EASTERN PENNSYLVANIA
HEALTH CARE QUALITY UNIT

It's Your Health Winter 2013

the Advocacy Alliance
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The Gut Brain

Most people are aware of the good bacteria present in the gut, but many people are unaware that a second brain resides there as well — the ***Gut Brain***. Research is raising awareness of the importance of this brain in maintaining a healthy immune system. When functioning properly, the sympathetic nervous system slows the GI system and the enteric nervous system regulates digestion and wellbeing — messages pass back and forth between the brain and the gut.

There are over 800,000 good bacteria residing in the gut. The gut is sterile in utero but the bacteria colonize when the baby goes through the birth canal, and so research is being done to determine if treatment should be provided for babies born by C-section, possibly with probiotics, due to their higher risk of gastrointestinal issues.

What is in your Gut?

* The **#1 risk factor for gut disease is stress** as it causes good bacteria to decrease. One reason for this decrease is **Serotonin** produced in the gut is necessary for both gut and brain functions.
* **Zonulin** is a protein that regulates the permeability of the intestine, and when increased, destroys the tight junction of the intestine, protective channels loosen, and bacteria can enter the blood stream causing liver enzymes to increase and the immune system to break down. Black pepper (use ground peppercorns) may block the formation of zonulin.
* **Bacteroides** are the peacekeepers in the gut, and they assist in breaking down food and producing nutrients and energy the body needs. If they enter the blood stream they can cause or exacerbate infections and ulcers throughout the body. **Actomyosin** is another protein that regulates intestinal permeability.

Plaques and tangles of Alzheimer's are also present in the gut as well as **alpha-snyuclein**, a precursor of Parkinson's Disease. It can take four weeks for good bacteria to return to normal levels after antibiotic treatment.

Gut Issues:

Irritable bowel syndrome (IBS) occurs in the large intestine but causes no damage to the gut and can be controlled by probiotics, dietary adjustments and stress reduction.

Crohn's Disease can occur anywhere along the GI tract and is treated by anti-inflammatory medications (e.g., Asacol or corticosteroids). There is no cure for Crohn's

Ulcerative colitis begins at the bottom of the large intestine and is confined to that organ, and like Crohn's, may be treated by anti-inflammatory medications (e.g., Asacol or corticosteroids). UC can be cured by a colectomy, where an internal pouch can be formed, making a colostomy unnecessary. Fecal microbiota transplantation (FMT) has been used successfully in Europe and the Mayo Clinic in Arizona for treatment of UC.

Clostridium difficile, or C.diff, is a bacterium that can cause symptoms ranging from diarrhea to life-threatening inflammation of the colon. Illness from C.diff most commonly affects older adults in hospitals or in long-term care facilities and typically occurs after use of antibiotic medications. Fecal microbiota transplantation (FMT) has been used successfully in Europe and the Mayo Clinic in Arizona for treatment of C.diff as well.

Maintaining Gut Health

There some things you can ingest to help maintain your gut health:

* **Probiotics:** Multiple strains are better and pay attention to shelf life since the bacteria need to be alive.; should be taken an hour before eating/drinking hot foods; and can also be effective in the treatment of halitosis.
* Fermented foods (e.g., sauerkraut, pickles, Gouda cheese)
* Eggs contain 1000 mg. of tryptophan, which produces 5HTP, which in turn produces serotonin; Eggs should be prepared *intact* as scrambling oxidizes them, potentially raising LDL
* Fiber (e.g., fruit with skin, solid foods, not juice)
* Olive or peanut oil
* Raw nuts
* Whole Mother's oats
* Flax seeds, work up to ¼ cup/day (Soak for 3-6 hours or grind fresh; eat within 20 minutes)
* Quinoa
* Broccoli sprouts
* Lentils, asparagus and spinach are good sources of fish oil

Keep in mind wheat is refined and genetically engineered, and may not be as healthy as we believe. Also, rice may contain arsenic from ground contamination.

