Promoting Physical Health and Health Care Guidelines for Adults With Down Syndrome

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Physical Health

• Mirriam-Websters:
  – “The condition of being sound in body, mind or spirit;
  – freedom from physical pain or disease;
  – A condition in which someone or something is thriving or doing well”

• Achieved by care of our bodies for optimal health and functioning
  • Physical Activity
  • Proper Nutrition
  • Proper Sleep
  • Mental Well-being
  • Avoidance of disease
  • Functional Doctor-Patient Relationship
Physical Activity

• According to CDC Exercise has the following benefits:
  – Helps control weight
  – Decreases risk of cardiovascular disease
  – Decreases blood pressure
  – Strengthens bones and muscles
  – Decreases osteoporosis by decreasing bone density loss
  – Decreases risk of some types of cancers (colon/breast)
  – Reduced risk of Type 2 Diabetes
  – Improve ability for ADLs and helps prevent falls
  – Improves mental health
    • Decreased depression, improved sleep
  – Increase chances of living longer
How to Incorporate Exercise Routine

• Make it fun
• Make it social
• Add dance
• Exercise videos
• Wii Sports/Just Dance/Dance, Dance Revolution
• Use both variety and repetition – different activity each day of the week, repeating week after week
• Our Center’s Exercise Classes
• Consider pairing with “mentor”
Exercise & Activity Recommendations for Adults with DS

• 20-30 minutes of exercise 3-5X/week
• Regular social activities that incorporate movement – shopping, museums, dancing
• Increased movement in daily life
  – stairs instead of elevator, yard-work, household chores.
• Turning off the TV/phone/tablet
Weight Management

• Children with DS have been found to have lower resting metabolic rate (Luke et al., 1994)
  – 200-300 fewer calories burned in 24 hour time period
  – Attempts at making up for this by cutting back on dietary calories can cause loss of important nutrients
• 2004 study women with DS more likely to be obese than matched peers and men more likely to be overweight than matched peers (Melville, et al./ 2004)
  – More recreational and social activities = more likely adult with DS to be closer to ideal body weight
Proper Nutrition

- Contributes to Weight Control
- Improves Heart Health
- Increases Bone and teeth strength
- Increases Energy
- Helps keep the Brain Healthy
- Reduces risk of diabetes, heart attacks, stroke
- Lowers blood pressure
- Decreases kidney stones, decreased osteoporosis
- Decreases constipation
- Improves skin
- Improves immune function, improves healing
Attaining Proper Nutrition for Adults with Down Syndrome

- Use preference for repetition in DS population to advantage
- Teach portion sizes visually
- Smaller bowls/plates
- Family members should eat healthfully also
- Never Using Food As a Reward
- Encourage small changes each week
- The Down Syndrome Nutrition Handbook by Joan Guthrie Medlen
- Our Classes
- Other group programs – Weight Watchers
- Choosemyplate.gov
- Sparkpeople.com, myfitpal.com
Nutrition Guidance

• **USDA: MyPlate**
  • Introduced along with updating of USDA food patterns for the *2010 Dietary Guidelines for Americans*
  • Replaces Food pyramids
  • Focus on 5 food groups
  • “Everything you eat or drink matters”
  • Eat right amount of calories for age, sex, size, activity level
MyPlate

• Supertracker - can help you plan, analyze, and track your diet and physical activity.
  – Personalized with goal setting, virtual coaching, and journaling.

• Recipes, menu-building

• BMI calculator, quizzes

• Daily Checklist – based in age, gender, weight, activities
# MyPlate Daily Checklist

Find your Healthy Eating Style

Everything you eat and drink matters. Find your healthy eating style that reflects your preferences, culture, traditions, and budget—and maintain it for a lifetime! The right mix can help you be healthier now and into the future. The key is choosing a variety of foods and beverages from each food group—and making sure that each choice is limited in saturated fat, sodium, and added sugars. Start with small changes—"MyWins"—to make healthier choices you can enjoy.

