

UNSEEN BATTLE WITH THALASSEMIA

A DROP OF HOPE, BELIEF, AND FAITH



Author's Edition

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Unseen Battle with Thalassemia
A Drop Of Hope, Belief and Faith

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Dedicated To ,

To every Thalassemia warrior,

who wakes up every day not knowing how their body will feel,

but still chooses to fight, smile, and move forward this book is for you.

To my parents, who stood like a shield between me and every storm.

To my family, who never let me feel alone in the darkest hours.

To my friends, who stayed even when they could have walked away.

To every teacher, doctor, and blood donor whose contribution, advice, and support kept me alive and learning.

And to every single personal known or unknown who held my hand, offered a word, gave a unit of blood, or simply hoped the best for me without saying a word.

Thank you.

You are a part of this journey.

You are a part of this story.

Raj C.

Acknowledgment

Writing this book was not just about putting words on paper it was about revisiting every wound, every win, and every moment that shaped me.

First and foremost, I bow my head in gratitude to every Thalassemia patient who continues to live with unimaginable strength. Your silent battles inspired me to speak mine out loud.

To my parents, who never gave up on me even when I almost did. Your love, patience, and sacrifices are behind every word in this book.

To my joint family, whose care and togetherness gave me strength when my body was failing. I especially thank my dadi, chacha, bua, dadu, and every hand that helped me through transfusions, hospital nights, and exam days.

To my friends, especially Raghav, Kuldeep, Vaibhav and Dharmik for sharing both school benches and life tests with me. Our bond helped me survive and smile even when life wasn't kind.

To my doctors , Dr. Vinita Agrawal, Dr. Kamna Jain, Dr. Shikhar Jain, Dr. Gauri Rao, Dr. Shivani Patel , Dr. Sudhesh

Sharda , Dr. Sandeep Khatod, Dr. Anil Verma, and Dr. Prashant Agrawal ,your words and wisdom became the thread that held my life together.

To every hospital staff member especially Kale Didi, Anju Didi, and the countless others whose names I may not remember, but whose care I will never forget.

To the blood donors known and unknown who gave me life without asking anything in return. You are my unseen angels.

To my teachers and mentors, who encouraged me not just to pass exams, but to tell my story. Your belief became my voice.

To every reader holding this book thank you for choosing to listen. I hope these pages leave you more hopeful, more aware, and more human.

Lastly, to the voice inside me that never stopped whispering, "Write it down, someone needs to hear it."
This book is my answer.

Raj C.

Preface

“This is not just about blood. It’s about everything that kept me alive in between the blood.”

I wasn’t born with a story.

But life had a different plan.

At the age of two, I was diagnosed with a rare genetic blood disorder ,Thalassemia Major. Since then, hospitals became a second home before I even learned to spell the word. While most children feared exams or teachers, my fears were different a falling hemoglobin count, unfamiliar machines, or a delayed donor.

This book isn’t about winning anything , it’s about surviving everything.

It’s about:

Waking up early not for school, but for a blood transfusion.

Every few weeks, we travelled nearly 60 kilometers to reach Indore ,just for a bottle of blood and a few more days of life.

Watching dreams fall apart... and then somehow, choosing to dream again.

I've written this not as a hero, but as a human ,who got tired, broke down, lost people, lost himself... and still stood up.

There were days I felt like I was just a number on a hospital file.

But there were also days when someone's blood gave me breath ,and a stranger's kindness reminded me that I mattered.

If you're a patient, a fighter, a dreamer, or just someone who's been through pain ,this story is yours too.

And if you've never heard of Thalassemia before ,maybe this book will help you understand someone's silent battle.

Read it not because I lived through something rare ,

Read it because somewhere in these pages, you might find your own strength.

[**Raj C.**]

(2025)

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Introduction

(Why I wrote this book)

I never planned to write this book.

It wasn't a dream or a goal it just happened.

There was a fear that kept building up inside me.

In the Thalassemia ward, I've seen friends
disappear friends who were with me in the last
transfusion, suddenly not there the next time.

The people I spoke to yesterday... were just gone.

That fear started stealing my sleep.

Sometimes, I just wanted to write everything down
maybe it would lighten my heart.

After failing again and again in exams, and facing
one problem after another, I felt like my story
shouldn't stay locked inside me.

Maybe someone out there is going through the
same thing.

Maybe it will help them feel less alone.

This book is made of everything I lived through ,the words I couldn't say, the feelings I never shared.

If even one person reading it feels, "Yes, I've felt this too,"

or if it gives someone a little hope —
then all this writing will be worth it.

This book is not just about pain.

It's about hope, belief, and the will to keep moving forward.

Part A : The Beginning

Chapter :1 What Is Thalassemia?

(The Medical Side : A simple explanation in my words)

Thalassemia is a genetic blood disorder that affects the body's ability to produce hemoglobin, the protein in red blood cells that carries oxygen.

There are two main types:

Thalassemia Minor (Trait): A person may carry the gene but usually has no symptoms or mild anemia.

Thalassemia Major: A serious form where the body cannot produce enough healthy red blood cells, leading to severe anemia.

People with Thalassemia Major often need:

Regular blood transfusions (every 2–4 weeks)

Iron chelation therapy to remove excess iron from the body
(since transfusions build up iron)

Lifelong medical care

It is an inherited disorder, meaning both parents must carry the gene for a child to have Thalassemia Major.

♥ Now, in My Words...

Thalassemia isn't just a medical condition ,it's a way of life.

It's something I didn't choose, but it chose me when I was just two years old.

For me, Thalassemia has meant:

Missing school days for transfusion appointments

Watching other kids run in the sun while I waited in a hospital chair

Feeling tired ,not from playing, but from low hemoglobin

Learning to smile with a needle in my vein

Carrying a disease that no one can see, but that affects everything I do

At times, it has made me feel different.

At other times, it has made me feel stronger.

It taught me that even though my blood may not work like others',

my heart, my mind, and my spirit
are no less capable of fighting.

This chapter is not just about what Thalassemia is ,
It's about what it means to live with it, and still dare to
dream.

Understanding Thalassemia – Like Fuel in a Vehicle

"Thalassemia is like having a vehicle that cannot produce its
own fuel.

Just like a car needs petrol to run, the human body needs
blood to stay alive and active.

A healthy body makes its own blood, just like a good car
engine runs on the fuel inside. But a thalassemia patient's
body cannot make enough blood on its own ,it needs blood
from outside, regularly.

Imagine a car slowly stopping when the petrol runs out ,the
same thing happens with a thalassemia patient when their
hemoglobin level drops.

Weakness begins, energy fades, and life starts to slow down.

And just like a car needs fuel again and again, a thalassemia
patient needs blood transfusions again and again.

It's not a one-time treatment ,it's a lifelong journey.

The only difference is:

If a car stops, you can fix it. But when blood runs low in a human body, it's life that struggles."

Chapter : 2 When the Name Found Me

(Birth in 2000 – Diagnosis at age 2 – First emotions)

I was born on 15th September 2000, around 3:10 PM, in a small district called Dhar, Madhya Pradesh. I was the first child in my family, and that made me special. Even today, I still receive that little extra attention because of it.

I grew up in a joint family, surrounded by love, care, and laughter. Everything in life was going smoothly. But then, in 2002, things began to change ,not just for me, but for everyone around me.

It started with a case of jaundice, but something didn't seem right. My skin wasn't turning yellow ,it was becoming unnaturally pale. Around the same time, a doctor named Dr. Vinita Agrawal, who had recently moved from Mumbai to Dhar, was suggested to my parents. Without wasting time, they took me to her.

Dr. Agrawal took one look at me and said something that none of us expected:

“Get him tested for Thalassemia.”

We had never even heard that word before. Still, trusting her experience, we went ahead and got the tests done in Indore. The result came back: positive. I was diagnosed with Thalassemia Major.

To be sure, my parents also consulted our family doctor. He asked for another blood sample. At that point, only a few close members of the family knew about the situation. The repeated tests were making everyone more anxious.

Despite the stress, my father somehow managed everything and sent the second sample. The result came back the same, confirmed again.

Now, we were standing face-to-face with a disease we had never even heard of, let alone imagined living with.

From this moment on, a completely new journey began.

Dr. Agrawal advised us to consult Dr. Modi in Indore. But that visit turned out to be one of the worst experiences for my parents. His words were harsh, his behaviour even worse. The stress was so high that my father nearly fainted right there in the hospital.

Later, my father decided to share everything with bade fhupaji . As fate would have it, someone near his house had a child suffering from Sickel Cell Anemia. Through them, we

came to know about Mr. Lokesh, whose son also had Thalassemia.

Mr. Lokesh became a blessing in disguise. He helped us get registered at Choithram Hospital, under their Thalassemia Trust Unit. That's where we met Kale Didi and Anju Didi, who were part of the dedicated nursing team.

And so began the long journey of blood transfusions and regular tests ,a journey that continues to this day.

While all this was happening, another story was unfolding in parallel ,my mother was 5 months pregnant .

After my diagnosis, doctors were consulted again. Many of them gave a painful suggestion:

"You can apply for permission and terminate the pregnancy."

But my father wasn't ready to give up. He once again spoke to Mr. Lokesh, who strongly advised not to go for abortion. He also connected us with doctors in Mumbai, where testing had advanced enough to check for Thalassemia during pregnancy.

