

Promoting Health in Adults with Down Syndrome

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Health is more than the absence of disease. It also involves a lifestyle that promotes physical, mental and spiritual well-being. This is as true for adults with Down syndrome as it is in the general population. This paper focuses on the physical and mental health and then discusses the interaction of these two aspects in of adults with Down syndrome.

A HEALTHY LIFESTYLE

To maximize physical health requires a multi-faceted approach: living a healthy lifestyle, following certain preventive measures, participating in appropriate health screening and treating problems early in their course. A healthy lifestyle includes an appropriate diet, regular exercise, adequate sleep and opportunities for social and creative use of one's time.

Diet

Although coronary artery disease (heart attacks) and hypertension (high blood pressure) are less common in adults with Down syndrome, the dietary and exercise recommendations for people with Down syndrome are similar to those for the general population. These include following a diet like the one described in the "pyramid" diet program which recommends limiting fat intake and encourages a diet high in complex carbohydrates.

Obesity is more common in persons with Down syndrome. A recent study found that children with Down syndrome have a basal metabolic rate that is lower than that seen

in the general population. On average, at rest, those with Down syndrome burned 200-300 less calories per day. Reduction in calories alone led to nutrient deficiencies and, therefore, it is necessary to burn 200-300 calories more per day through activity to prevent weight gain. In addition, when making dietary recommendations to prevent weight gain or promote weight loss, we have had better success with offering choices such as fresh fruit or vegetables and low fat foods such as popcorn or pretzels rather than offering no dessert or snacks. Just as in the general population, better success is achieved in the long run by following good general nutrition principles and regularly exercising than is by dieting.

Exercise

Twenty to thirty minutes of aerobic exercise at least three days a week is recommended. Aerobic exercise includes such activities as walking, running, swimming, biking and cross country skiing. Prior to starting an exercise program, a physical exam and health screening are indicated. Forty to fifty percent of babies born with Down syndrome have congenital heart disease. Some adults with Down syndrome have had these surgically corrected and all they need is antibiotics when they go to the dentist (see below). Others have not had the heart condition corrected and many will need ongoing treatment. A few studies indicate that some adults with Down syndrome develop disease of their heart valves later in life. Exercise restriction may be necessary depending on the type of congenital or acquired problem. Physical examination and an echocardiogram and/or a stress test (treadmill test) may be necessary to determine the safety of exercise.

Another health problem that may make modification in exercise necessary is atlanto-axial instability. This condition in which the first vertebrae (bone) in the neck slips on the second is more common in persons with Down syndrome. The exact significance is not always clear but it may make contact sports or sports which could jar the neck more dangerous. For this reason, the Special Olympics requires lateral neck x-rays prior to participation. The need for these x-rays, however, is the subject of ongoing research and debate.

Exercise is believed to have many benefits. Although reduction in coronary artery disease and hypertension would not appear to be major benefits in adults with Down

syndrome (because of the infrequent occurrence of these diseases), exercise probably has several other benefits. Although this is not as well studied in persons with Down syndrome, in the general population exercise has been shown to help improve overall sense of well-being, self-esteem, and also the overall fitness of those who regularly participate. It is an excellent mechanism to help people deal with stress and reduce its effects.

Sleep

Adequate sleep is also an important part of a healthy lifestyle. The exact number of hours of sleep needed varies from person to person, but enough sleep to feel energetic throughout the day is recommended. Many families have commented that their son or daughter sleeps bent at the waist with his or her head resting on the legs. While this does not seem to be a significant problem or necessarily indicate a significant underlying problem, there are some sleep problems that can occur. Sleep apnea may be more common in persons with Down syndrome. Sleep apnea is often associated with restless sleeping, irregular breathing pattern, snoring or snorting sounds and daytime somnolence. It is generally caused by obstruction of the airway in persons with Down syndrome and may cause heart disease and several other health problems.

Social opportunities

We have demonstrated that adults with Down syndrome who have social opportunities tend to be healthier. Meeting with friends, being with family, and having opportunities for creative activities at work and socially all contribute to our sense of self-esteem, well-being and happiness. Studies in the general population and our study in persons with Down syndrome support the idea that these contribute to the health of an individual. In the general population, depression and stress have been shown to be associated with decreased immunity and increased physical illness.

