

World Duchenne Awareness Day

Parent Presentation Guide (Middle Grades)

Before You Begin

Thank you for helping your class learn about Duchenne muscular dystrophy, accessibility, belonging, and allyship.

This presentation is designed to:

- Build understanding
- Encourage respectful questions
- Explore accessibility and belonging
- Help students think about how they can be allies

The goal is not to make students experts in Duchenne. The goal is to help students recognize that there is often more to a person than what we can see, understand how accessibility supports participation, and consider ways they can help others feel included and valued.

You do not need to be a teacher or Duchenne expert. The notes below will guide you through each slide.

Suggested Time: 20–30 minutes

WORLD DUCHENNE AWARENESS

Understanding differences. Building Belonging.



Talking Points

- Today we're going to learn about Duchenne muscular dystrophy, often called Duchenne or DMD. September 7 is World Duchenne Awareness Day and the whole month of September is Duchenne Awareness Month.
- We'll talk about what Duchenne is, how it can affect people, and how we can help create communities where everyone belongs.
- This lesson is also about understanding people, asking respectful questions, and being an ally.

Ask

- What do you think the words understanding and belonging mean?

Key Message

There is often more to a person than what we can see.

WHAT CAN YOU TELL ABOUT SOMEONE?



Talking Points

- Looking at these images, we can make some guesses about what a person might enjoy.
- We might guess they like sports, reading, gaming, art, science, music, animals, photography, or baking.
- These clues tell us something, but they don't tell us everything.

Ask

- What can you tell about this person?
- What clues helped you make those guesses?

Key Message

We can learn some things about a person from what we see, but we never know the whole story.

WHAT DON'T WE KNOW YET?



Talking Points

- Even when we know someone's interests, there is still a lot we don't know.
- We may not know their strengths, challenges, dreams, family, values, health conditions, or what makes them laugh.
- Every person has experiences and qualities that aren't visible right away.

Ask

- Which of these things do you think are hardest to learn about someone?
- Why is it important not to make assumptions?

Key Message

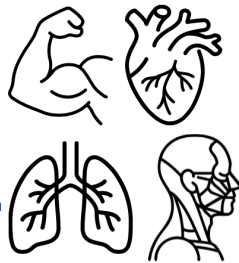
People are more than what we can see on the outside

WHAT IS DUCHENNE?

Duchenne muscular dystrophy (DMD) is a genetic condition that affects muscles.

Muscles help us move, breathe, smile, and do many other important jobs every day.

Because muscles are involved in so many parts of daily life, Duchenne can affect people in different ways.



Talking Points

- Duchenne muscular dystrophy, or DMD, is a genetic condition that affects muscles.
- Muscles help us move, breathe, smile, and perform many everyday tasks.
- Because muscles are involved in so many parts of daily life, Duchenne can affect people in different ways.

Ask

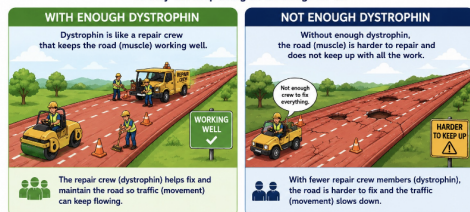
- What are some things you use muscles for every day?
- Which muscle jobs do people sometimes forget about?

Key Message

Duchenne affects muscles, and muscles do many important jobs throughout the body.

Why Does Duchenne Affect Muscles?

Muscles are always working. Dystrophin helps repair muscles so they can keep doing all the things we do.



Dystrophin helps repair muscles so they can keep working. People with Duchenne do not make enough dystrophin. This makes it harder for muscles to keep up with all they do over time.

Talking Points

- Duchenne muscular dystrophy, or DMD, is a genetic condition that affects muscles.
- Muscles help us move, breathe, smile, and perform many everyday tasks.
- Because muscles are involved in so many parts of daily life, Duchenne can affect people in different ways.

Ask

- What are some things you use muscles

for every day?

- Which muscle jobs do people sometimes forget about?

Key Message

Duchenne affects muscles, and muscles do many important jobs throughout the body

WHAT MIGHT DUCHENNE LOOK LIKE?



Walking differently



Mobility supports



Participating in class



Taking breaks



Using an elevator



Adaptive sports

Talking Points

- Duchenne can look different from person to person.
- Some people may walk differently.
- Some may use mobility supports.
- Some may take breaks to manage energy.
- Others may use elevators, accommodations, or adaptive sports equipment.
- These supports help people participate in everyday life.

Ask

- What similarities do you notice across all of these pictures?
- What are the people in these photos still able to do?

Key Message

Supports help people participate, learn, move, and enjoy activities.

ACCESSIBILITY IN EVERYDAY LIFE



Accessible Ramp



Closed Captions



Elevator



Audiobooks



Automatic Door



Accessible Parking

Talking Points

- Accessibility means creating spaces, tools, and systems that help people participate.
- Many accessibility features benefit more than one group of people.
- Closed captions, elevators, audiobooks, ramps, automatic doors, and accessible parking all help remove barriers.

Ask

- Which accessibility features have you used before?
- Which of these help people besides those with disabilities?

Key Message

Accessibility helps people participate and belong

INCLUSION	BELONGING
	
Being invited	Feeling valued
Being present	Feeling connected
Having a seat	Having a voice
Being allowed to participate	Feeling accepted

Talking Points

- Inclusion and belonging are related, but they are not the same thing.
- Inclusion means being invited and having the opportunity to participate.
- Belonging means feeling accepted, valued, and connected.
- Accessibility helps create inclusion, but belonging happens through relationships and community.

Ask

- Have you ever been included but still felt left out?
- What helps people feel like they belong?

Key Message

Inclusion is being invited. Belonging is feeling valued.

QUESTIONS YOU MIGHT HAVE

Can I catch Duchenne?

Can people with Duchenne still do things they enjoy?

Is it anyone's fault?

Why do some people use wheelchairs and others don't?

Will there ever be a cure?

Talking Points

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- Accessibility helps create inclusion, but belonging happens through relationships and community.

Ask

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Key Message

Inclusion is being invited. Belonging is feeling valued.

WHAT DOES A DUCHENNE ALLY LOOK LIKE?



Include others



Listen and Learn



Ask before helping



Speak respectfully



Invite someone in



Help everyone belong

Talking Points

- An ally helps others feel welcomed, respected, and included.
- Being an ally doesn't mean having all the answers.
- Allyship happens through actions.
- Small actions can make a big difference.

Ask

- Which ally action do you think has the biggest impact?
- Which one feels easiest to practice?

Key Message

Allyship is something we do, not just something we say.