My parents travelled to Mumbai. But during the first test attempt, when the needle was inserted, the baby moved suddenly, and the test had to be stopped. We had to wait three more days.

On the second attempt, the test was completed. This time, the report brought relief, my younger brother did not have Thalassemia. However, there was one small complication. During the first failed test, when the needle had touched the baby, a small blood clot had formed, though we didn't know it at the time.

Back home in Dhar, when my brother was born, he cried a lot. Local doctors thought it might be pneumonia. He was treated locally and given steam and medication almost five times a day, but his condition didn't improve.

Finally, we took him to Dr. Kutumble in Indore. After reviewing the reports, he said:

“There's fluid in his lungs, we need to operate immediately.”

And so it happened.

On one side, my little brother was in the operation theatre, and on the other side, I was in the blood transfusion room, both of us fighting battles we never choose.

Chapter : 3 Learning from the Warriors

(Meeting other thalassemic patients and their families – learning what lies ahead)

In 1993, a group of selfless individuals started something powerful ,The Thalassemia and Sickle Cell Society of Indore.

It was more than just an organization. It became our extended family.

Led by Shri Lokesh Khubnani (President) and Shri Ashok Mandwani (Secretary), it gave us identity, guidance, and hope.

People like Manoj Pahwa, Ramesh Harshpal, and many others whose names I might not remember ,yet whose actions changed lives ,became the silent architects of our journey.

And for anyone I forget to mention ,please forgive me. This gratitude is not about one name, but the spirit behind all of you.

It was through their tireless efforts that I got registered at the Thalassemia Society of Indore, and with that, a new phase of my life began ,one with a little more structure, a little more support, and a whole lot more hope.

From that moment on, I wasn't just a patient with thalassemia.

I was part of a community.

A family that never asked for anything ,yet gave everything.

Because real heroes aren't always found in comic books.

Sometimes, they sit quietly in hospital waiting rooms...

...fighting battles no one can see,

...changing lives without ever asking for credit,

I stepped into a world I had never imagined ,a room full of kids like me, each one carrying the same invisible burden.

Until then, I thought I was alone. But the hospital showed me I wasn't.

There were many children, coming from different towns and villages, each with the same routine ,transfusions every few weeks, test reports in hand, and hope in their eyes.

Their parents, too, looked tired, but strong.

They waited with quiet patience, helping their kids pass the time during long transfusion hours ,with stories, food, or just a gentle pat on the back. My father was one of them.

Over time, we all started to recognize each other ,not just faces, but lives. We'd exchange smiles, small talk, sometimes even lunch.

Through those small interactions, I learned what my future might look like ,not through medical books, but through real people living it, every day.

Many of them had been walking this path for years.

And watching them, I slowly understood ,

This journey was hard, but not impossible.

Our parents became each other's support. They discussed doctors, test results, side effects, and shared little tips that made things easier.

And while we children sat with needles in our arms, we somehow made space for laughter too.

I didn't find heroes in comic books.

I found them in that hospital room ,wearing no heroic attire , but carrying unmatched strength in silence.

Chapter : 4 First Day, First Fight

(My first visit to hospital , the staff , the circumstances and my tiny hands)

I still remember my first day at Choithram Hospital ,not because I was brave, but because I wasn't.

Everything felt too big:

The building.

The machines.

The wires.

Even the smell of the hospital felt strange.

I was too young to understand what Thalassemia really was. But I could tell that life was going to be different now.

I held my father's hand tightly as we walked into the Thalassemia Unit. My mother looked worried, trying not to show it.

That's when we met two
faces I would never
forget ,Kale Didi and
Anju Didi.

Kale Didi was the head nurse of the Thalassemia department ,calm, clear, and experienced. Anju Didi worked with her ,soft-spoken, caring, and always quick to notice if something wasn't right.

They didn't treat me like a number or just another patient. They treated me like a child ,scared, confused, and new to this whole process.

When I saw the needle, I cried. I didn't care who was watching. My hands were tiny, and that needle felt like it didn't belong there.

But Kale Didi held my hand, looked straight into my eyes, and said,

"It will hurt a little, but we're here with you. Just trust us."

And somehow, I did.

That day wasn't just my first transfusion ,it was my first fight.

A fight with fear.

A fight with pain.

A fight I didn't choose ,but couldn't escape either.

After the transfusion, I was given a small chocolate. Not because I had been strong, but because they knew I needed something sweet to hold on to.

That room would soon become familiar. So would the nurses, the process.

But that first day ,with its fear, tears, and quiet strength ,has stayed with me till today.

Some beginnings are not grand.

They are just real.

And mine began with two kind nurses, a long needle, and a small act of courage.

Part B : Growing up on a different road

CHAPTER : 5 A Childhood with Blood Sets and Books

(Schooling memories + balancing transfusions and class)

Most kids grow up between playgrounds and notebooks.

I grew up between school bags and blood sets.

My childhood was a little different ,not because I didn't go to school, but because I carried something extra with me:

a disease that didn't look visible, but stayed with me every day.

Every 15 to 20 days, when most of my classmates were planning holidays or playing cricket, I was in a hospital bed, lying still, with a needle in my arm and a blood bag hanging beside me.

In the beginning, it was tough.

I had to miss school on transfusion days, and sometimes even the next day if I felt weak or tired. But I was lucky to

have a few understanding teachers and classmates who didn't make me feel left behind ,at least not always.

There were days when I would sit in class with low energy, trying hard to concentrate while my body quietly asked for rest.

But then there were also days when, just after a transfusion, I felt full of life again ,reading aloud in class, solving math sums faster than usual, or just enjoying the feeling of being "normal."

One of the hardest parts was explaining to people why I was absent so often, and why I sometimes looked pale or thin.

Some kids would ask directly,

“Tu baar-baar hospital kyu jaata hai?”

I didn't always have the words to answer.

But slowly, I learned to smile, nod, and move on.

School became more than just a place to study.

It became a place where I tried to feel like everyone else ,where I could forget about needles, reports, and hospital smells, even if just for a few hours.

Books became my friends.

They didn't care about my condition.

They didn't ask questions.

They just welcomed me into stories, poems, and ideas where I could escape for a while.

Looking back, my childhood was
never easy ,but it taught me balance.
Balance between hospital beds and
classroom benches, between blood
drops and ink pens, between what I
had to fight, and what I still wanted to
become.

CHAPTER : 6 Sympathy or Empathy?

(How people treated me: kind, awkward, or cruel ?)

Living with Thalassemia didn't just mean managing blood counts or hospital visits ,It also meant managing people.

As I grew older, I started noticing something strange in the way people looked at me ,Not anger.

Not fear.

But something between pity and confusion.

Some people would lower their voice while talking to me, As if I was too fragile to handle normal conversations.

Others would avoid eye contact, unsure of what to say. And some... would just ask straight questions without realizing how sharp they sounded.

“Kitna blood chadh gaya ab tak?”

“Yeh bimari kab tak chalegi?”

“Thik hote ho ya nahi?”

I never had a clear answer.

And honestly, sometimes I didn't want to answer at all.

Then there were those who became extra nice
,offering help I never asked for, Or clapping for
things I didn't think were achievements.

It was confusing.

Was it kindness? Or just sympathy wrapped in
awkwardness?

Very few people actually tried to understand me
,not as someone with a disease, but as someone
who still had dreams, jokes, anger, mood swings
,like anyone else.

That's when I first understood the difference between
sympathy and empathy:

Sympathy says, “I feel bad for you.”

Empathy says, "I may not know your pain, but I'm here if you need me."

I didn't need people to feel sorry for me.

I just needed them to treat me normally ,to see me, not just the illness.

Some did.

There were friends who never brought it up, unless I did.

There were classmates who waited after school when I looked tired, without making a big deal out of it.

There were moments when people saw me, not as weak ,but as strong without saying it out loud.

Those people made the difference.

In a world full of
quick judgments and
casual pity, They
chose quiet
understanding.

And that, I've learned, is the rarest kind of support.

And then, there was cricket.

Because of my low haemoglobin, I was strictly told not to play outdoor games. The risk of getting hurt or overexerted was always there.

But tell that to a child whose heart beat faster every time he saw a bat and ball.

My mind knew
I shouldn't
play, but my
heart ,It never
agreed.

My friends understood that.

So instead of excluding me, they found a way to include me.

Whenever we played cricket, they
always gave me a chance to bat ,From
both teams.

That meant I got to
play twice ,once for
each side. And when

my energy ran low or I
couldn't run much,

They'd let me switch to umpiring, with full respect, no
teasing.

They didn't feel sorry for me.

They just made me feel normal, without saying a word.

That was empathy.

Not through big words or emotional speeches ,

But through small acts of acceptance, respect, and
friendship.

CHAPTER : 7 First Spark of Competition

(The merit exam that changed my path)

After finishing Class 8 at St. Teresa School, I had two paths ahead:

Stay in the same environment... or take a step forward into something bigger, something tougher.

My aim was to get admission into Government Excellence School ,a reputed school where merit, not money, decided your seat.

But getting in wasn't easy.

You had to clear a district-level entrance exam, and only the top scorers were selected.