Preventive measures

Immunizations

In addition to the preventive measures discussed as part of a healthy lifestyle, there are several other recommendations to promote health. Immunizations are recommended for all adults. After receiving the usual immunizations of childhood, a diphtheria-tetanus

booster is recommended every ten years. For persons older than sixty five and for persons with certain chronic illnesses, an annual influenza (flu) shot is recommended as well as a pneumonia vaccine every seven years. Some investigators have recommended that adults with Down syndrome should receive the flu and pneumonia vaccines in their fifties instead of waiting until 65 because of their relatively weaker ability to fight infections. Down syndrome is not one of the conditions that requires a child or younger adult to receive these immunizations, however, those with associated health problems such as congenital heart disease or recurrent pneumonia should receive them. In addition, flu vaccine is recommended annually for people living in residential facilities.

Hepatitis B immunization is recommended for residents of residential facilities. In addition, some studies have found that other adults with Down syndrome are at greater risk for getting hepatitis B, possibly in workshops or other settings. Although hepatitis B transmission is generally considered to occur through blood (blood transfusions, shared needles) and sexual activity, hepatitis B virus is actually shed in all body secretions. In any setting where regular contact with an infected persons secretions can occur or where hygiene may be limited, hepatitis B may be transmitted. Hepatitis B immunization is given in a three shot series. The second and third doses are given one and six months after the first. A blood test (Hepatitis B surface antibody) should be drawn one to two months after the third dose to confirm the effectiveness of the vaccine in providing immunity.

Antibiotic prophylaxis

Another preventive measure is antibiotic prophylaxis. Some people with congenital or acquired heart disease need antibiotics, to prevent an infection in their heart, before and after going to the dentist (even for a routine cleaning) or when they undergo procedures to their gastrointestinal or urinary tracts. This is usually done with Amoxicillin 500 mg tabs: 6 tabs 1 hour before the procedure and 3 tabs 6 hours after. For those allergic to amoxicillin (or other penicillins), alternative regimens are recommended.

Education

Sexuality and reproduction are areas in which adults with Down syndrome often need education. Men with Down syndrome have generally been considered to be sterile, although there is one reported case of a man with Down syndrome fathering a child. Women with Down syndrome may have a slightly reduced fertility rate but can have children. Roughly 50% of children born to a woman with Down syndrome will have Down syndrome. Birth control pills, depo-provera, Norplant, and other forms of birth control generally are considered to have less complications than tubal ligation. Depo-provera, an injection of progesterone every 3 months is both effective and allows for easy compliance. Barrier methods such as condoms and diaphragms are often not effective because of limitations in the ability of the person to use it correctly each time. Other than condoms, birth control measures do not prevent AIDS and other sexually transmitted diseases. Also, sexual abuse is a concern and, therefore, education is necessary even if birth control is being used or sterilization has been performed.

HEALTH SCREENING AND TREATMENT OF MEDICAL PROBLEMS

In addition to a healthy lifestyle and preventive measures, appropriate health screening measures are recommended. The Adult Down Syndrome Center of the Advocate Health System was developed in response to a request by the National Association for Down Syndrome (NADS), a local parent group, to fill the need for screening and other health care for adults with Down syndrome. The staff of NADS surveyed its members to determine the needs of the patients and their families. The staff of the Center reviewed the available literature, especially the Preventive Medicine Checklist developed by the Ohio and Western Pennsylvania Down Syndrome Clinic Directors Group. Based on this available information and the subsequent care of over 500 patients, we recommend the following health screening.

An annual health maintenance evaluation including a review of the patient's history and a physical exam will help find problems early in their course and provide an opportunity to review the issues of a healthy lifestyle. Routine health screening that is recommended for the general population is recommended for adults with Down syndrome as well. This would include mammograms, pap smears, screening for colo-rectal cancer

and cholesterol screening. With further study these recommendations could change depending on the frequency of these diseases in persons with Down syndrome.

The history and physical exam should give special attention to the areas in which adults with Down syndrome have problems that are more common or present differently than in the general population.

