

Dravet and me

Growing up with a sibling with
Dravet syndrome



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Created originally with
Alliance Syndrome de Dravet

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Design and production:
Strategik & Numerik



FOREWORD

Why Dravet and me?

Hi, I'm Lily! I'm 9 years old. I like chocolate and bike rides, and I dream of becoming a dancer when I grow up! This is my story.

This comic book is filled with the adventures of me and my brother, Leo, who I love playing with. He has Dravet syndrome. Maybe you have a sibling with Dravet too?

You may be wondering — do I really exist? No! But my story is inspired by people who have agreed to share their stories of having family members with Dravet.

Having a sibling with Dravet is different for everyone. People with Dravet have different skills and abilities. They may have some but not all things in common with Leo. But I hope you'll see a bit of your life in my stories and feel less alone. I hope you find comfort that others are going through the same thing as you!

If you have questions or don't understand something while reading this comic book, you can ask an adult.

I can't wait for you to read my story. I hope you will like it and that it helps you!

Best,
Lily

CHAPTER 1

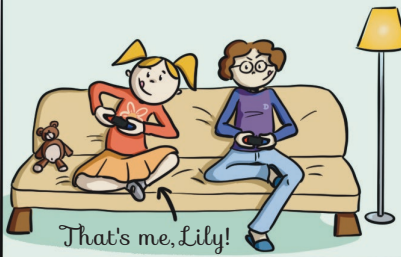
My brother has Dravet!



This is my brother, Leo! He is 11 years old and he loves to pose like a rockstar for photos! Some of his favorite hobbies are ...



Playing video games with me ...



... he also likes to watch his favorite TV shows ...



... sometimes playing outside with Dad ...



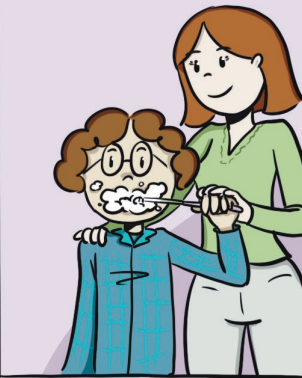
... or he'll listen to bedtime stories with Mom.



Is Leo like the other children? Sometimes Leo can't do the same things other kids his age can do.



He needs help from Mom to brush his teeth, get dressed, and eat.



He enjoys riding his adaptive bike!



He also enjoys the pool with family!



And he can be very clumsy at times!



My brother has a disorder called:

Dravet syndrome

What?!

It is a rare disease. Only 1 out of 40,000 children have Dravet in the world.

It is an epilepsy disorder. The doctor diagnosed Leo at one years old.



That's when my parents knew that their lives would be different from what they imagined ...

Dravet has a lot of symptoms:
Leo has trouble sleeping. He wakes up in the middle of the night and doesn't get enough sleep.



He likes to listen to the same music and watch the same movies over and over again ...



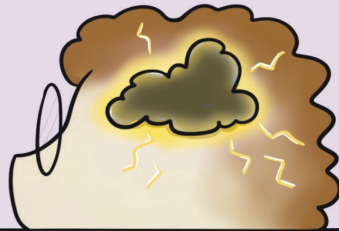
He has behavior problems:
Sometimes he can get hyper or angry. It is not always easy for us when he gets like this!



Because he has Dravet syndrome, he has seizures ...



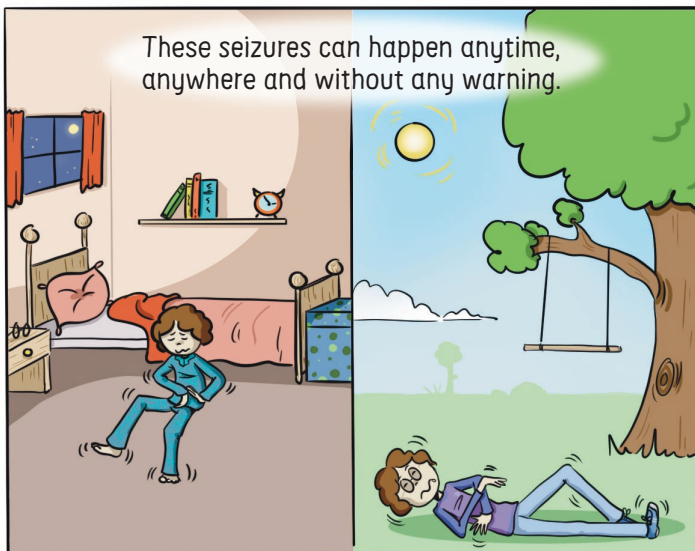
A seizure is like an abnormal electric pulse that starts in his brain and goes through his body ...



The seizures make his whole body shake. He starts drooling and can't speak to us. He stares into space and can't answer our questions.

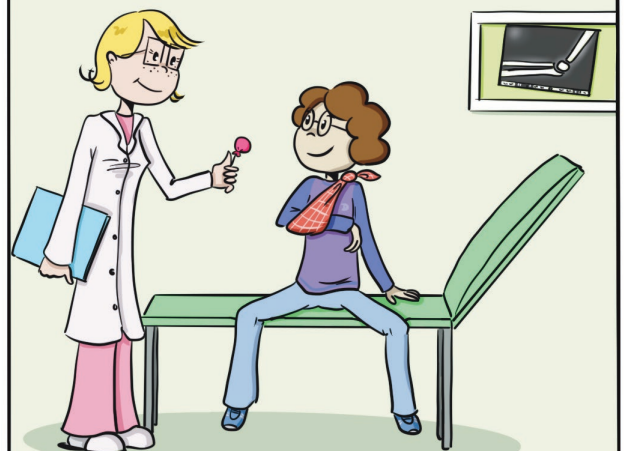


These seizures can happen anytime, anywhere and without any warning.



