BEYOND THE SCARS

Boehringer Ingelheim

Life forward

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BERKER NOYAN

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BERKER NOYAN

PUBLISHER : Ayşe Tuğba Dedeoğlu
EDITOR-in-CHIEF : Hakan Demir
PUBLISHING COORDINATOR : Berker Noyan
COVER DESIGN & ILLUSTRATION : Sheilvy Salazar
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iletisim@ceresyayinlari.com
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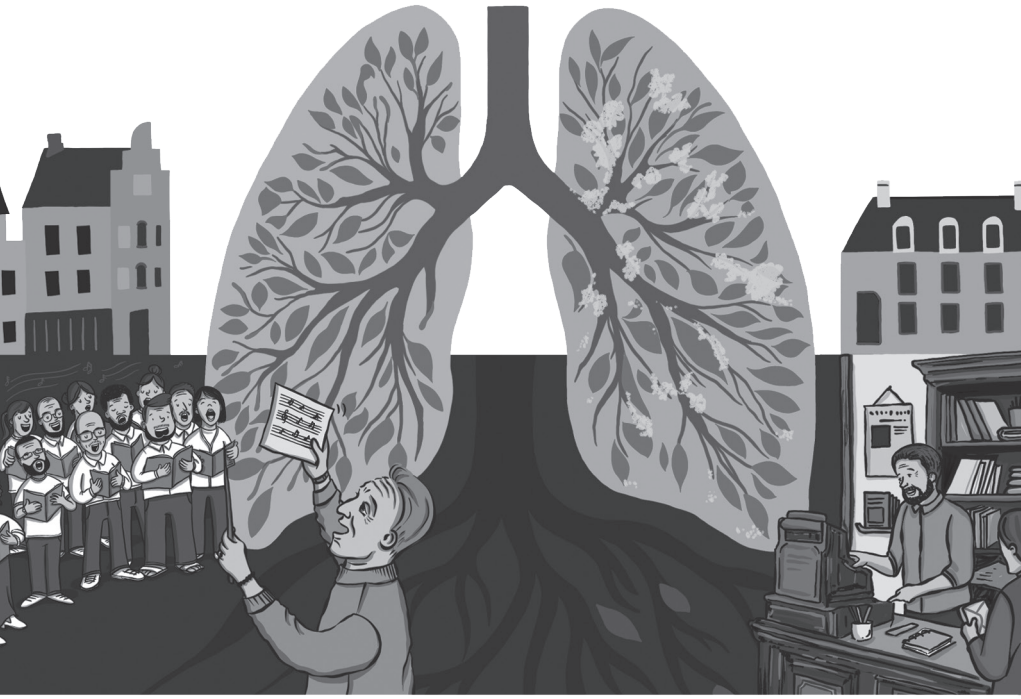

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INTRODUCTION

THE UNEXPECTED TURN

It was supposed to be a routine check.

Something that had already been delayed once. Something that could have been delayed again. There were other things to get through that week. Work. Plans that felt more immediate.

Most people go in expecting to get it done and move on.

Then the conversation changes. It is not dramatic. Just enough for something to feel odd.

A name comes up that does not sound familiar. The explanation follows, but it does not fully register. By the time the appointment ends, there is information, but not clarity.

The day continues. That is what makes it difficult to process.

Nothing outside reflects what has just happened. The same messages come in. The same expectations remain. There is no pause, no clear break between before and after.

And yet, something has shifted.

It is not always understood immediately. It shows up later, in questions that are harder to answer.

What exactly was said?

How serious is it?

What do you tell your family?

There is no simple way to explain something you have not yet understood yourself.

So, most people do the same thing.

They continue.

They go home. They read about the diagnosis. They try to make sense of it in between everything else that still needs to be done.

And slowly, the shape of it becomes clearer. It is not a stop. It cannot be a stop.

It is a turn. Like missing an exit you had planned to take. The road does not end. It keeps going. But it is no longer the one you expected. There is no immediate way back. No clear sign telling you how far the next turn is.

So, you adjust.

You keep driving. You start paying attention differently. You measure distance in another way. You think ahead more carefully. What was automatic and known now becomes deliberate. Because even after that appointment, even after that diagnosis, life continues.

Just not in the same way. That little unexpected turn changes something, and then everything.

This book is about that unexpected turn.

About what life looks like before it, and what it becomes after.

“Apparently,” he says, smiling, “singing after sixty was written into my fate.”

PART ONE
EDİP

THE CONDUCTOR RAISES HIS HAND

Forty people in the row stand a little straighter. Scores lift. Edip Özdener, near the middle, draws breath with the rest of them. There is a half second where forty pairs of lungs fill at once, and then the room, for that half second, holds more air than it did before. Then the downbeat falls and the first note opens.

He is seventy-two years old. He is breathing. With effort.

Edip was born in Mardin in a slightly cooler May, in 1952. On the first day of the month. The house he grew up in had three storeys and seventeen rooms, and it looked out over the plains. There were eight children, four sisters and four brothers, and Edip was the youngest of them all. His father was a produce wholesaler, and the shop opened early.

From the time he was small until the year he finished high school, Edip woke at half past four in the morning. He went with his father to the shop, just after the dawn prayer. He opened the shutters. He ran the errands, collected the money in the afternoons, did the accounts, handed his father the day's takings. This was his brothers' job first, then his sisters', and only then did it become his, in a rotation his father had worked out years before any of them were old enough to argue with it.

"Even at that age," Edip says now, "opening the shop was my responsibility. Just as each of my siblings."

He does not describe this as hardship. He describes it the way a man describes the weather of his childhood. It was simply what mornings were.

The other thing mornings were was music.

