

Assessments & Health Visits for People Living with Down Syndrome

Guided Checklist

Regular well-care visits

- Continue updating and obtaining family history from past lab requisitions
- Perform physical exam and review past and current health conditions
- List current or past medications
- Assess family and intra-familial relationships status
- Annual visit with family; schedule any necessary follow-ups
- Discuss transition process; GPs to establish rapport with family during adolescence

Monitor growth

- Continue to monitor growth/BMI; onset of obesity very common
- Establish diet planning and exercise program; refer to dietician for planning as needed
- Discuss supplements (i.e. adequate calcium and vitamin D, iron and others)

Immunizations

Heart

- Examine annually for acquired mitral and aortic valvular disease in older patients
- Request echocardiogram if history of fatigue, shortness of breath, or exertional dyspnea

Hearing

Obtain annual ear-specific audiologic eval.

Vision

- Obtain ophthalmologic eval. every 3 years
- Check for onset of cataracts, refractive errors, and keratoconus (blurred vision, corneal haze and thinning)

Lab tests

Measure hemoglobin and TSH concentration annually; increased risk of hypothyroidism with age

Stomach or bowel problems

Review symptoms for PNS/CNS dysfunction (constipation) and symptoms related to celiac disease; evaluate if present

Musculoskeletal

- Maintain neutral positions during anesthetic, surgical, or radiographic procedure to minimize risk of spinal cord injury
- Assess for Myopathic signs/changes; discuss history of myopathy if present

Sleep Issues

- Discuss symptoms related to OSA with family
- Refer to physician specialized in sleep issues; may refer for sleep study and/or CPAP
- Discuss obesity as risk factor for OSA

Skin

Discuss general skin, hair and, scalp care

Brain and nervous system

Monitor for signs of neurologic dysfunction; increased risk of seizures with age and neurodegenerative diseases (i.e. Alzheimer's)

Behaviour and mental health

- Evaluate for medical problems that may underlie behaviour changes; thyroid abnormalities, celiac disease, sleep apnea, gastroesophageal reflux, and constipation
- Increasing risk of Alzheimer's and neurodegeneration with age; monitor changes in typical behavioural and social states
- Refer for specialized evaluation and intervention for chronic behavioral problems or acute deterioration in function

Sexuality

- Continuously monitor and encourage independence with hygiene and self-care

- Routine gynecologic exams and pre-menstrual/ menstrual behavior problems
- Guidance given to patient on healthy, normal, and typical sexual development/behaviours; encourage opportunities for advancing comprehension of sexuality
- Discuss with family and evaluate for sexual exploitation/abuse and domestic violence
- Discuss need for contraception and prevention of STDs; advocate for LEAST invasive and permanent method of birth control

Transitions

- Age 12 – 24: follow guidelines for transition from pediatric to adult care (involve Pediatrician and GP); transfer patient's medical history and physician contacts [transition guidelines and tools can be found: <http://ontracbc.ca/>]
- Discuss with family: guardianship, long-term financial planning, vocational training or related school placements; inform family on morbidities related to premature aging and Alzheimer's
- Discuss group homes, independent living opportunities, workshop settings and other community supported employment