They can last a few minutes or even hours!!

The seizures can make him go unconscious. When that happens, he can fall and get hurt.



To limit the seizures, Leo takes two types of medicine:
One every morning and every evening ...



... and the other is an emergency medicine to stop a seizure when it happens.



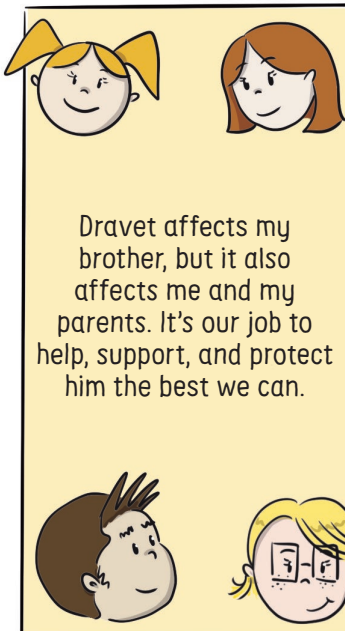
Now that Leo is older, seizures are often short, and I've gotten used to it. But if the seizure does not stop, we have to call 911. Then my brother has to go to the hospital.



The longer the seizures are, the more dangerous it is for Leo and his brain. He has trouble learning simple things such as counting and the alphabet. Sometimes he has to relearn simple things. The seizures also make it difficult for him to walk.



Sadly, this disorder cannot be cured. But there are medicines that can help control his seizures ... But no matter what, my brother is a fighter! He has a happy-to-go-lucky personality, has fun with everything and is often fun to play with!

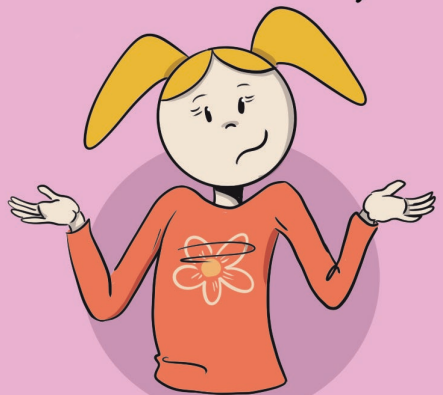


Dravet affects my brother, but it also affects me and my parents. It's our job to help, support, and protect him the best we can.

At first, my parents had to change their work hours to help Leo during the day. For example, they have to take him to different doctor appointments and care for him when he has seizures.



And for me, it is not always easy being the sister of someone who has Dravet syndrome. But he's my brother and I love him a lot!!



CHAPTER 2

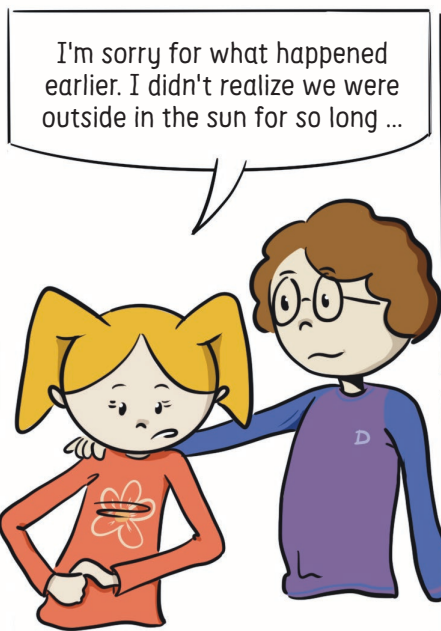
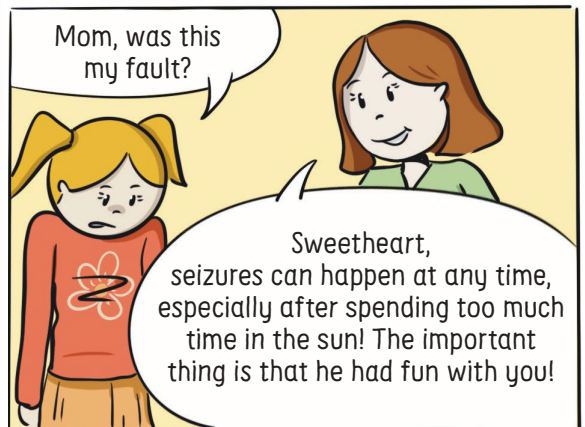
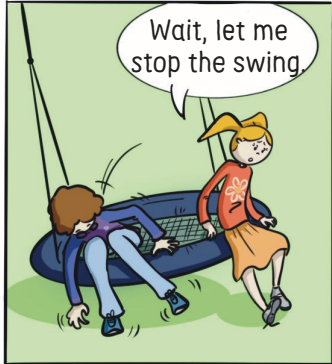
I just want to