Mardin houses are known for their courtyards, and his family's courtyard had a radio that played most of the time anyone was awake. His parents loved music deeply. The melodies came through the static and folded into the stone of the walls, and a boy moving through that courtyard at dawn, on his way to open a shop, did not yet know that those songs were settling somewhere inside him for safekeeping.

"That's where my love of it began," he says.

In 1971 he left for Ankara to study electrical engineering. He was nineteen.

He worked during the day and studied at night. He never found this strange. He says this twice, in slightly different ways, when he talks about that period, as if he wants to be sure no one mistakes his life for difficulty.

In his early years at university, he became seriously ill. He was hospitalized. He had to be operated on. He lost a kidney.

He was twenty-one.

"It was the greatest trauma of my life," he says now. "I was only twenty-one. I had lost an organ. I was far from my family and home, with no idea how my life would unfold from that point on."

It is a fact he states the way an engineer notes a load-bearing wall. A thing the structure had to be designed around.

What that wall taught him, perhaps, was that a body could lose something and continue. That losing a part did not make a person less. That you could go on, and that going on was a choice you made every morning, the way he once chose to wake at half past four and walk to the shop.

He finished his degree. He stayed in Ankara. He went to work at the General Directorate of what was then the Turkish Electricity Authority. He stayed there, in the same institution moving through different roles, from 1977 until 2004. Twenty-seven years.

Twenty-seven years of arriving on time. Twenty-seven years of files, of meetings, of the small daily rituals of a state engineering job, and of growing steadily within the walls he had chosen at the start. He liked it. He says he liked it.

"I worked actively at the general directorate," he says. "I loved my job and never once abandoned discipline."

He retired in 2004. He was fifty-two.

A man who has woken at half past four every morning of his working life does not know how to stop. So Edip did not stop. He went into trade with a friend, importing charcoal from abroad, and worked another nine years, until 2013.

It was in 2013 that he finally allowed himself the second life.

He joined a choir.

He had loved music for sixty years. He had loved it from the courtyard in Mardin, through the cold winters in Ankara, through the years at the directorate, through the years after. He had never sung in a choir. Now he did.

"Apparently," he says, smiling, "singing after sixty was written into my fate."

The first rehearsal taught him something he had not expected.

Engineering had trained one kind of attention in him. The attention of a man who reads a circuit diagram, who sees where the load goes, who notices when a component is wrong before the meter does. That attention is silent. It happens behind the eyes.

Singing required a different attention. It required him to listen to himself while listening to forty other men at the same time. To notice, mid-phrase, whether his breath would carry him to the end of the line. To plan air the way an engineer plans current. To feel, in the chest and the diaphragm, the thing that was actually happening, rather than thinking about it.

He found, after a few weeks, that he could do it.

He found, after a few months, that he could not stop.

Two hours a day, three hours, sometimes four. Singing became the spine of his week. He did not yet know that his lungs were keeping a record of those hours. He did not yet know that the music, which he had loved as a child, and a young man, and a working engineer, was preparing him for something.

He had built one life carefully, between half past four in the morning and the end of every long working day. Now, at sixty-one, he was building a second one. Not a hobby. A second life.

"I couldn't stay still," he says. "I was used to working."

So he worked at this, too. He practiced. He learned the discipline of breath the way he had once learned the discipline of current and resistance. He sang.

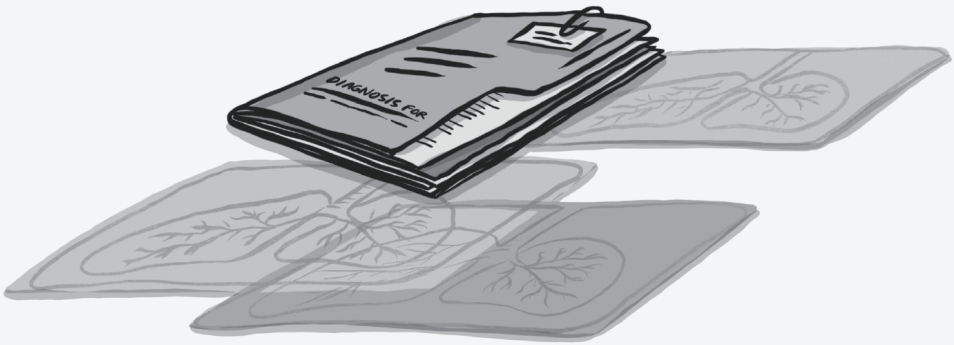
In a few years, doctors would tell him that something was wrong inside his lungs. He would learn a word that had also belonged to his older sister. He would begin to understand, slowly, what the second life was actually for.

But that was still ahead of him.

For now, in Ankara in 2013, a man who had built a state engineering career and survived a lost kidney was standing in a row of singers, score in hand, drawing breath with the rest of them.

The conductor raised his hand. The music began.

“About twenty-five years ago, my eldest sister was diagnosed as well,” Edip says. “Despite treatment, we lost her.”



WHEN IT RUNS IN THE FAMILY

There are diseases a person learns about from people, from reading, and there are diseases a person learns about from their family.

Unfortunately, Edip learned about pulmonary fibrosis the second way.

About twenty-five years before his own diagnosis, his eldest sister was diagnosed with the same condition.

She went back and forth from Mardin to Ankara for nearly a year before the diagnosis was confirmed. She was cared for. And in time, despite the treatment, she lost the battle.

"About twenty-five years ago, my eldest sister was diagnosed as well," Edip says. "Despite treatment, we lost her."

He says this plainly, but there is grief in the sentence.

He was the one who drove her to the hospital and back, in those years. He came to know this disease through her, at close range, before it was ever his own. By the time her diagnosis was confirmed, it had already advanced too far.

He also believes his eldest brother may have had it. The brother had an incredible cough, year after year. He was never formally diagnosed. He died at sixty-five or sixty-six of something else, before anyone had thought to look at his lungs. But the suspicion sits in the family.

