

Weight Gain in Duchenne Muscular Dystrophy

This fact sheet is about weight in people with Duchenne muscular dystrophy. This fact sheet is written for parents and caregivers. You might want to start by reading the Endocrine Information Sheet, which introduces you to some basic topics.

What causes weight gain in Duchenne?

People with Duchenne muscular dystrophy are at risk of increased weight gain for several reasons, including:

1. They do less physical activity,
2. Taking steroids can cause an increase in appetite and promote weight gain, and
3. People with Duchenne may have a lot of free time that is easy to fill with too much eating.

People with healthy muscles can do exercise to reduce their weight. For people with Duchenne, though, some forms of exercise can cause damage muscles. Exercise programs are not usually part of the weight management in Duchenne.

Can I help my child prevent weight gain associated with using steroids? If my child is overweight, can I help him lose weight?

Yes, but it is hard work. It is very common for people on long-term steroids to gain too much weight. The best way to prevent gaining too much weight is by starting early with healthy eating. Since he can't be very physically active, your son will not be able to burn off extra calories through exercise, so his diet is extremely important.

It won't seem fair to your son if he has to eat healthy foods and the rest of your family doesn't eat well. You can make it easier on him (and help everyone in your family be healthier) if you engage the whole family in maintaining a healthy lifestyle. Remember, it is easier to prevent weight gain than to lose weight. If your son has gained too much weight you'll have to work extra hard to help him make good food choices. Parents of children with Duchenne need to be careful about using unhealthy foods for rewards or allowing their children with Duchenne to eat because they are feeling bored or sad.

Nutritional counseling is an important part of the overall care of people with Duchenne. You can read the standard recommendations for the prevention of weight gain at the end of this fact sheet.

What tests and measurements does my son need?

- Your son should have his height (or arm measurement if he is unable to stand), weight, and blood pressure measured at each doctor appointment. Your son's doctor will plot his results on a growth curve to keep track of changes in his height and weight over time.
- If your son has gained too much weight, the doctor may order blood tests to monitor for complications of obesity.
- Obesity can cause obstructive sleep apnea or sleep disordered breathing. Your son's doctor may order an overnight sleep study if there is any reason to think he might have sleep apnea.
- You should work with your son's healthcare providers to figure how many calories he needs each day. This can help your son's dietician make specific food recommendations.

What can I do to help my son manage his weight?

- Management of weight must be a family effort. The whole family needs to learn about healthy choices and portion control.
- A dietitian can give you education and support to help your son avoid too much weight gain, or help your son prevent any more weight gain.

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- There are medications that your son’s doctor might recommend if he develops complications of weight gain such as diabetes or high blood pressure.

Important facts to remember:

- People with Duchenne are at risk for weight gain, particularly when they are on long-term steroids.
- Preventing too much weight gain is an important part of managing Duchenne.
- You can reduce your son’s risk for gaining too much weight gain by engaging the whole family early in making healthy choices.
- Nutritional counseling is a necessary part of Duchenne care.

Recommendations for the prevention of weight gain

Standard recommendations include:

- Replacing sugary beverages and juice with water and low fat milk.
- Eating regular meals as a family.
- Eating all meals and snacks at the kitchen or dining room table with screens turned off.
- Limiting eating out or ordering food in to no more than once per week.
- Getting a good night’s sleep as often as possible. Getting less than the recommended number of hours of sleep at night is associated with weight gain.
- Eat breakfast every morning and don’t skip meals.
- Don’t have high-fat, processed, sugary foods in the house.
- Use smaller serving plates and cups.

Additional recommendations for managing increased appetite in a child on steroids include:

- Drink water before meals.
- Include protein with each meal and snack.

- Carbohydrates should be high in fiber (4 grams of fiber per serving).
- Eat slowly.
- Allow at least 20 minutes between first and second helpings.

What should I read to learn more?

The Diagnosis and Management of Duchenne Muscular Dystrophy: A Guide for Families

http://www.parentprojectmd.org/site/DocServer/Family_Guide.pdf?docID=9321

The No-Diet Obesity Solution For Kids—Miriam B. Vos

Your Child’s Weight, Helping Without Harming—Ellyn Satter

<http://www.aap.org/obesity/families.html?technology=1>

http://www.aap.org/obesity/families_at_home.html

<http://win.niddk.nih.gov/publications/PDFs/overwtchild7-04.pdf>

<http://www.choosemyplate.gov/>