



The ~~Once Upon A~~ Lifetime

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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 Jana in this story.



Dedication

To me, for surviving and accepting life gratefully. and to whoever has beautiful blemishes on their skin.

Introduction

People always say: “Actions have consequences!”

Now if I say, I disagree with this fact, I’d be considered a hypocrite for I use this on a daily basis.

Yet was it ever even a choice to be known as ‘unique’ by millions of doctors simply for the mere fact that I had a ‘special’ condition?

Perspectives and Maturity

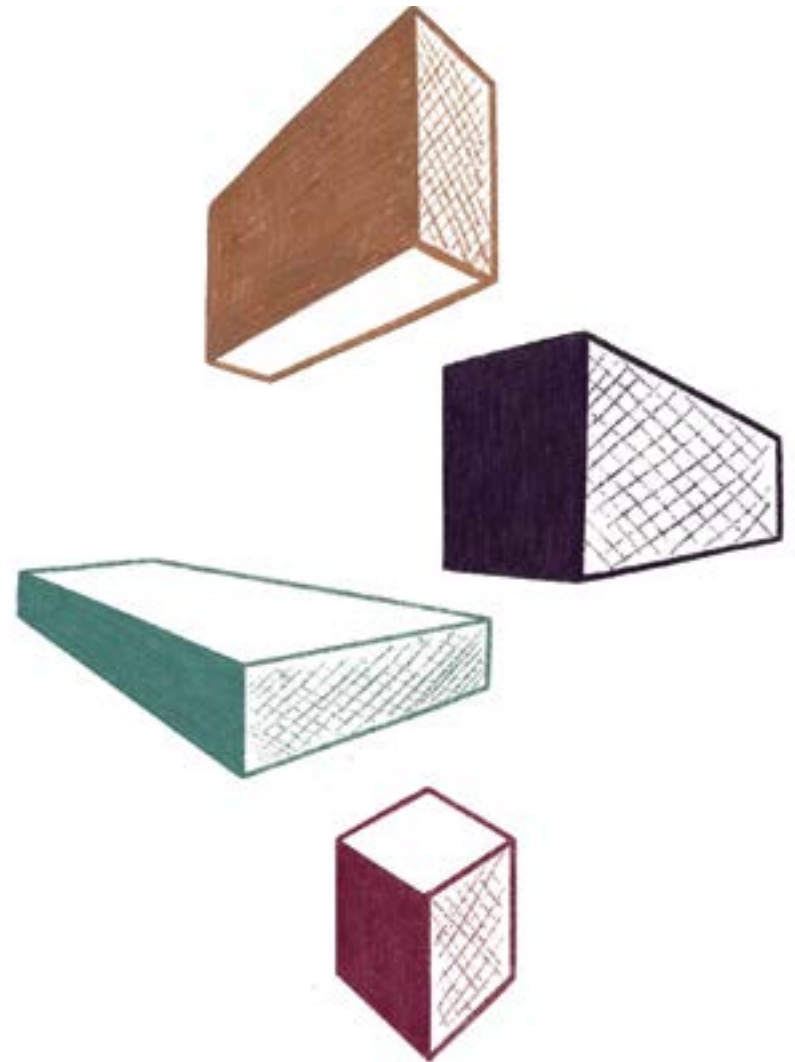
Allah SWT has given humans a mind of their own to make their own decision depending on their perspectives.

Now, here is the question, what would a young girl's perspective be on living with a skin problem?

The correct answer here would depend on the girl's maturity and of course perspective.

If I ask any other person what's their perspective on the young girl's life, it would be varied again depending on their maturity and perspective. Some may please the girl while others may mess with her feelings.

Let's dive into this young girl's feelings.



Jana

Jana is a young Lebanese girl, at the ripe age of 14. Jana suffers, or at least that's what the doctors like to say from an unknown skin condition.

Hey, I'm Jana!

Despite being diagnosed by multiple doctors, none of them ever really got to the bottom of my skin condition, always ending up with many other diagnoses, and after looking them up, I couldn't help but feel pure disagreement, for I have lived with myself more than these doctors have and yet they ever so casually misdiagnosed me.

Sometimes, it angers me, yet are these doctors not trying their best? It isn't their fault; how could it be? They didn't afflict me with this condition or that's what I used to think.



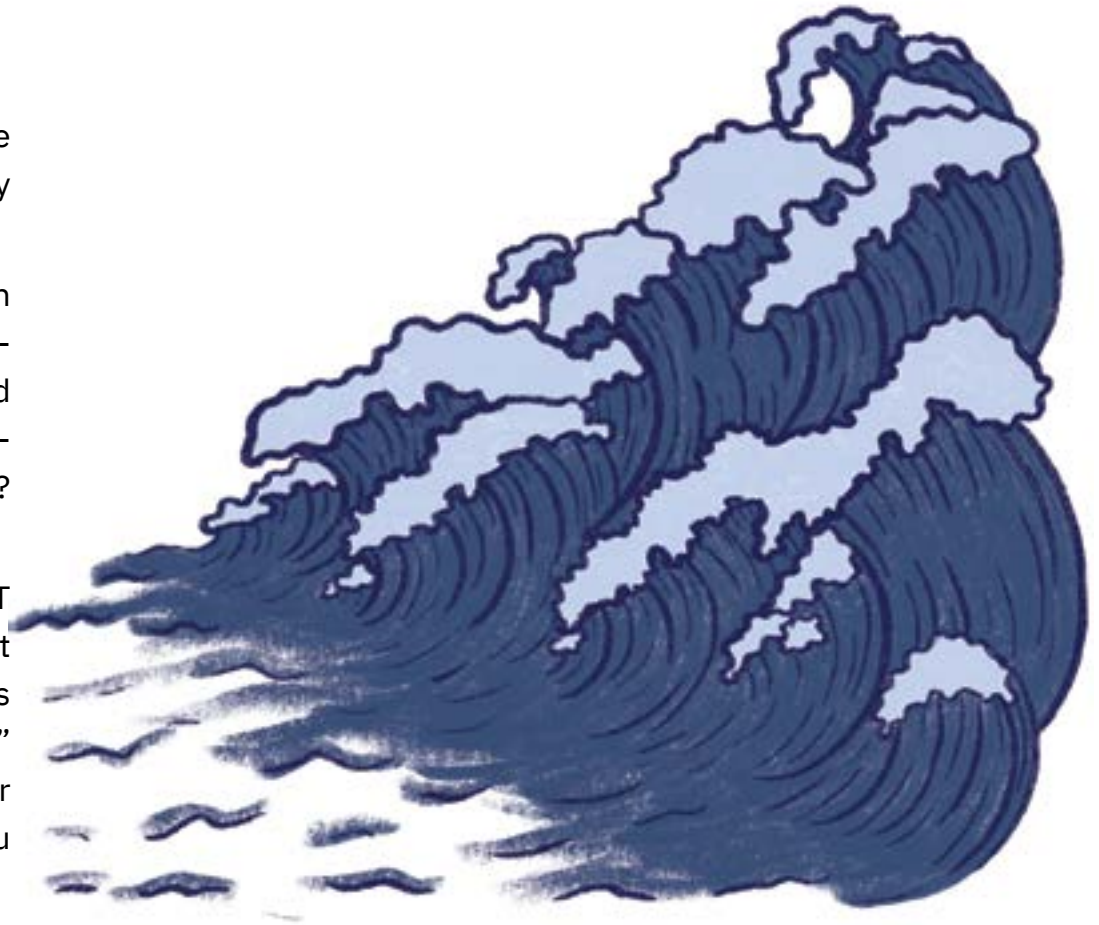
Growing Up

Just like everything, good or bad has side effects, having a skin condition had many side effects.