This is what it means to have a familial dimension to a disease. Not that everyone gets it. Not that anyone is certain. Only that the shape of one person's illness becomes a kind of map for the rest of the family, even when no one wants the map.

In the years after his sister's death, Edip carried a quiet knowledge that he had not asked to carry. He did not dwell on it. He went to work. He retired. He went into trade. He joined the choir. He lived an active life.

But somewhere underneath all of it was the awareness that a disease he had watched in someone he loved might one day arrive in him.

When it did, in 2016, he was not surprised in the way some patients are surprised. He had been quietly preparing for years, without knowing it.

What the sister's death taught him, more than anything, was vigilance.

Not fear. Vigilance is different from fear. Fear closes a person down. Vigilance opens a person up to what is actually happening.

In his family, after the sister, anxiety became attention. Early diagnosis, in his family, became less a piece of luck than a piece of inheritance.

He could not save his sister. But he could pay attention to himself. And he could pay attention to the others. Not long ago, a niece, the daughter of his late brother, developed a cough. Edip took her to his own doctor, because of the family history. Everyone, now, is on alert. Twenty-five nieces and nephews. Eight siblings. The whole family watching, because once you have seen this disease up close, you do not unsee it.

This, perhaps, is the largest gift his sister left behind with him. The reminder that bodies tell the truth, eventually, and that listening is not vanity.

It would be wrong to say that Edip was grateful for what his sister's illness taught him. No one is grateful for that. The teaching costs too much.

But by the time the routine check in 2016 found something in his own lungs, he was the patient she had not been able to be. He went in early. He did not look away from what was on the imaging.

The disease arrived in him. And he was, in his own quiet way, ready.


Ankara University
Department of Chest Disease
DIFFUSE INTERSTITIAL
LUNG DISEASE WITH
FIBROSIS
PATIENT NAME:

THE DAY IT WAS SAID

In 2016, life was full for Edip.

His daughter, an architect, was starting her own family in Istanbul. He had been retired for twelve years and had stayed busy. The choir filled his weeks. Music had become the center of a second life he had not expected to build. He was sixty-four years old, and on most days, he felt the way a man feels when the things he has worked for are settling into place.

Then he went for a routine check.

This is how it begins, almost always. Not with a symptom. Not with a fall. With a routine check.

The first check, at a hospital in Ankara, raised a question. Something in the lungs the doctor could not quite settle.

What followed was a search. A scan at one oncology hospital, where the first clear signs appeared. A small biopsy at another, where a diagnosis still could not be confirmed. Months of imaging and tests and uncertainty.

Finally, on the recommendation of a pharmacist friend, his path crossed with a pulmonologist at Ankara University's Department of Chest Diseases. And there, after extensive testing, the diagnosis was made: diffuse interstitial lung disease with fibrosis.

He had no symptoms. No shortness of breath. No chest heaviness. His body did not confirm what the imaging said.

But Edip had heard this language before. He had heard it in the room where his sister was diagnosed, and in the years that followed, in the conversations among his siblings, in the quiet preparation his family had been making, without quite naming it, for the possibility that one of them might be next.

So when the doctor said the words, Edip did not flinch.

"My greatest advantage," he says now, "was receiving the diagnosis early."

Early is a word that does a great deal of work in this book.

Edip's diagnosis was early in two senses. It was early in the disease, before symptoms had begun. And it was early in his life, while he still had the energy and the discipline to organize a response.

Both kinds of earliness matter. The first gives the doctors more to work with. The second gives the patient more to work with.

Edip had both. He knew it.

"Early diagnosis is very important," he says. "My greatest luck was that this came out by chance, through a check-up, while there was no problem at all, no trouble with my lungs."

He met the diagnosis the way he had met the loss of a kidney at twenty-one. Not with denial. Not with collapse. With the engineer's instinct to ask what the situation was now, and what it required.

The answer was to stay close to his doctors. Since 2017 he has remained under specialist care without interruption: breathing tests, imaging, the steady watching that early diagnosis makes possible. He gave it his full attention. He was ready to do whatever was asked of him.

On the day his doctor said the words, Edip's family received the news the way families do. Quietly, at first. Then with attention. Then with action.

His wife, who has been with him for about fifty years, became, in the careful way that long marriages allow, his second pair of lungs. Watching. Noticing. Reminding.

"When I cough," he says, "my wife looks at me with such tenderness. 'Don't push yourself,' she says. And everything eases."

His daughter, far away in Istanbul, became a vigilant guardian, following every step of his health journey. She calls. She asks. Father, what did you do, did you go, do not miss your check-up.

The diagnosis had entered the house. The house adjusted to receive it.

Outside, life continued.

The choir met. The walks happened in the mornings. The radio played in the kitchen. The grandchild visited.

The diagnosis was not the end of his life. It was the beginning of a new arrangement of the same life.

Edip understood this from the first day.

Edip came to this disease at a different time, and he knows it. He has something to take. His sister did not.

"My lungs," he says, "are better off than hers were allowed to be."

A NEW DAILY RITUAL EVERYDAY

Edip takes his pills everyday, and he knows exactly what it does for his condition.

He is not a man who needs convincing to follow a doctor's plan, but this is more than obedience. He understands what is at stake if he lets it slip. He has seen this disease before, in someone he loved.

These medications are a relatively new class of drugs prescribed for pulmonary fibrosis. They are not a cure. There is no cure. They are a daily intervention designed to slow the rate at which lung function declines.[1]

His eldest sister, twenty-five years ago, did not have what he has now.

