

My Life with
skelly and DSM
Story



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I am Yassen

I am 9 years old



I am 9 years old, and I have special abilities. As a child I used to enjoy running, playing and riding the bicycle especially when I visited Bayt Abdullah. I used to run fast. But now if I ran too fast, I might fall. This is because I have special muscles. I have a disease that I called **DSM**. It stands for Duchene Special Muscles.

I have
**special
abilities**



My Brother Zeyad

is 18 years old



Zeyad is my older brother.

He likes Sonic and music. He can play PlayStation better than me. Like me, he has special abilities. He is also diagnosed with DSM. Although he can only move his fingers, he smiles all the time. At the time, I didn't know what was wrong with my brother Zeyad. I was never curious. I loved him just the way he is. Even when my muscles started getting tired, I didn't think I had the same condition as my brother.

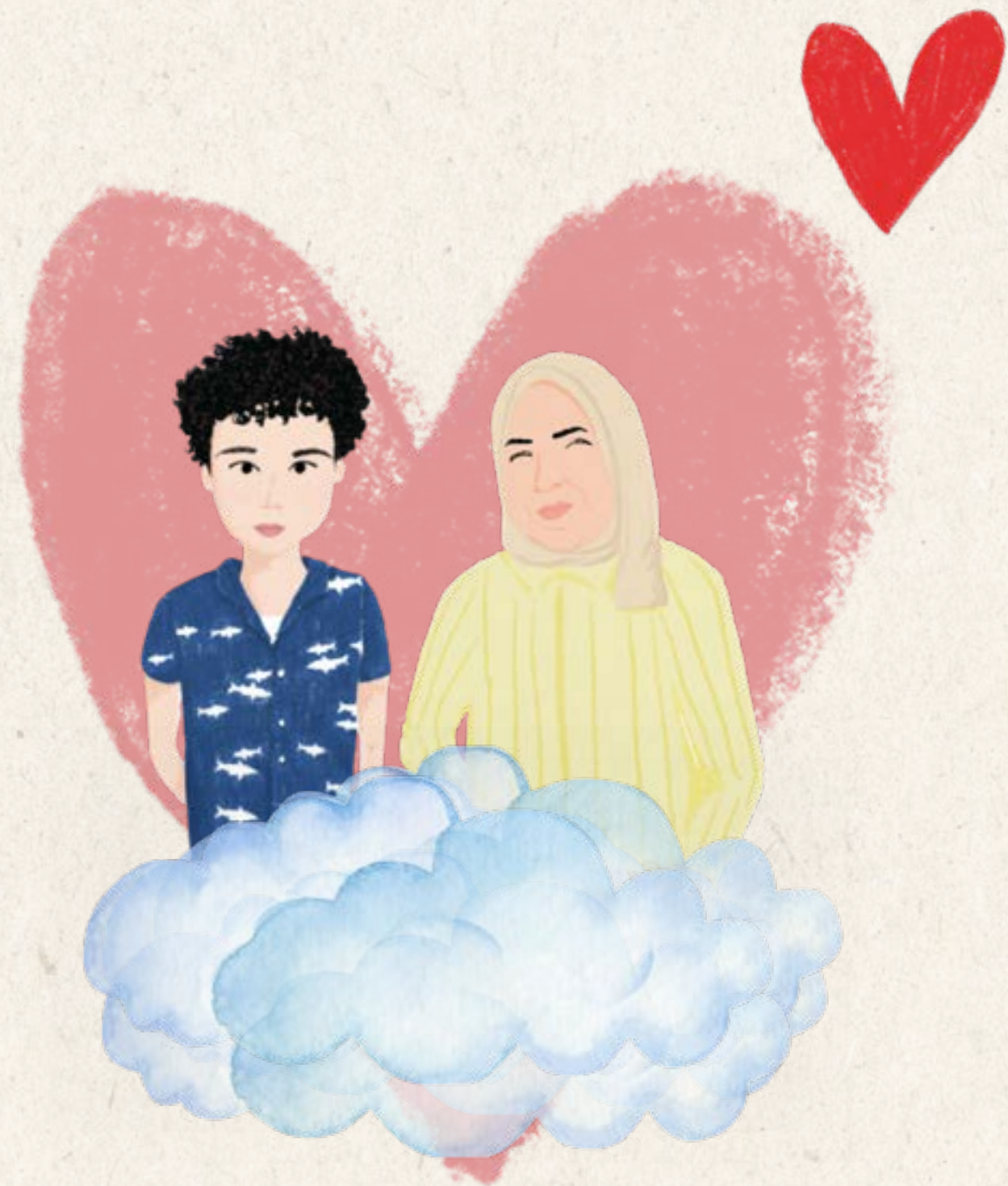


My Mother

is 49 years old



She is smart, beautiful, and makes the best food. She is hard working. She is helpful. She knows how to draw. When I told my mom that I wish I could run as fast as my friends, she hugged me and told me that I am different in my own unique way. She also said that at least I am guaranteed heaven, and that Allah rewarded me with other blessings.