Growing up having a skin condition which I hated as a child, caused me many problems. For whom could an innocent child blame for such a burden? Their loving parents? Of course not! Their God, perhaps? Exactly.

Bearing the idea in my mind that Allah SWT had the ability to do the impossible, I felt anger and hurt, since my lovely aunt always used to tell me; “Allah SWT loves children!” Adding to my resentment towards Him, for was I not a child too? Since when do you love those, you hurt?

Was that love? It drove me away from Allah SWT seeing children happy and able to live with no judgement being Allah’s favourite



while I felt like a complete burden to anyone I loved.

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With doctors always telling me I'm 'unique' and I'm 'special' and so casually lying through their teeth enraged me. It made me feel the exact opposite. Every time a doctor would call my parents telling them there's a new doctor from here or there that would like to meet me, I would be dragged to the hospital like a guinea pig. I didn't feel 'special' or 'unique' I felt like a lab experiment and that thought follows me to this day.

Going through all that and still experiencing it. Still surviving it? It made me subconsciously prideful. Why shouldn't I be proud? I was merely surviving, not living, I had every right to be proud! Yet with pride came rage.

Hot, boiling, unbridled rage. Anger at the doctors who kept on spilling sugar-coated words. Anger at Allah SWT for ignoring my pain. Anger at the world for keeping me in it. It was pride and anger, and having no one to

talk to, what could a child do other than repress an ocean of pain till the ocean breaks free by itself.

A child misled by anger.

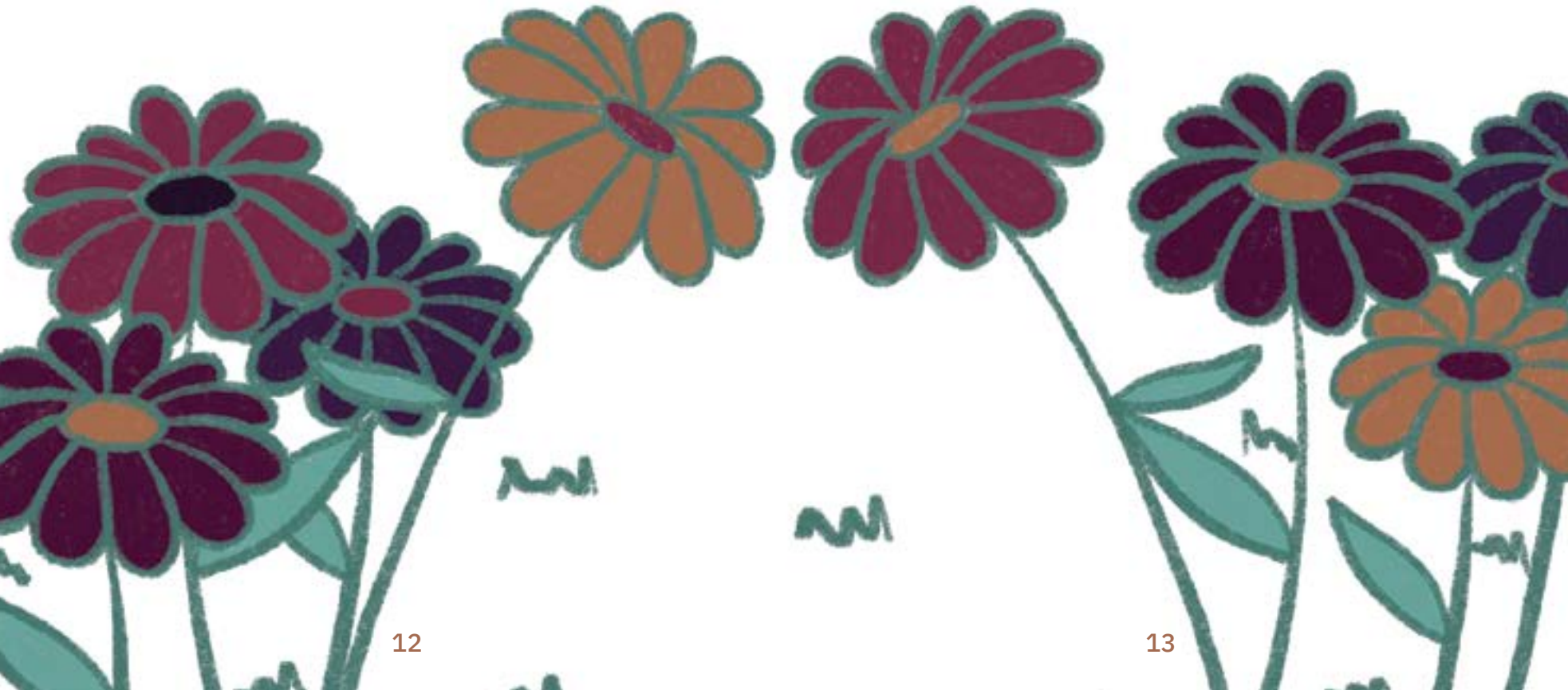
Education and Words

Registering for school was far from easy.

School principals would ask for medical files, and proof that my skin condition wasn't infectious, they would have the audacity to ask if

my skin condition altered my brains logic, yet can I even blame them? Can I blame a school owner for making sure their students use their brains? No, perhaps not.

