Jana Zlunkova Cystic fibrosis

**Breathless – Life of a Cystic**

“I don’t want to just give up, there is so much stuff I want to do before death comes for me. I always make sure to keep on fighting not only for me but for everyone who died of cystic fibrosis at a young age and wasn’t able to fulfil his dreams.”

It is freezing cold today. Hard blowing wind makes it difficult to open the heavy glass door of Edinburgh’s coffee house. Trying to squeeze through a crowd of people standing by the till, I spot a pretty young lady with a big smile on her face sitting nearby. At that moment, I am sure she has a lot to say. Katie Jefferson was diagnosed with a terminal disease called cystic fibrosis when she was only six weeks old. This genetic disorder affects mostly lungs, but also the pancreas, liver, kidneys and intestine. Cystic fibrosis is one of the most common life-threatening genetic diseases in the United Kingdom. Approximately one in ten people are diagnosed before or soon after birth. Unfortunately, there has been no cure discovered yet and the average life expectancy is no higher than fifty years.

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Jana Zlunkova Cystic fibroris2

“I kept very well until quite recently. When I was younger, my condition didn’t stop me from doing anything,” says twenty-two-year-old Katie. “I’ve started realizing having a disease during the past three years when it has been holding me back a bit,” she adds after taking a long sip of her coffee. At the beginning of this year, Katie’s right lung collapsed. She spent twelve long weeks in hospital due to big damage that has been done to her organ and she is still in the process of recovery. Not really physical but mental because as she says “It doesn’t really add on confidence.” When she went out after more than one week, her lung started to collapse again. “It was really scary and I’ve probably never been as unwell as I was in that moment.” Her eyes are slowly watering and you can tell how many emotions are hidden behind them.

Katie has to be really conscious now, she can’t just go somewhere without making sure she will have oxygen supply available. Whenever she wants to fly, she needs to check with her doctor as there is different pressure on the plane. “My boyfriend and I were meant to go abroad in the summer. However, it was really hard to get in touch with people to set up oxygen in the hotel, so we just spent our holidays at home at the end,” she sighs and gives me a warm look.

Gesticulating passionately, she explains that having a life-shortening disease is actually really interesting. She says that it gives you a completely different outlook on life. “You need to make sure to do everything you can, to live your life to the fullest and try not to think about what you can’t do and what limits you. There is actually so much I want to do and I don’t want my life just let go. Sometimes it bothers me to hear people murmuring about stupid stuff, thus it makes me a bit jealous,” responds Katie.

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Jana Zlunkova Cystic fibrosis3

She thinks that if she had only that kind of things to worry about, her life would be completely fine. On the other hand, seeing healthy people wasting their chances to take their lives fully into their hands and spending time watching TV series all day instead makes her want to show the world that even a person with the terminal disease can actually enjoy life to the fullest.

“My mum and dad have never treated me any differently and they’ve been very surprised how well I deal with everything,” says Katie with a sparkle in her eye. She doesn’t really think about being ill. She knows that when her cystic fibrosis gets worse, it will always get better afterward.

Katie is on different pills that she needs to take several times a day. She sleeps with oxygen on and feeds through the feeding tube overnight. Physiotherapy, that is done two times a day, is a key part of her treatment as well. She explains that if your mind is in denial of the treatment, then your body suffers even more. “You just need to live in the present moment and stick to your treatment to keep well,” says young cystic fibrosis survivor. Katie has a special diet as well. Her diet consists of everything considered to be unhealthy for everyone else. She is advised to have sweets, to snack on crisps, cakes and basically anything that includes carbohydrates in order to keep her energy at the normal level. Diabetes is, indeed, one of many medical complications that can be carried along with cystic fibrosis. Fortunately, Katie has never had problems will the high level of sugars, but sometimes she really craves salad. “When I was younger, every time I was offered to take a sweet I would rather go for a piece of fruit because I’ve always loved fruit and vegetable, and used to really struggle to eat unhealthily.”

