# Loss Love & Growth

## Stories of Families Caring for a Person with Special Needs

WE CARE & EMPOWER
AMC

**ENRICH Project**
Bangalore | June 2023

# Disclaimer

The book ‘Stories of Families Caring for a Person with Special Needs’ is a compilation of 25 stories of unique live in experiences of the caregivers of persons with intellectual and developmental disabilities (IDD). The stories are based on the interviews held with the caregivers and families of persons with IDD. All the names and identities have been changed to maintain confidentiality and protect their identity. The publisher (AMC) is providing this book and its contents on an “as is” basis and makes no representations or warranties of any kind with respect to this book or its contents. The publisher disclaims all such representations and warranties, including but not limited to warranties of healthcare for a particular purpose. The content of this book is for informational purposes only and is not intended to diagnose, treat, cure, or prevent any condition or disease. You understand that this book is not intended as a substitute for consultation with a licensed practitioner.

# Loss, Love & Growth

**Prof. R. Srinivasa Murthy**
Professor of Psychiatry(retd)
Mental Health Advisor

**Ms. Divya B**
Project Consultant

**Ms. Nischitha S.**
Project Consultant

**Mr.Srikanth B R.**
Former Executive Editor, Deccan Chronicle

**ENRICH PROJECT**

The Association for the Mentally Challenged, Bangalore
June 2023

# Acknowledgements

We are thankful to all the persons with special needs and their families of The Association for the Mentally Challenged, Bangalore, for sharing their life experiences and joining hands in developing the 'Lived-in" stories. All of the names have been changed to protect the identify of the families. They have been a source of inspiration to the ENRICH Team in developing the interventional modules.

The funding for the ENRICH Project came from the Foundation Juan Jose Lopez-Ibor, Madrid. Professor R. Srinivasa Murthy was awarded the International Juan Jose Lopez Ibor award 2012.

'The prize recognises initiatives in favour of the human dignity of those who suffer from mental disorders carried out from a scientific perspective. Bridging rational thinking and respect towards those who suffer mental illnesses is the goal of the Award'.

The award amount of Euro 40,000/ awarded to Prof. R. Srinivasa Murthy, was donated to AMC. These funds were utilized for the ENRICH project.

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# About AMC

The Association for the Mentally Challenged (AMC) was started in 1960 by Dr. D. L.N. Murthy Rao, then Director of All India Institute of Mental Health, Bangalore (now NIMHANS). AMC is a one-of-a-kind institution providing lifelong support for 120 – 140 individuals with Developmental Disability Disorders (DD). AMC is working with the goal to improve the quality of life of persons with developmental disabilities and their families. The wide range of services offered at AMC are provided free of charge, as 90% of the beneficiaries are from low socio-economic background.

**Mission:**

To promote development, independence, economic sufficiency, community inclusion, self-determination of persons with IDD

Empowerment of their families through coordinated services of training, research, technical assistance and dissemination activities.

AMC has the following facilities

- **Special school** for children with IDD. Besides classroom instruction, lifeskill training, the school activities include training in yoga, sports and various art forms.
- **Multi-category vocational training centre** trains adolescents and adults with IDD in weaving, candle making, pottery, carpentry and making paper products . The effort here is to identify their abilities and strengthen further to make them economically productive.
- **Sheltered workshop** which offers gainful employment to the trainees who able to carry on the activities without much supervision. Recognising the difficulty for these persons to enter

the mainstream job market, AMC is providing a protected and supportive work environment to help them discover a life that is self-governing. They get to take home a small amount of stipend/ incentive every month.

- **Day Care Centre for the severely affected e**ngages the adults with severe issues with various activities through the day.
- **SAMRUDHHI,** a model programme of lifelong support to families of those with DD. Periodic counseling sessions by psychiatrists, psychologists and social workers provide comprehensive assessment and guidance. Monitoring and ensuring that the families avail the benefits of the various Govt. schemes for the special individuals, training the mothers of beneficiaries in various vocations and making them job ready are some of the initiatives under this programme. A parent's Self Help Group provides the perfect platform for an active engagement among the parents of beneficiaries and exchange of knowledge.
- **Clinic:** A multidisciplinary team from NIMHANS visits AMC periodically to provide medical care to the beneficiaries of AMC.

The other services provided without any cost to the beneficiaries include

- Supply of Uniforms, Shoes, Bags
- Serving Milk with multi millet porridge, vitamin supplements
- Nutritious lunch everyday
- Transport facility for everyday commute
- Outdoor activities like visit to exhibitions, fairs, picnic, etc.
- Yoga Practice & Training in Painting, Dance and Music

AMC is certified by Credibility Alliance and is recognised as Tier 1 NGO by Give India. It is also listed on Guide Star and India Cares. AMC was awarded The Best Institution by His Excellency the Governor of Karnataka and by Rotary for its excellent service to the society in 2009.

Shri. K. Jairaj, IAS (Retd.) offers leadership as the President of the AMC Committee. The office bearers, members of the Managing Committee, Staff, Volunteers, Donors and Parents of beneficiaries have been contributing significantly towards building this institution and continue to work selflessly.

AMC depends on support from individual donors and corporates in leading these initiatives. There is no aid from the Government other than support towards one teacher's salary.

# Foreword

The Association for the Mentally Challenged, Bangalore, popularly known as AMC is the second oldest special needs organization in the country. AMC was started by Prof.D.L.N.Murthy Rao, of Mental Hospital. Bangalore in 1962. He authored some of the first scientific papers on special needs in the country.