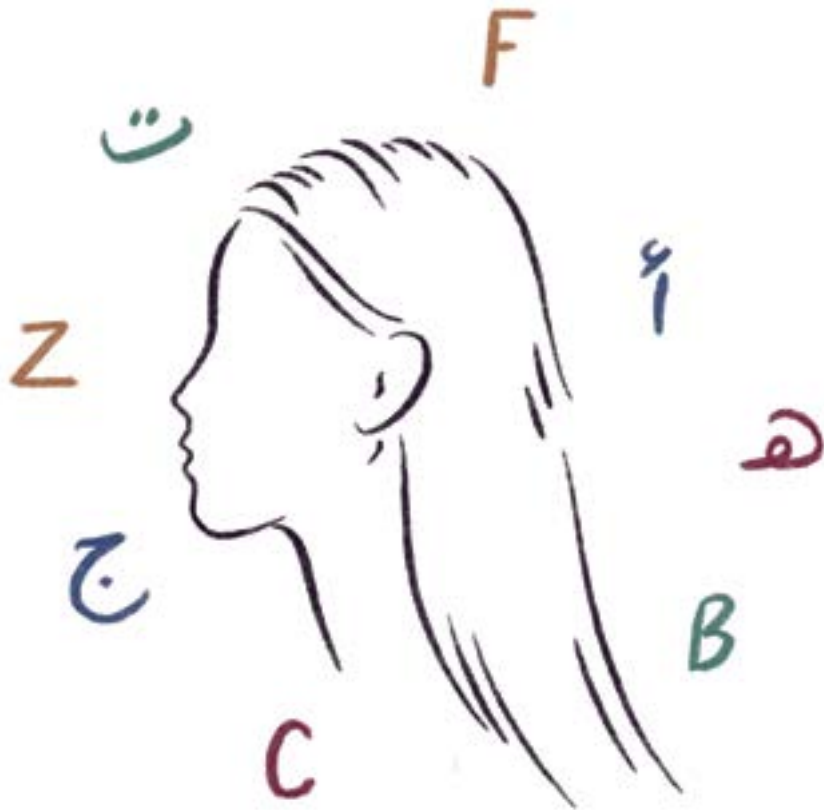
Even after successfully enrolling in school, not everything went smoothly. Fitting in with the students was almost insurmountable.



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Students saw me as 'weird' or 'scary looking' and having a mean resting face didn't help.

Fortunately, none of that effected my grades, but it did affect my mentality, making me



avoid students and scarcely interact with them, only doing so in case it was absolutely necessary.

All that 'mysterious' aura I had around me due to the walls I had built around myself, it scared kids away, in fact, I scared kids so much that they themselves avoided me, making sure to stay away and not even mention my name.

Yet so far, I've went through the beauty and misery of friendships, and finally with Allah SWT's blessing, found the most precious friend, more precious than I could wish for, and to Annie, you're one of the best blessings Allah SWT blessed me with.



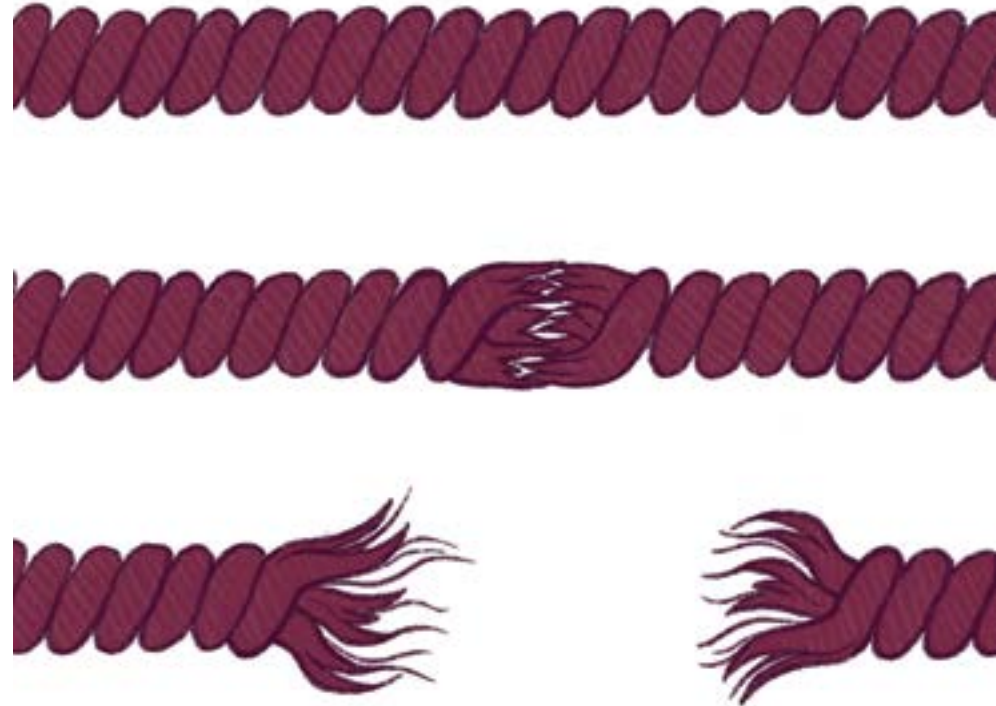
Friendships?

Eventually, I joined a friend group of 5 girls, me included. If I say they were bad I would be lying, and if I say they were good, again I'd be lying. So, I'll say that we all were not meant for each other as a friend group.

For the first few years of being in the group, it was fine, a few excited children living life jubilantly. However, going into middle school, we became 4 girls including myself.

Our preferences started changing due to our minds growing. Fights started happening, backbiting ensued, and by then I had felt a creeping loneliness due to not sharing the same mindset as the other girls in the group.

On entering 7th grade, I got separated from my group, leaving me with other girls. At that time, I joined a different group, meeting my now precious friend Annie.



As I have mentioned in the third chapter of this book, I have always struggled with my religious views and my closeness to Allah SWT. Yet when Annie became my friend, many of my views changed, and it would be a catastrophic lie if anyone says I didn't grow into

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a more mature and religiously faithful person. She has never left my side, never once has she given me a glossed over opinion for, she knows that we both are straightforward. If anyone asks me about her, I'm ready to

paint, write and carve descriptions of her into rough stones, for a real friendship with some arguments and discussions is better than a sugar-coated one with no arguments whatsoever.

