

DUCHENNE AWARENESS DAY

7 sept



NUTRITION IN DUCHENNE MUSCULAR DYSTROPHY



CHILDREN (UP TO 10 YEARS OF AGE)

What should we be aware of?

- The primary nutrition concern during childhood is weight management. Boys with DMD can experience excessive weight gain from as early as 5 years of age. Many factors can contribute to weight gain, including steroid therapy and reduced physical activity. Increased weight can make walking and movement harder and can increase the risk of developing obstructive sleep apnoea.
- Steroid therapy as well as DMD can impact bone health. It is important to make sure that the diet includes appropriate nutrients (calcium, vitamin D and protein) to support bone health from early in childhood.
- This is an important time to develop lifelong healthy eating habits for all children.
- You may read or hear about a range of nutritional supplements that are proposed for use in DMD. Currently, there is limited scientific evidence to recommend any supplements for boys with DMD. In addition, improper or uncontrolled use of supplements can cause harmful interactions with drugs used as standard of care, with important implications for health.

What should we be doing?

- Get to know the dietitian in your neuromuscular clinic.
 - The dietitian can complete a dietary assessment to ensure there is adequate calcium and that the amount and composition of nutrients in the diet is appropriate.
 - If your son does experience weight gain, the dietitian can suggest food strategies to assist with weight management.
- Regular height and weight measures (at least every 6 months) are important to monitor weight status and growth. These can be completed in your neuromuscular clinic or by your local doctor, nurse or dietitian. Height and weight measurements should also be plotted on a growth chart for monitoring weight and growth over time.
- A key period for weight gain is when boys commence steroids. Steroids can increase appetite. A dietitian can assist by suggesting food strategies to manage increased appetite.
- Your physiotherapist can provide safe suggestions to keep your son active. This will help with both weight management and bone health.
- Focus on developing healthy food habits: e.g. eating as a family, involving your son in food preparation, exploring and trying new foods.

- Your neuromuscular doctor will monitor your son's vitamin D levels. This will determine whether your son needs a vitamin D supplement. Most boys will need a vitamin D supplement.
- Any supplements other than calcium and vitamin D, have to be considered carefully by health specialists according to specific diet insufficiencies and the medications your son is currently taking. Do not make your own decisions on using supplements based on false assumptions of safety.

Is there anything specific my son should be eating?

- There is no specific diet for boys with DMD. Focus on eating a wide variety of foods from the five main food groups: fruit, vegetables, meat, meat alternatives and eggs, dairy products, grains and cereals.
- Choose whole wheat or whole grain breads and cereals to increase fibre in the diet and assist with glucose control.
- Choose fish, olive oil and nuts and seeds (in proper portion to avoid high calories) as natural dietary intake of mono- or polyunsaturated fatty acids.
- Your son should be eating dairy foods or a variety of calcium fortified dairy alternative products (e.g. almond or soy milk)

3-4 times per day. Please be aware that excess soy products contain phytoestrogens which may contravene the action of androgens (eg testosterone). If your son does not like dairy or is intolerant, a calcium supplement may be required.

- Key sources of Vitamin D include sunshine, oily fish (e.g. salmon, trout), fortified food products (milk, margarine) as well as mushrooms exposed to ultraviolet light. It is important to follow sun safety recommendations. If your son does have low levels of vitamin D in the blood, a supplement will be required.
- Be mindful of salt intake. Reduce or remove salt from cooking and at the table. Herbs and spices can be used to add flavour. Salt is also high in packaged, processed and fast foods.
- Don't forget about fluids! Water is the best drink, with some milk throughout the day. Avoid juices, soft drink, sports/energy drinks and other sugar sweetened beverages. This is also very important for dental health. Sweetened yoghurt drinks should be avoided as the combination of a low pH and sugar can cause tooth decay.
- For dental health, avoid sticky sweet foods or high sugar foods that stay in the mouth for long periods (eg. hard candy, lollies). Reduce or combine the number of times sugary food and drinks are consumed during the day.

- Limit high calorie foods that provide little nutrition (e.g. fast foods, deep fried foods, chips, sweets, chocolate).
- When you eat is also important. Three meals a day with a nutritious snack (e.g. plain Greek yoghurt) between meals or small frequent meals is recommended
- Aim to include protein rich foods at all meals and snacks instead of just at the main evening meal. Boys should be consuming at least the recommended dietary intake for protein as set by your country. There are some proteins that the body uses more efficiently, such as eggs and whey protein. These have a high biological value. If your family or son follows a vegetarian or vegan diet, it is important to eat a variety of plant-based proteins. A dietitian can work with you to ensure there is adequate protein in your son's diet.
- Enjoy FOOD!

TWEENS AND TEENS (10 – 18 YEARS OF AGE)

What should we be aware of?