AMC has been in the forefront of innovations for the care of persons with developmental disabilities and their families. **ENRICH** (**EMPOWERING** families to fulfil their **NEEDS** and **REBUILD** families through **INFORMATION**, and **SKILLS** of **CAREGIVING** towards **HOLISTIC DEVELOPMENT OF THE FAMILIES**) is in line with this leadership activities of AMC.

Persons with developmental disabilities, require three S's for their growth and development. These are Services, Support and Strengthening of family.

**SERVICES** should the needs from birth till the end of life. These needs are for early identification, early intervention, inclusive education, special education, continuous medical care, aids and appliances, support to families in the caregiving skills, day care facilities, prevocational and vocational training, sheltered workshops, residential care for those without families.

**SUPPORTS** are essential as persons with special needs cannot compete in the general community. Specific supports needed are increasing community awareness of the rights of persons with special needs, prevention activities as part of health services, financial support(monthly 'pension'), medical insurance(eg. NIRAMAYA SCHEME ), bus pass, loan Facilities, housing support, income tax benefits, legal aid, and employment reservation.

**STRENGTHENING THE FAMILY** is vital in the Indian context as majority of the persons with special needs live with families. Supports needed are caregiving skills, crisis support, self-care for physical and emotional health and support groups of families.

The book 'Loss, Love and Growth' brings together the 'lived-in' situation of families with a person with special needs. The striking aspect of the commitment of the families to the person with special needs of their family member. In addition, the challenges faced by the families at various stages of caring and nurturing in the Indian situation are brought out vividly in the 20+ stories. The stories bring forth the role of the Government, community, professionals to minimize the challenges of the families.

It is towards the goal of supporting the families both the memorandum and the Vision for Developmental Disabilities for Karnataka have been prepared and submitted to the Government.

The central message from the stories is for all of us to recognize the 'losses' exby the families with a person with special needs and minimizes the barriers and proactively support them in their caregiving journeys.

I want to thank the Foundation Juan Jose Lopez-Ibor, Madrid and Professor R. Srinivasa Murthy who was awarded the International Juan Jose Lopez Ibor award 2012 for the financial support for the project. Prof.Murthy, Ms.Divya and Ms.Nischitha have given their best to make the book 'Loss, Love and Growth' a reality. My sincere appreciation to the ENRICH Team.

I am hopeful that this will be a milestone in the care of persons with special needs in the country.

K.Jairaj,
President, AMC

# Introduction

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**SCHEMA OF CAREGIVERS SUPPORT**

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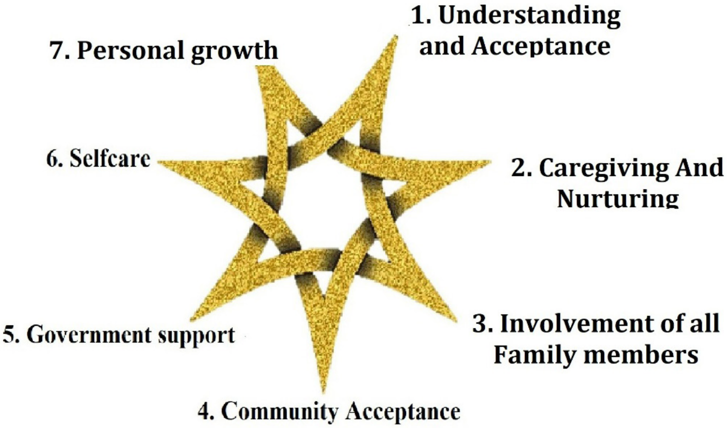
### Understanding the 'Lived-In' situation of families

All the families utilizing the services of AMC were individually interviewed to understand the emotional health needs and their current approaches to self care. More than half of the families expressed 'DISTRESS' levels needing medical care. Further, majority were either not aware of self-care measures or not practicing the same.

Based on interactions, personal life experiences of nearly 100 families, ENRICH team identified 7 needs/challenges (Figure 2)

# FAMILY LEVEL CHALLENGES WITH A ‘SPECIAL CHILD’



**ENRICH STAR MODEL**

These experiences are presented under the 7 areas through 17 ‘live-in’ experiences of the families. What is striking about Indian families is the commitment and resilience. What is clear are the feelings of LOSS of having the expected type of child, the LOVE of families for the special member, to do the best for the child/person and GROWTH/ finding purpose in the changed life situations.

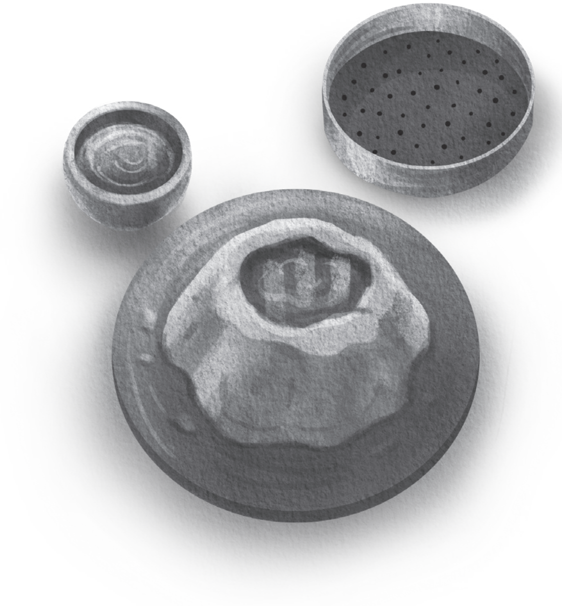
It is hoped that these ‘lived-in’ experiences will bring to the readers minds the various challenges of being a caregiver and stimulate each of the reader- be a family member, relative, local community member, the larger society, the professionals, the planners and administrators to reach out to the families and a MAKE A DIFFERENCE towards A BETER LIFE.

