeting basic human needs, key assessment and monitoring roles, to complex case management. Irrespective of the particular arena of nursing, the priority is to ensure that healthcare retains a focus on humane actions that increase the quality and effectiveness of care.

Much can be achieved by a skilled 'child-friendly' approach that leads to minimal intervention and trauma and includes the family as caregivers and, where appropriate, the child in decision making.

Children are unique, both as individuals and as a group, with rights enshrined by the UN Convention on the Rights of the Child (UNCRC) 1989. They are not 'small adults' – they have physical, psychosocial and physiological needs and responses that are different from those of adults. Effective nursing requires knowledge of these differences (recording vital signs means little without an understanding of the normal range).

Role and education of nurses

The role and status of nurses, together with the education that they receive, varies widely, although there are steps to increase standardisation. Many countries provide no specific training in the nursing of sick children. Good care is often delivered despite many challenges, but optimum care can only be consistently achieved by education and professional accreditation that relates specifically to the holistic physiological, physical and psychosocial care of the child and their family.

The increasing demands of healthcare sometimes result in an overlap of roles undertaken by nursing and medical staff. In many situations, the nurse may be the most experienced or skilled healthcare professional present.

The value of involving families in care

Hospitalisation is often a frightening experience in an unfamiliar environment, where the family no longer have their usual control over everyday life. Nurses should aim to return much of that control back to the child and family, and work to ensure that they receive the best care possible, given the environment and resources at their disposal.

The potential benefit and contribution of the parents cannot be overestimated. If the child's family is available, they should be encouraged and supported to participate in the child's care. Parents provide valuable information about what is normal for their child and how this may have changed. Since they know their child best they are often the first to notice small changes in his or her condition that may later prove significant. However, this critical knowledge can only be utilised for the benefit of the child if the contribution of families is recognised and valued.

Nurses as communicators and advocates

Nurses are central to communication between the multidisciplinary team and the family. They have a key role as an active advocate for the child, although this is often easier to say than to do. The hierarchical cultures in some healthcare systems can conspire against this, often to the detriment of the child. It is the responsibility of all healthcare professionals to promote an environment in which the views of all involved in the child's care, but especially the views of the child and their parents, are heard.

Inappropriate and unnecessary painful interventions and investigations, long hospitalisations without good reason and unnecessary separations from the family cannot be justified and are an abuse of children's rights under the UNCRC. Hospitals and other healthcare settings present numerous potential risks to children. It is the responsibility of every healthcare facility to be a place of safety, and of every healthcare worker to protect the best interests of children.

Basic nursing care

Organising care

In many places a small number of nurses have to look after many children. This makes it very difficult to provide good care, and this is a major (and sometimes overwhelming) challenge for nurses.

It is important to organise nursing care well and efficiently, particularly when resources and the number of nurses are low. Even when there are good resources, poor organisation will result in suboptimal and inequitable care.

A system of allocating certain numbers of patients to nurses, or grouping children by the acuteness of their needs, can help to make the best use of available resources

and ensure some continuity of care. However, any system of care is likely to be better than no system at all.

In busy settings is it also important to place the sicker children (particularly children without a parent present) in beds where they can be easily and most frequently seen – for example, near to the nurses' station.

The importance of basic care

Although patients may sometimes require complex treatment, there are basic needs that will always have to be met. Unfortunately, these are sometimes viewed as being of secondary importance, but providing good basic care often reduces the need for further intervention, and can enhance other therapies (e.g. the beneficial effect of improved nutrition on wound healing), whereas poor basic care has the opposite effect (e.g. the adverse effects of stress on respiratory and cardiac function). Where therapeutic options are limited due to lack of availability, limited financial resources, etc., or perhaps where no further curative treatment is possible, the provision of good basic personal care is particularly relevant. It is invariably viewed as part of the nursing role, but in fact the underlying approach required is common to all healthcare professionals, and it should be understood that the provision of such care is rarely a simple task. It requires understanding, skill and patience, and is a subject that justifies a separate or expanded publication. Only the bare essentials are covered in this manual.

Information, participation and comfort

Hospitalisation often represents a traumatic change in the life of a patient. Much that was previously familiar and predictable in their life has now been replaced by an unfamiliar environment and fears about an uncertain immediate (and maybe long-term) future over which they have little control. Our words and facial expressions convey a stream of messages, but we often have little understanding of how we are perceived. Effective communication plays a vital role in the care of patients, and has a dramatic impact on their experience of and response to treatment.

Both the patient and their family have a need to trust those who are caring for them, to be told what is wrong and also to know what is going to happen to them. This is a major factor in helping them to adjust to the situation, develop coping strategies and make decisions about their own care.

The 'information needs' of children are often neglected, sometimes because it is assumed that their understanding is limited. However, even young children have a need to be given information in a language that is understandable to them. In the absence of reliable information, a child's fantasy may well be far more distressing than the reality.

These issues are also very important in preparing the patient (and their family) for a procedure. They need to be told truthfully and sensitively what will happen, particularly if it might be painful. If the patient is not warned, their trust in those around them can be destroyed, future procedures will be feared, their anxiety will be increased and the nursing task will be made more difficult.

Communication is a two-way process. It involves both conveying the message effectively and having an understanding of the thoughts and feelings of the other person. Children and their families should be allowed and encouraged to participate in decisions that affect them. This requires a willingness and ability to engage with them and actively listen to them, and to interpret non-verbal signs that often tell a different story to the words that are actually spoken. Patients need to express their worries and anxieties. Young children do not always have sufficient vocabulary to convey how they feel, so the use of play and other activities, such as drawing, is a useful way to enable them to express themselves and to give them control.

Factors that may appear trivial to an adult may be important to a child. There may be issues causing distress that can be easily resolved, and in cases where there is not a solution, the feeling of isolation that is often experienced by these children can be helped by having someone to share their anxieties with.

Where the situation is grave, families sometimes struggle to discuss distressing subjects with their child. Although these are difficult and emotional situations, even very young children are extremely sensitive to the distress and anxiety of their family. They often have a much greater level of awareness than is generally realised, and failing to acknowledge the reality of their position may intensify their feelings of isolation by denying them the opportunity to express how they feel or to ask questions.

This all takes time, which may well be in short supply (another reason for encouraging family involvement), so it is important to make the most effective use possible of the little time you may have with a patient. The way you approach, talk to and touch the patient can make a big difference to the way they feel. It helps to build trust and it influences their compliance. Touch is a powerful tool and can convey more than words in terms of comfort and reassurance. Having their personal needs attended to may unfortunately be one of the few times during the day that a patient has the opportunity for human touch, so it is important to be kind, gentle and thoughtful in your approach.

Personal hygiene and protection of privacy and dignity

Personal care can contribute significantly to the way a sick or dying patient feels, and can prevent further problems such as sores at pressure areas. Attention to personal hygiene needs should always be given in a manner that protects the dignity of the patient. Even very small children often feel shy or uncomfortable when being attended to by an unfamiliar person, and this is particularly the case with older children and teenagers. It is another very good reason for encouraging the family to be involved in the patient's care, as well as helping to fulfil the natural wish of many parents to participate in this way.

When washing the patient, extra attention should be paid to skin folds, the neck, the back, the ears and the genitals, and the child should be encouraged to do as much as they are able. Patients who are malnourished, who have been sick for a long time or who have malignancies can have fragile skin that easily breaks down and requires special attention. An effective method that can be used by both professional and family carers is to gently change the patient's position at frequent intervals. This relieves the pressure on any given part of the body, and prevents reddening and breakdown of the skin. Pain relief should be given to prevent discomfort (*see* Section 1.15) and, when possible, pressure-relieving measures are also helpful.

Good mouth care is very important, and the patient should be encouraged to maintain this when in hospital. For children who have not brushed their teeth before, this

is a good opportunity to start, and help needs to be given to those who are unable to do this. In patients who are very sick or who are dying, mouth care can help to prevent many problems, including bad breath, bleeding, infection, ulceration and pain, that can significantly add to their suffering. For these patients the following measures can be helpful:

- using a soft toothbrush or mouth sponge to clean the patient's mouth regularly
- using wet mouth swabs if the patient's oral intake is low
- using lip balm for dry lips.

Hydration and feeding

Children can quickly become dehydrated, particularly if they suffer from diarrhoea, vomiting and/or fever, or when they are too tired and lethargic to drink. Any caregiver should be able to recognise the observable signs of dehydration (for signs and symptoms, see below and Section 5.12.A).

Severe dehydration: two or more of the following signs are present:

- Lethargy/unconsciousness
- Sunken eyes
- Unable to drink or drinks poorly
- Skin pinch goes back very slowly (2 seconds or more).

Some dehydration: two or more of the following signs are present:

- Restlessness/irritability
- Sunken eyes
- Thirsty/drinks eagerly
- Skin pinch goes back slowly.

Other signs include the following:

- Reduced urine output/concentrated urine
- Increased pulse rate
- Increased respiratory rate
- Dry mouth
- Sunken fontanelle, where relevant.

A swift response to a patient who either is, or is likely to become, dehydrated can prevent a further deterioration and the need for IV fluids. Oral rehydration solution (ORS) powder to be mixed with boiled and cooled water (and also daily zinc supplementation) should be available in all hospitals, but in its absence the following will be suitable:

- To 1 litre of boiled water that has been allowed to cool add 6 level teaspoons of sugar and half a level teaspoon of salt (the solution should taste no saltier than tears).
- Dhal water, rice water, bean broth, fruit juices and thin porridge cereal are also effective.
- Breastfeeding mothers should be advised to breastfeed their child more often during episodes of diarrhoea.

Trying to persuade a patient, particularly a sick young child, to drink is not always easy:

- Encourage the patient to drink small amounts and often.
- Give them an age-appropriate explanation of why this is important.
- Involve the patient and decide together with them how much they will try to drink each hour.
- A child under 2 years of age needs to drink between a half and a quarter of a 250-mL cup for every watery stool.
- A child over 2 years of age needs to drink between a half and one full 250-mL cup for every watery stool.

For small children or those who are too tired to drink by themselves, the following measures can be helpful:

- Use a small cup, spoon or syringe.
- Encourage the child to play, or to participate by using the syringe him- or herself.
- Give small rewards for drinking.
- Give praise when fluid is taken.

Patients often lose their appetite when they are ill. In short acute episodes, the main priority is fluid intake and the replacement of salts. However, in longer periods of illness it is essential to ensure an adequate nutritional intake.

Anxiety caused by separation from their family can cause children to lose their appetite, and when they find themselves in an unfamiliar environment such as a hospital, a choice over whether or not to accept food or drink may represent the only control that the child still possesses.

Feeding difficulties often cause distress to families. The parents of a child who is dying may feel that a lack of nutrition will contribute to or hasten their child's death. These anxieties should be understood. It should also be explained to the parents that loss of appetite is sometimes part of the deterioration process, and the patient should be encouraged to eat what they want.

It is important to recognise and manage other factors that have an effect on oral intake, such as sore mouth, nausea, vomiting and constipation.

Try the following:

- Provide familiar food for the patient, and let them choose the food if possible.
- Encourage children to feed themselves if they are able to do so, and encourage the parents to help.
- Avoid performing invasive procedures immediately before or during a meal.
- Try giving small amounts of food often, rather than two or three large meals a day.
- Avoid giving the child highly spiced or strong-smelling foods unless such foods are the cultural norm for them.
- Give food at familiar times for the child, and try to make mealtimes fun.
- Praise the child when they eat, but do not criticise or punish them when they cannot.

Where possible, keep an accurate written record of all the patient's fluid and dietary intake, and also their output (urine, stool and vomit) (for an example of a chart, *see* Section 9, Appendix). Compare the total intake and total output over a given time period (usually 24 hours), and add an amount for insensible losses through perspiration and breathing (approximately 15 mL/kg/day, or more if the child has fever or is in a hot environment). Alongside clinical observations, this will give an indication of the patient's hydration level, and will also give warning of a patient who is becoming dehydrated. In reality, written records are often inaccurate and frequent weighing (e.g. once each day at the same time, wearing clothes of similar weight) can provide a valuable guide to fluid balance.

Elimination

For the management of constipation and diarrhoea, *see* Sections 5.12.A and 5.12.C.

The elimination habits of children vary with the individual, but often change when they are sick or in hospital. There are many possible causes of this, including the disease

process, surgery, injury, and medication. Anticipating problems can do much to help. However, awareness of basic issues is always important.

- Maintain an adequate level of hydration.
- Obtain information about the child's normal elimination pattern.
- Children may be too frightened to go to the toilet in a strange place.
- Pain (e.g. from a urinary tract infection, anal fissure or post delivery in pregnant adolescent girls) may cause a patient to retain and deny the need to go to the toilet. Analgesia and simple measures such as sitting the patient in warm salty water can help to ease the pain and encourage urination or defecation.
- A patient who is passing bloodstained stools may be frightened and need reassurance.
- Praise and encouragement are important and effective.

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4.2.B Nursing care for adolescents

Introduction

Adolescents are not small adults. Between the ages of 10 and 19 years their needs are complex as they make the difficult transition from dependency to responsible and independent adulthood. They are feeling their way towards this independence but at the same time may not feel confident, even if they are reluctant to admit this. When they are ill enough to require hospital care, frequently because of pregnancy and delivery, these pressures are even more marked.

Changes in adolescence that are relevant to hospital care

Sexual risk in adolescence

Adolescents, particularly girls, are vulnerable to sexual exploitation, especially if they are living in poverty. They may not know how to negotiate whether to have sex or not, or how to protect themselves from sexually transmitted infections (STIs) and pregnancy. They may have no caring adult to turn to. There are many stories of adolescent girls being coerced into unwanted sexual activity by those in positions of responsibility. They may be promised high school marks, or clothing, or money they need to help their families. They may fear reporting this, feeling that they will be shamed or not believed. They may be raped by men whom they know or to whom they are related, or by strangers, particularly in times of conflict and displacement. They may be endangered when rape is seen as bringing shame on the family. It may be difficult or impossible to prevent pregnancy, or they may not know how to do so. They may fail to report a pregnancy until it is too late for much of the antenatal care that is available. They may attempt to abort the fetus with extreme risk to their own life because they do not know what else to do. At the very least, these young women are vulnerable to STIs, including HIV and human papilloma virus (HPV) (the latter being a cause of cervical cancer). Such diseases (*see* Section 6.1.J) may be silent, or these young women may not know what to do or who to tell about symptoms that they experience. There is a high risk that pelvic inflammatory disease will result in infertility.

Pregnancy and childbirth

For an adolescent girl, pregnancy itself brings additional threats. She may not yet have completed her own growth and physical development. Her pelvis may not be fully developed, and the risk of obstructed labour and its consequences, namely fetal damage or death, maternal death or fistulae, is greater than for older women. She needs good nutrition for her own growth but has to provide for the fetus, and then for lactation, at the same time. The potential for malnutrition is high unless she has access to all the nutrients she requires. For this reason it is important that her nutrition status is monitored during pregnancy. She should also be given advice, help and micronutrient supplementation.