It was the first real competitive exam of my life ,the kind where you don't just study, you fight for a place among hundreds of students.

I still remember the long forms, the pressure, the endless questions that danced in my head:

“Will I make it?”

“What if I fail?”

“Can I compete with all these kids?”

But I wasn't alone.

My childhood friend Raghav was preparing for the same exam ,and somehow, that made the journey lighter.

We studied, motivated each other, and kept pushing forward quietly.

The day of the exam came. I was nervous ,but not scared.

Somewhere deep inside, I had started to believe that maybe... just maybe... I could do this.

And then came the result.

Both Raghav and I cleared the exam with the same marks.

We didn't just pass ,we made it to the merit list.

We earned our place.

That moment was more than just a mark sheet.

It was proof.

Proof that I wasn't just a kid fighting a disease.

I was a student who could compete, who could qualify, who could move forward.

That day gave me confidence that books, not just blood tests, could define my identity. And walking into that new school ,as a selected student, not a special case ,was one of the proudest feelings I've ever had.

It wasn't luck.

It was effort.

It was the first spark that would one day become fire.

CHAPTER : 8 The Exit Bell Rang Too Early

(Dropping out of school and why)

Getting selected in the merit list for Excellence School felt like a dream.

I had entered with confidence ,my childhood friend Raghav beside me, the new uniform, the new benches, the hope of something big.

But dreams, sometimes, are short-lived.

The truth hit us on the very first day ,this wasn't like our old school.

There, we were among the toppers.

Here, everyone was a topper ,from their own schools, from their towns, and now all competing in the same room.

We found ourselves from the front to the back, suddenly behind in pace, in preparation, in comfort.

Still, we didn't give up.

We attended classes, tried to adjust, and slowly caught up.

Then came the quarterly exams, and
somewhere in the middle of it ,

I celebrated my birthday at school.

It felt good. For once, things seemed normal.

But just after two papers, things started falling apart.

My health took a sharp turn.

My body gave up.

My platelets dropped to 35,000, and energy left like
someone had unplugged me from life.

That same night, we rushed to Indore.

I was admitted immediately.

Reports confirmed:

Typhoid. And jaundice. Both together.

Days turned into nights inside the hospital room.

Despite all efforts, my condition kept getting worse.

Doctors tried everything ,but improvement was slow, almost invisible.

Later, I came to know that there was a moment when even the doctors told my parents,

“We’ve tried all possibilities. Now, it’s in God’s hands.”

I didn’t know this back then.

But years later, that sentence shook me.

Then came Dr. Gori ,and with her, a small ray of hope.

She told my parents honestly,

“You know the situation. I want to try something experimental. If it works, it’ll be fate. If not... we at least tried.”

It was around Diwali.

And somehow, her treatment worked.

Slowly, I began to recover.

A few doses were still left. But I requested,

“Please let me go home for Diwali.”

She agreed ,and gave us the remaining doses to continue from home. And that’s what we did.

But by the time I regained some strength, two months had passed.

Meanwhile, two notices from school had already reached home.

When I finally visited the school, I went straight to the principal’s office, explained everything, and handed over the medical reports.

She understood ,but rules were rules.

“You have to appear in the 6-monthly exams,” she said.

But I wasn’t ready.

My body was still healing. My mind wasn’t focused.

I knew I could go and copy like some might do, but...

“I don’t want to pass with sympathy,” I told her.

She nodded, but there was nothing more she could do.

The school had strict rules:

75% attendance and no failure in any subject.

So, I had to make a choice.

And that’s when I dropped out.

Not because I didn’t want to study.

Not because I gave up.

But because my body didn’t allow me to fight two battles at once.

From that point on, I continued my education privately ,filling forms, studying from home, and walking a path that wasn’t common... but was still mine.

“That school might’ve closed its doors... but my journey of learning had just begun.”

Part C : Detours and Discoveries

CHAPTER : 9 Four Years of Self-Made Living

(Small business + studying from home)

When I left school, I thought I was only saying goodbye to a building.

But soon, I realized ,I had also stepped away from a routine, a classroom, and a system that gave structure to my life.

I couldn't even fill the private form from the same school.

For a few weeks, I stayed home, treating it like a vacation.

And let's be honest ,who doesn't like some time off ?

But slowly, the silence started asking questions.

“Am I falling behind ?”

“Is this how dreams end ?”

At the same time, some financial stress was building at home.

Around that period, my cousin brothers opened a game parlour in Indore. Watching them do something of their own made something spark inside me too.

I began dreaming about having my own game parlour.

With help from my Bua and Fhupaji, I got two PS2 consoles, and started a small game parlour right from home.

On the third day, I earned around ₹340–₹350.

I felt proud ,but suddenly, one of the games stopped working.

That evening, I went alone to Indore, carrying the little money I had. I handed it to Fhupaji and explained everything.

I don't know what he saw in me that day.

But instead of just helping fix the game, he called my cousin, and the same night ,they got me two new games, and repaired the damaged one too.

That was the first time someone invested in my will, not just my need.

From 2 consoles, my parlour grew to 10 games.

There were days when customers lined up outside as early as 6 or 7 AM.

Things were going well.

But I also knew ,I couldn't ignore my studies forever.

So my family stepped in to support me,
running the parlour during exam time. I
filled my Class 10 private form from a
government school.

And then came a twist.

When the admit card arrived, I realised it was mistakenly
filled for Hindi medium, though I had studied everything in
English.

Panic. Frustration. Tension.

I even started hunting for Hindi notes, thinking I would have
to start over in a few days.

But when I approached the school principal, he understood my condition.

The admit card couldn't be changed officially,

But he allowed me to write the exam in English with a signed note.

There was one more twist.

On the day of the final paper, I had to rush to Indore for a transfusion.

I finished my written exam, and the teachers ,already aware of my condition ,let me skip the viva.

But the system didn't.

They marked me absent for practicals.

And when I came out, I discovered my bag was stolen

A few days earlier, my phone was also stolen ,right from my home by a customer. Life wasn't running in parallel lines ,it was constantly testing me, up and down, again and again.

Still, I scored 65%, with distinction in two subjects.

That result changed everything.

My family celebrated like it was a festival.

Relatives, neighbours, friends ,all came home with sweets, smiles, and blessings.

For the first time in a long time,
it felt like I wasn't "catching up"
,I was winning on my own
terms.

Soon after, I slowly wrapped up the parlour and refocused
on my studies.

When it was time for Class 12, I was more careful.

This time, no mistakes.

And the result ? Even better.

But then came the biggest decision ,choosing a stream.

People said Arts was for the weak.

Some said Commerce was the safer option.

But I didn't care about opinions.

For the first time among 11 cousins, I choose Arts ,not
because it was easier, but because it felt right.

I had tried commerce classes for a couple of days , but my base was too weak , and nothing made sense.

That's when I remembered how a coaching centre called Safal Institute had once helped me in Class 10.

They had guided me gently through my weak areas.

And even now, most of my learning wasn't from school ,it was from YouTube, websites, and my phone.

I even completed my Master's degree with the help of the same phone ,no big library, no classroom.

My mother, too , taught me everything she could ,especially in the early years.

When things got tougher, she helped me find the right teachers.

And those teachers I still salute them . Because they didn't just teach me they believed in me .

“School chhoda tha... par maqsad nahi.”

“Life ne system se nikal diya, par maine system se seekhna chhodha nahi.”

CHAPTER : 10 A Decision with **Shubham Bhaiya**

(Choosing subjects, future, and discovering purpose)

After clearing my Class 12 exams, a new confusion stood in front of me. Commerce or Arts?

Everyone around had different opinions.

“Arts is too easy.”

“Commerce will give you more options.”

“You’re smart, why not go for science?”

But my heart wasn’t answering.

And my mind? It was completely blank.

That’s when I met Shubham Bhaiya.

He was one of my cousin’s best friends ,calm, focused, and someone I had always heard good things about.

I never thought one meeting with him would change my entire future.

He started talking to me about competitive exams ,UPSC, MPPSC, NET... At that time, I honestly didn't even know what those were.

I had only heard the word “collector” from my uncle, and sometimes in movies or public speeches.

But I didn't know who a collector really was, or what they actually did.

When Subham Bhaiya explained that IAS officers are the ones we call collectors, something clicked inside me.

“So this is how it starts?”

“This is the path to becoming someone who makes a difference?”

He never rushed the conversations.

Even though he had a busy schedule, he'd sit with me at my cousin's restaurant and explain things ,calmly, patiently.

Slowly, I started understanding the structure of exams, the importance of subjects, and how Arts could actually be a powerful stream if taken with clarity.

Had I listened to people around me and blindly chosen Commerce, I know I wouldn't have been happy.

I would have studied out of pressure ,not purpose.

But because of Subham Bhaiya, I chose Arts with confidence, not compromise.

That single choice changed everything.

It gave my preparation a direction.

It gave my dreams a name.

And it gave me something I had been missing all along ,

Purpose.

I still remember how he'd say,

“You don't need to be in a race. You just need to know your destination.”

Thanks to him, I found mine.

That was the beginning of a new dream ,
to crack a competitive exam and become something bigger
than my problems.

And as this story
moves forward,
you'll see ,Shubham
Bhaiya wasn't just a
mentor.