play

with

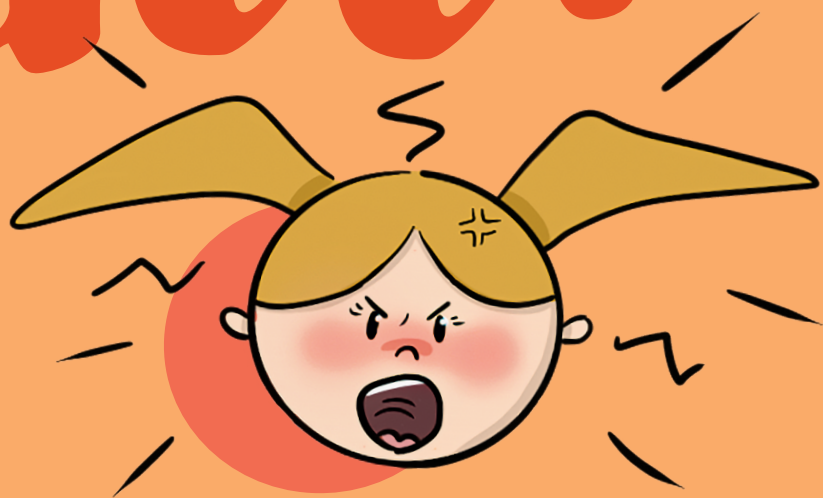
my brother

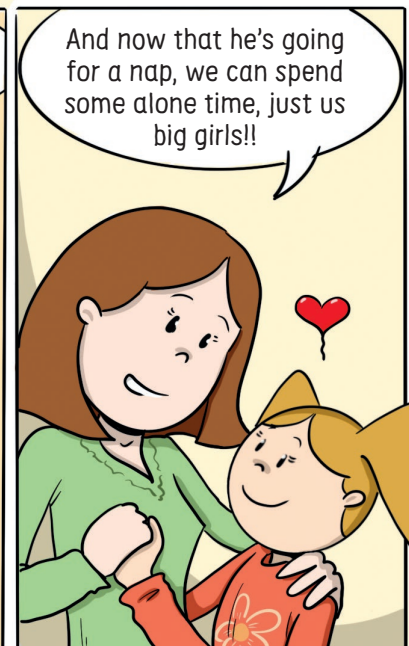
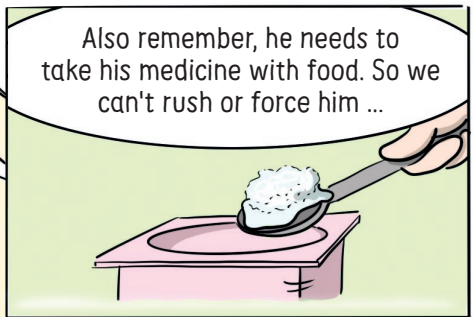
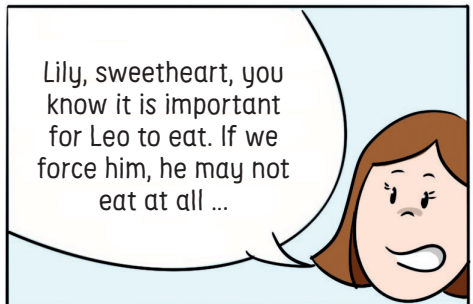
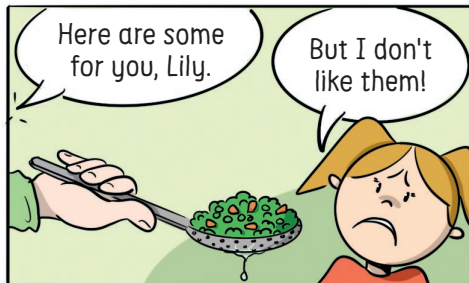
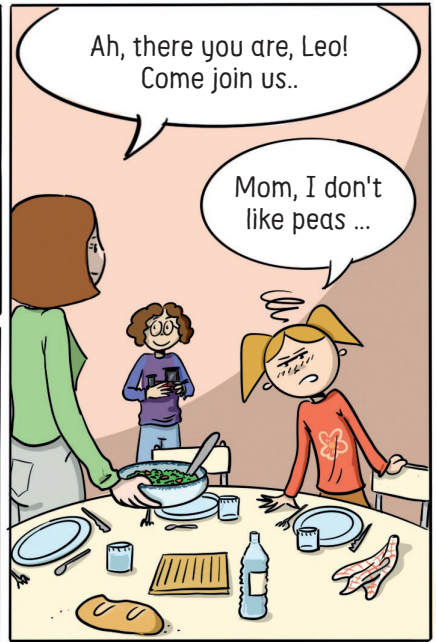
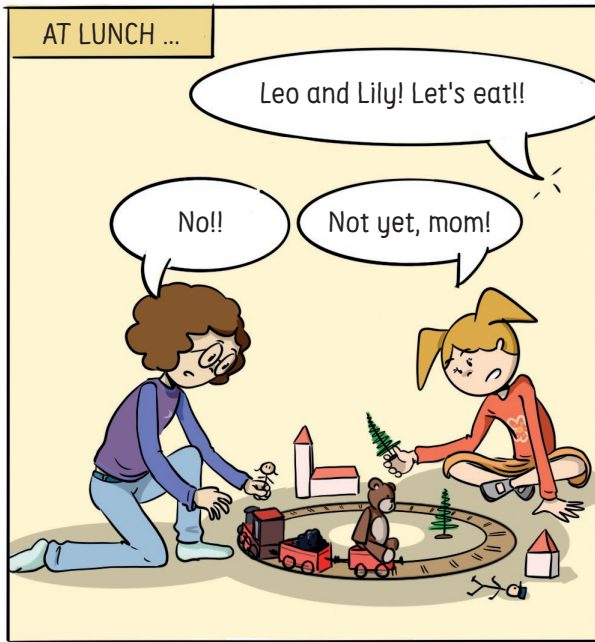




CHAPTER 3

It's not
fair!





