



WHAT INDIVIDUALS
WITH DOWN SYNDROME
WANT YOU TO KNOW...

Information for
caretakers.

What Is Down Syndrome?

- Down syndrome is a genetic condition that occurs in 1 of every 691 live births
- It affects people of all ages, races and economic levels and is the most frequently occurring chromosomal abnormality
- The most common form of Down syndrome, Trisomy 21, occurs when there are three instead of two number 21 chromosomes in every cell of the body. Instead of 46 chromosomes, a person with Trisomy 21 has 47
- This extra genetic material alters the course of development and causes the characteristics associated with Down syndrome

What Is Down Syndrome?

- Many couples are postponing parenting until later in life and the incidence of Down Syndrome conceptions is expected to increase.
- Life expectancy has dramatically increased in recent decades
- Age 9 in 1910
- Age 25 in 1983
- 60+ today
- More than 400,000 people have Down syndrome in the United States

Is It Downs, Down's or Down?

- The correct terminology is Down syndrome. There is no apostrophe and there is no capital "s" in syndrome
- The syndrome is named after the physician, Dr. John Langdon Down, who identified the common characteristics as a syndrome in 1866
- People "have" Down syndrome, they do not "suffer from" it and they are not "afflicted by" it.
- An adult with this condition is an adult with Down syndrome, not a Down's man or the Down's woman.
- Parents and caregivers will greatly appreciate your sensitivity when you address their loved one as a "person first" and not merely as a syndrome

Speech and Communication

- Understanding a person with Down syndrome when they are speaking can be difficult. This is due to low muscle tone, jaw movement difficulties, motor planning difficulties, and a high narrow palate
- To understand how an individual with Down syndrome may feel, imagine speaking while your mouth is full
- Upon evaluation, many individuals with Down syndrome exhibit great differences between receptive (understanding) and expressive (spoken language production) language abilities. For this reason, their intelligence is often underestimated
- ***It is important to remember that the way an individual who has Down syndrome speaks is NOT a reflection of their intellectual ability***

Speech and Communication

- Recognize that situational factors can impact communication and performance , e.g., an impatient listener, anxiety, perceived pressure, embarrassment or lack of confidence
- Use simple questions (5 Ws and H), and allow EXTRA response time
- If you don't understand what the person is saying, ask him/her to repeat or to "show" you.
- Some adults with Down syndrome may use sign language to communicate

Speech and Communication

- When giving directions, use no more than 2 to 3 step instructions
- Visual aids can help individuals with Down syndrome perform tasks/steps
 - Checklist
 - Pictures
 - Visual Schedules
 - Timers

Visual aids can be posted where necessary – bedroom, bathroom, social or work areas.

Steps to Successful Communication

GETTING STARTED	FACIAL EXPRESSION	TONE OF VOICE	BODY LANGUAGE
<ul style="list-style-type: none">• Approach from the front• Smile• Identify yourself• Use the person's name• If possible, be at eye level	<ul style="list-style-type: none">• Establish & maintain eye contact• Be friendly & relaxed• Always remember humor: smiles & laughter go a long way• Be patient and supportive	<ul style="list-style-type: none">• Speak slowly & clearly• Use a gentle & relaxed tone of voice• Convey an easy-going manner	<ul style="list-style-type: none">• Avoid sudden movement• Be open & relaxed with your stance• Remain calm & confident to provide reassurance• Use gestures such as pointing• Give visual cues

Physical and Health Conditions



Individuals with Down syndrome can be affected by several different physical and health concerns that cause additional disruptions in learning, behavior and general daily life.

It is important for individuals with Down syndrome to be seen regularly by a physician with knowledge about the health care guidelines.

