Down Syndrome and Celiac Disease

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What is Down Syndrome?

Down syndrome (DS) is a genetic disorder characterized by a full or partial extra copy of chromosome 21 in all or some of the cells in an individual's body and is the most common chromosomal disorder. Chromosomes usually come in pairs of two, one from each parent, and are responsible for our inherited traits. This additional chromosome, or portion of a chromosome, causes the common features of DS:

- Delayed language
- Impaired long and short-term memory
- Small head
- Small neck
- Decreased muscle tone
- Upward slant in eyelids
- Single crease in palm
- Flattened face

While some people with DS may possess all these traits, others may express very few. Although most individuals with Down syndrome have mild to moderate cognitive delays, intellectual disabilities can range from very mild to severe. In addition to physical traits and cognitive function, DS can impact other areas of the body such as the heart and gastrointestinal tract.

What causes DS?

Older maternal age is the only factor known to increase the chance of certain types of DS, especially after the age of 35. However, approximately 80% of children with DS are born to a mother under the age of 35, suggesting a largely unexplained syndrome.

Due to advancements with antibiotics, clinical treatment, and corrective heart surgeries, adults with DS are living longer. 80% of adults with DS live until age 60, but some may live longer, which increases the need for related knowledge and awareness.

Screening for DS

Testing for DS is typically offered in prenatal care appointments, but can only analyze risk of having a baby with DS. These tests can help parents make informed decisions about higher sensitivity diagnostic tests. For newborns, a baby's appearance will often prompt healthcare providers to test for DS through a blood test that analyzes chromosomes.

What is the connection between DS and celiac disease (CD)?

DS is closely linked with autoimmune diseases, including celiac disease (CD), but this connection is often overlooked. Many people quickly justify gastrointestinal symptoms, cognitive behavior, and other medical ailments as simply part of the syndrome. However, experts believe that 5-15 % of people with DS have CD compared to the population without DS, who have about a 1% chance of developing CD. This prevalence warrants consideration of medical screening of CD for those with DS.

CD can cause a variety of symptoms or produce no symptoms at all. Patients with DS generally present a symptomatic form of CD, but many of these symptoms overlap with those experienced by children who have DS without CD.

DS symptoms

- Anemia
- Intermittent diarrhea
- Constipation

CD symptoms

- Low weight gain
- Diarrhea
- Vomiting
- Constipation
- Anemia
- Nutritional deficiencies
- General irritability
- Behavior changes

Although the genetic causality of each of these medical conditions is clear, further studies are needed to understand the underlying mechanism. *(Note that genetic characteristics are necessary for the development of CD, but other factors are also involved.)*

CD testing for those with DS

Delayed diagnosis of CD can lead to malnutrition, decreased growth, and severe complications including lymphoma. Since CD is more common in children with DS, screening is important for management of the disease. Due to the high percentage of those with DS who have CD, The National Down Syndrome Society (NDSS) recommends that all children with DS between the ages of two and three undergo testing for CD. Many in the medical field recommend CD testing for those with DS, but it is important to explicitly ask about having your child tested.

At first, children should be screened for CD through a simple blood test that detects CD antibodies. If a child tests positive for these antibodies, a small intestine endoscopy is generally used to confirm CD diagnosis. However, this may not be advised for very young children; discuss this with your healthcare provider.

The NDSS additionally encourages doctors to screen adults with DS, especially if bowel changes, weight loss, and poor nutrition are reported. Once diagnosed with CD, treatment includes removing all wheat, barley, and rye from a person's diet and avoiding cross-contact with these foods as well.

Learn more about specific testing for CD through our educational bulletin: gluten.org/kids/celiac-disease-testing-children/

Nutritional concerns for DS and CD?

There are no specific nutrient deficiencies identified for those with both DS and CD other than those frequently seen in CD or those resulting from poor dietary choices. Refer to common nutrient deficiencies associated with CD in this educational bulletin: gluten.org/resources/diet-nutrition/nutrient-deficiencies/

How do I support a GF diet for my child with DS?

Providing your child with a GF diet can feel intimidating and overwhelming. Focus on small changes that empower you and your child.

- Educate yourself on gluten-containing foods, gluten-free grains, and naturally delicious gluten-free foods. If possible, involve your child with this process.
- Watch for cross-contact
- Include your child in picking out GF recipes
- Offer a variety of GF foods and let your child pick which ones they want
- Try to limit heavily processed foods and support whole food choices such as fresh fruits and vegetables
- Join a support group
- Some children and adults may require a specialized Registered Dietitian to consult based on their unique dietary needs

Use these educational bulletins as a guide to gluten-free living for your child:

- gluten.org/2019/12/18/celiac-disease-in-children/
- gluten.org/community/kids/
- gluten.org/category/kids/

For more information about DS, please visit NDSS: www.ndss.org/

References

www.ncbi.nlm.nih.gov/pmc/articles/PMC5797057/#!po=4.54545

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GIG is on a mission to make life easier for everyone living gluten-free.

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