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Understanding Life with Beta-Thalassemia

Actor portrayals throughout.
Not real patients.

Since you are someone with an important role in my life, I want to share more about the rare genetic disease I live with called transfusion-dependent beta-thalassemia (or TDT) so that you can better understand me and my situation.

Everyone who has TDT may have a different experience. TDT is often an invisible disease, so you may not know that I have an illness just by looking at me. For me, every day is different and some days are better than others. Living with TDT has its challenges, and this guide may help you better understand how I manage them.

WHAT IS TDT?

Beta-thalassemia is a noncontagious genetic blood disease that comes in different forms, including TDT. Having TDT means that my body needs blood transfusions to function properly, produce energy, and keep me alive. But to understand the impact TDT has on the body, it helps to first know how your body delivers oxygen to your organs.

RED BLOOD CELLS

- Your red blood cells are responsible for carrying oxygen from the lungs, through the bloodstream, and delivering it to your organs
- Inside your red blood cells there is a protein called hemoglobin that does the actual work of carrying oxygen

HEALTHY ADULT HEMOGLOBIN

- Hemoglobin is made up of 2 subunits of **alpha-globin** and 2 subunits of **beta-globin**. Hemoglobin requires a correct balance of both **alpha-globin** and **beta-globin** to function properly

HEMOGLOBIN AND TDT

- As someone with TDT, I have a mutation in my **beta-globin** gene that causes my body to produce little or no **beta-globin**, which causes an **alpha-**/**beta-globin** imbalance

WITHOUT ENOUGH FUNCTIONING HEMOGLOBIN, MY ORGANS CAN'T RECEIVE THE OXYGEN THAT THEY NEED TO FUNCTION PROPERLY. THIS MEANS I MAY HAVE ANEMIA, WHICH CAN CAUSE A WIDE RANGE OF SYMPTOMS, FROM FATIGUE AND WEAKNESS TO MORE SEVERE SYMPTOMS, SUCH AS HEART FAILURE, DIABETES, OR ORGAN MALFUNCTION; IF SEVERE ANEMIA IS LEFT UNTREATED, IT CAN LEAD TO EARLY DEATH.

MANAGING TDT

MY THAL. MY PLAN.

Since I'm not able to make enough hemoglobin on my own, I need regular red blood cell transfusions to treat my anemia and keep me alive. These transfusions require me to go to the hospital every few weeks. After I receive my red blood cell transfusion, my hemoglobin levels go up and I usually feel good and energized. Over time, however, these red blood cells die and my hemoglobin levels decrease, making me feel weak and tired. When my hemoglobin levels get low, it's time for another red blood cell transfusion. If I don't stick to my transfusion schedule, my symptoms can progress to some of the more severe ones listed earlier.

LIVING WITH TDT

IMPACTS HOW I LIVE MY LIFE IN THE FOLLOWING WAYS:

- Causes me to miss time at work or school (people with TDT may struggle to find or keep a job)
- Takes time away from participating in certain activities and sports
- Makes travel difficult, requiring careful planning

MY PATH FORWARD

My doctor and I are working on managing my TDT so that I can still accomplish the goals I set for myself. Managing my TDT is a big commitment and it will not be easy on me or my body, but I know it'll be worth it if I can achieve my goals.

I have a long journey ahead of me and I'm going to need people to help me throughout my process.

I WOULD LOVE FOR YOU TO SUPPORT ME ALONG THE WAY!

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