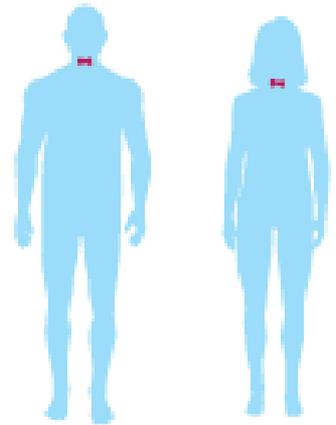
Pain Tolerance

A recent study has confirmed what parents already knew. Individuals with Down syndrome express pain more slowly and less precisely than the general population.

However, they are not insensitive to pain. Therefore, a health professional may have to be alert to other signals from the individual to determine if they may not be feeling well or are in pain.

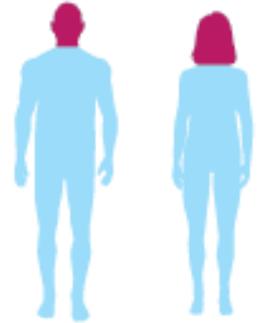
Thyroid Problems

- ❑ The thyroid gland is involved in metabolic processes controlling how quickly the body uses energy, makes proteins and regulates hormones.
- ❑ Thyroid dysfunction is common in adults with Ds but is easily detected via screening blood test and is typically easily treated via medications.
- ❑ Thyroid dysfunction can lead to:
 - ❑ Fatigue
 - ❑ Mental sluggishness, weight fluctuations
 - ❑ Irritability



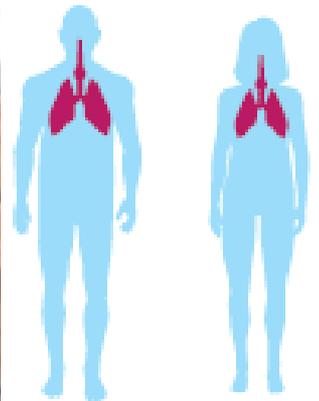
Ear, Nose and Throat

- Individuals with Down syndrome typically have compact bone and soft tissue structure of the ear, nose and throat.
- This increases their susceptibility to, and the severity of, upper respiratory and sinus infections.
- Adults with Down syndrome are at risk for conductive hearing loss. They are also at risk for wax impactions which can impair hearing due to small ear canals.
- Adults with Down syndrome are at risk of early cataracts and keratoconis. Both can be screened for by an eye doctor and should be assessed regularly.



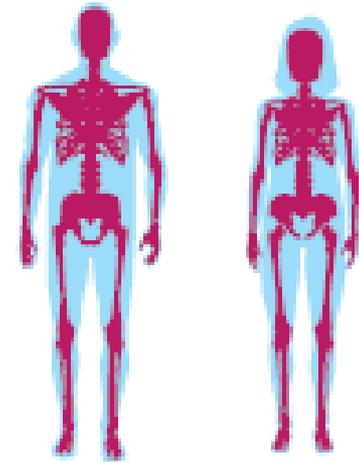
Sleep Apnea

- Recent studies indicate that as many as forty-five percent of individuals with Down syndrome may suffer from sleep apnea. This term is used when someone stops breathing for a very short period of time during sleep.
- Signs of sleep apnea include snoring, gasping noises, daytime sleepiness, morning fatigue, excessive napping and fragmented sleep.
- Sleep apnea can cause:
 - Memory loss
 - Intellectual impairment
 - Irritability
 - Behavior changes



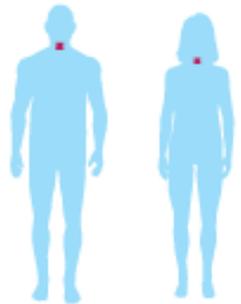
Osteoarthritis & Osteoporosis

- ❑ People with Down syndrome are typically hyperflexible. They can put increased wear-and-tear on their large joints over the years and adults who are overweight or were previously overweight are at increased risk.
- ❑ Pain can express itself through negative behavioral changes and decreased mobility.
- ❑ Pay attention to changes in walking or activity level. Adults with Ds may underreport pain.
- ❑ Individuals with Ds are also more prone to Osteoporosis and may cause high risk of bone fracture.