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Jana Zlunkova Cystic fibrosis4

“The hardest part of my whole cystic fibrosis journey has been to decide whether to get my name on a transplant list and realizing what I could possibly do after having my lungs transplanted,” says Katie in a little bit shaky voice. The thing is that you adjust yourself to how you are, you get used to the fact that you can’t, for example, run as much, but lung transplant is basically what every cystic fibrosis patient wants. Katie points out that you have to keep yourself as well as you can in order to be able to get a transplant, but you also need to get to the point when you’re so ill that you need it. “It’s very difficult and scary to talk about it. I’m thinking about getting a lung transplant but my biggest goal in life is not to get to the stage of being so ill that lung transplant will be my only chance,” adds Katie gazing out of the window.

Three of Katie’s friends have recently died of cystic fibrosis at very young age. She was very close to one of them in particular. “When I was ill at the beginning of the year, she would send me packages of sweets and we became really good friends. It is horrible to lose the only person who really knows what you’re going through, but it also makes you keep on fighting and not giving up.” Katie’s eyes are watering again. She takes a long sip of latte and puts her hands with precise manicure down to her lap.

Connecting with other cystic fibrosis patients is not easy. When Katie was a child, doctors didn’t realize the damage that two people with cystic fibrosis could do to each other. Everybody would sit in a waiting room and then called each to a different room. Now a patient goes straight to a room, and doctors and nurses come there. However, Katie has a lot of people having the same disease as she added on Facebook.

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Jana Zlunkova Cystic fibrosis5

“When I was in the hospital, I wrote down all names of cystic fibrosis patients that I saw pinned on the board in a hallway,” she explains. “It’s really frustrating to be in a hospital up until three in the morning, messaging a person who is right next doors and not being able to just go knock on his door to say hi.” In reality, you can’t really avoid meeting people with cystic fibrosis though. The girl with black curly hair who is sitting at the next table can be a cystic fibrosis patient as well as the waitress who is handing a bill into my palm. You just never know.

Katie loves going out with her friends and spending time with her boyfriend. She enjoys taking her dad’s dog for a walk. She has got a new job in a clothes store just now after not being able to work for almost a year. “I’m enjoying it but I don’t think it’s something I would like to do for the rest of my life. I’ve always wanted to work with children,” says the inspiring young lady whose dream is to travel to Australia, get married and have children one day.

If she would like to do so, her boyfriend would have to be tested if he carries the faulty gene. If both parents carry that gene, there is a twenty-five percent chance that each child they have will be born with cystic fibrosis. Katie would have to make sure that she is healthy enough to get pregnant as some of the pills can’t be taken by gravid women.

Katie Jefferson is a fighter who won’t just give up and who will make the most of her life until the very last day. She inspires people to start living instead of just surviving whatever their condition is. She brightens up even the darkest days of many individuals. As her younger brother Sam says “Living with Katie makes you understand people better, appreciate them, appreciate your own life and appreciate her.

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**Sources Contact List**

**Name of interviewee:**

Katie Jefferson

**Address of interviewee:**

4 Garvald Street, Edinburgh

**Place of interview:**

Starbucks, 120 Princes Street, Edinburgh

**Date, time and duration of interview:**

6November 2017, 1.30pm, 30 minutes

**Method of interview:**

face-to-face

**Telephone contact number:**

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**Background Sources List**

NHS.UK, 2016. Cystic fibrosis. [online]. United Kingdom: NHS.UK. Available from: https://www.nhs.uk/conditions/cystic-fibrosis/ [Accessed 12 November 2017].

**Range of Interview questions**

Q: How does cystic fibrosis affect your everyday life?

Q: How does it feel to have a life-shortening disease?

Q: What keeps you motivated to keep on fighting?

Q: Have you ever met any cystic fibrosis patient in person?

Q: Have you thought about a lung transplant?

Q: Are you currently having any health complications?