

Good Health in Teens and Adults with
Down syndrome
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A Unique Collaboration

- The families of the National Association for Down Syndrome
- Advocate Medical Group and Advocate Lutheran General Hospital

Mission Statement

- To enhance the wellbeing of adults with Down syndrome by providing comprehensive, holistic, community-based health care services by a multi-disciplinary team.

Health

- More than the absence of disease
- Physical, mental and spiritual wellbeing

The Medical Home

- Family-Professional Relationship
- Respect
- Coordination
- Communication
- Remodel
- Person-Family-Professional Relationship

Leo Foley
1907-1947

Two Syndromes

- Expectations
- Life Expectancy
- Opportunities
- Goals

Meet the Patients

Samantha, age 17

- Seen for annual evaluation
- To start horseback riding program
- 5'4", 155#

Counseling

- Nutrition
 - Slow metabolism
- Exercise
- Activity
- The Groove
- Visual memory
- Social/Family

Labs/Tests

- TSH with reflex
- Vitamin D
- Audiogram
- Refer for eye exam
- Lateral cervical spine xrays

Immunizatons

- dTaP
- Gardasil

- Meningitis
- Influenza
- Hepatitis B vaccine
- Varicella

William, 36

- Decreased interest in work and activities
- Fatigue
- Weight loss/decreased appetite
- Diagnosed with depression

The Interaction Between Physical and Mental Health

- Any and all behavioral change should be viewed as a possible communication tool
- Detectives Looking for the Cause of a Change in Behavior
- People with DS have difficulty communicating the cause or source of their physical or mental health pain or symptoms
- Not unusual for their to be a number of different causes

Health Problems that are More Common

- Hypothyroidism and hyperthyroidism
- Hearing impairment
- Vision problems including cataracts and keratoconus
- Cancer of the testicle and ovary
- Celiac Disease
- Lactose intolerance
- Sleep apnea

Health Problems that are More Common, cont.

- Leukemia
- Cervical subluxation
- Vitamin B12 deficiency
- ?Vitamin D deficiency

Health Problems that are More Common, cont.

- Gastroesophageal reflux disease
- Constipation
- Boils
- Fungal infections
- Osteoarthritis
- Secondary disabilities

Health Problems that are Less Common

- Hypertension
- Coronary artery disease
- Cancer
- Asthma

David, age 55

- Not doing as well on his job
- Difficulty with multi-step tasks
- Possible memory impairment

Aging

- Life expectancy: 56 years
- One of oldest well-documented person with Down syndrome, 83 years old at death
- Premature aging issues
- Decline and normal aging process

Intervention Strategies: When there is a loss of function

- Think medical
- Consider medications
- Consider psychosocial
- Consider behavior as a form of communication

Decline in Function and Alzheimer Disease

- Neuropathologic changes
- Differences in Alzheimer Disease in DS
 - Earlier onset

- More rapid decline
- Seizures
- Incidence of clinical Alzheimer Disease

Healthy Aging

- Regular exercise
 - Aerobics
 - Weight training
 - Stretching
- Healthy diet
- Vitamin D supplement?
- Retirement
- Cognitive stimulation