ONE DAY AT A TIME

CARING FOR A PARENT WITH DEMENTIA

A FAMILY'S CAREGIVING JOURNEY – EXPERIENCES AND LEARNINGS

ROHIT R. CHOWDHRY

ONE DAY AT A TIME

CARING FOR A PARENT WITH DEMENTIA

A FAMILY'S CAREGIVING JOURNEY – EXPERIENCES AND LEARNINGS

ROHIT R. CHOWDHRY

OrangeBooks Publication
www.orangebooks.in

OrangeBooks Publication

1st Floor, Rajhans Arcade, Mall Road, Kohka, Bhilai, Chhattisgarh 490020
Website: **www.orangebooks.in**

First Edition, 2026

ISBN: XXXXXXXXXX

Price: Rs.00.00

Printed in India

Dedication

For our mother, Dr. Gayatri R Chowdhry

(13th May 1934—20th May 2023)

Who showed us, through her life, what strength, grace and love truly mean.

With gratitude and love,
From all of us—her children & their spouses, and her grandchildren.

Rohit—Preeti; Vandana—Yatendra; Rajeev—Sonal;

Aasheesh—Naina; Dr Shefali, Vivek, Rupali, Arjun.

A Family Note

This book is more than a story.

It is a shared journey.

A journey of caring, learning, adjusting and, above all, being present—*one day at a time*.

As a family, we experienced this phase together in different ways—across homes, across countries, but always connected through our love for our mother.

Each of us saw her through a different lens.

Each of us shared moments—some joyful, some difficult and many deeply meaningful.

This book brings together those experiences in our shared voice.

It reflects not just what happened, but what we learnt as a family—about care, patience and what truly matters.

This book is also being made available as a free eBook for anyone who may be navigating a similar journey with Dementia. (At www.rohitrchowdhry.com/dementia)

If it offers even a small sense of clarity, comfort or companionship, it will have served its purpose.

Please feel free to share it with others who may benefit from it.

With love,

Rohit—Preeti; Vandana—Yatendra; Rajeev—Sonal;

Aasheesh—Naina; Dr Shefali, Vivek, Rupali, Arjun.

◆

Contents

Introduction

Part - 1

Before the Change

Part – 2

Understanding the New Reality

Part – 3

Living Through the Change

Phase 1: Adjusting to the Reality

Phase 2: Building a Sustainable System

Phase 3: Advanced Care & Awareness

Chapter - 15

Part – 4

The Inner Journey

Chapter - 16

Chapter - 17

Part – 5

What Remains

Chapter - 18

Introduction

When Life Changes Quietly

When a parent begins to forget, life does not change overnight.

It changes quietly.

Conversations become simpler.

Routines become uncertain.

Moments of recognition come and go.

And slowly, you realise that something has shifted—not just in them, but in everything around them. In the way your days are organised. In the way you speak. In the way you measure what a good day looks like.

This book is about one such journey.

It is about caring for a parent with Dementia—a progressive condition that affects memory, cognition and the way a person experiences the world.

But more than that, it is about a gradual realisation:

This journey is not about restoring memory.

It is about redefining care.

My mother, Dr. Gayatri R Chowdhry, lived a full and remarkable life. She was a doctor, a leader and a pioneer in her field—the first woman to head a State Forensic Science Laboratory in India. To us, she was a source of strength, stability and quiet wisdom.

Over the years, we saw a gradual change.

At first, it was easy to explain.

Forgetting small things.

Repeating questions.

Moments of confusion.

We attributed it to age, to circumstances, to life events.

But slowly, it became clear that this was something more.

Dementia does not arrive all at once.

It unfolds—gently at first. Then steadily.

It does not just affect memory—it changes the way a person sees the world, understands reality and connects with others.

And in the process, it changes the family too.

When I began this journey, I was looking for answers.

How do you manage daily life?

How do you communicate?

How do you handle difficult situations?

But over time, I realised that the answers were not always technical.

They were human.

This book is not a medical guide.

It is a sharing of lived experience—drawn from a journey navigated together as a family. While written through my voice, the experiences, decisions and moments reflected here were shared with my wife, my sister, my brother and their families. Each of them saw my mother through their own lens. Each of them contributed to her care in ways that shaped everything we learnt.

It is about the small moments, the unexpected challenges, the quiet learnings and the gradual shift in perspective that comes with caring for someone whose memory is fading.

One of the most important lessons I learnt was this:

You cannot manage Dementia with logic.

Trying to correct, convince or reason often leads to frustration—for both sides.

What works instead is something simpler—and yet not always easy.

Patience. Acceptance. Presence.

There were moments of difficulty.

Moments of helplessness.

Moments when I did not know what the right response was.

And there were also moments of connection.

Unexpected smiles.

Simple conversations.

Quiet companionship.

Over time, I began to understand that this journey is not about fixing things.

It is about adapting.

And perhaps the most important realisation of all was this:

When memory fades, the ability to feel remains.

Which means that even when someone can no longer remember a conversation, a visit or a name—they can still feel warmth, comfort and love. And that becomes the most important thing we can offer them.

This book is for anyone who is caring for—or will care for—someone with Dementia.

It is also for families trying to understand what their loved one is going through.

You may find practical ideas here.

You may find reflections that resonate.

But most of all, I hope you find reassurance.

That what you are experiencing is not unusual.

That your struggles are valid.

And that there is a way to navigate this—one day at a time.

If there is one thought I would like you to carry with you as you read:

You may not always be able to change the situation.

But you can change the way you respond to it.

And sometimes, that makes all the difference.

◆

Dr Gayatri R Chowdhry - At work

Part - 1

Before the Change

Before we understood what was happening, we were simply noticing small changes—without yet knowing what they meant.

Chapter - 1

The Woman Behind the Memory

Before Dementia slowly began to take away her memory, my mother was a woman of extraordinary strength, intellect and purpose.

Dr. Gayatri R Chowdhry was not just a doctor—she was a pioneer.

Born in Hyderabad on 13th May 1934, she chose a path that, at the time, very few women pursued. She completed her B.Sc. from Women's College, Koti, in 1955, and went on to study medicine at Osmania and Gandhi Medical Colleges between 1956 and 1961. She later completed her MD in Obstetrics and Gynaecology.

Her early years were spent serving as a doctor—first as a Woman Assistant Surgeon at the AP ESI Hospital, and later as a Civil Assistant Surgeon at Osmania Hospital and the Government Maternity Hospital.

In 1968, she made a transition that would shape the rest of her career. She joined as an Assistant Chemical Examiner under the Medical Department, which later became part of the Andhra Pradesh State Forensic Science Laboratory (Police Department).

Over time, through dedication and continuous learning, she rose through the ranks. She underwent specialised training in Biology and Serology and became a Fellow of the Forensic Science Society of India.

In 1983, she achieved a remarkable milestone—she became the first woman Director of a State Forensic Science Laboratory in India. She led the Andhra Pradesh State Forensic Science Laboratory with distinction until her retirement in 1992, after 24 years of service.

She also introduced the X-ray diffraction technique in forensic investigations in India—an example of her forward-thinking approach and commitment to advancing her field.

But beyond her achievements, it is who she was as a person that stays with me even more deeply.

She was incredibly humble.

A great listener. Patient. Composed.

She believed in doing her work sincerely without worrying too much about the outcome. That quiet philosophy shaped the way she lived—and influenced the way I think even today.

As a working woman, she managed the balance between professional responsibilities and family life with remarkable grace. We saw her navigate work challenges, bureaucracy and office politics, yet she never allowed these to disturb her inner calm. She remained steady and grounded.


Sitting . I Row L to R....1.Gowri Jayaram.2.Dr.Gayatri. 3.Dr.Chandrakala.4.Dr.Sita Anand.5.Dr.Mrudula Kirloskar.6.Mrs.Rohini Deshmukh.7.Dr.Vijaya NandanSingh.8.Dr.Ramasrikrishna.9Mrs.Pushpa pimpelnekar.10.Dr.Laxman pimpelnekar.

Sitting. II Row L to R.....1.Dr.Nandan Singh..2.Chris Surainder.3.G.Indira.4.Dr.Khaja Fareeduddin.5.Mrs.Angelo Fareeduddin.6.Dr.Khalid Abdus Sami.7.Mrs.Zinath Sami.8.Mrs.Aneesa Ashraf.9.Syed Habeeb Ashraf.10.Dr.Zamarud Arastu.11.Dr.Madhu Sudan Murty.12.Dr.Narayan Deshmukh.

Standing L to R. 1 .Dr.Suri Surainder.2.Mr.Premanand.3.Dr.B.K.Sahay.4.Dr.P.satyanarayana.5.Dr.Srinivas Itikala.6.Mrs.Sudha Kulkarni.7.Dr.J.R.kulkarni.8.Dr.D.Vidyasagar.9.Mrs.Shanta Raghunandan.10.Dr.Raghunandan Dundoo...

Her MBBS classmates

She set high standards—not just in her work, but in her values.

Integrity. Honesty. Commitment.

These were not things she spoke about often—but things she lived every day.

At home, she was the anchor of the family.

She loved to travel and stay connected with people. She would meet her MBBS classmates at least once every year without fail. She never missed a visit to the "numaish." In her younger days, she had even travelled to Sri Lanka with a close friend—something quite uncommon at that time.

Over the years, she travelled across India for meetings and conferences and internationally to places like Singapore, Japan and the United States.

She was also a wonderful cook.

Whether it was North Indian or South Indian cuisine, she cooked with passion and precision. She maintained handwritten recipes for dishes that required exact proportions—her mango pickle and certain cakes were always special.

Cooking, for her, was not just about food. It was about care.

She was selfless in every sense.

A constant source of strength for my father, my siblings and me. She was always there—for guidance, for support and for reassurance.

She never judged.

She listened. She understood. She stood by us.

She was someone I could trust completely. Someone whose blessings I always felt.

She was not just my mother.

She was my superhero, my role model and my inspiration.

My sister often described our mother as a quiet, reserved person—someone who spoke little, but with clarity and authority when she did. She was a pillar of strength and a role model, especially in how she balanced work and family. She believed that children remember the quality of time, not the quantity—and lived that belief every day.

She also had a remarkable memory.

She would remember birthdays and special occasions of family and friends without fail.

Ironically, this was one of the strengths that Dementia would slowly take away.

After my father's passing in 2015, we began to notice subtle changes.

At the time, they did not seem significant.

But looking back now, they were the beginning of a different phase.

A phase where memory would slowly fade, but something deeper would remain.

Today, when I think of her, I do not define her by her illness.

I remember her for the life she lived.

For the values she stood for.

For the strength she showed.

For the love she gave.

Because Dementia may take away memory.

But it does not erase a life well lived.

Our Father – Shri Rajan Chowdhry passed away in 2015, at the age of 91

* * *

Chapter - 2

When Something Begins to Shift

There is no clear starting point to Dementia.

No single moment where everything changes.

Instead, it begins quietly.

So quietly that, at first, it is easy to overlook.

After my father passed away in 2015, life had already gone through a significant emotional shift. My mother had spent years caring for him with dedication and strength. His absence created a void—not just in routine, but in purpose.