**The following are 10 salient aspects of caregiving of persons with special needs.**

1. Persons with special needs is both a challenge and opportunity for families.
2. Persons with special needs and the family will continue to find love and mutual satisfaction from the relationship.
3. Challenges are throughout the life course, both to the person and the family.
4. Challenges start with understanding the nature of special needs and reorganising the total family life in its life cycle.
5. The goal is to maximise the utilisation of the capacities of the person with special needs by all means.
6. Self care is important and should be a priority of all the family members.
7. Acceptance by the caregivers will lead to the acquisition of special skills of to nurture the person with special needs.
8. Community has a vital role in understanding the person with special needs and their families to include them in the community life and not discriminate in different life situations.
9. Support from the government at all stages of life to the individual and the family is vital to make the life journey meaningful.
10. It is possible to find meaning and purpose in the nurturing relationship with the person with special needs and the family.

All the stories are based on real families and their 'lived-in' experiences. They have been written by the ENRICH Team and Mr. Srikanth. All the names and identities of families have been changed to maintain confidentiality and protect their identities.

Our sincere thanks to the families for their generosity in sharing the experiences.



## Theme

## 1

# UNDERSTANDING AND ACCEPTANCE

## 1.1

## The Story of Anjum

Tears of joy rolled down my cheeks when she brought home Rs.300.

It was her first “salary”.

My daughter, Anjum, had learned to earn money by rolling covers out of old newspapers. And help me with household chores too. She spoke a word or two whenever I coaxed her to help me in the kitchen. Sometimes, I hear her hum songs which she has picked up from some teleserial, utter the names of actresses and actors. On odd occasions, she accompanies us to social gatherings like weddings or for a stroll on a big road nearby.

Such changes in Anjum’s behaviour--slow and steady--came about after she joined a school, Association for Mentally Challenged (AMC). We learned about this school from a teacher who visited our home as part of a survey. My mother, Abeeha, was skeptical about Anjum's admission to this school until she noticed children with special needs but more acute health issues. I convinced her that Anjum would learn to mingle with the children and participate in vocational training.

Perhaps, an unpleasant experience at a regular school weighed on my mother's mind. When Anjum was six, we admitted her to a school in Siddapura, but she would cry as soon as I left for home. I often got calls from the teachers that Anjum was crying and not moving about like other children. I remained in the school for some time to prevent her from screaming. One day, the teachers said it would be impossible to manage in this manner and asked us to enroll Anjum in another school.

My mother had remained a strong pillar of support through the traumatic years when we realised that Anjum not only missed several milestones—baby talk or crawl but fell ill frequently. She had a persistent cough, oozing from her ears until she was six. My baby girl used to turn blue whenever she cried because of a hole in her heart.

Like all mothers, I cried a lot because I could not watch my baby suffer from many ailments. When Anjum was a toddler, I woke up one night when I heard her crying. She started to turn blue—first her ears, then her cheeks and lips. Watching my baby suffer like this was traumatic, so I decided to seek divine intervention and make space for Namaz. I prayed to Allah: "Take this child with you or give her the life she deserves. "

My husband, Umar, and I decided to meet doctors and seek their opinion because Anjum had not spoken a word or walked like children her age. We rushed to St. Philomena's Hospital, where she was born, and heard the nursing staff whispering amongst themselves that Anjum was a victim of Down's Syndrome.

“Down’s Syndrome?” We had never heard of it. My husband, an autorickshaw driver, and I were not well-educated and knew nothing about this debilitating ailment.

The doctors were very supportive, but our conversation with them was traumatic. It torments me even today though Anjum is now 22 years old.

Doctors: Your child has a genetic disorder. We call it Down’s Syndrome.

Parents (Umar and myself): Sir, we don’t know anything about this. Could you please explain what it means?

**This is a Chromosomal disorder. Your baby girl has an extra Chromosome, so her development will not be like that of other children. She will remain like a child all her life.**

Doctors: This is a Chromosomal disorder. Your baby girl has an extra Chromosome, so her development will not be like that of other children. She will remain like a child all her life.

Parents: Are we responsible for it?

Doctors: No, it’s not your fault. It occurs in some children owing to mutation.

Parents: Can we have normal children in future, or will they also be born like Anjum?

Doctors: We will conduct blood tests and help you plan your future.

Parents: What should we do now (with Anjum)?

Doctors: The future of your child is in your hands. It would be best if you began a particular way of bringing up Anjum and made her independent as soon as possible. Several schools in the City groom such children using unique training methods.

As we walked out of the hospital, we were shattered when we realised we could not raise our little angel like others of her age. It took us a long time to come to terms with the bleak prospect that Anjum would not grow up like other children. One ray of hope was that we could make a difference in Anjum's life through proper care and special training sessions. Thanks to doctors and teachers at AMC, we gradually gained the strength to provide Anjum with sufficient opportunities to lead an independent life.

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I was only 14 when my parents decided to get me married. I was just a teenager who gave birth to my children at the age of 15 years and 18 years. I did not know the world around me. I did not know about pregnancy as I dropped out of school after 7th standard (Urdu medium). So, I did not know how to take care of children. My mother is the pillar of support and helped me raise my children. My elder son, Ryan, stayed with his grandmother and rarely visited us, even today. He passed his Class X, but neither got himself into a good college nor joined a job. I was always on edge and running to hospitals along with my husband for Anjum's treatment. My father, Mohammed, helped immensely by giving us money for her treatment.

At one point, however, my husband was forced to sell his autorickshaw to pay for the medical bills. We were not even in touch with our parents-in-law to inform them about Anjum because I clashed with them soon after our wedding and moved out of their place. I found earning money by attending tailoring classes challenging, but it did not work either.