Other health dangers await pregnant adolescent girls. They are at greater risk of developing anaemia and pregnancy-induced hypertension, including pre-eclampsia and eclampsia. Stillbirth and neonatal mortality rates are higher in this age group, and babies are often of low birth weight. These girls may also have undergone female genital cutting (FGC) (*see* Section 2.10), with the many and lifelong health problems this may cause, and even social exclusion because of resulting fistulae or death from obstructed labour. Overall, complications of pregnancy and childbirth are the leading cause of death among female adolescents according to the World Health Organization (WHO).

Despite the dangers, many girls achieve a successful pregnancy outcome and become competent mothers. They may have to do this without the support of the baby's father or even their parents, and will have their education disrupted or even ended. They will often have to bring up the child in poverty, perhaps also being excluded socially. Others are married at a very young age, not necessarily willingly. Any adolescent mother (and father) will need help with parenting and the development of life skills to prevent their circumstances from spiralling downward. Family planning advice will be very important to enable these young

women to avoid further pregnancies too soon, which would add to the downward spiral.

Mental health problems

Mental health problems are not confined to adults. Apart from having psychiatric disorders such as schizophrenia, young people may be depressed and confused, bullied, abused emotionally and psychologically as well as physically, and have to take part in activities that cause great stress. They may be forced to become child soldiers, they may have to take responsibility for other children in their family and even care for adult relatives such as parents with AIDS, and they may experience personal loss. An unhappy home life may lead to self-harming, to life-threatening eating disorders and to attempted suicide, any of which may result in hospital admission.

Malnutrition

It is not just in pregnancy that young people become malnourished. Malnutrition may occur because of poverty, or lack of access to healthy foods, or because of peer pressure and habit. This has substantial implications for their growth and development, their general health in the future, and their ability to recover from adolescent illness.

Implications for hospital care

Hospital care for adolescents is particularly difficult. Providers need to be sensitive to the needs and fears of these young people, and avoid being judgemental. A bad experience or poor-quality services may lead to adolescents failing to return, and possibly spreading the word to their friends. For a girl to have to attend an antenatal clinic alongside older and obviously married women is hard. To have to sit in a family planning clinic alongside women from her own community, and to have to tell a nurse (who may be a relative or who may know her parents) that she is sexually active is even harder. Young men will find it equally difficult to attend for contraceptive advice, and for adolescents of both sexes, attending an STI clinic could be an ordeal that they do not wish to repeat. At the same time, the pressures on young people are often so great that bad experiences are not effective deterrents to risky behaviours.

Dignity, privacy and confidentiality

Hospital care can be an experience of dignity and acceptance, or of rejection and embarrassment. Adolescents are unlikely to have special areas or wards except in the most well-resourced units. However, some kind of arrangement is needed to ensure that they are not nursed in the same space as very much older people, or with young children, and certainly not in mixed-sex areas. Facilities for privacy are needed, such as curtains around beds and interview spaces, and some arrangement should be made to ensure that interviews and conversations cannot be easily overheard.

Preservation of dignity, privacy and confidentiality is as important for adolescents as it is for adults. Going through puberty can make adolescents particularly self-conscious and even traumatised when examinations, such as those of their genitals, are performed insensitively or roughly. This may be especially difficult for young women (or men) who have experienced violence or sexual assault. Adolescent males may also feel great shame that an assault has happened and that they have been unable to prevent it. Therefore every effort needs to be made by care providers, from healthcare professionals to cleaners and porters, to maintain the privacy, dignity and confidentiality of these young people.

Confidentiality can be a particular issue when patients are minors, under the age of consent for the country in which they live. Parents or guardians may need to be given information that young people would prefer was not shared. There is no clear answer about how much those responsible should be told if the adolescent indicates that information should be withheld. Carers will need to be guided by their ethical codes and make decisions according to the best interests of each individual young person, as well as to the prevailing laws.

Parents or guardians may have legal powers to decide what treatment adolescents should receive, such as giving consent for surgery, but every effort needs to be made to take the young person's wishes and views into account. In some countries, even a court of law will take a child's wishes into account as they near the age at which they have the right to make decisions.

Services for young people with a disability

Care providers need to be particularly vigilant in providing services for young people living with disabilities, especially mental or learning disabilities. These people are vulnerable to abuse, to finding services inaccessible or inappropriate, and to misunderstanding of their needs. When they are away from their normal environment, as when in hospital, they may become withdrawn, confused and possibly uncooperative. Ensuring that young people with a disability feel secure and well treated is the responsibility of all grades of staff.

Emergency services

Emergency services for young people should not be neglected. Young women may need gynaecological assistance, for example, for the consequences of female genital cutting or sexual assault. They may need access to post-exposure prophylaxis for HIV, or to emergency contraception where this is acceptable, or to post-abortion care. Mental health problems may be acute and arise as emergencies, especially following major emotional stresses, when illnesses such as schizophrenia first arise, or when young people self-abuse or attempt suicide.

Building relationships

Trust is of primary importance for young people. Services that take into account the need to build trusting relationships are likely to be more acceptable, and therefore more effective and better used. Continuity is important, so that adolescents do not see a new face every time they attend for healthcare or counselling, but instead have the opportunity to develop a relationship of trust. This is a significant management issue, but it is important in terms of service uptake, effective use of human and other resources, and overall effectiveness of treatment programmes.

Advocacy

Healthcare providers have a strong advocacy role for adolescents, particularly in the context of working together, as for example in professional associations. This may involve campaigning for better services, talking to colleagues about

their behaviours, or providing professional development opportunities. It may involve listening to young people, working with them, or campaigning against harmful local practices such as female genital cutting, early and/or forced marriage, ritual sexual initiation by older men, and erroneous and damaging beliefs (e.g. that having sex with young girls will cure HIV).

Hospital care summarised

The WHO suggests that services need to be accessible, acceptable, equitable, appropriate and effective. This means that young people need:

- appropriate, acceptable, accessible and gender-sensitive hospital and community services
- carers who have approachable, accepting and non-judgemental attitudes
- confidentiality, preservation of dignity and privacy
- accurate and honest information
- choice and some control over what happens to them
- avoidance of inappropriate hospital inpatient facilities where possible
- targeted health promotion
- targeted services, for example:
  - for young people with long-term physical disability or illness
  - for young people with learning and developmental disability
  - for family planning
  - for STIs and HIV
  - for pregnant adolescents, including post-abortion care, emergency contraception (if permitted), antenatal, labour and postnatal services, and nutrition services
  - for young mothers, whether supported or not, and young fathers
  - for displaced adolescents (e.g. refugees, internally displaced persons, the homeless)
- emergency health and counselling services for support in crisis
- advocates who understand their needs and can support them both as a group and individually (e.g. with families).

Finally, nurses, midwives and doctors may be the only people whom adolescents feel able to talk to, especially as others, such as parents, teachers and religious leaders, may be seen as authority figures. This vital role goes way beyond simply providing medical, surgical or obstetric care.

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4.2.C The child with a disability in hospital

BOX 4.2.C.1 Minimum standards

Prevention of avoidable disability

- Good antenatal care, including folic acid, iodinisation of salt, iron, antimalarial drugs and anti-tetanus immunisation.
- Good care during delivery, including access to obstetric surgery and blood transfusion.
- Effective neonatal resuscitation and care of the newborn.
- Injury prevention.
- Effective immunisation programme.
- Good management of acute illness and injury.

Management of existing disability

- Access to diagnostics.
- Multidisciplinary care.
- Aids for disabled children.
- Promoting equality of opportunity for children with a disability.

Introduction

Around 10% of children in most developing countries are disabled in some way. All children who are hospitalised for illness or injury are at risk of becoming disabled due to their condition and/or their management.

Disabled children: definitions

- Disorder is a medically definable condition or disease.
- Impairment is the loss or abnormality of physiological, anatomical or psychological structure or function.
- Disability is any restriction, due to an impairment, in the child's ability to perform an activity in the normal way for a child of that age.
- Handicap is the impact of the impairment or disability on the person's pursuits or achievement of goals that are desired by him or her or expected of him or her by society
- Special needs refers to children who have needs greater than the normal needs of children of their age.

In 2001, the WHO introduced a new system of classification, The International Classification of Functioning, Disability and Health (commonly known as ICF) (www.who.int/classifications/en/) which uses two lists, a list of body functions and structure, and a list of domains of activity and participation. Since an individual's functioning and disability occur in a context, the ICF also includes a list of environmental

factors. The ICF replaces the previous classification based on 'impairment', 'disability' and 'handicap', and shifts the emphasis to functioning. The ICF puts the notions of 'health' and 'disability' in a new light. It acknowledges that every human being, through illness or injury, may develop a disability. It 'mainstreams' the experience of disability and recognises it as a universal human experience. Furthermore, the ICF takes into account the social aspects of disability, and does not see disability only as a 'medical' or 'biological' dysfunction, but includes contextual factors, such as environmental factors. The ICF encourages assessment of the impact of the environment on the person's functioning. For example, hospital staff should be vigilant about preventing the development of contractures in a comatose child because they are concerned to ensure the best functioning of the child when he or she recovers.

Children's rights

Article 23 of the UN Convention on the Rights of the Child (www.ohchr.org/en/professionalinterest/pages/crc.aspx) defines the right of disabled children to special care, education and training designed to help them to achieve the greatest possible self-reliance and to lead a full and active life in society. It also encourages states to develop free and accessible services where possible, and to share information with other countries regarding the latest findings of research into the management of disabling conditions.

The main care of children takes place in the community. Children with special needs and chronic illness and their parents are entitled to receive the same standard of care as any other family when their child is in need of acute care for any other condition described in this book. The attitude of healthcare professionals should reflect this important principle. Many cultures in resource-limited countries have a greater degree of acceptance of disabled people than is found in more well-resourced countries. However, some cultures regard disability as a punishment or as a cause of shame. Accepting, encouraging and supportive behaviour of healthcare providers towards children with disabilities will go some way towards dispelling these attitudes.

Planning of services

Ministries of health and hospitals should consider establishing a register of disabled children, but only after careful consideration of the aims of registration, the likely benefits and costs, and the resources available.

The aims of a service for disabled children

These are as follows:

- to provide health services which ensure that children reach their maximum potential, optimising their independence and ability to lead a high-quality life
- to ensure that disabilities are promptly identified and treated where possible
- to promote active involvement of disabled children and their families in all aspects of healthcare, working in partnership with healthcare professionals
- to promote access to the healthcare facility for families with disabled children
- to provide comprehensive, integrated and coordinated services both in the healthcare facility and in the community, utilising outreach and community-based services, including community-based healthcare workers
- to enable health services to work with other key agencies, such as social services and education and training services.

The prevention of impairment and disability in children

This is the main issue in resource-limited countries, where facilities to support such children are very limited. Of most importance are the quality of antenatal care, the quality of neonatal resuscitation (*see* Section 3.2), the prevention of cerebral oedema due to inappropriate fluid management (*see* Section 5.12.A), the prevention of hypoxic-ischaemic cerebral injury (*see* Section 3.2), provision of adequate nutrition, the avoidance of accidents and protection from abuse (*see* Section 7.6). Adequate immunisation to combat poliomyelitis, measles, malaria, TB and meningitis, which are major causes of disability, is also mandatory.

Antenatal, peripartum, infant and child care

- Doctors and nurses working in hospital maternity services should work closely with local leaders, women's groups, and the Ministry of Health to improve pregnancy outcomes. This will involve promotion of early attendance at antenatal clinics. Detection and treatment of diseases such as syphilis and malaria, which can cause intrauterine growth retardation (IUGR) and prematurity, management of HIV and prevention of mother-to-child transmission, and the detection and management of intestinal worms and nutritional deficiencies are all essential.
- Every attempt should be made to provide good nutrition for women who may become pregnant. Folic acid supplements at the time of conception are vital for preventing spina bifida and other congenital abnormalities.
- Iodinisation of salt is inexpensive and should be universal.
- Iron-deficiency anaemia during pregnancy is associated with low-birth-weight babies and should be screened for and prevented. Malaria in pregnant women is another cause of low birth weight and prematurity, and should be prevented or, if contracted, be treated vigorously (*see* Section 2.8.D). Ministers of Health should be persuaded of the value of providing malaria prophylaxis or intermittent preventive treatment (IPT) for all pregnant women in endemic areas.
- Immunisation against tetanus (*see* Section 1.17) is essential.
- Obstetric care within hospitals should aim to prevent impairments due to complications of labour and delivery. Crucial to this is the availability of oxygen, obstetric surgery and anaesthesia, and a blood transfusion service.
- Effective neonatal resuscitation should be available 24 hours a day in every maternity unit and for all home deliveries. Staff must be trained and should have the basic equipment (*see* Section 3.2) necessary to prevent those causes of birth asphyxia which arise after the delivery of the baby.
- Simple interventions such as not bathing immediately after birth, prevention of hypothermia, and 'kangaroo care' for low-birth-weight babies should be taught to village health workers and traditional birth attendants in regions where they play an important role in home deliveries.
- Recognition of danger signs and the setting up of

community-based referral systems to deal with emergencies should be implemented at village level.
- Breastfeeding must be encouraged (*see* Section 3.3), and special support must be given to help mothers provide breast milk for babies with developmental impairments that make sucking or attachment difficult.
- Adequate training and facilities for the correct management of dehydration in gastroenteritis (*see* Section 5.12.A), hypoxic-ischaemic injury (e.g. in injuries) (*see* Section 7.3.C) and severe anaemia from malaria (*see* Section 6.3.A.d) all reduce the frequency of preventable brain damage.
- Paediatricians in hospitals should advocate for programmes of injury prevention and the prevention of injuries to children resulting from conflict, displacement or other social factors.

Management of disabled children: identification and primary diagnosis

All babies should be systematically examined at birth and, if possible, at 6 weeks of age to detect preventable disabilities such as dislocated hips and congenital cataracts. In regions where most babies continue to be born at home, community health workers (CHWs) should be trained to detect these problems or to encourage mothers to attend for postnatal checks at a clinic where these can be undertaken.

Postnatal services should be established in all healthcare facilities that provide antenatal care and delivery services.

Protocols for postnatal care should be developed based on WHO guidelines.

Signs or symptoms of an emerging disability should be actively sought. Findings which suggest that the child may be disabled should be communicated to the parents in a culturally sensitive manner in accordance with locally developed guidelines. This communication must include information about the local availability of services and social support.

Comprehensive interdisciplinary assessment

- This should always include the child's strengths as well as their weaknesses, and an assessment of their home circumstances and educational needs.
- It should result in decisions about management, including any immediate surgical or medical treatments available to alleviate the condition.
- It should include an assessment of sensory, motor, behavioural and intellectual capabilities as outlined below.

Convening a team to plan long-term management

- The team will include those people whose skills and training are relevant to the needs of the child. The team is often led by a named paediatrician.
- Representatives from outside agencies such as education and social services must be included if they are available.
- A care manager or key worker should be appointed, who will act as a liaison between professionals and the parents to ensure that the child fully benefits from the available resources.