The medication that slows the disease today did not exist for her in this form.[2] She was treated with what was

1 Wang J, et al. Pathogenesis and therapeutic targets in pulmonary fibrosis. MedComm. 2024;5:e744. 7. Podolanczuk A, et al. Update in interstitial lung disease 2023. Eur Respir J. 2023;61(4)

2 Wang J, et al. Pathogenesis and therapeutic targets in pulmonary fibrosis. MedComm. 2024;5:e744. 7. Podolanczuk A, et al. Update in interstitial lung disease 2023. Eur Respir J. 2023;61(4)

available, brought at great cost from another country, and what was available was not enough.

Edip came to this disease at a different time, and he knows it. He has something to take. His sister did not.

"My lungs," he says, "are better off than hers were allowed to be."

Around the time he began treatment, his walks continued.

Four to five kilometers a day. He rarely drives. The walking is older than all of it. It comes from childhood, from running between the rows of his father's wholesale shop, fetching, carrying, collecting, accounting.

He does not have to push himself to walk. Something in him asks for it. Get up, walk. There is no forcing.

He does not smoke. He has not smoked since 1983, when a severe gastric bleed sent him to the hospital and a doctor told him to stop that day. He stopped that day.

"Forty-three years," he says. "I see it as the most important decision of my life."

The hardest symptom of his disease is the cough. It comes often, and it comes hard. He thinks, sometimes, about what it would have been like if he had kept smoking. He is certain it would have been far worse. He is grateful, in the plainest sense of the word, that he stopped when he did.

He sings. Several hours a week, with the choir he leads. The choir is, increasingly, a deliberate part of his care.

"Singing," he says, "seems to do my lungs a great deal of good. I realized this much later."

The walking and the singing are not symbolic. They are exercise. The lungs do the work, and the work keeps them working.

Discipline, in his case, is not separate from medication. They are part of the same project. The pill is one piece of the work. The walk is another. The song is another.

All of it is keeping him here.

The fear visits at night, mostly. It comes as a question, and the question is never the same size twice.

How many good years are left? Will the breathlessness come, the way it came for his sister?

WHAT IT COSTS TO STAY POSITIVE

Everyone who meets Edip says the same thing about him. That he is positive. That he is light to be around. That for a man with a serious illness, he carries it remarkably well.

He would not argue. He says it about himself, and he says it in three words, the same three every time, as though he keeps them ready. Positivity. Attachment to life. Joy of living.

What people do not see is that these are not three things he has. They are three things he does. Every day. The way other men do push-ups.

Here is what it costs.

Edip has watched this disease before. His eldest sister died of it, twenty-five years ago, when there was far less anyone could do. He suspects his eldest brother had it too, the one with the cough that went on for years.

So when Edip says he is not afraid, this is not a man who does not know what is coming. He has already watched it come, twice, for people who shared his blood.

He knows the road. He has stood at the end of it.

The fear visits at night, mostly. It comes as a question, and the question is never the same size twice.

How many good years are left? Will the breathlessness come, the way it came for his sister?

And one more, smaller and sharper, that he does not say out loud to many people.

He has been singing since he was a boy in Mardin, where a radio played in the courtyard from morning until night. The music has been with him through everything since. It is the one thing that followed him out of childhood and into the middle of his illness and kept him company in both.

And singing, he has come to believe, is part of what keeps his lungs working at all.

So the question he does not say out loud is this. Which goes first. The breath, or the song that needs it.

He does not know. He has decided he would rather not find out by thinking about it.

This is the part people miss when they call him positive. They think it means he is not afraid. It does not mean that. It means he has looked at the fear, recognized it, and chosen, every single morning, to spend his day somewhere else.

"Negative thinking never benefits health," he says. "So why choose it?"

In another man's mouth that is a fridge magnet. In Edip's mouth it is a decision, made by someone who has every reason to think the other way and refuses to. He has been disciplined his whole life. He woke at half past four as a boy. He sat at the same desk for twenty-seven years. He quit smoking on a single afternoon and never touched it again. He has simply pointed all of that discipline, now, at his own mind.

It is the hardest thing he has ever made himself do. It does not show. That is rather the point.

He says it about himself, and he says it in three words,
the same three every time, as though he keeps them ready.
Positivity. Attachment to life. Joy of living.

2026

Edip is past seventy now. He walks most mornings. He sings most weeks.

On rehearsal nights the singers wait for him, because he is the one who holds them together. The conductor lifts a hand, forty people breathe in at once, and the sound comes out as a single long note. Edip carries his part the way he always has, his breath full, the note reaching the end of the line.

A diagnosis sits somewhere inside all of this. It has not been allowed to run the day.

He is still here. Still himself.