Things to Avoid

* Artificial flavors because they are made from petroleum
* Cans and aluminum water bottles are lined with BPA, so you should use steel instead
* High fructose corn syrup causes inflammation)
* Trans fat—you should limit cholesterol to 3 mg. per day
* Eating well not only benefits cardiovascular health and reduces obesity, but it helps to maintain intestinal health. This can help to prevent or reduce a host of diseases caused by a compromised immune system.

Resources: www.mayoclinic.org, www.huffingpost.com/julie-chen; Seminar: Gut-Brain Connection, Institute for Brain Potential; www.michaeljfox.org for research information; http://www.mayoclinic.com/health/c-difficile/DS00736

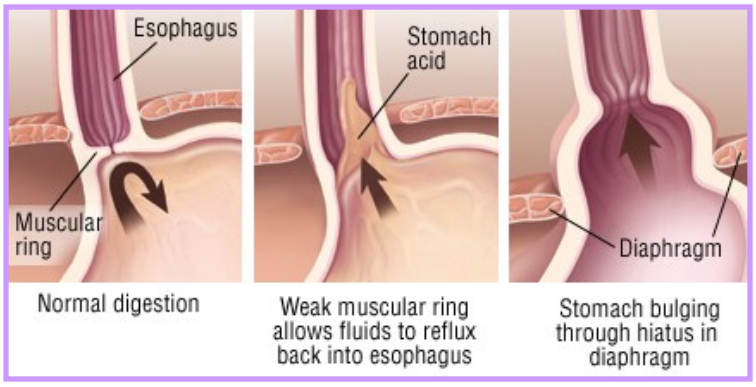
GERD

Do you ever have bouts of heartburn or a sour taste in your mouth after a meal? If you've been popping antacids like crazy or longer than two weeks, it's time to see the doctor. You may have a condition called GERD, Gastro Esophageal Reflux Disease. GERD happens when stomach acid backs up into the esophagus from your stomach. This backwash of acid irritates the mucosal lining of your esophagus and can cause inflammation and strictures (narrowing) in your esophagus. At the top of the stomach is a sphincter that allows food to go in the stomach and it's called the Lower Esophageal Sphincter. In GERD, this sphincter or valve relaxes abnormally, allowing food and acid to flow back upward. Over time, it can cause the lining to become inflamed (esophagitis) and cause complications of bleeding or breathing problems.

Signs and symptoms that may be associated with GERD include:

* A burning sensation in your chest (i.e., heartburn), sometimes spreading to the throat, along with a sour taste in your mouth
* Chest pain (sometimes so painful that it has lead some people to the ER)

* Difficulty swallowing (i.e., Dysphagia)
* Dry cough
* Hoarseness or sore throat
* Regurgitation of food or sour liquid
* Sensation of a lump in the throat



Risk factors that can increase your chances of having GERD:

* Obesity
* Hiatal Hernia (when the stomach protrudes upward and sits on top of the diaphragm)
* Pregnancy
* Smoking
* Dry mouth
* Asthma

GERD Treatment

In the United States treatment generally consists of a medication to reduce acid production (e.g., Zantac), or proton pump inhibitors to block acid production and help heal the esophagus (e.g., Prilosec). The #1 treatment in Europe for is deglycyrhizinated licorice (DGL), and it is used exclusively by 80% of those needing treatment. This treatment should be used under the supervision of a physician and blood pressure should be monitored frequently, as well as liver and kidney function and observation for edema.

There are a variety of medications that can help alleviate some symptoms:

* **Antacids** (e.g., Mylanta, Tums) neutralize the acid and relieve heartburn, and H2 blockers reduce the acid in the stomach. If these non-prescription medicines do not relieve your symptoms, talk to your health care provider about trying prescription strength medicine.
* **Proton pump inhibitors** such as **omeprazole** (e.g., Prilosec) and **lansoprazole** (e.g., Prevacid) reduce the amount of acid and allow your esophagus to rest.

Medicine may not prevent all of your GERD symptoms all the time. You may still have heartburn from time to time, and you may need to try different medications until you find the right one for you

Besides medication and lifestyle changes, surgery is the only other effective treatment option to prevent GERD symptoms from coming back. You should discuss this with your health care provider.

