

General Health Care Guidelines for People Living with Down Syndrome

Listed in order of clinical significance

Health Problem		Prevalence	Recommendations
Endocrine	Hypothyroidism	15–50%	Check TSH annually; with positive results follow-up every 6 months.
	Hyperthyroidism	More common	
	Diabetes Mellitus	Greater risk due to autoimmunity	Screen for every 3 years until 45, screen yearly after
Mental Health	Depression	Up to 30% have a psychiatric disorder	Review behavioural concerns regular and ascertain neuropsychiatric history; Consider checking thyroid as cause for changed behaviour/mental status
	Obsessive-Compulsive Disorder		
	Abuse (physical or sexual)		
	Conduct disorder		
Otolaryngology	Obstructive Sleep Apnea (OSA)	50–80%	Get detailed sleep history; consider CPAP and sleep studies/assessments
Hearing	Otitis Media	50–70%; more often in children	Auditory testing every 2 years and review for otitis media; ENT referral as needed
	Hearing Loss	50–80%	
Ophthalmic Disorders	Cataracts	15%	Vision screen yearly/glaucoma and ophthalmic exam every 1–2 years with special attention to mentioned conditions
	Refractive Errors	20–70%	
	Keratoconus	5–15%	
Musculoskeletal	Spinal Cord Compression	Continued risk	Assess with annual neurological exam
	Atlanto-axial subluxation	1–2%	Lateral cervical spine X-rays; confirm cervical spine is in neutral position for surgeries, anesthetic procedures
	Hip Dislocation	6%	Assess for risks; osteoporosis presence
	Osteoporosis	May be more common	Bone mineral density screening at reg. intervals for high risk patients
	Fall Risk	Risk at any adult age	Part of yearly physical examination; risks and gait/balance issues (influence from meds); Get-up and Go test performed

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Cholesterol & Lipid Disorders	Obesity	95%	Measure yearly height and weight (BMI)
	Diet	N/A	Diet planning and exercise program
	Cholesterol and Lipid disorders	N/A	Order fasting lipid panel every 5 year; more frequent if patient on atypical antipsychotics or has diabetes
Gastrointestinal Disorders	Celiac disease	5–16%	IgA tissue transglutaminase and total IgA testing if chronic symptoms present
	Intestinal Dysmotility	Very common	Treat constipation with physical therapy and diet management
Infectious Diseases	Respiratory Illnesses	5th highest cause of death	Most lethal, ensure annual influenza vaccine and serial boosters of Pneumovax
	Other acute diseases		
Periodontal Disease	Gum disease or tooth decay	Incr. risk with age	Perform annual oral exam; referral to dentist for regular care every 6 months
Alzheimer's Disease	Signs of Dementia	Incr. risk with age from 11–77% by age 60	Yearly cognitive screen/assessment of ADLs and IADL; changes in behaviour or new onset seizures
			DS Specific baseline battery of Dementia testing once before age 35 and every 1–5 years after
Neurological Dysfunction	Seizures	75%	Increased incidence in 5th/6th decade
	Spinal Cord Compression		
Hematological Problems	Anemia	3%	Monitor for anemia and iron deficiency; Hemoglobin, ferritin and CRP performed annually
	Iron Deficiency	10%	
	Leukemia	Low risk – 1%	Assess for history of Transient Myeloproliferative Disorder
	Hypertension	Normal pop risk	Measure blood pressure annually

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Cancers	Testicular Cancer	Increased risk	Perform yearly testicular exams
	Breast or Cervical Cancer	Lower risk for breast cancer compared to normal pop	Mammography of inconclusive value; cervical cancer dependent on sexual history; pap smear assessments after age 21 and every 2–3 years with aging
	Colorectal Cancer	Not indicated	Screen at age 50
	Other neoplasms	Increased risk	Yearly ophthalmic and lymphatic exams
Sexual Function	Fertility in Women	Documented	Counsel for fertility and risk of DS (50%) in offspring; discuss contraception
	Menopause	Early in population	Treat symptoms with hormone therapy
	Fertility in Men	Rare but reported	Offspring have been reported normal; discuss protection during sexual activity
	STIs	Not indicated	Ages 13–64 screen once for STIs; test annually for at risk-patients (multiple partners, unprotected sex, all pregnant women, history of STI's)
Abuse	Domestic Violence	Not indicated	Screen for physical, psychological, and sexual abuse at every clinical encounter
	Sexual Assault	68%–83% of females	
Dermatological Issues	Dry Skin	More common than in general population	Examine skin as part of routine care and treat as per general population; referral to dermatologist as needed
	Atopic Dermatitis		
	Cheilitis		
	Impetigo		
	Alopecia Areata		
Cardiovascular Disease	Acquired Mitral Valve Prolapse	50%	Get history and do annual cardiac exam with echocardiogram and follow-up; monitor those with prior heart surgery
	Valvular regurgitation		
Immunizations	Required annual influenza vaccine and immunizations	N/A	Follow CDC Adult Immunization Sched.

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Counselling	
Lifestyle & Quality of Life	<p>Discuss:</p> <ul style="list-style-type: none"> • Adequate Calcium and Vitamin D supplementation • Advanced directives • Dental hygiene • Fall risk assessment and prevention • Nutrition and physical activity • Any substance abuse cessation • Sexual health including: contraception, STI prevention, and healthy relationships • Assess family status of parents, guardians, and other interfamilial relationships, need for Community Living BC (CLBC) or other care forums; provisional guardians or caregivers
Medication Review	<ul style="list-style-type: none"> • Review medications at regular intervals with patients • Review patient's adherence with regimen • Evaluate for side effects and/or drug interactions
Safety	<ul style="list-style-type: none"> • Review safety practices • Review stranger and street safety • Review prevention of falls and head traumas (especially for those who have seizures)

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