

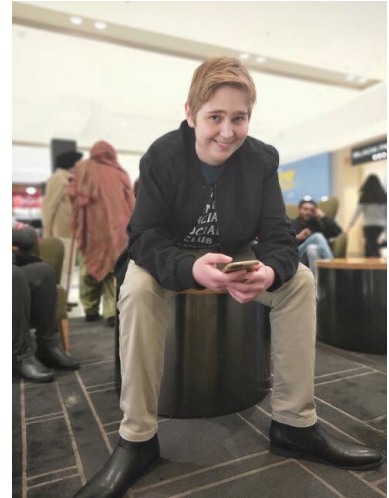
Cameron

What are you doing these days?

I am studying as a secondary education teacher in food and textiles technologies which is a fancy name for home economics teacher which is pretty much a full-time thing. So that's what I do.

He smiles

Long Pause



That's it? Just so you know, don't do this with someone you are trying to date. This is what is generally referred to as *the awkward moment*.

Oh, you want to know what I do for fun. It's worth noting I'm awkward and I've never had a girlfriend. So, I haven't gotten past that point.

Consider this your practice run. Tell me about yourself.

I play video games. I cook. I sew. I'm good at making things. I carve things out of wood. I watch a lot of NetFlix. I'm going to make someone a great housewife one day.

Are you still drawing?

I'd like to. I just don't have the time. Uni takes up so much time. I have an eleven-hour class load. On Wednesday I am in class at one campus for six hours. On Thursday I am in class for three hours, then I travel across town for another two hours of school. I have five other days for studying and time to rest which allows me to recover and manage my load pretty well.

Thursday must be brutal.

I'm used to being tired. I've got ways to deal with being tired. So, it doesn't really get in the way. I've just gotten used to it. I get on with it. I do get tired, but I'll rest when I get a moment to rest. I do have special provisions at Uni. I can get extra time for my assignments if I need it. Mostly I am on my own. I have to be independent at school. It is different from when I was in high school. I'm pretty good at keeping on top of myself.

How far along are you in school.

I am currently finishing my first year of Uni following my foundations course which was really helpful in preparing me for my course load this year. I have three more years to go. I believe the things I have learned through my own life experiences will help me to be a better teacher.

Looking back do you feel your mom did a good job in preparing you for this stage in life?

I credit mom with everything. I cannot think of one thing she could have done better. She was bloody fantastic. She still is. She helps me with a lot of stuff. If I don't understand something, I know she is there for me to call. She nailed it. I couldn't have asked for a better mom.

What has helped with giving you your independence now that you aren't living at home anymore?

Dad made me get my learner's permit when I was sixteen which has been so important for me to have independence. I don't enjoy driving. I have now been driving on my own for two or three years now. It is amazing to be able to have that freedom to go where I need to go when I need to go. It is a Godsend for me to be able to take myself back and forth to my appointments. It also took a lot of worry off of mom. I do find that driving isn't too tiring if I keep it under two hours. I also drive an automatic because it's a lot easier.

Do you have good friends who understand what you are going through?

My friends have always been very supportive. Now that I am in Uni my friends are very thoughtful. They call to check on me. They make sure I am not overdoing it. One of my friends got on the BSF website to learn more about BTHS. I'm a lot like my dad. I will talk to anyone. I try to be a good friend too. I will do anything for the people I love.

Are you still giving yourself G-CSF injections?

Oh yes. I would not stop that. I missed about six weeks of school or more and was really sick. The G-CSF made all the difference. There is nothing anyone could do to make me stop it. It isn't pleasant but the benefits outweigh the annoyance.

Tell me about this interest with cooking.

It has been helpful to learn how textures and tastes of food work together to make it possible for me to eat foods I don't necessarily like. By experimenting I have found different combinations that work well for me. That way I am able to cook for

myself and eat vegetables and things I need to eat to stay healthy. Granted there are sometimes when I just have to suck it up and eat which is really difficult.

When given the chance I will experiment with different things like chopping foods very finely or mixing up tastes and texture. Through experimenting with cooking, I have found really good ways to do that. I love fried rice. I will chop vegetables very finely and mix it through the fried rice with lots of seasoning. By doing this the texture becomes one palatable thing where all I taste are the seasonings I like. Sometimes I'll add an egg to even out the textures. There are a lot of different ways to make food more palatable.

What are ingredients have you found that work well to mask food tastes that you don't like?

For me there are three things that really help with masking tastes. (1) Hot sauces help. The spice overpowers other things. (2) Kewpie mayonnaise is not as tart as regular mayonnaise. It's smoother and you can use that with a lot of stuff. (3) Soy sauce is still right up there at the top of the list. I can identify different brands of soy sauce. Some are disgusting and some are amazing. My family can't taste the difference.

What advice would you give a little guy with Barth syndrome?

I have debilitating anxiety. It's important to take your moment and collect your thoughts. I get that it's not easy. But take care of yourself. It won't be like this forever. Carry on. It's your life. Don't care what anyone else thinks. As long as you are happy, who cares where happiness comes from. It gets the job done.

There may be that occasional person who thinks you're faking it because you don't look sick. So what? You aren't here to live up to their standards. You know what you have to do and what you can do. At the end of the day you have to look out for yourself. That person must have a pretty crappy life if they feel compelled to make the kid with Barth syndrome feel bad. They don't know you.

Sometimes it's a good thing to be a little oblivious. Don't pay attention to the references about your height. So what? You might be the shortest kid in the class, but height doesn't measure character. If my input would ever be helpful, don't hesitate to reach out to me.