



MEET ALFIE

Wow, it's been a long time since I've seen you. It's weird when you don't see someone for a long time. Even though 10 years lapse you still think of them as a child. Now you are tall.

Yeah, I know the first time I met you I was six and the last time we saw each other I was nine. I was small for a very long time and really shot up in height when I was around 16 years old.

How old are you now?

I'm 19.

Are you still growing?

I don't know, hopefully.

What are you studying in school?

I'm studying chemistry at University of the West of Scotland in Paisley. Right now, all of my classes are online. Normally, I would have a thirty-minute taxi commute between home and university. The taxi picks me at the door to take me to school and right there when classes are over at the accessible door to take me home. It is very convenient. The taxis are always on time.

What is your school workload?

On Monday I have a 2-hour lecture that starts at 9:00 followed by an hour workshop. After that, I have lunch followed by another two-hour lecture and workshop. Monday isn't very fun, but it is manageable because of the proximity between classes. Thankfully, I only have one six-hour day. I have labs and experiments for three-hours on Tuesday afternoon. I have a one-hour class on Wednesday. I am in class for four hours, from nine until one on Friday.



I don't touch homework on Monday. I would do most of my homework on Wednesday. If I am feeling up to it on Tuesday, I would push myself to do it because I never know what my energy level will be. I am organized and I don't tend to put things off, because I just never know how I might be feeling from one day to the next.

What made you decide to go into chemistry?

When I was in my last year of secondary school, I applied for an apprenticeship to work with children. Children carry a lot of germs and stuff. So that didn't seem like a good fit for me. Going through school I loved science. In the fourth year I took chemistry. In the fifth year I took high level of chemistry and physics. In the sixth year I took a higher level of chemistry and physics.

Then I went to college, I took an applied science biology course, which is like the first year of Uni. I want to teach. My mom found this course that included an option to teach. Normally, you would have to do a year of post-graduate study to teach, but this has everything included which saves me a year. With my first year of college behind me I am in my second year at Uni now, I have two more years to go after this.

Did you find it to be a difficult transition between secondary school and college or from college to university?

Not really, because I understood all of it. I understood the concepts of what I was studying. I had a good disability advisor who put a care plan in place to help me at college and again when I went to uni. The disability advisor at university is very good. They were very thorough with making the campus accessible for me. They also reviewed emergency protocol which relieved any anxiety I may have had. It makes life easier not to have to worry about those things

Are you still playing music?

Yes, I play the drums. I'm learning to play the bass right now. I'm not taking any formal training, mostly I'm just picking things up that I am learning through videos I find on YouTube.

We have one of the rooms here set up as a man cave. I have a sofa and PlayStation and refrigerator in there. My brother moved to Glasgow for university, but my mom still wants him to have a room. Right now, Jay is home because we are in quarantine. It's good to have him here. My brother plays the guitar. We are enjoying playing music together while he is home. I got rid of my drums because they took up so much space. I have a small Cajon box set of drums that I bring out and play with my brother and friends.

With your school load you don't have a lot of discretionary time. What other hobbies do you have?

I make time for myself. I work hard on my Uni work but not to the extent that I would tire myself out. If I see that I can't keep up or that I am too tired to complete a project I reach out to my professors. As long as you let them know, they are very understanding. Thankfully, the lectures and everything that is covered in class during the day are uploaded in the evening.

I like playing video games. I just got FIFA. I have been playing that with my dad and my brother. I can play that online with my friends who aren't in the house with me.

Do you have a favorite football player?

I like Cristiano Ronaldo. He played for Manchester United. When someone plays for your team you can't say you have a favorite on another team. I love watching football. It is cancelled right now. We have 3 weeks without football. I miss it. When I play FIFA, it brings them right back where they should be; playing football.

The only player I know of from Manchester United is David Beckham.

Yes, he went over to the US and started the Inter Miami team in Florida. You must have to be very rich to do that.

What does it feel like when you get tired?

I have a heavy feeling. It's like your mind wants to do something but your body tells you know. I have learned over the years that you can't keep going when your body is depleted. No good comes from trying to go on. The farther over the line you push it the harder it is and longer it takes to recover. It's best to rest when I need to. I learned when I was young.

Can you think back on a definitive moment when you said, never again, never will I push myself that hard again? What was the breaking point?

I used to go to youth group on Sunday night. It was only for a couple of hours. I would just run and run and run, playing the games. I was having so much fun. I pushed myself, somehow thinking if my mind pushed my body harder, I could go on. I couldn't. I pushed myself to exhaustion. I spent the next few days in bed totally shattered. At that point I said never again. I learned that I could still enjoy my life without pushing myself beyond my limit.

I didn't do myself any good by pushing myself. There was no benefit from missing school or having to make up work I was behind on because I didn't stop myself when I should have. I learned my lesson.

What advice would you give to a younger person with Barth syndrome based upon this lesson you learned over the years?

Things can be done in moderation. Don't try to do too much all at once. It's better to pace yourself.

Are you dating?

No, oh no. When I have time and energy, I like spending time with my friends, playing PlayStation, watching football and things like that. There are just other things I prefer to do with my time other than dating.

Would you consider yourself to be shy?

No, not really. My mom says I am a social butterfly. I'll just start talking to anyone. I like getting to know people. I'm pretty easy to talk to and I enjoy meeting people.

I've met many scientists over the years. They are all wonderful people, but I can't think of any right off had that I would describe as being a social butterfly.

[Alfie laughs]

Does it make you timid to talk with friends about Barth syndrome?

No, not really, with going to Uni I have had to learn how to self-advocate. It's not something that I would discuss with some right off the bat. I carry a defibrillator with me. If something should happen, I would need the people around me to respond. So, I explain that I have this medical condition (BTSH), what it is and what people should do if something should happen. I do tell them that it is highly unlikely that anything will be needed. It's not that I am trying to make a big deal of it or draw attention to myself, but it gives me peace of mind to know that people who are around me know what to do in the event that something does happen.

Is that an awkward conversation to tell someone here's my black box, shock me if I fall?

I guess it could be, but I'm used to it now. It's (the defibrillator) is not who I am or a part of me, it's just something that goes along with me. My friends are really nice and understanding about it. One of my friends has fatigue similar to what I have with BTSH. It's nice to have a friend there at Uni who understands the fatigue. I'm not

glad she has a condition that causes her to feel that way, but it is nice to have someone there with me who just gets it without me having to explain it.