Around a year later, when she was about 82, my brother and sister, who live in the United States, took her there for a couple of months so she could spend time with them.

There was familiarity in the context. My sister and her family had lived in Hyderabad for a few years earlier and my mother knew that home well.

In the initial days in the U.S., something felt slightly different—but not enough to raise concern.

My mother would often say that she was in my sister's house in Hyderabad. She spoke as if she was still in India. At times, she would express a desire to "go back home," even though she had already travelled across continents.

At that time, we didn't think too much of it.

We explained it to ourselves.

It must be the long journey. Jet lag.

The emotional impact of my father's passing.

All of these seemed like reasonable explanations.

And perhaps, in some way, we wanted them to be true.

My sister recalled that one of the first signs she noticed was when our mother mentioned her age incorrectly—something very unlike her, given her sharp memory with numbers and details.

In hindsight, it feels different.

That may have been one of the early signs.

Not dramatic. Not disruptive. But present.

A subtle confusion of place.

A blending of realities.

Something that did not yet have a name—but was beginning to take shape.

As time went on, there were other small moments.

Forgetting recent conversations.

Repeating questions.

Pausing mid-sentence, searching for words.

Each of these, on its own, seemed minor.

After all, we all forget things sometimes.

We all lose track of words occasionally.

So it was easy to dismiss them.

That is perhaps one of the most challenging aspects of Dementia in its early stages.

It hides in plain sight.

It mimics normal ageing.

It blends into everyday life.

It does not demand immediate attention.

And so, we continue as usual.

Looking back, I realise that early signs are often not about what happens once, but about what begins to repeat.

It is not a single incident that matters—it is the pattern.

Small repetitions in conversations. Moments of forgetfulness that felt unusual. Occasional difficulty with things that had always been routine. Individually, none of these seemed significant. Each one had an explanation. And at that time, we were looking for explanations—and finding them.

Until gradually, the explanations no longer felt sufficient.

It was my brother who first named what we were all sensing but had not quite articulated. He had an analytical way of looking at things—connecting the dots between small incidents that we might otherwise have dismissed in isolation. It was not about any one moment, he would remind us. It was about what was beginning to repeat.

That framing helped. It shifted our attention from individual events to the pattern beneath them.

Seeking Clarity

As these small moments began to repeat, we felt the need to understand what was really happening.

Around a visit by my brother—who was particularly keen on establishing a clear benchmark for our mother's cognitive condition—we decided to seek medical evaluation.

We consulted a neurologist.

The consultation was detailed and thorough. The doctor asked her a series of questions—simple on the surface, but designed to assess memory, orientation and cognitive function. Questions about time, place, recall and recognition. There were also diagnostic tests, including CT scans.

The doctor explained that my mother had **Alzheimer's—a form of Dementia.**

She described it as a progressive condition that gradually affects memory, thinking and behaviour. It often begins with small signs like forgetting recent events or repeating questions, and over time, leads to increasing confusion and dependence.

She also explained that Dementia is an umbrella term, and Alzheimer's is one of its most common forms. While there is no cure, medications can help manage symptoms and offer some support along the way.

My brother, who had always approached things with a clear and analytical mind, shared something that stayed with all of us.

When the doctor explained what was happening to the brain—how Dementia causes it to gradually shrink—she used an image that he could not let go of.

"When a child grows," she had said, "their brain expands with learning and possibility. With Dementia, the reverse happens—the brain contracts, and with it, the very capabilities and memories that once defined a person begin to fade."

He told me he kept returning to that image.

The same brain that had once absorbed medicine, mastered forensic science, led an entire laboratory—was now, quietly and irreversibly, going in the other direction.

For someone who had always sought to understand things clearly, that image provided clarity. But it also carried a grief that clarity alone could not resolve.

The diagnosis helped bring clarity for all of us. It also gave us a reference point—a baseline from which future changes could be understood.

Over time, follow-up scans showed what the doctor had explained: the gradual shrinking of the brain. It was not something we could see day-to-day. But it was happening.

Medication was prescribed to help manage the condition and slow its progression. We followed the treatment as advised.

But one question always remained in my mind.

How much was the medication helping?

There was no clear answer. There was no comparison point. No way of knowing how the condition might have progressed without it.

What the diagnosis did provide, however, was something else.

Not certainty. But acceptance.

What this Taught Us

- Early signs of Dementia are often subtle and inconsistent
- It is easy to attribute them to ageing, stress or circumstance
- Awareness comes slowly—and often in hindsight
- A diagnosis provides clarity—but not complete answers

Dementia does not announce itself.

It reveals itself, one small moment at a time.

A Gentle Reminder

- Notice repeated confusion around time, place or people
- Pay attention to patterns, not isolated incidents
- Trust your observation—even if it feels too early

Sometimes, the beginning is only visible when you look back.

◆

Part - 2

Understanding the New Reality

As the condition progressed, we began to understand not just what was changing—but how to respond to it.

Chapter - 3

When Logic Stops Working

For most of our lives, we rely on logic.

We explain things.

We correct misunderstandings.

We expect conversations to follow a sequence.

Logic helps us make sense of the world.

And naturally, when something feels off, our instinct is to use more of it—to explain better, to clarify more clearly, to help the other person understand.

In the early stages of my mother's condition, we found ourselves doing exactly that.

If she forgot something, we would remind her.

If she said something incorrect, we would correct her.

If she seemed confused, we would try to explain the situation logically.

It felt like the right thing to do.

After all, that is how we normally communicate.

But gradually, something began to change.

The more I tried to explain, the more confused she seemed.

The more I tried to correct, the more restless she became.

And sometimes, it led to frustration—on both sides.

That's when something deeper began to make sense.

What I was trying to do was restore her reality.

But her reality had already changed.

Dementia does not just affect memory.

It changes how a person processes information, understands context and relates to the present moment. What seems obvious to us may not exist for them in the same way.

And when we try to impose our version of reality on them, it does not bring clarity.

It creates discomfort.

There came a point when I had to pause and ask myself something honestly.

Was my role to make her understand?

Or was my role to make her feel comfortable?

That question changed everything.

Because the answer, I slowly realised, was not the one I had assumed.

I began to shift my approach.

Instead of correcting, I started observing.

Instead of explaining, I started simplifying.

Instead of insisting, I started accepting.

This shift does not come naturally.

We are wired to correct, to guide, to fix. It is how we show care. It is how we communicate love, in the ordinary sense of things.

Letting go of that instinct requires conscious effort—and patience. And sometimes, it requires the humbling recognition that what feels helpful to us may feel distressing to them.

She was not being difficult.

She was experiencing a different version of reality.

And once I truly accepted that—not just intellectually, but in the way I responded moment to moment—communication began to change.

It was no longer about being right.

It was about being kind.

It was no longer about clarity.

It was about reassurance.

When that shift happens, something else becomes possible.

Connection.

Not the kind built on shared memory or detailed conversation. But a simpler, quieter kind.

Presence.

Sitting together.

Sharing a moment.

Allowing things to be as they are.

In the chapters that follow, you will read about specific moments where this shift was tested—and where it made all the difference. But the shift itself begins here, in this quiet recognition:

Logic was no longer the bridge. Emotion was.

What this Taught Us

- Logic does not always help—it can sometimes create distress
- Correcting facts is less important than maintaining comfort
- Acceptance is more effective than resistance

You cannot bring them back into your reality.

But you can choose to step into theirs.

A Simple Shift that Helps

- Pause before correcting—ask yourself whether it will help or harm
- Use simple, reassuring responses instead of detailed explanations
- Focus on how they feel, not what is factually accurate

In Dementia care, connection matters more than correctness.

When logic stops working, compassion begins to lead.

* * *

Chapter - 4

A Different Way of Connecting

One of the more subtle changes in this journey was not just in memory—but in conversation.

For most of our lives, conversations form the foundation of connection.

We share stories. We exchange ideas. We build on past experiences.

There is continuity.

One conversation leads to another.

With Dementia, that continuity begins to fade.

Conversations no longer follow a predictable flow.

They may repeat.

They may drift.

They may begin and end abruptly.

And slowly, you realise that something has changed—not just in what is said, but in what is possible.

I became aware of this more clearly after an interaction involving my brother.

After the day my mother asked me who I was, I shared the experience with my sister and brother, both of whom live in the United States. My sister had recently visited India and spent time with our mother, so she had already begun to see some of these changes.

My sister shared how, during her visit, our mother no longer recognised her. She would introduce herself, only to be met with polite conversation—as if they were meeting for the first time. It was deeply painful, and yet required holding back emotion in that moment.

My brother decided to come to India and spend a few days with her. He wanted to be with her. To reconnect. To spend time.

On the second day of his visit, he said something that stayed with me.

"What should we talk about?"

"She can hardly remember anything."

"Our conversations are all superficial… we're just talking about what she had for breakfast, how she is feeling… trying to see if she recognises people from old photos…"

There was no frustration in his voice.

Just a quiet realisation.

And in that moment, something became very clear.

When someone is physically unwell, you can still connect through conversation. You can discuss. Reflect. Share memories.

But with Dementia, that changes.

You cannot rely on memory.

You cannot build on previous conversations.

You cannot expect continuity.

So the purpose of conversation shifts.

It is no longer about exchanging information.

It becomes about creating a feeling.

We began to understand that our role was not to have meaningful discussions in the way we once did. Our role was simply to keep her engaged, comfortable and above all, happy.

Even if the conversation was repetitive.

Even if it felt superficial.

Even if it lasted only a few minutes before drifting away.

Because in those moments, what stayed with her was not the content of the conversation—but the emotion behind it.

This required a shift in expectation.

We had to let go of what conversations "should" be.

And accept what they had become.

Instead of asking open-ended questions, we began to simplify.

Instead of expecting recall, we focused on response.

Instead of depth, we focused on ease.

We would talk about simple things—what she had eaten, how she was feeling, who had visited.

Sometimes we would show her old photographs—not to test her memory, but to create a moment of familiarity. Sometimes she would recognise someone. Often, she would not. But the attempt itself created engagement.

There was a different kind of connection in these moments.

Not intellectual. Not structured. But real.

Over time, I realised something important.

We often associate meaningful conversations with depth, insight and continuity. But meaning can also come from something much simpler. Presence.

Sitting together without expectation. Allowing silence. Letting the moment be enough.

Sometimes, words were not enough. A smile, a gentle touch, or simply sitting beside her would communicate far more than conversation.

The Wider Family Circle

We found that staying connected with the wider family mattered enormously—not for memory, but for emotion.

My mother had an elder sister, two younger sisters and a younger brother. Her elder sister had passed away several years back. Her brother lived in Hyderabad, as did one of her sisters—who had, in fact, worked in the same Forensic Science Laboratory that my mother had headed. That shared history made their bond particularly close. Her other sister was a doctor based in Mumbai.

Her Hyderabad brother and sister visited regularly. These were not formal visits. They were simply family—familiar faces, familiar voices, the warmth of people who had known her across a lifetime.

Even as her memory faded, something in her responded to their presence. She could not always name them. She could not always follow a conversation. But you could see the ease in her—the way her body relaxed, the way she smiled without having to try.