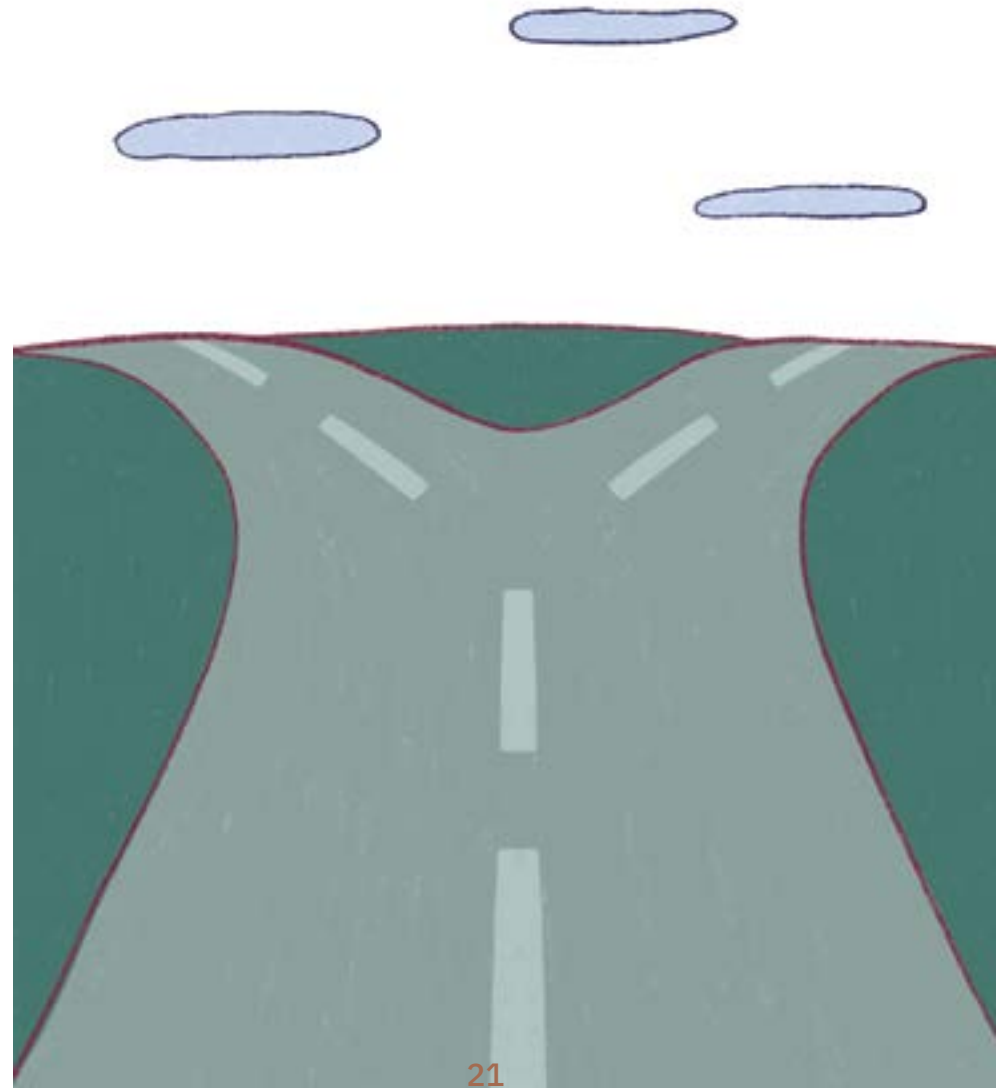


Heart Or Mind

After finding Annie, despite us being of completely different religions, she helped me get closer to my own religion, changing my morals to the better and my way and perspective of thinking.

At this juncture, I had gotten so much help to change my lifestyle. To reach out to someone far greater than anyone. I ultimately knew what I had to do. I knew I needed the help; I knew getting help from someone maybe more mature and professional than me would help, and for me to get closer to Allah SWT for He is the One who draws our path and way of life.

My heart still held the grudge of all the pain I went through, yet in my mind I wanted to make a new start, another chance. I wanted to turn over a new page, a better start, one where I can make my own choices, a start



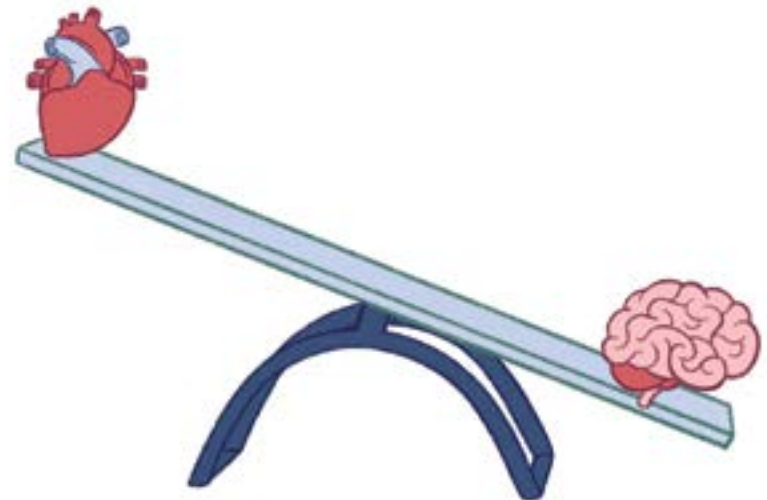
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which would satisfy and heal me. However, what's harder than when your heart and mind aren't in agreement? What happens when you've carved the past into your skin and are unable to put a bandage on it and let it heal?

Having no one to talk to about this, I sought my "human diary", my Annie, my beautiful friend which Allah SWT blessed me with.

I told her, I revealed my honest thoughts; I expressed how I was unable of letting go of my wasted childhood. However, she said something that caught my mind and though I don't remember the exact words, I do remember the important part, which was what's on my mind, "At least people tried, believe me they didn't enjoy having to put you through what you went through either, at least your parents tried, at least some cried for you. What if no-one tried? Wouldn't your mind have been plagued with what if's?"

And there, these words made the one difference and helped me make a choice. Those words made me let go of my past and hang onto the present as my past won't help my future.

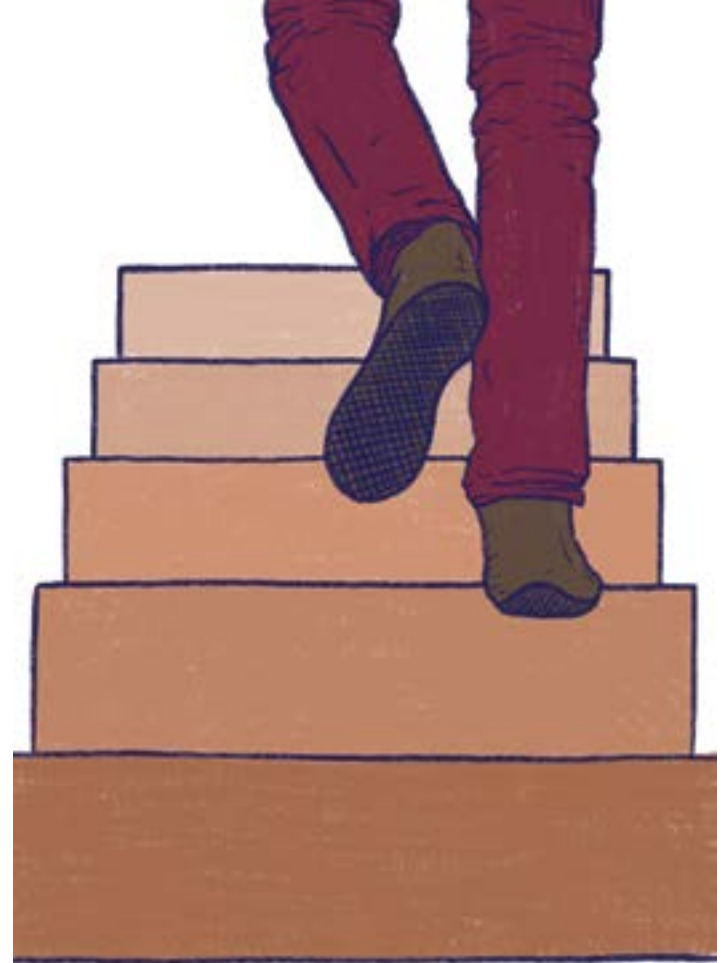


Winds Of Resilience

A person can change in many ways, for we're humans and Allah SWT has blessed us with brains. Whether it's physical change we need, mental or spiritual, it's all considered change. However, what I needed was change of heart. I needed my heart to heal, so that my mind can take more mature decisions and choices. Of course, that has a healing journey, so let's begin with it.