Let's go on a

CHAPTER 4

Bike ride!

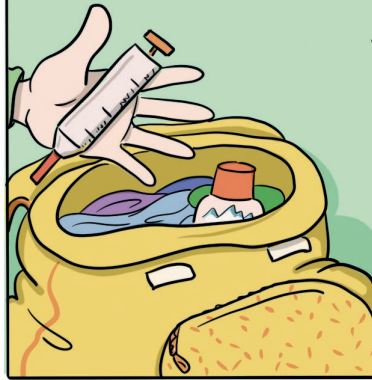


ONE AFTERNOON ...

I packed water bottles, cookies, a map, sunscreen, and helmets for everyone ...



And I've packed a change of clothes and emergency medication for Leo ...



We are ready to go on our bike ride!



Hold on! Leo is getting tired. We should stop before he has a seizure!!



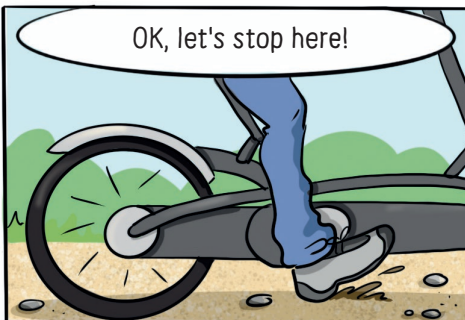
This is a perfect spot for a break anyway!



Let's head home now! The last one home is a rotten egg!!



OK, let's stop here!



Sometimes I wish I could ride with Dad on the tandem bike too ... Maybe next time I'll ask!

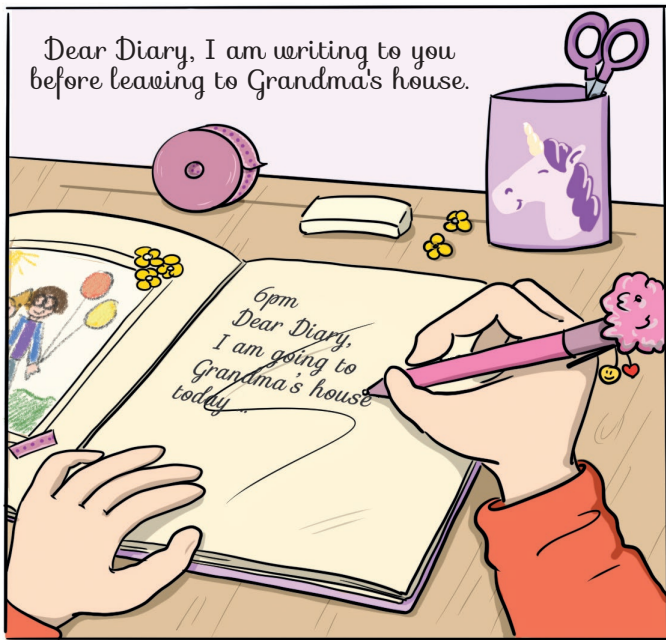


CHAPTER 5

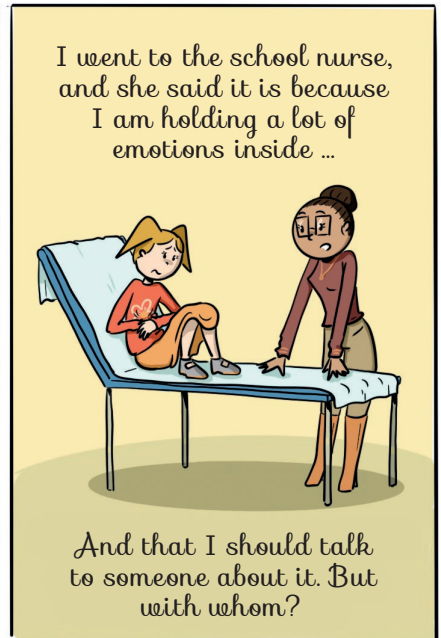
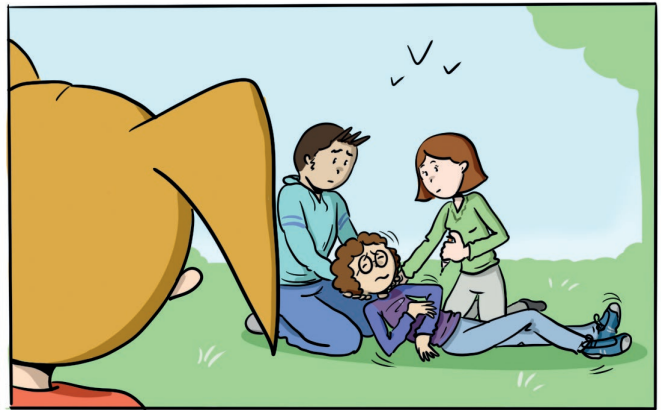
I have a

stomach
ache





I am not feeling well today. I have a tummy ache, and I don't want to tell my parents. I feel bad for telling them when I feel sick because they already have so much on their plate with Leo ...