My Sister **Jana**

is 15 years old



Jana is the middle child in our family, the only girl among us. She is known for her kindness and intelligence. She spends her time reading stories and drawing, just like my mom. She also loves listening to music. Jana has a very compassionate heart; she often helps me just as she often helps my brother Zaid.

She is the best sister ever.



Child Life Specialists (CLS)

CLS is a person who helps kids.

They make children happy. They play with you, teach you about life, and they tell you what you are going to experience at Bayt Abdullah.

They will also teach you about Duchene Special Muscles (DSM).





The CLSs I know are **Hanadi and Nourah**; they are strong. When they told me that I have DSM, I remember I went to the physiotherapist, Dr. Hazem, and told him that I didn't have specific feelings at that point.



Skelly

Hi, my name is Skelly, and I am friends with Yaseen, even though I am just a skeleton.

I am going to tell you what I like and what I don't like.



Things that I DO like:

- I like Bayt Abdullah.
- I like to sit and do nothing.
- I like to shower.



Things that I DO NOT like:

- I don't like to read.
- I don't like writing.
- I don't like to talk.

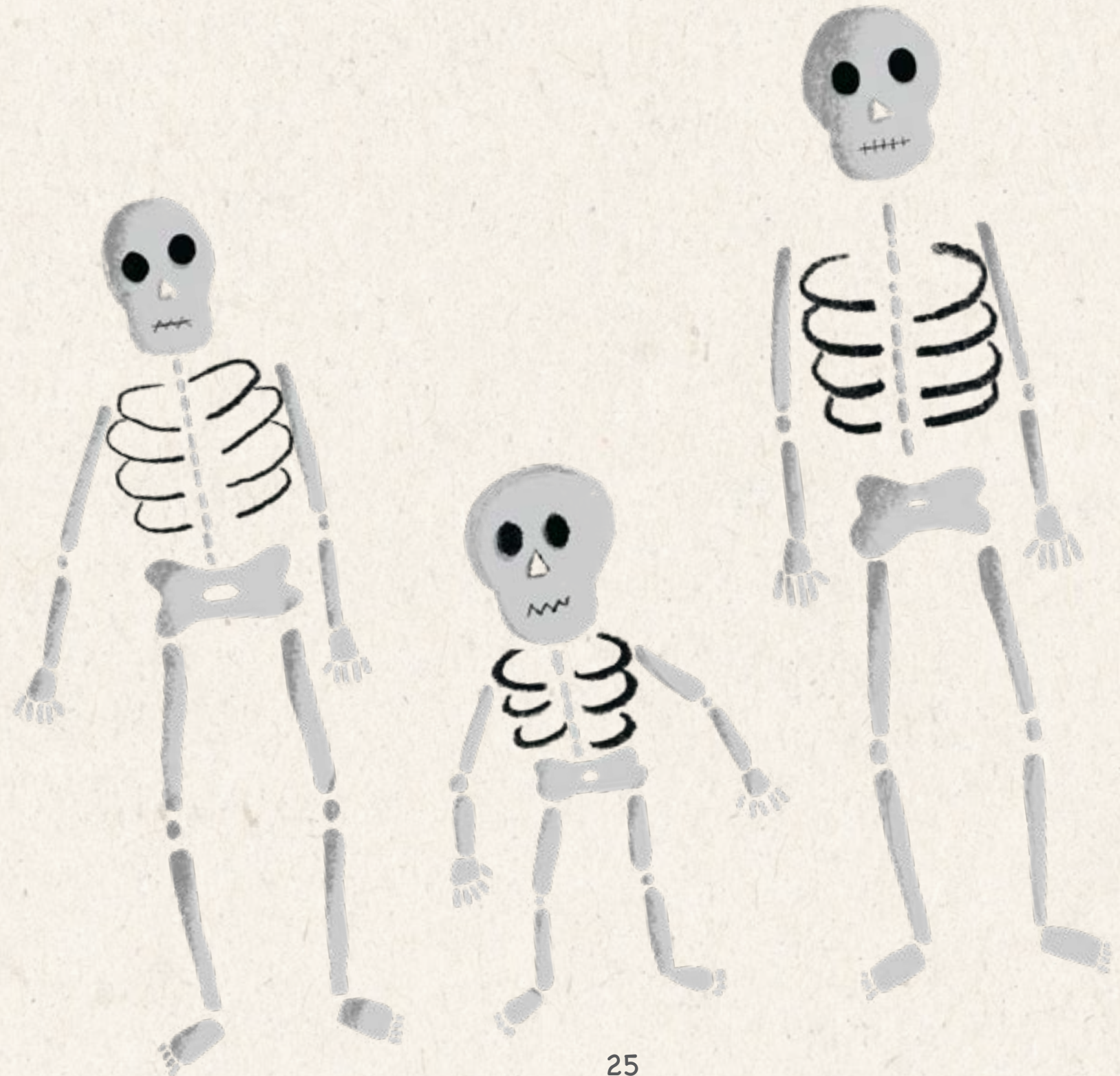
All about Skelly's family

Skelly has a brother named Bob.

