

Weight Gain in Duchenne Muscular Dystrophy

This fact sheet is about weight gain in people with Duchenne muscular dystrophy. You might want to start by reading the Endocrine Information Sheet, which introduces you to some basic topics. When we say “you” in this fact sheet, we mean the person with Duchenne.

What causes weight gain in Duchenne?

People with Duchenne muscular dystrophy can gain too much weight for different reasons, but mainly it is because:

- They do less exercise, and
- Taking steroids can cause a person to feel hungry and eat too much.

People with healthy muscles can do exercise to lose weight. For people with Duchenne, some types of exercise can hurt your muscles. Doing a lot of exercise is not part of the plan for keeping your weight down.

If I am taking steroids, can I keep from gaining weight? If I am too heavy, can I lose weight?

Yes, but it is hard work. It is very common for people taking steroids for a long time to gain too much weight. The best way you can keep from gaining too much weight is by starting early to keep your weight down and sticking with it over time. Remember, it is easier to prevent weight gain than to lose weight. If you have gained too much weight, you need to work hard to eat healthy foods with less calories.

It is hard for you to do this alone. You need to talk to your whole family about keeping a healthy lifestyle. Working with a dietician is important for your weight and your overall care. You can read recommendations for the prevention of weight gain at the end of this fact sheet.

What tests and measurements do I need?

You should have your height (or arm measurement if you are unable to stand), weight, and blood pressure measured at each doctor appointment. Your doctor will plot your results on a growth curve to keep track of changes in your height and weight over time.

If you have gained too much weight, your doctor may order blood tests to monitor for complications of obesity.

Obesity can cause problems with breathing, especially when you sleep. Your doctor may order an overnight sleep study if there is any reason to think you might have sleep apnea.

You should work with your healthcare providers to figure out how many calories you need each day. This can help your dietician make specific food recommendations.

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 the 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.

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- 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/>