

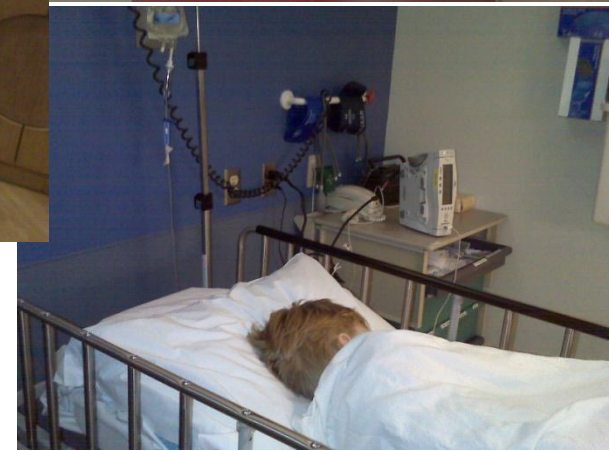
My name is Nolan. I am 7 years old. I am in second grade.  
My teacher is Mrs. K.



I am a lot like other kids my age. I like to have fun and play with friends. I have a cat named Charlie, a gerbil named Luna, and a fish named Joey. I love motorcycles, firefighters, cars and music. I like going for walks, swimming and dancing. Sometimes I like to pretend that I am a doctor. I have a big collection of stethoscopes, keys and walkie-talkies.



In some ways I am different from other kids my age. I was born with a special problem called Prader-Willi Syndrome, also called PWS. PWS is rare, so most people have never heard of it. I have to go to a lot of doctor appointments, tests and therapies, and that makes me miss school and other fun stuff. It can get really boring waiting for doctors. But sometimes I have fun, like the time I met Ellie Mae, the therapy dog at Children's Hospital. She helps kids do their therapy exercises so they can get stronger.



Having PWS means that my tummy never feels full, even after I am done eating. Do you know how it feels when you are really hungry, when you haven't eaten in a long time, and you can't wait to have some food? That is how my tummy feels all the time, every day. Even after I eat something, the feeling hungry part never goes away. My body doesn't know when I am full, so I am always wanting something to eat. At home we have to lock the cabinets and refrigerator and put up gates so I won't take extra food. Otherwise, I could get really sick.

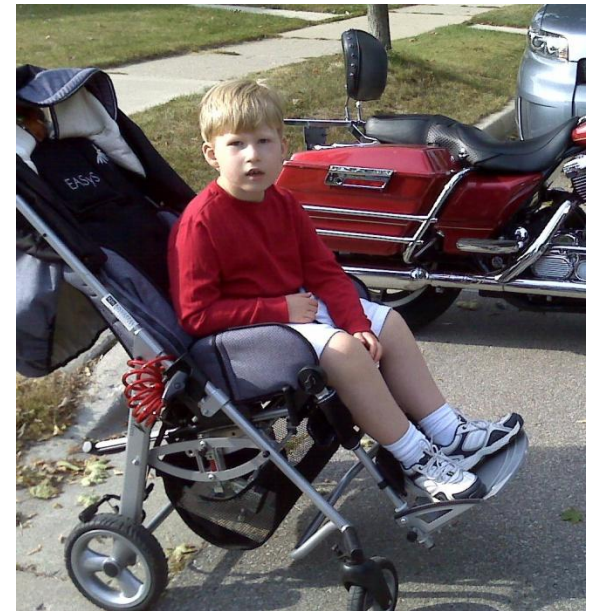


Because I am always hungry, I think about food a lot. But I am only allowed to have a little bit of food each day, about half the amount of other kids my age, because my body doesn't use food the way other kids' bodies do. My mom has to count every calorie so I don't eat more than my body can use. If I am not really careful, I can gain weight very quickly, which is not healthy. That is why I almost never get to eat yummy stuff like cookies, cupcakes, candy, soda, ice cream and chocolate milk. I wish I could, because I see other kids eating them and then I feel bad because I can't have any. Sometimes I have to miss out on parties and other fun events because of the food.



Having PWS also means that my muscles have to work extra hard, so my body is tired a lot. Things like running, jumping, climbing, throwing a ball and even walking are a lot of work for me. Sometimes I have to rest or take a nap at school to get more energy.

I wear braces inside my shoes to help support my ankles when I am walking and running. I have a cool bicycle that gives my body support so I can ride like other kids do and stay safe. Sometimes I use a special chair to ride in when I get tired.



Tired muscles also affect my handwriting, and the way I talk, so I have to practice those things a lot.

Mrs. W is my Occupational Therapist. She helps me work on my handwriting and do exercises to make my hands stronger, so it won't be so hard for me to hold a pencil. Mrs. X is my speech teacher. She helps me learn to talk more clearly so others can better understand me. I get to use the computer or play games with friends in my speech sessions. I practice taking turns and using nice words to ask for what I want.



Mrs. Y is my Physical Therapist. She helps me get better at moving my body, kicking a ball, and climbing on the outdoor play equipment at school. At home, we have a big slide. This year I went down all by myself, which is something I have been working on for a long time! I practice other activities too, like hitting a wiffle ball with my Dad and sister.



Having PWS makes it hard for me to learn things as quickly as other kids do. Mrs. Z, my special education teacher, spends extra time working with me on reading and math. I have to practice a lot until words and numbers become easier for me to remember.

Other things are easy for me to remember, though, like people's names and faces. I can remember people's names even if I met them a long time ago! Often I can also remember the kind of car they drive, and the names of their children or pets. I have a good memory for places too and can recognize buildings I've only seen once. I like talking to people and asking questions, so I make friends no matter where I go!

