

Assessments & Health Visits for People Living with Down Syndrome Guided Checklist

Regular well-care visits

- Obtain family history and review any pre and postnatal conditions
- Establish rapport with family and schedule regular visits for health checkups, as needed

Monitor growth

Determine BMI, weight, and height trends using standard growth charts of the National Center for Health statistics or WHO

Immunizations

Administer immunizations including influenza vaccine unless contraindicated

Heart

- Monitor infants with cardiac defects; typically ventricular or atrioventricular septal defects
- Tachypnea, feeding difficulties, and poor weight gain as indicators of heart failure
- Manage through nutritional support until cardiac surgery; repairs performed as soon as possible to limit development of pulmonary hypertension and other complications
- General increased risk of hypertension in DS

Blood test

Obtain hemoglobin concentration at 1 year to assess for iron deficiency; get serum ferritin concentration and C-reactive protein (CRP)

Hearing and vision

- Review: risk of serious otitis media with family and previous hearing evaluation if done; rescreen at 6 months for confirmation
- Referral: (1) otolaryngologist and (2) ophthalmologist; (1) to determine if middle ear abnormality is present and (2) evaluate in first 6 months of life for strabismus, cataracts, and nystagmus

- Use tympanometry if poorly visualized tympanic membrane

Thyroid

- Increased risk of acquired thyroid disease
- Repeat measurements of TSH at 6 and 12 months of age

Stomach or bowel problems

- Perform clinical examination; assess for duodenal atresia or anorectal atresia/stenosis
- Constipation; evaluate for restricted diet, limited fluid intake, hypotonia, hypothyroidism, or gastrointestinal tract malformation (Hirschsprung disease)
- Assess for gastroesophageal reflux; refer for subspecialty intervention if severe

Sleep issues

Discuss once during first 6 months about symptoms of obstructive sleep apnea (OSA), heavy breathing, snoring, uncommon sleep positions, frequent night awakenings, daytime sleepiness, apneic pauses, and behaviour problems associate with poor sleep

Cervical spine positioning

Maintain neutral positions during anesthetic, surgical, or radiographic procedure to minimize risk of spinal cord injury

Myopathy

Perform physical examination for myopathic signs and symptoms; clinical history discussed

Neurologic Dysfunction

Monitor for signs of dysfunction such as seizures; infantile spasms, Moya Moya disease

Developmental services

- Review infant development program with family and other early intervention services

Social support services – each visit:

- Assess parents' emotional status and intra familial relationships
- Review availability of DS support groups, organizations, and other resources, if possible
- Refer to social support services and counseling

Recurrence risk counseling

- Refer to genetic counseling; discuss risks of DS recurrence with family
- Discuss at least once the availability of prenatal diagnostic testing with family