STATIONERY SHOP
OPEN
PLEASE
COME IN
STATIONERY SHOP

PART TWO
HASAN

THE STATIONERY SHOP IN KONYA

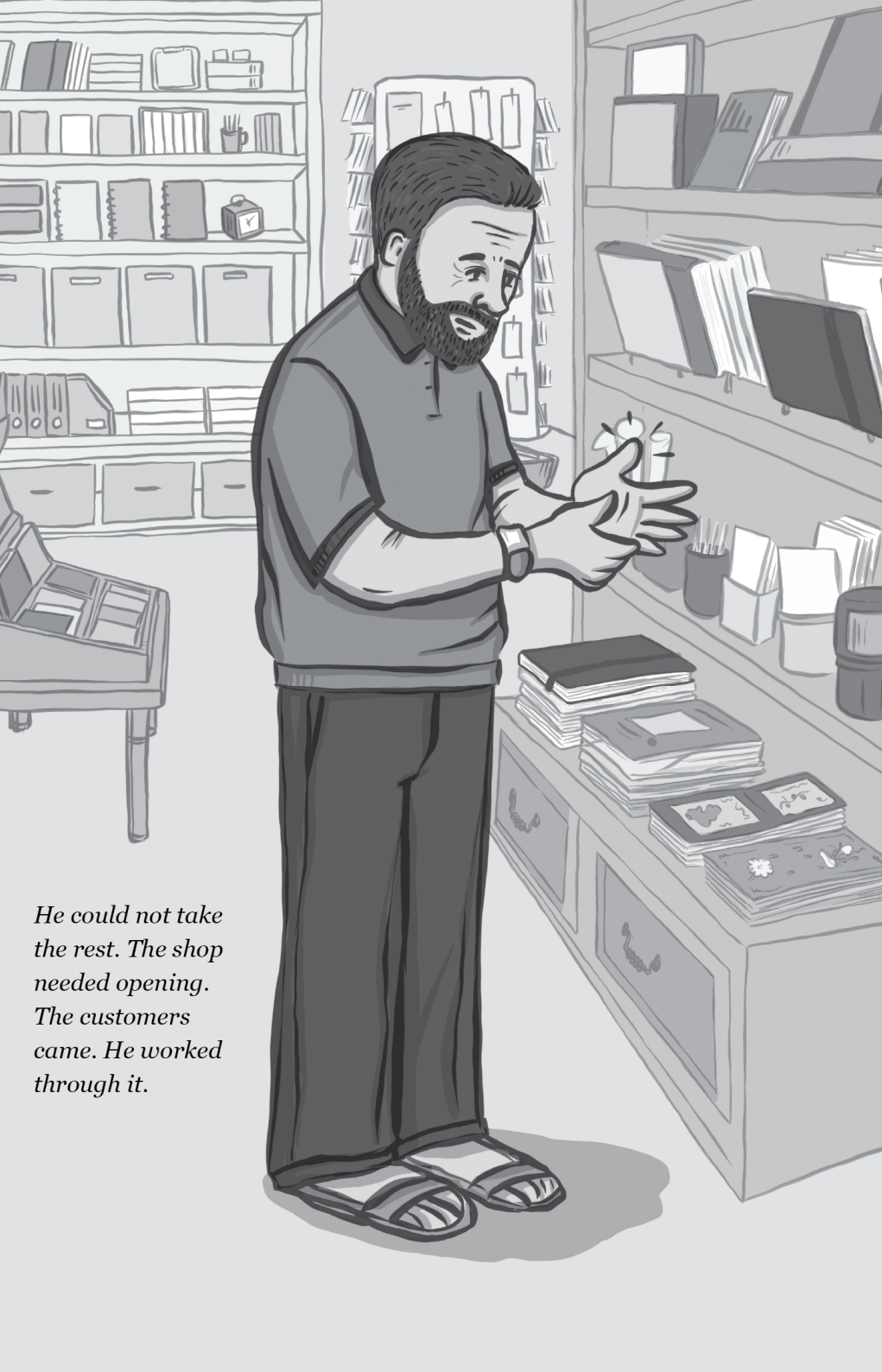
The bell on the door is the first sound of every morning.

Hasan turns the key. The shutter rolls up. Inside, the smell of paper. New notebooks stacked in the back. Pens in their cups by the counter. The light coming in slowly, the way it does in Konya in early spring, settling on the wood of the desk.

He has been doing this for almost thirty years.

He knows the people who come to his shop. The woman who buys a notebook for her grandson. The child who needs something for a school project at the last minute. With many of them he does not have to ask; he reaches for the thing before they finish the sentence. Thirty years of mornings taught him that.

This is a Tuesday in 2014. Nothing has happened yet.



He could not take the rest. The shop needed opening. The customers came. He worked through it.

He was born in Konya in 1965. An only child.

"I was very mischievous as a student," he says with a tiny smirk.

He says it with the pleasure a man takes in a younger self he has long since forgiven. He could not sit still. He could not be contained. The teachers said he was clever, and he turned out to be clever in a way that surprised even him.

He ranked in the top one percent of the country on the university entrance exam.

He chose agriculture. Ankara University, the Faculty of Agriculture. He went to Ankara, finished his studies, and came home.

He could have stayed in Ankara. Many of his classmates did. But he came back to Konya.

There, he opened his stationery shop. It gave him a reason to get up in the morning, and it kept giving him one for the next thirty years.

He married. He had two children. The shop did well enough. He did not become rich and he did not become poor. He became known. In a city like Konya, that is its own kind of wealth.

The shop was a few minutes from the house. The customers were the same customers, mostly, year after year. Their children grew up and brought their own children, and every time someone came in for a notebook before the first day of school, Hasan understood, without saying so, that he was watching the city renew itself one small purchase at a time.

He never needed the world to admire him. He needed to know his work was done well, his customers treated fairly, his family content, and that he was where he was supposed to be, in the same place he had been the day before.

This is what he means when he says he loves his life. Not that it is large. That it is his.

Even in those early years, before anything had a name, his body was sending him small signals.

"I used to feel fatigue, weakness, a lack of energy even back then," he says. "Compared to my friends, I was always the one who got tired more quickly."

He could not have read those signals then. No one could. He was a young man with a shop and a family, and tiredness was simply the cost of running a business.

There was one early sign, in particular, that no one could have read at the time. During his military service in 1993, his fingers began to swell. One day a middle finger, another day a different one. It came and it went. It did not seem to mean anything, so he let it pass.

Years later, it would turn out to have meant a great deal.

Then, one winter, an ordinary illness turned into something else.

A cold settled into his knee and would not leave. Walking became difficult. Bending the knee was almost impossible. He went to the hospital.

They told him he had acute rheumatic fever, and prescribed a course of injections.

He asked, in the voice of a man who has been brave about many things and was not, that day, in the mood to be brave about needles, whether there might be a pill instead.

There was a pill. He took it. He went home.

The illness lingered for weeks. He went to another doctor, who treated it fully and told him to rest for a month. Hasan took the treatment. He could not take the rest. The shop needed opening. The customers came. He worked through it.

Years passed. The shop opened and closed and opened again. His children grew up.

