# Health Watch Table - Down Syndrome - Adult

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<table>
<thead>
<tr>
<th>CONSIDERATION</th>
<th>RECOMMENDATION</th>
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<tbody>
<tr>
<td><strong>1. HEENT (HEAD, EYES, EARS, NOSE, THROAT)</strong></td>
<td>□ Arrange ophthalmological assessment every 1 – 2 years, with special attention to cataracts, keratoconus, and refractive errors</td>
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<td>Adults: ~15% have cataracts; 5 – 15% have keratoconus; 20 – 70% have significant refractive errors; 50-90% have a hearing deficit</td>
<td>□ Undertake auditory testing every 2 years</td>
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<td><strong>2. DENTAL</strong></td>
<td>□ Undertake every six months clinical exams with referral as appropriate</td>
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<td>Adults: have increased risk of periodontal disease</td>
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<td><strong>3. CARDIOVASCULAR</strong></td>
<td>□ Ascertain comprehensive cardiovascular history</td>
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<td>Adults: &gt;50% have cardiovascular concerns, commonly including acquired mitral valve prolapse (MVP) and valvular regurgitation</td>
<td>□ Undertake annual cardiac exam, with echocardiogram to confirm new abnormal findings and follow-up depending on the type of cardiovascular problem present or refer to Adult Congenital Heart Disease clinic</td>
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<td></td>
<td>□ Monitor on an ongoing basis those that have had surgery in childhood</td>
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<td>□ Echocardiogram is indicated if new abnormal physical findings or inability to assess adequately by physical exam. Echocardiogram should be considered to establish baseline if not previously done or records unavailable ¹</td>
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<td><strong>4. RESPIRATORY</strong></td>
<td>□ Ascertain detailed sleep history, with special attention to OSA symptoms. Refer to ENT, including sleep study if OSA is suspected</td>
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<td>Adults: 50%-80% have obstructive sleep apnea (OSA)</td>
<td>□ Investigate possible gastro-esophageal reflux/swallowing disorder if aspiration pneumonia is suspected</td>
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<td><strong>5. GASTROINTESTINAL</strong></td>
<td>□ Monitor for obesity</td>
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<td>Adults: ≤ 95% have obesity; ~7% have celiac disease</td>
<td>□ Screen for celiac disease which may present in adulthood; screening tests used are the same as in the general population ²</td>
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<td></td>
<td>□ Test for <em>Helicobacter Pylori</em> and treat if positive regardless of symptoms</td>
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<td>□ Manage constipation</td>
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<td><strong>6. GENITOURINARY</strong></td>
<td>□ Annual clinical exam with surgical referral as appropriate ³</td>
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<td>Adults: Have increased risk of testicular cancer</td>
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<td><strong>7. SEXUAL FUNCTION</strong></td>
<td>□ Counsel regarding fertility possibility and the 50%⁴ risk of Down syndrome in offspring</td>
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<td>Adults:</td>
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<td>Fertility has been documented in women</td>
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<td>Fertility in males rarely reported</td>
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8. **MUSCULOSKELETAL**

*Adults*: Continued risk for spinal cord compression secondary to AAI

- Undertake annual neurological exam to look for signs of spinal cord compression
- Arrange lateral cervical spine films if not previously done, if presenting with signs and symptoms of AAI or if participating in Special Olympics
- Take detailed history and attend to joint complaints, scoliosis, and hip abnormalities

9. **NEUROLOGICAL**

*Adults*: Dementia is frequent and occurs earlier:

- 40 – 49 y, 11%
- 60 – 69 y, 77%

Up to 75% with dementia have seizures with frequency increasing with age

- Screen for early signs of dementia
- Ascertain neuropsychiatric history at every visit with particular attention to change in behaviour, loss of function/ADL, and new onset seizures
- If functional decline and/or signs/symptoms of dementia, use history, exam, and blood work to check for other conditions and treatable causes (e.g., chronic pain, medication side effects, depression, obstructive sleep apnea, menopause, hearing/vision deficits, hypothyroidism, low folic acid/vitamin B12)
- Undertake EEG and neurology consult for possible seizures

10. **DERMATOLOGICAL**

*Children & Adults*: Dry skin, atopic dermatitis, seborrheic dermatitis, chelitis, impetigo, and alopecia areata are more common than in general population

- Examine skin as part of routine care
- Treat as per general population, with referral to dermatologist as needed

11. **MENTAL HEALTH/BEHAVIOURAL**

*Adults*: ≤ 30% have psychiatric disorder – including depression

- Autism spectrum disorder in 5-10%

- Review regularly with respect to behavioural concerns
- Self-talk very common; Review for positive or negative signs suggesting psychosis
- Ascertain neuropsychiatric history at every visit, with particular attention to changes in behaviour, loss of function/ADL, and new onset seizures

12. **ENDOCRINE**

*Adults*: 15 – 50% are hypothyroid

- Hyperthyroidism, autoimmune thyroiditis, and subclinical hypothyroidism are more common than in the general population

- For adults who are euthyroid, check TSH and free T4 levels at least every five years (some recommend annually)
- If subclinical hypothyroidism (i.e., elevated TSH with normal free T4) then follow free T4 every six months to one year (some recommend treatment if antibodies positive)
- Consider checking thyroid function with changes in mental status, behaviour or functional abilities

13. **HEMATOLOGICAL**

*Adults*: do not have an increased risk of leukemia
References


Published Down syndrome health care guidelines reviewed and compared:


Down syndrome websites that may be useful for families and caregivers:
Canadian Down Syndrome Society [http://www.cdss.ca/]
Down Syndrome: Health Issues by Dr. Len Leshin [http://www.ds-health.com/]
National Down Syndrome Society [USA] [http://www.ndss.org/]
Down Syndrome Medical Interest Group [DSMIG-UK] [http://www.dsmig.org.uk/]
Down Syndrome Education International [DownsEd] [http://www.downsed.org/]

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