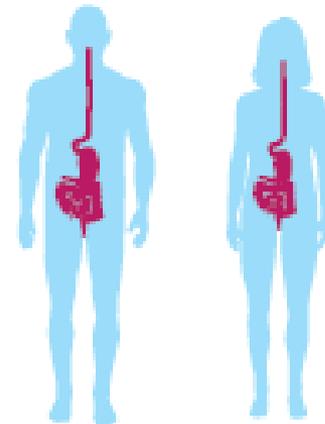
Atlantoaxial Instability & Cervical Spine Concerns

- The region of the spine located in the neck is called the cervical spine.
- In adults with Ds, there is increased risk of instability between the first (atlas) and second (axis) spinal bones below the base of the head.
- A gradual narrowing of the spinal canal may also occur.
- These changes may cause weakness in arms or hands, walking abnormalities or incontinence.



Celiac Disease

- Celiac disease is a condition where one's body cannot digest wheat gluten and wheat products, causing damage to the lining of the intestine and preventing absorption of nutrients.
- Celiac disease can cause gastrointestinal distress, nutritional deficiencies and general irritability or behavior changes.
- A wheat free diet is the primary way to treat this.



Alzheimer's Disease

- Estimates show that Alzheimer's disease affects about 30% of people with Ds in their 50s and closer to 50% of those in their 60s.
- Alzheimer's is a type of dementia that gradually destroys brain cells, affecting a person's memory and ability to learn, make judgments, communicate and carry out basic daily activities.



Alzheimer's Disease

- Chromosome 21 plays a key role in the relationship between Down syndrome and Alzheimer's disease as it carries a gene that produces one of the key proteins involved with changes in the brain caused by Alzheimer's.
- There are several other genes on chromosome 21 that are involved in the aging process.
- While all people with Ds are at risk, developing Alzheimer's is not inevitable.

Alzheimer's Disease

- Establishing a baseline is important in order to determine and recognize changes in functioning.
- Regular memory screening is important beginning in mid to late adulthood. Look for symptoms of confusion or memory loss as well as changes in skills and daily functions.
- If dementia is suspected, it is important to pursue a comprehensive evaluation that takes into consideration other medical or emotional conditions.

Emotional and Psychiatric Well-being

- As adults with Ds grow older, there is increased risk of experiencing certain common mental health disorders like depression, anxiety, OCD and behavioral disturbances.
- It is important to have a thorough medical examination to determine if any physical or medical conditions are contributing to abrupt changes in behavior or mood before exploring psychiatric illness.

Emotional and Psychiatric Well-being

- Significant changes in environment or social structure, as well as personal loss, conflict or other interpersonal relationship issues may affect behavior or mood as well.
- Seeing a mental health professional with experience or expertise in working with individuals with developmental disabilities is ideal.

Self-Talk

- Self-talk is very common in adults with Down syndrome. The Adult Down Syndrome Center in Chicago reports that 81% of the adults seen engage in conversations with themselves or imaginary companions.
- Families and caregivers should understand that self-talk is not only “normal” but also useful.
- Adults with Down syndrome show some sensitivity about the private nature of their self-talk – may occur when adults think they are alone.

Self-Talk

- Adults with Down syndrome use self-talk as an important coping tool to:
 - Problem solve
 - Vent their feelings
 - Process the events of their daily lives
 - Entertain themselves

Self-talk should not be viewed as a medical problem or mental illness.

Self-Talk

- Intervention may be warranted if there are changes in:
 - ▣ Frequency
 - ▣ Context (talk becomes more negative)
 - ▣ Tone (loud or threatening)