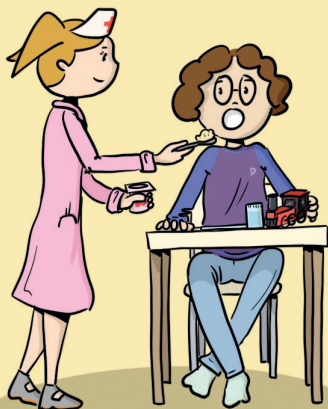
And that I should talk to someone about it. But with whom?



But I also know that's not true. I know that my parents love me, and they are doing their best to spend time with me.



In the future, I would like to be a nurse. That way, I can help my parents with Leo.



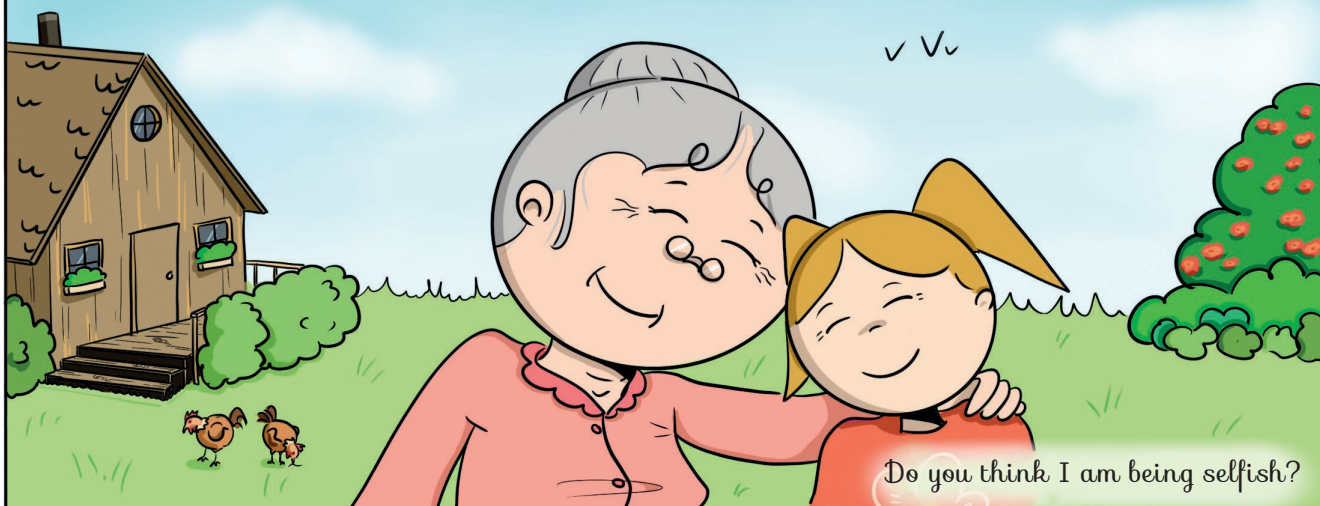
But ... I think I would be better at dancing!



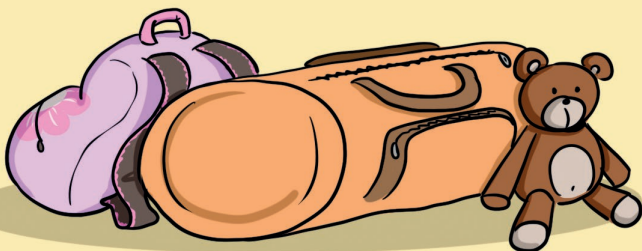
What if I become a super famous dancer? Then I would have plenty of money to help with Dravet syndrome research!



Grandma will be here soon. I love going to her house on the weekends and spending one-on-one time with her. I love that somebody is there to take care of me, just me ...



I always pack my bag on my own. Sometimes I pack extra clothes because I might need to stay at grandma's house a little while longer ...



Sometimes I think it would be easier to live with her, but I can't! I would miss Leo too much!!

Sounds like grandma is here!



I still have a stomachache. Do you think I should tell grandma about it?