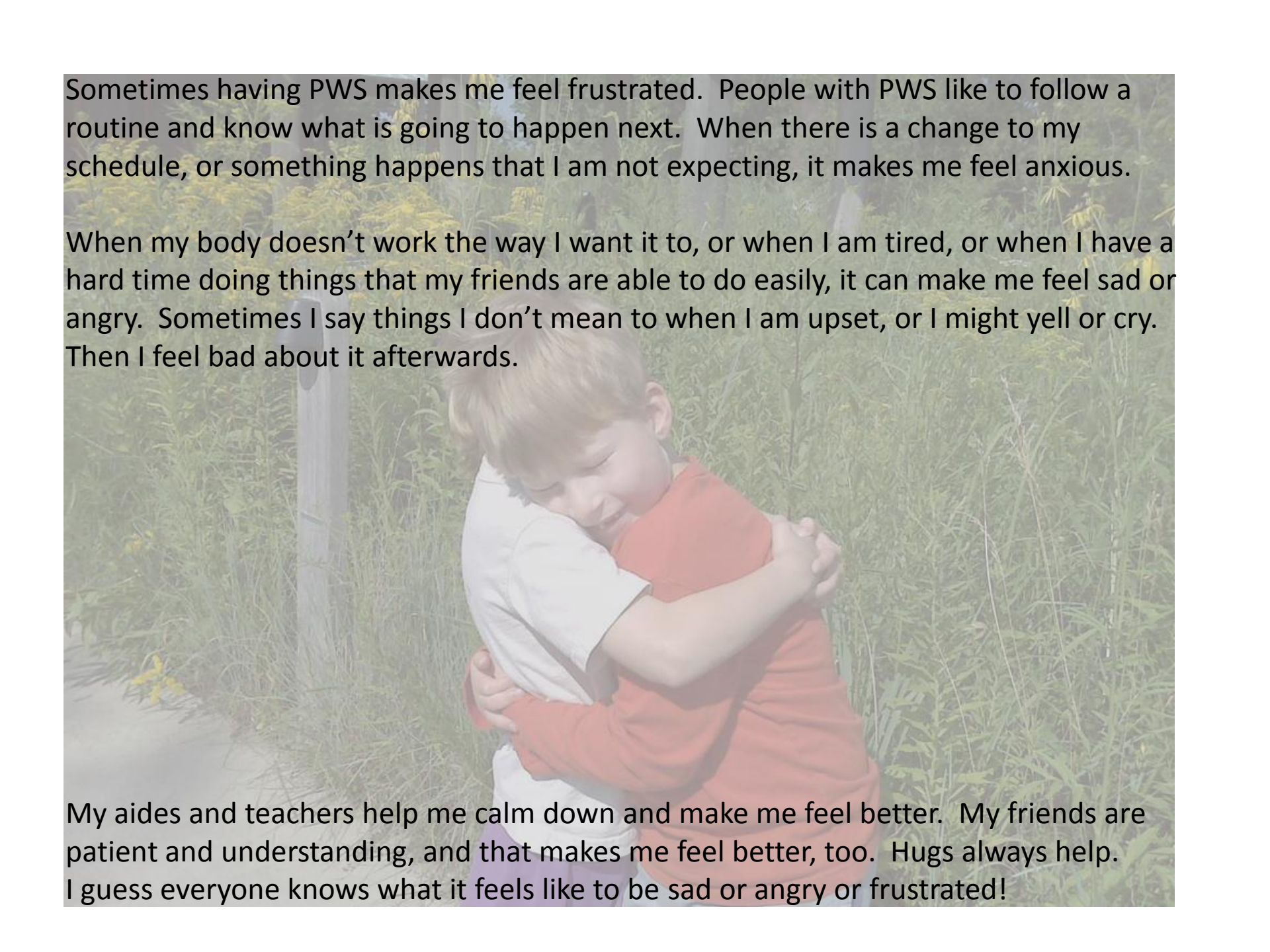


Sometimes it is hard for me to sit still and pay attention. I have been working really hard on that, and last summer I was able to go to a movie theater for the first time ever! I saw Toy Story 3. I almost made it through the whole movie. Next time I just know I will make it to the end.



During the winter, I have to stay indoors most of the time because my body is very sensitive to the cold. It makes me feel good when a friend joins me for indoor recess so I don't feel left out while the other kids are playing outside. We get to play games or practice throwing a ball. Some friends get to join me for therapy sessions, and we try out different yoga poses. I love yoga! This is me doing Tree Pose.



A young child with light hair, wearing a red long-sleeved shirt, is being hugged from behind by an adult wearing a white short-sleeved shirt. They are standing in a field of tall green grass and yellow wildflowers. The scene is outdoors and appears to be a moment of emotional support.

Sometimes having PWS makes me feel frustrated. People with PWS like to follow a routine and know what is going to happen next. When there is a change to my schedule, or something happens that I am not expecting, it makes me feel anxious.

When my body doesn't work the way I want it to, or when I am tired, or when I have a hard time doing things that my friends are able to do easily, it can make me feel sad or angry. Sometimes I say things I don't mean to when I am upset, or I might yell or cry. Then I feel bad about it afterwards.

My aides and teachers help me calm down and make me feel better. My friends are patient and understanding, and that makes me feel better, too. Hugs always help. I guess everyone knows what it feels like to be sad or angry or frustrated!

Having PWS isn't always easy. That is why I am glad that I have many friends and teachers at school who help me be the best I can be!