Her Mumbai sister would call regularly. Even over the phone, that familiar voice seemed to reach something in my mother that went below the level of memory.

Her siblings also gave us something practical that we came to value enormously—flexibility.

In the period before we had full-time attenders, there were times when we needed to travel or manage other commitments. During those times, my mother would stay with her brother or sister in Hyderabad or Mumbai. She was comfortable there. She knew those homes. She knew those people.

That familiarity meant that her world did not feel disrupted. She was not in an unfamiliar environment being looked after by strangers. She was with family, in a home that held its own memories.

We also made it a point to take her to family gatherings—festivals, celebrations, get-togethers at each other's homes. The idea was not to overwhelm her with people, but to surround her with familiar faces and the gentle rhythm of occasions she had known all her life. To give her something recognisable to hold on to.

These gatherings could not always prevent the confusion. But they created warmth. And warmth, we learnt, has its own memory.

The Grandchildren

One of the connections that remained meaningful throughout this journey was the one she had with her grandchildren.

As her Dementia was growing, my son had to leave for the United States to do his MS. That transition—a grandchild going abroad at the same time as her world was slowly narrowing—carried its own quiet poignancy.

But distance did not mean absence.

My sister's and brother's children, who were based in the United States, would connect regularly on video calls. These calls were not long. They were not structured. But they brought young voices into her day—voices she had known since those children were small.

She did not always know who was calling. She could not always follow what was being said. But she responded to the warmth of those calls—the liveliness, the affection, the simple fact of young faces on a screen looking at her with love.

The grandchildren, in their own way, were part of the care ecosystem. Not through tasks or responsibilities, but through presence and connection.

And in those moments, even briefly, something in her lit up.

When Social Grace Remains

One of the interesting things we noticed over time was that even as my mother's memory was fading, her social instincts remained remarkably intact.

When relatives or visitors came home, she would greet them warmly.

She would ask: "How are you?" "How is everyone at home?"

She would engage in conversation with ease.

What was even more striking was that this was not limited to in-person interactions. Even on phone calls or video calls—with relatives and friends, including those from overseas—she would respond in the same way. She would greet them, speak naturally and ask about their well-being.

To someone observing from the outside, it might even feel like everything was normal.

But there was a subtle difference.

If the visitor or the person on the call asked her: "Do you know who I am?"—that's when things would change. You could see her pause. Search. Try to place the person.

It would put her in a difficult position.

Because in that moment, the expectation shifted from connection—to recall.

And recall was what she was struggling with.

When a Voice is Enough

There was something we noticed that went even deeper than social grace.

There were moments when a familiar voice—even without a face, even without a name—could reach her in a way that little else could.

My cousin in Mumbai would call regularly. And on those calls, something quiet but unmistakable would happen.

My mother could not always place who was calling. She could not necessarily attach a name to the voice or recall the relationship.

But she would smile.

Not a polite smile. Not the social grace of greeting a stranger warmly.

A smile of recognition—at a level below memory. As if something in her knew, without being able to explain how, that this voice belonged to someone safe. Someone loved.

It was one of the clearest illustrations of something we came to believe deeply:

Familiarity lives at a level that memory cannot fully reach—and cannot fully take away.

Over time, we learnt to guide visitors and callers differently.

We would gently tell them: "Please don't ask her to identify you."

Instead, we would encourage them to say:

"Hi, I'm [Name]… I spoke to you last week…"

or "I'm your cousin's daughter…"

The moment that was done, everything became easier. She didn't have to struggle. She didn't have to guess. She could simply engage.

And the conversation would flow naturally.

That small shift made a big difference.

It protected her from discomfort.

And allowed her to remain who she had always been—warm, gracious, socially present.

In many ways, her social grace outlasted her memory.

What this Taught Us

- Conversations are no longer about depth—they are about connection
- Repetition is not a failure—it is part of the reality
- The goal is not to be understood—but to create comfort
- Don't test memory—enable connection
- Familiarity operates below the level of conscious memory—familiar voices, faces and places still reach them
- The extended family—siblings, grandchildren—is part of the care circle, even from a distance

Help them engage, not recall.

In Dementia care, the question is not "What did we talk about?"

It is "How did they feel while we were talking?"

A Simple Shift that Helps

- Use simple, familiar topics
- Ask closed-ended or gentle questions
- Avoid testing memory
- Focus on tone, not content
- When calling or visiting, introduce yourself—don't ask them to identify you
- Keep visits and calls regular—the familiarity of a voice or presence matters even when the name does not come
- If siblings or other family can provide care when you travel—use that. Familiar environments are part of good care

It's not the conversation that matters—it's the connection it creates.

When memory fades, conversation changes—but connection doesn't have to.

The Evening Tea routine in the Balcony

* * *

Part – 3

Living Through the Change

As the reality became clearer, our focus shifted from understanding the condition to learning how to live with it, day by day.

Phase 1: Adjusting to the Reality

Chapter - 5

Entering Their World

There comes a point in this journey when you realise something fundamental.

You cannot always bring them back into your world.

But you can choose to step into theirs.

Understanding this in principle is one thing. Living it, in an unexpected moment, is quite another.

Two incidents taught me this—not through reasoning, but through experience. Each one, in its own way, showed me that the path forward was not correction. It was accompaniment.

The Day She Asked Who I Was

During the COVID period in 2020, I was working from home. Like many others, my days were filled with back-to-back calls.

But there was one thing I made sure of.

Every evening, from 5 to 5:30 PM, I blocked my calendar.

That time was reserved for tea with my mother.

From her working days, 5 PM had always meant chai. Continuing that routine felt important. It gave structure to her day—and gave me a moment to pause and simply be with her. We would sit together, often in the balcony, have tea and talk about small things.

Nothing structured. Nothing important. Just being together.

One evening, as we sat across from each other, she looked at me and asked:

"Who are you?"

For a brief moment, everything felt still.

I had known this day would come. I had read about it, thought about it, even braced myself for it in some abstract way.

But knowing it in theory and experiencing it in reality are very different things.

I asked her gently, "Who do you think I am?"

She looked at me and said, "My brother."

There was no confusion in her tone. Just a quiet certainty.

In that moment, I had a choice.

I could have corrected her. I could have said, "No, I am your son." I could have tried, once more, to bring her back into my reality.

Instead, I chose to step into hers.

I smiled and said, "Yes."

And we continued our tea.

What mattered in that moment was not whether she recognised me as her son.

What mattered was that she felt comfortable.

She was at ease. She was happy. And that was enough.

That evening, I understood something that I have carried with me ever since:

When memory fades, identity becomes fluid—but emotions remain real.

The Day I Took Her Back to Work

Sometime before this, during an earlier phase of her condition, there was another morning that tested me differently.

She woke up convinced that she had to go to the office.

She got ready just as she would have during her working years—with the same purposefulness I remembered from childhood mornings. She wore her saree. She wore her watch. Everything about her preparation said: today is a workday.

At first, I tried to gently distract her. I assumed the feeling would pass.

It did not.

As the day progressed, she became more insistent. By lunchtime, she was clear. She had to go.

That day happened to be a second Saturday—the office would be closed.

I told her so.

She did not accept it.

"Let's go and check," she said.

At that moment, I had a choice.

I could continue to argue—to explain, to reason, to try once more to correct her understanding of what day it was and what that meant.

Or I could find another way.

I chose to go with her.

We drove to her office. It was, as expected, closed. There was a police guard at the entrance.

I quietly explained the situation to him and requested his help.

He walked up to the car, stood straight, gave her a respectful salute and said:

"Madam, today is a holiday. The office is closed."

She accepted it immediately. No argument. No distress.

We returned home. She had her lunch. And the rest of the day went smoothly.

That moment stayed with me—not because it solved a problem cleverly, but because of what it revealed.

The guard's words carried no more factual weight than mine had. What was different was the context she trusted. The uniform. The salute. The register of authority that matched her memory of that world.

She was not refusing my words.

She was living in a reality where a different kind of confirmation made sense.

And once I understood that, something shifted permanently in how I approached these situations.

What Both Moments Had in Common

In the tea moment and the office visit, the solution was the same.

Not correction. Not logic.

Active adaptation—meeting her where she was, rather than pulling her toward where I thought she should be.

- I did not correct her when she misidentified me
- I did not argue when she insisted on going to work
- I chose to align with her reality, not override it

This is not the same as giving up. Or being dishonest. Or abandoning your own sense of what is real.

It means choosing, deliberately, to prioritise her comfort over your need to be right.

You don't have to prove what is real.

You have to preserve what is felt.

What this Taught Us

- Reality is not always shared—and that is not something to fix
- Correction can create distress; validation can create ease
- Sometimes the most loving response is the one that makes no argument at all

A Simple Shift that Helps

- When they say something incorrect, pause before responding
- Ask yourself: will correcting this help them, or is it for my own reassurance?

- Look for ways to validate the feeling, even when you cannot validate the fact
- When they insist on something, ask: is there a way to go with them rather than against them?

Sometimes, peace matters more than precision.

Caregiving is not about bringing them back—it is about walking with them where they are.

◆

Chapter - 6

Redesigning Everyday Life

One of the gradual realisations in this journey was this:

It is not enough to understand Dementia.

You have to redesign daily life around it.

In the early days, we continued with our normal routines. We assumed that with some reminders and gentle support, things would work as before.

But over time, it became clear that what felt simple to us was becoming increasingly difficult for her.

Not because she was unwilling.

But because the process itself had become complex.

Everyday life involves constant decision-making. What to wear. What to eat. Where things are kept. What to do next.

These are things we do without thinking. They happen automatically, almost invisibly.

But for someone with Dementia, each of these can become a point of confusion—a small moment of uncertainty that accumulates through the day into something exhausting.

That is when we arrived at a realisation that changed how we approached everything:

The goal is not to help them think better.

The goal is to reduce the need to think.

Simplifying Communication

Communication was one of the first areas where we had to make changes.

We noticed that she would pause after being asked a question, searching for an answer that didn't always come. Open-ended questions—the kind we use naturally in conversation—created confusion rather than connection.

So we simplified.

Instead of asking: *"What would you like to eat?"*

We began asking*: "Would you like rice or roti?"*

Instead of: *"What do you want to do now?"*

We would say: *"Let's sit in the balcony for a while."*

We also became more mindful of tone. Not passive. Not directive. But calm, clear and unhurried.

The difference was immediate—less hesitation, less anxiety, more ease.

What we learnt was that the form of the question matters as much as the content. A closed question with two simple options is not limiting. For someone with Dementia, it is a gift. It removes the effort of having to generate an answer and replaces it with the simpler act of choosing between two things.

Reducing Daily Decisions

We realised that too many choices created stress—even when those choices were small.

So we began organising things in a way that reduced decision-making from the start of the day.

Clothes were kept in sets—everything needed together, already matched. There was no need to search, no need to decide what went with what, no need to open multiple drawers.

Items used every day were kept in the same place, always. Predictable location reduced the effort of retrieval, and with it, a quiet source of daily frustration.

These may seem like small changes. But they shaped how her mornings began—and a smoother morning made everything that followed easier.

Creating a Predictable Routine

Routine became one of the most important things we could offer her.

Not a rigid schedule. But a reliable shape to each day.