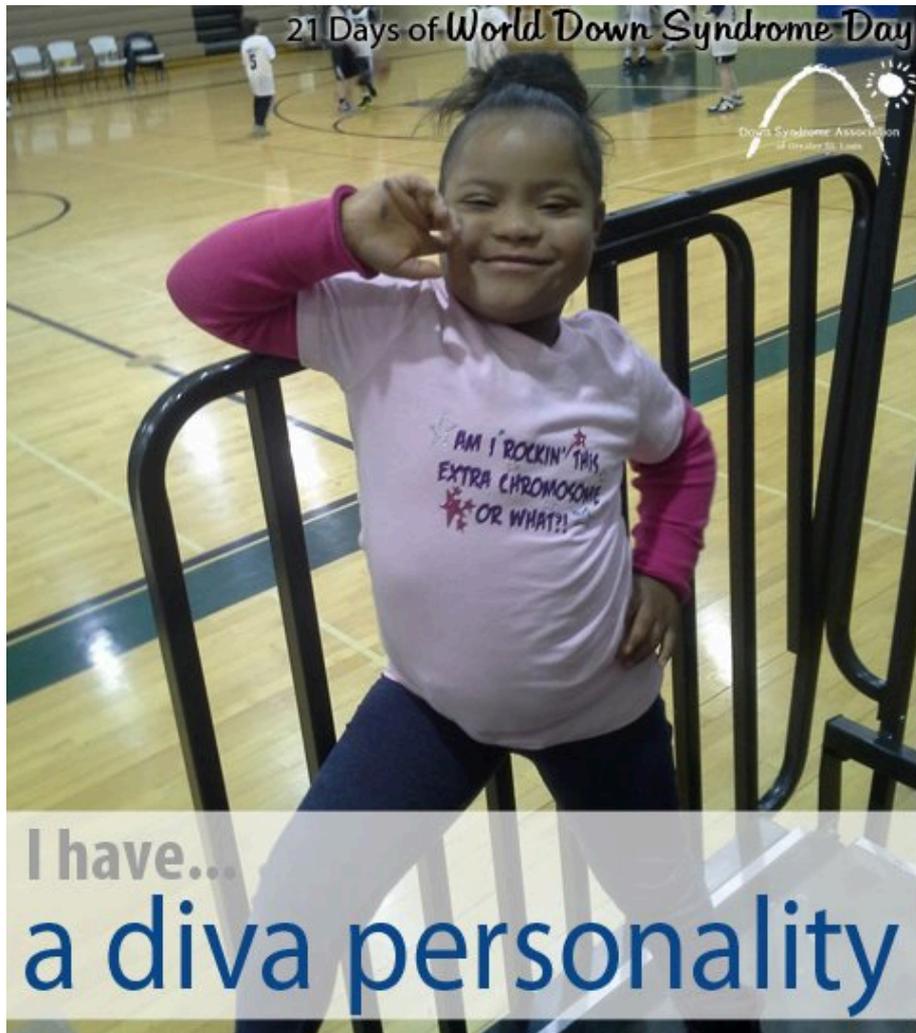
A dramatic change in self-talk may indicate a mental health or situational problem and a mental health professional may need to be consulted.

Memory

- Most people with Down syndrome will have short term or working memory difficulties. This makes it harder for them to access, understand, and process information at the speed of the others.
- It does not prevent them from learning the same information. Individual motivation is the key to learning!



Behavior



- “Stubborn”
- Attention problems
- Routine oriented
- Autism – as many as 1 in 10 individuals with Ds also have Autism