Then in 1999, in his mid-thirties, something arrived and did not leave.

The doctors gave it a name. Rheumatoid arthritis.

"I met it," he says, "in 1999. We've been walking arm in arm for about twenty-five years now."

It is the voice a man uses for an old neighbor. Someone difficult. Someone permanent. Someone who has, against all expectation, become part of the furniture of a life.

In the beginning, he fought it.

"It was hard to accept," he says. "When it first came, my chest felt as if someone had glued my body together. I could not breathe properly. I threw myself into bed. I asked, why this, why me?"

He grieved. He stayed in bed. And then, after some days, he got up.

"In the end," he says, "you will always find the strength within yourself to endure."

He went back to the shop. The customers came in. The body argued with him, and he worked anyway.

Without knowing it, he had begun to learn the thing this book is about: how to keep being yourself inside a body that has started making its own demands. He could not know that, sixteen years on, a different doctor would find something quieter happening in the same body, something that had been there longer than anyone could say.

But that day was still ahead of him.

For now, in his mid-thirties, he had learned the first lesson the body had taught him directly. Illness arrives, and you can grieve it, and the shop still opens at the same time tomorrow.

So you show up.

A NEW TEST

There are sentences that change life and are spoken in such ordinary voices that no one in the room notices them passing.

In 2015, in a doctor's office in Konya, Hasan heard one of those sentences.

The doctor had been about to write him a prescription. Hasan had been adjusting treatment for his rheumatoid arthritis for sixteen years by then, and a new prescription was nothing unusual. He knew the shape of the visit.

Then the doctor said: before I prescribe this, let us just get a chest X-ray.

Routine. The kind of caution a careful doctor takes. The kind of sentence Hasan would have forgotten within the hour, if the X-ray had come back clean.

It did not come back clean.

The imaging showed unusual findings in his lungs. Further assessment followed, and then a phrase, written on paper and read aloud to him: usual interstitial pneumonia. A UIP pattern.

He did not know what it meant. Most people, hearing it for the first time, do not. It is a shape that appears on a scan, associated with fibrotic lung disease, a phrase that means a great deal to a chest physician and almost nothing to the person whose chest it describes.

The doctors said the finding could be monitored, and that referral to a chest specialist could be considered if needed.

If needed.

Those were the words that did the most work in the room that day, though no one knew it yet. The body had said something. The doctors had heard it, and written it down, and decided to watch.

Then everyone went home.

What Hasan still remembers as strange is that he felt completely well.

On the day a scan found something wrong in his lungs, he could walk on a treadmill for nearly an hour at five kilometers an hour without trouble. His oxygen saturation at rest was 97 percent.

"I could walk," he says. "I could run. I could spend half an hour, an hour on the treadmill."

Ninety-seven is a healthy number. His body, on paper, was in trouble. His body, as he lived in it, was telling him nothing was wrong.

That was the disorientation he carried home. A finding on a scan that pointed to a serious disease, and a body that disagreed with the scan. Which one do you believe?

"I did not imagine," he says, "that this disease could be so serious. I thought, what is shortness of breath, what will happen."

He looked online, the way people do. In 2015 there was little written about what he had been told he might have. So he carried the finding home, set it beside the rheumatoid arthritis he already knew, and waited.

His other illness was the louder one.

Rheumatoid arthritis had been with him for sixteen years. He knew its rhythms, its bad weeks, its quieter months. In 2017 his doctors added weekly injections, and a needle every week is its own ritual, its own claim on a person's attention.

The lung finding made no such claim. It did not hurt. It asked for nothing.

A person knows where to put their attention when something hurts. When nothing hurts, the quiet thing waits.

So the lung finding, for the most part, receded.

He went home. He opened the shop. He walked on the treadmill. He felt fine.

What he could not see was that the clock had started in that room with the scanner, and that it would keep moving whether he watched it or not.

Looking back, he has thought a great deal about those years.
"Maybe if my doctor had sent me to a chest specialist that day," he says, "I would have been better. I would have been more aware of my illness."

THE YEARS THAT WERE QUIET

This is one of the quietest, hardest things to grasp about pulmonary fibrosis. It can sit inside a person for years before it speaks. A person can carry it and feel almost nothing. Then, one day, the body is different than it was, and the person notices.

Between 2015 and 2020, Hasan's lungs were not standing still. He could not feel it. Neither, in any day-to-day way, could anyone around him.

Part of why the years felt quiet was that the rheumatoid arthritis was loud. Joints swelled. Pain came and went. Treatment shifted. From 2017 the weekly injections set their own rhythm, and a body busy managing one chronic illness has little attention left over for one that makes no noise.

The lung finding sat outside all of that. It did not ask for anything, so it did not get anything.

This is not a failing. It is simply how chronic illness works. The illness that hurts gets the appointments. The illness that whispers waits its turn.

There were infections in those years, too. For lungs already carrying quiet fibrotic change, an infection is never a small thing. Each infection took something from the lungs, and the lungs give a little of themselves to answer.

Hasan came through them. He went back to the shop. He carried on.

Looking back, he has thought a great deal about those years.

"Maybe if my doctor had sent me to a chest specialist that day," he says, "I would have been better. I would have been more aware of my illness."

He says it without anger and without blame. He says it in a way a person states something they have turned over many times and finally understood. The disease was already there in 2015. What was missing was the bridge between the door he had walked through, his rheumatoid arthritis, and the chest specialist who might have been waiting on the other side of it.

Two small words. Think lungs.

He did not know then how much they mattered. He knows now. And he says them out loud so the next person might hear them in time.

THE STAIRS

It began with the stairs.

Hasan does not remember the exact day. Around 2020. By then he had moved the shop to a street-facing spot with a small staircase to the second floor. Ten steps. He used to climb them without thinking, to go up and pray.

