Living Healthy

A guidebook for Teens and Adults with Down Syndrome

prepared by the
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About Down Syndrome

Down syndrome (DS), the most common of all genetic conditions, occurs in approximately one out of every 733 live births, usually causing delays in physical, intellectual and language development.

Although having DS presents some challenges, individuals with DS often enjoy some health benefits! For example, the occurrence of heart disease is less in individuals with DS, and dental caries (or cavities) are seen less frequently as well.

Most health considerations for an individual with DS are the same as anyone in the general population. However, there are a few conditions which are seen more frequently in individuals with DS and require closer monitoring than the general population.

This booklet will focus on healthy living advice for those with DS and will highlight some of the medical issues seen more frequently in these individuals.

With appropriate medical care, adults with Down syndrome can lead healthy and productive lives. Our goal at the Adult Down Syndrome Clinic at UAB is to provide a comprehensive medical resource with multidisciplinary medical and psychosocial care for teens and adults with Down syndrome. Our emphasis is clearly on health promotion.
Eating a well-balanced diet is important for everyone - those with DS and the general population as well. Although those with DS have less coronary artery disease and hypertension, it is still recommended that you eat a "Heart Healthy" diet. This is a diet which is low in fat and is high in complex carbohydrates such as whole grains.

A common issue for adults with DS is obesity. Obesity is not always caused by overeating or by eating the wrong foods. People with DS often have a lower basal metabolic rate. This means that their metabolism is slower and they do not burn as many calories as the non-DS population. One study showed that people with DS burned 200-300 less calories per day. What does this mean? It means that reducing calorie intake alone will not help one control or lose weight. Exercise must be added in order to burn those extra calories! Cutting back on the number of calories is important, but that alone will not control or reduce weight.

Another issue for people with DS is constipation. A diet high in fiber and including 6 to 8 glasses of water per day is recommended to manage the constipation.

Tip:
Here's a suggestion on how to cut some calories:
Instead of a bowl of ice cream, substitute a juicy piece of fruit!
Live Healthy - Exercise

Did you know that regular exercise is good for MANY reasons? It helps control weight, improves muscle strength, balance and mobility, improves cardiovascular fitness, helps control constipation and improves general well-being!

It is recommended that you get 20-30 minutes of aerobic exercise at least three days per week. Aerobic exercises include activities such as brisk walking, running, biking or playing sports. A slow walk to the mail box does not count! Exercise should be brisk enough to get your heart rate up and even, to break into a sweat!

Before beginning an exercise program, a physical exam and a health screen should be done. If the person with DS has had a heart defect or an acquired heart problem, a cardiologist exam may be necessary prior to beginning an aggressive exercise program.

Individuals with DS are more likely to have a condition called atlanto-axial instability, or AAI. This is a condition in which the first vertebrae (bone) of the neck slips on the second one. The exact significance of this condition is not clear, but the Special Olympics requires an x-ray of the neck before participation in some of their activities.

Remember . . .
People with disabilities tend to follow the activity level of those around them. So a family pattern of daily walking (at least 3 times per week) is a good habit for everyone to follow!
**Live Healthy - Sleep**

We all know what happens when we have a bad night's sleep. We feel slow, drowsy, and grumpy and we do not perform at our best. Adequate sleep is essential to good health. The term "adequate" does not refer only to the amount of sleep, it also refers to the quality of that sleep. Restless sleep with frequent waking is not "adequate".

It is important to have a good "sleep routine". When bedtime is nearing, stimulation from activities such as television and video games should be minimized. Foods or drinks containing caffeine should be avoided as evening approaches. The routine of a regular time for bed and regular activities (such as brushing teeth, bedtime prayers, soft music) also help the individual fall asleep.

A relatively common problem experienced by individuals with DS is something called "sleep apnea", a condition in which the person stops breathing for several seconds during the night. Some evidence of sleep apnea includes snoring, snorting, sleepiness during the day and unusual sleeping positions, such as bent at the waist with the head resting on the knees. Sleep apnea can be a serious problem for some individuals.

Sleep apnea* is diagnosed by a professional in a sleep lab. Once it is diagnosed, treatment consists of the individual using a mask and a machine called a CPAP machine. Teens and adults with DS may have some difficulty adjusting to the mask, but it should be attempted. The younger the individual is when the CPAP is begun, the greater the chances for success in using the machine.

The health benefits for an individual (and the benefits to the people around them) are well documented.

_Sweet Dreams . . . . . . ._
Live Healthy – Socialize

Studies consistently show that individuals with DS, as well as those in the general population, who regularly engage in social activities live healthier, happier lives. Time spent with family in family activities is great, but it is important that other social opportunities are included as well. Social events such as bowling, swimming, dancing, participating in sports, art class or other activities are helpful for maintaining a healthy, happy attitude.