He became a chapter of hope.

CHAPTER : 11 Second Hospital

Admission

(Same Battle, Bigger Fear)

Just when I thought the worst was behind me, my health gave me a sharp reminder.

Platelet count dropped again ,this time to 30,000.

Same weakness. Same tired eyes. Same rushed ride to Indore.

But this time, something had changed inside me.

I wasn't just a child anymore.

I had dreams now.

I had clarity.

And this disease wasn't just affecting my body ,it was delaying my future.

Lying on that hospital bed, looking at the white ceiling and the I.V. drips again, I felt both frustrated and helpless.

“Why again?”

“Why now?”

But in that moment, I also realized:

This illness doesn't take breaks.

So neither can I.

I recovered, slowly. And once again, life tried to return to normal.

But before it could... something happened that shook me more than anything I had ever faced , which is mention on the following chapter .

CHAPTER : 12 ♥ When Dad Fell, I Froze

(Father's cardiac attack)

It was a regular day. My cousin sister was getting ready for school. She went upstairs ,and that's when she saw it.

Papa was struggling to breathe.

Within minutes, neighbor gathered.

We rushed him to the nearest hospital.

The situation was critical.

Doctors gave urgent medication and said he needed to be shifted to Indore immediately. Everything was happening so fast, I couldn't think straight.

And then I saw something I'll never forget ,

My father, usually the strongest person I know, lying there helpless.

That was the first time I cried.

Not from pain.

Not from needles.

But from fear, real - raw fear.

Inside the ambulance, with sirens screaming and roads blurring, Papa looked at me, Mummy, and my brother and said something that broke me:

At the operation theatre papa call us through the staff and said

“Beta... without family, everything feels meaningless. No one stands alone.”
Kisi k chale jane se kuch nhi rukta

There are moments in life that leave a scar and a strength.

This was both.

When we reached Indore hospital,
something unexpected happened ,All
our relatives were already there.

Approximately 20 people including Buas, Fhupajis, cousins
already waiting for us.

And somehow, seeing all those faces brought strength.

Papa's condition stabilized.

The next day, a stent was placed.

He was safe.

That day, I realized ,

Family doesn't just support you.

Sometimes, they hold your world together.

CHAPTER : 13 Friends in the Same Storm

(Bachelor's group ,joy, friendship, distractions)

Bachelor's first year was a mixed bag.

Most students had come to Arts with one goal ,to crack competitive exams.

But not everyone was serious.

Some were there because their scores were low, or they had no better choice.

But I found a strong study group ,full of like-minded friends and dreamers.

One day, a few of us were called by our History professor, Dr. Shiv Mehra. He had noticed our efforts ,and wanted to personally guide us.

That small gesture became a huge turning point.

Mehra Sir became my anchor in History ,guiding, supporting, and pushing me forward.

In Geography, I had Paul
Ma'am and Vibhute Ma'am
,both of whom treated me
not as a patient, but as a
potential.

Their trust in me kept me going, especially during rough
days.

But then, came COVID.

Colleges shut down.

Classes went online.

And slowly, my academic base started slipping again.

Exams were held from home ,but they didn't feel real.

Learning wasn't the same.

Discipline faded.

Still, I didn't give up.

Thanks to those few
amazing teachers ,I kept the

fire alive. I knew I had a lot to fix. But now, I had the courage to rebuild.

Part D : A World on Pause

CHAPTER : 14 Lockdown of a Lifetime

(COVID, Dadu's death, isolation)

The world had stopped.

And slowly, so did we.

It was the COVID lockdown ,roads empty, homes closed, fear everywhere.

My Dadu, who used to walk almost 5 kilometers daily, had now been asked to stay inside.

For years, he had been the healthiest and most active member of our family.

Even after suffering two heart attacks in the past, he had climbed the OT stairs on his own ,without support, without fear.

He never let age define him.

And he never let anyone care for him more than he cared for others.

But during the lockdown, his walks stopped.

His routine broke.

And slowly, I saw something change in him ,boredom, restlessness, silence.

Dadu and I weren't like grandparent and grandchild.

We were more like friends.

He had never treated me like a "patient." I was just "his boy."

I had gone to Indore for my blood transfusion.

The lockdown's second phase had started, but transportation was allowed again. I don't know why, but I decided to stay one extra day.

Suddenly, we got a call ,Dadu had been admitted to the hospital.

Mummy and I rushed back from Indore.

Halfway through the journey, another call came:

"Return to Indore. Dadu is COVID positive."

At that time, the fear of COVID was at its peak.

And with my own medical condition, people would never let me near a COVID patient. But I didn't care.

When we reached, Papa was standing at the bus stop to pick me up.

I told him, "I'll see Dadu first."

He knew I wouldn't take no for an answer.

Somehow, Papa managed to get me in for a few minutes.

Dadu looked weak ,the weakest I had ever seen him.

And I... couldn't say a word.

That evening, I was sent back home.

Later, I got a call from my cousin,

"Get ready. I'm coming to pick you up."

I hadn't told anyone that I had already seen Dadu.

But something in my heart was unsettled.

At the hospital, Dadu told Papa, Chacha, and my younger brother to go get tea from the canteen.

And just as the tea cups touched their hands...

Doctors came running.

“Your father is no more.”

I froze.

Not when I was sick.

Not when I saw blood.

But now ,I shattered.

This was the man who laughed with me, walked with me, and never made me feel different. Now, he was gone ,just minutes after I had seen him.

They wrapped Dadu in black hospital plastic.

Papa tested positive too and was immediately admitted.

My brother, Chacha, and Papa were all tested.

Civil surgeons and even higher officials did not give permission for Papa to attend the funeral.

The next morning, Dadu was taken to the cremation ground in an ambulance. Only Chacha, in a PPE kit, was allowed to light a small flame.

Some people still came ignoring their fears.

Being there for us.

Shamshan was full ,something we never expected in such times.

Later, the whole family was tested.

Mummy and I were also COVID positive.

We got a call from the hospital:

“Home isolation is allowed.”

Two days later, Papa was sent home too.

All the rituals that followed ,we couldn't attend.

We were present in the house, but not physically a part of the crowd.

And yet, somehow...

The support of neighbours and family became our shield.

It took Papa a long time to recover ,not just from the virus, but from the loss.

As for me, I had cried before in hospitals.

But this time, the silence was louder than anything I'd ever heard.

CHAPTER : 15 Infusion Pump and Inner Strength

(Starting the infusion pump, managing alone)

My Master's degree had just begun.

And with it, came one of my biggest fears.

The infusion pump.

For years, I had heard about it.

Kids, younger than me, wearing it for 8–9 hours every night, carrying it around their waist or shoulder.

I always wondered ,“How do they bear it? How do they sleep through it?”

Maybe that's why I never tried.

I avoided it.

But now, my iron levels were dangerously high.

There was no other option.

The tablets weren't enough anymore.

One of our doctors told us about a fellow
Thalassemia patient ,Sudhir Bhaiya. He used to help
patients by providing the infusion pump on rent, as
buying one was too expensive.

I contacted him.

And that one call changed everything.

He invited us to his home.

There, his father ,who had trained many patients ,agreed to
teach us how to use the pump.

He didn't just teach.

He removed our fear.

He treated us like family, with patience and kindness.

He gave us confidence when we had none.

He fixed the first dose himself.

I still remember sitting there, nervous, holding my breath.

But the way he spoke, the way he explained everything...

the fear slowly melted.

And I finally started using the pump.

For the first few days, I was on complete bed rest during the infusion.

It was hard, boring, and uncomfortable.

But slowly, as I got used to it, I
realized the pump was compact
,I could even carry it around.

One day , I decide to take a chance I put my pump on the side bag and went to college.

And guess what?

Nothing bad happened.

People didn't stare.

No one questioned.

And I felt free.

Over the next few
months, the pump
became a part of me.
And when my first
course of treatment got
over ,so did my fear.

CHAPTER : 16 Spleen Battles and Remedies

(Spleen problems, pain, fear, and treatments)

Now it was time to face my second biggest fear ,maybe even more for my mother than for me. The doctors had suggested splenectomy ,the removal of the spleen ,because it had grown too large, and if any accident happened, it could become life-threatening. We listened to the doctors, but I also shared it with Sudhir bhaiya. He suggested I meet someone who might offer a different solution.

That person gave me some strict precautions to follow. He also told me that I would need to come regularly for some processes. So, I shifted to my bua's house in Indore for two months. I followed the instructions carefully. Slowly, I started seeing some improvement.

I've always believed in both faith and science, and many times in life, I've seen them work together in unexpected ways.

But one day, a tragedy struck ,my dadi's brother passed away. We went there late at night, and since sleep was incomplete, I dozed off for a while. When I woke up, my vision had turned completely blurry. At first, I panicked. Then I told papa and chhote dadu about it. But within 30 minutes, my vision returned to normal.

Later, I told doctors in Dhar about it. Since I could now see normally, they didn't consider it serious, but one of them still

advised me to consult in Indore. I delayed it for a few days, then finally went to Dr. Mahajan, an eye specialist. He did a number of tests, took images of both eyes, and examined them with special lights.

He said it was a blood leakage, which had caused the temporary blur ,but as soon as the blood cleared, the vision came back. He couldn't identify the exact reason.