Some unpleasant incidents have forced me to keep Anjum indoors. For example, when I took her for a walk after dinner, an ill-mannered boy called “Oyee Motti.” Overcome by anger, I chased him and wanted to hit him. A few of the neighbours who witnessed this came rushing to stop me and soothed me, saying that he didn’t know about your child, so let him go.

Recently, I gathered the courage to escort her to some weddings. She ate very slowly at one of the wedding dinners, and I was pretty embarrassed about people waiting for us to leave. I told one of our relatives that she is a slow eater and that I would take her plate somewhere else not to disrupt the dinner for others. But she said, “Sarah, don’t speak like that. She is our Anjum! Let her take how much ever long as she wants. She is God’s child, and it’s okay for us. You should bring her out of your house more often. She will also like the change of environment and learn to interact with people more frequently.”

I feel sad that I cannot get Anjum, now 22 years old, married and help her settle down like other children. My other worry: “who after me?”. I am in my 40’s now and see my health deteriorating. Recently, I was diagnosed with gastric ulcer and my husband’s diabetes well before my illness. My youngest daughter, Inaya, says she will take care of Anjum, but who knows what her future husband will say? I want to save some money for Anjum so that someone will take care of my child. But her pension is not credited on time, so I find it difficult to save money. I requested my younger daughter, who passed her BCom degree and has started working now, to help keep some of her earnings for Anjum's future, but even she says that she just started earning and there is time to do this. I am always worried about Anjum's future.

Looking back, I missed the opportunities as a child when my mother tried to help me learn a skill to be independent in life. I should have been more patient with my in-laws, but I came out of their house with one inconvenience. Now we don't have their support at all. I take responsibility for how my life is today.

## 1.2

## The Story of

# Anuradha

Elderly family members often caution youth to expect the unexpected in life. With sufficient education and awareness, however, some couples accept and cope with challenges that stare in the face of caregivers of children with special needs.

Anuradha and Niranjan, both graduates, were leading a blissful married life. While his wife was content playing the role of a homemaker, Niranjan was a working professional. His parents, Manikanta and Saraswathi, were also educated and held respectable societal positions. The young couple and Niranjan's parents were looking forward to the arrival of their bundle of joy.

For medical reasons, however, their baby girl, Vanitha, had a premature birth on Christmas eve in December 2015. In the Operation Theatre (OT), Anuradha overheard doctors discussing complications during the delivery. The newborn, weighing a mere

1.8 kg, was rushed to the Neonatal Intensive Care Unit (NICU) and remained away from the mother for 21 days.

As the first grandchild, Vanitha was showered with much love and affection by her parents and grandparents. They eagerly looked forward to every developmental milestone but turned very anxious when the baby's speech was delayed. They immediately sought medical attention. "Our goal was to provide the best medical care for our baby girl," said Anuradha while recalling the couple's approach to the child's ailment.

In 2016, the couple enrolled Vanitha in occupational and speech therapy at the Centre for Child Developmental Disabilities. When she turned three, they sought admission at a play home. She learnt many rhymes and used to repeat them as she loved the attention she received from everyone in the family for reciting the verses.

The couple decided to have their second child, with Vanita showing good progress at the play home. In March 2020, the play school was closed as the Government announced a lockdown because of the pandemic. The entire family spent quality time together but gradually noticed that Vanitha had trouble following instructions when attending online classes. Her grades started declining, and she needed to catch up on her studies.

Anuradha and her husband helped Vanitha to focus on her studies. Her grandparents kept her engaged with indoor games during the lockdown. Despite such support, she could not match her classmates in her studies. The couple felt it would be better to make Vanita repeat the class and approached the principal of her school in this regard.

Principal: Hello! Please sit down. Nice to meet you

Anuradha: Thank you, madam. We want to talk to you about our child Vanitha in LKG.

Niranjan: Since the online classes began, we see she needed help understanding the lessons; even her marks are coming down. We are apprehensive about her academics. She will find it tough to follow the lessons if she is promoted. We are okay for her to repeat the class again. What are your thoughts, ma'am?

Principal: I understand your concern, but as it is an online class, she has found it challenging. We will give her more attention and tell her teacher to involve Vanitha more in learning activities. Don't worry; she will learn eventually with the help of teachers and your support.

The principal's assurance gave the couple much-needed confidence about Vanitha. However, Niranjan discussed his child's problem with his sister, Bhavana, who lived abroad. She suggested a meeting with a psychiatrist for an IQ test to discover why Vanitha was finding it difficult to focus on her studies.

They delayed the appointment with the psychiatrist as the second baby's delivery date was approaching. With the arrival of a baby boy, Varun, the couple found it tougher to manage Vanitha. She turned stubborn, demanded the complete attention of her mother and threw temper tantrums. Again, her grandparents stepped in to help by taking Vanitha out of the house and distracting her attention.

A pious woman, Anuradha's mother-in-law, suggested visits to many temples to offer a special pooja in the name of Vanitha. Her father-in-law, however, was keen on the couple seeking an appointment with the psychiatrist for the child's IQ test.

In July 2022, the couple got the appointment and took Vanitha for the IQ test. It meant assessments throughout the day. In the evening, the doctor discussed the outcome of the test with the couple: Vanitha had a learning disability. This was the cause for the child's inability to focus on tasks or take more than usual time to complete them, plan any activity and remember the steps involved in executing the task. The doctor concluded that Vanitha would be slow in her studies but improve in the future.

Anuradha found it challenging to accept that Vanitha had a learning disability. She was confident her child could be helped to match her classmates in studies.