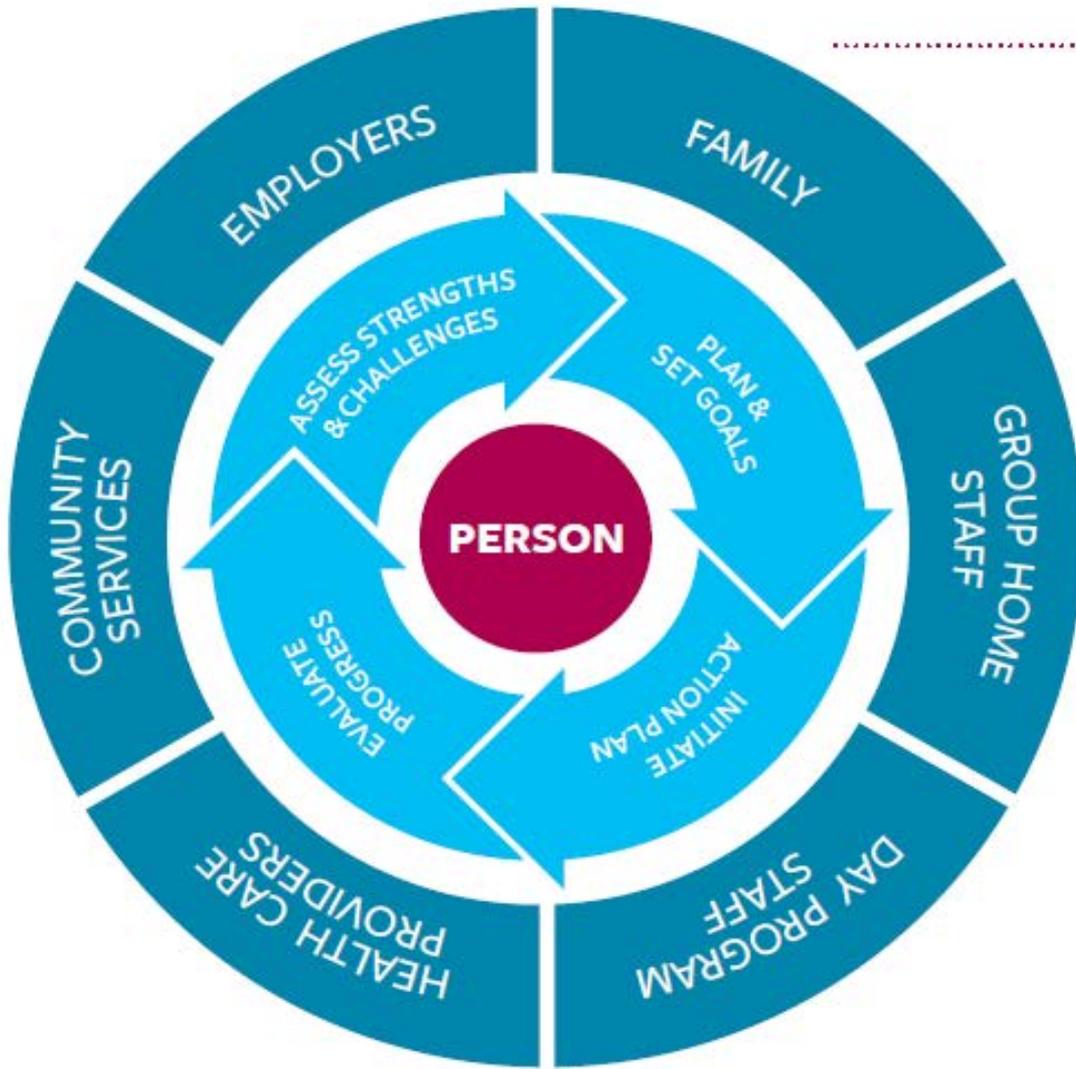


FIGURE 1

Example of person-centered care. The team members surround the center person, and the steps of care coordination are an ongoing and evolving process between all members.

Topics to Consider in Care Coordination

ABILITIES & CAPABILITIES	ENVIRONMENT & ACTIVITIES	CONDITIONS	RESOURCES
<ul style="list-style-type: none">• Physical• Psychological/ Behavioral• Cognitive• Functional Abilities (activities of daily living)• Sensory (vision, hearing, touch, smell)• Communication	<ul style="list-style-type: none">• Living Arrangement• Employment/ Retirement• Social Engagement/ Activities• Day Program Activity• Daily Routines• Spiritual Support• Likes/Dislikes• Safety Risks	<ul style="list-style-type: none">• Nutrition• Oral/Dental• Elimination Pattern• Sleep Pattern• Medical Conditions• Allergies & Intolerances• Medications• Prevention Care• Treatment & Services• Palliative & End of Life Care Needs	<ul style="list-style-type: none">• Community Services & Support• Funding• Staffing Requirements• Transportation Needs• Legal