Development of local guidelines for clinicians

- Hospital staff should aim for an early diagnosis and identification of treatable causes of disability.
- Resources to support the child and their family should be sought.
- In the absence of social support, hospitals must develop sensitive policies to inform parents of the diagnosis and expected prognosis in a way that is compatible with the best outcome for the child.
- Such policies should be decided by each hospital, and all personnel should be informed of the policy.
- Culturally sensitive disclosure of information about the diagnosis and expected prognosis should be given by a senior clinician who has experience in this area and is aware of local attitudes and beliefs regarding disability and the services available to the child and their family.
- Services should be developed as resources allow.
- Policies with regard to the intensity of resuscitative treatment given to children with various impairments should be developed by doctors, other healthcare professionals, representatives of the local community, including disabled people, and politicians. These policies must take into account ethnic and cultural issues and local support available for the care of severely disabled children. Such policies must be reviewed frequently. A hospital ethics committee can be valuable in this respect (*see* Section 1.20).
- Development of services for and the rights of disabled people should be promoted wherever possible. Front-line staff should feel confident that they know and can work within the framework of the policy.

Diagnosis

All newborn babies should be examined before leaving hospital by a member of staff (usually a nurse or midwife, or a paediatrician if one is available), who has been trained to perform a competent neonatal examination. Any possible impairment must be reviewed by an experienced paediatrician.

The neonatal examination

- **General:** Signs of dysmorphism should be looked for. The baby should be examined for tone and observed to have normal limb movements. Disordered tone, feeding difficulties, irritability and seizures should be noted.
- **Hips:** The hips should be checked for dislocation, remembering the three major risk factors, namely family history, female gender and breech presentation. Dislocated or dislocatable hips should be referred to an orthopaedic specialist.
- **Jaundice:** Any jaundice in the first 24 hours should be taken seriously and monitored appropriately. Causes of jaundice, such as blood group incompatibilities, glucose-6-phosphate dehydrogenase deficiency and sepsis, should be diagnosed and treated. Severe jaundice can lead to deafness and cerebral damage (*see* Section 3.4).
- **Cardiovascular system:** This should be examined looking in particular for cyanosis and equality of pulse volumes, and listening to heart sounds. If abnormalities are detected, the baby should be referred to a paediatrician (*see* Section 5.4.A).

- **Hearing:** Behaviour should be observed, although hearing defects are difficult to detect in the neonatal period without special equipment.
- **Vision:** The child's eyes should be examined for infection, which must be treated with suitable medication. The absence of cataracts should be ascertained by the presence of a good red reflex in each eye (*see* Section 5.15).

Comprehensive assessment of disabled children

Most children in resource-limited countries are born at home, and therefore children with disabilities are more likely to present at the hospital in later life.

History

A complete paediatric history, including antenatal, perinatal, postnatal and family history, should always be taken. Many countries have found that the 'Ten Questions' are helpful for establishing the prevalence and distribution of various disabilities:

1. Compared with other children, did he/she have any serious delay in sitting, standing or walking?
2. Compared with other children, does he/she have difficulty seeing, either in the daytime or at night?
3. Does he/she appear to have difficulty hearing?
4. When you tell him/her to do something, does he/she seem to understand what you are saying?
5. Does he/she have difficulty in walking or moving his/her arms, or does he/she have any weakness and/or stiffness in the arms or legs?
6. Does he/she sometimes have fits, become rigid or lose consciousness?
7. Does he/she learn things like other children of his/her age?
8. Does he/she speak at all? Can he/she make himself/herself understood in words. Can he/she say any recognisable words?
9. For 2-year-olds: 'Can he/she name at least one object (for example, an animal, a toy, a cup, a spoon)?' and 'Compared with other children of his/her age, does he/she appear in any way to have difficulties in learning?'
10. For 3- to 9-year-olds: 'Is his/her speech in any way different from normal (not clear enough to be understood by people other than his/her immediate family)?'

Examination

A full clinical examination of all physical, sensory and psychological systems should be undertaken.

Additional issues

- Determine how the child and their family have adapted their lives in response to the child's difficulties.
- Determine the extent to which the available treatment, training and management will improve the situation.
- Evaluate the emotional adjustment of the child and their family to the disability.
- Investigate the educational facilities available to the child and how they may be adapted to his/her needs.
- Determine the child's and family's strengths, abilities and positive personality traits which can be encouraged to help them to cope with the disability.

Protocols for particular conditions

These should be developed to ensure that the child is thoroughly investigated initially and reviewed at regular intervals to ensure that they can reach their maximum potential.

For example, a protocol for a child with Down's syndrome could include the following:

- full medical examination
- chromosome studies (if facilities are available)
- ECG and chest X-ray with echocardiography (if available)
- development of a care plan with the parents/carers as partners
- audiological assessment
- visual assessment
- assessment by a speech therapist (if available) to promote communication skills
- assessment by an occupational therapist (if available) to determine any aids or equipment which may be of help
- thyroid function test at appropriate intervals.

Sensory impairments

Liaison between health services and local education facilities is particularly important for the support and understanding of children with sensory impairments.

Visual impairment

Evaluation (*see* Section 5.15)

Most newborn babies can focus on and follow the mother's face and large brightly coloured objects. Impaired vision can therefore be detected soon after birth. It is normally the mother who will suspect this because the baby is not looking at her when she is breastfeeding. There may be roving eye movements.

- Use appropriate objects to confirm visual impairment – for example, human face for neonates, toys for older infants, and pictures (whose dimensions correspond to Snellen letters) for older children.
- Determine whether visual impairment is an isolated problem or associated with other developmental defects (e.g. cerebral palsy) by undertaking a detailed history and physical examination.
- Check for the red reflex as follows. Shine a light on the pupil from arm's length. Normally it will appear red because of light reflected from the retina. If it appears white, consider the possibility of dense cataract, severe retinopathy of prematurity, or retinoblastoma. If the red reflex is normal, check the pupillary response to light. If the latter is normal, a local cause (i.e. optic nerve or retinal degeneration) is unlikely, and impaired vision is then most probably due to occipital lobe damage.
- Check the retina and optic nerve by fundoscopy to exclude optic atrophy and retinal degeneration. If in doubt, refer the child to an ophthalmologist.

Causes of visual impairment

Common causes of blindness in children include optic atrophy, congenital cataracts and retinal degeneration, and in resource-limited countries they include vitamin A deficiency, measles, onchocerciasis and meningitis.

Trachoma remains a major cause of blindness in many developing countries. Early detection and treatment can prevent blindness. Prevention activities should include hygiene. Mass drug administration in affected areas can be considered.

Close liaison between paediatricians and

ophthalmologists is required to develop policies to detect and treat visual defects as early as possible.

Management of impaired vision

- **Treatable causes:**
  - **Cataract:** Children with congenital cataract should be referred to an ophthalmologist as soon as possible for early treatment. If no treatment is available, the parents should be shown ways of stimulating residual vision by playing with bright lights and presenting visual stimuli to the child as much as possible.
  - **Xerophthalmia:** Treat with vitamin A (*see* Section 5.10.A).
  - **Eye infections** (*see* Section 5.15).

Community healthcare workers should have training sessions on eye care emphasising simple hygiene measures and sources of food rich in vitamin A to be found in local diets.

- **Non-treatable causes:**
  - Perform a visual assessment and provide suitable visual aids.
  - Surgical correction of squints should be undertaken (when possible).
  - Mobility training should be provided for blind children and their carers.

The family will need support and advice about appropriate schooling, changes to the home, and mobility training.

Hearing impairment

Hearing loss is a hidden defect and may easily be missed if healthcare workers are not vigilant. Because hearing defects often lead to lack of development of speech and language, the child is sometimes assumed to have learning difficulties and may be further isolated from their family and society because of this. All children who present with failure to develop language should have a good-quality hearing assessment.

Hearing is essential for language development, so early detection of hearing impairment is essential. A newborn responds to sudden noise with the startle response. A normal baby will listen to the mother's voice. Formal hearing assessments in the newborn are possible using the acoustic cradle. The distraction test is used at 4 to 8 months of age, and audiometry is used in older children.

There are two types of hearing loss:

- **Conductive hearing loss:** The commonest cause is recurrent/chronic infective otitis media (*see* Section 5.1.C).
- **Sensorineural hearing loss:** The commonest causes are meningitis, cerebral malaria, genetic defects, drugs (e.g. excessive doses of aminoglycosides) and intrauterine infections. A hearing aid is required, and the child may need to learn a sign language.

Children with the following are at risk of hearing impairment:

- family history of sensorineural hearing loss
- dysmorphic features
- abnormalities of the pinnae
- severe birth asphyxia
- severe neonatal jaundice
- other neurological abnormalities
- postnatal infections (e.g. meningitis, measles)
- treatment with ototoxic drugs (e.g. gentamicin, streptomycin).

It is most important to identify and treat causes of conductive deafness, such as chronic otitis media (*see* Section 5.1.C).

- Treatable causes of sensorineural hearing loss are very rare.
- Hospitals in association with community health services and education authorities should seek to develop services for early identification and prompt treatment of children with irreparable hearing problems. These should include simple audiological assessment and the provision of hearing aids.

Neurological problems

General advice

- Parents and carers should be given information and training so that they can modify daily activities to promote the development of the child and enhance functioning (e.g. information on prevention of contractures). Lifting, carrying, seating, playing and bathing will all need to be discussed and demonstrated.
- Physiotherapy should be commenced as early as possible to prevent the development of contractures in hypertonic children.
- Good positioning and movement are helped by appropriate aids and appliances (*see* Section 4.2.D).
- Local people are often resourceful in developing appropriate equipment for their own children out of locally available materials (see *Disabled Village Children* referenced on p. 405). Advice from occupational therapists and physiotherapists is very useful (if available).
- Communication aids may also be required, and the advice of speech and language therapists is very useful.
- Children with motor difficulties often have feeding difficulties, and may not have the same access to food sources as children without impairments. Hospital staff, community health workers and family members should receive training on safe feeding techniques in order to improve the nutritional state of these children.
- Feeding may require the placement and management of a nasogastric tube, and parents or carers should be shown how to undertake this.
- A care plan should be developed and a key worker appointed to monitor long-term plans to support the parents and keep them informed and involved in the long-term planning of services for their child.
- Aids to enable the child to have mobility, an effective means of communication and access to education should be developed in the community.
- All hospitals should seek to develop specialist therapy services to help such children.

Neural tube defects

(See also section on paraparesis and incontinence below.)

- Where possible, neural tube defects should be prevented by adequate maternal nutrition, including folic acid and vitamins at the time of conception.
- Children born with neural tube defects should be treated urgently to prevent worsening of their condition (*see* Section 5.16.K).
- Parental wishes in terms of surgical treatment are very important.
- Later complications involve the urinary tract and bowel

function. Poor blood flow to the lower limbs associated with a lack of sensation and mobility may result in pressure sores.
- Many children with spina bifida require alternative means of mobility.
- Spina bifida occulta may result in clumsiness and continence problems. Some of the associated problems may be improved by surgical intervention.

Delayed development (see Tables 4.2.C.1 and 4.2.C.2)

Delayed development presupposes knowledge of normal development. Development proceeds in an orderly fashion, but there is considerable variation in the age at which milestones are achieved.

TABLE 4.2.C.1 Normal milestones in development

Age	Milestone
Birth	Focuses with eyes and responds to sound
4–6 weeks	Social smile
6–7 months	Sits without support, transfers objects from one hand to the other
9–10 months	Pulls to stand, pincer grasp, waves bye-bye
12 months	Stands, walks with one hand held, two or three words, stranger anxiety
15 months	Walks, drinks from cup
18 months	Says ten words, feeds with spoon
2 years	Runs, draws straight line, says two-word sentences
3 years	Draws circle, draws cross, says three-word sentences, dresses in simple clothes without assistance
4 years	Stands on one leg, fluent speech **Note:** in societies where access to pens and paper is very limited, even adults find drawing a line or a circle difficult as such an action is outside their experience

Developmental assessment

The purpose of developmental assessment is threefold:
1 to confirm normal or delayed development
2 to identify possible causes of delayed development
3 to plan a strategy for intervention.

To achieve these aims, a detailed history and physical examination are essential. Particular emphasis is placed on perinatal and developmental history. As well as looking for signs and symptoms of severe malnutrition or micronutrient deficiencies, allowance must be made for prematurity. Evidence of microcephaly, dysmorphic features and signs of neglect must be looked for, and a detailed neurological examination, including primitive reflexes, undertaken. The following questions must be addressed:
- Does the child have global delay (i.e. delay in all areas of development)?
- Is the delay confined to one area of development? If it is confined to the motor area, this suggests a possible neuromuscular disorder. Delayed speech development with normal motor and social skills could suggest a hearing disorder.
- Has the child lost previously acquired skills, and if so, has the loss been progressive? This suggests a neurodegenerative disorder.

TABLE 4.2.C.2 Warning signs in development

Age	Sign
10 weeks	Not smiling
3 months	Not responding to noises or voice, not focusing on face, not vocalising, not lifting up head when lying on stomach
6 months	Not interested in people, noises or toys, does not laugh or smile, has squint, hand preference, primitive reflexes still present
9–12 months	Not sitting, not saying 'baba' or 'mama', not imitating speech sounds, no pincer grasp
18 months	Not walking, no words, no eye contact, not naming familiar objects, not interested in animals, cars or other objects Passive – not moving about exploring, excessive periods of rocking and head banging
3 years	Unaware of surroundings, not imitating adult activities, little or no speech, long periods of repetitive behaviour, unable to follow simple commands
4 years	Unintelligible speech
At any age	Parental concern, regression of acquired skills

Delayed walking (not walking by 18 months)

- Family history of late walking and otherwise normal: give reassurance.
- Global delay (especially in language and social skills): the child probably has mental impairment.
- Child failing to thrive, and showing signs of malnutrition and poor nurture: this suggests neglect.
- Cerebral palsy with upper motor neuron signs (spasticity, clonus, brisk reflexes) or dystonia, ataxia and involuntary movements.
- Neuromuscular disorders (*see* Sections 5.16.F, 5.16.G and 5.16.H) with flaccid weakness, wasting or fasciculation of muscle, absent or diminished reflexes.
- Congenital dislocation of the hips or rickets can cause delayed walking.

Delayed language development

For meaningful speech to develop, the infant must be able to hear, and have intact language pathways and normal oropharyngeal structures. The child must also receive verbal communication.

The following approach to evaluating a child with language delay is useful:
- Is there a hearing defect?
- What is the problem in language delay? Is it in understanding or in expressing thoughts, or both?
- Is the delay confined to language or is it part of global delay (consider severe learning difficulty)?
- Is there any dysfunction or defect of the mouth and pharynx (obvious on physical examination)?

If the child cannot communicate and has normal intelligence, they will try to compensate by using gestures and/or signs. They are also likely to be frustrated and angry. The

child whose language delay is part of a general learning difficulty is likely to be more passive and less frustrated.

Does the child have a problem with social interaction? Consider autism, signs of which include loss of social interaction, little or no non-verbal communication, no eye contact, and repetitive ritualistic behaviour.

Cerebral palsy (see Table 4.2.C.3)

Cerebral palsy refers to the disturbance of movement and/or posture that results from a non-progressive lesion of the developing brain. The commonest causes are hypoxic-ischaemic insult to the brain occurring prenatally or perinatally, or occasionally postnatally (e.g. meningitis, head injury). There are several different types of cerebral palsy, including the following:

- spastic diplegia (common with prematurity)
- spastic quadriplegia and spastic hemiplegia
- dyskinetic type (abnormal non-purposeful writhing movements induced by voluntary activity).
- ataxic type (involves mainly the cerebellum and is rare).