Having a mentally unwell mindset and being disconnected from Allah SWT causes a person to make poor decisions, a special canon event of mines would be playing ninja fruits on my arms.

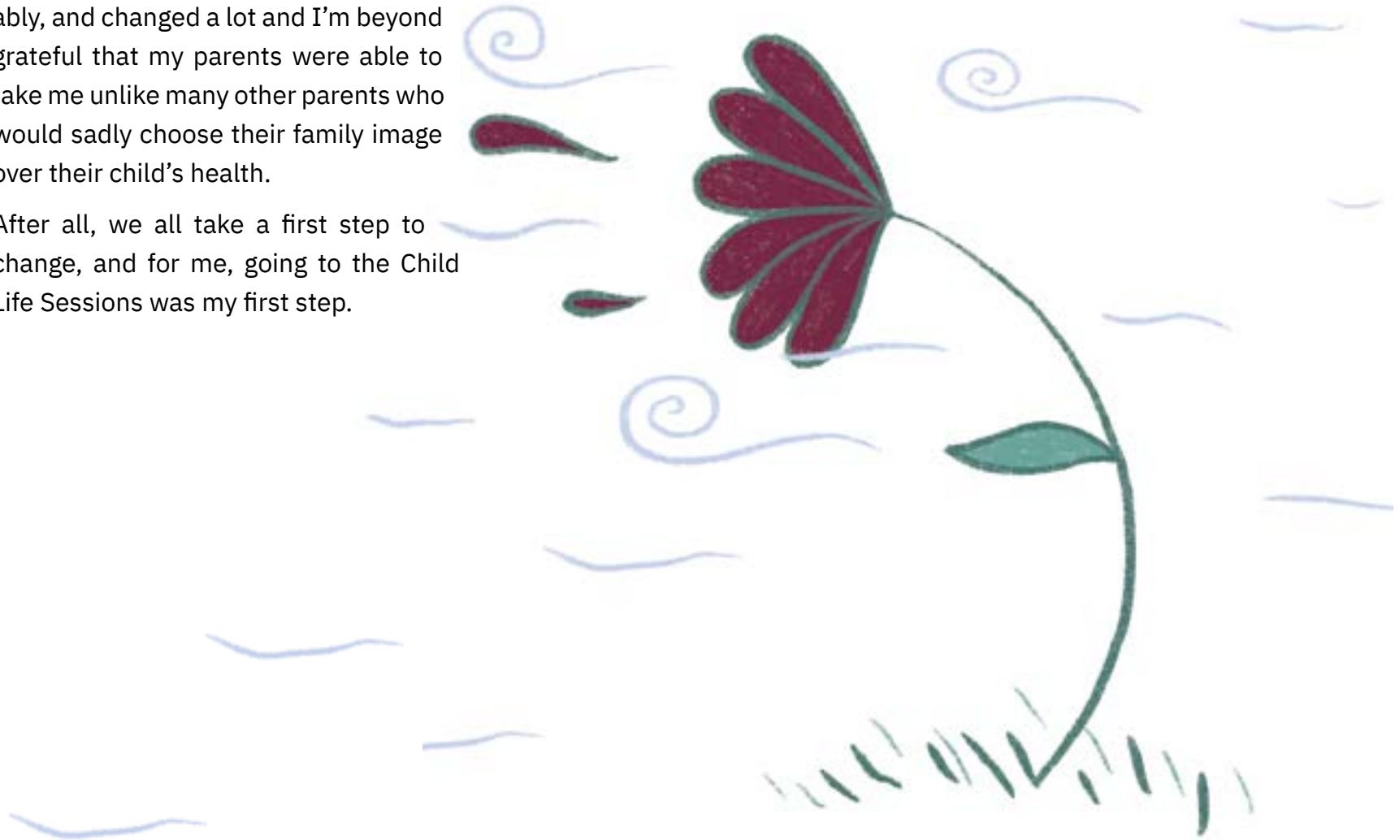
After my mom sadly found out, she decided to take me to Child Life Sessions which needed to be impartial.



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Child Life Sessions helped considerably, and changed a lot and I'm beyond grateful that my parents were able to take me unlike many other parents who would sadly choose their family image over their child's health.

After all, we all take a first step to change, and for me, going to the Child Life Sessions was my first step.



Baby Steps?

If anything, going to someone professional and letting your guard down is not at all easy. It takes so much courage and for me that was the first step.

Going there not only helped me change my perspective on so much, it also helped me

modify my behaviour, and I truly have no complains at all.

However, I still wasn't close to Allah SWT at all, and as they say religion is a journey and mine really was a long one.

Then one day, I was listening to a religious lecture, and the Shiekh said something that deeply resonated with me, his words were:

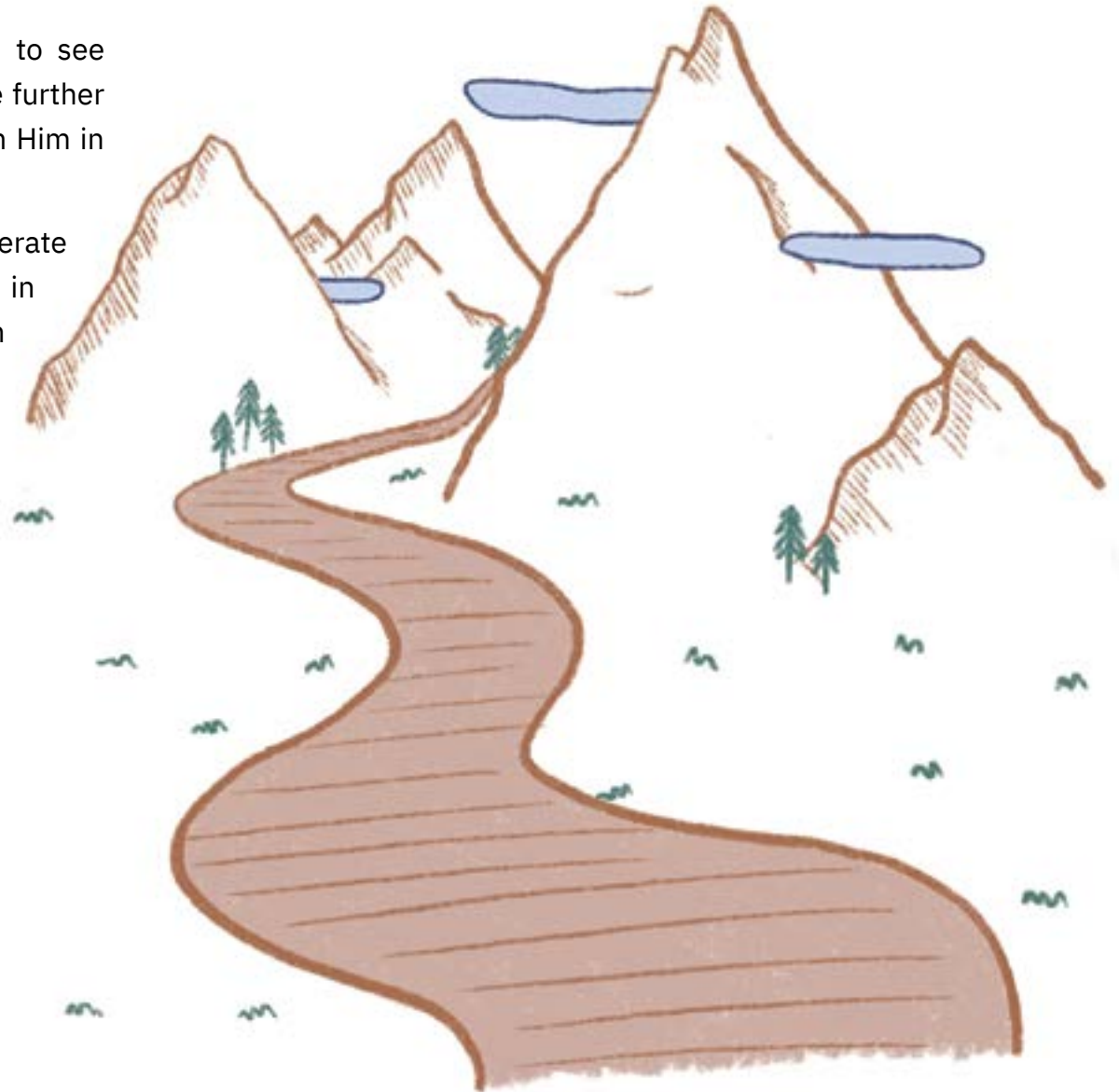


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“Allah SWT places burdens on you to see whether you’ll seek His help, and He further burdens you as you move away from Him in order for you to come closer to Him.”

Now, these said words will not reverberate with everyone, and I expect no one in the slightest to have the same opinion as me to the above words at all.

Yet, these words helped me a lot, and thankfully drew me closer to Allah SWT. Here I took my steps, and I believe that anything’s possible if you’ve got enough nerve.



Acceptance Problems

Despite the acceptance of my skin, and of my achievements and where I am in life, there's still plenty to get used to and learn about and much to accept.

In this generation, many girls apply makeup and at some point, in life, even I got interested. Yet due to my skin condition, I wasn't sure what I could apply and what I couldn't, so to no surprise and again definitely not the first time and absolutely not the last, I asked Annie, she replied: "Why don't you ask your doctors? You're a girl after all, they should know that you'd reach an age where you'd get interested in such stuff?", now to no shock, there's a great deal that doctors don't know.

Although there's not much I knew. People go through bodily changes as I do; I won't get



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too deep into it for the sake of whatever privacy I have left. Yet there's quite a difference and I had to learn much after it.

However, making friends while having a skin problem wasn't hard due to my social personality, in fact a lot of my friends would remark about it, even my relatives, which I'm truly proud of. Yet, the only problem was the level of maturity since experience changes your headspace, making friends was a bit boring in my eye due to the difference in the level of maturity between us.



Waves Of Judgement

As human beings, many of us have a habit of judging almost everything we dislike or see as unusual.

A skin problem is **definitely** unusual, so the amount of judgement I got and still get was profuse.



However, judgement comes in many forms, for me it came in pity, staring gazes, loose lips and tongue wagging.

For it wasn't fun when little kids would get scared and go to their moms, and who am I to blame them, I myself am a very big scaredy-cat.

It wasn't fun when kids would look at me as if I was **something** new on the surface of Earth.

It wasn't fun when parents would randomly come up to my mother or father and ask them about my skin. Sure, curiosity exists, but curiosity killed the cat, didn't it now? The pure scrutiny I would feel is indescribable, and if I have to force myself to describe it, I'd say that the only way to let it out is scream and cry till I fall asleep.

However, by the age of 13, I became quite nonchalant to anyone's opinion, I became

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more direct, more straightforward than I ever was, and these traits changed the way I act in many ways.

If I would see someone staring at me, I would walk up to them and casually ask, “Do you need something?” or, ‘Is something the matter?’ and to be fair, it was quite hilarious seeing the frantic panic in their gaze, for truly we fear what we do not know.

Although I stopped caring about people’s opinions, many of their words remain instilled in me no matter how hard I try.

I’d rather not literally write what I’ve been told for truly it’s so much that I’m able to list them from ‘Quite mediocre’ to ‘Damn, that has a hit’.

No matter how confident a person is, in their time of sadness or need of help, every bad word or cruel sentence *will* come back whether a person likes it or not. It in fact changes their whole perspective.

For me, I’ve never been one who’s insecure about my skin, actually almost 15 years of having this skin problem, I’ve accepted it even if a bit forcefully by myself.

Even with much confidence about my skin, I still view it as a problem and once when I told Annie about it, she said: “I’ve never seen your skin as a problem. I never even noticed it”.

It isn’t even a problem, it’s barely noticeable. You view it as a problem due to everyone else viewing it as so when it isn’t.

And until she uttered those words, I have been stuck trying to accept them.

Truly, everyone needs an Annie in their life and Alhamdullilah, I have my Annie.

Home

As we reach the end of this book, I wanted to reserve a chapter for my parents. My Mama and Baba. Seeing that I didn't mention them much because I think they deserve this chapter, their own chapter.



Many times, when we get sad or angry with our parents, we often show it rather a lot and make it obvious, for Allah SWT in his Holy Book said:

Surah Al-Isra (17:23) in English:



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“And your Lord has decreed that you not worship except Him, and to parents, good treatment. Whether one or both of them reach old age [while] say not to them [so much as], ‘uff, and do not repel them but speak to them a noble word.”

