



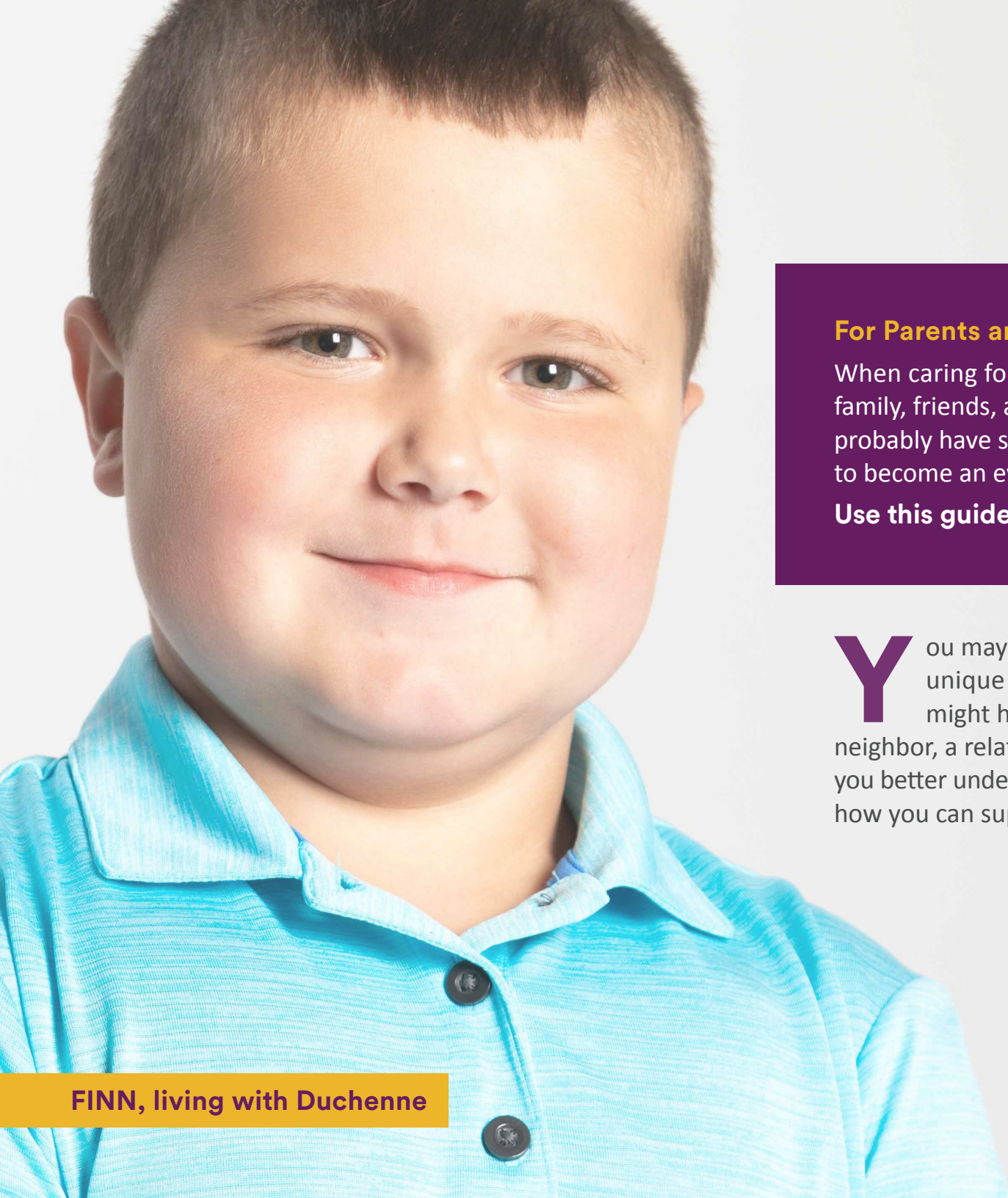
Let's start the conversation

10 questions you may have

about an individual living
with **DUCHENNE**
muscular dystrophy

DILLON, lives *with* Duchenne.
Lives *for* playtime.





For Parents and Caregivers:

When caring for a young child with Duchenne, your family, friends, and anyone who knows your child will probably have some questions and want to know how to become an even stronger source of support.

Use this guide to get the conversation started.

You may have noticed that my child has some unique challenges, and it's natural that you might have some questions. Whether you're a neighbor, a relative, or an educator, this guide can help you better understand my child's medical condition and how you can support us in managing everyday life.

FINN, living with Duchenne

1

What medical condition does your child have?

My child has a rare condition called Duchenne muscular dystrophy. Duchenne (Doo-SHEN) is a genetic condition that mainly affects boys. It occurs when the body does not make enough of a working protein called dystrophin. Without dystrophin, muscles become weak and damaged over time.

A **genetic condition** is caused by a mutation or mutations in a gene. In Duchenne, the mutation is usually inherited, though it develops spontaneously in about 1 out of 3.



Is Duchenne contagious?

Duchenne is not contagious. Children are born with a gene mutation that causes the condition; therefore, it is not contagious.

2

FINN, living with Duchenne, and his brother

3

How does Duchenne affect the body?