Diagnosis

The child normally presents with delayed development and is found to have abnormalities of tone, delay in motor development, abnormal posture or movements, and persistence of primitive reflexes. The diagnosis is made on clinical grounds and investigations are not required.

Evaluation

Assess the functional status of the child with regard to the motor system (this is best performed by a physiotherapist), and identify associated problems.

Management

The child with cerebral palsy has multiple problems and invariably will require care from a multidisciplinary team. The doctor and the physiotherapist play a prominent role. Physiotherapy advice enables the parents to move and handle the child in their daily activities to improve mobility and aim to prevent contractures. Parents need support in ensuring both that the educational needs of the child are met and that the child is integrated as fully as possible into society.

Deterioration in children with cerebral palsy

Children with cerebral palsy usually remain stable. If a child shows apparent deterioration consider the following possible causes:

- pain from dislocation of the hips
- dyspepsia from gastro-oesophageal reflux
- non-convulsive status epilepticus
- deterioration in mobility during growth spurt
- wrong diagnosis – the child may have a progressive neurodegenerative disease.

Paraparesis and incontinence

Paraparesis (paralysis of both legs) is usually due to a spinal cord problem. This may be congenital, as in spina bifida, or acquired (e.g. following trauma, infection or malignancy). Some causes are treatable if diagnosed early (e.g. TB of the spine). Burkitt's lymphoma with paraparesis is a sign of advanced disease and is often associated with a poor prognosis. Both thorough clinical assessment to establish the level of the lesion, and reassessment to look for changes, are essential. Any suspected space-occupying lesion needs surgical advice.

TABLE 4.2.C.3 Problems in children with cerebral palsy

Problem	Action
Visual and hearing impairment	Refer to appropriate specialist
Epilepsy	Anti-epileptic drugs
Contractures	Physiotherapy and (rarely) surgery
Dislocation of hips	Surgery to relieve pain
Feeding difficulties, failure to thrive	Monitor intake Correct positioning for feeding Increase energy content of food Consider gastro-oesophageal reflux
Recurrent aspiration	Close attention to feeding position, pacing of feeds, and positioning
Respiratory infections	Antibiotics
Gastro-oesophageal reflux	Feed thickener (starch), H_2-receptor antagonist (e.g. ranitidine) or proton-pump inhibitor (e.g. omeprazole) Exclude oesophageal stricture and/or aspiration
Constipation	Diet and stool softeners
Learning difficulties	Additional help with education

Many children with paraparesis **will** suffer preventable complications **unless** carers and staff are aware of the risks of the following:

- **Poor nutrition:** many children with paraparesis find it difficult to eat and drink. They need good food to enable them to withstand infection, keep their muscles from wasting, prevent constipation and maintain good skin.
- **Contractures:** all joints need to be moved through their full range of movement to prevent contractures developing. If the child has presented late and contractures are already established, a programme of gradual passive stretching may help to improve the range of movement.
- **Pressure sores:** these are prevented by ensuring that the child is moved regularly. The child can often learn to do this by using their arms and upper body strength to pull on a suspended strap or ring to move their own position. The child can use a mirror to inspect their own skin to look for sore patches. Established pressure sores take a long time to heal. They must therefore be kept clean and free from pressure.

Rehabilitation should start immediately, but will depend on whether the child's spine is stable. A creative approach to mobility, using locally available materials (see *Disabled Village Children* by David Werner), is more likely to succeed than waiting for sophisticated rehabilitation equipment to be purchased.

Incontinence is usually associated with paraparesis, and can be both socially and medically disastrous. Some children have neuropathic bladders which are usually full, empty incompletely and may lead to reflux nephropathy, hydronephrosis and renal damage. These children need intermittent clean catheterisation to prevent back pressure and infection. Clean catheterisation may be required up to every 3 or 4 hours. This technique can be easily learned by

a carer or by the older child. Other children have bladders that are not full and which empty themselves frequently. These children are at less medical risk of kidney problems, but it is much more difficult to enable them to be socially dry without complex surgery to enhance the size of the bladder.

Most children with bowel continence problems associated with paraparesis will be constipated due to their relative immobility. A healthy diet and plenty of fluids will prevent constipation. Bowel evacuation in young children is often managed by abdominal massage. Older children can learn to use a Shandling catheter, which is a plastic tube that is passed up the rectum for a washout of the bowel contents with saline.

Learning difficulties and developmental delay

- Children who do not meet their expected developmental milestones should be assessed for possible causes.
- Some children have specific learning difficulties and may be assumed to have general learning difficulties unless they are carefully assessed. Full psychological assessment is helpful (if available).
- Treatable causes (e.g. hypothyroidism, abuse/neglect, malnutrition, anaemia, etc.) should be ascertained. Problems such as autism and attention deficit disorder, with or without hyperactivity, should be documented.
- In planning services for these children, social and educational involvement is essential.

Severe learning difficulties

Severe learning difficulties (formerly referred to as mental retardation) are suspected when there is global developmental delay especially in language, social and fine motor skills. Gross motor milestones may be normal. Causes include fetal alcohol syndrome, hypoxic-ischaemic injury to the brain, Down's syndrome, fragile X syndrome and neurocutaneous syndromes, among others. **Treatable causes should be excluded** (e.g. hypothyroidism, phenylketonuria).

The parents will need considerable support in coming to terms with the diagnosis and its implications. They should be encouraged to stimulate the child's cognitive, language and motor development. Provide advice on appropriate play activities, suitable toys and reading material. Some children will be able to attend mainstream schooling but will need additional help; others will be better supported in special schools (if available). Their progress must be continuously monitored and associated problems dealt with. They deserve the same care as normal children.

Autism and communication disorders

- Autism usually presents in the second or third year of life.
- It is primarily a communication disorder associated with an absence of or disordered speech and language development.
- It is often associated with obsessional behaviours or interests.
- It may or may not be associated with mental retardation.
- It is often associated with learning difficulties because of inability to understand social situations.

The following should arouse the suspicion of autism: no babbling by the age of 1 year, no pointing by the age of 1 year, no single-word utterances by 16 months, no spontaneous two-word utterances by 24 months, and any regression in social skills and language.

Developmental coordination disorder

About 5% of children have difficulties with coordination which may affect their ability to perform motor tasks such as writing or sport. It is important to exclude a serious neurological cause and identify that the child cannot do these activities well, so that teachers and others do not conclude that the child is 'lazy'.

Attention deficit disorder

This is a major problem associated with the following:

- difficulty with concentration
- impulsivity
- difficulty in predicting the outcome of actions, so the child does not learn from their mistakes
- a strong association with hyperkinesis/hyperactivity
- poor listening skills.

Attention deficit disorder improves with maturity.

Treatment is difficult. The most important points are to recognise the disorder, explain it to the parents and provide them with family and/or other support to cope with it. **Stimulants, such as methylphenidate, used by an experienced health worker, may be very helpful.**

Behaviour disorders

- Exclude attention deficit disorder and other developmental impairments.
- Try to exclude abuse, although a behaviour disorder may coexist with abuse (*see* Section 5.9).

Psychiatric disorders (see Section 5.9)

- These are rare in young children.
- Severe malnutrition, deprivation and abuse can lead to depression and the signs of frozen awareness/watchfulness (*see* Section 7.6 on child abuse).

Surgically treated disabilities such as hare lip and cleft palate are addressed in the section on surgical problems (*see* Section 5.19).

Transition to adulthood for children with disabilities: a human rights perspective

The transition from childhood to adulthood takes time, and the process of adolescence is experienced and managed in very different ways in different cultures. This transition is much more challenging for disabled children whose abilities to achieve independence may be constrained by their condition. Disabled children are at higher risk of abuse and exploitation, and are likely to be more vulnerable as they pass through adolescence into adulthood. It is best to view this transition from a **human rights perspective**. Thus the disabled child has rights as stated within the UN Declaration of the Rights of the Child, and the same perspective informs any consideration of the transition to adulthood.

Conditions, cultures and economies

Different cultures and economies make it relatively easy or difficult for young people with different types of conditions to integrate and find a role. For example, a young person with a severe physical disability, such as spastic quadriplegia, but of normal intelligence may find it relatively easy to find

a fulfilling role as an adult in a technologically advanced urban environment where there are relatively few physical barriers for wheelchair access. However, a young person with learning difficulties and good mobility may find it difficult to find a fulfilling role in such a society. By contrast, a less technologically advanced society can be much more accepting of the young person with learning difficulties, for whom there are many welcome roles in the rural economy, and the intellectually competent but physically impaired young person may find it much more difficult to find fulfilment in such an environment.

There may be very different cultural expectations of young men and young women, and deep-seated prejudices and cultural taboos that cause further disablement and devaluing of young disabled people unless the human rights perspective is paramount.

Child-friendly and child-safe environments

- All buildings that are used as healthcare facilities and playgrounds for children should be surveyed with the needs of their disabled users in mind.
- When new buildings are planned, it should be remembered that wheelchairs need wider doors and that where steps are needed ramps should also be provided.
- If the building has several floors, lifts should (when possible) be in place. If this is not possible, clinics serving disabled people should be located on the ground floor.
- Areas used by visually impaired people should be well lit, with steps and drops highlighted. Written notices should be as large and clear as possible.
- Special facilities may need to be provided for deaf and blind children to access information.

The challenges of transition

Independence

Good practice includes involving children in decision making about their own lives well before they enter adolescence. Learning from failures as well as successes is part of normal development. Many children in resource-limited communities are expected to work on the land or in industry, to look after livestock or to take responsibility for the care of their younger siblings at an age when they are not developmentally equipped to do so. Many children who have been involved in civil war and other armed conflict have been deprived of an ordinary childhood and may have had 'independence' forced upon them at an early age (*see* Section 1.23). Disabled children may have similar experiences or worse (e.g. being used as beggars), which deprive them of their human right to a childhood. If 'independence' means the insecurity of street children progressing to prostitution or a life of petty crime, this is not the sort of independence that young people need.

At the other extreme, disabled children worldwide are often overprotected by their families, who may feel ashamed, or there may be cultural taboos and beliefs about the origins of particular conditions. The parents may wish to do everything for their disabled child, but this can result in the child not learning from experience. The end result may be that the disabled young person does not get the opportunities for education and training that would enhance their self-esteem and ability to at least make some contribution to society, rather than be seen merely as an object of pity and charity.

Enabling the disabled child to become an integrated member of adult society is a challenge that requires the following:

- imagination, resources and flexibility on the part of the health, education and social services
- active engagement with the young person, their family and their community
- a real commitment to working with the strengths of the young person and minimising their weaknesses by reducing the barriers to their participation in society
- anticipating difficulties in advance and balancing the risk of failure against the benefits of increasing independence.

Information

Disabled young people often do not have access to information about their own condition, necessary health education to prevent secondary problems developing, training and employment opportunities, self-help groups and their rights.

Sexuality

The challenge of emerging sexuality is often more difficult for the disabled young person. Young people commonly have inaccurate information about the basic facts of sexual development, and disabled young people often miss out on the opportunity to learn these facts in a straightforward way. Many young people may be unaware of any genetic implications of their own condition, although it is more common to assume that there are genetic risks to their offspring when this is **not** the case.

Families, and indeed some healthcare professionals, may make inaccurate assumptions about the ability of disabled young people to have normal sexual experiences. These young people may have their own inaccurate beliefs which may cause much unnecessary suffering unless they have the opportunity to understand the facts about their own bodies. Even when there are some physical problems that will affect sexual experience (e.g. lack of genital sensation for some young people with paraplegia), this does not preclude an active and fulfilling sexual relationship.

Services for the transition to adulthood

Healthcare facilities that provide services for children with disabilities should develop expertise in enabling children to make the transition to adulthood. This expertise is likely to be achieved by developing shared knowledge among a group of relevant professionals working in partnership with young people. The service should be able to offer the following:

- information that is relevant and up to date
- individual counselling
- opportunities to meet other young people with similar difficulties
- careers advice
- a service to loan out equipment to increase independence
- close links with education facilities and any social and housing services.

Further reading

- Werner D (1987) *Disabled Village Children: a guide for community health workers, rehabilitation workers and families*. Palo Alto, CA: Hesperian Foundation.

4.2.D Care of children and young people with a spinal cord injury

BOX 4.2.D.1 Minimum standards
- Cervical collars.
- Dexamethasone.
- Physiotherapy.
- Jewett brace.
- Urinary catheters (in–out and Foley).
- Glyceryl trinitrate.
- Laxatives.
- Suppositories.
- Parent training.

Introduction

The acute and immediate management of children and adolescents with a traumatically injured spine in the context of major injury is described in Sections 7.3.A and 7.3.G. Much of the important advice given in this section is adapted from the following excellent book, which is essential reading for all healthcare workers in resource-limited settings:

- Werner D (1987) *Disabled Village Children: a guide for community health workers, rehabilitation workers and families*. Palo Alto, CA: Hesperian Foundation.

Mechanisms

- The following conditions predispose to spinal injuries: achondroplasia, Klippel–Feil syndrome, Down's syndrome and juvenile rheumatoid arthritis.
- Injuries can occur during birth and from abuse.
- Most of the injuries occur in road traffic accidents, sports, falls from trees or donkeys, bullet wounds and diving accidents.
- Non-traumatic causes include transverse myelitis (e.g. epidural abscess, tuberculosis of the spine, neuroblastoma, astrocytoma, eosinophilic granulomata, lipoma, teratoma and aneurysmal bone cysts).

Diagnosis

- In the conscious patient, localised tenderness in the spine, and impairment or loss of sensation, voluntary motor power and reflexes can help to determine the level of vertebral involvement.
- In the semiconscious or unconscious patient, hypotension associated with bradycardia, dilated peripheral veins in the lower limbs, paradoxical respiration, lack of spontaneous movement of limbs, lack of response to painful stimuli applied by pressure over bony prominences at various levels, and urinary retention are all signs suggestive of a spinal cord injury.
- Around 10–20% of injuries are in more than one site. Therefore an X-ray of the whole spine is necessary.
- Other associated injuries are common, and loss of sensation may delay their diagnosis.

Level of the injury

The magnitude of the area of the body that is affected will depend on the level of the injury. The higher the injury is, the greater the area of the body that is affected.

In paraplegia:

- there is loss of controlled movement and feeling in the legs
- the hips and part of the trunk may be affected (the higher the injury, the greater the area of the body that is affected)
- there may be partial or complete loss of urinary and bowel control
- there may be spasticity (muscle spasms) or hypotonia in the legs.

Complete and incomplete injuries

When the spinal cord is damaged so completely that no nerve messages get through, the injury is said to be 'complete'. Feeling and controlled movement below the level of the injury are completely and permanently lost. If the injury is 'incomplete', some feeling and movement may remain. Alternatively, feeling and controlled movement may return (partly or entirely) little by little over a period of several months. In incomplete injuries, one side may have less feeling and movement than the other.

X-rays often do not show how complete a spinal cord injury is. Sometimes the backbone (spinal column) may be badly broken, yet the spinal cord damage may be minor. And sometimes (especially in children) the X-ray may show no damage to the backbone, yet the spinal cord injury may be severe or complete. Often only time will tell how complete the injury is.