Meals at fixed times.

Tea at the same hour.

A walk after lunch.

A familiar program in the evening.

A predictable day reduces uncertainty. And uncertainty, in Dementia, is one of the greatest sources of restlessness and distress.

Even small rituals mattered more than we expected. The 5 PM tea, for instance, was not just a habit—it was an anchor. Something she could feel coming. Something that said: this is how the day goes. You are safe here.

Organising the Physical Space

As part of redesigning daily life, we also looked at the home itself—not through the lens of safety, but of ease.

We made sure frequently used items were within reach and visible. We reduced unnecessary clutter. We organised her belongings so that things were where she expected them to be, day after day.

The idea was not to restrict her world, but to simplify it—to remove the small frictions that added up through the day.

As the journey progressed, the physical environment would need to be looked at through a safety lens too. But in this phase, the focus was simpler: make the day easier to move through.

Allowing, but with Awareness

There were activities she was used to—like going into the kitchen, being involved in small household tasks.

In the earlier stages, we allowed these—but with quiet supervision. It gave her a sense of normalcy and continuity. A sense that her life still had a shape she recognised.

But as the condition progressed, we had to gradually and gently limit certain activities. That shift was never easy. But it was done with care, and always with her dignity in mind.

What this Taught Us

- Complexity creates confusion; simplicity creates ease
- The form of communication matters as much as the content
- Routine is not restrictive—it is reassuring
- A well-organised environment reduces invisible daily effort

The less they have to figure out, the more comfortable they feel.

A Simple Shift that Helps

- Replace open-ended questions with two simple options
- Keep essentials in fixed, visible, predictable places

- Lay out clothes and daily items in advance
- Build small, consistent rituals into the day

Design the day so that it supports them—without overwhelming them.

When life becomes confusing, simplicity becomes care.

◆

Chapter - 7

Safety Becomes Critical

Redesigning daily life—simplifying routines, reducing decisions, creating predictability—goes a long way.

But there comes a point in this journey where something more is required.

A point where the question is no longer just: how do we make each day easier?

It becomes: how do we keep her safe?

As the condition progressed, we began to notice a change in the nature of the challenges. What had once been about confusion now began to involve risk. Not through carelessness or intention—but because the connection between an action and its consequence was no longer always clear to her.

Familiar things were still being done. But not always safely.

When a Simple Routine Became a Risk

One morning, my mother went for her bath as she always did. She locked the bathroom door from inside—as she had done thousands of times before.

After a while, we noticed she was taking unusually long.

When we called out, there was no clear response. When we checked the door, it would not open. She had locked it—but could no longer work out how to unlock it.

She was struggling. Confused. And as the minutes passed, becoming increasingly anxious.

We had to intervene—speaking to her calmly through the door, eventually helping her get out.

That morning led to a decision that felt uncomfortable to make, but was clearly necessary.

We replaced the bathroom door latch with a simple knob. The door could still be closed—her privacy was preserved—but it could no longer be locked from inside.

It was a small change. But it carried a weight that many such decisions carry.

Safety sometimes has to take precedence over independence.

Not because independence doesn't matter—it does, deeply. But because there are moments when protecting someone is the most respectful thing you can do for them.

When Movement Became Unpredictable

Sometime later, during a different phase, another challenge emerged.

My mother became convinced that her parents—who had passed away many years earlier—were living on the ground floor of our apartment building. We lived on the first floor.

On a couple of occasions, we found her downstairs, speaking to the watchman, completely calm and entirely certain she was where she was meant to be.

In her mind, she was simply going to visit her parents.

This was not confusion. It was not aimless wandering.

It was purposeful movement—driven by a reality that was fully real to her, even if it no longer matched the world around her.

And that made it more concerning. Not less.

Because it meant she could step out again at any time, guided by a logic we couldn't anticipate or predict.

We had to act.

We added locks to the main door—ones that required a key to open. It was not an easy decision. It felt restrictive in a way that the bathroom change had not. This was not just a door in a room. This was the boundary between home and the world outside.

But I held on to something that helped me make peace with it:

You are not limiting them. You are protecting them from a world that no longer makes sense in the same way it once did.

Thinking Ahead, Not Reacting After

Both of these incidents carried the same lesson.

We had responded—but we had responded after something had happened. After the locked bathroom. After the ground floor visits.

What we needed to learn to do was anticipate.

To look at our home not as a familiar, comfortable space—but as an environment that would need to be continuously reviewed and adapted as the condition progressed.

We began to think differently about the spaces she moved through.

- Was the bathroom safe if we weren't immediately nearby?
- Was the corridor well-lit at night if she got up while we were asleep?
- Were there things within reach that could cause harm—not through misuse, but simply through being picked up in a moment of confusion?

None of these questions had dramatic answers. Each change was small. But together, they created something important: an environment that was working quietly in her favour, rather than waiting to become a hazard.

My brother, during one of his visits, quietly made sure the shower room had proper safety handles in place. It was not something any of us had asked for. He simply noticed, and acted.

Not specifically because of the Dementia—but because he saw his mother growing older and wanted the environment around her to be safe. That kind of quiet, practical love was its own form of caregiving.

And it was a reminder that proactive care—acting before something goes wrong, out of foresight rather than fear—is one of the most valuable things a family member can offer.

Balancing Safety and Dignity

One of the hardest parts of this phase was the emotional weight of each decision.

Replacing a latch. Adding a lock. Stepping in when she headed for the stairs.

These are not clinical decisions. They are deeply personal ones. And each one carries a feeling—of taking something away, even as you know you are giving something more important back.

Over time, I came to understand something that helped.

Dignity is not only about independence.

Dignity is also about being protected. About being kept safe by people who love you. About not being allowed to come to harm because someone looked away.

Seen that way, these decisions were not diminishments.

They were acts of care.

What this Taught Us

- Familiar actions can become unsafe as the condition progresses
- The ability to perform a task and the ability to do it safely can diverge

- Safety must be proactive—waiting for an incident is not a strategy
- Each protective change, however uncomfortable, is an expression of care

In Dementia care, prevention is not overprotection. It is responsibility.

A Simple Shift that Helps

- Walk through your home periodically with fresh eyes—what could become a risk?
- Address bathroom safety early: consider knobs over latches, grab rails, non-slip mats
- Ensure main exits can be secured without restricting normal family movement
- Improve night lighting in corridors, bathrooms and bedroom
- Act before an incident, not because of one

The safest environment is one that has already thought ahead.

Care is not just about comfort—it is about safety.

◆

Phase 2: Building a Sustainable System

Chapter - 8

When Systems Fail

In caregiving, we often rely on systems.

Organised routines. Structured processes. Clear instructions.

We assume that if something is well-designed, it will work.

But one of the lessons I learnt the hard way was this:

A system that works for us may not work for someone with Dementia.

The Day a Simple Mistake Became an Emergency

One evening, I returned home at around 7 PM.

I saw my mother sitting in front of the television—but something felt off.

She seemed unusually drowsy. Almost drifting in and out of sleep.

This was before we had hired attenders, so she was managing things on her own during the day.

I tried to speak to her, but her responses were slow.

That's when I felt something wasn't right.

I went to check her medicine box.

We had organised her medicines in a weekly pill box—28 small compartments. Four for each day: morning, afternoon, evening and night. The idea was simple. She had to take one column per day.

But what I saw was alarming.

Instead of taking the medicines for the day, she had taken all four doses from the night row.

These included blood pressure medication and mild sedatives.

She had unknowingly consumed multiple doses during the day.

That explained her condition. She was extremely drowsy. Her pulse was low.

There was no time to think. We rushed her to the hospital immediately.

At the hospital, the doctors acted quickly. Her stomach was cleaned. She was monitored through the night. Thankfully, by the next morning, she had stabilised.

But the situation took an unexpected turn.

The doctors informed us that this would be treated as a medico-legal case, as it resembled a possible overdose or suicide attempt.

Soon after, a police officer arrived.

I had to explain everything—what had happened, how the medicines were organised and how she had mistakenly consumed them. I showed him a photograph of the medicine box.

I also shared her background—that she had served in a senior role in the forensic science system supporting the police department.

After a series of questions, the matter was understood and closed.

But for us, the real learning had already become very clear.

That night reminded me how quickly things can go wrong—and how vigilant we need to be, every single day.

Rethinking the System

We had assumed the system was clear.

- The box was labelled
- The structure was logical
- The routine was familiar

But Dementia does not work on logic.

It does not follow sequence.

It does not interpret structure the way we expect.

That day, we changed our approach completely.

We moved from a weekly medicine box to a daily box with just four slots.

Morning. Afternoon. Evening. Night.

Simple. Clear. No room for confusion.

What this Taught Us

- Complexity increases risk
- Assumptions can be dangerous
- Systems must be designed for current ability—not past capability

Clarity is safety.

Simplicity is protection.

A Simple Shift that Helps

- Use daily medicine boxes instead of weekly ones
- Avoid multi-layered systems
- Supervise or cross-check where possible

If something can be misunderstood, it eventually will be.

A small gap in understanding can lead to a big consequence.

◆

Chapter - 9

Managing the Day-to-Day

As the journey progressed, one thing became increasingly clear.

The quality of each day was not determined by big decisions or long-term plans.

It was shaped by the small things. Meals. Sleep. Movement. The rhythm of hours.

Dementia is lived at this level—in the texture of the ordinary day. And how these small things are managed often determines whether a day feels smooth or difficult, calm or unsettled.

Over time, we came to understand something that sounds simple but takes time to truly absorb:

Structure is not restrictive. It is supportive.

A predictable day—one that moves in a familiar shape—reduces the invisible effort of having to constantly orient oneself. And for someone with Dementia, that reduction in effort matters enormously.

Food: Making it Simple

One of the challenges with food was not just what to eat—but how.

There were times when she would forget whether she had eaten. At other times, managing multiple items on a plate—deciding what to pick up, in what order, with which utensil—became more effort than it appeared.

So we simplified.

Instead of serving food in separate portions, we would often combine everything in a bowl. One utensil. One action. Less decision, less effort, less confusion.

We also kept a clear rhythm to meals.

Fixed times.

Fruit in the afternoon.

Tea or coffee in the evening with a light snack.

These small rituals created something beyond nutrition—they created familiarity. A sense that the day was moving as it should. That nothing unexpected was coming.

It was not just about what she ate. It was about the comfort of knowing when.

Sleep: Observe, Support, Adapt

Sleep became another area that needed attention.

Her physical movement had reduced considerably. Her daily engagement was more limited than before. As a result, her body was not tiring naturally, and her sleep patterns became irregular.

We learnt fairly quickly that sleep could not be forced or scheduled into existence.

What helped was increasing physical activity during the day—even gently, even briefly. Short walks. Simple movement. Enough to create a natural readiness for rest.

Over time, we became better at reading the patterns—when she was more restless, what kind of day led to better sleep. And we adjusted the shape of her days accordingly—not rigidly, but responsively.

This is covered in more depth in the next chapter, where the challenge of encouraging movement revealed something important not just about managing her day, but about managing my own responses.

Television: When it Becomes Real

Television, we discovered, was not simply entertainment.