Bob used to work in a hotel. A creature named Jeff took Bob to a haunted hotel.

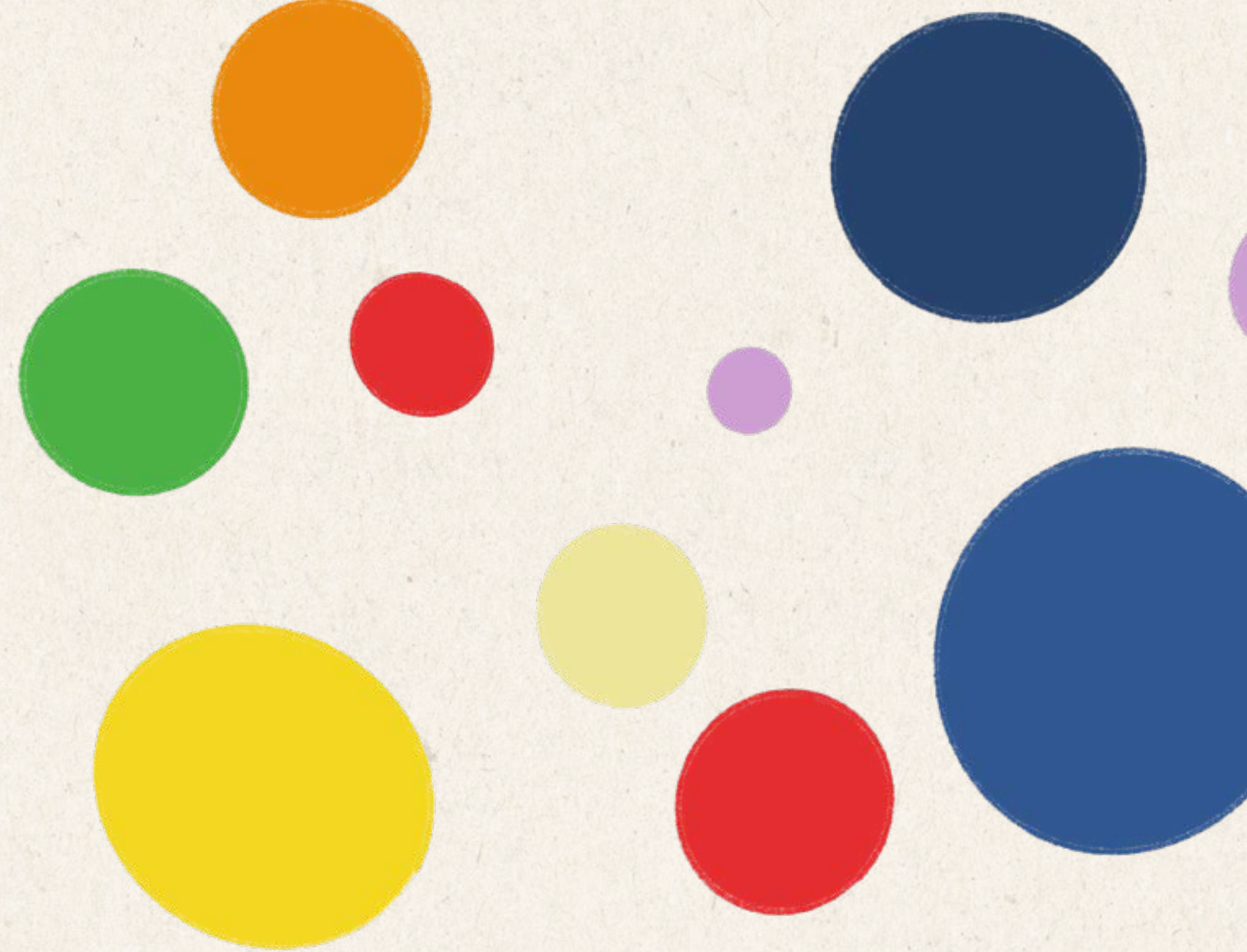
Bob died and then he became a skeleton and went to door 52. Jeff opened the shop and let Bob sit there.

Bob has a father named Dud. Dud left Bob when he was 2 years old because he hated his mother and Bob.