## Food Group Amounts for 2,200 Calories a Day

<table>
<thead>
<tr>
<th>Food Group</th>
<th>Amount</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fruits</td>
<td>2 cups</td>
<td>Focus on whole fruits. Focus on whole fruits that are fresh, frozen, canned, or dried.</td>
</tr>
<tr>
<td>Vegetables</td>
<td>3 cups</td>
<td>Vary your veggies. Choose a variety of colorful fresh, frozen, and canned vegetables—make sure to include dark green, red, and orange choices.</td>
</tr>
<tr>
<td>Grains</td>
<td>7 ounces</td>
<td>Make half your grains whole grains. Find whole-grain foods by reading the Nutrition Facts label and ingredients list.</td>
</tr>
<tr>
<td>Protein</td>
<td>6 ounces</td>
<td>Vary your protein routine. Mix up your protein foods to include seafood, beans and peas, unsalted nuts and seeds, soy products, eggs, and lean meats and poultry.</td>
</tr>
<tr>
<td>Dairy</td>
<td>3 cups</td>
<td>Move to low-fat or fat-free milk or yogurt. Choose fat-free milk, yogurt, and soy beverages (soy milk) to cut back on your saturated fat.</td>
</tr>
</tbody>
</table>

## Limit

Drink and eat less sodium, saturated fat, and added sugars. Limit:
- Sodium to 2,300 milligrams a day.
- Saturated fat to 24 grams a day.
- Added sugars to 55 grams a day.

## Be active your way

Children 6 to 17 years old should move 60 minutes every day. Adults should be physically active at least 2 1/2 hours per week.

**Use SuperTracker to create a personal plan based on your age, sex, height, weight, and physical activity level.**

[SuperTracker.usda.gov](http://SuperTracker.usda.gov)
What About Supplements?

• Multi-vitamin possibly helpful
• Vitamin C supplementation may help immune function
  – 1000mg daily recommended
• Zinc supplementation may help immune function
  – 100mg daily recommended
Beverages

- Recommended amount
  - 48-64 oz water daily
  - More fluid required if exercising
- People with DS seem to have impaired thirst mechanism →
  - Dehydration
- Decreased fluids →
  - dizziness, decreased energy, constipation
Sleep

- Sleep problems more common in DS
  - Sleep Apnea
  - Abnormal Sleep Patterns
  - Inadequate amount of sleep
- Adults need 7-9 hours/night
- Teens need 8-10 hours/night
- Keep low threshold for sleep studies – Treat apnea!
- Sleep Hygiene is key!
- Consider picture schedule for bedtime

Sleep Hygiene

- Scheduled and regular sleep and wake up
- Daily exercise (early in day)
- No caffeine after noon
- Decrease distractions
- Calming routine in evening
- Bed is only for sleeping
- Warm shower or bath before bed
Social Health

- Friends and family play important role
- Self accomplishment and self worth
- Self-esteem
Preventing Disease

• Eye Health
• Ear, Nose, and Oral Health
• Heart and Lung Health
• Gastrointestinal Health
• Endocrine Health
• Gynecologic/Urologic/Sexual Health
• Orthopedic Health
• Neurologic Health
• Skin and Hair Health
Eye Health

• Eye Exams at least every 2 years
  – Should test for visual acuity, glaucoma, retinal changes, and health of surrounding eye tissue
  – Screen for: Keratoconus, cataracts, blepharitis, strabismus, retinal detachment, macular degeneration, glaucoma
  – Testing should be done more frequently if there are eye problems
  – Most with DS are able to cooperate, and if not exam can be done under anesthesia if needed
  – Consider eye glasses, contacts or corrective surgery
Ear health

• Hearing Loss
  – Need hearing screens at least every 2 years
  – Age related hearing loss – high frequency - occurs younger in DS
  – May not distinguish consonants, may not ask for repeat
  – Conductive hearing loss secondary to middle ear fluid
    • Fluid also cause balance problems, irritability, pain
    • May need abx, tubes, etc.