For someone with Dementia, the boundary between the screen and reality can become genuinely unclear. What appears on the television does not necessarily register as something happening elsewhere. It can feel like something happening here, in the room.

One evening, I returned home around dinner time. My mother was watching television. When I suggested we eat, she gestured for me to sit quietly.

"Amitabh Bachchan is here and is talking," she said, pointing to the screen. "Once he's done, we'll eat."

An episode of Kaun Banega Crorepati was playing. To her, it was not a program. It was a guest.

I sat down. We watched together. We had dinner after it ended.

My sister had a similar experience. One evening, they had tea together. A little later, my mother asked if tea had been made yet—and then pointed to the television, saying that guests had arrived and they should prepare extra.

The guests were the people on the screen.

In both these moments, there was no point in correcting. The experience was real to her. The most useful thing we could do was adapt to it.

We began paying close attention to what she watched.

We moved away from the news—which could be distressing, confusing, or feel alarmingly immediate. We avoided intense or emotionally charged content.

Instead, we chose things that were calm and familiar

- Old film songs, particularly of actors she had always loved, including Sadhana
- Light comedy
- Quiz shows
- Mythological programs

Content that did not agitate. Content that felt like home.

What the Mind Still Holds on To

Amid the forgetting, there was something that stayed with us.

A close friend would visit us regularly during the summer months. He had a warm and generous habit—he would arrive with a basket of the finest, ripest mangoes he could find, and take great delight in sharing them.

This became a ritual. He would visit, bring mangoes, spend time with us, and my mother would always be part of it.

What surprised us was that even as her memory faded—even as many names, faces and associations became harder to hold on to—she continued to remember him.

Not through accumulated history. Not through years of association.

Through mangoes.

She remembered him as "Balaji—the mango man."

That connection stayed long after others had gone. He remembers it fondly to this day.

It made something very clear:

Memory may weaken. But associations rooted in feeling—in warmth, in sensory pleasure, in repeated joy—can remain far longer than we expect.

It was a reminder to keep creating those associations. To make mealtimes pleasant. To make visits warm. To fill the ordinary moments of the day with as much ease and comfort as possible.

Because something of those moments, even if not consciously remembered, seemed to stay.

Enjoying a glass of Mango shake

What this Taught Us

- Structure and routine are among the most powerful tools available to a caregiver
- Simplify meals—the goal is ease of eating, not variety
- Observe sleep patterns and use gentle activity to support rest
- Choose television content carefully—it shapes mood and reality
- Positive associations can outlast factual memory

A well-managed day is built on small, thoughtful choices.

The mind may forget details—but it often remembers what brought happiness.

A Simple Shift that Helps

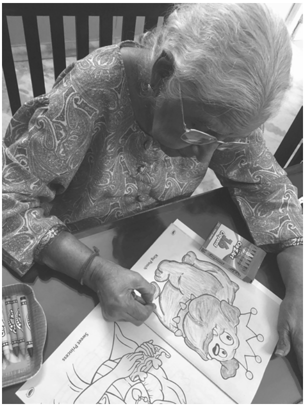
- Serve food in a way that is easy to manage—bowls over plates where helpful
- Keep mealtimes consistent and unhurried
- Use gentle daily activity to support natural sleep
- Choose calm, familiar television content; avoid news and intensity
- Create small rituals that repeat—they become anchors

Do not try to control the day.

Shape it gently.

Care happens in the small moments of the day.

Solving the Sudoku puzzle in a Restaurant



Trying her hand at drawing & painting

* * *

Chapter - 10

Engagement Over Ability

As Dementia progresses, one of the subtle losses is not just memory—but initiative.

The desire to start something.

To choose an activity. To engage independently.

But that does not mean the ability to engage is gone.

It simply needs to be supported.

What was Once Familiar

Before her memory began to fade, my mother loved solving Sudoku.

It was part of her daily routine. She would spend her mornings with the newspaper, carefully working through a puzzle—focused, patient and determined to complete it.

I also remember a restaurant we would often visit on weekends for breakfast. The disposable table mats had Sudoku puzzles printed on them, meant to engage customers. She would immediately notice it, borrow a pen from the waiter, and begin solving it right there at the table.

It was something she genuinely enjoyed.

Over time, as Dementia progressed, that began to change.

She slowly lost interest in Sudoku.

Not because she no longer liked it—but because she was no longer able to solve it.

There was a quiet shift.

From engagement… to withdrawal.

And that's when we began to understand something important.

It is not about what they can do independently.

It is about what they can enjoy with a little support.

Rediscovering Something New

During the COVID period, weekends became quieter.

I would often spend time drawing or painting—something I've always enjoyed. Creativity came more naturally from my father's side, not my mother's. She was a doctor, precise and methodical, not someone we would typically associate with drawing or art.

At least, that's what we believed.

One day, I decided to involve her.

I gave her a simple colouring sheet—the kind meant for children—and some crayons.

There was no expectation. Just an attempt to engage her in something.

She took it up.

And then, something unexpected happened.

She began colouring. Slowly. Patiently. With complete focus.

There was no hesitation. No self-doubt.

No sense of "I can't do this."

She was simply present in the activity.

And she seemed to enjoy it.

That moment stayed with me. Because it made me realise something deeper.

Over the years, we all build mental blocks—ideas about what we are good at, what we are not, what we should or should not try. Somewhere along the way, we stop experimenting.

But as memory fades, those blocks seem to fade too.

She was not trying to be good at it.

She was not judging herself.

She was simply experiencing it.

And in that simplicity, there was joy.

Rethinking Engagement

That experience changed how I looked at activities.

It was no longer about skill, output or achievement.

It became about participation, experience and enjoyment.

We began introducing simple, low-pressure activities. Nothing complex. Nothing demanding. Just small ways to engage.

Encouraging her to walk. To sit in the balcony. To watch something familiar. To interact with her surroundings.

Even brief moments of engagement made a difference.

Letting go of Expectations

One of the biggest shifts was letting go of expectations.

Not expecting consistency.

Not expecting improvement.

Not expecting continuity.

Just allowing the moment.

Some days were better than others. Some activities worked. Some didn't.

And that was okay.

What this Taught Us

- Engagement matters more than ability
- Enjoyment matters more than outcome
- Simplicity creates participation

When expectations fade, experience becomes richer.

A Simple Shift that Helps

- Introduce easy, familiar activities
- Avoid complexity or pressure

- Focus on the process, not the result

It's not about what they do.

It's about how they feel while doing it.

When memory fades, the ability to feel joy still remains.

Talking to the Birds after a walk

* * *

Chapter - 11

When Patience is Tested

There is a quiet assumption that comes with caregiving.

That because you love the person, patience will follow naturally. That warmth will always be your first response. That you will instinctively understand, and understanding will make the difficult moments easier.

The reality is more nuanced than that.

There are moments—ordinary moments, not dramatic ones—when something simple becomes surprisingly difficult.

And in those moments, what you are confronted with is not just the situation. It is yourself.

Your own frustration.

Your own expectations.

Your own sense of what should be possible.

This chapter is about one of those moments.

The Walking

In the chapter on managing daily life, I mentioned that encouraging physical activity helped support better sleep. What I did not describe there was how hard that encouragement could actually be.

My mother needed to move. Her days had become much more sedentary after my father passed away—there was less structure, less natural purpose, less that called her body into motion. Without enough physical activity, she wasn't tiring naturally, and sleep was suffering.

The solution seemed obvious: encourage her to walk.

We had a balcony at home. I would try to get her to walk there for ten to fifteen minutes after lunch, and again after dinner.

But within a couple of minutes, she would stop.

"I can't walk anymore," she would say.

And she meant it.

This is where I found myself genuinely struggling—not with her, but with myself.

I knew she needed to walk. I could see the logic clearly. I had the best intentions. And yet, every day, the same two minutes and the same words.

Why is something so simple so difficult?

Why won't she just continue a little longer?

I noticed the impatience rising. And I noticed something else—that the more I pushed, the more she withdrew. The more I insisted, the more the whole thing became a source of tension rather than care.

That is when I had to stop and honestly ask myself:

Who was this about?

Was I trying to help her? Or was I trying to satisfy my own need to feel that I was doing the right thing?

The answer, I had to admit, was a little of both.

And once I acknowledged that, something shifted.

She was not being resistant. She was not being difficult. She was telling me, truthfully, that she could not walk anymore—and I was not listening, because her answer did not fit what I had decided was needed.

Finding Another Way

Instead of pushing harder, I began to think differently.

If she wouldn't walk for the sake of walking, perhaps she would walk for something else.

I started introducing small incentives—gentle and genuine, not manipulative.

"Let's walk now and we'll have coffee later instead of chai."

Small trades. Small rewards. Things that gave the walk a purpose she could feel.

Then we tried something else entirely.

We hung a traditional brass bell at one end of the balcony. Each time she walked to that end, she could ring it. That small act—the sound, the physicality of it, the tiny sense of arrival—made the walk feel like an activity rather than an obligation.

We also had birds in a cage on the balcony. She would walk to them, pause, speak to them softly, and then walk back.

Slowly, walking became something she moved towards, rather than something she was moving because of me.

It wasn't perfect. Some days worked better than others. There were still days that required more effort, more creativity, more patience than I felt I had.

But we found a rhythm. And the rhythm worked.

What this Really Taught

I have described this as a chapter about patience. But looking back, it was really about something else.

It was about the gap between what we intend and what we impose.

When we care deeply for someone, we can become convinced that our understanding of what they need is more reliable than their own experience of what they can do. We override their reality with our logic—and then wonder why they resist.

What the walking taught me was this:

Patience is not simply waiting longer before reacting.

It is the willingness to question your own approach before blaming the situation.

Is what I am doing working? And if not, is the problem them—or me?

That kind of patience is not a natural trait. It is something built—through experience, through repeated moments of choosing differently, through the slow accumulation of being wrong and adjusting.

Learning to Adapt Yourself

Caregiving changes the person being cared for.

But it also—quietly, persistently—changes the caregiver.

You learn to pause before reacting. To understand before responding. To adapt rather than insist.

You learn that some battles are not worth having—not because you are giving up, but because you have found a better path.

And perhaps most importantly, you learn to extend to yourself the same patience you are trying to extend to them.

There will be days when you feel you handled things badly. When you were sharper than you meant to be, or more impatient than felt acceptable. Those days are part of this journey too.

What matters is not that you are always patient. It is that you keep returning to the intention.

What this Taught Us

- What feels simple to us can feel genuinely impossible to them
- Pushing creates resistance—engagement creates participation
- Patience is not passive—it is an active, repeated choice
- When something isn't working, question the approach before questioning them
- The caregiver's inner state directly shapes the quality of care

Sometimes caregiving is not about insisting. It is about finding a different way.

A Simple Shift that Helps

- When an activity meets resistance, pause—don't push harder
- Ask: is there a way to make this feel like something they want to do, rather than something they must do?
- Add small elements of engagement, purpose or reward

- Accept that some days will be harder than others—that is not failure
- Be as patient with yourself as you are trying to be with them

The goal is not to complete the task. It is to make it possible.

Caregiving is not just about caring for them—it is also about learning to manage yourself.