- As boys transition into a wheelchair, energy needs are reduced. This can result in weight gain if these changes are not accompanied by an equivalent change in energy intake.
- Constipation may become more problematic due to decreased movement.
- Steroid therapy as well as DMD can impact bone health. It is important to make sure that the diet includes appropriate nutrients (calcium, vitamin D and protein) to support bone health.
- Upper limb strength may begin to decline, which can impact independent eating.
- Chewing and swallowing some foods may become more difficult.
- DMD may impact the body's ability to manage glucose (sugar).

- There are many complex factors affecting adolescents' food choices including school, social situations, and developing a sense of identity and independence. These are important to acknowledge and consider.

What should we be doing?

- If you don't already, get to know the dietitian in your neuromuscular clinic.
 - The dietitian can complete a dietary assessment to ensure there is adequate calcium and that the amount and composition of nutrients in the diet is appropriate.
 - If you/your son does experience weight gain or is having trouble managing constipation, the dietitian can suggest food strategies to assist.
- Regular height and weight measures (at least every 6 months) are important to monitor weight status and growth. These can be completed in your neuromuscular clinic or by your local doctor, nurse or dietitian. Height and weight measurements should also be plotted on a growth chart for monitoring weight and growth over time.
- You/your son may require medication to help with constipation. Avoid uncontrolled use of laxatives and enemas. Your neuromuscular doctor or family doctor can help with this

to reduce the improper use of laxatives that may interfere with electrolyte balance and adsorption of medications. Fibers in diet and fluid intake are important to help with constipation.

- An occupational therapist can help with different types of feeding equipment to make meals easier and less tiring.
- Changes to food textures or selection of foods with specific textures might be required to help with chewing and swallowing. A speech pathologist can help with this.
- Your/your son's neurologist or primary physician can monitor your son's glucose levels through blood tests. A referral to an endocrinologist may be required if abnormalities are found in blood tests.
- Your neuromuscular doctor will monitor you/your son's vitamin D levels. This will determine whether you/your son needs a vitamin D supplement. Most boys will need a vitamin D supplement
- Support your son in developing healthy food habits throughout adolescence, and talk about all the external pressures on food choices.

Is there anything specific my son should be eating?

- There is no specific diet for boys with DMD. Focus on eating a wide variety of foods from the five main food groups: fruit, vegetables, meat, meat alternatives and eggs, dairy products, grains and cereals.

- Choose whole wheat or whole grain breads and cereals to increase fibre in the diet and assist with glucose control.

- Choose fish, olive oil and dry nuts and seeds (in proper portion to avoid high calories) as natural dietary intake of mono or polyunsaturated fatty acids.

- Your son should be eating dairy foods or a variety of calcium fortified dairy alternative products (eg almond or soy milk) 3-4 times per day. e.g. testosterone). Please be aware that excess soy products contain phytoestrogens which may contravene the action of androgens (eg testosterone). If you/your son does not like dairy or is intolerant, a calcium supplement may be required.

- Key sources of Vitamin D include sunshine, oily fish (e.g. salmon, trout), fortified food products (milk, margarine) as well as mushrooms exposed to ultraviolet light. It is important to follow sun safety recommendations. If you/your son does have low levels of vitamin D in the blood, a supplement will be required.

- Be mindful of salt intake. Reduce or remove salt from cooking and at the table. Herbs and spices can be used to add flavour. Salt is also high in packaged, processed and fast foods.

- Don't forget about fluids! Water is the best drink, with some milk throughout the day. Avoid juices, soft drink, sports/energy drinks and other sugar sweetened beverages. This is also very important for dental health. Sweetened yoghurt drinks should be avoided, as the combination of a low pH and sugar can cause tooth decay.

- Drink water after meals to clear your/your son's mouth and throat from remaining food.

- Water combined with high fibre foods (wholegrains, fruit and vegetables) can reduce constipation. A fibre supplement may also be helpful.

- For dental health, avoid sticky sweet foods or high sugar foods that stay in the mouth for long periods (e.g. hard candy). Reduce or combine the number of times sugary food and drinks are consumed during the day.

- Limit high calory foods that provide little nutrition (e.g. fast foods, deep fried foods, chips, sweets , chocolate).

- When you eat is also important. Three meals a day with a nutritious snack (e.g. plain Greek yoghurt) between meals or small frequent meals is recommended.
- Aim to include protein rich foods at all meals and snacks instead of just at the main evening meal. Boys should be consuming at the least the recommended dietary intake for protein as set by your country. There are some proteins that the body uses more efficiently such as eggs and whey protein. These have a high biological value. If your family or son follows a vegetarian or vegan diet, it is important to eat a variety of plant-based proteins. A dietitian can work with you to ensure there is adequate protein in your son's diet.
- Enjoy FOOD!

ADULTS (18 > YEARS OF AGE)

What should I be aware of?

- Managing weight can be difficult. Men with DMD can struggle with being underweight or overweight, or sometimes both at different times.
- Increased weakness in lung muscles can increase energy (calory) needs, which can lead to being underweight. However, when lung support is commenced, this reduces energy needs and may lead to gaining weight. Managing eating and lung support can also be tricky.
- If weight drops too low, sometimes a feeding tube is required.
- Chewing and swallowing problems are common.
- Gastrointestinal problems can become more prominent, such as constipation, slowed digestion, feeling of fullness, bloating. These problems can also reduce appetite and make eating less desirable.