• Ear Wax
  – Small canals, different shaped canals, dry skin
  – If impaction – can see hearing loss, pain, poor balance
  – Tx w/ debrox or baby/mineral oil (if tm intact), or removal by MD

• Otitis Externa
  – More common due to wax and ear size/shape
  – Consider ear plugs when swimming, “swimmer’s ear drop”
  – May need prescription drops to tx
Nose/Sinus/Throat

• Smaller sinuses and/or less sinuses & smaller openings to sinuses
• Combined with decreased immune function
  ➔ increased sinus/nasal congestion and rhinorrhea
  • Avoid cigarette smoke
  • Avoid allergens
  • Humidifier in winter
  • Use nasal saline or Neti-pot
  • Antihistamines, decongestants, nasal steroids
  • Oral antibiotics only with bacterial cause
Oral Health

- High/narrow palate, small nasal passages, small nose/midface/maxilla, small/misshapen teeth
- Mouth Breathing
  - Tongue fissures and bad breath
  - Need to brush tongue
  - Decreased saliva can increase cavities and gum disease
- Teeth Misalignment – due to anatomy and tongue protrusion
  - Makes chewing difficult
  - Causes plaque buildup
  - Orthodontic care can be significant help
- Cavities – less common in DS but still an issue
- Gum Disease – leading cause of tooth loss in adults with DS
  - Decreased saliva and impaired immune function
  - Gingivitis (gum inflammation) and periodontitis (chronic - gums, ligaments, and bone)
    • Infection can spread to adjacent tissue and thru the blood
Oral Hygiene

- Regular brushing and flossing
  - try to use “grooves”, use pictures
  - Electric toothbrush/timer
  - Flossers or WaterPik
- Limit sugar
- Visit dentist every 3-6 months
  - Social Story with pictures
  - Light sedation
  - If necessary – sedation dentistry
Cardiac Care

• 50% of babies with DS born with structural heart disease
  – VSD, ASD, AV Canal Defect, mitral or aortic valve problems
  – Overtime, surgically corrected area can deteriorate
    • Increased risk of infection, rhythm disturbance, irregular heartbeat
    • so see Cardio at least every 5 years and prior to anesthesia
    • May need antibiotic prophylaxis
  – If unrepaired: higher risk of cyanotic heart disease
  – watch for fatigue, decreased exercise tolerance, sob, psychological changes, cp, dizziness

• DS has lower risk of CAD and HTN
• Only need to treat cholesterol if other risk factors present
  – Family history, DM, etc
  – Could get Coronary CT Angiography to stratify risk
Pulmonary Health

- **Pneumonia**
  - Higher incidence in DS b/c of swallowing problems and immune dysfunction
    - Encourage slower eating, better chewing, putting fork down b/w bites, drink b/w bites, cutting smaller
    - Get proper vaccinations

- **Asthma** – less common in DS

- **Chronic Cough**
  - **PND**, asthma, **GERD**, Chronic bronchitis, smoking, medications, cancer, chronic infection

- **Influenza** – more common in DS
  - Get annual flu shots, proper hand hygiene, stay away from those who have the flu
Gastrointestinal Health

- Celiac Disease – 7-15%
  - Should be screened as child and with new symptoms
  - Dx – blood tests, genetic test, small bowel biopsy
  - Tx – avoid gluten
- Food Sensitivities – ie lactose
- IBS – diagnosis of exclusion – motility problem
- GERD/PUD – lifestyle changes, medications, may need H.pylori treatment
- Constipation (low muscle tone)
  - Need to increase fiber, water, and activity, regular attempts at bms
  - Careful with meds
  - Miralax and colace generally ok long term
- Liver Problems
  - Fatty liver – look for DM, lose weight, decrease simple carbs, decrease saturated fats
  - Hepatitis
- Hernia – defect in the abdominal wall and abdominal tissues push through
  - Inguinal, umbilical, epigastric, at previous surgical site
  - Tx - surgery
Endocrine Care

• Increased risk pf Hypothyroidism and Hyperthyroidism in DS population
  – Hypothyroidism – underfunction
  – Hyperthyroidism – overfunction
    • Screen with annual TSH Reflex
    • Watch for symptoms
    • If on thyroid medication – replacement needs vary with age, malnourishment, medications