Then, one day, the ten steps felt different.

"I felt out of breath," he says. "Ten steps. I thought, I must see a good chest doctor."

A small catch in the breath, the kind a man explains away the first time. He is older. He is tired. It has been a long day. He felt it again the next week, and the next.

The body does not lie. A body that has begun to disagree with the stairs is a body that has begun to change.

By 2021 the change could no longer be set aside. He needed a chest specialist now, not to watch, but to treat.

In October 2021, Hasan began treatment for pulmonary fibrosis at Ege University, where a specialist started him on antifibrotic treatment. His rheumatologist added a second medication for the autoimmune side of his disease.

Two illnesses. Two treatments. One body holding both.

The trips from Konya to Izmir were long. Trains. Hotels. A clinic where the specialist, however excellent, carried a great many patients at once.

"I would go all the way from Konya," he says, "and I could barely get a minute to talk about my own illness. She is a very good doctor, perhaps the only one of her kind. But she was busy, and understandably so."

So Hasan searched again, the way he had in 2015. This time he found a chest specialist in Ankara who could not take on new patients as she was busy with a high number of existing cases. He asked her anyway and she accepted him. Through her, he met a second doctor who joined his care. From then on, two physicians held the structure of his treatment together.

"They are people you cannot find easily," he says. "And whenever I need them, I can reach them."

This is one of the truths Hasan returns to. A patient with a serious illness needs more than a good doctor. He needs a good doctor he can actually reach. One who answers the message. One who makes room for the question.

"The communication with the doctor," he says, "is everything."

After 2021, infections were harder to shake. A cold that once cleared in days now took weeks. Each one left him a little less than it found him.

This was the next stretch of the road, and he walked onto it the way he had walked onto every other. He kept opening the shop. He kept seeing his customers. He kept being the man whose name was on the sign.

He weighed it for a long time.
Then he closed it.

"It was unavoidable," he says.

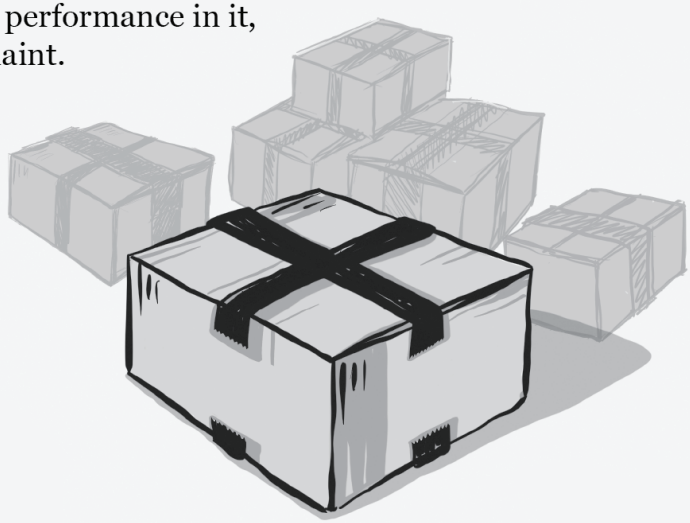
CLOSING THE SHOP

In June 2025, Hasan closed the shop.

He had run it for almost thirty years. The bell had been the first sound of his mornings for as long as anyone could remember.

Then, one morning, he did not open it. And then he did not open it ever again.

Hasan set it down quietly. He weighed what his body could give, decided honestly, and went home. There was no performance in it, and no complaint.



The decision came not from a single moment but from a slow accumulation. After 2021, every infection cost him something, and every recovery took longer than the last. The simple work of lifting the shutter, standing behind the counter, making change, talking with customers, the easiest part of his day for thirty years, had become the most expensive.

He weighed it for a long time. Then he closed it.

"It was unavoidable," he said.

There is a particular grief in closing a business you built. It is not the grief of leaving a job. A job can be left and replaced. A shop that carries your name, that you opened with your own hands, that the city knows you by, cannot be. To close it is to set down a part of who you have been.

Hasan set it down quietly. He weighed what his body could give, decided honestly, and went home. There was no performance in it, and no complaint.

He never spent the time since looking for ways to stay busy. That was never who he was.

"I do not interfere with anything," he said, with a small smile. "I drink tea all day. If there is somewhere to go and my daughter can take me, I help. Otherwise, I am comfortable with the new way of working."

He never needed the world to admire him. The only thing he needed to know was that the people he loves are well, and that he is where he means to be.

Family had become the structure of the day.

His wife has been his strongest support through every hard stretch. His daughter is around. His two young grandchildren, one three and a half, the other seven or eight, filled the house with the kind of noise that reminds a person why the days are worth having.

"Family," he said, when asked what keeps him going.

That was it. The whole answer. Family.

“Family,” he says, when asked what keeps him going.

That is the whole answer. Family.

TEN HOURS OF OXYGEN

There was always a machine in Hasan's living room.

It hummed. It drew in the air of the room, concentrates the oxygen, and feeds it through a length of clear tubing to the small prongs that rest at his nose.

He used it for more than ten hours a day.

At rest, his oxygen saturation sat around 90 percent. When he moves, it drops. A short walk across the house can bring it down; a thirty steps can leave him reaching for breath.

So the concentrator stayed on, and the tubing stayed within reach, and the room had arranged itself around the machine , over time, around the needs of the body that lives in them.

There is more to manage than the fibrosis.

In December of last year, an infection put him in hospital in Ankara for two weeks. One of his doctors took him in. He came home with a steadier breath than he had arrived

with. His treatments continue. The medication for the autoimmune side of his disease, paused for a time, is back. In all, he takes many medications a day for his conditions.

Ten hours of oxygen. Ninety percent at rest. A thirty steps.

Numbers, all of them. They tell one kind of story.