Hopefully everyone in the family helps around the house with household chores! An individual with DS should be encouraged to perform tasks for which he or she is capable of completing. Folding clothes, clearing the table and making beds are tasks frequently given to individuals with DS to routinely do at home.

Many individuals with DS work outside the home. Some people do well with repetitive tasks in a sheltered environment. Others do better and a strong sense of well being is achieved by doing for others. Just as in the general population, each person has his or her special bundle of talents they bring to the workplace. Parents, educators, counselors and healthcare providers must strive to match an individual’s special talents and skill set to a work situation that is appropriate to them.

Some individuals with DS may date and get married. Occasionally some individuals are able to live independently with someone monitoring their safety and well-being.

Remember: Have fun!
Live Healthy – Sexuality

A difficult topic for most parents to discuss with their child is “SEX”. This may be an especially daunting task for the parents of a teenager or young adult with DS. Parents must carefully assess their child’s current knowledge level and must gauge their information to match the child’s ability to comprehend. The talk about sex must be given in small increments over a period of time and must be presented in a way in which the individual with DS can understand. As with any teenager, changes in one’s body, such as the beginning of a girl’s menstrual cycles, can be a frightening event. Information given in a gentle, loving and honest manner can alleviate many concerns. An excellent resource for having the discussion about sexuality and personal safety is the book Teaching Children with Down Syndrome about their Bodies, Boundaries and Sexuality by Terri Couwenhoven.

As stated earlier, some individuals with DS do get married. A rare few will also raise a family. Men with DS are typically sterile, but women with DS can become pregnant. These women have a 50% chance of having a child with DS. Married individuals with DS generally require appropriate supervision, even if they are living alone. There should be appropriate counseling prior to pregnancy or child rearing.

Tip

Discussions about sex and sexuality must be given in small increments in a manner appropriate to the individual’s ability to understand.
SAFETY is a huge concern for most parents of an individual with DS. As a rule, people with DS tend to be very trusting and warm to everyone they meet. Unfortunately, the world is full of people who are unkind and, in some cases, just plain dangerous.

From an early age, children need to be taught about appropriate behaviors and boundaries. This teaching should extend into the teen years and be reinforced throughout adulthood. Knowing what behaviors are supposed to be private can help protect the individual with DS from exploitation by others. It also arms them with the knowledge of what to do if the "rules" of personal boundaries are being challenged or violated by others.

Obviously parents or guardians will need to talk gently and often with the individual with DS and advise them about general safety considerations:
1. Do not talk to strangers without permission, 2. Never go with a stranger without a parent, guardian or trusted designee 3. Don’t wander away from home or school. 4. What is “good touch” and “bad touch”?

Individuals with DS should be taught how to call 911 and what to do in case of a fire, tornado, etc. It is also suggested that they obtain a non-driver’s ID that they have with them when away from home. This can be done through the local DMV (Division of Motor Vehicles).

It is also imperative that a long-term plan be in place for the individual with DS. This should include not only a financial plan but also a plan about care of the individual should parents become unable to provide that care.

Tip
Individuals with DS should know how to call 911 and what to do in case of a tornado.
Live Healthy – Special Health Concerns

Generally, except as mentioned earlier, the same medical issues apply to individuals with DS as within the general population. There are, however, a few conditions that are different and must be assessed more closely.

Individuals with DS are more likely than the general population to experience certain medical problems, specifically:

**Obesity** – as discussed earlier, obesity is a major concern for those with DS. Because of the low metabolic rate typically seen in DS, exercise MUST be a major part of the weight control plan along with proper diet.

**Constipation** – constipation can usually be managed by a diet that is high in fiber and includes adequate water intake (6-8 glasses per day).

**Thyroid** – Problems with thyroid function are seen more frequently in individuals with DS. It is generally hypothyroid (low thyroid) but it can also be hyperthyroid (high thyroid). It is treated with medication. Annual blood tests are used to monitor thyroid function.

**Sleep apnea** – snoring, snorting, abnormal sleeping positions, grumpiness, and daytime sleepiness can be symptoms of sleep apnea. This condition is diagnosed in a sleep lab with a “sleep study”. If sleep apnea is diagnosed, the use of a CPAP machine at night is recommended for treating this problem.

**Dry skin** – A number of skin problems are seen frequently in people with DS. Dry skin and seborrheic dermatitis are very common and are managed with over the counter lotions and shampoos. The choice of lotion should be one that does not have alcohol in it and contains good emollients, such as cocoa butter, glycerin, etc. Pat the skin gently to dry after a shower.

**Folliculitis** – Folliculitis is an inflammation of the hair follicles and is often found on the back or buttocks. Washing with an antibacterial soap such as
Dial is recommended. Occasionally these hair follicles become infected and may need further medical attention.