About two months later, I met my regular doctor and showed her the eye photos. She immediately understood. She said it was due to internal bleeding caused by the enlarged spleen. We had only been monitoring for outer bleeding, but this proved that internal bleeding had started.

She gave us a month's time and asked us to postpone our trip to Uttar Pradesh, which was already booked. That same day, she also helped us apply for financial support through CM Relief Fund and got the paperwork done.

That evening, only me, my bua, and the doctor were in the room. The whole day went by in tests and transfusion, and I was too tired to even think. I had decided not to tell anyone about the surgery until the day itself, because my family is quite emotional when it comes to me. But when I reached home and lay down to rest, a few calls came in. People had found out. I had to tell papa and mummy eventually. They were already suspicious. But I still didn't tell dadi at that time.

A couple of days later, we met Dr. Sharda, the surgeon, and began pre-surgery preparation. After discussions with both

doctors, and seeing their confidence, I made up my mind. The surgery date was fixed ,14th October 2022.

I returned home for a few days. Suddenly, everyone was treating me like I was made of glass. I was getting water on the bed, and dadi was confused why no one was letting me do even the smallest task.

She scolded me, saying, “Beta, can’t you even do a small thing now?” I smiled. She didn’t know yet.

A week before the surgery, I returned to Indore. One dose of a required injection was given before the operation ,the second was to be given after.

The night before surgery, sir ran a few final tests but didn’t admit me. He told me not to eat or drink anything after a certain time.

On 14th October, I was admitted at 6:00 AM. The hospital staff already knew me, and many were surprised to see me coming in for a major surgery.

By 10:00 AM, all pre-op procedures were done. Miraculously, the CM fund also got approved that morning.

Now everyone knew about my splenectomy. Almost 50–60 people came to meet me before the operation. Since dadi couldn’t climb stairs anymore, she stood in the garden and called my name, crying. She had been scolding me for a few days without knowing anything, and now was heartbroken.

I was taken into the OT. Normally, such surgeries take 1–2 hours, but in my case, it took nearly

5.5 hours from entry to exit. Everyone was worried.

They showed the removed spleen to my family before bringing me out. Everyone ,doctors, family, friends ,was anxiously waiting. I was kept in PICU for 2 hours.

The surgeon's confidence deserves respect. Even though I wasn't allowed to move after surgery, he came in and, with the help of assistants, made me sit up the same evening.

There was pain, yes, but the relief was bigger. Now, my spleen was gone, and so was my fear.

Of course, my natural immunity was also gone, and I'd need timely vaccines and precautions from now on. But I noticed an unexpected benefit ,my transfusion interval increased, and my hemoglobin started maintaining for the first time in years.

I was first told about splenectomy in 2012, but my fear delayed it by 10 years.

CHAPTER : 17 A New Label: Disabled by Law

(When Thalassemia became a disability in 2016 – RPwD Act)

It was the year 2016.

By now, I had learned to live with Thalassemia ,when to take transfusions, which medicines to follow, and how to manage daily life.

But then, suddenly, a new word got added to my identity , "Disabled."

At first, it felt strange.

I never thought of myself as disabled.

Yes, life was different, but I never saw myself as less than anyone else.

Then came the "Rights of Persons with Disabilities Act, 2016". In that Act, one line changed everything for people like me:

“Persons with blood disorders like Thalassemia, Sickle Cell, and Hemophilia will now be considered persons with disability.”

That day, Thalassemia officially became a disability in the eyes of the law.

I didn't know whether to feel happy or confused.

Was this good news or bad?

Would people now treat me differently?

Would they feel pity for me?

But slowly, I
understood
something
important, This
label was not a
weakness.

It was a support.

It meant the government finally recognized our struggle.

Now, I could apply for a disability certificate, which could help me:

Get discounts in travel and education

Apply in reserved quota for jobs

And get priority in medical treatments

But getting the certificate was not easy.

Every hospital, every doctor had a different rule.

Some doctors didn't even believe that Thalassemia is a real disability.

They would say, "You look fine, you can walk... why do you need this?"

That was the painful part ,

Even after the law changed, people's thinking did not.

Even today, when I show my certificate, people ask,

"Thalassemia? What is that? What problem do you really have?"

And I have
to explain
again and
again , "My
pain is
inside. It
doesn't

show
outside.”

Every month I take blood, live with side effects, and fight tiredness. But just because it's not visible doesn't mean it's not real.

Still, one thing was clear ,

After 2016, the system finally saw us. It heard us. It accepted us. And that was a big step forward.

CHAPTER : 18 The Certificate Struggle

(How hard it was to prove what I lived with every single day)

After Thalassemia was included under disability in 2016, I came to know that I needed to get my disability certificate from the medical board of my district hospital.

But it wasn't simple.

The board only sat on Thursdays, and that too for just a few hours.

At first, I didn't even know this, so I kept going to different hospitals and departments, asking where to go. After a lot of running around, I finally reached the right place and got my certificate made.

But when I looked at it...

I realised something important was missing ,

The percentage of my disability.

That blank space made the certificate useless for many official works.

For almost one year, I kept visiting the hospital again and again. But every time, I was told,

“It’s already made. What more do you need?”

I felt stuck.

Then I started searching on my own ,

I found the Gazette of India rules, where clear guidelines were written about how Thalassemia patients should be given percentage based on their condition.

I also came across photocopies of certificates of two other Thalassemia patients from my district ,both had percentages written clearly on their certificates.

I gathered all this proof, prepared a file, and finally went to meet the Civil Surgeon.

He heard me patiently and then said something surprising:

“We know Thalassemia deserves 100% disability... but we can’t give it. Because if we give 80% or more, you may not get any job at all.”

He thought he was doing me a favour.

But he didn't understand ,

Without percentage, the certificate was of no use.

I calmly told him,

“Sir, I am not here for pity. I'm here for what's legally mine.
And I've brought the official guidelines to prove it.”

I showed him the Gazette, the other certificates, and
explained everything.

He paused.

Then he said,

“Leave this file here. Write down your phone number. We'll
call you.”

That same afternoon, I got the call.

They had held a special meeting, and finally ,I was called
back to the hospital.

They updated my certificate and wrote my disability percentage.

It had taken more than a year.

But I didn't stop there.

I also applied for my UDID (Unique Disability ID) card, which was supposed to be the permanent proof.

Even that process took a long time.

No one around me even knew how to do it.

So I did it myself ,using my brother's laptop, I registered online, uploaded documents, and waited.

The card never reached my house physically.

But I could see it online, and the word "Permanent" was finally printed there.

I downloaded it and printed it myself.

It wasn't just a card.

It was a victory ,

A proof that I had fought, waited, and finally got what I rightfully deserved.

Part E : Dreams vs Dead Ends

CHAPTER : 19 Failures in a Loop

(Repeating exam failures, how it hurt, and what kept me going)

The real journey into the world of competitive exams started here ,with my first MPPSC attempt.

Yes, I had appeared for a competitive exam in 9th class, but that was just for school admission.

This one was completely different ,a whole new battlefield.

I appeared for MPPSC right after finishing my Bachelor's. Looking back now, I realize I wasn't fully prepared. But at that time, I was filled with energy, hope, and confidence ,mixed with fear, nervousness, and a lot of hesitation.

That fear showed up right at the exam centre gate.

I had brought a photocopy of my Aadhaar card ,not the original. During checking, the staff stopped me and told me to leave the line.

I had no mobile phone to call anyone ,I had left it at home. And although my house was just a few kilometres away, there was no time to run back and return before the gates closed.

I stood still for a second, frozen in panic.

Then I turned back... and to my surprise, I saw Papa standing there at a distance.

I ran to him, explained everything in a hurry, and without saying a word, he rushed back home and brought my Aadhaar card just in time. Thanks to him, I was able to enter the exam hall.

He waited outside until I went in ,only then did he leave.

That was my first exam.

MPPSC has two papers in a day ,Paper 1 (General Studies) and Paper 2 (Aptitude + General Awareness). When the results came, it was clear ,I hadn't cleared it. Then began the long season of exams.

I appeared for almost every competitive exam I could: SSC, RRB, and others. I even joined some offline institutes for coaching ,but my health and condition didn't allow me to keep up.

So I switched to online studies ,and later, online classes became my main learning path.

But no matter how hard I tried, one subject kept pulling me back ,Mathematics.

Math was my weak point. And again and again, it stopped me from getting selected.

Each failure felt heavier than the last. And when people around you know that you're preparing for competitive exams, they naturally start waiting for your result too.

But here's what I feel grateful for ,

Not even once did anyone ,not neighbours, not friends, not family ,ever taunt me for failing. Instead, they always encouraged me. And the biggest support came from my father.

He once told me,

“At least every exam is teaching you something. That learning will never go waste.” That line stayed in my heart.

And because of that belief, even after falling many times... I stood up again.

CHAPTER : 20 ❓ UPSC – First Step, First Fall (Hope, attempts, disappointment)

Now came the turn of the exam that could give me my dream job ,

The exam people call “One of the toughest in India” ,UPSC.

I gave my first attempt in 2022, and honestly, I was scared.

My preparation wasn't complete ,I knew that.

But by then, I had already appeared for many other competitive exams, so I wasn't afraid of the paper itself.