◆

Chapter - 12

The Care Ecosystem

One of the biggest realisations in this journey was this:

Caring for someone with Dementia is not a one-person responsibility.

It cannot be.

In the early days, my instinct was to be as involved as possible. To be present. To be available. To take responsibility.

At one point, I even started sleeping in my mother's room. The intention was simple—to be there if she needed anything during the night.

But very soon, reality set in.

This was not sustainable. I had work commitments. I needed rest. And the demands of caregiving were continuous.

It became clear that if this approach continued, it would affect not just me—but the quality of care itself.

It was also around this time that my wife and I had an honest conversation. She helped me see what I had not fully acknowledged—that while we wanted to do everything ourselves, it was not sustainable. Caregiving was not just about intention; it was about consistency and endurance.

That conversation became an important turning point in how we approached care.

We decided to bring in help. My sister and brother were also aligned with this approach and fully supportive of the decision.

The First Step: A Full-Time Attender

We hired a full-time female attender who would stay in the same room as my mother and take care of her needs through the day and night.

This was a significant shift—from doing everything ourselves, to building support.

It was not an easy decision. There is often a hesitation in bringing in external help. A feeling that family should manage everything.

But over time, I realised:

Support is not a compromise. It is an enabler.

The Reality of Attender Turnover

What we had not fully anticipated was how frequently attenders would change.

Over the three years of my mother's care, we went through around sixteen attenders. The first attender joined us in November 2020, during the COVID period, and stayed for nearly a year—which, in hindsight, was exceptional. After that, they kept changing. Some left for personal reasons. Some were not suited to the demands of the role. Some simply moved on.

Each change brought its own challenge.

In the early days, the attenders we found had some prior experience with patients—they came with a basic understanding of how to handle someone who was unwell. But as time went on and we needed to find replacements more frequently, that prior knowledge could not always be assumed.

So I developed a different approach.

For every new attender, I prepared a four-page document—written simply and clearly—explaining what Dementia is, how it affects a person, and how patients typically behave. I would sit with each new attender, walk them through it and answer their questions before they began.

It was not a formal training programme. But it made a real difference.

Because the issue we kept encountering was this: when a new attender arrived, my mother would see an unfamiliar face in the house. And that unfamiliar face would then ask her to take her medicine, or have her food, or bathe, or come inside—and she would wonder: who is this person, and why are they telling me what to do?

A new attender is not just a practical challenge. For someone with Dementia, they are a disruption to the sense of familiarity and safety that daily care depends on.

A relationship had to be built—and built quickly.

Some attenders understood this instinctively. They were firm without being harsh. They did not take her responses or her resistance personally. They understood they were dealing with a patient—not a person who was being deliberately difficult. They found small ways to establish warmth and trust in the first few days, and once that was in place, care became smoother for everyone.

Others found it harder. And that is understandable. Caring for someone with Dementia requires a particular combination of patience, firmness and emotional detachment—and not everyone comes to it naturally.

What this taught us was that the attender is not just a helper. They are a central part of the care environment. Their ability to connect with the patient—quickly, genuinely and consistently—shapes the quality of every day.

The Invisible Layer of Care

While the attender was caring for my mother, there was another layer of care happening—led by my wife.

She ensured that the attender herself was comfortable. Food. Bedding. Basic needs. The attender shared the same room and bathroom as my mother, so her own well-being directly affected the quality of care she could provide.

This is something we often overlook.

When you bring someone in to care for a family member, you become responsible for their welfare too. Caregiving does not transfer. It expands.

Building a Support System

We were fortunate to have a long-time household helper who had been with us for many years. She became an important part of the ecosystem—present whenever we had to step out, ready to support the attender, familiar to my mother in a way that new attenders were not.

Relationships built over years become invaluable in times of need.

Exploring Day Care and Community Support

During this journey, I also became aware of other forms of support that exist—and others that should exist more widely.

A former colleague had shared her experience of using a day care centre for her mother, who was living with Dementia. She would drop her mother at a centre run by the Red Cross and Nightingales Trust in Hyderabad on her way to work and collect her in the evening. The centre provided care and supervision, and also engaged patients through simple group activities—table games, conversations, shared routines with others navigating a similar phase. Her mother, she said, would look forward to going.

I considered this option for my mother but did not pursue it—we were in the period just after COVID and did not want to take additional risks. But the idea stayed with me.

In many ways, it mirrors how families arrange day care for young children during working years. And there is something quietly circular about that—as Dementia progresses, the level of care, engagement and supervision a parent needs is not so different from what a child needs.

Beyond day care centres, there is something else that is still largely absent in India—and that is structured support for caregivers themselves.

Caring for a parent with Dementia is an isolating experience. You are often navigating situations no one around you has faced. You make difficult decisions without a reference point. You carry an emotional weight that is hard to explain to those who have not lived it.

What makes a meaningful difference—and what I would encourage families to seek out or create—is connection with others on the same journey.

A caregiver support group. A WhatsApp community of families dealing with Dementia. A space where you can share what is working, ask what to do when something isn't, and simply feel that you are not alone.

These do not need to be formal or professionally run. Sometimes a small group of families in the same city, connected informally, is enough. The value is not in the structure—it is in the shared understanding.

If you are navigating this journey and do not yet have that connection, I would encourage you to look for it—and if it does not exist near you, to consider starting it.

Evolving with the Situation

As the condition progressed, the level of care required increased. In the final year, it became clear that one attender was not enough. My mother required constant presence—and at times, physical support.

So we hired two full-time attenders.

This brought multiple benefits. They could support each other. They could manage physically demanding tasks together. And they had companionship in what is, by nature, a demanding and sometimes lonely role.

Care became more continuous and more sustainable.

Designing for Sustainability

Looking back, what we created was not just support. It was a system—a care ecosystem built from family involvement, professional support, backup layers and shared responsibility.

Because caregiving is not a short-term responsibility. It is a long journey. And it needs to be designed accordingly.

What this Taught Us

- You cannot do this alone—recognising that early makes everything more sustainable
- Attender turnover is common; preparing for it, rather than being surprised by it, reduces disruption
- A new attender needs to be onboarded—not just placed. The patient's sense of familiarity depends on it

- Supporting the caregiver is as important as supporting the patient
- Community support for caregivers—however informal—fills a gap that formal systems often leave

Care is not just about effort. It is about designing a system that can sustain that effort.

A Simple Shift that Helps

- Accept help early—don't wait until you are overwhelmed
- When bringing in a new attender, invest time in onboarding—explain the condition, the patient's personality, what works and what doesn't
- Prepare a simple written guide for new attenders so key information is not lost each time someone changes
- Ensure attenders are looked after—their comfort directly affects the quality of care
- Seek out or create a caregiver community—the shared understanding of others on the same journey is invaluable

Caregiving becomes sustainable when it becomes a shared system.

◆

Chapter - 13

Losing Things, Finding Patterns

One of the recurring challenges in this journey was something that, at first, seemed minor.

Things going missing.

A mobile phone. A small object. Something that had just been used—and suddenly, it couldn't be found.

In the beginning, we approached it the usual way.

We searched. We retraced steps. We tried to remember where it might have been kept.

But with Dementia, this process becomes different.

Because the act of keeping something is not always followed by the memory of where it was kept.

The Phone that was Never Lost

One incident made this very clear.

One day, we couldn't find my mother's mobile phone. We knew she had kept it somewhere—but she couldn't remember where. We tried calling it. The battery had drained out. We searched everywhere—rooms, drawers, tables.

Days passed. The phone was still missing.

Nearly a couple of weeks later, we found it.

Carefully placed behind a stack of clothes in her cupboard.

In her own way, she had kept it safe.

That moment made us pause.

This wasn't carelessness. It was a different way of interacting with objects.

From her perspective: she had kept it in a safe place. There was no reason to move it again. There was no memory of having kept it there.

From our perspective: it was missing, it was untraceable, and it created unnecessary stress.

This gap is where many small frustrations arise.

When Objects Lose their Meaning

Alongside this, we began to notice something deeper.

It was not just about where things were kept—but about how they were understood.

During one of their video calls, my sister realised that my mother no longer recognised what a mobile phone was. When asked to adjust it, she reached for the landline instead—trying to connect in the only way that made sense to her.

It was a subtle but powerful indication that even familiar objects were beginning to lose their meaning.

From Searching to Preventing

That experience changed our approach.

We stopped focusing on finding things after they were lost—and began thinking about how to prevent them from being misplaced in the first place.

We secured her phone to her chair so it was always within reach. We simplified her surroundings and reduced access to items that could easily get misplaced or create risk—jewellery, cash, sharp objects, other valuables.

The goal was not restriction. It was simplification.

Understanding the Pattern

Over time, we began to see patterns more clearly.

Items were not randomly lost. They were placed somewhere intentionally—but without recall.

Once we understood this, our response changed. We became less reactive. Less frustrated. More prepared.

Alongside this, another pattern became visible.

Her memories seemed to recede in a particular way. She would first speak of us as children, then of earlier phases of her life—our father, her work years, her medical college days, and eventually her childhood with her parents.

It was as if her memory was travelling backwards in time.

And yet, in moments, her clarity would return in unexpected ways. My sister recalls how she once explained an entire surgical procedure in detail—something she had never shared before.

What this Taught Us

- "Lost" often means "kept somewhere without recall"
- Searching repeatedly is less effective than preventing
- Understanding patterns reduces frustration

It is not just about where things are kept.

It is about whether they can be found again.

A Simple Shift that Helps

- Keep essential items in fixed, visible places
- Limit access to valuables or risky objects
- Simplify the environment
- Focus on prevention rather than recovery

The simpler the environment, the fewer the disruptions.

Things are not lost—they are simply no longer traceable in the same way.

◆

Chapter - 14

When Independence Changes

One of the less visible but deeply significant changes in this journey is the gradual shift in independence.

It does not happen suddenly. It happens in small, almost unnoticed ways.

In the early stages, there were moments when my mother spoke about handling finances—filing taxes, managing investments, going to the bank. It made us realise how important it was to stay aware and involved, as judgment in such matters can gradually be affected.

Tasks that were once effortless begin to require support. Decisions that were once routine begin to feel uncertain. And slowly, the ability to manage one's own affairs begins to change.

One such moment brought this home very clearly.

When Her Signature No Longer Matched

One day, we needed to withdraw money from my mother's bank account—the same account where her pension was credited. It seemed like a simple task.

She sat down to sign the withdrawal slip.

But something wasn't right.

She tried once. Then again. And again. Each time, the signature didn't match. The bank could not process the transaction.

I remembered her signature in green ink. As a gazetted officer, she would always sign with a green pen—firm, confident and unmistakably hers. What had once been automatic—a simple act she must have performed countless times—had now become difficult.

There was a quiet discomfort in that moment. Not just because of the practical problem. But because of what it represented.

We went to the bank together. The manager understood the situation. My mother was asked to sign in his presence, in whatever way she could. That signature was accepted. The withdrawal was completed.

A practical resolution. But also a quiet transition.

From independence—to dependence.

Preparing for What Comes Next

That incident made one thing clear. Her ability to manage financial matters independently was changing—and we needed to prepare.

