Unexplained Weight Loss

Brian Chicoine, MD
Medical Director

We were sent a question about unexplained weight loss. We are sharing some information here for general knowledge and/or information that can be used in consultation with your provider.

While overweight and obesity are common in people with Down syndrome (and without Down syndrome), we have seen a smaller but significant number of individuals with Down syndrome who are underweight and/or have problems with unexplained weight loss.

One of the first things to consider is inadequate intake. People with Down syndrome eat inadequate amounts or decline to eat for a variety of reasons. It is a common enough problem that we wrote a whole chapter on the topic in our book Mental Wellness in Adults with Down Syndrome (https://www.woodbinehouse.com/main.asp?PRODUCT_ID=1-890627-65-8). Reading the chapter can provide much insight. We have seen a number of individuals who had a physical condition that caused discomfort with eating (a choking episode, an ulcer, gall bladder disease, and many others) who then stopped or reduced their eating to avoid pain. While this had significant short-term benefit (reduction in discomfort), it had even more significant negative long-term implications (weight loss, poor nutrition). Many of these individuals developed obsessive compulsive disorder (OCD) - an obsession about not eating. Treatment is focused on addressing the cause of the discomfort and we have often found that some treatment for OCD was necessary. Supporting nutrition while assessing and treating is important. Consultation with a dietitian, use of supplements, and, in some cases, even feeding with a tube have been parts of the treatment. Depression, regression syndrome, and catatonia are among additional mental health conditions that may be associated with poor intake.

What about the situation in which the person is eating enough but the calories or nutrients are not getting absorbed? There are many reasons this can occur. Celiac disease is probably the most common in people with Down syndrome. For more information on celiac disease, go to our Resources section on our website and put "celiac" in the search box (https://www.advocatehealth.com/luth/health-services/adult-down-syndrome-center/resources/families-caregivers). It should be noted that celiac disease is more common in people with Down syndrome and the blood tests for celiac disease seem to be less accurate in people with Down syndrome. Therefore, if we suspect symptomatic celiac despite a normal blood test, we will recommend proceeding with an EGD (scope to look at the esophagus, stomach, and the first part of the small intestine) to get a biopsy and assess for celiac disease. Celiac disease is an auto-immune disease - a disease in which the body's immune system attacks some part of the body. In celiac disease, it is the small intestine that is attacked.

Auto-immune disorders are more common in people with Down syndrome and many of them can cause weight loss. Some of them directly affect the intestines, pancreas, liver, and other parts of the gastrointestinal tract and some have a secondary effect of weight loss. These may include: systemic lupus, scleroderma, Crohn's disease, ulcerative colitis, rheumatoid arthritis, and others. A rare complication of auto-immune diseases is amyloidosis which can affect the GI tract. Also, consider Addison's disease (reduced adrenal gland function) which can also be auto-immune.

In some conditions, the food/nutrients are being absorbed but the body is not able to use the calories. Diabetes mellitus (DM) is a classic example. DM limits the body from using the food that has been absorbed and can be caused by inadequate insulin (type 1 diabetes) or resistance to insulin (type 2 diabetes). Studies have found both
of these to be more common in people with DS (but some studies found type 2 to be less common). Type 1 DM is an auto-immune condition.

In some conditions, the calories are absorbed, and the body is using them but at a higher rate causing weight loss. Hyperthyroidism (overactive thyroid) causes an increased metabolic rate and can cause weight loss. This is more common in people with Down syndrome.

A variety of other conditions cause weight loss as a symptom of the disease including:

- Kidney and liver disease
- Cancer - In adults, solid tumors are less common but can occur. Cancer of the stomach, intestines, brain, and breast are all less common. Leukemia is more common in children and young adults. Lymphoma may also be found and may be more common. Multiple myeloma (cancer of plasma cells - a type of white blood cell) may also be more common (we have seen 2-3 people with it).
- Alzheimer's disease can be associated with weight loss for a variety of reasons (but the individual in the case sent was only in his 20s so that is very unlikely in this case).

With unintended weight loss, a systematic assessment is necessary to evaluate for a large number of potential causes. A careful history and physical as well as knowledge of conditions that are more (or less) common directs the assessment. Supporting the individual with attention to nutrition is important while assessing for the cause.