- Steroid therapy as well as DMD can impact on bone health. It is important to make sure that the diet includes appropriate nutrients (calcium, vitamin D) to support bone health.
- Periods of stress on your body (e.g. surgery or illness) can impact your nutritional status and weight.
- DMD may impact on the body's ability to manage glucose (sugar), more so in the boys/men who are not using steroids.
- Extended periods with little or no food intake (orally or via PEG) can cause metabolic complications (ketoacidosis). It is important to eat regularly, even when ill.

What should I be doing?

- Monitor your weight. Ideally, try to measure your weight every 3-6 months. Weight can change quickly, so watch for other signs that your weight might be changing. For example, are your clothes feeling looser or tighter?
- If you do need some help to manage your weight, a dietitian will be able to assist with food strategies to help you gain or lose weight. If there is no dietitian attached to your neuromuscular service, dietitians working with your respiratory team can be helpful.

- A speech pathologist can help by ensuring foods and fluids are the right texture to support chewing and swallowing.
- An occupational therapist can help with different types of feeding equipment to make meals easier and less tiring.
- Your neurologist or primary physician can monitor your glucose levels through blood tests. A referral to an endocrinologist may be required if abnormalities are found in blood tests.
- A referral to a gastroenterologist may be required to help with managing gastro problems you are having. Talk to your neuromuscular doctor or local doctor if you are noticing these problems.
- Your neuromuscular doctor or local doctor will need to monitor your vitamin D levels to determine whether you require a vitamin D supplement. Most men will need a vitamin D supplement. If you are unable to eat food regularly for an extended period, seek medical advice to avoid metabolic complications.

Is there anything specific I should be eating?

- There is no specific diet for DMD. Focus on eating a wide variety of foods from the five main food groups: fruit, vegetables, meat, meat alternatives and eggs, dairy products, grains and cereals.
- Choose whole wheat or whole grain breads and cereals to increase fibre in the diet and assist with glucose control.
- Choose fish, olive oil and nuts and seeds (in proper portion to avoid high calories) as natural dietary intake of mono- or polyunsaturated fatty acids.
- Dairy foods are important for bone health. You should be eating dairy foods or a variety of calcium fortified dairy alternative products (e.g. almond or soy milk) 3-4 times per day. Please be aware that excess soy products contain phytoestrogens which may contravene the action of androgens (eg testosterone). If you do not like dairy or are intolerant, a calcium supplement may be required.
- Key sources of Vitamin D include sunshine, oily fish (e.g. salmon, trout), fortified food products (milk, margarine) as well as mushrooms exposed to ultraviolet light. It is important to follow sun safety recommendations. If you do have low levels of vitamin D in the blood, a supplement will be required.

- Discuss salt intake with your cardiologist. Herbs and spices can be used to add flavour. Salt is high in packaged and processed foods.
- Changes to food textures, or selection of food with specific textures, might be required to help with chewing and swallowing. A speech pathologist can help with this.
- Don't forget about fluids! Water is the best drink, with some milk throughout the day. Avoid juices, soft drink, sports/energy drinks and other sugar sweetened beverages. This is also very important for dental health. Sweetened yoghurt drinks should be avoided as the combination of a low pH and sugar can cause tooth decay.
- Drink water after meals to clear your mouth and throat from remaining food.
- Water combined with high fibre foods (wholegrains, fruit and vegetables) can reduce constipation. A fibre supplement may also be helpful.
- For dental health, avoid sticky sweet foods or high sugar foods that stay in the mouth for long periods (e.g. hard candy). Reduce or combine the number of times sugary food and drinks are consumed during the day.



- Limit high calorie foods that provide little nutrition (e.g. fast foods, deep fried foods, chips, sweets, chocolate).
- When you eat is also important. Three meals a day with a nutritious snack (e.g. plain Greek yoghurt) between meals or small frequent meals is recommended. Small frequent meals may be helpful if reflux, bloating or slow digestion are a problem.
- Aim to include protein rich foods at all meals and snacks instead of just at the main evening meal. You should be consuming at least the recommended dietary intake for protein as set by your country. There are some proteins that the body uses more efficiently such as eggs and whey protein. These have a high biological value. If you follow a vegetarian or vegan diet, it is important to eat a variety of plant-based proteins. A dietitian can work with you to ensure there is adequate protein in your diet.
- To reduce bloating it is advised to check which foods can cause bloating (such as onions, carbonated drinks, food containing gluten, yeast and more) and test if reducing the intake of these foods is helpful. A probiotic supplement may also assist with bloating.

In addition to the well known health risks of drinking alcohol, especially in young people, there are additional reasons to be careful with alcohol when having DMD: alcohol can impact on drug metabolism altering therapeutic drug levels with unwanted effects. Alcohol can cause dehydration and alcohol is calorie dense so it needs to be considered when managing weight. Alcohol has also been linked to poor bone density.

- Enjoy FOOD!

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