Here a few tips to help fight the fire of heartburn:

* **Watch what you eat** — there are certain foods and drinks that cause heartburn triggers and cause the LES to relax, such as the following:
    * **The five "C"s:** chocolate, caffeine, cigarette smoking, citrus and carbonation are the classic group that can aggravate the condition. In addition, garlic, onions, tomatoes, spicy, fried foods, citrus fruits, soda, peppermint, and alcohol.
* **Reduce portion sizes.**
* **Watch when you eat** — and try not to eat three hours before bedtime or lie down right after a meal.
* **Lose weight** — excess abdominal fat can press against the stomach, opening the sphincter allowing the acid to backflow.
* **If you smoke, quit** — smoking can reduce the ability of the sphincter that keeps acids in the stomach.
* **Loosen your belt** — tight clothes put extra pressure on the abdomen.

For Individuals with Intellectual and Developmental Disabilities, GERD is More Common

Communication skills may be limited and making a diagnosis difficult to confirm. Here are some signs that a person with limited communication skills may have GERD:

* Drooling
* Meal refusals
* Unexplained weight loss
* Coughing/aspiration during the night
* Night time awakening seeking water/milk to soothe burning
* Self-injurious behaviors
* Hands in mouth
* Body posturing-stiffening to relieve pain
* Noisy or wet respirations

In conclusion, if you or if you think someone you know may have GERD, seek medical attention.

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Check out these websites mentioned in this edition of "It's Your Health"

http://www.pchc.org/Documents/Publications/PDFs/GERDbooklet.pdf
http://www.webmd.com/heartburn-gerd/features/top-10-heartburn-foods?print=true
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Sexuality & Intellectual/Developmental Disabilities

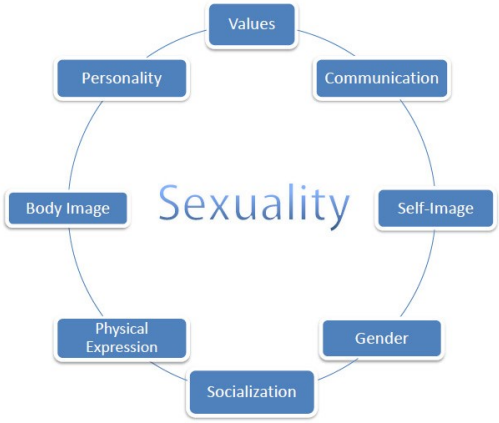
Friendship is important. And the desire to love and be loved, whether as a friend or an intimate companion, is a drive that defines a person in a way that no disability ever can. **-Liz Dore**

As a greater understanding about human sexuality and intellectual and developmental disabilities is gained, more attention is being paid to the obstacles faced by this population with respect to the things the typical population takes for granted. Human beings are reflective — we thrive and flourish when faced with our counterparts and human interaction is needed in order to learn more about oneself. Praise as well as any positive recognition from those around you helps to build a solid sense of self-image, self-esteem and so much more. The Intellectual/Developmental Disabilities (IDD) population is no different in the fact that they require interaction with the world around them in order to develop all areas of their sexuality. Furthermore, these experiences are necessary in order to understand relationships and the different types of boundaries.

Loneliness can lead some people to act out inappropriately in social, emotional and physical manners, and misconceptions, lack of education and lack of consistency exacerbate these ineptitudes. Disability advocate, David Pitonyak, says, "many people who experience disabilities live lives of extreme loneliness and isolation." Most individuals with developmental disabilities have an inability, lack of education or opportunity to make friends and learn basic reciprocity and mutuality skills — which also leads to increased loneliness and other issues. When discussing sexuality as a complication that the dually-diagnosed population faces, there is often a lack of understanding of what comprises human sexuality. Sexuality is an all-encompassing concept, and perhaps the best description of sexuality is that it is an ***expression of an age-blind desire for meaningful intimacy and connection with others*** (Schalet, 2004).

Sexuality is an essential and often neglected aspect of life for people with intellectual disability.