But when I reached the exam centre, fear hit me in a different way.

My centre was at a big institute in Indore.

I reached before time, submitted my belongings... and just sat there silently, watching the other aspirants around me.

And somehow , I felt too... small .

Everyone around looked so confident, so prepared.

And I? I was just trying to gather my courage.

Soon, the checking began and Paper 1 started.

The format was similar to MPPSC ,two papers on the same day. But the difficulty level? It was on another level entirely.

I managed to complete Paper 1 ,it was moderate to tough.

And then we waited for Paper 2 ,the CSAT ,which was scheduled a few hours later.

I was fully ready for Paper 2.

In fact, I felt confident ,because I had practiced previous years' papers and mock tests for months.

But when I opened the actual paper... My mind went blank

UPSC had changed everything.

That year, for the first time, UPSC made the qualifying paper (CSAT) unexpectedly tough.

All my mock tests and practice felt useless.

It was like nothing I had studied even mattered.

Now, the result was clear to me even before it came out.

The only thing that could save you that year was luck or guesswork ,and I had neither.

When the results came , just I had expected

I didn't qualify the prelims.

That was my first fall in UPSC.

I haven't appeared for a second attempt yet.

But one thing is for sure ,

Next time, I will go fully prepared. No fear, no guesswork ,only strategy.

And when I do...

I'll go to win.

CHAPTER : 21 👁 When My Eye Bled Hope

(Blood leak in eye ,mental + physical breakdown)

This was the moment that shook me deeply ,both mentally and physically.

It started with something small.

We were at a family gathering ,one of our relatives had passed away.

That night, I didn't get proper sleep, and the next morning, when I woke up...

My vision was completely blurry.

I got scared.

I didn't tell anyone immediately ,just shared it softly with my dad and a close family member.

Luckily, within 30–40 minutes, my eyesight returned to normal.

But I still felt uneasy inside.

I told my doctors about it, and they didn't find anything serious in the initial check-up. Still, one doctor suggested visiting a specialist in Indore, just to be sure.

I took time to act, but when I finally went to Dr. Mahajan, an eye specialist, he did detailed testing , captured photos of both my eyes, used lights and instruments, and examined everything thoroughly.

And then he said,

"There was a blood leakage inside your eye. That's why your vision went blurry. Once the blood moved away from the centre, you could see again."

He couldn't say why it happened.

Later, I showed the photo reports to my main doctor. She took one look and knew the reason immediately:

"This happened because of your enlarged spleen," she said.

"We were monitoring outside bleeding. But this was internal bleeding."

And that's when the decision became clear.

She gave me one month's time, and we canceled a planned family trip to Uttar Pradesh.

She helped push my CM
Relief Fund application
quickly ,and within a few
hours, it got approved.

My surgery date was fixed: 14th October 2022.

I didn't want to tell anyone at home right away.

But after some calls and emotional conversations, I had to.

Everyone got so serious ,
They started treating me like fragile glass.
Even water was being brought to my bed.

I still remember...

Dadi got confused and frustrated,
not knowing what was
happening. She said, "He can at
least do small tasks, right?" She

had no idea what was about to happen.

That one moment ,when blood leaked into my eye ,was what finally pushed me to get the splenectomy surgery done.

That moment blurred my vision...

But it cleared the biggest decision of my life.

CHAPTER : 22 ✓ A Small Win: Patwari

Qualified

(First official win ,hope rekindled)

This was the first time I decided to appear for the Patwari exam, and I filled out the form with full hope. Later, I found out that my father had also cleared this exam years ago, but because of some unfair issues during the interview stage, he couldn't complete the process.

When I heard this, my motivation doubled.

I felt like I was now walking the path he once tried to complete.

Along with me, two close friends also filled the form, and we started preparing together. We even practiced mock tests as a group.

But I also had my own plan. I had taken a subscription course on an online platform that helped me a lot.

My study schedule included long nights, and during this exam, I probably slept the least compared to any other preparation phase.

Our exam centres came out different ,two of us had centres in Bhopal, and one in Indore. And since there were over 17

lakh applicants, the exam was held on multiple days, in two shifts per day.

I went to Bhopal a few days early to check my centre. I stayed at my bua and fhupaji's house, and they took such good care of me.

On the exam day, my paper was in the first shift, starting at 9 AM.

The centre was 17 km away from the railway station, and many students who came directly by train barely reached on time.

Some arrived late and couldn't appear ,it was heartbreaking to watch.

The paper had 200 questions to be solved in 180 minutes ,and it ended by 12 PM.

As I left the examination hall, I wasn't feeling very happy.

Because this was a computer-based test, your score flashes on screen right after the exam. My score showed as 111 out of 200.

Later, after normalization, it became 118, but even then, I felt unsure.

Still, bua and fhupaji appreciated me a lot and encouraged me to stay positive. My family also showed full support.

Then, a few days later, the result was declared ,And next to my name, it was written:

“Qualified”

Seeing that single word made me emotional.

Of course, being “qualified” didn’t mean I got the job ,just that I had cleared the cutoff and was eligible for the next stage.

But just when I started to feel hopeful, news of a scam in the exam broke out.

Despite the mess, interviews were held, and some candidates even got the job.

I didn’t ,

Maybe God had something else in mind.

But there’s one more interesting coincidence:

My friend Kuldeep, whose centre was in Indore, couldn't perform well in the paper. But me and Raghav, who both gave our exam in Bhopal, had an 11-day gap between our exams, yet we both scored the same ,111 out of 200.

After normalization, Raghav got 115 and I had 118,
And both of us qualified together ,just like our old school days, when our marks used to match.

This wasn't the final destination,
But it was the first real win ,
And it gave me the push to keep dreaming again.

CHAPTER : 23 ♡ Surgery and a Shattered Soul

(Spleenectomy + cousin's accident + mentor's death)

The day of my spleenectomy was one of the most emotional days of my life ,not only because of the surgery, but because of what followed.

That morning, when I was getting ready to be taken to the OT (operation theatre), my mother couldn't control her tears. She walked beside my wheelchair ,silently crying ,holding my hand until the OT doors came. She didn't say anything, but her silence and tears said more than a thousand words.

Inside, the estimated time of my operation was around 1-2 hours, But it took much longer ,nearly 5 and a half hours. Downstairs, my grandmother, uncle, and aunt were waiting with worried hearts. And when time passed beyond the estimate, even they couldn't stop their tears. All I could say later was ,“I survived. But something inside me broke today.”

But this wasn't all. Just days after my surgery, a tragedy even bigger shook my soul.

My mentor and guide, Shubham Bhaiya, who was also my cousin's close friend, met with a terrible accident.

Here's what happened—

His group of friends had planned to visit Pachmarhi. Shubham Bhaiya, who was working in Ujjain, asked his boss for leave, but it was denied. So, he decided to resign and go on the trip anyway. Nobody in the family knew about this resignation ,not even his close friends.

That day, eight of them left from Indore, in a Scorpio, around noon. They were full of excitement. But the next morning came with a shock that none of us were ready for.

Their car met with a severe accident.

Only one person was completely conscious ,He had somehow returned to Indore to inform everyone. But he wasn't my cousin, and he wasn't Shubham Bhaiya.

Everyone else in the car had serious injuries. They were rushed to the nearest hospital ,but since the accident was found out late, treatment also got delayed.

Within hours—

One friend passed away on the spot, And the second, who died before reaching the hospital... Was none other than my mentor, Shubham Bhaiya.

My cousin and one of their school friends were among the most injured. Both had brain clots and were kept at the local hospital for a few days. Later, the rest were shifted to Indore.

After 2 days, my cousin was given special permission to be transferred to Indore too. He was not fully conscious, and for many days, didn't recognize anyone. We were told that full

recovery would take years, or perhaps may not happen at all.

His friend was later shifted to a hospital in Bhopal. He stayed in coma for 45 days, with no movement. But somehow ,by what I can only call a miracle ,he began to wake up.

Recovery was still slow ,it took many months. But slowly, he came back to life.

Meanwhile, my cousin was showing signs of improvement too. He couldn't recognize us at first, but time teaches everything ,And what doctors expected to take years, he recovered from in a few months.

But some losses are permanent.

Shubham Bhaiya's death left a wound in my heart that still hasn't healed. He wasn't just my cousin's friend. He was the one who helped me discover my dream, the one who introduced me to the world of competitive exams, the one who made me believe that I could do more.

After my father's attack and my grandfather's death, This was the third time in life I found myself unable to control my emotions.

I wasn't just healing from a physical surgery... I was carrying a pain that cut deeper than any wound.

CHAPTER : 24 ✂ Third Time, This Time:

MPPSC Prelims Cleared

(Victory after setbacks)

I had already faced two unsuccessful attempts at the MPPSC exam.

But still, I didn't give up.

I kept going ,kept studying ,even when the results weren't in my favor.

This time, after all the effort and waiting,

The result finally came ,and it was in my favor.

I had cleared the MPPSC Prelims.

As soon as the result was out,

A wave of happiness ran through all my relatives and friends.

People started calling and congratulating me.

No one cared whether it was just the prelims or the final exam —

They only saw that I had finally achieved something after so many setbacks.

For me, it wasn't just a result —

It was a moment of relief, pride, and hope.