As for my parents, they’re the nicest and loveliest parents in the history of the whole universe’s timeline.

I’ve seen them try everything to help me with whatever I’m struggling with, from friends, the first day of school, to random mental breakdowns in the hospital after I take an injection and never ever have they failed me.

Although it’s hard to sometimes prove and assure them of my love, I hope I do so from this book for wallahi they are a blessing from Allah SWT. My precious Mama who has never made me feel unwanted and never tired of searching and trying and had always strived for the best in me.

My precious Baba that I share my humour, good looks and my impatience from.

I thank them both for their own imprints that they’ve left on me and for making home an actual home.

Advice Or Truth?

Dearest Gentle Reader, as we reach the chapter that will probably be the last one in this book, I want to thank you and hope you enjoyed me spilling my thoughts out to you, and I hope that you took both a truth and a fact from each chapter, in fact a lesson too.

Yet, after all is said and done, a person doesn't have the ability to go back in time and change a word, action, or practically anything.

So, if I was to give you a life lesson, I'd ask you to believe in yourself, you are the only thing that's truly yours and no one can control that unless you allow them to do so. If you like something and your friends don't, don't change it, wait till you just grow out of that liking phase or just love it as much as you want. For in the end no matter what you do you'll get judged, whether you act



like a fool in the streets, or a professor in Harvard, people will always judge, for that is human nature. I, who is giving you advice, could make mistakes.

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However, if I had to tell you a truth, which I want to, I'd say: Everything is planned by Allah SWT. Although, it took me 15 years to Finally accept so, it's a big truth, for every cough, or sneeze or tear, it is all through His power, He wrote, planned for this moment to happen and we are but 'Ibaad Allah Al Saliheen' meaning the righteous servants of Allah SWT. I have given you the truth and my advice, now I can give you my honest thoughts and ask of you to live for yourself and not for anyone else. I can ask of you to stand up for yourself. I can ask you to have sabr (patients) for that's what's kept me alive for so long, and finally I can ask you to do good in the world for it is only our good deeds and words that count in this illusion called Al-Dunya since 'Inna lillahi wa inna ilayhi raji'un.' meaning in simple literal English that 'Indeed, we belong to Allah, and indeed to him we return.

So, live on and enjoy what Allah SWT has blessed you with and show your gratitude

to those around you and if you should say one word that I think is good, say 'Alhamdulillah' for all praise really is due to Allah SWT.



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True Home

I've noticed in many biographies that I've read, or to be more accurate, looked over, there was really awful mentions of the writers' extended family, extended family as in, grandparents, uncles or aunts, cousins, and so on.

But, in this book that I write, I refuse to release it to people without writing about my own relatives, for no matter what I am; a family girl through and through on my paternal and maternal sides of my family, I have fond, lovely memories with both sides.

Extended family is a real big blessing, and a person doesn't realise what they have until they look around and find such blessings like this, for example, are not accessible to everyone to the same extent, I for one, have always been one of my grandparents' little girl, on both sides for I do not do favouritism, since I

believe favouritism in families shouldn't even be a thing unless there's a solid reason. I've always been close to all my cousins, and they make up most of my memories even while in hospital and that's something I'll cherish even when I grow up. As much as I'd love to mention them by name, I will enter a loop of vulnerable gratitude and lose my spiral of thoughts. Yet the love for my cousins on both sides of my family even if they're far, they're



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near in my thoughts, each one of them I'm almost 99% sure that I have a special moment with her or him that changed my perspective to the better of them.

Should you ask me if I like attention, I'd say 'No, attention is for pick me 's!' yet if you asked me on a deeper level, I'd say 'yes! I thrive on attention!', and that indeed is why I have favourite uncles or aunts, on both sides of my family so to speak, and to hear me talk about them, it obviously shows who from my family is my favourite. Frankly if my adorable family read this, I'm pretty sure this mystery will not go unnoticed.

As for grandparents, I love mine on both side for actually they're the sweetest, kindest souls that have walked the earth. I must say, while surfing the internet and wasting time on social media apps, I'd often find videos of both young and old people vent about their grandparents and it baffles me every time, for aren't grandparents meant to be sweeter

than parents?! What's going on?! That's when a person realises, they're not aware of their blessings at all.

No matter what happens, after all is said and done with everyone, a person shall always be known and hopefully accepted by their number 1 home, their family.

Resentment Blindness

Acceptance comes in many stages, let's say for example, its stages are:

- 1. Denial: Refusal to accept the reality of the situation.
- 2. Anger: Frustration and resentment towards the situation or those perceived to be responsible.
- 3. Bargaining: Attempting to negotiate or find a way out of the situation.
- 4. Depression: Feeling of sadness and hopelessness.
- 5. Acceptance: Coming to terms with the reality of the situation and finding a way to move forward.

Resentment typically falls under the anger stage. It is a form of anger directed towards others or the situation itself.

Let's ask ourselves, what is resentment? Now if I asked Google what's resentment, I'd get: "Resentment describes a negative emotional reaction to being mistreated."

Very simple? Very simply put, no?

Yet if I ask a human the same question, will I get the same simple-minded answer? No, no I will definitely not.

Now, our dear Google wasn't wrong on the brief and simple-minded explanation or briefing of this feeling, yet the question remains, 'what is resentment?'

To me, resentment is a very ugly and selfish feeling that I've lived in for a good amount of years, the best way to describe resentment is using its blindness.

In the 14 years I've lived, I've been neck deep in resentment, pushing away other thoughts and only listening to my selfish logics. It took me 14 years to get out of resentment, and oh

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I've never been happier now that I've gotten out of it. Although, looking back, I realised how little gratitude I had.

Family? Don't care. Friends? Couldn't care less. Food and basic human needs and shelter? I do not care. I was as you can see blind to the simple yet great blessings, I had that others did not and would die and indeed have been dying for. It was at this moment when I realised that I had been blind to the simplest yet greatest of things Allah SWT has given me.

A good family? A good house? Siblings? Food? Water? A phone? The list goes on and on with never ending options and as great as they are, to a person with resentment they mean nothing as long as they're still holding onto whatever it is that adds to their resentment. For example, sometimes when I'd vent to friends, about my skin problem, they'd reply with sentences like:

'Okay but like be grateful you have a mind'.



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Chapter 14

‘Jana, some people don’t have eyes, at least you have them!’

‘Girl, I get you, but like at least you have a brain?’

Look now, there’s 600,000 words in English yet none of them would describe the way I’d want to scream and cry and throw a tantrum and absolutely tweak at the person who said that. For in my resentful mind, I didn’t care. The sentence that would irk me most was the last one about brains. Now listen here, I would always be trying so hard, literally clenching my jaw from giving a smartass retort because the way you’re trying to reason with me DID NOT AT ALL make sense to my resentful mind.