Skin

A number of skin problems are seen frequently in adults with Down syndrome. Dry skin (xeroderma) is very common. The handout provided to our patients is included at the end of this paper. Seborrheic dermatitis occurs frequently also. This is often seen on the scalp as dandruff. Anti-dandruff shampoos such as Head and Shoulders, Denorex and Selsun Blue are helpful. Tar shampoos are also a good treatment. Recent evidence suggests that some of this may be caused by a fungal infection and, therefore, some people benefit from Nizoral shampoo, an anti-fungal prescription shampoo. When it occurs on other parts of the body, a steroid cream can help clear it.

Another skin condition, folliculitis (infection or inflammation of the hair follicles) can be treated by washing with an anti-bacterial soap such as Dial or Lever 2000. Since so many patients also have dry skin, we generally recommend Lever 2000 or Dial with moisturizer which tend not to dry out the skin. Folliculitis is often on the back or buttocks which can be hard to reach. Therefore, a soft brush on a handle is helpful.

Tinea infections (fungal infection of the skin) and onychomycoses (fungal infection of the nails) occur more commonly. Tinea pedis (athlete's foot) is treated with good daily cleaning followed by thorough drying. Since the fungus thrives in warm, moist environments, it is sometimes necessary to change socks in the middle of the day to keep the feet adequately dry. Anti-fungal preparations such as Desenex, Tinactin, or Lotrimin help kill the fungus. The treatment of onychomycoses is problematic. Topical preparations usually don't work well. Until recently, the oral medications (pills) for this problem had to be taken for 6 to 12 months and could cause inflammation of the liver. Recently, Sporanox was approved for use in onychomycoses. It only has to be taken for 3 months and seems to cause less liver problems. It, however, is very expensive. Toenail removal is painful and if the nail is allowed to grow back the fungal infection can recur.

If the toenail bed is destroyed so that the nail does not grow back, then the toe is left without its protective nail and can be sensitive to even mild trauma. Since the condition does not usually cause any symptoms, daily foot soaks followed by thorough drying and keeping the toenails cut straight across is a simple but helpful recommendation. Sometimes podiatric care is needed to aid in toenail cutting.

Eyes

Poor visual acuity (eyesight) is a common problem just as it is in the general population. However, the adult with Down syndrome may have a difficult time perceiving the problem or communicating it to someone who can help. If work skills or other daily skills deteriorate, the cause could be as simple as a decline in eyesight.

Cataracts are more common. Keratoconus (thinning of the cornea) is more common and can be a sight-threatening problem that needs regular follow-up by an ophthalmologist. Corneal transplant becomes necessary in the later stages of keratoconus. Strabismus (crossing of the eyes) usually needs to be corrected in childhood for any chance of significant vision in the crossed eye. Blepharitis (inflammation or infection of the eyelids) is treated by careful, regular washing with a warm washcloth and half strength baby shampoo and sometimes antibiotic drops. Good treatment of seborrheic dermatitis of the scalp may also be beneficial because sometimes the blepharitis is related to the scalp condition. The increased frequency of eye problems requires regular screening by an eye doctor, probably at least every two years and more frequently if problems exist.

Hearing/Ears

Hearing loss is also more common in adults with Down syndrome. It can be from reversible causes such as ear wax or fluid behind the drum or it can be permanent and associated with inner ear problems. Some inner ear hearing losses are stable for many years; others are progressive. These inner ear problems are made worse if excessive ear wax or fluid behind the eardrum (in the middle ear) is overlaid on the irreversible inner ear hearing loss. Ear wax (cerumen) building up until it obstructs the canal is common in persons with Down syndrome. Wax softening drops can be used to help the natural body function to remove the wax. However, ear drops should not be used if the eardrum is

punctured or perforated. We advise people to “never put anything smaller than your elbow in your ear” because anything, such as cotton swabs, put down the canal interrupts the body’s natural ability to remove wax and may push the wax further inward, thereby making it more difficult to remove. Sometimes the excess wax must be irrigated or suctioned out. Another cause of hearing loss is fluid behind the eardrum and this may require placement of tubes through the eardrum to drain the fluid and increase hearing. A person who seems to be losing daily life skills may have a problem as simple as decreased hearing from wax obstruction. Removal of the wax and restoration of hearing can sometimes help restore skills.