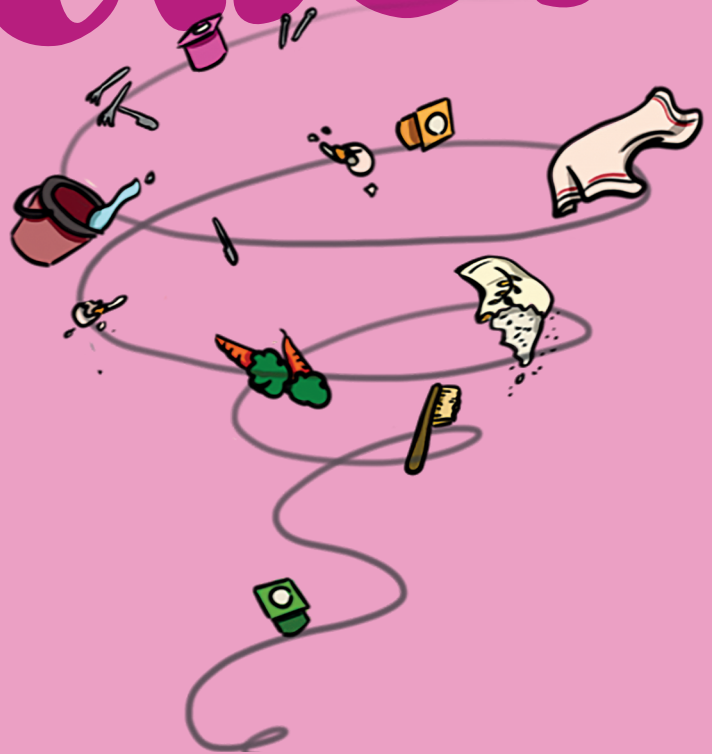


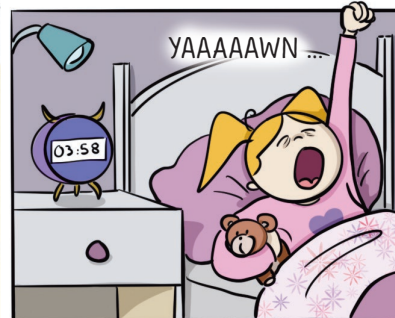
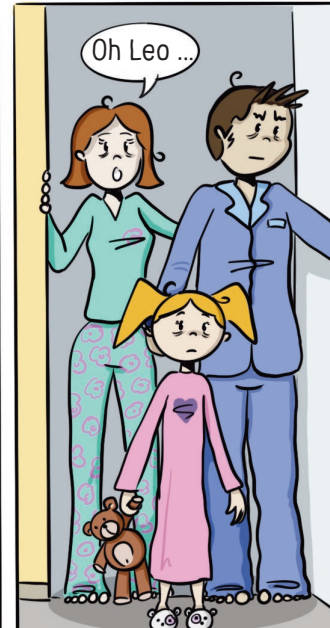
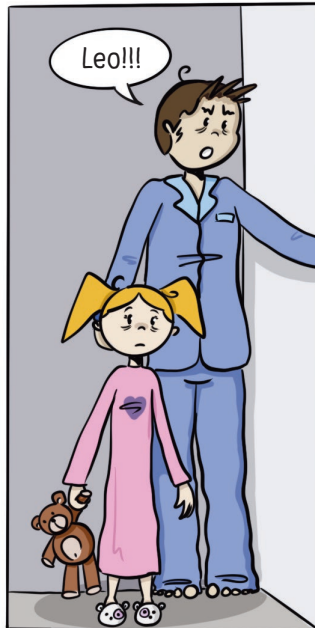
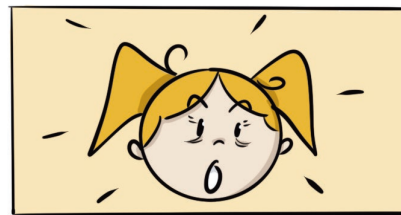
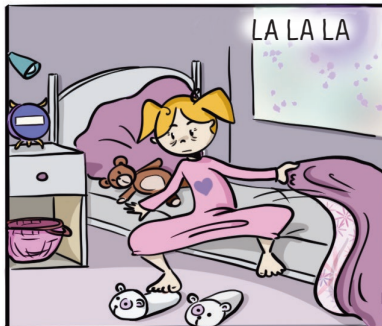
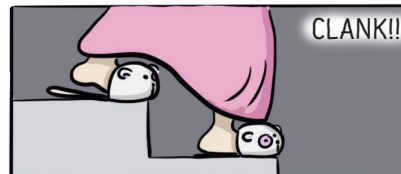
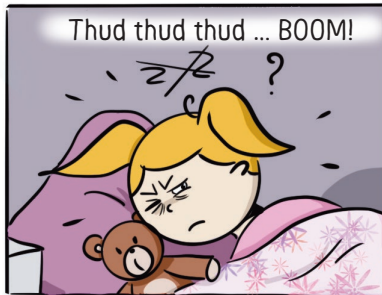