Neurological deterioration

This may be caused by:

- further mechanical damage and/or further non-mechanical damage to neural tissue during treatment
- hypoxia, hypotension and sepsis that develop due to poor management of the multisystem malfunction.

Acute management of spinal cord injuries: overall approach

For acute ABC management in the context of major traumatic injury, *see* Sections 7.3.A and 7.3.G.

- Aim to prevent complications related to multisystem dysfunction by good ABC resuscitation.
- Aim to contain the 'biomechanical instability' of the spinal column by preventing movement at the site of the fracture.
- Dexamethasone should not be given routinely to children with spinal injuries, as there is no evidence that steroids improve the neurological outcome, and the risk of complications is high.
- Dexamethasone should only be considered if there are signs of neurological deterioration following acute spinal injuries. The recommended dose is 500 micrograms/kg immediately, followed by 50 micrograms/kg every 6 hours for 48 hours.
- 'Rehabilitation' should begin in parallel with the medical treatment as soon as possible.
- Arrange early counselling and psychological support for the child, their parents and family members.
- Start physiotherapeutic procedures to prevent contractures of paralysed muscles, chest infections and pressure sores.
- Train all systems of the body to function as safely and with as near normal convenience as possible.

- Aim for psychosocial and physical reintegration of the child in the community without significant loss of education.
- Ensure a teaching programme for the child and/or their parents aimed at minimising the development of complications (medical, physical and psychological) in the medium and long term.
- Offer lifelong regular hospital assessment and treatment if necessary to maintain health and rehabilitation.

Acute spinal injury

- Keep the spine in a neutral position (with pillow arrangements). For cervical spine injury, immobilise with a cervical collar or sandbags at the side of the head for about 6 weeks, followed by bracing for 6 to 8 weeks. In children under 6 years of age, the sagittal diameter of the skull exceeds that of the chest, forcing the neck into flexion. A cut-out should be made in the board or the mattress to recess the occiput.
- Children with an unstable fracture of the spine but with intact neurology can be adequately braced in a Minerva cast for cervical spine injuries and a body cast for thoracolumbar injuries. Alternatively, or later, surgery can be undertaken, but only in a specialist centre (if available).
- Minerva and body casts should not be applied to children with sensory loss, because of the risk of pressure sores.
- A hard cervical collar for the quadriplegic patient and a Jewett brace for the paraplegic child are likely to provide adequate support until healing occurs.

Temperature control

The patient may not be able to control their body temperature, becoming pyrexial in a hot environment or hypothermic in a cold environment.

Cardiovascular and peripheral vascular system problems

- Spinal shock (autonomic areflexia) may cause bradycardia with hypotension.
- Care is needed with IV hydration, as circulatory overload and pulmonary oedema can easily occur.
- Hypoxia, hypothermia and tracheal suction can aggravate the bradycardia.
- Postural hypotension is most profound during the state of spinal areflexia. Early mobilisation can result in a significant drop in blood pressure which may affect spinal cord blood flow and adversely affect neurological recovery.
- Following the return of autonomic reflex activity, patients with cord lesions above T6 can develop autonomic dysreflexia (sudden onset of pounding headaches, flushing, blotchiness of the skin above the level of the injury, conjunctival congestion associated with sweating, and high blood pressure). The commonest causes are urinary retention and constipation. Treat this condition by placing the patient in the upright position (usually sitting) and if they are over 12 years of age the administration of sublingual glyceryl trinitrate (300 micrograms). If urinary retention is the cause, catheterisation following the liberal instillation of urethral lubricant with local anaesthetic will rapidly reduce the blood pressure and relieve the symptoms.

Respiratory system

- Children with injuries above C4 are unlikely to be able to breathe spontaneously.
- Children with lesions below C4 (most children with activity in the biceps) are able to breathe independently using their diaphragm, provided that no major chest injury is present.
- Encourage deep-breathing exercises and postural drainage, assist coughing and monitor oxygen saturation if possible.

Gastrointestinal system

- In the acute phase after a spinal cord injury, all patients are at risk of developing paralytic ileus. The resulting abdominal distension can embarrass the diaphragm and further impede diaphragmatic breathing. Avoid oral intake in the first 48–72 hours following injury and until bowel sounds are audible.
- The risk of gastrointestinal bleeding from stress ulcers is high. Therefore administer H_2-blockers such as ranitidine, 2–4 mg/kg twice daily up to a maximum of 150 mg twice daily, or antacids, for the first 3 to 4 weeks following injury.
- A regular bowel regime consisting of suppositories at fixed and regular intervals not exceeding 24 hours should be instituted initially by a nurse or parent, and later by the child (see below for details).

Hypercalcaemia

- This occurs in 10–20% of children, especially in quadriplegia and complete spinal cord injuries. The onset is insidious in the first few weeks following injury. Nausea, anorexia and vomiting can mimic an acute abdomen. Polydipsia, polyuria, dehydration, lethargy and occasionally psychosis can occur.
- Adequate hydration and furosemide are the first-line treatment.

Management of nutrition

What food should be given?

If the child is malnourished, give them 200 kcal/kg/day (*see* Section 5.10.A and 5.10.B). The daily number of kilocalories should be divided by the number of meals given during the day, usually four meals per day.

F100 can be used to correct malnutrition (*see* Section 5.10.B).

Commercial F100

This special milk is prepared in a sachet. All that the family has to do is open the packet and dilute the contents in 2 litres of water.

Home-made F100

When commercial milk is not available, F100 can be prepared from the recipe shown in Table 4.2.D.1.

The basic diet is composed of F100 meals. However, when the patient is gaining weight quickly other foods can be introduced. For example, the usual food eaten in the area can be used, but this should be enriched with the addition of oil and vitamin and mineral mix, and sometimes dried skimmed milk.

Example of calculation:

A child who weighs 20 kg should receive
200 kcal × 20 = 4000 kcal per day.

They will receive 4 meals per day, therefore 1000 kcal per meal.

Doses of supplemental nutritional aids

These are as follows (*see* Section 5.10.A and 5.10.B):

- **Zinc:** 2 mg/kg/day, or for children over 5 years of age, 40 mg once a day (of the elemental formula).
- **Vitamin C:** 45 mg/day.
- **Iron:** one ferrous sulphate tablet of 200 mg once weekly for children over 5 years of age.

TABLE 4.2.D.1 Recipe for preparing 1 litre of high-energy food

Food item	Quantity
Dried skimmed milk (DSM) or oiled full cream milk	80 grams (900 mL)
Vegetable oil	60 grams (20 mL)
Sugar	50 grams
Water (boiled)	Add water to make 1 litre of preparation
CMV (minerals and vitamin mix)*	20 mL (should be added after the water)

*The CMV should be added when the preparation of milk is ready. Whisk to prevent the oil from separating. This keeps for 12 hours.

Subsequent nursing and medical management and education of the child and their family

Early questions that a child with spinal cord injury and their family may ask

Will my child always remain paralysed?

This will depend on how much the spinal cord has been damaged. If paralysis below the level of the injury is not complete (e.g. if the child has some feeling and control of movement in their feet) there is a better chance of some improvement.

Usually the greatest improvement occurs in the first months. The more time that goes by without improvement, the less likely it is that any major improvement in feeling or movement will occur.

After 1 year, the paralysis that remains is almost certainly permanent. As gently as you can, help both the child and their parents to accept this fact. It is important that they learn to live with the paralysis as best they can, rather than waiting for it to get better or going from clinic to clinic in search of a cure.

Immediately after a spinal cord injury, the paralysed parts are in 'spinal shock', and are hypotonic. Within a few days or weeks the legs may begin to stiffen, especially when the hips or back are straightened. Also, when it is moved or touched, a leg may begin to 'jump' (a rapid series of jerks, or 'clonus').

This stiffening and jerking is an automatic reflex called 'spasticity'. It is not controlled by the child's mind, and often happens where spinal cord damage is complete. It is **not** a sign that the child has begun to feel where they are touched or is recovering control of movement. Some children with spinal cord injury develop spasticity, while others do not.

If the spinal cord injury is above the level of the top edge of the hipbone (above the second lumbar vertebra), spasticity is likely. If the injury is below this level, paralysis is usually floppy (no muscle spasms).

Severe spasticity often makes moving and control more difficult. However, the child may learn to use both the reflex jerks and spastic stiffness to help them to do things. For example:

- When the child wants to lift their foot, they hit the thigh, triggering the jerks that lift the leg.
- In lower back injuries, the spasticity or stiffness of the legs may actually help the child to stand for short periods.

Will my child be able to walk?

This will mainly depend on how high or low in the back the injury is.

If the child's injury is in the lower back and if their arms are strong and they are not overweight, there is a chance that they may learn to walk with crutches and braces. However, they will probably still need a wheelchair to go long distances.

It is best not to place too much emphasis on learning to walk. Many children who do learn to walk find it so slow and tiring that they prefer to use a wheelchair.

It probably makes sense to give most paraplegic children a chance to try walking. However, do not make the child feel guilty if they prefer a wheelchair. Let the child decide which is the easiest way for them to move about.

For independent living, other skills are more important than walking, and the family and child should place greater emphasis on these skills, such as dressing, bathing, getting in and out of bed, and toileting. Self-care in toileting is especially important, and is made more difficult because of the child's lack of bladder and bowel control.

What are the prospects for my child's future?

The likelihood of a child with **paraplegia** leading a reasonably normal life are good, provided that:

- Three major medical risks are avoided:
  - skin problems (pressure sores)
  - recurrent urinary tract infections
  - contractures (shortening of muscles, causing deformities); these are not life-threatening, but they can make moving about and doing things much more difficult.
- The child is helped to become more self-reliant:
  - home training and encouragement to master basic self-help skills such as moving about, dressing and toileting
  - education: learning of skills that make keeping a household, helping other people, and earning a living more achievable.

It is more difficult for children with **quadriplegia** to lead a normal life because they are more dependent on physical assistance.

In well-resourced countries, many children with paraplegia manage to lead full rich lives, earn their own living, get married, and play an important role in the community.

With effort and organisation, the same potential for leading a normal life can exist in all countries.

Can anything be done about loss of bladder and bowel control?

Yes it certainly can. Although normal control rarely returns completely, the child can often learn to be independent in their toilet, and to stay clean and dry (except for occasional accidents). Often they will need to learn to use a urinary catheter, and learn to bring down a bowel movement with a finger or suppository (see below).

What about sexual relationships and having children?

Many people with spinal cord injuries marry or have fulfilling sexual relationships. Women with spinal cord injuries can become pregnant and have babies.

Helping the child and their family to adjust to and accept the injury

Perhaps the biggest problem is that one day the child is physically active and able, and the next they are suddenly paralysed and (at first) unable to do much for themselves. They have lost all feeling and control in part of their body, which feels like a 'dead weight'. This is very hard for both the child and their family to accept. Both have enormous and partially justified fear and uncertainty about the future. The child may become deeply depressed, or angry and uncooperative. They may refuse even to sit in a wheelchair because this means accepting that they are unable to walk.

There are no easy ways to address the child's fear and depression, but here are some suggestions that families have found helpful.

Recognise that **the child's fear, depression and anger are natural responses**, and that with love, understanding and encouragement they will gradually overcome them.

Be honest with the child about their disability. Do not tell them 'We will find a cure for you' or 'Soon you will get well and be able to walk again.' Very probably this is untrue, and misleading the child in this way only makes it more difficult for them to accept their disability and begin to shape a new life. Also, as the promised 'cure' fails to materialise, the child will become more uncertain, distrustful and afraid. In the end, it will be much easier if you gently tell them the truth.

Provide opportunities to **keep the child's mind active by playing, working, exploring, and learning through stories, games, and studies**. But at the same time **respect and be supportive of the child when they feel sad and frightened**. Let the child cry, comfort them when they do so, but do not tell them not to cry. Crying helps to relieve fear and tension.

Start the child with **exercises, activities and relearning to use their hands and body** as soon as possible. Start with what the child can do, and build on that.

Try to arrange for the child to **watch, talk with and get to know other people with spinal cord injury**.

Invite the child's friends to come and visit, play with him or her, and let the child know that they are eager for the day he or she will be back in school.

Encourage the child to do as much for him- or herself as possible, even if it takes a little longer.

As far as possible **avoid the use of 'tranquillisers'** or other inappropriate medication. The child needs an alert mind and the ability to move actively all day.

To prevent or reduce the harmful effects of the complications of spinal cord injury, **special precautions need to be taken early and continued throughout life**.

Early care

Early care following spinal cord injury is best provided in hospital. Family members should stay with the child to make sure that he or she is kept clean and turned regularly, so that bed sores and pneumonia are avoided. Busy hospital staff with little experience of treating spinal cord injuries sometimes allow severe bed sores to develop, which may be life-threatening for the child.

The damage that has already been done to the spinal cord cannot be corrected with surgery or medicine.

Preventing pressure sores (bed sores)

When sensation has been lost, pressure sores can easily form on the skin over bony areas, especially on the hips and bottom. The time of greatest risk of sores developing is in the first weeks after the injury. This is because the child must stay very still, and has not yet learned to move or turn over their body. Prevention of pressure sores is extremely important, and needs understanding and continuous care, both by the child and by those caring for them.

Early prevention of pressure sores

- Lie the child on a soft mattress or a thick firm foam rubber pad.
- Place pillows and pads to keep the pressure off bony areas.
- Change their position (turn over from front to back and side to side) every 2 to 3 hours. To avoid pressure sores, lying on the abdomen is the best position.
- Keep the skin and bedclothes clean and dry.
- Give the child healthy food rich in vitamins, iron and protein.
- Move and exercise the child a lot to promote healthy flow of the blood.
- Check their skin daily for the earliest signs of pressure sores, and keep all pressure off areas where sores might be developing until the skin is healthy again.

Avoiding contractures

In the first weeks following a spinal cord injury, when the child is in a lying position, joint contractures (muscle shortening) can easily develop, especially in the feet and elbows. Pillows and pads should be placed to keep the feet supported, the elbows straight, and the hands in a good position. Gentle range-of-motion exercises of the feet, hands and arms should begin as early as possible, taking care not to move the back until the injury has healed.

Movement and exercise

Do range-of-motion exercises for about 10 minutes for each leg. In the first weeks, do the exercises twice a day; later on, once a day may be enough. If any signs of contracture develop, spend more time and effort on those parts of the body. From the start, exercises should be both **passive** (someone else moving the child's body parts) and, whenever possible, **active** (the child moving them).

Range-of-motion exercises should begin with great care the day after the spine is injured. The exercises will help to improve the flow of blood (which reduces the likelihood of bed sores), prevent contractures, and build the strength

of the muscles that still work. Range-of-motion exercises should be **continued throughout life**, when possible as a part of day-to-day activity.

Cautions

- Until any breaks or tears in the spine have healed (this takes 6 weeks or more), exercise must be very gentle and limited, with smooth motions and no jerking.
  - Especially at first, take great care that exercises do not move the position of the back and neck (depending on the site of injury). Start with the feet, ankles, hands, wrists and elbows.
  - If exercises trigger severe muscle spasms or jerking, do not do them until the break in the spine has healed.
- Do not use force in trying to get the full range of motion, as joints can easily be damaged.
- Try to keep the full range of motion of all parts of the body, but **work most with those joints that are likely to develop contractures**, especially:
  - paralysed parts that tend to hang in one position, such as the feet
  - joints that are kept straight or bent by spasticity or by muscle imbalance.