Many adults with Down syndrome have an inner ear problem which affects the ability to hear high pitched sounds, including many speech consonants. Because inner ear hearing loss cannot be seen by an exam of the outer ear and eardrum, a referral for a comprehensive audiologic (hearing) evaluation may be indicated to clarify hearing status and to identify the high frequency (pitch) impairment. This problem can gradually develop and contribute to increased misunderstandings, attention difficulties and general confusion especially in groups or in any situation that is not optimally quiet. Sometimes the best option for hearing loss is a hearing aid. Careful attention to fitting and sometimes a gradual increase in the amount of time the aid is worn will help adults with Down syndrome adjust to the device.

Sinuses

Sinusitis (sinus infection) is usually readily treatable with antibiotics and decongestants. The acute presentation includes fever, headache and face pain. It may present as chronic runny nose or congestion. Sometimes the ability to communicate the pain is lacking and, therefore, a change in behavior is noted that will resolve with appropriate treatment of the sinus condition.

Teeth and gums

Periodontal (gum) disease is common and can be prevented by good teeth brushing, flossing, and regular dental evaluations. Persons with Down syndrome often need more dental care to keep the gums healthy because of a tendency for problems in

this area. Most people who lose their teeth do so because of gum disease. Cavities are actually less common in persons with Down syndrome than in the general population.

Gastrointestinal

Constipation is fairly common but can usually be managed by increasing the fiber in the diet by eating more fruits, vegetables and whole grains. Drinking plenty of water (6-8 eight ounce glasses per day) also helps. Metamucil or other fiber supplements can also be used. Hernias can also occur in adults with Down syndrome and surgical correction is the only cure, although trusses can be used for symptom relief. The need for surgery should be based on the symptoms associated with the hernia, the general activity level, the age, the size of the hernia and the overall health of the person. Another problem, incontinence of stool is not a common finding in our patients although hygiene issues are a problem for some and may need further attention with education.

Gynecologic

General gynecologic care includes daily care issues and evaluation in the physician's office. Education is important for self-care and to prepare the woman for the office evaluation. In the office, a slow, gentle approach is often all that is needed although sometimes light sedation is necessary. Modified exams can be done to get a pap smear and sometimes an ultrasound of the pelvis can be done to provide some information that is not obtained in the exam.

Dysmenorrhea (painful periods) is common in women with Down syndrome just as it is in the general population. It is usually effectively controlled with Tylenol, Advil, Nuprin or similar medications. A woman with Down syndrome may have difficulty communicating her pain and the only outward sign will be a behavior change around the time of her period. Use of medication to reduce cramping can be extremely helpful in reducing the behavior changes. Likewise, behavioral or other changes that occur cyclically before the period should be noted and the woman evaluated for premenstrual syndrome (PMS).

Urinary

Incontinence of urine that starts in adulthood may be more common than in the general population. Urinary tract infections, nervous system disorders, behavioral issues

and anatomic problems must all be considered. We have seen a number of adults with urinary retention (inability to adequately empty the bladder) that leads to incontinence and often discomfort. In addition, incontinence can be seen in Alzheimer's disease.

Orthopedic

In addition to atlanto-axial instability being an issue in exercise as previously discussed, it must be considered as part of evaluation prior to any surgery. Persons with Down syndrome who have atlanto-axial instability have received severe neck injuries during surgery when their necks were extended to allow for placing the endotracheal (breathing) tube. The anesthesiologist must make adjustments to prevent this. Even with normal x-rays, special care should be given to the neck of a person with Down syndrome during anesthesia.

Another more common orthopedic problem is hallux valgus (bunions). They can usually be treated conservatively with wide shoes, acetaminophen (Tylenol) or anti-inflammatory agents (Advil, Nuprin, ibuprofen) and soaking in warm water. Surgery is indicated when the pain is not responding to these treatments and is severe enough to warrant the discomfort of the surgical correction.

