

**Duvyzat®** ▼ (givinostat)

This medicine is subject to additional monitoring

# The day I met my muscles

**A story about how treatment can help your muscles**

Information about reporting side effects can be found on the back page. If you have any questions about dosing or administering Duvyzat®, please speak with your healthcare team.



Story written and illustrated by Sauce Health

## Feeling tired

Gym class was over. Sam, jogged past, calling, "Come on, Leo! Race you to the changing rooms!"

Leo laughed, but his legs wobbled a bit.

"You go. I will catch you up. See you at lunch!" he said.

Everyone else had left, but Leo walked slowly across the quiet gym. His legs felt tired again, and he whispered under his breath, "I really wish I understood why."



## An unexpected path

At that moment, he noticed a door in the darkest corner of the gym. On it were the words **MUSCLES AT WORK**.

Leo was curious, so he pushed it open.



Leo expected a cupboard, but to his surprise he stepped into a long, glowing tunnel that hummed softly. The tunnel guided him to a larger room that pulsed like a slow heartbeat. The walls were made of smooth strands rising up around him like living pillars.



## The muscle room

A lady in green overalls looked up from a clipboard. She smiled kindly.

“Oh! You are here early. Come in. Mind the walls, they are working hard today. I am Miss Flex. I look after this place.”

“Where am I?” Leo asked.

“You are inside your muscles,” said Miss Flex.

Miss Flex touched one of the tall rope-like fibres.

“These are your muscle fibres. They help you move and stay active.”

She showed Leo a few tiny rough patches and Leo took a closer look.



“Everyone’s muscles get little tears when they run, jump or play, and that’s totally normal. Your muscles just get those tiny tears more easily because you do not have something called dystrophin. Without it, things can get a bit messy inside.”

She smiled gently.

“It just means your muscles need a little extra care, and that is okay.”



## All mixed up

They walked past fibres that looked messy and swollen.

“When these little tears happen, your body tries to fix them,” Miss Flex explained as she knelt down to take a closer look.



A jumble of tiny sounds buzzed around the fibres. There were chirps, beeps, and little bursts of noise.

“All these sounds are meant to tell the repairs what to do, but when too many happen at once, it just becomes noise.”

“With Duchenne, your muscles do not get clear instructions to carry out those repairs, and the signals can get mixed up,” she said, raising her voice over the noise.

Leo winced as the sounds overlapped.

“It is like trying to tidy your room while lots of people shout different instructions,” Miss Flex added. “You want to help...but it is confusing and you do not know who to listen to.”

“That means the fibres do not get repaired in the right way. The body builds the wrong things instead of neat new muscle, and this can cause swelling and create extra mess that slows everything down.”

“It is not your fault,” she added. “It is just how your muscles react without dystrophin.”

Leo nodded. It finally made sense.

## A moment of calm

Miss Flex stopped at a smooth section of the wall with a small silver tap nestled between two glowing fibres.

“Now, let me show you how your medicine works,” she said. “It spreads through the whole place, keeping everything calm.”



She turned the tap gently. A soft mist drifted out, like your breath on a cold winter day, but this was pink, warm and light. As it spread, the rough patches along the fibres eased, the harsh noise softened into a quiet, tuneful melody, and the busy areas settled into a gentler rhythm.

Leo watched, amazed.

“So... that is my medicine?”

“Yes,” Miss Flex said. “It helps your muscles repair, so everything can work as well as it can.”

The mist made the room glow softly.



## Leo returns with new hope



Miss Flex spoke gently.

“Your muscles are not broken. They are hardworking, just like you. Some days they get tired quickly. That is alright. You give them rest when they need it, and they keep doing their best.”

Leo felt a warm sense of relief.

Miss Flex pointed to a small door at the end of a tunnel.

“This will take you back, and if you ever need to know more about what is happening inside your muscles, your healthcare team can always help you find the answers.”



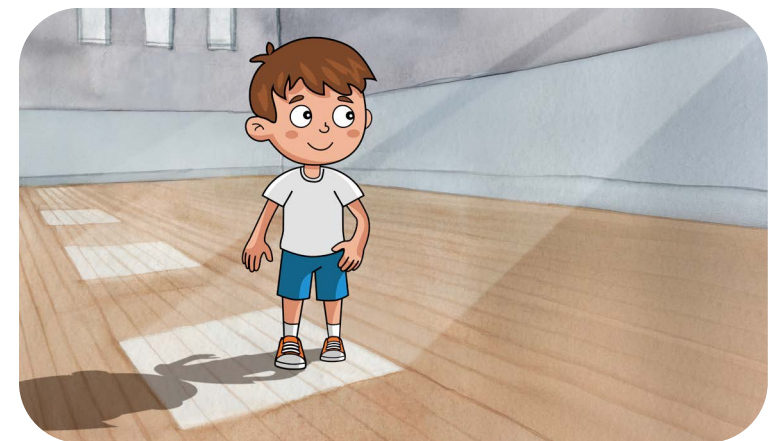
## Home again

Leo stepped through the door and found himself back in the school gym.

He had no idea how long he had been in that room, but he hoped he had not missed lunch.

He looked down at his legs and whispered, "I understand you a bit better now."

Leo glanced back at the door for a second, but now there was only a plain wall. Did I dream it? he wondered, as he headed off to meet Sam.



# A farewell note

After Leo had found Sam and had eaten his sandwiches, he pushed aside his empty lunchbox.

Something crinkled in his pocket. Leo reached in and pulled out a small, folded note.

Hello Leo, it was great to meet you.

Remember to take your medicine just the way your doctor showed you, and here's a reminder for when you need it.

**P.S.**  
You are doing a wonderful job.  
— Miss Flex

The doctor works out the amount based on how much you weigh. You take it orally (in your mouth) using a small syringe from the bottle (not a regular spoon) to make sure it's right.

Duvyzat® is a special liquid medicine that helps slow muscle damage from Duchenne.

You take Duvyzat® two times every day, once in the morning and once at night. It's best to take each dose with food, like breakfast or dinner.

Your parent or guardian can help you.

Before each dose, you or a grown-up shake the bottle for about 30 seconds so the medicine mixes well.

Leo noticed there was writing on the back of the note too. It looked like important information about his medicine.

## Important!

Here are some things you might notice when taking your Duvyzat® medicine.

Most feelings are mild and go away after a few weeks, but it is important to tell an adult if you feel funny.

Common things you might feel are:



Tummy troubles like diarrhoea, tummy ache, feeling sick, or vomiting



Feeling feverish or having a little temperature



Feeling tired or not as hungry as usual

Things you should tell your adults about right away



Bruises or bleeding easily, like nosebleeds or purple spots



Stomach pain or diarrhoea that does not stop



Feeling dizzy, faint, or like your heart is racing or skipping beats

Tell someone right away if you feel really unwell, that includes parents, or your teacher, and keep drinking fluids especially if you have diarrhoea or vomit.

Leo smiled, folded the note neatly, and tucked it safely back into his pocket, a tiny piece of that glowing room to carry with him through the rest of the day.

## Reporting side effects:

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at: <https://yellowcard.mhra.gov.uk>

By reporting side effects, you can help provide more information on the safety of this medicine. This medicine is subject to additional monitoring. This will allow quick identification of new safety information. You can help by reporting any side effects you may get. See <https://yellowcard.mhra.gov.uk> for how to report side effects.



This booklet has been created and funded by ITF Pharma Ltd. It is intended to provide helpful information and should not replace advice from your healthcare team.