

# DOWN SYNDROME HEALTH CARE GUIDELINES

(Based on 1999 Down Syndrome Health Care Guidelines)\*

## Neonatal (Birth-1 Month)

- < Review parental concerns. Chromosomal karyotype; genetic counseling, if necessary.
- < If vomiting or absence of stools, check for gastrointestinal tract blockage (duodenal web or atresia or Hirschsprung disease).
- < Evaluation by a pediatric cardiologist including echocardiogram. Subacute bacterial endocarditis prophylaxis –(SBE), in susceptible children with cardiac disease.
- < Exam for plethora, thrombocytopenia.
- < Review feeding history to ensure adequate caloric intake.
- < Thyroid function test - check on results of state-mandated screening at birth.
- < Auditory brainstem response (ABR) or otoacoustic emission (OAE) test to assess congenital sensorineural hearing (at birth or 3 months).
- < Pediatric ophthalmological evaluation (by 6 months) for screening purposes.
- < Discuss value of Early Intervention (infant stimulation) and refer for enrollment in local program.
- < Referral to local Down syndrome parent group or family support and resources, as indicated. Referral to NDSS.



666 Broadway, NY, NY 10012  
(800) 221-4602 / [www.ndss.org](http://www.ndss.org)

\*[HEALTH CARE GUIDELINES FOR INDIVIDUALS WITH DOWN SYNDROME: 1999 REVISION (Down Syndrome Preventive Medical Check List) is published in **Down Syndrome Quarterly** (Volume 4, Number 3, September, 1999, pp. 1-16) and is reprinted, duplicated, and/or transmitted with permission of the Editor. Information concerning publication policy or subscriptions may be obtained by contacting Dr. Samuel J. Thios, Editor, Denison University, Granville, OH 43023 (email: [thios@denison.edu](mailto:thios@denison.edu)).]

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## Infant (1-12 Months)

- < General neurological, neuromotor and musculoskeletal examination.
- < TSH and T4-Thyroid Function Test (6 & 12 months).
- < Evaluation by pediatric cardiologist including echocardiogram (if not done at birth). Consider progressive pulmonary hypertension if VSD or atrioventricular septal defect and little or no symptoms of heart failure.
- < Subacute bacterial endocarditis prophylaxis (SBE) (as indicated).
- < Well child care - immunizations.
- < Feeding consult, especially if constipated. Consider Hirschsprung disease.
- < Auditory brainstem response (ABR) or otoacoustic emission (OAE) test to assess congenital sensorineural hearing (by 3 months if not already, or if suspicious).
- < Ear, nose and throat exam (as needed), especially if suspicious of otitis media.
- < Well-balanced, high-fiber diet.
- < Vision exam (by 6 months and annually; earlier if nystagmus, strabismus or indications of poor vision).
- < Discuss Early Intervention and refer for enrollment in local program.
- < Application for Supplemental Security Income (SSI), depending on family income.
- < Consider estate planning and custody arrangements; continue family support.



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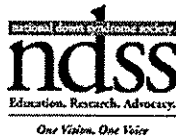
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## Childhood (1-12 Years)

- < TSH and T4-Thyroid Function Test (annual).
- < Echocardiogram by a pediatric cardiologist if not done previously.
- < Behavioral Auditory Testing (every 6 months to age 3, then annually).
- < Lateral cervical spine x-rays (neutral view, flexion, extension) to rule out atlanto-axial instability. Radiologist to measure atlanto-dens distance and neural canal width (at 3-5 years, then as needed).
- < Pediatric and neurological exam with evaluation for spinal cord compression: deep tendon reflexes, gait, Babinski sign.
- < Use Down syndrome growth charts and head circumference charts with others.
- < Eye examination (annually, or as indicated).
- < Screen for celiac disease IgA antiendomysium antibodies and total IgA (btwn 2 & 3 yrs)
- < Question about obstructive sleep apnea; ENT exam (as needed).
- < Dental Exam (2 years; follow up exams every 6 months after). Twice daily brushing
- < Reinforce need for subacute bacterial endocarditis prophylaxis (SBE) for cardiac problems (as indicated).
- < Brief vulvar exam for girls.
- < Well child care: immunizations; pneumococcal vaccine (2 years).
- < Evaluation by speech/language pathologist.



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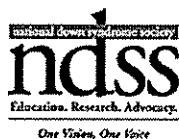
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## Adolescence (12-18 Years)

- < TSH and T4-Thyroid Function Test (annual).
- < Auditory Testing (annually).
- < Monitor for obstructive airway; sleep apnea.
- < General physical and neurological exam; check for atlanto-axial dislocation. Cervical spine x-ray (as needed for sports).
- < Eye examination (annually).
- < Monitor for obesity by plotting height for weight on growth charts for typical children
- < Clinical evaluation of the heart to rule out mitral/aortic valve problems. ECHO - Echocardiogram (as indicated by findings).
- < Reinforce need for subacute bacterial endocarditis prophylaxis (SBE) in susceptible adolescents.
- < Adolescent medicine consult for puberty/sexuality issues; health, abuse prevention and sexuality education. Pelvic exam (only if sexually active).
- < Low calorie, high fiber diet; regular exercise
- < Smoking, drug and alcohol education.
- < Begin functional transition planning (16 yrs). Monitor independent functioning.



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## Adulthood (More than 18 Years)

- < TSH and T4-Thyroid Function Test (annual).
- < Auditory testing (every 2 years).
- < Cervical spine x-rays (as needed for sports); check for atlanto-axial dislocation.
- < Ophthalmologic exam, looking especially for keratoconus & cataracts (every 2 yrs)
- < Clinical evaluation of the heart to rule out mitral/aortic valve problems. Echocardiogram-ECHO (as indicated).
- < Reinforce the need for subacute bacterial endocarditis prophylaxis (SBE) in susceptible adults with cardiac disease.
- < Baseline Mammography (40 yrs; follow up every other yr until 50, then annual).
- < Pap smear and pelvic exam (every 1-3 yrs. after first intercourse). If not sexually active, single-finger bimanual exam with finger-directed cytology exam. If unable to perform, screen pelvic ultrasound (every 2-3 years). Breast exam (annually).
- < General physical/neurological exam. Routine adult care.
- < Clinical evaluation for sleep apnea.
- < Low calorie, high-fiber diet. Regular exercise. Monitor for obesity.
- < Health, abuse-prevention and sexuality education. Smoking, drug & alcohol ed.
- < Clinical evaluation of functional abilities (consider accelerated aging); monitor loss of independent living skills.
- < Neurological referral for early symptoms of dementia: decline in function, memory loss, ataxia, seizures and incontinence of urine and/or stool.
- < Monitor for behavior/emotional/mental health. Psych referral (as needed).
- < Continue speech and language therapy (as indicated).

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