Health Issues for adults with Down syndrome

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Health is more than the absence of disease. Health is a sense of physical, mental and spiritual well being. It is a process that involves health promotion, health monitoring, and early intervention for health problems. Understanding what is typical or in the normal range for a person with Down syndrome is essential for providing health care.

1. Understanding Normal/Typical

Adults with Down syndrome have a number of typical behavioural issues that are important to understand so as not to over-diagnose disease states.

A. Self-talk and imaginary friends

These appear to be developmental stage-appropriate behaviours that are used as coping strategies, defence mechanisms and to alleviate boredom.

B. The Groove

People with Down syndrome often show a tendency towards needing sameness, repetition and order in their lives. It can be very functional.

C. Grief

A delayed response to grief is often seen and it may be demonstrated in alternative ways.

D. Pain Tolerance

People with Down syndrome may have an increased tolerance to pain. However, limited communication skills may also limit the ability to express/convey pain that can lead to the pain being expressed in alternative ways.

E. Behavioural change as a potential communication device

Sometimes a behavioural change may be an attempt to communicate physical or psychological discomfort. A thorough medical evaluation is indicated when a person with Down syndrome presents with a behavioural change to assess for an underlying physical condition.

2. Health Promotion

A. Regular exercise

We have found that adults with Down syndrome are more likely to be closer to their ideal body weight if they have opportunities for recreational and social activities (not necessarily exercise). We generally recommend 20-30 minutes of exercise at least 3-5 times per week. In addition, (or alternatively) social activities like shopping, visiting museums, etc. that involve walking can be very beneficial. Increasing energy expenditure by parking a little farther away, taking the stairs, and working in the house and yard are all beneficial. Generally, turning off the television and being more active is beneficial.

B. Recreational Activities

As noted above, recreational activities can have a benefit for physical health. In addition, they are an important part of mental health as well as part of life's enjoyment. Sometimes as parents naturally slow down with age or the adult with Down syndrome ages out of the school system, few activities are available. That is a particularly important time to seek other reliable people who can assist in participation in recreational activities.

C. Nutrition

Obesity is the most common nutrition-related disorder.
Attention to a healthy diet as well as regular activity and exercise are required to prevent and treat obesity.

D. Opportunities for Accomplishment and Sense of Worth

Adults with Down syndrome have the same need as others to feel a sense of accomplishment and worth. For some, that may be a repetitive job that fulfils their need for order and regimen. For others, it may be a particular sense of being needed achieved through doing for others. As assessment of what the individual would like to get from a job, as well what his skills are to do the job is encouraged.

E. Immunizations

(These recommendations assume all childhood immunizations were given appropriately.)

- Diphtheria – Tetanus – Pertussis – recommended every 10 years.
- Influenza – consider annually each fall especially if exposed to many people. Recommended annually for persons with certain other health problems.
- Pneumonia – We recommend considering the pneumonia vaccine at age 50 for adults with Down syndrome. Recommended at a younger age for persons with certain other health problems and then repeat in 5 years.
- Varicella (Chicken Pox) – recommended testing for immunity by blood tests if there is no history of having had chicken pox. Recommended the 2-shot series if not immune.
- Hepatitis B – recommended for people living in group facilities. We also recommend it for persons working in a group setting (e.g. workshop) and considering it for all others. We recommend a blood test before administering the vaccine for adults with Down syndrome to see if they have immunity (thus, they do not need the vaccine). In addition, we recommend drawing a blood test (hepatitis B surface antibody) to document attaining immune status 4 to 6-weeks after the third shot.

F. Osteoporosis prevention

Osteoporosis is more common in adults with Down syndrome.
Adequate calcium intake throughout life is essential. Recommend 1000mg a day of calcium for men and non-menopausal females and 1500mg a day for menopausal females (by diet or supplement). Recommend taking Calcium with Vitamin D to promote absorption. Consider bone density scanning to screen for osteoporosis. Consider appropriate medical therapy for prevention or treatment of osteoporosis.

3. Health monitoring

A. Health Screening
History and Physical exam recommended annually.

B. Some important aspects of the history:

- Decline in skills
- Memory impairment
- Swallowing difficulties, choking
- Change in gait, unsteadiness
- Incontinence of urine and/or stool
- Change in appetite
- Change in weight
- Behavioural issues
- Psychological concerns, Change in mood, Change in interest of life

C. Thyroid
Recommended annual thyroid blood testing.

D. Celiac Disease
Consider blood testing (anti-endomysial antibody or anti tissue-transglutaminase antibody and antigliadin IgA and IgG).

E. Neck x-ray
Once in a lifetime; (additional neck x-ray if previous abnormal or symptoms develop).

F. Cancer of the cervix
Recommend pap smear every 3 years (after two annual tests normal) if not sexually active and asymptomatic. If sexually active, may want to do annually.

G. Breast cancer
Recommend mammogram every other year from 40-50 and annually after 50. Annual breast examination and teach/encourage breast self-examination (if possible).

H. Cancer of the testicle
Recommend annual testicular exam and teach self-exam (if possible).

I. Vision
Recommend exam every 1 – 2 years.

J. Hearing
Recommend audiogram every 1 -2 years.