Soon after, I had my name added to her account and arranged a debit card. Future transactions would no longer depend on repeated visits or signatures. It simplified access, reduced friction and brought continuity.

Beyond Finances

While this incident was about banking, the learning extended further.

Dementia does not just affect memory. It affects decision-making, judgment and confidence. And over time, this impacts multiple aspects of independence—handling money, managing documents, making everyday decisions. Each of these may gradually require support.

A Role Reversal That is Never Easy

There is something that happens in this journey that is difficult to name at first—and harder still to accept.

At some point, the relationship quietly shifts.

You are no longer simply the son or daughter. You are also, in some ways, the one responsible. The one who decides. The one who guides, reminds, protects and sometimes overrules.

You become, in a sense, a parent to your parent.

And that is not an easy thing to be.

Not because the love is any less. But because the dynamic has changed in a way that neither of you chose—and only one of you fully understands.

There were moments when I would have to coax her into something she did not want to do. To redirect her when she was insistent on something that was not safe. To make decisions on her behalf that she would once have made entirely on her own.

Each of those moments carried a weight. A quiet grief—not for what had been lost all at once, but for what was changing, gradually and irreversibly.

I do not think this role reversal ever becomes entirely comfortable. But it does become something you learn to carry—with care, with patience and with the understanding that it is, in itself, an act of love.

Balancing Support and Dignity

Through all of this, one thing had to remain constant—dignity.

Providing support without making the person feel incapable. Stepping in without taking over. Being present without being overbearing.

That balance is not always easy. But it becomes essential.

Support should feel like assistance. Not replacement.

The goal, always, is to let them do what they still can—and to support what they cannot, in a way that preserves their sense of self for as long as possible.

What this Taught Us

- Independence changes gradually—not suddenly
- The role reversal is real, and it is emotionally significant—acknowledge it rather than push through it
- Early practical preparation prevents future stress
- Dignity must be actively preserved, not assumed

What feels like a small adjustment today can prevent a larger challenge tomorrow.

A Simple Shift that Helps

- Add a trusted family member to financial accounts early
- Simplify processes—cards, digital access, fewer steps
- Keep documentation organised and accessible
- When the role reversal happens, name it—for yourself if not for others. It is easier to carry something when you know what it is

Independence may change—but dignity must remain.

◆

Phase 3: Advanced Care & Awareness

Chapter - 15

A Caregiver's Practical Checklist

A Guide to Return to, Not Just Read Through

This chapter is different from the others in this book.

The chapters before it are about experience—about what happened, what was felt, what was learnt. They are meant to be read.

This chapter is meant to be used.

It brings together the practical learnings from this journey in one place, organised by the stage of the condition rather than the order in which they appear in the book. The intention is that you can return to it at different points—early in the journey, when things are shifting, or later, when the demands have changed—and find what is most relevant to where you are now.

It is not a rigid prescription. Every person is different. Every family is different. Take what is useful and adapt it to your situation.

Stage 1: When You First Notice Something Is Changing

The early signs are often subtle—easy to explain away, easy to dismiss.

What to Watch for

- Repeating the same stories or questions within a short time
- Forgetting recent events while remembering older ones clearly
- Difficulty managing tasks that were once routine—finances, appointments, navigation
- Getting disoriented in familiar places
- Changes in mood, personality or social behaviour

What to do

- Pay attention to patterns, not isolated incidents—one forgotten name means little; a consistent pattern of confusion means more
- Seek a medical evaluation—frame it as a routine check-up rather than a response to something being wrong
- Consult a neurologist; assessment typically involves structured questions and diagnostic imaging such as CT or MRI scans

- Use the diagnosis, if one is given, as a starting point—not just emotionally, but practically. It establishes a baseline from which future changes can be tracked and understood
- Begin having honest family conversations early, while everyone can participate fully

The diagnosis made it real—but it also gave us a way to prepare.

Stage 2: Early Care—Adjusting to the New Reality

The condition has been identified. Daily life is changing, but the person is still largely independent. This is the time to begin adapting—gently, thoughtfully, ahead of need.

Communication

- Move from open-ended questions to simple choices—"tea or coffee?" rather than "what would you like?"
- Use calm, clear, unhurried speech—tone matters as much as content
- Avoid correcting or arguing—respond to the feeling behind the words, not the factual accuracy
- Never test memory by asking "do you know who I am?"—let them engage without the pressure of recall
- If they misidentify you or insist on something incorrect, ask yourself: will correcting this help or harm? Choose accordingly

Daily structure

- Begin building a predictable shape to each day—consistent mealtimes, a regular morning routine, a familiar rhythm of activities
- Create small rituals that repeat—evening tea, a walk, time in a favourite spot. These become anchors
- Reduce the number of daily decisions they have to make—lay out clothes in advance, keep things in fixed and visible places, simplify choices wherever possible

The Home Environment

- Remove unnecessary clutter—a simpler environment is easier to navigate
- Keep frequently used items in consistent, accessible locations
- Begin removing or securing items that could become hazardous—sharp objects, excess medications, valuables
- Ensure good lighting throughout the home, especially in corridors and bathrooms at night

Planning ahead—do this early

This is the stage at which certain practical and legal steps are most easily taken. Once the condition progresses, some of these become significantly more difficult to arrange. Acting early is not pessimistic—it is responsible.

- **Bank accounts:** Add a trusted family member to the person's accounts. This ensures continuity of access when independent management is no longer possible
- **Debit or credit cards:** Arrange simplified banking access—a card that a family member can assist with reduces the need for repeated branch visits
- **Power of Attorney (PoA):** Arrange a legal PoA while the person still has the capacity to grant it. This enables a trusted person to make financial and medical decisions if needed later. Consult a legal professional to understand the process in your region
- **Important documents:** Gather and organise key documents—identity papers, medical records, property documents, insurance policies, pension details, investment records. Keep them in one accessible place known to key family members
- **Care preferences:** If possible, have a gentle conversation about the person's preferences—where they would like to be cared for, what matters most to them, what they would and would not want. This becomes invaluable guidance later

Plan early—not out of fear, but out of care.

Stage 3: Middle Care—Managing the Day-to-Day

Independence is reducing. Daily support is now ongoing. The focus shifts to making each day manageable—for them and for you.

Food and Meals

- Keep meals simple and easy to consume—a bowl with a spoon often works better than a plate with multiple items
- Track food intake; they may not remember whether they have eaten
- Maintain consistent mealtimes and small food rituals—fruit in the afternoon, evening tea—these create comfort and predictability
- Encourage hydration; this is often overlooked but significantly affects mood and energy

Sleep and Physical Activity

- Observe sleep patterns rather than trying to force a schedule
- Encourage gentle physical activity during the day—even short walks—to support natural tiredness
- Use small incentives and engaging elements to make movement feel like an activity rather than an obligation
- If activity is met with resistance, adjust the approach before increasing the pressure

Television and Sensory Environment

- Choose content carefully—what is on screen can feel real, not merely viewed
- Prefer calm, familiar content: old songs, light comedy, quiz shows, mythological programs
- Avoid news, violent or emotionally intense content—these can create anxiety and confusion that lasts well after the program ends

Engagement

- Introduce simple, low-pressure activities—colouring, familiar music, short walks, gentle conversation
- Focus on enjoyment and participation, not skill or output
- Avoid overstimulation—too much activity or too many visitors at once can cause distress
- Let go of expectations about what they should be able to do. Allow the moment

Safety—Review Regularly

- Reassess the home environment periodically as the condition progresses
- Replace bathroom door latches with knobs—the door can be closed but not locked from inside
- Secure main exits with key locks if there is a risk of unsupervised wandering

- Ensure night lighting is adequate in all areas they might move through
- Understand that purposeful movement—going somewhere with intention, based on their reality—can be more unpredictable than aimless wandering. Stay alert to this

The goal is not to control each day. It is to shape it gently.

Stage 4: Advanced Care—Sustained Support

The level of care required has increased significantly. Independence in daily tasks may be limited. Constant or near-constant supervision is often needed. This stage is as much about sustaining the caregiver as it is about supporting the person.

Building a Care Ecosystem

- Recognise that this cannot be managed by one person alone—it is not a failure to need help, it is a realistic response to an increasing demand
- Bring in professional caregivers when needed—a full-time attender provides continuity and allows family members to maintain their own health and responsibilities
- When bringing in a new attender, invest time in onboarding—prepare a simple written guide explaining the condition and the patient's personality

- Ensure the caregiver is also cared for—their comfort, rest and well-being directly affects the quality of care they provide
- Build backup layers into the system—a second person who can step in, a trusted household member who knows the routine
- Consider day care facilities if available and appropriate—these provide structured engagement, supervised company and social interaction

Preserving Dignity

- Continue to let them do what they still can—do not step in before it is necessary
- Support should feel like assistance, not replacement
- Speak to them, not about them in their presence
- Maintain warmth, gentleness and respect in every interaction—even when there is no recognition, there is feeling

Caring for Yourself

- Accept that not every day will go well—that is not a measure of your commitment
- Take breaks without guilt—you cannot sustain care if you are exhausted
- Ask for help without waiting until you are overwhelmed

- Be patient with yourself as you are trying to be with them
- Acknowledge the emotional weight of this journey—grief, frustration, helplessness and love can coexist. All of it is valid

You cannot pour from an empty vessel. Caring for yourself is part of caring for them.

Most Important of All

Across every stage, through every change, one thing remains constant:

- Focus on how they feel—not what they remember
- Let go of the need to correct, to fix, to restore what was
- Be present—in the simplest, quietest sense of the word

Because in the end, memory may fade.

But the ability to feel remains.

And that is where your role truly lies.

Care becomes easier when it becomes simpler.

◆

Part – 4

The Inner Journey

Alongside the external challenges, this journey was also shaping something within us—changing how we thought, felt and responded.

Chapter - 16

What this Journey Does to You

Caring for someone with Dementia is not just an external journey.

It is an internal one.

It changes how you think. How you respond. How you see life.

In the beginning, the focus is on the person you are caring for.

What they need.

What they are going through.

How to manage the situation.

But slowly, something else begins to shift.

You begin to notice what the journey is doing to you.

There are moments of helplessness.

When you cannot explain.

Cannot correct. Cannot restore what once was.

There are moments of frustration.

When something simple becomes difficult.

When repetition feels endless.

When progress feels invisible.

There are moments of emotional conflict.

When you know what is right to do—but it is not easy to do it.

And then, there are moments of quiet realisation.

That this journey is not about control.

It is about acceptance.

Over time, I began to see that many of my natural responses had to change.

From reacting… to pausing.

From correcting… to allowing.

From expecting… to accepting.

This was not always easy.

It required conscious effort. Again and again.

But slowly, it began to feel natural.

I also realised something else.

Patience is not something we either have or don't have.

It is something we build.

Through experience. Through reflection.

Through repeated moments where we choose how to respond.

This journey also changes how you relate to time.

We are used to thinking in terms of progress, improvement and future outcomes.

But Dementia does not follow that path.

There is no clear improvement.

No defined milestones.

No sense of "getting better."

So your relationship with time changes.

You begin to focus on the present.

On the day. On the moment.

One day at a time.

You learn to value small things.