Her father-in-law's old friend was a psychiatrist and retired from NIMHANS. He offered to counsel and guide Anuradha further about Vanitha's future.

Anuradha: Sir, I am aware that my daughter is having difficulties. But the reports said she needed to attend a special school. Is it essential for her to go to a special school? We also had a thought to make her repeat a year in school. Will that help her? Please advise us to help make decisions about Vanitha?

Psychiatrist: Firstly, I appreciate you for reaching out for help. I am happy that you have put all the effort into starting early intervention to help Vanitha. It is a commendable effort from your family.

Secondly, I completely understand what you are going through. It must have cost a lot of money for all her therapies. There is also good progress in Vanitha. I have gone through her case history and progress.

Thirdly, on whether Vanitha needs a special school, I would say no. Let me tell you why. There are three types of schools available for a child. One regular school where all the children are around, and about 20 - 30 students in the class. The teacher might need help to focus on each and every student. The children could cope with studies according to their level, along with the guidance of the teacher and parents.

The next is a special school where children with different disabilities are grouped according to their mental age. They are given all the attention to learn fundamental and daily living skills to lead their life.

The third one is an integrated school. Here, children with mild to moderate disabilities and normal children are taught under the same roof. The child with mild and moderate disabilities will be given extra attention or a shadow teacher to guide them in their academics. This integrated organization will provide the necessary care for the child and help them develop on par with their classmates.

In Vanitha's case, she does not need a special school because her level of disability is not severe, but a regular school would be difficult for her as she needs one-on-one care and attention to learn. So the best option for Vanitha would be to find an integrated school where she would receive one-on-one attention when necessary and build her skills for an independent life.

Whichever school you decide on, I advise you to talk to the principals of these institutions and let them know about the challenges faced by Vanitha. Please request them to disclose their methods of addressing them. If you are convinced that the institution would be able to give the necessary care, then go ahead and enrol her in that school. With proper support, she could complete her academics satisfactorily until secondary education. You may need help to go on to professional education. But suppose Vanitha is given additional skills training like arts and other things; she could be independent and earn from the skills. She will grow to be a self-sufficient human being; please don't worry about that aspect.

Niranjan: Thank you very much for your guidance, Sir. We are really thankful and appreciate for explaining in detail and making this understandable. We also have some hopes that we will be able to make the right decision for Vanitha and her future, as no doctor told us this hard truth. Even though it is difficult to digest, we needed to hear it from a professional. This would help us make Vanitha a better person.

Manikanta: I am very much relieved after hearing from you, Sir. Now the next step is to find an integrated school in Bengaluru. Thank you very much for helping us make the right choice for my granddaughter. We all love her and want to give her the best in life.

The strengths of this family are the parents' educational background, grandparents' support and their social position in supporting their special child. The fact that they started early helped optimize the growth and development of Vanitha.

## 1.3

## The Story of

# Lahari

We chose a name for our little bundle of joy well before she arrived in this world.

Lahari was the name because we craved long-lasting happiness.

Our joy, however, lasted only a few hours. Within four hours of her birth, she had her first episode of seizures. Doctors rushed to examine her but expressed their helplessness about the lack of advanced equipment for diagnosis. They advised us to shift the newborn to Vanivilas Hospital, Bengaluru, where doctors placed her in the neonatal intensive care unit (NICU) for a fortnight. I told the doctors I did not hear her birth cry. They said it was due to an impact on her brain.

We returned home after 20 days with tablets to prevent further seizures.

My parents were devout Hindus who offered pooja every day. We, too, performed poojas and many rituals like offering gold ornaments to God to prevent our baby from suffering further, but she was crying all the time. She proved a disturbed infant with all her milestones delayed. She was around 20 months when she had her second episode of seizures. We rushed her to Parijama hospital. The consultant doctor told us that she is a child with special needs, all her developmental milestones will be slow, and she will not be like other children her age. This diagnosis was a big shock for my husband, Prasad, and myself. My husband and I had immense faith in God. We were left wondering why God would do this to us.

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Once, we visited St. John's Hospital, and the doctor suggested a genetic test for a better diagnosis, but we failed to get good results. So, we went to NIMHANS, and the doctor told us that the report was incomplete and that we had to repeat all the tests.

Prasad looked at me. We wanted a proper diagnosis and cure for our baby girl's medical problem. So, I nodded, saying that we would repeat the tests. Doctors told us to visit the child psychiatry division after completing the tests. The conversation is still fresh in my mind.

*Nandini: Doctor, please tell us what is wrong with my daughter?. What is the reason for undergoing these tests for a second time? Please tell us that there is some medication or cure for this condition.*

*Doctor: I understand that this is a big shock for you both. Your child is diagnosed with Attention Deficit and Hyperactive Disorder. She* *has a seizure disorder and mild intellectual disability. It means all her developmental milestones will be slow; even when she is 20, she will have a mental ability of about five years. All you can do is give her all the attention needed for her development and teach her everything possible. I will provide you with medicine to control her seizure and overactivity behaviour. Don't miss the medication, as it will save her life.*

I felt despondent and cried all night. I looked forward to some medication for a cure, not the type of reply provided by the doctor. My husband and I never stopped looking for treatment. We kept our search for a drug along with the medicines the doctor had prescribed.

Within a few years, I conceived again. I had two other children: a girl, Siri and a boy, Tharun. I observed them very closely this time, and both had achieved all the milestones on time. I was a little relieved that they had everyday life and development.

I enrolled Lahari at a special school. During the last few years, she has improved. Unfortunately, due to the pandemic, a lockdown was announced. It was challenging to keep her at home all the time and handle her. She was stubborn and would not listen to any of us. She was disturbing her siblings a lot. It was difficult for them to focus on their studies. I was very angry with her.

