



MEET AIDEN

How old are you now?

I'm eight now.

Tell me about school.

I'm in grade 2. I like sports best.

What are some of your favorite sports or hobbies?

I like playing cricket. I was the captain last night. I like playing football. I like reading.

What books do you like?

Harry Potter. I'm up to book number 3. I like Pokeman.



Aiden's mom (Mel): He loves to read. Sometimes he will just disappear with a book. He likes to pretend that he is Harry Potter. He says he would like to live at Hogwarts.

Could you describe Aiden?

Aiden's mom: Aiden is bit of an enigma. He likes to do his own thing. He doesn't like being told what he can do or confined by being told what he can't do. He is quite assertive in knowing what he likes to do. He's a bit like me he can be a little bit stubborn. I think that's pretty normal for an eight-year-old boy. He isn't afraid. He has an ability to make us laugh. He is like a magnet; you are just drawn to him.

Do you ever get tired as school?

Yes, sometimes after recess and lunch my legs get heavy.

Aiden's Mom: Occasionally we will get a call from school to tell us that Aiden is a little flat but that doesn't happen often. The teachers are really good about giving us a call if Aiden is a little bit flat or left of center. Either his dad or I will go to the school to pick him up. But it really doesn't happen that much.

He is very good at reading his own signals. He knows his limits. Maybe it's his way of reading his own triggers and not going beyond his limits.

We have regular communications with his teachers, including his PE teacher. We have asked his PE teacher to let us know if there is anything significantly different between Aiden and his classmates. She has told us that he is always willing to try. He does tend to tire before his peers but nothing significant.

Mel, I've always been impressed with your ability to let go and let Aiden try? Has that been difficult for you to give him those opportunities and letting go?

I'm getting teary. Yeah, every day is hard for a range of reasons. Sometimes you see the reactions of his body language when he can't do the same things as his older brother. We saw it last night at the cricket game when he was batting because he didn't get as many runs as he wanted to. We had to have that difficult conversation with him that not everyone can be a good batter every day and maybe this will be his fielding day. As it turns out he had a great fielding game. He kept the other team from scoring probably 30 runs because he fielded so well. Those times to hurt.

In the early days when he was in the hospital so regularly. I was seeking counsel from the counselor at the hospital. She said something that has always stuck with me. In those days I was in tears every day. She said, "You're living in fear of the future and if you live in fear of the future, you are not going to grasp today." That resonated with me.

Regardless of whether you have a child with Barth syndrome or not, you constantly worry. Raising a child is a complex jigsaw and with Aiden, Barth syndrome is just another piece we are trying to put in place.

So back to the question...Does it worry me when I let go to let him try? Yes. It does. But I am going to worry about him every day anyway. By letting him go I can enjoy the moments of seeing him live to the fullest today.