A calm conversation.

A moment of recognition.

A shared smile.

Things that might have once felt ordinary now feel meaningful.

You also begin to let go.

Of expectations.

Of how things "should be."

Of the need for things to make sense.

And in that letting go, something unexpected happens.

There is a certain calm.

Not because everything is easy.

But because you are no longer resisting what is.

This journey also brings a deeper appreciation.

For care. For relationships. For presence.

You begin to understand that being there matters more than doing more.

And perhaps most importantly, you begin to understand yourself better.

Your limits. Your responses. Your capacity to adapt.

At some point, the journey shifts. As my sister once reflected, it becomes less about them remembering us—and more about us holding on to our memories of them.

What this Taught Us

- Acceptance reduces struggle
- Patience can be developed
- Presence is more valuable than control

You cannot change the path of the journey.

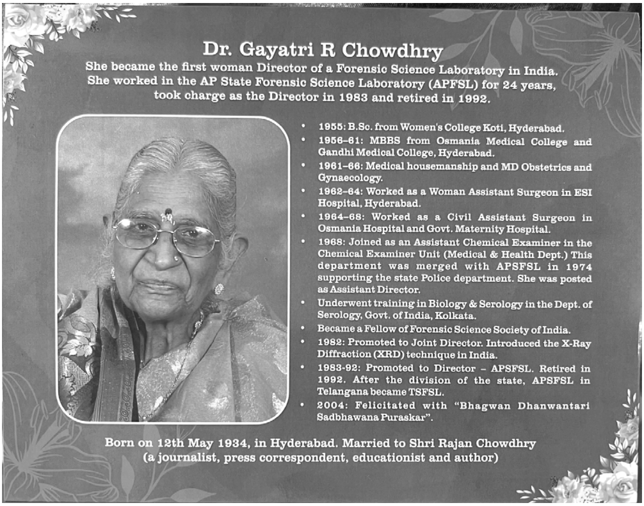
But you can change how you walk it.

A Simple Shift that Helps

- Pause before reacting
- Focus on the present moment
- Let go of expectations
- Acknowledge your own emotions

Caring for someone else also means learning to care for yourself.

In caring for someone else, you slowly transform yourself.



Dr. Gayatri R Chowdhry

She became the first woman Director of a Forensic Science Laboratory in India.
She worked in the AP State Forensic Science Laboratory (APFSL) for 24 years,
took charge as the Director in 1983 and retired in 1992.

- 1955: B.Sc. from Women's College Koti, Hyderabad.
- 1956–61: MBBS from Osmania Medical College and Gandhi Medical College, Hyderabad.
- 1961–66: Medical housemanship and MD Obstetrics and Gynaecology.
- 1962–64: Worked as a Woman Assistant Surgeon in ESI Hospital, Hyderabad.
- 1964–68: Worked as a Civil Assistant Surgeon in Osmania Hospital and Govt. Maternity Hospital.
- 1968: Joined as an Assistant Chemical Examiner in the Chemical Examiner Unit (Medical & Health Dept.) This department was merged with APSFSL in 1974 supporting the state Police department. She was posted as Assistant Director.
- Underwent training in Biology & Serology in the Dept. of Serology, Govt. of India, Kolkata.
- Became a Fellow of Forensic Science Society of India.
- 1982: Promoted to Joint Director. Introduced the X-Ray Diffraction (XRD) technique in India.
- 1983-92: Promoted to Director – APSFSL. Retired in 1992. After the division of the state, APSFSL in Telangana became TSFSL.
- 2004: Felicitated with "Bhagwan Dhanwantari Sadbhawana Puraskar".

Born on 12th May 1934, in Hyderabad. Married to Shri Rajan Chowdhry
(a journalist, press correspondent, educationist and author)

Celebrating her 89th Birthday

* * *

Chapter - 17

Before the Memory Fades

There comes a point in this journey when you begin to see things more clearly.

Not in terms of improvement. But in terms of direction.

You begin to understand where things are heading. And more importantly, what may no longer be possible.

The Last Time We Were All Together

A year before my mother's 89th birthday, my sister and brother were visiting India. It was one of those rare windows when all three of us siblings were together in the same place—with her.

We spent several days together as a family. And during that time, something unexpected and quietly beautiful happened.

Seeing the three of us together—her children, all grown, all there—she seemed to slip back in time. In her mind, we were school-going children again. The ages, the years, the decades in between—all of it seemed to dissolve. She looked at us the way she must have looked at us when we were young.

We went out together to her old favourite restaurants—the places she had taken us to years ago—for coffee and snacks. She was happy. Present. Connected to something familiar and warm.

And then, one afternoon, my brother danced with her.

A simple, spontaneous moment—a ball dance, the two of them together.

I watched her face as it happened.

There was a glint in her eyes. A happiness that was uncomplicated and complete—the kind that does not need memory to explain itself. It simply was.

That visit stays with me because of what it also represented.

It was the last time she was in a stage where she could partially remember—where the world around her still held some of its familiar shape, even if imperfectly. After that, her memory began to decline more rapidly. The windows of recognition became shorter. The clarity, less frequent.

We did not know then that it would be the last time of its kind.

But looking back, I am grateful we were there. That we went out. That we danced.

That we did not wait for a better time that never came.

The 89th Birthday

As her 89th birthday approached, I had a strong feeling—one that was hard to explain but impossible to ignore.

Her memory was fading more rapidly. There were fewer moments of recognition. Fewer instances of clarity. Her movement had become quite restricted.

I also remembered something she used to say when she was well—that she would want to leave the world while still being able to walk and move around. She never wanted to be bedridden.

And somewhere within, I sensed this: if people wanted to meet her, see her, spend time with her—it had to be now.

Waiting for a milestone—like her 90th birthday—did not feel right. I was not sure what her condition would be by then. Whether she would recognise anyone. Whether she would be able to engage.

So we made a decision. We would celebrate her 89th birthday—not as a formality, but as a moment of connection.

We created a WhatsApp group to reach out to family, relatives, friends and her classmates from her MBBS days—people who had been part of her life for decades.

And they came.

It was a large gathering. Around a hundred people—each one carrying memories of who she had been.

She recognised some of them. Not everyone. Perhaps around a dozen.

But in those moments of recognition, there was a spark. A connection. A glimpse of what once was.

It was not consistent. It did not last. But it was there.

And that made the decision worthwhile.

That day was not about celebration in the usual sense. It was about presence. About allowing people to meet her as she was. About giving her the opportunity to experience connection—however brief.

It was also a moment of quiet acceptance.

Acceptance that memory was fading. That time, in this form, was limited. That waiting for the right moment might mean missing the moment entirely.

She was born on 13th May 1934.

We celebrated her 89th birthday on 13th May 2023.

Exactly a week later, on 20th May 2023, she passed away.

The same WhatsApp group that had been created to invite people to her birthday carried, a week later, the news of her passing.

There are no words adequate for that moment. But there is this:

We had not waited. We had chosen the moment we had—rather than the milestone we might have missed.

And she was surrounded, in her last days, by love.

What Both Moments Shared

The sibling visit and the birthday gathering were different in scale and in nature. But they carried the same truth.

Connection does not require perfect memory. It does not require recognition to be complete, or joy to be sustained.

It requires only presence—and the willingness to create a moment rather than wait for one.

In journeys like these, timing is not about dates.

It is about awareness. Knowing when to act. When to bring people together. When to create the moments that may not be possible later.

What this Taught Us

- Don't wait for milestones—act when the moment feels right
- Connection matters, even when recognition is partial or brief
- The last time of something often isn't recognised until it has passed—which is why presence now matters so much
- Joy does not need memory to be real

Sometimes, the right time is not later. It is now.

A Gentle Reminder

- Encourage family and friends to visit earlier rather than later
- Create opportunities for connection while recognition still exists
- Don't delay meaningful moments—outings, gatherings, simple time together
- When you have a window of clarity or happiness, enter it fully. Don't save it for later

Even a few seconds of recognition—a glint in the eyes, a moment of warmth—can mean everything.

Don't wait for the perfect moment. Create it while you still can.

* * *

Part – 5

What Remains

And beyond all the changes, something essential remained—quiet, steady and deeply human.

Chapter - 18

What Truly Remains

Different religions offer different perspectives on life after death.

In Hindu philosophy, there is a belief in rebirth—where the next life is influenced by the deeds of the current one.

Over time, I have come to see it a little differently.

I feel that beyond deeds, what truly stays with us is the feeling of our lived experience.

If a person's life journey allows their soul to feel content, peaceful and happy at the time of leaving, perhaps that in itself shapes what comes next.

And if there is restlessness or regret, perhaps that too carries forward.

I do not claim to know the truth.

But this belief has guided how I look at life—and more importantly, how I approached caring for my mother.

This belief helped me make peace with many moments that were otherwise difficult to accept.

Because in Dementia, memory fades.

The person may not remember events, conversations or even people.

But one thing seems to remain longer than anything else:

The ability to feel.

Which makes one thing very clear.

For someone living with Dementia, it becomes even more important that they feel safe, respected and happy.

Not because they will remember it.

But because they will experience it.

And perhaps, that experience is what stays with them at a deeper level.

Dementia may erase facts, but it doesn't erase feelings.

In a way, there is something paradoxical here.

They may not remember the difficult moments of their past.

They may not even hold on to the happiest memories either.

But what we create for them in the present—moment by moment—becomes their reality.

Which is why, as caregivers and family, our role shifts.

It is no longer about helping them remember life.

It is about helping them feel life—in the best way possible.

Because maybe, just maybe

What matters in the end is not what we remember, but what we feel.

What this Means for Us

- Focus on creating positive experiences in the present
- Let go of correcting the past
- Prioritise emotional well-being over factual accuracy

In Dementia care, happiness is not a long-term goal—it is a moment-to-moment responsibility.

And perhaps, in the end, what remains is not memory—but the love we helped them feel.

If this Helped You

If this book resonated with you or helped in any way, consider sharing it with someone who may be going through a similar journey.

Sometimes, knowing that you are not alone makes all the difference.

For those walking this path—one day at a time.

◆

Dr. Gayatri R Chowdhry, during her work days

Finding connection through simple joys

When a parent begins to forget, life does not change overnight.
It changes quietly.
Conversations become simpler.
Routines become uncertain.
Moments of recognition come and go.
And slowly, you realise — this journey is not about restoring memory.
It is about redefining care.

In ***One Day at a Time,*** Rohit R Chowdhry shares a deeply personal account of caring for his mother, Dr. Gayatri R Chowdhry — a pioneering doctor and the first woman to head a state forensic science laboratory in India — as Dementia gradually changed the person they had always known.

Drawing from a journey navigated together as a family, this book moves between lived experience and hard-won insight — tracing the gradual, quiet shift in understanding that this journey demands of everyone it touches.

This is not a medical manual. It is a human story.
A reminder that even when memory fades, the ability to feel remains.
And that in the end, it is not what we remember — but how we make each other feel — that truly lasts.

Also available as a free eBook for caregivers and families.
Download at : www.rohitrchowdhry.com/dementia

Also available as an eBook

NON-FICTION

ISBN

OrangeBooks
Publication
www.orangebooks.in