**Unfortunately, due to the pandemic, a lockdown was announced. It was challenging to keep her at home all the time and handle her. She was stubborn and would not listen to any of us.**

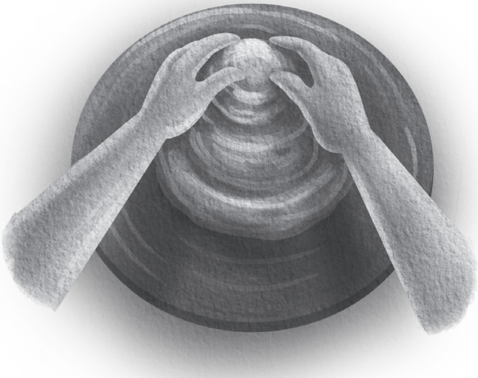
We visited our hometown when my father-in-law passed away. I never thought she would do this. So many behavioural issues, being stubborn. After coming from the death ceremony, I only had one thought that I needed to do something. I thought, like, take poison for myself and offer it to Lahari so we can die. My husband and two other children could live peacefully. But the other thought was, why my other children should live without their mother? That was not okay. So, I decided I would look for other alternatives. I spoke with Lahari's school teachers and told them that I plan to look for a hostel that will allow her to visit home regularly and stay in touch with her family and help her in her condition. I can also arrange some funds and other necessary things for her. We are ready to do anything for her betterment in life. The teacher said they would look into it.

I am doing my best to be more patient and look after her.

My husband will keep saying, 'believe me, one day our daughter will be much better than today. This difficulty will not last forever for us. We will overcome it.' Those were the days when I would share that hope with him and continue living.

Recently we performed a pooja for the child's well-being and the family's wellness. Now things seem to have settled down. She is a little more understanding now. Before, her father and grandfather would get angry very quickly. But now they seem to be a bit more patient. It is all because of the pooja we performed. After that pooja, my mind relaxed a little more.

The acceptance of a special child is a lifelong struggle. It is the journey and not a destination.



## Theme

# 2

# CAREGIVING AND NURTURING

## 2.1

## The Story of

# Ganesha

I cannot afford to skip work at this school even when I am sick.

For, when I do, every child comes looking for me the following day, anxious to know whether I took ill. “Auntie, why were you not here yesterday? Were you not well? I will ask my mother to give me some money. You go to the doctor and be well again,” is the chorus that makes me emotional and teary-eyed.

Such overwhelming love and affection showered by 100-odd special children helped strengthen my resolve to work in this school (AMC) even when I was getting old.

My son, Ganesha, is a special child, too. He works in a workshop at this school. And that’s how I got an opportunity to join as a kitchen staff member. The headmistress, who had watched me sitting idle after accompanying my son to school, initially offered me a job in the housekeeping wing. Later she listed me for work in the kitchen.

He is a young man now, but like men of his age, he will never be able to marry and bring up a family. He has missed many milestones, although he grew up like an average child until about nine months. His sister, Chaitra, two years older than him, is married and settled.

Ganesha was nine months old when he had an extremely high fever one night. My husband, Nandeesha, and I did not know that high fever among infants could lead to debilitating consequences. Nor were we aware of using wet towels on his forehead to bring down the temperature. The baby threw up whenever I fed him some milk.

The following morning, we rushed him to a small clinic nearby, only to be scolded by the doctor for not doing anything to bring down his temperature. He was administered an injection. Suddenly he started to shake unusually. It was his first epilepsy attack. His iris went up. Everything went blurry. I began to cry, scared, looking at my child's condition. I was holding him in my hands, utterly clueless about what was happening to him. What if he had an epileptic attack when we were at home and did not know what to do? Several negative thoughts occupied my mind, but the doctor's stern voice brought me back to my senses. "*He is in a critical condition. Rush him to some big hospital for treatment,*" said the doctor.

**I did not know that high fever among infants could lead to debilitating consequences. Nor were we aware of using wet towels on his forehead to bring down the temperature.**

We took him to a private hospital nearby, and the doctors admitted him. They attended to him for three days, but the seizures did not stop. No one assured us or clarified what was happening to our baby.

We were shattered when they said he might or might not survive. Both my husband and I were in tears, helplessly waiting to hear from the doctors that they could save our baby's life. Ultimately, the doctors advised us our baby should get treatment at NIMHANS. We were extremely nervous as we raced with our baby to the emergency wing at NIMHANS. "*The child is in a critical condition. We don't know what could happen, but we will admit him and start the treatment. Just pray that this treatment works,*" was Dr Nandita's advice while we were waiting in emergency care at the hospital.

It took 10 to 15 days to stabilise our baby's health, but he spent one-month undergoing treatment at NIMHANS. My parents helped my husband and me during stressful times at the hospital and cared for our daughter.

**This child will not grow regularly. His milestones will be delayed, and his brain functioning will be slow from now. He will talk late and start walking late.**

A senior doctor at NIMHANS broke the bad news. The baby suffered epileptic attacks because of extremely high temperature on that ill-fated night. "*This child will not grow regularly. His milestones will be delayed, and his brain functioning will be slow from now. He will talk late and start walking late. He cannot grow according to his age.*" Medicines were prescribed for his epileptic attacks. We were advised to visit the hospital after a week for a thorough check-up of our baby.

Another shock was looming while I was still trying to come to terms with Ganesha's epilepsy and visits to the hospital. About a month after we returned from NIMHANS with tons of medications for the baby and our daughter Chaitra set off to Anganwadi, I received a call from my husband's office. This was very unusual. It was Nandeesha's colleague who told me that my husband was admitted to NIMHANS. I was in a state of shock and utter disbelief. I reached out to my brother, Suranjan, who also lived in Bengaluru. I requested one of our neighbours to take care of Ganesha for a couple of hours before setting off to NIMHANS.