CHAPTER 6

Tornado

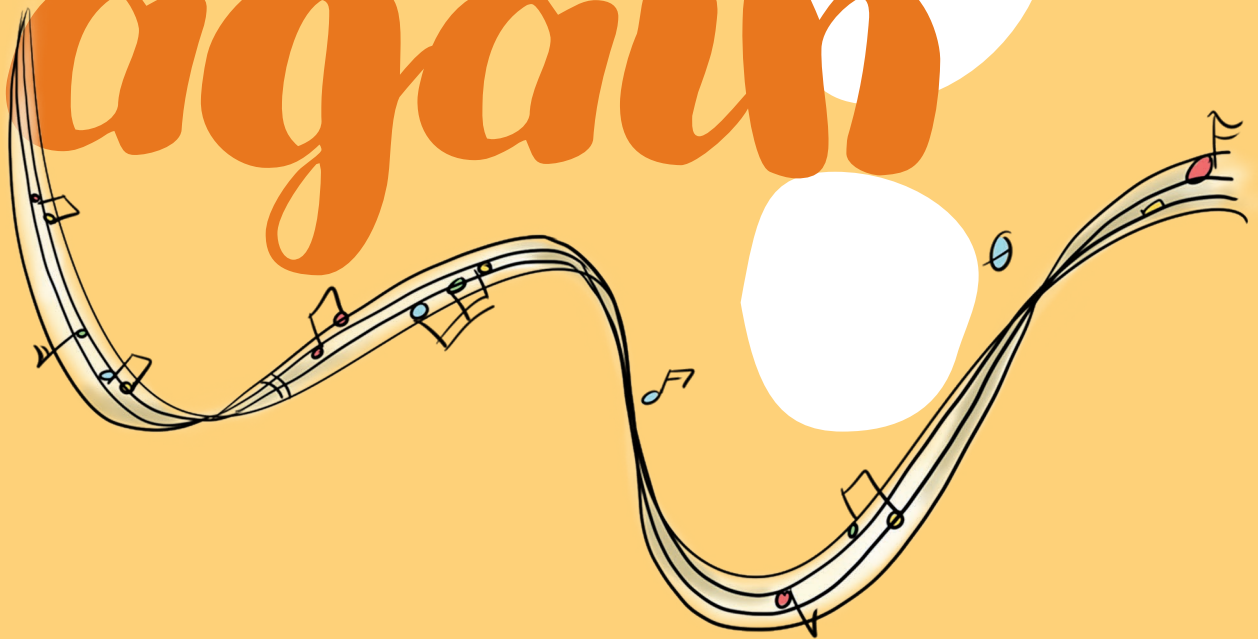
in the
kitchen





CHAPTER 7

Again
and
again!



Sometimes Leo gets obsessed with his favorite TV show. It's not easy for me and my parents ... especially today, he's watching the same episode over and over again on full volume...



In a meeting, my Dad says to his colleagues

Could you repeat that?



And there, my mom is trying to get some rest ...

I can't concentrate ...



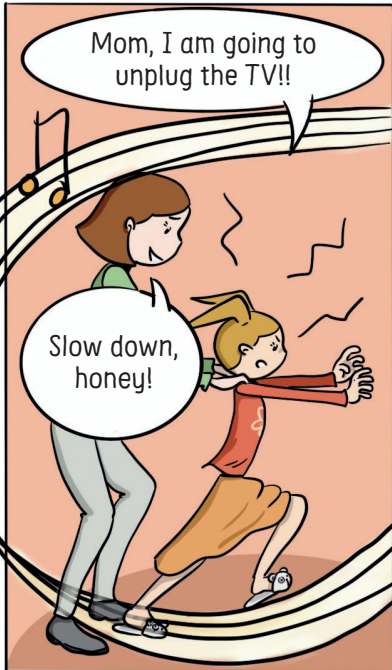
As for me, I'm trying to do my homework!

ENOUGH!!!

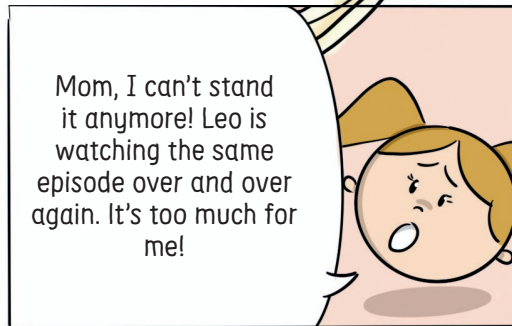


Mom, I am going to unplug the TV!!

Slow down, honey!



Mom, I can't stand it anymore! Leo is watching the same episode over and over again. It's too much for me!



I know, honey, it can be frustrating!



But remember, your brother learns by repetition. And the tv show is calming for him to watch. It is good for him!



And you know, if we stop the show before it ends or if we lower the volume, he will get frustrated and throw a tantrum. He has a hard time managing his emotions, sweetie.



But, you are right, he has been watching tv for a while now. Maybe you and Leo can play together?

Hey Leo! How about we read ...



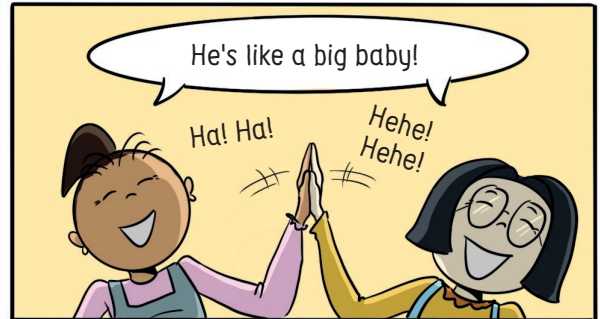
... The Three Bears?