However, even having got out my resentment, I still hate such comparative sentences and personally, I truly believe they did increase in whatever resentment I felt, and I will not hesitate anymore, if someone comes up to comment, ‘Oh well, at least you have a brain!’ you

are getting smacked because I will be GIVING YOU a piece of that brain you speak of which you so clearly DO NOT HAVE.

After all, said, clearly said and fully done, dealing with resentment comes in many shapes and forms.

For resentment is a sensitive and blind feeling, any word or sentence can come the wrong way, so truly resentment is blind.

Gratitude Of Healing

I for myself, am a very grateful person, especially after getting over my resentment, which I believe and hope you could too, I have frankly been grateful for the very sip of water and bite of food I take. Gratitude for me and to me is such a beautiful feeling. It is so in depth and carefree, you can be grateful for walking and bam!



Gratitude.

This life and this world lack many things, but gratitude is quite lacked too.

You see kids and children these days get upset over the toys they get when their family has a celebration, you see adults not happy with their salary, you see a father not happy with his child, or a child nor satisfied with his father... Now in all this and more, where is the gratitude?

It is not easy to acknowledge gratitude, or to be more specific, to actually feel it, for I think half of this universe agrees that the world is a beautiful lie and only fools get lost in it along the way, so what is there to be grateful for? The pain? The suffering? The losses and deaths?

However, let's hypothetically assume we aren't grateful, then what is life? There will be no point what-so-ever in it. Woke up? Okay.

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Breakfast? Okay. School or college or even work? Okay.

Then if we keep on going with 'Okay's, why even wake up? You made your life a routine by not caring about the simplest acts, honestly, why are you still going? If you have no goals, no motivation, no gratitude for the present or for anything, then what are you living for?

As much as this book is meant to make you, ahem... love life, there definitely are many harsh truths, for this is life, however, if you're not ready to accept them, life will send you its own special message in a very fitting way by sending you a lesson your way.

For me, I love reading and I love movies, yet if I've observed anything from both, I've observed that characters that are 'difficult' to love are always called 'cruel lovers'.

Now I do not have much say on that name, yet isn't it almost like life? Its cruel yet it's beautiful, it's made for us to live, to laugh, to expe-

rience, to love, for everything beautiful comes with its flaws and we are to accept it if we truly even love it.

There's no specific thing a person should feel gratitude towards. Be grateful you can wake up another day, see your loved ones, eat your favourite food, repent, pray. It's all in the smallest acts.



The end...

A Message from Family to Jana



“You will always be the first candle that lights my life, even if you become a hundred years old. You are my princess and companion from whom I learned strength, patience, endurance, and standing up to the impossible. I have always been and will be your supporter, just as you have been my supporter since you came into my life. You are the reason for my smiles, pride, and hope that never ends.

I love you endlessly and I am so proud that you are my daughter, and that God chose me for this greatest role, which is to be your mother. You have always been smart and aware of your surroundings, and you are far ahead of your age; as you have always been the leader in all situations and with all your friends and relatives, and you deserve this position.

Despite all the bumps you have gone through, now you finally have begun to achieve your hopes, and I proudly and honourably wish you to reach to the top, as your success in life is the most beautiful reward for me.”

Mama

“Jana is my firstborn who lit up my life and her mother’s life, and she is the candle of my home. Jana has been a very smart child since she was born, and she was a quick learner when she was young, and she has many talents.

I love Jana very much because she is my first, beautiful, and obedient daughter. Despite being sometimes harsh towards her, I only do so because of my intense love for her and my extreme care for her. I wish that she achieves all of her dreams and to see her in the highest places so that I can be proud of her among people knowing that she is my beautiful and special daughter. I wish you, my love, the most beautiful life filled with happiness, success, and love. Your loving and proud father, I love you very much, the most beautiful candle that lit up my life “

Dad

KACCH & BACCH is a unique charitable organization that cares for extraordinary children and teens like Jana 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 same level of support through our dedicated Child Life teams, no matter where they are.

In Bayt Abdullah Children’s Hospice children receive support that is tailored to their individual needs. 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.

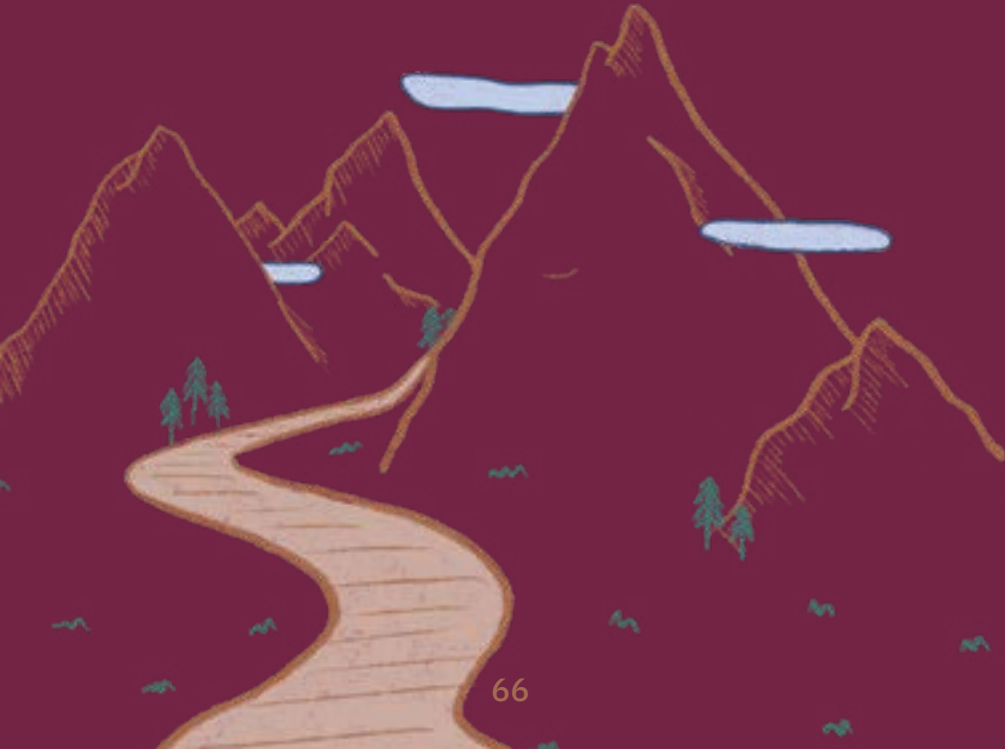
To learn more about us, visit www.kacch.org or follow us on social media @kacchbacch.



About The Story

“The Once upon a Lifetime” is a story that explores how to live with an undiagnosed skin problem and how it leaves its lessons.

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