On reaching NIMHANS, I discovered my husband had suffered a stroke on his right side. His right hand and leg were twisted, as was the right side of his mouth. I realised my husband had crumbled under pressure. Some nasty comments made by his colleagues that Ganesha would not grow up like an average child affected him. Sometimes, he shared his helplessness with me. I could do little as he was the sole breadwinner for our family.

**It struck me that I would also be the caregiver for our baby boy and my husband. My parents and my brother stood by me as pillars of strength.**

It struck me that I would also be the caregiver for our baby boy and my husband. My parents and my brother stood by me as pillars of strength. My father, Krishnappa, provided much-needed emotional support.

With my husband's salary, we could buy medicines, pay doctors for consultations and get groceries. We, however, could not pay the rent for three-four months. The owner's wife came in the evening to ask for the due rent.

*Owner's wife: You last paid the rent almost 3-4 months ago. Please vacate our house and find accommodation elsewhere. It is getting difficult for us too.*

*Me: You know our situation right now. Please give me some more time.*

*I have written a letter to my father about this, and he will be here in the next three days to clear the dues. We will vacate the house after paying the rent.*

The owner was more considerate. He agreed to give us some time.

*"Please take care ma'am. I understand your husband is still not able to go to work. But we are also in need of money. I can only extend the due date to a week. Try to pay us by then,"* was his request.

If you ask me whether God was with us through such hardships, I would say: We see God in those people who help us at times like these. I was so grateful to him. My father reached home two days later and settled their dues.

I took my husband to our home town for his recovery. After a few months, we spoke to his officer, who said the salary would be paid until he returned to work. I see God in all these people.

Everything is going on well now. We returned to Bengaluru after a year or more, and my husband returned to work. I, as a mother, am still healthy and earning to take care of my child. But who will look after my son after my demise? Sometimes these thoughts bother me so much, even today, when I know just worrying will not help my child or me.

**If you ask me whether God was with us through such hardships, I would say: We see God in those people who help us at times like these. I was so grateful to him.**

Ganesha was four-years-old but could not walk or talk though he got admission to a school. He would crawl around in the school and scribble on the floor. One teacher told me about a special school for children like him.

Deepa, a girl, living near our residence, came like an angel. I shared my interaction with this school teacher. She guided me to the special school and said my son would improve if sent there. We joined him in the special school around 5 years of age. The school guided us to get an IQ test and a certificate and told us to visit NIMHANS. Until then, we did not know what was wrong with our son. We thought he would be okay soon.

**The headmistress asked if I would work in the school. I am close to all the children in this school because I work in the kitchen. They miss me when I do not come to school for a single day.**

Some of our relatives suggested we perform some rituals and offer pooja in temples to ward off bad omens in our family. I did it all, hoping it would cure all my difficulties.

When I walked around with Ganesha, some neighbours would say, “what would you do keeping this child!’ I would get furious. What do they mean? He is my son, not any commodity you throw because it did not turn out as you expected. Of course, I will take care of him. Even if that takes all the extra effort and love from us.

I would go to this special school with him and sit down doing nothing. The headmistress asked if I would work in the school. I am close to all the children in this school because I work in the kitchen. They miss me when I do not come to school for a single day.

Sometimes, I regret the night my son developed a high fever and subsequently suffered epileptic attacks. Like other children his age, Ganesha would have attended school and college, secured a job, and married. Now he will forever be this child of 10 years old, even in his 20’s, even in his 40’s.

And I will still love him the same.

## 2.2

## The Story of

# Chaitra

“I wish my two children pass away before I do”.

Her distress is discernible.

It results from a traumatic past and anxiety about an uncertain future. Chaitra’s stress is compounded by the fact that she is the sole caregiver of both sons, who are special youths having developmental disabilities.

Clueless about who will take care of her sons, Raghav and Shyam, after her demise, Chaitra airs a shocking wish filled with much pain: “I wish my two children pass away before I do. No mother will pray for her children’s demise.” After her death, she dreads thinking of a situation when her sons would be forced to beg on the streets because her relatives would not take care of them.

At 55, she has endured many family setbacks. Still, with grit and determination, she has raised and tended to her special sons with much care and attention. In recent days, the spectre of a bleak future for her sons has been weighing heavily on her mind.

Her husband, Madan, and she were taking good care of their children who has special needs. Tragedy struck her family in 2008 when her husband suffered a massive heart attack and passed away. "My husband was a source of tremendous support for me and anyone who approached him for help. He would step forward whenever someone was in distress. Many people took advantage of his helpful nature," recalls Chaitra.

A tearful Chaitra rued the attitude of her relatives on the day of her husband's demise. "How can I forget that day? I was devastated and found both Raghav and Shyam weeping. I am unsure whether they understood their father was no more or were crying upon noticing our relatives shed tears. Our relatives took my husband's body away for cremation late in the evening. Upon their return, each demanded money for the ambulance and other expenses at the crematorium. I was shocked that they forgot how my husband spent money while helping them. They did not even bother to think about my children at that moment. I threw all my savings at them and asked them to leave," she said, choking with emotion.

**A devout person, she knew God would extend his helping hand. She moved into a house gifted by her mother and took up two jobs to earn enough to support her sons.**

A devout person, she knew God would extend his helping hand. She moved into a house gifted by her mother and took up two jobs to earn enough to support her sons. First, she took up a housekeeping job that she retained for over a decade. Next, learnt tailoring and made some extra money with the help of an advanced tailoring machine belonging to her friend.