• Diabetes Mellitus
  – Makes diet and exercise even more important
  – Requires additional annual testing, daily feet checks
Hypothyroidism

- Trouble sleeping
- Tiredness and fatigue
- Difficulty concentrating
- Dry skin and hair
- Depression
- Sensitivity to cold
- Frequent, heavy periods
- Joint and muscle pain
- Weight gain

Hyperthyroidism

- Anxiety/irritability
- Moodiness
- Hyperactivity
- Sweating
- Sensitivity to heat
- Hand trembling (shaking)
- Hair loss
- Missed/light periods
- Weight Loss
Gynecological Care

• Exams should begin at age 21
  – Graduated exams
  – Consider avoiding stirrups
  – If speculum not tolerated – do 1 finger exam and blind pap
  – Use visual aids to help prepare patient with DS
  – Keep trusted female support person in the room
  – Q3 years in 20s, q5 years in 30s+

• Menstruation/Sexuality education important

• Anticipate and treat Menstrual Pain/PMS
  – Tylenol/NSAIDS, OCPs, regular exercise, B1 (thiamine) and fish oil supplementation, low fat diet
  – Good sleep, b6, calcium, omega-3 FA, Vitamin E, magnesium, manganese supplement, OCP, SSRIs/Buspar, NSAIDS, Aldactone for swelling, Parlodel for breast tenderness
Lack of Periods

• Evaluate for cause – thyroid, weight change, meds (antipsychotics), pregnancy, menopause

• Evaluate for complications – endometrial problems – use U/S

• Menopause earlier in DS population
  – 42 vs 52.
  – Defined by no period for 12 months
  – Can check FSH
Urological Health

- **Difficulty Emptying Bladder**
  - Low muscle tone, infrequent urination
  - Causes bladder stretching, obstruction
    - Increased UTI
    - Urinary Incontinence
    - Discomfort
    - Backflow to damage kidneys
    - Need to encourage frequent bathroom trips,
      - Proper hygiene/wiping technique

- **Kidney Problems**
  - Dehydration, obstruction (constipation)

- **Penile care**
  - Proper hygiene instruction for uncircumcised penis to prevent balanitis and posthitis, phimosis

- **Prostate Cancer Screening** – not recommended for those with DS
  - Prostate Cancer is uncommon in men with DS
  - Slow growing so treatment often not recommended if life expectancy less than 20 years
  - F/u testing has risk
Orthopedic Care

• Concerns due to ligamentous Laxity
  – Vertebral Subluxation (Including AAI)
    • SX - Holding head in unusual positions, pain, weakness, incontinence. Abnormal breathing
    • Risks – paralysis, decreased neurological drive to breath, death
    • Dx – xray lateral – head upright, flexed and extended - >5mm is abnormal
    • Do one baseline, for sx, or for preoperative evaluation
    • Avoid contact sports, diving, tumbling, butterfly stroke
    • Extra care with anesthesia
  – Bunion – avoid high heels, warm water foot soaking, NSAIDS or Tylenol, pads/inserts. Or surgery
  – Patellar subluxation – patella-femoral syndrome with chondromalacia
    • Treat/Prevent by wearing good supportive shoes, strengthening of inner thigh muscles
    • Knee brace and/or PT for Patellar dislocation, Surgery
  – Over pronation of Ankle – flat feet – cause foot, ankle, knee, hip, and back pain
    • Treat w/ special shoes, use insert or use custom orthotic

• Problems Associated with Early Aging
  – OA – tx with Tylenol, NSAIDS, avoiding problem activities, PT, OT, regular exercise
  – Osteoporosis – prevent with regular weight bearing exercise – 1000-1500mg calcium and 800 unis
    • Dxa once woman reaches menopause or with celiac diagnosis or high risk meds. Repeat every few years
  – Spinal Stenosis – osteophytes narrow the canal - May need narcotic, steroid injection...
Neurological Care

• Headaches in DS – less common than in GP
  – not due to typical causes
  – Evaluate for trauma, AAI, stroke, epidural hemorrhage, sinus infections, allergies, strep throat, eye strain

• Seizures – more common in DS population
  – Most commonly start 0-2 or >35, often associated with Alzheimer's
  – Need EEG, Brain Imaging
  – Special Precautions: No swimming alone, no driving, caution with fall risk activities, extra caution with starting new meds

• Strokes – less likely to have atherosclerotic cause
  – Moyamoya – can cause ischemic or hemorrhagic stroke
  – Alzheimer's – causing protein build up compresses small vessels
  – Tic disorder, Vertebral Subluxation, Blood Clots
  – Requires specialist care, PT/OT, meds, Speech Therapy.