**Fungal infections** - The occurrence of fungal infection of the toenails is fairly common. Fungal infections, in the form of athlete's foot, is also seen in people with DS. Since fungi thrive in a moist environment, it is essential that the feet are kept dry during the day. An extra change of socks mid-day may be necessary for some people.

**Sinusitis (sinus infection)** - Sinus infection is more common in people with DS, partly due to the altered structure of the facial bones often seen. Fever, headache and face pain are frequently seen initially. Sinus infection can also appear as a chronic runny nose and congestion. Medical treatment with antibiotics and decongestants can treat the problem, although reoccurrence is possible.

**Periodontal disease** - "gum disease" Even though dental caries occur less frequently, there is a high incidence of periodontal disease in people with DS; often beginning in the mid to late teen years. Regular dental care, both in the home and in the dental office, is essential. Occasionally anesthesia is required to achieve adequate dental cleaning and repairs.

**Hearing loss** - Hearing loss is more common in individuals with DS than in the general population. Hearing loss can be from temporary causes, such as fluid in the ear from infection or excessive wax buildup, or it can be permanent. It is imperative that individuals with DS have hearing tested at least every one to two years.

**AAI** or atlanto-axial instability - As discussed earlier, AAI is a condition in which the first vertebrae (bone) of the neck slips on the second one. If a person with DS has been diagnosed with AAI, it is critical that this information be communicated to the anesthesiologist before any surgical procedure. Incorrect positioning of the head and neck during surgery could cause serious injury.
Vision problems - As with hearing loss, vision problems are more prevalent in individuals with DS. Depending on the individual's ability to communicate with others, identifying vision loss in an adult can sometimes be difficult to establish. Evaluation every 2 years is recommended.

Heart Disease - The occurrence of certain congenital heart abnormalities in babies born with DS is well known. Many of these abnormalities are self-correcting; others require surgical correction. Once into adulthood, the individual with DS who had a problem in the past should be periodically evaluated by a cardiologist. Some individuals who have had heart problems must receive antibiotics prophylaxis prior to some dental or surgical procedures. (See appendix at the back of this booklet)

Alzheimer's Disease - Estimates vary, but a reasonable conclusion is that 25 percent or more of individuals with Down syndrome over age 35 show clinical signs and symptoms of Alzheimer's-type dementia. The percentage increases with age. In the general population, Alzheimer's disease does not usually develop before age 50, and the highest incidence (in people over age 65) is between five and 10 percent. The incidence of Alzheimer's disease in the Down syndrome population is estimated to be three to five times greater than in the general population, and oftentimes, symptoms begin much earlier.
Good mental health is essential to everyone whether the individual has Down syndrome or not. Since people with DS may have some difficulty expressing themselves easily, those around them - parents, guardians and caregivers - must be alert to signs of mental health issues. Even when verbal skills are good, the ability to communicate feelings such as frustration and sadness may be limited. Not all "unusual" behaviors seen in a person with DS are abnormal, such as self-talk. Sometimes these behaviors are coping mechanisms they have developed to deal with their limited abilities for communication and understanding.

**Grief** - Individuals may deal differently with grief. It often takes them much longer to process and come to a resolution with the grief. It is not unusual for an individual to talk about the death of a loved one as if it had just happened when, in actuality, it may have occurred 10 years previously. Individuals with DS should be allowed time to grieve and be given a great deal of support. Parents and caregivers must be alert to signs of depression if the grief is not resolved.

**Self-talk** - It is fairly common to learn that individuals with DS talk to themselves. Often this is a way of thinking out loud or of dealing with frustration. Sometimes it is a means of self entertainment. Self-talk is not a bad thing and can be used to direct behavior. Parents and caregivers should be alert to potential self-talk warning signs. A marked increase in frequency of self-talk or self-talk that becomes loud, threatening, agitated and increasingly self-critical could be a sign of a significant problem and should be evaluated.

**Obsessive-compulsive behavior** - Obsessive-compulsive behavior is not the same as obsessive-compulsive disorder. Those who have been around a person with DS probably knows how neat their bedroom is or how carefully they stack their favorite magazines! You also know that it is not a good idea to "mess" with their things! This type behavior can be called obsessive-compulsive behavior. Often these behaviors are a means of
reducing anxiety and exerting a degree of control over their environment. Behaviors such as this, as long as they do not interfere with personal care, school or work, are not considered to be a problem.

**Depression** - Depression is seen in persons with DS slightly more often than in the general population. Depression can be difficult to diagnose in a person with DS and can last for years if unrecognized. Communication challenges may make it more difficult for the person to express feelings of depression and sadness. Often a decline in their functional level is the symptom which prompts parents to bring them to the clinic. An individual who previously attended to his personal hygiene then stops doing so should be evaluated for depression. Depression is usually treatable and remarkable returns to previous functional levels have been seen.