It felt like the long wait was finally about to end.

Like life was slowly turning in my favor.

And maybe ,just maybe ,my dream was now within reach.

CHAPTER : 25 Mains – The Real War

(Experience in mains, challenges, pressure)

For the MPPSC Mains, I took guidance from Raghav's cousin.

He suggested an institute which had produced good results in English medium over the last few years.

So, I joined their online coaching.

But this time, something was different.

To focus better, I shifted to my badi bua's house in Indore.

And honestly, they supported me in every possible way.

Along with the Mains classes, I also joined an English institute nearby —

It helped me improve my answer writing and communication.

My day was packed:

Coaching from 7:30 AM to 9 or 9:30 AM,

Then breakfast, followed by 6 hours of online Mains classes,

Which also included writing practice,

After that, lunch and full-day revision,

And finishing all the work given by the teachers.

12-hour study days became my new normal.

But even that didn't feel enough.

As the exam dates came closer, I couldn't sleep at night.

At first, I ignored it, but slowly it started affecting me.

By the third paper, the pain became unbearable.

I had a terrible headache ,so bad that tears started rolling down my face.

My old operation stitches ,which hadn't hurt in weeks
,suddenly started hurting.

Back pain started.

And my head was pounding so badly that I couldn't even
hold the pen properly.

For a moment, I stood up ,ready to leave the exam hall.

But when the invigilator asked if everything was okay, I
didn't say anything.

I just sat back down.

And in those 2 minutes...

My entire life flashed before my eyes ,like a reel.

I asked myself,

“Will I ever get this chance again?”

I knew the answer.

So, I picked up my pen...

and kept writing.

I couldn't finish the full paper ,a part of it was left.

But I gave all the remaining papers, in the same painful condition.

There was no gap between the 6 papers —

Six papers. No holidays. Only pressure.

Then came the wait.

The exam was in April 2023.

The result?

It came on December 31, 2024 ,almost one year and eight months later.

That day, I was out with two of my closest friends, celebrating New Year's Eve.

But the moment I saw the result,
the celebration ended.

And so did... a part of my hope.

Part F : More Than Just Survival

CHAPTER : 26 Heart Racing. Yet Standing Still

(Fever, lung pressure, heart rate ,yet I reached the MPSET exam hall)

My heart rate had started acting strange again.

It wasn't the first time ,low hemoglobin often causes this — but this time it felt different.

Even after walking just a few steps, I would feel extremely tired,

and my heart would start racing like never before.

But after some rest, it would settle down... temporarily.

I had just returned from a Vaishno Devi trip with family, and the moment we reached Indore,

my family insisted that we consult my doctor.

When I met her, she immediately stopped my transfusion and shifted me to NICU for monitoring.

I stayed there for 2 days before being discharged.

But just a few days later ,right before Diwali ,I got a high fever.

At first, we thought medicines would work ,they gave temporary relief, but it always returned.

I went again to consult the doctor in Indore.

After getting my tests done, I went to have lunch at my cousin's house.

But my doctor had already seen the reports from pathology.

She noticed I didn't show up at the hospital and directly called my father.

He immediately called me and asked me to rush to the hospital.

My platelet count had dropped from 4 lakhs to 40,000, and with fever + high heart rate, it became a critical condition.

On Dhanteras, I was admitted again.

Due to my spleen removal, my recovery was already very slow.

The worst part ,even after several tests, the exact reason for the fever wasn't found.

This time, I could see the fear in everyone's eyes — especially my parents.

They didn't leave me alone for even a single day.

They stayed right there, next to me ,quiet, alert, and scared.

Our home, usually full of life, now felt silent and heavy.

Family members came to visit me daily.

But my body was burning with continuous fever, and slowly my hemoglobin dropped too,

so blood transfusion had to be started.

But my body temperature wouldn't go down.

Ice packs, cold sponges, everything was being tried.

My father, mother, bua, fufaji, and brother worked non-stop ,just to help my body stay cool enough

so that the transfusion could go smoothly.

And finally, after days of prayer, struggle, and medical care

—

on the 5th day, my fever started to come down.

After 2 more days, I was discharged.

But the heavy antibiotics had drained me.

I was technically recovered, but standing up felt impossible.

Even sitting, standing, lying down ,everything made me feel dizzy.

I had no energy left at all.

And of course, my MPSET preparation was completely broken in between all this.

But about 20 days after my discharge, the admit card was released.

And the exam was just 10 days away.

My family didn't want me to go.

They were scared for my health.

But my heart wanted to try.

And I did go.

Even though I didn't clear that exam,

I'll always be proud of this moment —

because I didn't use my illness as an excuse.

I showed up.

And that matters more than a result sometimes.

CHAPTER : 27 NET/SET – Preparing While Healing

(Academic comeback attempt)

NET/SET was always my backup plan.

The MPPSC exam cycle is long and uncertain, so I wanted something parallel —

a stable option that could still keep my academic dreams alive.

Some of my bachelor's friends had already cleared NET, and one of them had even cracked JRF.

They were kind and supportive ,they explained the whole process clearly and motivated me to try too.

You already know how I attempted MPSET just after being discharged from hospital —

so it didn't go well.

But for UGC NET, I was fully prepared.

I had done multiple revisions, solved thousands of MCQs from different platforms, prepared short notes, and tried to cover every possible area. This time, I really believed I had done enough.

But when the actual exam came, NTA completely changed the pattern.

It felt like they had turned it into another UPSC CSAT — unexpected, twisted, and far beyond the expected level.

My previous year paper analysis, mocks ,none of it helped. What I had prepared wasn't what they had asked.

When the result came, it was again... a disappointment.

Not because I didn't study — but because the paper didn't match what anyone had imagined.

Still, I know one thing —
I gave it everything I could,
even while I was still healing.

CHAPTER : 28 With Dad, Side by Side

(Starting to work with Papa ,balancing it with duty)

My father works as an RTO agent,
and sometimes, I started learning things from him.
I even sat in his office for a few days.

But Papa always said,
“Tu ghar par aaram kar, main sab sambhal lunga.”

Still, I wanted to help.
So I slowly started supporting him in his work —
observing how things are done,
how to talk to customers,
how to handle people politely,
and how important it is to stay calm, even under pressure.

I began to realize,
these small lessons might help me someday —

in life, in work, maybe even in service.

I also wanted to learn his work for another reason —
so I wouldn't sit idle,
or feel like I was doing “nothing,”
especially when exam failures had become a pattern.

Helping Papa gave me a sense of purpose,
a feeling that I was still moving forward,
even when results said otherwise.

CHAPTER : 29 Iron Overload – Restart Again

(Infusion pump returns – quite strength returns too)

This time, I wasn't afraid of the infusion pump.

But when doctor told me to start using the Infusion pump again because of high iron overload,

I was already in the middle of preparing for my NET exam.

And once again, those same fears started coming back —

"What if my selection gets affected because of the pump?"

But before even starting the pump, another problem appeared.

Desferal, the medicine, wasn't available anywhere in Indore.

Many chemists even said,

"Buy it from wherever you got it last time."

Finally, at one drug house,

they gave me two boxes after checking the prescription.

Now I had the medicine,

but it took three days just to find the required syringe.

Once I had everything,
I started my infusion.

For the first five days, I used the pump in the morning,
but no matter how hard I tried, I couldn't study well.
The pump was placed near my lower abdomen,
and sitting for long hours caused pain and discomfort.

I tried adjusting things,
but my mother didn't want me to use it at night.
Still, I finally started the night routine —
and slowly, everything began to settle.

Using the pump at night gave me proper time during the day
to focus on my preparation.

And I gave my 100% effort in the exam.

Not just that ,I continued my infusion without missing a single day

for 42 days straight.

The result?

My iron reports improved significantly.

And once again,

I proved to myself that

quiet strength can heal, fight, and still prepare for a better tomorrow.

Part G : Looking Ahead

CHAPTER : 30 ♥ People Who Kept Me Alive

(Blood donors, Doctors, Hospital staff - The Unsung Heroes)

In this journey filled with endless transfusions, surgeries, and unexpected emergencies —

some people never let me fall.

They were not always family, not always friends,

but they were always there ,quietly, selflessly, and powerfully.

From the beginning, my Chacha, Papa, their friends, and even the people who worked with them,

stood by me like a protective wall.

My Fhupaji and cousins also never hesitated ,whenever a need came, they were ready.

But beyond them, there were many I never even met — people from trusts, donor groups, and even strangers who only knew my name.

Special thanks to Ravi Bhaiya's group and Prakash Bhaiya's group —

they donated regularly without ever expecting anything in return.

Some donors would quietly walk into the blood bank, donate in my name,

and leave without ever waiting to be thanked.

I don't know their faces, but they are forever part of my story.

And I can't forget the backbone of this system —

the Blood Bank Staff, especially Mishra Sir, Kanhaiya Bhaiya, and every single staff member

who made sure the process ran smoothly and safely ,again and again.

Doctors – The Guides Who Never Gave Up

This journey would have stopped long ago
if it weren't for the doctors who believed in me.

Whether it was saving me from an emergency,
guiding me through a surgery, or handling my complications
with care —

I've been incredibly lucky.

