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## MEET ALEX

### How old are you now?

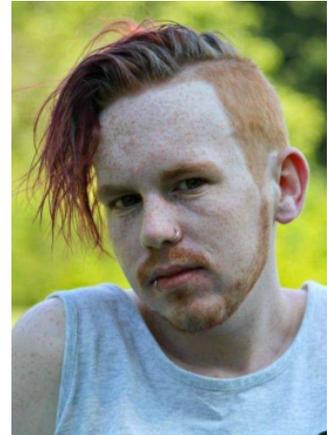
I'm twenty-five.

### Are you still in quarantine?

Yes, but apart from that I do go on a daily walk. So far, I have pretty much been in since March.

### Tell me about your interests?

I have a big garden which allows me to get out safely. I enjoy photography. I have a drone, but I haven't flown it lately. I spend a lot of time with my family. That's important to me. I have quite a big family. I live about an hour's drive away since I moved out. I live in a smaller countryside village now.



### Would you consider doing photography as a profession?

When I started, I lived in a much larger city. I have done photo shoots for my friends who are in a band. I have done two weddings shoots as well. But, since I moved here there isn't as much of a demand. If something pops up, I would say yes because I still find it fun. I don't do much with photo editing beyond the basics. I prefer to rely on my camera to take a good photo.

### How do you like living in the country?

I prefer it over the larger city. The countryside is lovely. We have nice neighbors. I can go for walks and get out. It's not too far if I want to go visit my family. My partner and I enjoy taking pictures when we go out on our walks. Yeah, I like it quite a lot.

### You had a heart transplant, right?

Yes, I was transplanted about 22 years ago. I have done really well with it.

### **How do you conserve energy or manage fatigue?**

I find it helps to be mindful of what I do and where I expend my energy. I enjoy walking. That is something that is important to me but it requires energy. I have to vacuum; that takes energy too. I have a lightweight Hoover which is easier to pick up. I do things in small portions rather than all in one go. Living on your own is manageable if you do it at your own pace. It also helps to have a partner who understands and helps out with the chores.

### **What is your body's signal to let you know you have reached your limit?**

Generally, I won't let it get to that point. If I feel fatigue coming on, I stop and take it easy. It's not a tiredness where you could just use a good sleep. I guess it would be like you just ran a marathon and you feel like you have exhausted all your energy. You just can't go any further. You just have to stop and relax. It's not like I have a need to sleep, it's more like I have a need to just stop. It's hard to describe. I am pushing against my own body. It takes concentration just to move when I reach my limit. It's hard to concentrate on anything else. I tend to lose focus when I get to that point.

### **What was that like managing school with energy limitations like that?**

I don't remember it really being too bad or too much of an issue in my early years. As I got older, around eleven through sixteen, during physical education I could do other things when I couldn't manage what they were doing. When I went to college my mum would pick me up at the bus stop because I wouldn't be able to walk home after a full day of classes. It was helpful because the schools were accommodating in allowing me to work at my own pace.

### **What did you study in college?**

I studied animal care. I learned behavior and health of animals. I studied for that for three-years.

### **Do you have pets?**

I have a small koi pond out back. I had a larger one when I lived with my parents. I keep fish. I have a rabbit. He has quite a big space to live in. We have a cat and two guinea pigs.

### **Congratulations on your engagement.**

Thank you. We met online. We got to talking and it just took off from there. Here we are two-years later with our own place together and planning to get married. We have been engaged for a year now. It's nice.

### **Tell me about this online approach to meet people. A few of the people we have talked with who have Barth syndrome have told us they met significant others in that manner.**

It's not too bad. I don't know about anyone else but for me the most daunting part is explaining Barth syndrome to someone or telling them about the medical stuff when it comes to the online dating. I didn't list that I had Barth syndrome in my profile. I didn't tell her right out of the gate that I had Barth syndrome. But I wouldn't do that with someone I had met in person either. It's not like I held anything back. I shared more as the conversation evolved and as I got to know her better. She understood and it didn't really get in the way. Having Barth syndrome or telling others about it has never stopped me from meeting people. But yeah, it was fun getting to know her. She's great.

### **What is the first thing you want to do when quarantine is lifted?**

I want to do a hangout thing that I do with all of my friends. I look forward to catching up with them in person. We chat online but it's not the same as being together. Every Saturday night we do video games, but it isn't the same.

### **What are you doing to maintain your mental health and wellness?**

I enjoy our daily walks. I have a support worker who has been set up by the doctors. So, if I need anything, I can call them to sort things out. But all-in-all I'm doing well.

### **What genre of music do you like?**

I guess it would be best described as Indie Brit Pop Rock. Deaf Havana is one of the groups I like.

### **Is there anything else you would like to share with younger people who have Barth syndrome?**

There is always a way around things. I have my own place complete with pets and a partner. It's on the ground floor. It's small. It doesn't take a lot of energy to keep up or to look after. It's still my own place. I still have independence. You can achieve what you want. There is a way around things. You just have to figure out what it is you want, what matters, and figure out how you can achieve those things.

To me, it was important for me to live independently from my parents. I love my parents and I was fine living at home, but it was always in the back of my mind to one day have a place of my own. I think that is the case with anyone as they grow up. I started thinking about it when I was in my early twenties. I thought about what I needed to do to manage living on my own. After meeting my partner, I started thinking about it much more seriously and we found a place of our own that was suitable for both of us.