**Functional decline** - As mentioned above, a decline in functional level can be a significant sign. Not only could it signal depression, but a decline in function could be occurring because of a physical problem, such as arthritis in the hip which makes mobility and activity painful. Individuals with DS often have a high pain tolerance and they may lack the verbal skills to communicate the reason for their decline in function. Parents and health professionals must become skilled in digging deep to discover the hidden cause of a functional decline.

**Alzheimer's** - Alzheimer's Disease, a degenerative neurological disorder characterized by progressive memory loss, personality changes and loss of functional motor capabilities, is more common in individuals with Down syndrome than the general population. However, not all individuals with Down syndrome will develop Alzheimer's disease, and even those showing Alzheimer-type symptoms may not have Alzheimer's disease since other conditions can mimic the symptoms. A careful history and assessment is necessary to establish the cause of these symptoms to rule out other physical causes before a diagnosis of Alzheimer’s Disease is made.
Live Healthy – Health Maintenance

Routine physical exam – It is recommended that individuals with DS have a routine physical exam every 1-2 years, depending on the age and general health of the individual. The exam should include the measurement of height, weight, and blood pressure with comparison to previous readings. General assessment of all body systems should be done including, skin, head, eyes, ears, nose & throat, teeth & gums, gastrointestinal, neurological, orthopedic, urinary, and gynecologic. An general assessment of mental health should also be conducted. Blood testing for thyroid function should be done every year. Additional tests, such as a folate and B12 level may be ordered. (See appendix at the end of booklet for other assessment timeframes.)

Immunizations – recommendations for immunizations for individuals with DS should follow the guidelines for the general population. In addition, Chicoine suggests: influenza immunization annually; pneumonia vaccine beginning at age 5, repeating in 5 years. He also recommends Hepatitis B vaccine for people living in group facilities or working a group setting (e.g. workshop). A blood test to confirm the need for the Hepatitis B vaccine should be done first.

Antibiotic prophylaxis – In 2008 changes the American Heart Association changed their guidelines for antibiotic prophylaxis, reducing the number of times antibiotics are needed prior to a procedure. (See Appendix at the end of this booklet for recommendations.)

Tip
Antibiotic prophylaxis guidelines have changed.
Appendix

Antibiotic Prophylaxis (per the American Heart Association)
Preventive antibiotics prior to dental procedures are still advised for patients with:
- Artificial heart valves
- History of IE (infective endocarditis)
- Unrepaired or incompletely repaired cyanotic congenital heart disease, including those with palliative shunts and conduits
- A completely repaired congenital heart defect with prosthetic material or device, whether placed by surgery or catheter intervention, during the first six months after the procedure or any repaired congenital heart defect with residual defect at the site or adjacent to the site of a prosthetic patch or a prosthetic device
- Any cardiac transplant that develops a problem in a heart valve

DOWN SYNDROME HEALTH CARE GUIDELINES
(Based on 1999 Healthcare Guidelines for Individuals with Down Syndrome: 1999 Revision)
Individuals with Down syndrome should plan to have the following done:

Every Year:
General physical exam
Neurological exam, check for decline in function, memory loss, seizures, bowel, bladder control problems, new onset of balance problems
Functional abilities, check for loss/reduction of daily living or other skill,
Thyroid (TSH and T-4) test
Folate and B12 test
Mammogram (after age 50)
Check heart for murmurs
Breast exam
Evaluate for sleep apnea
Monitor weight – nutritional counseling
Health education: abuse prevention, sexuality, smoking, drug, alcohol
Behavior/emotional/mental health assessment, check for changes, depression, withdrawal
Speech and language assessment

**Every two years:**
Hearing test
Eye exam
Mammogram (age 40 to age 50)
Pap smear & pelvic exam every 1 -3 years (if sexually active)
Pelvic Ultrasound every 2-3 years if unable to do pelvic or manual exam

**One time:**
Neck x-ray to check for AAI (atlanto-axial instability). May be done again prior to participation certain Special Olympics sports.

**Monthly Self-examination by the individual (if possible)**
Breast self-exam for women
Testicular self-exam for men

* Informational booklet available at the ADSC at UAB
References:


Health Care Guidelines for Individuals with Down Syndrome

Alzheimer's and Down Syndrome
http://www.ndss.org

Health Care Guidelines for Individuals with Down Syndrome Adults (Over 18 Years)

Folliculitis
www.mayoclinic.com/health/folliculitis/DS00512

New guidelines regarding antibiotics to prevent infective endocarditis.
http://www.americanheart.org/presenterjhtml?identifier=3047051

Health Issues for Adults with Down Syndrome. Brian Chicoine and Dennis McGuire
www.advocatehealth.com/luth/services/other/adsc/publications.html

Self Talk. Brian Chicoine and Dennis McGuire
www.advocatehealth.com/luth/services/other/adsc/publications.html


For additional information, visit the National Down Syndrome Society (NDSS) website: ndss.org