Duchenne affects the muscles in the body and causes them to become weak and damaged over time. Every child will be affected by Duchenne differently, but you might notice that my child may be slower to sit, stand, walk, or perform other physical activities. You may notice my child:



Has difficulty walking and may need some help getting around



Falls down often and may need help getting up



Walks on toes with legs apart, belly pointed out



Needs help rising from the floor or uses arms to “walk” the body to a standing position (Gower’s Maneuver)



Gets tired easily and may need breaks from activities



Has trouble staying focused or transitioning between activities; may also get easily frustrated and need things repeated



Has delayed speech and may need some time to respond to questions



May require the use of an assistive device to move around and access spaces that may seem easy to navigate

Because the protein that is missing is believed to play a role in brain development, some children with Duchenne may have learning difficulties or behavioral issues.

4

Is Duchenne curable?

While there is currently no cure, there are options to help manage the condition. Management can involve frequent visits to the doctor, so my child may occasionally have to miss school or social gatherings.

5

Are there specific things I should watch out for when with your child?

Because Duchenne will affect a child's everyday life in many ways, here are some important things to keep in mind when spending time with my child:

Behavioral differences

Because Duchenne can affect cognitive skills, my child may get easily frustrated, so it's important to remind others to be patient. You may also need to repeat something multiple times, because they may have trouble retaining information.

Bruising

Don't be alarmed if you notice some bruising. Children with Duchenne may fall and bump into things more often because they have extra challenges getting around.

Playing with other children

Choosing activities that are accessible to everyone, such as board games, coloring, cards, and video games, can help create a supportive environment.

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Will your child need extra help with any activities?

When overseeing activities, it's important to remember that my child may need some extra attention and may need to take breaks. Duchenne causes muscles to weaken over time, and certain activities may get more difficult as my child gets older. Being understanding and patient is key to ensuring that both you and my child have the best experience when spending time together.



ETHAN, living with Duchenne

Phases of Duchenne:



Early Phase (ages 1 to 7)

In the early phase, a child with Duchenne may have trouble sitting, walking, or talking. They also may get tired easily.



Transitional Phase (ages 6 to 9)

During the transitional phase, a child may have difficulty going up the stairs and getting up from a seated position.



Assistive Devices Phase (ages 10 to 14)

In this phase, a child with Duchenne may become more dependent on assistance when getting around, which could include use of a scooter or wheelchair.

7

What can I do to make getting around easier for your child?

It's important to make sure my child feels safe and comfortable when navigating a space. Rearranging obstructive furniture can make it easier for them to move around, especially if they are using a wheelchair. Also, please be sure to clear the floor of any clutter, as my child can easily trip and fall. If possible, having access to an elevator or a ramp can aid in entering and exiting a building. At school, my child may need a wheelchair-accessible desk and may need some help getting through classroom doorways. Organizing activities during playtime or physical education class that require less movement or take place at ground level can ensure my child is able to fully participate.

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What can I do for you or your other family members to make things easier?

Taking care of a child with Duchenne can be incredibly rewarding, despite some additional challenges. Many families find that it's valuable to build a network of support among trusted friends and members of the community. Learning about Duchenne, how it affects our family, and the things to look out for when spending time with my child are helpful to everyone and much appreciated.



It takes a village to raise a child who has a condition no matter what it is, but [we have a] good support network... through our family and friends.

—Dawn, mother to Brett, an individual living with Duchenne muscular dystrophy

9

How can I help my own child understand that their friend has different needs?

Although children with Duchenne are different in some ways, they have many of the same interests as other children their age. Maintaining strong friendships will help my child discover their unique talents and ensure that Duchenne does not hold them back. Teaching children who do not have Duchenne about our family's challenges may take some time, but having these conversations can help my child feel more included and less isolated during school and playtime. Children will most likely have a lot of questions, so here are some tips on ways you can address their curiosity:

- **You can start the conversation with statements like** “You may have noticed your friend has trouble keeping up during playtime when you are running or jumping around” or “You’ve probably noticed your friend sometimes has to miss school to go to the doctor”
- **Remind them that my child was born with Duchenne**, just like your child was born with things that make them unique. If they are concerned about catching Duchenne, remind them that it’s not contagious
- **Avoid using negative words** such as “problems,” “issues,” or “normal.” Instead, use phrases like “may have some challenges,” “different needs,” or “has difficulty”
- **Encourage them to be supportive and patient, and remind them that everyone needs a little help sometimes.** Teach them to be sensitive to their friend’s condition, but not to view them differently because of it



FINN, living with Duchenne



Where can you go to find additional information about **Duchenne**?

The Duchenne community is committed to education and awareness.

You can learn more about Duchenne at [Duchenne.com](https://www.duchenne.com)

Visit the site to find:

- Explanations on the science behind Duchenne
- A Duchenne Dictionary full of useful terms
- Resources and advocacy groups

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CALEB, living with Duchenne



Learning that someone in your life has Duchenne can be a lot to take in, but educating yourself on the condition will strengthen the relationship you have with them. Remember that you are not alone in this process and are welcome to reach out with any additional questions you may have as you spend more time with my child and get to know their individual needs. Ultimately, I think you will find that knowing a child with Duchenne can enrich your life in ways you never expected.



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FINN, living with Duchenne