Maintaining a healthy position

The position that the body is in during the day and night is also important to prevent contractures.

Contractures that cause 'tiptoeing' of the feet can develop easily, especially when there is spasticity. Keep the feet in a supported position flexed at 90 degrees to the lower leg, not in the extended position, for as much of the time as possible when lying down and when sitting.

Teach the child to check that their feet are in a good position. Even for the child who may never walk, maintaining the feet in a flexed position makes moving from chair to bed, toilet or bath easier.

Another common problem for children with spasticity is that the knees pull together and in time contractures prevent the legs from separating. To prevent this, when the child lies on their side, they should learn to place a pillow between the legs, and to keep it there most of the time.

A common problem with wheelchair users is that they slump forward. In time this can deform the spine. In a wheelchair with a straight-up back a person with spinal cord injury slumps like this in order to balance. A chair can be designed (or adapted) so that it tilts back. This provides balance for a better position.

A special cushion also helps to prevent the child's bottom from sliding forward (and also helps to prevent pressure sores). If possible, use a cushion mad of 'micropore' foam rubber (foam containing very tiny air bubbles). Rubber-coated coconut fibre also works well.

Early physical development

The goal is for the child to become as independent as possible in doing what they want and need to do. However, even before the skills of daily living are relearned, the child needs to **learn to protect the body where functions that used to be automatic have been lost**. The protective functions that may be lost or changed include the following:

- adjustment of the blood pressure to changes in body position
- sensation (including pain) that protects the body from injuries (e.g. bed sores)
- the sense of body position and ability to keep balance
- muscle strength and coordination.

A sudden fall in blood pressure in the brain when the person rises from lying to sitting, or from sitting to standing, can cause dizziness or fainting. This is a common problem in spinal cord injury because the blood pressure adjustment mechanism is partly lost. The body can be helped to gradually readapt, but precautions are needed. (These same precautions are the same for anyone who has been kept lying down for a long time.) Before beginning to sit, raise the head of the bed – a little more and a little longer each day. If the child starts to feel dizzy or faint when sitting, tilt their back and lift their feet. Lifting exercises help the body to relearn to adjust blood pressure, and also prevent bed sores and strengthen the arms.

The loss of sensation **in parts of the body can lead to pressure sores and other injuries**, such as burns and cuts. This is because the body no longer feels pain, so does not warn the child to change position or move away from danger.

It is important that the child learns to protect him- or herself by changing positions often and avoiding injuries. This includes the following:

- learning to roll over
- turning at least every 4 hours when lying or sleeping
- lifting from a sitting position every 15 minutes
- washing daily
- examining the whole body every day for signs of injuries or sores
- learning to protect him- or herself from burns and other injuries.

Keeping clean is very important for people with reduced sensation, especially if they lack bladder and bowel control. Take care to bathe them daily. Wash and dry the genitals, the bottom, and between the legs as soon as possible each time they get wet or dirty.

If redness, rash or sores develop, wash more often and keep the sore area dry. Keep the legs spread open and exposed to the air. When they must be covered, use soft absorbent cotton cloth.

For treatment of specific fungal, yeast and bacterial infections of the skin, *see* Section 5.18.

Loss of the sense of body position affects a person's sense of balance, as does **loss of muscle control**. The child needs to develop new ways to sense the position of their body and keep their balance.

Start with the child sitting on a bench, if possible, in front of a mirror, and help them to progress through the following stages:

1 Place both hands on the bench.
2 Place both hands on the knees.
3 Lift one arm sideways, forward and back.

After doing this in front of a mirror, ask the child to do it without the mirror.

- As the child begins to develop better balance, start doing different movements with first one and then both arms, such as lifting weights or playing ball.

- Some children may experience so much difficulty with balance that they have to start in a wheelchair or a chair with a high back and arm supports.

Redeveloping muscle strength and coordination. All muscles that still work need to be as strong as possible to make up for those that are paralysed. Even imagining movements helps to re-educate the brain about body posture. The most important muscles are those around the shoulders, arms and stomach.

Self-care

With the help and encouragement of family, friends and rehabilitation workers, the child can learn to become as independent as possible in meeting their basic needs, including moving about, eating, bathing, dressing, toileting, and in time other skills for daily living.

Progress toward self-care, especially at first, may be slow and frustrating. The child will need a great deal of understanding and encouragement. To make activities easier both for the child and for their helper, it is important that **they avoid becoming overweight**.

Useful methods and techniques have been devised for helping to relearn basic skills. Much depends on determination, imagination and common sense. Start with movements like rolling over and sitting up in bed.

Keeping active

Many of the 'complications' of spinal cord injury occur because the person spends a lot of time either lying down or sitting. To stay healthy, the body needs to keep active. Lack of movement and activity causes poor flow of the blood. This can lead to pressure sores, swollen feet, painful or dangerous blood clots (thrombosis), especially in the legs, increasing weakness of bones (osteoporosis) with the risk of fracture, bladder or kidney stones, increased risk of urinary tract infections, and general physical weakness and poor health.

It is important for both body and mind that people with a spinal cord injury keep physically active. Children should be allowed to do as much for themselves as they can, including pushing their own wheelchair, bathing, transferring, washing their clothes, helping to clean the house, and helping with work.

Active participation in games and sports can also be encouraged. Swimming, basketball and archery can be done well using only the upper body.

To keep the leg bones growing well and to prevent them from becoming weak and breaking easily, even children who may always have to use a wheelchair should if possible stand for a short time every day. This can be done by strapping the child to a 'standing board', or by making some kind of standing frame. Standing also helps to prevent constipation.

Management of bowel movements

When a person's spinal cord is damaged, they almost always lose control over when they will open their bowels. This makes it difficult to stay clean, which can be inconvenient and embarrassing. Although they can never regain complete control over the muscles that hold in or push out the stool, **they can learn to help the stool come out, with assistance, at certain times of day**. This kind of 'bowel programme' can greatly increase the person's self-confidence and freedom to take part in school, work and social activities.

People with spinal cord damage often have problems with constipation. Some constipation can be an advantage when a person lacks bowel control. However, sometimes it can lead to serious problems, such as impaction or dysreflexia. It is therefore important to prevent serious constipation by adopting the following measures:

- Drink plenty of water.
- Eat foods that are high in fibre (e.g. bran, wholegrain cereals, fruits, vegetables, cassava, beans, nuts).
- Stick to a scheduled bowel programme.
- Keep active.

Planning a bowel opening programme

Any bowel programme will work better if the child:

- does the programme every day (or every other day) and at the same time, even if they have had an accidental bowel movement shortly before, or have diarrhoea
- does the programme at the same time of day as they normally had bowel movements before their injury
- performs the task after a meal; often the bowels move best after a meal or a hot drink
- if possible, performs the task on a toilet or pot; the bowels work better in a sitting position than when lying down
- is patient; the bowels sometimes takes days or even weeks to change their pattern.

Types of bowel programme in spinal injury

Different people require different types of bowel programme, depending on whether their bowels are 'automatic', 'flaccid' or 'pull back'.

- **Automatic bowel** usually occurs in people who have muscle spasms in their legs, and an 'automatic bladder'. The muscle or 'sphincter' in the anus remains shut until there is a stimulation of the bowel to make it open, so that the stool can come out. An automatic bowel will 'move' in response to a suppository or stimulation by a finger.
- **Flaccid bowel** usually occurs in children with low spinal cord damage who have limp (not spastic) legs and bladder. The sphincter muscle in the anus is also limp, so the person tends to 'ooze' or 'dribble' faeces. A limp bowel does not respond to finger stimulation.
- **A bowel that pulls back** is neither automatic nor limp. When you insert a finger in the anus, the stool moves back up instead of coming out.

Management of an automatic bowel

1 Start with a suppository (Dulcolax or glycerine) prior to digital evacuation of the bowel. Glycerine suppository sizes are as follows: for an infant, 1 gram; for a child aged < 12 years, 2 grams; for a child aged > 12 years, 4 grams. With a finger covered with a glove or plastic bag, and then vegetable oil or Vaseline, push the suppository about 2 cm (1 inch) up the anus. Do not push it into the stool, but push it against the wall of the bowel. It is possible to try this same activity without a suppository; often finger stimulation alone is enough to stimulate a bowel action.
2 Wait for 5–10 minutes. Then help the child to sit on a toilet or pot. If they cannot sit, have them lie on their left side (on top of toilet paper or newspaper).
3 Put an oiled finger into the anus for a distance of about

2 cm. Gently move the finger in circles for about 1 minute, until the anus relaxes and the stool pushes out.
4 Repeat the finger action three or four times, or until no more stool is felt.
5 Clean the bottom and anus well and wash your hands.

Management of a flaccid bowel

Since the bowel does not push, the stool must be taken out with a finger. This is best done after each meal, or at least once a day.

- If possible, the child should be sitting on a toilet or pot, or lying on their left side.
- With a gloved and oiled finger, remove as much stool as you can.
- Since a limp bowel tends to ooze stool, the child should be given foods that make the stool firm or slightly constipated (**do not give the child stool-loosening foods**).

Management of a bowel that 'pulls back'

For this kind of bowel, the bowel programmes described above do not usually work. Finger stimulation makes the bowel act in the opposite direction and pull the stool back in. The child will have 'accidents' during the day. Often it is more effective to first put some anaesthetic jelly (e.g. lidocaine) up the anus. If you cannot obtain the jelly, you can mix some liquid injectable lidocaine with Vaseline or any other jelly. Wait for several minutes, and then proceed to the automatic bowel management.

Other important issues

- Children can almost always learn to do their own 'bowel programme'.
- Do not use enemas or strong laxatives regularly. They stretch the bowel, injure its muscles, and make following a regular programme more difficult. A mild laxative (senna or Dulcolax; *see* Section 5.12.C) may be taken occasionally when needed. However, drinking more liquid and eating food high in fibre is usually sufficient.
- If there is bright red blood in the stool, a blood vessel was probably torn during the management described above. Be more gentle! If there is dark old blood and the stools are black and tar-like, and the child is generally unwell, the parents should seek hospital advice urgently.
- A small amount of liquid stool (diarrhoea) may be a sign of 'impaction', which is a ball of hard stool stuck in the bowel. Only liquid stool can leak around it. Do not give medicine that is used to stop diarrhoea, as this could make the impaction worse. Try to remove the stool with a finger, or use stronger laxatives on a temporary basis (*see* Section 5.12.C).

A bowel management programme may at first seem difficult and messy, and is initially very embarrassing for the child. However, it soon becomes an easy habit. It is very important both for the child's health and for their social well-being. Do it regularly at the same hour of the day, and do not miss a day.

Constipation is almost always a potential problem, and can cause haemorrhoids, anal fissures and mucosal tears. For management of an acute episode, *see* Section 5.12.C. If constipation is regularly a problem, consider giving regular senna tablets (7.5 mg sennoside): aged 6–12 years, 1–2 tablets once daily; for 12–18 years, 2–4 tablets once daily or liquid (7.5 mg sennoside in 5 mL); for children under 6 years of age, 2.5–5 mL once daily; and for children over 6 years of age, 5–10 mL or 1–2 tablets once daily.

Locomotor system

- There is a high risk of contractures of muscles, limitation of the range of movement in the joints of the paralysed limbs, excess spasticity and fractures of long bones which are preventable.
- Passive movements and good positioning in bed and early splinting (if necessary) should prevent contractures.

Urinary system

- Urinary retention occurs during the stage of spinal areflexia, and is usually permanent in children with lower motor neuron lesions.
- Reflex micturition gradually develops in children with upper motor neuron lesions, usually from the sixth week onwards.
- Extra fluid intake should be encouraged.
- Up to the age of 2 to 3 years, 4-hourly gentle suprapubic pressure will empty the bladder.
- Children above the age of 3 years are best managed with intermittent catheterisation until effective reflex micturition occurs and the residual urine is consistently below 60 mL.
- Children with lower motor neuron lesions are likely to require intermittent catheterisation for the rest of their life. Initially this should be done by an attendant or parent. However, with teaching and training, a child with good hand function can learn to do clean intermittent self-catheterisation. Intermittent catheterisation is the safest method of bladder drainage.
- The use of indwelling urethral catheters is not recommended after the first 48–72 hours, but may sometimes be appropriate (see below).
- Antibiotics should be reserved for urinary tract infections with systemic manifestations.

Most children with spinal cord injury do not have normal bladder control. This can be inconvenient, embarrassing, and causes social and emotional difficulties. In addition, the loss of control can cause skin problems and **dangerous urinary tract infections**. For these reasons, it is important to learn ways to stay clean, dry and healthy. Most of the methods are not difficult, so children should be able to do this themselves, and this in turn will help them to feel more self-reliant.

The main goals of urine system management are as follows:

1 to prevent urinary infection
2 to promote self-care in staying as dry as possible.

Prevention of urinary tract infections is extremely important. **Infections of the urinary system (bladder and kidneys) are very common in spinal cord injury, and are one of the main causes of early death.** Therefore any method that is used for self-care or staying dry must also help to prevent urinary tract infections. Make every effort to prevent infection from entering the bladder. **Keeping clean is essential.** It is also important to empty the bladder regularly and **as completely as possible**. If some urine remains in the bladder, bacteria will grow in it and cause infection.

The ideal method of urinary control empties the bladder completely and in a clean, regular, easy and self-reliant way.

Types of bladder problems

Automatic bladder: A child with paralysis whose legs have 'reflex spasms' (uncontrolled stiffening or jerking) may have reflex spasms in their bladder. As the bladder fills with urine, the walls of the bladder stretch and cause a reflex spasm. As the bladder squeezes, the muscles that hold back the urine relax, letting the urine flow out. This is called an 'automatic bladder' because it empties automatically when it gets full.

Flaccid bladder: When a child's paralysed legs are limp (due to lower motor neuron damage) and do not have spasms, usually the bladder is also limp or flaccid. No matter how much urine fills the bladder, it will not squeeze to empty. The bladder stretches until it cannot hold any more urine. The urine then begins to drip out and overflow incontinence develops. The bladder does not completely empty, and because some urine remains in the bladder, there is an increased likelihood of infection.

The most simple methods of bladder management work well with an automatic bladder but do not work with a limp bladder. Therefore **it is important to try to establish which type of bladder the child has**.

For the first few days or weeks after the spinal cord injury occurred, the bladder is almost always flaccid. Urine either drips out or does not come out at all. Then, as the 'spinal shock' wears off, people with higher back injuries (above the second lumbar vertebra) usually develop an automatic bladder. In people with lower back injuries the bladder usually remains flaccid.

During the first weeks after the spinal cord injury, usually a Foley catheter is kept in the bladder all the time. However, after about 2 weeks it is a good idea to test how the bladder works by removing the catheter and trying one of the methods described below. If the child is often wet, try another method for that type of bladder.

Methods for managing the automatic bladder

Triggering programme: This method usually causes the bladder-emptying reflex to work when the person is ready to pass urine. It can be done using a urinal, toilet, potty or jar. **This is the first method to try**, because nothing is put into the bladder. It is easy, so a child can do it unaided.