• Alzheimer’s Dementia – Make sure to get baseline dementia screen
Skin and Nail Health

• Treat Dry Skin
  – Frequent skin moisturizer and apply right after bath
  – Mild soap (Dove, Cetaphil, Aveeno, Aquanil, CeraVe)
  – Avoid hot water
  – Decrease length and frequency of showers/baths
  – Keep skin covered in winter
  – Use humidifier
  – Don’t forget sunscreen
  – Avoid scratching (short nails, redirection, gloves, antihistamines)
Common Skin Conditions

• Seborrheic Dermatitis
  – reddish, scaly, greasy patches frequently on face and scalp
  – Tx – dandruff shampoos, topical creams, sunlight

• Psoriasis – Dry scaling patches with well-defined papules and plaques.
  – Commonly seen on knees and elbows
  – Tx – Emollients, Topical steroids, retinoid, calcipotriene, sunlight, oral immune suppressants

• Fungal Infections
  – Athlete’s foot, jock-itch, intertrigo
    • Clean and dry 2-3X/day, topical anti-fungal
  – Onychomycosis
    • Topical, oral med, nail removal, nothing, vicks?

• Folliculitis – hair follicle infection – can try antibacterial soap

• Boils – Abscess – collection of infection/pus under skin
  – May need oral antibiotic or may need I&D

• Acne – inflammation of the oil glands
  • Treat with acne wash, moisturizer, topical meds, oral antibiotic, accutain

• Hidradenitis Suppurativa – hair follicles become blocked and cyst-like abscesses form

• Rosacea – Chronic skin eruption with flushing and dilation of small blood vessels of face
  – Can cause pimples, large pores, thickened skin of nose, inflammation of eyes
  – More in women
  – Treat by avoiding triggers, oral antibiotics, sulfer lotions, other topical antibiotics
Cancer Screening/Prevention

• Less Common in DS: brain, lung, colon, stomach, prostate, kidney, and breast
  – Weigh benefit of screening with risks of screening, and risks of treatment
  – Mammograms still recommended annually at age 40
  – Can consider u/s if not able to do mammogram
  – Do not have to order screening colonoscopy

• More Common in DS: Childhood Leukemia, testicular, Lymphoma, Malignant Melanoma
  – Monitor for side effects of childhood leukemia treatment
  – self testicular exam, surgery on undescended testicle and medical exam annually
  – wear sunscreen, limit sun exposure, monitor moles
Immunizations

- Extra important for those with DS given decreased immune system
- Patients with DS should have all routine childhood/adolescent vaccines
- Td every 10 years, with at least 1 TdaP as adult, Td extra with wounds
- Influenza shot annually
- Pneumonia vaccine at age 50 for those with DS
- Varicella – recommended if not immune
- Hepatitis B – 3 shot series if living in residential facilities or working at sheltered workshop
- Hepatitis A – if working in food service
- HPV – if missed as a teenage, especially if considering sexual activity
- MMR/Meningococcal – if misses as teenager
Down Syndrome Health Care Guidelines

- 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 years).
- Clinical heart evaluation to rule out mitral/aortic valve problems. Echocardiogram-ECHO (as indicated).
- Reinforce the need for subacute bacterial endocarditis prophylaxis (SBE) if needed.
- Baseline Mammography (40 years; follow up every other year 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).
- General physical/neurological exam. Routine adult care.
- Breast exam (annually)
- Clinical evaluation for sleep apnea.
- Low calorie, high-fiber diet. Regular exercise. Monitor for obesity.
- 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).