2026 – IN LOVING MEMORY OF HASAN

The other story, the one the numbers could not hold, is the one Hasan went on living every day, right to the end.

His days had a different rhythm in that last stretch. He watched a little television, saw to small things on his phone, sat, and drank tea all day, the way he always had.

And he was surrounded by the people he wanted. The people he loved.

His wife was the center of the house. She knew his medications. She came to his appointments. She knew what he needed before he asked.

"My wife," he said, "is the greatest gift God has given me. If she were not here, life would be very difficult. She met every need without ever being burdened. That is the best thing that can happen to a person in this life."

The window he sat by let in the light of Konya, the city that had been his home since 1965. His daughter was near. The grandchildren came and went, and the house was loud on many days. Just the way he liked it.

"There is what they call the love of life," he says. "That joy of living. I have that. We do not let go of ourselves. That must have something to do with it."

Hasan passed away in July 2026, among the people he loved.

He did not let go of himself. Not once, not to the end. And the joy of living he spoke of stayed with him, right up until the quiet.

Pulmonary fibrosis is a serious illness. This disease can hide for years. The earlier it is seen, the earlier a chest specialist is brought in, the more room there is for everything that comes after.

PART THREE
BEYOND THE SCARS

LIVING BEYOND THE SCARS

At the beginning of this book, we spoke of an unexpected turn.

A turn no one plans to take. A road that keeps going, but in a direction you did not choose. No clear way back, no sign telling you how far the next turn lies. Only the decision to keep driving, and to start paying attention differently.

In Ankara, Edip's mornings begin early. He walks. He takes his pill. Several evenings a week he stands among his singers, and a roomful of people draws breath together, and one of them is him.

In Konya, Hasan's mornings began later, to the soft hum of the concentrator that ran through the night. His wife was in the room. He took the day's medications and sat by the

window. He spent the day's energy like a careful man spends from a small budget, on what matters.

Two different lives, in two different cities, shaped by two similar yet different realities. Both held on to the joy that shaped their days. This is what it means to live beyond the scars. Not to be free of them. Not to be cured, or returned to who you were before. Only to keep being yourself, fully, inside the body you have today.

Pulmonary fibrosis is a serious illness. It does not improve on its own. But an early diagnosis helps. Care helps. Treatment helps. Walking helps. Family helps. The will of the person living it helps most of all. No single one of these is enough alone. Together, they are what a life can be built on.

And there is one more thing, quieter than the rest, that runs underneath both stories. Time.

This disease can hide for years, especially behind a louder autoimmune condition like rheumatoid arthritis, where the link between the joints and the lungs is real but easy to miss. The earlier it is seen, the earlier a chest specialist is brought in, the more room there is for everything that comes after. A small question asked in time, a scan, a referral, a change in breathing mentioned out loud, can change the shape of the years that follow.

Think lungs. It is the simplest message in this book, and perhaps the most important. Edip and Hasan opened their lives to us so that anyone living with this condition does not feel that they have to walk theirs feeling alone.

LETTERS FROM EDİP AND HASAN, TO THE READER

A LETTER FROM EDİP

If you are reading this, perhaps you have just heard a word you did not expect to hear. I know something of that moment. I will tell you what I tell my own family, and what I would tell anyone who calls me, because they are welcome to.

Look at life positively. Do not sit and wrap yourself in darkness; nothing good for your health comes from there. Find the things that make you feel alive and hold on to them. For me it was walking, and music, and the people I love. For you it may be something else. Whatever it is, do not let go of it.

And do not delay your checks. My greatest fortune was that this was found early, while I still felt completely well. If something in your body asks a question, let a doctor answer it. Sooner is always better than later.

Positivity. Attachment to life. Joy of living.

— Edip

A LETTER FROM HASAN

To anyone who has just received this diagnosis, especially if you are young, I want to say a few simple things, because I learned them the long way.

Find a good doctor. Not only a clever one, but one you can reach when you need them. That matters more than you know.

Be patient. And accept the illness, because until you accept it, nothing goes well. We have to learn to live alongside it, no matter what. There is no other choice.

Hold on to the joy of living. My wife who is the greatest gift of my life, a daughter, grandchildren whose noise filled the house are my reasons. You will have your own. Do not let go of yourself.

— Hasan


THANK
you

A NOTE OF THANKS

To Edip, who opened his life to us with grace and patience, and whose voice runs through every page of his story: thank you.

To Hasan, who shared what he has lived with the same steady honesty he has brought to every other part of his life: thank you.

To the families of both, who have walked beside them through every chapter, and especially to the wives who have been the quiet centers of two long marriages: thank you.

To the doctors who have made their continued lives possible, at every stage of these journeys: thank you.

To the reader, who has stayed with us to the end: thank you.


NADiR
HASTALIKLAR
FEDERASYONU


PAHSSc
Pulmoner Hipertansiyon ve
Skleroderma Hasta Derneği

A diagnosis should never feel like an ending. It's merely a missed exit, sudden and uncalled for. The journey must go on. It's simply no longer the one you expected.

Edip and Hasan took that unexpected turn, in different cities, years apart, and lived it in their own ways. Edip found his answer to living with an irreversible condition in music, in walking, and in a stubborn refusal to let fear run his life. Hasan found his answer in his family, in patience, and in his wife, whom he called the greatest gift of his life.

This is the story of two brave men who lived with pulmonary fibrosis but didn't let the illness define their lives.

Beyond the Scars is a book about hope, about people who refused to give up and wanted to share their journey to inspire those living with this condition.

Two men. Two different cities.
They've never met, but they shared the same diagnosis with the same determination.

ceres YAYINLARI
www.ceresyayinlari.com
iletisim@ceresyayinlari.com
/ceresyayinlari
/ceresyayinlari
/ceresyayinlari
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