1 Tap the lower belly (over the bladder) firmly with your hand for about 1 minute. Stop and wait for the urine to flow.
2 Tap again. Repeat several times until no more urine flows.

If possible, once a week after triggering, use an in–out catheter to see how much urine is left. If there is less than a cupful (150 mL), continue the triggering programme. It there is more than a cupful on several occasions, the bladder is not emptying well enough, and another method should be tried (see below).

Periodic use of a catheter: This method allows the bladder to be emptied completely before it becomes too full. Sometimes it can be used to prepare the body for triggering. Put a clean or sterile standard catheter into the bladder every 4–6 hours to empty the urine, and then remove the catheter. If the child drinks more liquid than usual, put in the catheter more frequently to keep the bladder from stretching too much.

To reduce the risk of urinary tract infections, **regular frequent use of the catheter is more important than using a sterile catheter**. It is a mistake to stop using the catheter only because you have not had an opportunity to boil it (e.g. when travelling, or at school). Just wash out the catheter with clean drinkable water after use, and keep it in a clean jar or towel. **Do not go too long without catheterising, and do not stop catheterising altogether.** It is important not to leave a large amount of urine in the bladder.

How to insert a catheter

Healthcare workers and parents can easily be taught to put in a catheter. With a little practice, children with paraplegia can also learn to do this. A mirror can help girls to see the perineal area.

- The best catheter size is usually #8 or #10 for a small child, and #14 or #16 for a large child.
- Vigilance about cleanliness (i.e. boiling the catheter and wearing gloves) is important when using a fixed (Foley) catheter. However, for periodic use of a regular (in and straight out) catheter, a clean rather than sterile technique is more practicable (and therefore may be safer). Wash the catheter well with clean water after each use, and keep it in a clean container. Wash your hands well before using it.

The procedure for insertion of a catheter is as follows:

1 If possible, boil the catheter for 15 minutes, or at least wash it well and keep it clean.
2 Bathe the child well (at least daily). Wash well under the foreskin or between the vaginal lips and the surrounding areas.
3 Wash your hands with soap. After washing, touch only things that are sterile or very clean.
4 Put very clean cloths or towels under and around the area.
5 Put on sterile gloves, or rub your hands well with alcohol or surgical soap.
6 Cover the catheter with a lubricant (slippery cream) such as KY Jelly that dissolves in water (do not use oil or Vaseline).
7 Pull back the foreskin or open the vaginal lips.
8 Holding the foreskin back or the vaginal lips open, gently put the catheter into the urethra. Twist it as necessary, **but do not force it**. Hold the penis straight at this angle.
9 Push the catheter in until urine starts to flow out, then push it in 3 cm further.
10 If using a regular catheter, each time the child passes urine they should tighten their stomach muscles or gently massage the lower abdomen to empty all urine. Then take out the catheter, wash it well, boil it, and store it in a clean jar or towel.

To avoid introducing infections when using a catheter, it is important to be very clean and to use only a catheter that is sterile, boiled or very clean.

Using a fixed (Foley) catheter: With this method, the catheter is left in all the time to drain the urine from the bladder continuously. A Foley catheter is often used immediately after injury, and in some cases for many months or years. The catheter connects to a collection bag that can be attached to the leg and worn under the clothes. The catheter should be changed using a sterile technique once weekly or more frequently if there is a urinary tract infection (see below).

In many areas this is the easiest method because other

supplies are difficult to obtain. However, a Foley catheter can cause many problems, including the following:

- bacteria entering the bladder, causing a **high risk of infection**
- **continuous bladder irritation**, which can cause bladder stones to form.

If you have tried other methods unsuccessfully or no other equipment is available, a Foley catheter may be the only option. To prevent complications from occurring **it is very important that the Foley catheter is used carefully**:

- Always wash your hands thoroughly before touching the catheter.
- Clean the skin around the catheter with soap and water at least twice a day, and after each bowel movement.
- Do not disconnect the collection bag except to empty and wash it. Wash out the collection bag with soap or diluted bleach and water once a day.
- If the catheter must be clamped, use a sterile plug, **never a glass ampoule (small bottle)**, as this may break and cause injury.
- **Keep the collection bag below the level of the bladder** to keep the urine from flowing back into the bladder via gravity.
- Tape the catheter to the leg when the child is in a wheelchair.
- Check regularly to make sure that the urine is emptying and that the catheter is not blocked. Make sure that there are no sharp bends or folds in the tubing.
- When turning, lifting or moving the child, remember to move the bag, too. Do not let it pull at the catheter or stay under the child.
- If the catheter becomes blocked, take it out, squirt boiled water through it, and put it back. Alternatively, use a new catheter. Use a sterile or very clean syringe.

Condom catheter for male children: This is a practical method for male children and adolescents who cannot control their urine flow. It can be used in combination with triggering, to avoid accidental wetting.

A condom catheter is a thin rubber bag that fits over the penis. It has a tube that connects to a collection bag. Condom catheters are available in different sizes. If they are too costly or not available, a regular condom can be attached to the collection tube with a rubber band or tape. Alternatively, a thin, very clean plastic bag or the finger of a rubber glove (or a 'finger cot') can be used.

To hold the condom on the penis, stretchy adhesive tape can be used.

Important precautions for condom catheter use include the following:

- Ensure that it is not too tight, otherwise it could stop the blood flow and seriously harm the penis. Avoid the use of non-stretch tape.
- If the penis has erections, try to put on the condom when it is erect.
- Remove the condom once a day and wash the penis well.
- If possible, remove the condom at night, and use a bottle or urinal to catch the urine.
- Check the condom and penis often, to ensure that everything is all right.
- If the penis becomes injured, swollen or looks sore, remove the condom until it is healthy again.

Methods for the limp bladder

If the person's bladder is flaccid, it never empties by reflex. The bladder will constantly contain some urine unless an effective emptying method is used.

Girls can use a Foley catheter. This is often the simplest method, but it can lead to urinary tract infections. Alternatively, try an 'intermittent' (in-and-out) programme, using a regular catheter every 4–6 hours. If there is leaking in between catheter times, use diapers, rags or a thick sanitary pad to catch the urine. Change them often and wash the skin often to protect the skin and prevent sores.

Boys can use an intermittent catheter every 4–6 hours.

Other suggestions for the flaccid bladder

- **The push method:** Strain to push the urine out by tightening the abdominal muscles. This method is recommended by many professionals, but it can cause problems. If the muscles do not relax to let the urine flow out, pushing on the bladder can force urine back into the kidneys, causing kidney infection and damage. Therefore **the push method should only be used if the urine flows out easily with gentle pressure, or if no other method is possible**.
- However, it is best to also use a regular catheter at least three times a day. This is because the bladder may not have emptied completely, which makes infection more likely.

Management of urinary tract infections (*see* Section 5.6.A)

Children with spinal cord injury have a high risk of urinary tract infections, for the reasons discussed above. Long-term or untreated infections and kidney problems are a common cause of early death. Preventive measures are essential, but even when precautions are taken, some urinary tract infections are still likely to occur. Therefore it is very important to recognise the signs and provide effective treatment.

Clinical signs

When a person who has normal sensation has a urinary tract infection, pain is felt when they pass urine or when they pass urine more frequently, including at night. The person with spinal cord damage may not feel this pain or be able to have frequency or nocturia, and therefore has to use other signs to know when they have an infection. The child may learn to recognise certain unpleasant feelings, or may only know that they do not feel as well as usual. Parents and healthcare workers should learn to listen to the child and be aware of changes in behaviour or other signs that might mean that an infection is probably present.

Possible signs of a urinary tract infection include the following:

- cloudy urine, possibly with mucus, pus or blood specks
- dark or red urine
- strong-smelling or bad-smelling urine
- increased bladder spasms (cramps)
- increased wetting or changes in bladder function
- pain in the back or loins
- body aches
- general discomfort
- increased muscle spasms
- fever

- dysreflexia (headache, 'goose-bumps' when sweating, high blood pressure).

Treatment

At the first signs of infection, the child should drink even more water than usual. Antibiotics may also be necessary. However, avoid frequent use of antibiotics because they may become less effective as bacterial resistance develops.

If the child has had urinary infections before, they can start with the last medicine that was effective (for details of antibiotic treatment, *see* Section 5.6.A).

If a medicine seems to help, continue taking it for at least 1 week, or for 4 days after the last clinical signs have disappeared. Do not change from one medicine to another unless the medicine is not working or causes serious side effects.

Prevention of urinary tract infections in patients with spinal injury

- Drink plenty of liquid (for normal daily fluid intake that should always be maintained, *see* Section 9, Appendix), with higher intake if there is a high ambient temperature. An intake of at least 2 litres (eight 250-mL glasses) a day is required for a teenager.
- Eat apples, grapes or cranberries, or drink juice made from these fruits, or take vitamin C tablets to make the urine more acidic. It is more difficult for bacteria to grow in acidic urine. (*Note:* the fruit and juice of oranges, lemons and other citrus fruits do not have this effect, and in fact make the urine **less** acid.)
- Keep hands, catheter and collection bags very clean before, during and after the child's bladder programme.
- Encourage the child not to lie in bed all day, but to remain active.
- Do not clamp the Foley catheter or plug it with anything unless absolutely necessary, in which case always use a sterile plug.
- Adhere strictly to the bladder programme, and do not allow urine to remain in the bladder.
- Ensure that the catheter does not become bent or twisted so that the flow of urine is blocked.
- If you are using an in–out catheter, put it in regularly, at least every 4 to 6 hours. For prevention of infections, frequency of catheter use is even more important than cleanliness. It is safer to put in the catheter without boiling it, than not to put it in. If infections are common, catheterise more often.

Sexuality and fertility

- Discuss the situation with sensitivity as soon as the child reaches early adolescence.
- Advice about contraception is necessary for girls, as fertility is not affected, regardless of the level and severity of the spinal cord injury.
- Boys with upper motor neuron lesions will have reflexogenic but not psychogenic erections. Male fertility is significantly affected. However, male adolescents should be reassured that the results of assisted fertility (if available) are good.

Psychosocial integration, education, vocational training and employment

Continuing education, vocational training and employment must be pursued as the child grows older.

Skin problems

Sensory impairment or loss, impairment of vasomotor regulation of skin blood flow associated with paralysis, double incontinence, possible anaemia and urinary tract infections all render the skin of patients with spinal cord injuries vulnerable to breakdown and infections. **Skin breakdown is preventable.**

In the acute stage, regular turning of the child together with adequate management of the bladder and bowels and vigilance in maintaining cleanliness will prevent skin breakdown.

In the rehabilitation stage, training of the parents and the child in self-care, hygiene and the provision of adequate seating can all assist.

Pressure sores

Pressure sores, or 'bed sores', form over bony parts of the body when a person lies or sits on that part of the body for too long without moving. Where the skin is pressed against the bed or chair, the blood vessels are squeezed shut so that the blood cannot transport air to the skin and underlying tissue. If too much time passes without the person moving or rolling over, the skin and underlying tissue in that spot may become injured or die. First, a red or dark patch appears. Then, if the pressure continues, an open sore can form. The sore may start on the skin and work inwards, or it may start at a deep level, near the bone, and gradually work its way to the surface.

Risk factors for pressure sores

When a healthy person lies or sits in one position for a long time, it begins to feel uncomfortable, or even painful, so they move or roll over, and the formation of pressure sores is prevented. The people who are most likely to develop pressure sores are those who are unconscious or who have no **sensation** in parts of their body, and who therefore do not feel the warnings of pain or discomfort when their body is being damaged. This includes people with spinal cord injury.

Commonest sites of pressure sores

Pressure sores can form over any bony area. The sites where they are most likely to develop are shown in Figure 4.2.D.1.

Risks and complications associated with pressure sores

If pressure sores are not very carefully managed, they can become large and deep. Because they contain dead skin and tissue, they can easily become infected. If a sore reaches the bone, which often happens, the bone can also become infected. Bone infections can be very difficult to cure, may last for years, and may keep recurring even after the original pressure sore has healed.

Infections in deep pressure sores often spread to the blood and then affect the whole body, causing fever and general illness, including bacteraemia and septicaemia.

Incidence of pressure sores

In patients who have lost sensation in parts of their body, **pressure sores are very common**. Most people with spinal cord injuries in developed countries, and nearly all people with such injuries in resource-limited countries, develop pressure sores. **Often the sores start to develop in hospital shortly after the injury, due to inadequate nursing care. Therefore it is important that the families of patients with spinal cord injuries, and those patients**

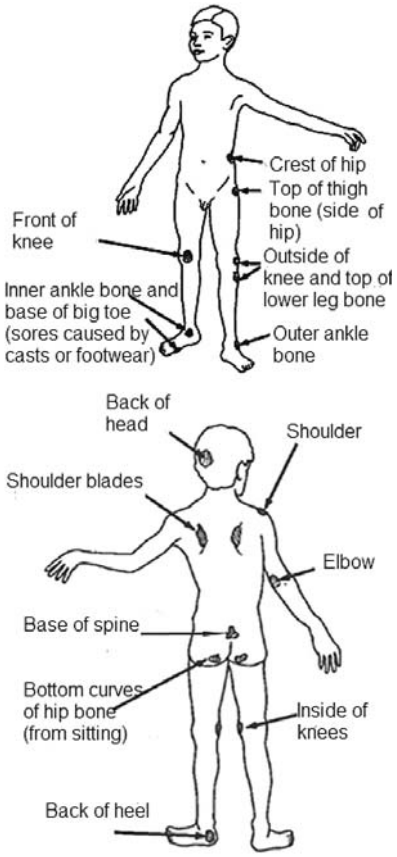

FIGURE 4.2.D.1 Sites where pressure sores are most likely to develop, with the most high-risk areas (in the hip region) labelled in bold type.

themselves, learn as early as possible about the prevention and early treatment of pressure sores, and put this knowledge into practice.

Prevention of pressure sores

It is important that both the child and their family are taught about the risk of pressure sores developing, and how to prevent them. The following actions are important:

- Avoid staying in the same position for very long. When lying down, turn from side to side or from front to back at least every 2 hours (or up to 4 hours if padding and cushioning are adequate). When sitting, lift the body up and change position every 10 to 15 minutes.
- Use thick soft padding, pillows or other forms of cushion arranged so as to protect bony areas of the body.
- Use soft clean dry bed sheets, and try to avoid them wrinkling. Change the bedding or clothing every day and also each time it becomes wet or soiled. A child who stays wet will develop pressure sores, especially if the wetness is caused by urine.
- Bathe the child daily. Dry the skin well by patting it, not rubbing it. It is probably best not to use body creams or oils, or talc, except on the hands and feet to prevent cracking, as these products soften the skin and make it weaker. **Never use heat-producing oils, lotions or alcohol.**
- Examine the whole body carefully every day, checking in particular those areas where pressure sores are most likely to develop. If any redness or darkness is present, take extra care to prevent all pressure over this area until the skin returns to normal.
- Good nutrition is important for preventing pressure sores. Make sure that the child gets enough to eat (but do not let them become overweight). Give them plenty of fruits, vegetables, and protein-containing foods (beans, lentils, eggs, meat, fish and milk products). If the child looks pale, check for signs of anaemia (*see* Section 5.11.A), and make sure that they are given iron-rich foods (meat, eggs and dark green leafy vegetables) or take iron tablets (ferrous sulphate), as well as foods rich in vitamin C (oranges, lemons, tomatoes, etc.).
- As far as possible, the child should learn to examine their own body for pressure sores every day, and eventually learn to take responsibility for all the necessary preventive measures themselves.