Neurologic

Alzheimer's disease is a frequently voiced concern about people with Down syndrome. At autopsy, studies have shown plaques in the brains of all adults with Down syndrome over the age of 35. These plaques are similar to the plaques seen in persons with Alzheimer's disease. Neurofibrillary tangles (also seen in Alzheimer's disease) have not been found generally until after the age of 50 and then only in approximately the same percentage as in the general population. Clinical findings and recent studies suggest that the tangles correlate better with the clinical manifestation of Alzheimer's disease and that the percentage of adults with Down syndrome who develop Alzheimer's disease may be similar to the general population. There is a tendency for persons with Down syndrome to develop Alzheimer's disease at a younger age (50's) than in the general population (70's). Most importantly, many other medical and psychological problems that are potentially reversible can mimic Alzheimer's disease and should be checked prior

to making the diagnosis. These include poor hearing , poor vision, hypothyroidism, brain tumors, vitamin B-12 deficiency and depression.

MENTAL HEALTH

It is also important to evaluate for mental health problems. However, it helps to understand the aspects of a healthy life that promote mental health prior to understanding mental illness.

The ability to communicate is a strong factor in mental health. For those for whom communication skills are weak, speech therapy, communication boards, sign language and other methods of communication can be helpful. Even when verbal skills are good, the ability to communicate concepts such as frustration and sadness may be limited. Sometimes it is helpful to have opportunities to gather with other adults with developmental disabilities to share experiences. This type of interaction and support can help the individual express his or her concerns and is beneficial just as self-help groups are for others.

Decent housing and jobs that are stimulating and interesting promote a sense of accomplishment and self-worth. Opportunities for recreation and relationships with family and friends are aspects of life that promote mental health as well as physical health as previously discussed. When mental illness is found, evaluation of these areas of a person's life as well as his or her communication skills and opportunity to share concerns may reveal some problem areas. In addition, changes in living arrangements, in staff or care-providers, and in family structure can be stressful and lead to mental health problems. Adults with Down syndrome seem to have a somewhat lower ability to adapt to the stress of such changes. Being aware of the potential for problems and informing the adult with Down syndrome of upcoming changes and allowing time for him to process the information and to express his concerns may lessen the stress and prevent problems.

Physical health that can effect mental health

A number of physical health concerns were noted above that can contribute to the psychological or mental decline of an adult with Down syndrome such as hypothyroidism, vision impairment, vitamin B-12 deficiency and hearing impairment. A

thorough evaluation for any of these problems should be performed if mental health is impaired.

Depression

Depression can be difficult to diagnose in persons with Down syndrome and sometimes lasts for years if untreated. It occurs a little more commonly than in the general population. Lack of verbal skills can contribute to the difficulty in diagnosing and treating depression. However, depression is usually treatable and remarkable improvement in daily living skills, motivation and interaction with others is often experienced. Anti-depressants, group or individual therapy and encouragement in participating in daily activities, especially exercise, are beneficial. Sometimes it becomes necessary to involve occupational therapists, respite workers and others to help the patient get moving again.

Obsessive-compulsive disorder

Obsessive-compulsive disorder can be seen with depression or on its own and is probably more common in persons with Down syndrome. It will often respond to structuring the environment to reduce the frustration of the compulsion and to medications.

Others

While other psychological problems such as attention deficit hyperactivity disorder and bipolar (manic-depressive) disorder can occur, there is no evidence to suggest that they occur more frequently than in the general population. Schizophrenia is actually thought to be uncommon in persons with Down syndrome.

LABORATORY EVALUATION

In addition to the history and physical, an annual blood test to screen for thyroid disorders is recommended. Hypothyroidism (underactive thyroid gland) occurs in approximately one-third of adults with Down syndrome. The symptoms of hypothyroidism include dry skin, constipation, weight gain, lethargy, depression, cold intolerance, coarsening of the voice, joint aches and muscle cramps. Since a number of these are common characteristics of people with Down syndrome, it can be difficult to diagnose hypothyroidism on the basis of clinical findings. In addition, hyperthyroidism

(overactive thyroid) is more common in adults with Down syndrome than in the general population (although much less common than hypothyroidism). Therefore, annual screening for thyroid conditions with a blood test is recommended.

CONCLUSION

Most adults with Down syndrome can live healthy lives. To achieve that goal requires a multi-faceted approach including living a healthy lifestyle, following certain preventive measures, participating in appropriate health screening, and treating health problems early in their course. While there are some disorders that occur more commonly in persons with Down syndrome (and some that occur less frequently), following this approach is a way to promote a healthy life.

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