CHAPTER 8

Leo's
twist
dance

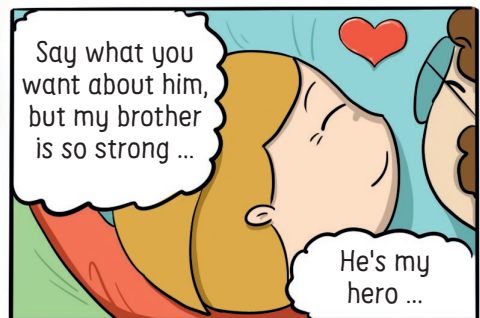
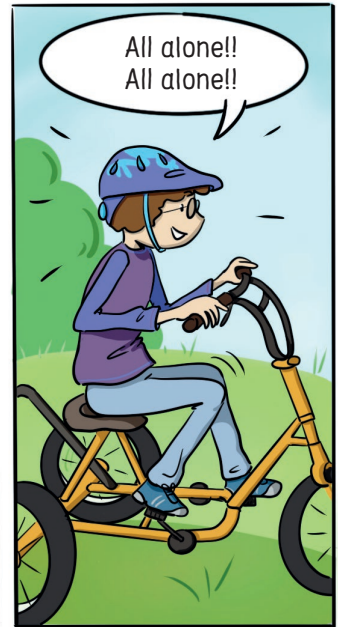
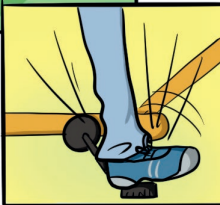
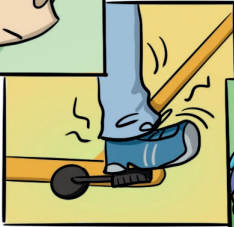
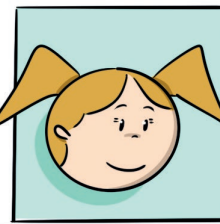
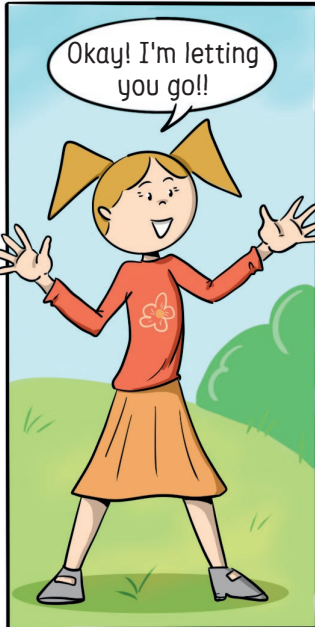
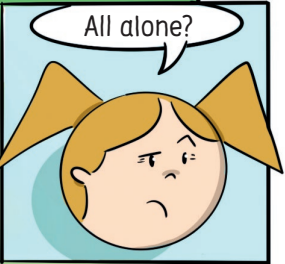
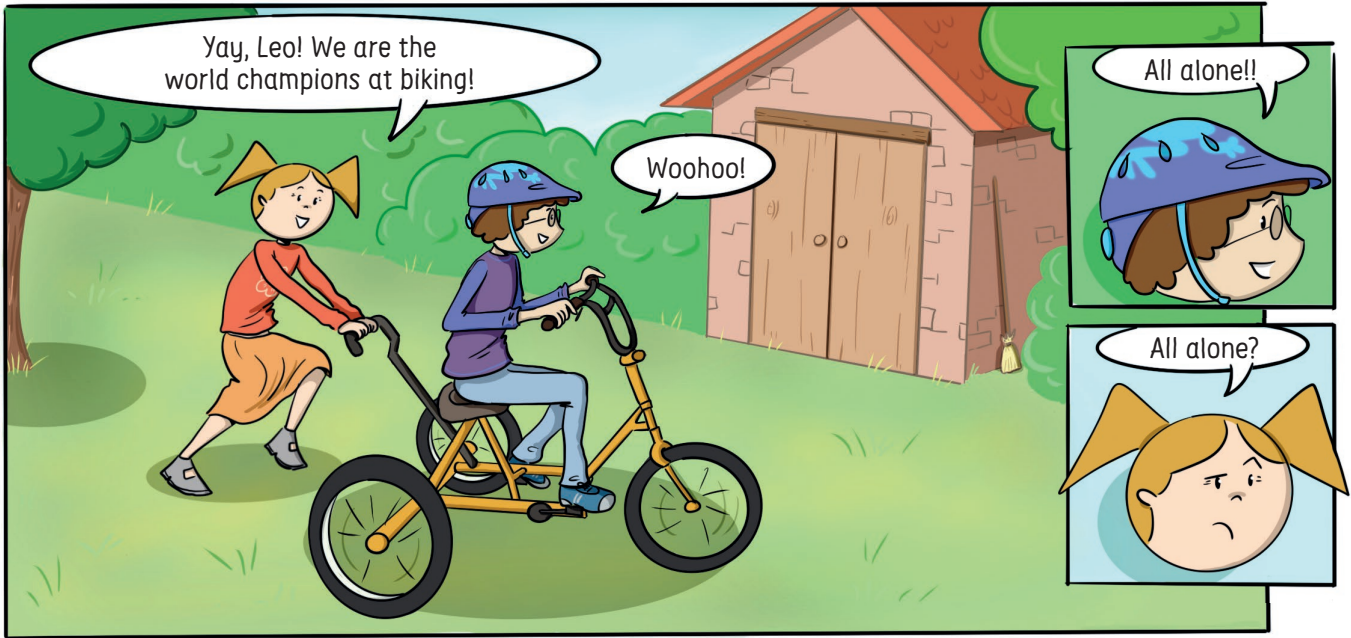


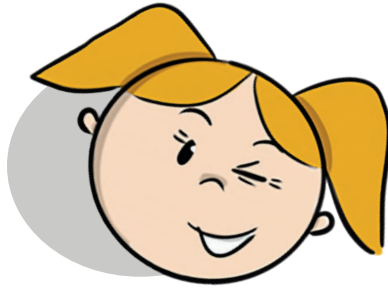


My Brother the hero

CHAPTER 9







This comic illustrates stories from the families of children with Dravet syndrome, with a focus on their siblings.

For readers ages 6 and up.

*Happy
reading!*