Discussing sexuality with an individual with developmental disabilities can be quite difficult, and at times embarrassing for both parties involved. It is vital that this discussion is done in a private area and with the understanding that the individual is likely to have the same urges and needs as typical individuals, but may not be able to express them as easily. There are often barriers to forming sexual attachments such as: an inability to socialize with others in the community as the typical population does; past/present sexual abuse; access to willing and capable partners; hormonal and chemical imbalances; fear; and lack of education regarding equal sexual relationships. Sexuality education should include information on all aspects of sexuality, and should be presented in a kinesthetic manner. The use of both multi- and mono-media instructional methods to provide visual stimulation as well as to fulfill the tactile needs of the individual can be most productive.



The Sexuality Wheel sheds light on the particular aspects of sexuality, Credit: Teaching Sexual Health, 2013

Relationships, boundaries and sexuality can be overwhelming concepts for not only the individuals we care for who have IDD, but also for their caregivers. In 2010, Swango-Wilson examined systems theory and the development of sexual identity for individuals with IDD and found that the caregivers of those with IDD must be cognizant of inclusion, use appropriate educational tools that are applicable to the individual's cognitive and developmental level and acknowledge the individual's role within their own environment.

The definition of what a *normal* life is lies in the eye of the beholder, the definition of *happiness* lies in the eye of the beholder — but life cannot be lived to its fullest extent if one does not know who they are and how to interact with those around them. If these measures are taken, the likelihood of an individual with IDD gaining an increase in appropriate and natural relationships, a greater understanding of general boundaries and an overall more satisfying life experience is increased significantly.

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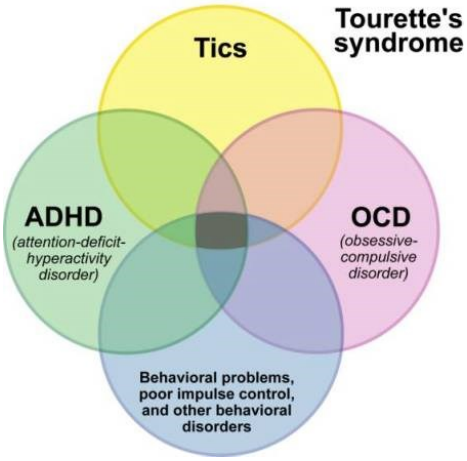
Tourette's Syndrome and Tic Disorders

Facts

Tourette's Syndrome is a neurological disorder which is characterized by repetitive, stereotyped, involuntary movements and or vocalizations called **tics**. First described in 1885 by French neurologist Dr. Georges Gilles de la Tourette, the disorder is first noticed in childhood between 3-9 years of age. Tourette's was once thought to be rare, but now is thought to be under diagnosed with the presence of tics thought to be a fairly common occurrence in children. It can last throughout a lifetime in10-15% of the cases. Most people experience the worst of the symptoms in their early teens with an improvement in their late teen/early adulthood years. The incidence of TS is equal across all ethnic groups, but 3-4 times more common in males. Estimates are that 200,000 Americans have a severe form, with 1 in 100 exhibiting milder, less complex symptoms. However, some milder cases may be going undiagnosed.



An individual can have tics associated with medical conditions without having Tourette's Syndrome. Some examples of this include cerebral palsy, infections or head injuries. Some disorders that often co-exist with Tourette's include Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), and Autism spectrum disorders. In these cases, tics may be thought to be part of these disorders and not given a separate diagnosis.

Some famous people who have revealed they have Tourette's include the former Philadelphia Phillies player Jim Eisenreich and actor Dan Ackroyd.

Types of Tic Disorders

Tourette Syndrome (TS)

- Have both multiple motor tics (e.g., blinking or shrugging the shoulders) ***and*** vocal tics (e.g., humming, clearing the throat, or yelling out a word or phrase), although they might not always happen at the same time;
- Tics have occurred for at least one year — and occur many times a day, usually in bouts, nearly every day, or off and on;
- Tics began before 18 years of age; and
- Symptoms are not due to taking medicine or other drugs, or having a medical condition that can cause tics (e.g., seizures, Huntington disease, or post viral encephalitis).