A heartfelt thank you to:

Dr. Vinita Agrawal,

Dr. Kamna Jain,

Dr. Shikhar Jain,

Dr. Gori Rao Pasi,

Dr. Shivani Patel,

Dr. Sudesh Sharda,

Dr. Prashant Agrawal

Dr. Sandeep Khatod,

Dr. Anil Verma

,and many others whose names may not be listed here,
but whose contributions are deeply written in my heart.

Hospital Staff – The Everyday Angels

I've spent more time in hospitals than I'd ever want,
and in those long days and nights, it was the nurses and staff
who gave me silent support, patience, and strength.

Special thanks to Kale Didi and Anju Didi,
two legends who treated me like family when I felt most
alone.

There are so many more —
and if I miss anyone's name,
please don't feel hurt ,your part in my survival is priceless.

They say "it takes a village to raise a child" —
but in my case, it took an army of angels
to help me survive and rise.
To all of you —
thank you for keeping me alive.

CHAPTER : 31 The Unseen Pillars

(Family, friends, how they stood, even silently)

In a world full of noise and rush,
some people stay quietly beside you —
holding you when you're falling,
listening when you're silent,
and loving you when you don't even ask.

For me, that strength has always been my family and friends.
From childhood to now, in every hospital, every exam, every
sleepless night,
you were there —
not just in presence, but in spirit, support, and prayers.

I've lived the life of a fighter, yes —
but I've never fought alone.

Whether it was help with medicines, meals, motivation, or
just a warm look that said "you'll be okay",
you became the reason I could stand back up, again and
again.

To each of you —

those who cared from near, and those who loved from afar
whether you were in the room with me or in my thoughts...

Thank you.

I may not be able to write all your names here,
but I carry each one of you in my journey —
and in my heart.

You are my unseen pillars —
the reason I never truly fell.

CHAPTER : 32 Can We Ever Stop Thalassemia?

(Hope, Awareness, and the Future of science)

Yes, we absolutely can stop Thalassemia.

In our culture, we give great importance to things like matching horoscopes before marriage. But what if—just what if—we gave even half that attention to awareness and prevention?

If couples simply got tested for thalassemia traits before marriage, we could save a child from being born with Thalassemia Major — a condition that brings a lifetime of medical struggles.

Please think about it, not just emotionally, but logically. Because when one child is diagnosed with thalassemia, it's not just that child who suffers — an entire family feels the weight, emotionally, physically, and financially, for life.

"Thalassemia" — a word that stirs a strange chill within. But what's even more heartbreaking is when an innocent child is born into this lifelong battle — a fight they never signed up for.

Like me, thousands of people live with a routine that revolves around a blood bag every 15–20 days. And in the middle of all this, one big question keeps coming back — can thalassemia ever be completely stopped?

This chapter is my honest attempt to answer that.

◆ **Living with It – Not the Cure, Just Survival**

For someone with thalassemia major, life means a never-ending cycle of blood transfusions and iron chelation therapy to remove the iron overload from our bodies.

Every transfusion saves us... and yet leaves behind extra iron in the body, which, if not removed, silently attacks our heart, liver, lungs — almost everything.

(Reference: Thalassemia International Federation. Guidelines for the Management of Transfusion Dependent Thalassaemia (TDT), 3rd Edition, 2014)

I've lived through infusion pumps, chelation tablets, and dozens of painful injections.

Let me be honest — this is not a cure.

It's survival. Just staying alive.

◆ Bone Marrow Transplant – The Only Real Cure (For Now)

Till date, the only recognized permanent cure is a Bone Marrow Transplant (BMT).

(Reference: CMC Vellore Thalassemia Unit Report, 2020; NIH Guidelines on Hematopoietic Stem Cell Transplant)

But BMT too has its conditions:

The patient should be ideally under 10 years of age

A matched sibling donor (HLA match) is a must

And the biggest hurdle — ₹10 to ₹25 lakh cost

(Reference: AIIMS Delhi, Pediatric Hematology Department Report, 2023)

In India, centers like CMC Vellore, AIIMS Delhi, Tata Memorial Mumbai do offer this procedure, but let's be real — it's out of reach for most.

◆ Gene Therapy – A Glimpse of the Future

Science has come a long way.

Gene Therapy is now becoming a new hope — a way to repair the faulty gene itself.

Some globally approved therapies include:

Zynteglo (by Bluebird Bio) approved by the European Medicines Agency (EMA)

Ongoing trials by CRISPR Therapeutics, Vertex Pharma, and others

(Reference: Bluebird Bio Official Website, EMA Public Assessment Report, 2021)

In India, it's still far from reach — extremely costly, experimental, and not widely available.

But maybe in the next 5–10 years... this hope will reach Indian mega-cities too. But the treatment or procedure is too costly .

◆ 100% Preventable – If We Just Wake Up

Now here's the truth — if curing it is tough, preventing it is not.

Yes, thalassemia can be 100% prevented.

(Reference: WHO Guidelines on Thalassemia Screening, 2018)

Thalassemia is not infectious. It's a genetic condition.

If both parents are thalassemia minor, their child has a 25% chance of being born with thalassemia major.

(Reference: Indian Journal of Pediatrics, 2020 — Thalassemia Carrier Screening in India)

→ So, what can be done?

A simple blood test — HPLC or Hemoglobin Electrophoresis — before marriage can detect thalassemia trait.

If both partners are minors, they should take medical counseling seriously before proceeding.

◆ Society and Government – Why Aren't We Doing More?

In our culture, so much importance is given to kundali matching before marriage.

If even half that focus went into thalassemia screening, we could stop this disease before it even starts.

If our government makes prenatal thalassemia screening mandatory through gynecologists,

we could see a future where no child is born into this painful cycle.

(Reference: Indian Medical Association Policy Brief, 2022; Health Ministry Circular on Genetic Disorder Screening, 2021)

◆ I've Done My Part. Now It's Your Turn.

Through this book, I've shared not just my story — but the truth of thousands like me.

If it touches even one person — if even one couple gets tested before marriage,

and a child is saved from this fate,

then this book, this pain, this writing — will all be worth it.

Thalassemia can be stopped.

But it doesn't start with medicine.

It starts with awareness.

It starts with us.

Sources :

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(2022)

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Conclusion: If You're Reading This...

(A closing letter to for the readers)

If you're holding this book or reading these last pages, know this ,it was not just written with words, but with years of lived pain, strength, and silent endurance.

Today, I'm being discharged from the hospital ,again. This book was completed not at a desk, not in peace, but in a hospital bed during yet another battle with fever. I had been meaning to write for a long time, but maybe it had to happen like this ,between I.V. drips, quiet tears, and the sound of hope trying to breathe.

This story isn't just mine.

It belongs to every Thalassemia patient who wakes up with uncertainty but still chooses to fight. It belongs to every parent, every sibling, every donor, and every doctor who has stood silently behind someone like me.

I don't talk much in the ward. Maybe some think I'm arrogant, or distant. But what they don't see is how many nights I've stayed awake after hearing that someone I just laughed with during transfusion... didn't make it to the next one.

It's happened more than once. And it never gets easier.

If you're someone like me, I want you to feel
one thing after reading this ,You are not
alone.

You are more than a diagnosis.

You are more than pity or sympathy.

You are a warrior.

And if you're not someone like me ,but someone who wants
to understand ,then I thank you. Truly.

Because awareness is how we build bridges between
survival and support.

Between science and society.

Between loneliness and love.

This book may end here.

But our stories...

They continue ,in every hospital corridor, every clinic chair,
every tiny act of courage.

Thank you for listening.

Thank you for feeling.

Thank you for being here.

With every drop of hope,

[Raj C.]

(A Thalassemia Warrior)

◆ **About the Author**

Raj Choudhary

Also known as Raj.C

I belong to Dhar, Madhya Pradesh ,a small town with big dreams. And one of those dreams, perhaps unknowingly, turned into this book.

I am a Thalassemia patient, and that alone doesn't define me ,but it has shaped most of my journey. The reason I wrote this book wasn't inspiration... it was fear.

A fear that built up silently inside the four walls of a hospital ward ,after seeing too many friends leave too soon. People I talked to, smiled with, even shared silence with ,they just... stopped coming back.

One thing you may find odd ,I've signed this book as Raj.C. Now grammatically, that's incorrect ,a capital 'C' after abbreviation mark (laghaw chinh). But I didn't choose it for grammar.

That 'C' denotes my surname but the abbreviation mark put after my name which is grammatically wrong but this identity is used to identify me from several years and I also accepted that too...

And somehow, over time, it became a part of who I am.

I know I don't talk much in the Thalassemia ward. Maybe some people think I'm cold or distant. But the truth is, I've seen people I talked to ,say goodbye forever.

So yes, maybe I don't speak much... not because I don't care,
but because my fear speaks louder inside me ,a fear I can
neither fully explain nor erase.

This book is not just my story.

It's a small attempt...

To give voice to those who couldn't speak,
To share stories that never got written,
And to bring you a little closer to the unheard world of
Thalassemia.

Thank you for reaching this far —
And for seeing me, not just as a patient,
But as a person.

Raj Choudhary
(Raj C.)
2025





"A blood donor is a life saver . Nothing is a more precious gift than gifting your life to someone in liquid form."



**RAJ
CHOUDHARY**