A note from the Child Life Specialists:

The child (Yaseen) used Skelly as a way to explain certain feelings. Skelly was the teaching item the CLS used to teach Yaseen about his diagnosis.



School

From my first year of school my teachers have always told me I am a top student. They told me I am very intelligent for my age, although all my schoolmates used to make fun of me for being slow and different. I always felt sad and would refuse to go to school even though I've always enjoyed going. I hated going with my wheelchair because of what people thought of me. But now I don't feel that way anymore because of my family and Bayt Abdullah's support. I am forever grateful for them.

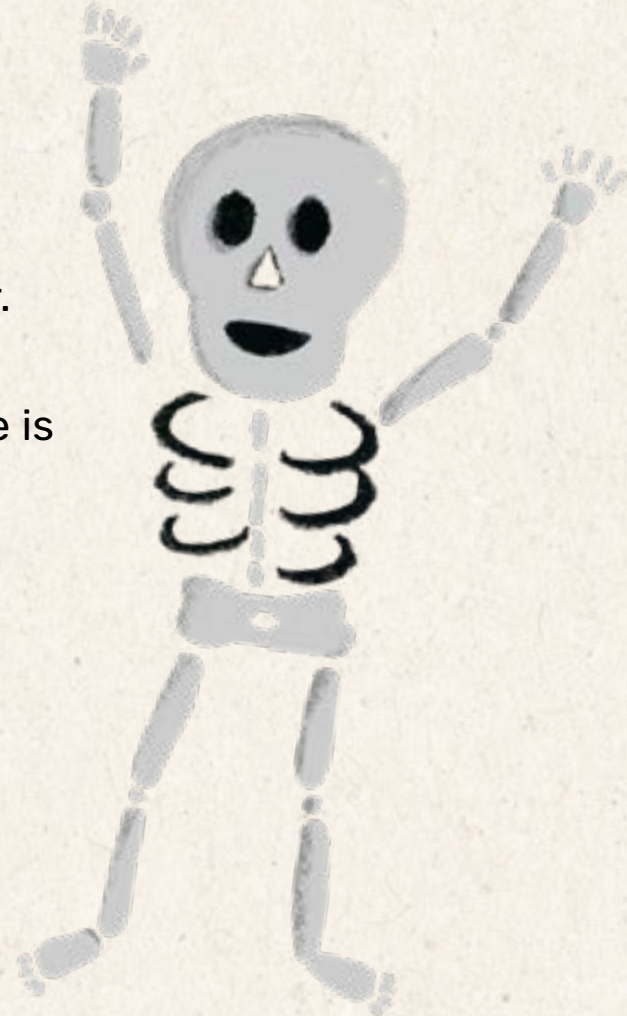


The Best Things About Sitting in a Wheelchair!

You get to rest while moving.

They can be electric so it can be like car.

You can hold your phone while someone is pushing you!



The aim of the Story

The purpose of this story is to tell you, the reader, that it is not easy to be a child with DSM. But with the support of family, society, and, most importantly, faith in Allah, life becomes easier and more adaptable. For those who are challenged with any kind of disease, you are not alone. If you have DSM, it's okay; if I'm living with it, you can too! Stay strong and consider your disease a gift. Allah will be with you all!

“Those who are patient shall receive their rewards in full, without reckoning” Sura Al-Zumar verse10.





شركة مركز شيماء نبييل الملا للبحوث والدراسات
Shaimaa Nabeel Almulla
Research and Studies Center Co.

At the Center of Shaimaa Nabeel Almulla for Research and Studies, and as part of our social responsibility, we are committed to supporting such initiatives for our talented and exceptional young individuals, like Yassin in this story.



KACCH & BACCH is a unique charitable organization that cares for extraordinary children like Yaseen to find comfort and care.

Through our mother organization, the Kuwait Association for the Care of Children in Hospital (KACCH), we offer compassionate care to children in hospitals across Kuwait to reduce the adverse effect of illness and hospitalization, ensuring they receive the highest level of support through our dedicated Child Life teams, no matter where they are.

In Bayt Abdullah Children's Hospice whether children share similar conditions like Yassin or face different illnesses, the care they receive here is always tailored to their individual needs. At Bayt Abdullah, our mission is to enhance the quality of life for both children dealing with life limiting or life-threatening conditions and their families. We provide specialized pediatric palliative care, managing distressing symptoms and pain, while also offering emotional and psychological support through our Child Life programs—all within a nurturing and welcoming environment.

To learn more about us, visit www.kacch.org or follow us on social media @kacchbacch.



About The Story

“My Life Story with DSM and Skelly” is a story about me (Yaseen), my family, my friend Skelly and a wheelchair.

Thank you to Bayt Abdullah and my mom, sister and brother, for helping me write and publish this book.



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