

Health Maintenance Checklist for People Living with Down Syndrome

Guided Assessment Tool For Annual Visits & Follow-ups

Review family history & most recent lab requisition results with caregiver & patient?

Review current and past medications taken for all conditions

Review past & current health/comorbid conditions

Obtain cardiac history —prior surgeries, cardiac defects, and symptoms of concern – shortness of breath, history of fatigue or exertional dyspnea (murmur or gallop). Perform echocardiogram and check for signs of infection/fluid buildup in the lungs.

Sleep history & concerns regarding sleep

- Determine current sleep issues/concerns
- How long issues have persisted
- Daytime behavioural and activity issues
- Childhood sleep issues
- Any sleep assessments, consultation conducted or medications given

Discuss with family any noticeable changes in typical behaviours, social states, or overall deterioration of regression (both in early & late adulthood)

- Evaluate for medical problems that may underlie behaviour changes (thyroid disorder, sleep apnea/ issues, celiac disease, gastroesophageal reflux, constipation)
- Any history of psychiatric issues (i.e. depression, OCD, other mood disorders

Discuss with family any myopathic or neurological issues that have been observed

- Onset of seizures; greater risk with age and comorbidity with dementia
- History of strange movements, gait and balance problems

Discuss sexual function and fertility for both men and women with Down syndrome

- Counsel fertility and risk of recurrence of Down syndrome (50%) for women with Down syndrome; few reported cases in men with normal phenotype in all cases
- Discuss contraceptive use and options as well as STI prevention for both genders.

Notes:

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Perform physical examination and measure BMI

Cardiac and pulmonary health — auscultation and imaging (e.g. echocardiogram, chest x ray) to assess for signs of congestive heart failure, pulmonary hypertension, or infections such as pneumonia

Celiac disease — chronic symptoms of dyspepsia, flatulence, mouth sores, and skin rashes

Dementia — conduct yearly cognitive screen and assessment of activities of daily living (ADLs and IADLs) – observe for changes in behaviour or new onset seizures

Changes in behaviour — in women, determine symptoms for early menopause; look for medical causes for changes; otherwise conduct screening for regression or dementia

Neurological exam — conduct annually to test for musculoskeletal or myopathic issues; risk assessment for gait/balance issues done through Get-up & Go test

Domestic violence and sexual abuse screening for traumas and abuse at every clinical encounter

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Measure BMI and BP — yearly to monitor for obesity risk or follow-up on diagnoses, hypertension

Auditory testing — every 2 years

Ophthalmic exam — every 1–2 years; vision screen annually

Oral exam – annually

Echocardiogram — for suspected acquired mitral valve prolapse or valvular regurgitation; monitor/follow-up those with heart surgery

Neurologic exam — for suspected myopathy and spinal cord compression

Bone mineral density screening — regular testing for suspected or confirmed osteoporosis

Lateral cervical spine X-rays — to confirm neutral position prior to any surgeries or anesthetic procedures.

Polysomnography/sleep study — for suspected obstructive sleep apnea and other sleep issues.

DS specific baseline battery of dementia testing — once before age 35, every 1–5 years after.

Testicular exam — done annually.

Mammography — inconclusive value and low risk for breast cancer in this population; done for suspected cases.

Screen for colorectal cancer — starting at age 50.

Pap smear assessments — to screen for cervical cancer and gynecologic concerns after age 21; performed every 2–3 years with aging.

STI screening — between age 13–64 screen once; test annually for at risk patients (multiple partners, unprotected sex, pregnant women, history of STIs).

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ENT specialist — review audiological evaluation; assess for otitis media.

Ophthalmologist — review vision screen; assess for glaucoma, cataracts, refractive errors & keratoconus.

Dentist — regular care and maintenance every six months; assess for gum disease and tooth decay.

Cardiologist — review echocardiogram; assess for acquired mitral and aortic valvular disease.

Radiologist — conduct imaging for atlanto-axial subluxation, bone density (DEXA) scans for assessing signs of osteoporosis.

Oncologist — for specific cancers that increase in prevalence with age; particular attention for testicular cancer screening.

Gynecologist — review specific reproductive health care needs of women with Down syndrome.

Dermatologist — review routine care evaluation; address concerns for atopic dermatitis, cheilitis, impetigo and alopecia areata.

Neuropsychiatrist — referral for specialized evaluation for chronic behavioural problems, acute deterioration in function or suspected dementia.

Sleep specialist — assess for underlying causes of sleep issues/disorders; referral to sleep study and/or CPAP evaluation.

Geriatrician — issues with aging and critical/palliative care for the elderly with Down syndrome.

Notes: