



Complex Child E-Magazine

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Young Children's Voices

Note: The following essays were written by children ages 3-10 about their medical issues or disabilities. We have corrected spelling and punctuation, but otherwise left the essays as they were originally written.

Jack G., age 6

I sometimes like having my feeding tube because then I don't have to take any horrible medicine, my mummy just puts it in my tube.

Sometimes I think this isn't fair as my friends at school don't get to have one, my little sister does though. We both have the same tube. My mum says that I have it because I didn't eat and was sick a lot. I don't like having tummy ache, I have to come home from school and have a bag put on my tummy to stop it. It hurts. I have to go to the hospital too. I don't like to go because it is scary sometimes, they have to put a straw in my hand to go to sleep but I get an ice lolly and yogurt when I wake up so that's ok.

They are going to find out what is wrong with my tummy.



Jonathan Z., age 3

Lord, bless you, eyes, amen

He had eye surgery and that night at the dinner table that was his prayer. He usually says, "Lord, bless you, eat, amen," which is his way of saying "Lord, please bless this food." This time he was saying, "Lord please bless my eyes."

Hospital, hurting something?

This is a phrase that he says a lot, especially when he returns from the hospital. At first I thought that he was telling us that something is hurting and he wants to go to the hospital but now I think he is just confirming that when something hurts, we go to the hospital.

Seizure, I go hospital

This really is a request to go to the hospital because he feels like he's going to have a seizure. He somehow knows when one is coming.

Mommy, Daddy & Jonny go hospital

This saddens me a bit because I know what he's saying is that he'd like to go to the hospital to spend time with mommy AND daddy. My husband and I work separate shifts to take care of him so just about the only time we're all three together as a family is when he's in the hospital or we're going to doctors appointments.



Nitara S., age 4

What does EE [Eosinophilic Esophagitis] feel like?

It feels like a spike in my mouth. It feels like vomiting.

What makes you sad?

Being sick.

How do you feel about food?

I wish I could eat all of it.

What foods do you miss?

Spaghetti, because I ate them a long long time ago, remember. And noodles--mac and cheese with dairy. Regular chocolate--chocolate bars. I don't like meat. I will never eat burgers with animals in them.*

What are your favorite foods now?

I love special mac and cheese. I like dairy ones, too. It tastes better than special ones, right? I like pancakes with special syrup and blueberries.



Why do you have a feeding tube?

Because when I was born I was like that.

Like what?

But I forgot the way I was born because it was a long long time. I did not drink my bottles. I didn't like it.

What do you like to do for fun?

I like to play in the bath, and I also like to color.

What do you want to be when you grow up?

A nurse like you, because I want to take care of people. But Mommy, I don't want to grow up. I like being a kid.

Note: Nitara's Story was featured in the April Edition.

**Our family is vegetarian*

Laura B., age 10

I have lots of things and I can't say them as they are long words but they make me feel grumpy. I am angry, upset, worried and annoyed when I have to go to see the doctors. My scar from my tummy operation (Open Nissen Fundoplication) makes me feel left-out. I went to a friend's once and they were doing those tummy tattoos that wash off, and they wouldn't let me have one because they didn't like my scar. Mummy and me call it a zip. I was little when I had it done and I don't remember it.

I got angry because they are my friends and should not get upset. My friend Emily, she is in my school class, thinks my scar is "cool." I don't like wearing bikinis because I have to show my tummy and then I get angry again as I want to wear a bikini.

I have a sticker chart because I pretend that I take my medicine when I should. Mummy found out that I was pretending and now I take it and get £1.50 if I take it. If I don't then I lose money.

I think it doesn't work but Mummy says I'm better taking it. The tummy pains don't go away and I still get sick in my mouth. Yucky. I want it all to go away and it won't. It makes me sad.

Laura's primary diagnosis is Ehlers-Danlos Syndrome (hypermobility).