Other precautions

- To avoid pressure sores or other injuries developing on feet that have lost sensation, use well-fitted, well-padded sandals or shoes.
- Changing positions is important. When a child has recently had a spinal cord injury, they must be turned regularly, taking great care not to bend their back. Using a sheet under the body can help with turning.
- As the child gets stronger, hang loops and provide other aids, if necessary, so that they can learn to turn themselves.

At first it is important that the person turns, or is turned, at least **every 2 hours day and night**. Later, if there are no signs of pressure sores, the time between turns can gradually be lengthened to 4 hours. To avoid the child (or the person turning them) sleeping through the night without turning, an alarm clock can be very helpful.

When the child begins to sit or to use a wheelchair, there is a new serious danger of pressure sores developing. The child must now get into the habit of taking the pressure off their bottom at least every 30 minutes.

If their arms are strong enough, the child can lift up their whole body and hold it up for a minute or two. This allows the blood to circulate in the bottom.

If the chair has no arm rests, or if they can be removed, the child can lie sideways over a pillow on a high bed. They can rest for 15 to 30 minutes like this.

To prevent pressure sores, it is essential that the person who has lost sensation lies and sits on a soft surface that reduces pressure on bony areas. It is best for them to lie on a flat surface with a thick spongy mattress. A **thick foam rubber mattress** often works well. However, some foam is so spongy that it sinks completely under a person's weight, so that the bony area is not protected from the hard board underneath. A firm sponge with very small air bubbles (microcell rubber) works well, but is expensive.

A 'waterbed' (a bag-like mattress filled with water) or air mattress also works well.

In some countries, an excellent mattress material is made from rubber-coated coconut fibre. Urine can be washed out of the material by pouring water through it. Because this material is costly, a rehabilitation programme in Bangladesh has adopted the practice of cutting a square out of a cheap mattress and replacing it with a square of the coconut fibre sponge.

Careful placement of pillows, pads or soft folded

blankets can also help to prevent pressure sores. Such measures are especially important in the first weeks or months after a spinal cord injury, when the person must lie flat and be moved as little as possible. Pillows should be placed to avoid pressure on bony areas, and to keep the person in a position that is healthy and that helps to prevent contractures.

Chair and wheelchair cushions

For the child who has lost sensation in their bottom, the type of seat cushion used is very important, especially if the paralysis makes it difficult for them to lift up or change positions. All patients with spinal cord injury should use a good cushion. Sitting directly on a canvas seat or a poorly padded wooden seat will cause pressure sores.

Good cushions can be made of 'microcel' rubber, which is fairly firm. It works best if it is cut and shaped to reduce pressure on bony areas.

A useful low-cost way to make a fitted cushion is to build a base out of many layers of thick cardboard glued together, and then cover it with a 2 or 3 cm thick layer of sponge rubber.

Wet the cardboard and sit on it wet for 2 hours, so that it moulds to the shape of the bottom. Then let it dry, and varnish it.

Before making a specially fitted cushion, you can make a 'mould' of the patient's bottom by having them sit in a shallow container of soft clay, mud or plaster. Note the bony hollows and form the seat to fit them.

Air cushions made from bicycle tyre inner tubes are excellent for the prevention of pressure sores, and for bathing on a hard surface. Use one, two or more tubes, depending on the size of the tube and the size of the child. Bind loops of the tubes together with thin straps of inner tube. Then pump in enough air to ensure that the whole of the child's bottom is held up by air. (This idea was suggested by wheelchair rider-builders at Tahanang Walang Hagdanan (House With No Stairs), Quezon City, Philippines.)

Treatment of established pressure sores

Be alert for the first signs of a pressure sore by examining the whole body every day. Teach the child to do this using a mirror.

If early signs of a pressure sore (redness, darkness, swelling or open skin) are observed, change body positions and use padding to protect that area from pressure.

For larger areas (such as the bones near the base of the spine), you can try using a small (motor scooter) inner tube to keep the weight off the sore area. Put a towel over the tube to soak up sweat, as sweaty skin against the rubber can also cause sores.

Warning: For small areas such as the heels, never use a ring or 'doughnut' of cloth to keep the weight off the sore, as this can cut off the blood supply to the skin inside the ring and make the sore worse.

If a pressure sore has already formed:

- Keep the pressure off the sore area completely and continuously.
- Keep the area completely clean. Wash it gently with clean or boiled water twice a day. Do **not** use alcohol, iodine or other strong antiseptics.
- Make sure that the child has a healthy diet. If a large amount of liquid is lost from the sore, a lot of protein and iron will be lost with it. These must be replaced to allow quicker healing. The child should also take iron tablets if signs of anaemia are present, and they should eat foods rich in protein (beans, lentils, eggs, meat, fish and milk products).
- Do not rub or massage areas where pressure sores might be forming, as this could tear weakened tissue and make the sore inside larger.

If the sore is deep and contains dead tissue within it:

- Clean the sore three times a day.
- Each time you clean the sore, try to scrape and pick out more of the dead rotten tissue. Often you will find that the sore is much larger inside than you first thought. It may go deep under the edges of the skin. Little by little remove the dead tissue until you come to healthy red flesh (or bone).
- Each time you have cleaned out the dead tissue, wash the sore out well with soapy water. Use liquid surgical soap if possible. Then rinse with clean (boiled and cooled) water. A syringe without a needle can help with irrigation.

If the sore is infected (signs of this include pus, foul smell, a swollen hot red area around the sore, or the presence of fevers and chills):

- Clean out the sore three times a day as described above.
- If possible, take the person to a clinical laboratory where a sample from the sore can be removed and cultured to find out what organisms are causing the infection and what is the most appropriate medication to treat it.
- If this is not possible, try treating the patient with penicillin, cloxacillin or flucloxacillin.

If the sore does not get better, or if liquid or pus keeps draining from a deep hole, the bone may be infected, so tell the parents to take their child to the hospital.

Honey and sugar

Once a pressure sore is free of dead tissue, filling it two to three times a day with honey or sugar helps to prevent infection and speeds up healing. This treatment, which was used by the ancient Egyptians and was recently rediscovered by modern doctors, works remarkably well. It is now being used in some hospitals in the UK and the USA.

To make it easier to fill the sore, mix honey with ordinary sugar until it forms a thick paste. This can easily be pressed deep into the sore. Then cover the sore with a thick gauze bandage.

It is important to clean out and refill the sore at least twice a day. If the honey or sugar becomes too diluted with liquid from the sore, it will feed the bacteria rather than kill them.

The amount of honey that is needed on the wound depends on the amount of fluid that is being produced by the pressure sore. If there is a lot of fluid it will dilute the honey and make it less effective. The frequency of dressing changes required will depend on how rapidly the honey is being diluted. If there is no exudate, dressings need to be changed twice weekly to maintain the antibacterial properties of the honey as it enters the pressure sore. If the sore is producing a lot of fluid, the dressing will need to be changed twice a day.

To achieve the best results the honey should be applied to a dressing (cotton plus cellulose) which can absorb this

prior to application. If applied directly to the wound, the honey tends to run off and be less effective. Honey will not soak easily into absorbent dressings. Soaking is helped by warming the honey to body temperature and/or adding 1 part of water to 20 parts of honey to make the honey more fluid. If the pressure sore is producing a lot of fluid, the absorbent dressing can be secured in place using cling film taped over it to help to keep the honey on the wound.

Alginate dressings impregnated with honey are a good alternative to cotton/cellulose dressings, as the alginate is converted into a honey-containing soft gel. Any holes in the wound need to be filled with honey in addition to using a honey-impregnated dressing. As infection may be present in the tissues underlying the edges of the pressure sore, honey dressings need to extend beyond the inflamed area surrounding the sore.

Further reading

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Werner D (1996) *Disabled Village Children: a guide for community health workers, rehabilitation workers and families.* Palo Alto, CA: Hesperian Foundation.

El Masri WS (2006) Traumatic spinal cord injury: the relationship between pathology and clinical implications. *Trauma*, **8**, 29–46.

4.2.E Facilities for children with special needs and learning difficulties

Introduction

The most valuable asset is healthcare staff who can spend time with these children and their families, and preferably who are also able to visit them at home.

For children presenting at the hospital with established disabilities, the challenge is to ensure that they make the best use of their abilities and do not develop further disabilities.

TABLE 4.2.E.1 Equipment for assessment

Equipment for physical examination	Equipment for skills assessment
Tape measure	20 brightly coloured wooden cubes, 2.5 cm in diameter
Auroscope	Threading beads of various sizes, and string
Ophthalmoscope	20 culturally appropriate pictures of common domestic objects, some of which have similar sounding names in the local language
Tendon hammer	Soft ball, approximately 10 cm in diameter
128-Hz tuning fork	Denver Developmental Screening Test
Simple audiometer	

Aids for disabled children

This section outlines the types of aids that should be available for disabled children in all hospitals. There are many conditions which can cause disability, and **the aim of the aids listed is to minimise disability and maximise independent function**. It should be noted that some positions which may appear desirable (e.g. the upright walking posture in a child with excessive extensor tone) may adversely affect the child's ultimate mobility. The advice of a trained paediatric physiotherapist is invaluable.

David Werner's book, *Disabled Village Children*, is an excellent source of ideas and advice.

FIGURE 4.2.E.1 Lying aids.

General principles

- 'Look first at my strengths and not at my weaknesses': the preservation of best function is primarily achieved by education of the child and their carers, but aids and appliances can be very useful.
- Always consider the developmental stage of the child.
- An understanding of the home environment of the child is essential (e.g. in some regions a donkey may be a more useful mobility aid than a wheelchair once the child leaves hospital).
- The prevention of secondary disabilities (e.g. contractures or pressure sores) is a major priority in the care of disabled children.
- Always consider the purpose of the aid that you think will help, and ask yourself the following questions:
  - How will this aid help this child to function in their daily life?
  - Will the use of this aid reduce this child's abilities to do other things?
  - Will the use of this aid improve the way the child feels about him- or herself?
  - Who will review this aid to ensure that it is still helping the child and is still the right size for the growing child?
  - Who will maintain this aid to ensure that it still works?

Developmental aids

These are primarily used with children with delayed development, but may also be useful for children who have suffered a neurological insult, whether or not they are showing signs of recovery. Most children function better if they can experience a variety of positions and can be part of activities with others.

Lying aids

Many children who are ill or who are recovering from illness spend most of their time lying on their back or on their side. Lying on their front helps to develop trunk and arm strength and stretches muscles in the hips, knees and shoulders. **A pillow under the chest** helps to release the arms and hands for play.

A **wedge** is a more substantial version of the same idea, and can be made from material such as stiff foam plastic. Some children who need to have their legs separated because of adductor spasm will need a leg separator or pillow, also made of similar material.

Sitting aids

The type of sitting aids used will depend on the particular difficulties and developmental stage of the child. Most children with cerebral palsy benefit from being seated in a position in which their ankles, feet and hips are at 90 degrees and their legs are kept apart (abducted). There are many varieties of seats available. For a young child, a **corner seat** is often helpful. Special seating can also be fun (e.g. the 'steam engine').

Children with spasticity also often benefit from a slight tilt backwards. The position and amount of head support needed depend on the amount of head control and extensor tone.

Standing aids

These may be useful for children who are showing improvement in their motor skills and can be expected to learn to stand independently, but are also useful for children who may never stand independently, because the standing position aids the circulation and also bone growth and strength, particularly of the hip joints. Some children find standing frames difficult to get used to at first, and may need encouragement to use them.

Walking aids

There are a wide variety of these aids available. Perhaps the most useful is a walking frame that goes behind the child and which can have a variety of attachments depending on the child's balance and arm strength. Some **parallel bars** are also useful and will need to be set at different heights depending on the size of the child.

A selection of **underarm crutches, elbow crutches** and **tripod sticks** will be useful. These can often be made locally, and will need to be of various sizes.

Note that underarm crutches can cause nerve damage if the child hangs off the crutches when attempting to walk.

Wheelchair technology

This is beyond the scope of this book. The general principles listed at the beginning of this section apply. Remember that a wheelchair is not the only solution for an otherwise immobile child. If the child has no sensation in their buttocks as a result of spinal cord damage, they will be at risk of developing pressure sores if they remain seated in the same position for long periods of time. They can learn ways of taking the pressure of their buttocks. If pressure sores have developed, getting around the hospital may be better using a **gurney**.

Eating and drinking aids

Utensils with thick handles and cups with handles on both sides may be easier to use for children who find gripping difficult. It may be helpful to put a non-slip material underneath a bowl or plate to stop it sliding while the child is eating (a damp cloth works very well). Eating and drinking aids must be easy to wash. Assessments by occupational and speech and language therapists (if available) are invaluable for children with complex feeding difficulties.

Toileting aids

For details, *see* Section 4.2.D.

Communication aids

Children who are unable to communicate verbally because of deafness and/or inability to use their oro-motor muscles will often be able to use a **communication board** or book with pictures of objects, people and actions. If the child is unable to point using a finger, hand, toe or foot, they may well be able to 'eye point'. An attentive carer will be aware that the child is eye pointing, and the use of a communication aid may 'unlock' the child who had previously been assumed to be unable to communicate beyond indicating pleasure or distress. More technological solutions are available using computers with specialised software which enables children to 'speak', but the basic principle of being able to select a pictorial representation of an object or an idea is the same.

Aids to prevent common secondary problems developing in hospital

Preventing foot drop

One of the commonest preventable complications in children with weak legs is the development of foot drop. This should not happen in your hospital. Regular exercises to move the ankles through their full range of movement should be done at least twice a day. The use of tight or heavy bed covers should be avoided, as they may hold weak feet in a bad position. It is best for the feet to rest with the ankles at 90 degrees. This is easily ensured by positioning a roll of blanket or similar material so that the feet are braced in this position.

Preventing knee and hip contractures

Regular exercises that take the joints through as full a range of movement as possible are the mainstay of prevention. If possible, the child should spend some time each day lying on their front with their hips and knees extended.

Preventing scoliosis

This is achieved by symmetrical positioning of the child so that attention must be paid to both lying and sitting positions. With excessive and asymmetrical muscle tone it is often difficult to prevent scoliosis, and once it has developed, it often gets worse, particularly at times of rapid growth.

Preventing pressure sores

Pressure sores develop anywhere in the body where skin is kept under pressure for too long. This commonly happens in areas where sensation has been lost, and will develop more quickly if the circulation is poor. There is no substitute for good nutrition and regular moving and turning of the child. The skin should regularly be gently cleaned and dried, and moisturising lotion used. Prevent bony areas from pressing on each other and on the mattress by using pillows or foam wedges, for example, between the knees or under the heels (*see* Section 4.2.D).

Further reading

Werner D (1999) *Disabled Village Children: a guide for community health workers, rehabilitation workers and families.* Palo Alto, CA: Hesperian Foundation.