

# World Thalassaemia Day!

Friday 7th May 2021

## **What is Thalassaemia and how does it affect you?**

Thalassaemia is the name for a group of inherited conditions that affect a substance in the blood called haemoglobin. People with Thalassaemia produce either no or too little haemoglobin, which is used by red blood cells to carry oxygen around the body. It's a life long illness. Thalassaemia affects me daily with not having the ability to do things to the full capacity, sometimes I get tired really quick and out of breath which is a common symptom. Sometimes you're not allowed to go to certain places or travel, as it restricts you. People don't see the condition, as it's internal and therefore won't see the pain or physical disruptions to the body with people having this condition. People don't understand or see the illness, however they misinterpret the condition and believe that it is nothing or that I am doing fine, when it is the opposite of that. Being diagnosed with this since birth I have been going in and out of hospitals for check ups, scans and blood transfusions. I have also had a bone marrow transplant and this makes it hard for me as you notice that you might not get the same opportunities as a person without Thalassaemia due to having a long term illness. Many people think that because of this we need to be shown as vulnerable, which is true but to a certain extent. We are still human and should still be treated as a person without this condition. It affects us mentally and physically on a day to day basis and limits our opportunities.

## **Why are you speaking about it?**

This is my opportunity to get it out there, especially in an education environment people should understand that there are people with illnesses which haven't been spoken about that are not well known, and Thalassaemia is one of them. In primary and secondary school no one that I had spoken to had known what my condition was and I know that there are a lot of students who have this condition. Especially in this college. I have spoken to some of these students and they all believe that it is something that should be spoken about as they are all exhausted with trying to explain to each and every individual who comes up to them to ask what Thalassaemia is. Not only to their friends but also to teachers, some of the symptoms that I go through are headaches, shortness of breath, feeling tired constantly and because of this I have educated my teachers of the illness that I have. As a result of this they now understand if I have to take a break from my work or if I take days off from college due to being in the hospital. Raising awareness allows myself and other people with Thalassaemia to have a voice and to be heard. We don't want sympathy, we just want people to know that this is something that we go through. This will also allow us to build a platform where we can explain to others what the illness is and donate blood or money to help those in need of a blood transfusion.

## **What is the process of your treatment? (A day in the life of a Thalassaemia patient).**

We have a cross match, which is something that detects the presence of antibodies in the recipients against the red blood cells of the donor. If this is successful then you will be booked in for a blood transfusion, this could be for the next day or a week's time. Before the transfusion they will cannulate you, which is a tube that can be inserted into the body, often for the delivery or removal of fluid. They will check to see how many blood bags you will need for the transfusion and start the process, this could be up to 4 blood bags, depending on how much you need. The process could take from 4-8 hours. I would normally have to take 2-3 bags of blood which could take up to 7 hours. During this time I would complete some of my coursework, talk to my friends and families or listen to music to take my mind off the process. The transfusions take place one every month for me. I would also have to get cross matched 24 times within the year and also go to extra appointments for check ups, MRI scans and on going tests. Just to make sure that our heart, liver and iron levels are in check.

## **Why is it important for people to wear red?**

The main purpose for people wearing red on Friday, is to symbolise blood. For me, people wearing red shows acceptance, which is a key thing and it gives a sense of hope within patients who are dealing with Thalassaemia. It shows people who are with this illness that people are listening, we are being heard and that we are not alone. We stand united together.

## **Final words of wisdom.**

Don't be scared to show what you have, express it. We have a voice so use it on social media or in person to say what you need to about your illness, not just Thalassaemia but illnesses that are not spoken of. Don't let it define you, challenge yourself and go for those opportunities. Thalassaemia has made me who I am today and I am proud of that.

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*Hafizah Nawaz interviewed by Hajrah Rehman*

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