The World



- Up to 3% of the world's population have intellectual disabilities
 - 200 million people
- We are asking for YOU to help create a more accepting world for people with intellectual and developmental disabilities

The "R" Word

- Did you know the use of the R-word further perpetuates the stigma and negative stereotypes that face people with intellectual disabilities?
- People around the world are taking a stand & raising awareness of the dehumanizing & hurtful effects of the words RETARD and RETARDED.
 - THINK BEFORE YOU SPEAK

How Can I Help?

- Take the time to understand, learn new things, and make new friends
- SAY HELLO
- Acknowledge the individual by their name
- BE PATIENT AND LISTEN
- Include individuals with an Intellectual Disability in your life
- WE ALL WANT TO BE LOVED...ACCEPTED...VALUED...INCLUDED
- VOLUNTEER
- Down Syndrome Association of Greater Saint Louis – www.dsagsl.org
or a multitude of other worthy organizations

Professionals

- You are in a position to educate other professionals, their families, and the general public on the positive impact people with Down syndrome have on their families and their communities.

Professionals



Challenge yourselves to
Recognize & overcome our stereotypes
And treat people with down syndrome
And their families
With the highest level of
Respect
And care

Other Services Offered By The DSAGSL:

- ❑ New/Expectant Parent Support Program
- ❑ Medical Outreach Program
- ❑ Family Conference
- ❑ Educational seminars
- ❑ Down Syndrome Specialist Program
- ❑ Lending Library
- ❑ Quarterly newsletter
- ❑ Website: www.dsagsl.org

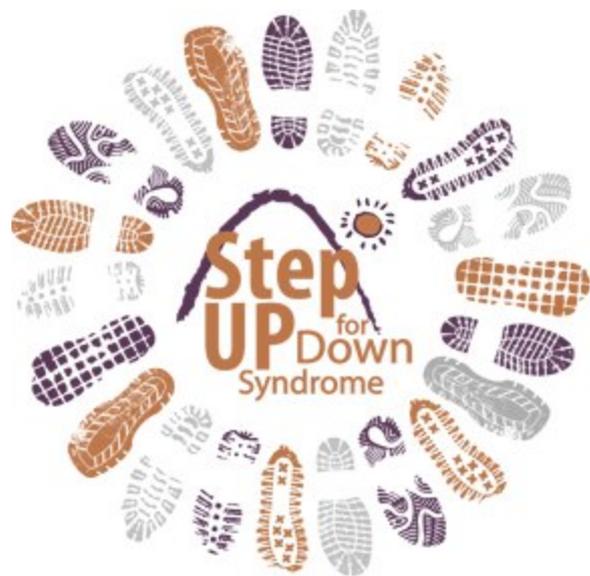
Other Services Offered By The DSAGSL:

- ❑ Bi-Weekly E-mail blast
- ❑ Facebook / Twitter Account
 - ❑ www.Facebook.com/DSAGSL
 - ❑ www.Twitter.com/DSAGSL
- ❑ Community Education Presentations
- ❑ Community Groups
- ❑ Information and Referral
- ❑ Family Events
- ❑ Bike Camp
- ❑ Advocacy and Public Awareness

Upcoming Events & Ways to Get Involved

Step Up for Down Syndrome!

Form a team and raise money and awareness for the DSAGSL! Have a blast at one of St. Louis's largest walks.



Down Syndrome Association of Greater St. Louis

<http://dsagsl.org/how-to-help/step-up-for-down-syndrome/>

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The Mission of the DSAGSL is to benefit the lives of people with Down syndrome and their families through individual and family supports, information, public awareness, and advocacy

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NDSS

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Go Make a Difference

- Take the pledge to end the r-word
 - Volunteer
 - Show respect, kindness, patience
 - Be inclusive, be a friend
 - Be an advocate
- Educate the public and other professionals