Persistent (Chronic) Motor or Vocal Tic Disorder

- Have one or more motor tics (e.g., blinking or shrugging the shoulders) or vocal tics (e.g., humming, clearing the throat, or yelling out a word or phrase), but ***not*** both;
- Tics occur many times a day, nearly every day ,or on and off throughout a period of more than a year.
- Tics began before 18 years of age;
- Symptoms are not due to taking medicine or other drugs, or having a medical condition that can cause tics (e.g., seizures, Huntington disease, or post viral encephalitis); and
- Have not have been diagnosed with Tourette Syndrome.

Provisional Tic Disorder

- Have one or more motor tics (e.g., blinking or shrugging the shoulders) ***or*** vocal tics (e.g., humming, clearing the throat, or yelling out a word or phrase);
- Symptoms have been present for no longer than 12 months in a row;
- Tics began before 18 years of age;
- Symptoms are not due to taking medicine or other drugs, or having a medical condition that can cause tics (e.g., seizures, Huntington disease, or post viral encephalitis); and
- Have not been diagnosed with Tourette Syndrome or a persistent motor or vocal tic disorder.

Symptoms are classified as Simple or Complex. Please see below:

Simple:

Movements are sudden, brief and repetitive, and they involve a limited number of muscle groups. (i.e., eye blinking, shoulder shrugging, facial grimacing, throat clearing, sniffing or grunting.)

Complex: Coordinated patterns of movements involving several muscle groups. (i.e., grimacing, head twist and shoulder shrug all grouped together). These movements sometimes appear purposeful, but are not. Vocalizations involve words or phrases. There are two types of vocalizations, and they are :

- **Coprolalia —** is the use of inappropriate phrases or swearing. It is rare and only occurs in 10-15% of those diagnosed with the disorder.
- **Echolalia** — the repeating of words or phrases of others.

Some Facts about Tics:

- The first appearance of tics is usually in the head or neck with a progression down to the body's trunk and extremities.
- Motor tics come before vocal, and simple symptoms prior to complex.
- There is a sensation, described as similar to the feeling you have prior to sneezing, that people report often precedes the tic.
- When the tic is performed, it relieves the urge, and this is referred to as a "**premonitory urge**".
- Tics can become worse with excitement or anxiety, and improve with calm or focused activity.
- Tics can be triggered by some physical sensations (e.g., a neck tick when wearing tight clothing in that region).
- Tics do not go away during sleep but are diminished.
- Tics can be suppressed, however people report a substantial buildup of tension until the tic must be expressed, or can no longer be contained.
- There can also be tics that result in self injury such as punching or biting of oneself.

Causes

There is no one known cause for these disorders, although certain brain regions (i.e., basal ganglia, frontal lobes and the cortex) as well as some neurotransmitters have been implicated. There have also been studies that show that it can be inherited, and some studies that show a genetic relationship to some forms of OCD and ADHD.

Diagnosis

There are no laboratory, blood or imaging tests used except to rule out other conditions. Diagnosis is made based on the presence of symptoms as listed in the above criteria.

Treatment

People often choose not take medications for tics. However, there are some medications that have proven somewhat effective including the neuroleptics, Haldol and Pimozide, but unfortunately there are many side effects associated with these medications. There has been much benefit seen by treating any of the co existing conditions such as OCD or ADHD. There has been some difference of opinion on whether some stimulants used for ADHD improve or worsen tics. Botox, benzodiazepines, anticonvulsants, and even cannabis, have also been used with reported improvement. Cognitive Behavioral therapies (e.g., awareness training; competing response training; Cognitive Behavioral Intervention for Tics (CBIT); biofeedback) have been used with some success. Deep Brain Stimulation involving the implantation of electrical leads into the brain has shown some promise, but this treatment is usually utilized when other treatments have failed, or when symptoms are severe enough to cause harm or a significant functioning impairment for the individual. ECT and Transcranial Magnetic Stimulation are other modalities being investigated.

There continues to be a great deal of research into possible causes and treatments since this disorder is now being recognized to be much more prevalent than previously thought.

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Tourette Syndrome "Plus" Leslie E. Packer, PhD, http://www.tourettesyndrome.net/

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