She recalled that the couple knew nothing about his condition when Raghav was diagnosed with an intellectual disability. “His developmental milestones were slow; we also thought he would learn that when he goes to school and mingle with other children. We sent him to the government school in our area.

When we learned that Shyam was missing his milestones, we left him in our hometown. Soon, we returned to Bengaluru, where we learned about AMC and joined our sons in this special school. We learnt about the pension and NIRAMAYA benefit scheme from the teachers and benefited from them,” she added.

Twin blows struck the family first in 2014 and later in 2018. Chaitra’s younger son was seriously ill, while her elder son was diagnosed with diabetes. The wages she earned, widow pension and disability pension helped her. She managed to pay the fee for Shyam’s dialysis thrice a week, some additional injections for his upkeep, and Ayurvedic medicines to treat Raghav’s diabetes. With so many visits to the hospital, she felt weak and could not find time for herself. Her employers were highly supportive and stood by her through those difficult times.

She had settled down to routine hospital visits and her housekeeping job when the first nationwide lockdown was announced in March 2020. How would she escort her sons to hospitals for dialysis and treatment of diabetes during the lockdown?

She shared her predicament with her employer and some neighbours about the lack of transport during the lockdown. One neighbour who owned an autorickshaw came to her rescue. She could use his vehicle to escort her sons to hospitals. With her savings drying up,

**With her savings drying up, she had no choice but to request her employer for a loan. “There were a lot of people around me who pooled in their money to help me during these tough times,” she said with a sense of gratitude.**

she had no choice but to request her employer for a loan. “There were a lot of people around me who pooled in their money to help me during these tough times,” she said with a sense of gratitude.

Two years later, Raghav had to undergo surgery, resulting in an additional burden of several thousand rupees. Her nephew came to her rescue, paid the amount and escorted her and Raghav home. “I have gone through several struggles in life. If you ask me how I managed, I believe I was given strength by God. God has given me the power to pull through during tough times. God may have given me two children with special needs, but they are both like two angels. There was not a single thing that was difficult for me to look after the children during the lockdown. They never made any rucks when they were left alone while I went to work. They would not even know if they needed food. Or ask in the neighbourhood for anything. They patiently waited for me until I returned and gave them lunch. The only thing that bothers me always is who will be there for my children after I am gone? No one will give them that love like a mother. Without me, my sons’ would be on the streets,” remarked Chaitra.

### 2.3

## The Story of

# Nanda

Caregiving is highly demanding.

For parents, it is like embarking on a journey through a tunnel with the environs turning darker by the day. There are numerous uncertainties as they grope their way through the dark tunnel, overcoming obstacles at every stage—from diagnosis to treatment and rehabilitation of their special child. Their daily routines are thrown into disarray, stress levels spiral, and life, as the family knew, will become passe.

So, what of parents who are caregivers to two children—one, child with special needs and the other, rendered inept following a road accident?

Their travails multiply, but through sheer grit and determination, Prabha and Raghuram are proving diligent caregivers of their sons—Nanda and Nagendra.

Prabha’s narration:

I was forewarned about the possibility of the arrival of a child with special needs by the doctor. I was about to enter the scanning room when he called me over and said, “there might be some problem with the child after birth because yours is a consanguineous marriage”. I was a little worried upon hearing from the doctor.

About 20 days before my child was born, I developed a fever. Gradually my fever reduced, but I started bleeding and was admitted to the hospital for treatment.

My child was frail when he was born. I thought he was weak because I had a fever before his birth. A few days after delivery, our baby boy was taking ill frequently. We tried to take him to many hospitals, but it was not helping. There were times when he had allergies too. We were in our village. We did not know much about what was happening to him or why he was falling ill frequently.

We noticed one other difference in our son. All his peers his age were growing and started recognizing people, making eye contact and even talking. But our son was not doing any of these things. We were worried, and we once went to the hospital and asked the doctor the reason for the delayed development. The doctor suggested getting a brain scan. We got the brain scan done, but the scan didn’t help in knowing what was happening and why our child had constant fever or allergies. We spent a lot of money on his checkups and medical tests. I am grateful to my parents, as they were the ones who helped us financially during this phase.

**There might be some problem with the child after birth because yours is a consanguineous marriage”. I was a little worried upon hearing from the doctor.**

We admitted him to a nursery school near my house as he grew. At this time, I had another child. He was growing up well. My first child and my second child both went to the same school. He studied till 6th STD. He was very good at writing, and his handwriting was beautiful. Still, when it came to reading, he was forgetting everything. He had poor memory.

**We admitted him to a nursery school near my house as he grew. At this time, I had another child. He was growing up well. My first child and my second child both went to the same school**

After 4th standard, teachers used to call for many meetings, and they would complain, saying that he was very poor in his studies. He does not concentrate in class. For the next 2 years, teachers did their best to teach him separately by giving him all their attention. I was also teaching him everything as much as possible. Then one day, teachers called us to talk.

*Teacher – Please come in and have a seat*

*I sat on the chair*

*Teacher – I think Nanda has some problem*

*I started listening even more carefully*

*Teacher – He doesn't really give much attention. We tried to give him special attention, but he was not concentrating on what we were saying. Also, he finds it very difficult to memorize things. Sometimes he looks lost. I think he might be slow in development. Why don't you take him to NIMHANS, Bengaluru, for EC valuation?*

The following day is still fresh in my memory. I cried the whole day, and the day after, we took him to NIMHANS. The doctor conducted some assessments and told us that he has delayed milestones and his memory will not be as that of his age group. I asked them what the reason was? Why did this happen to him? The doctor said your husband has a delayed milestone, so it occurred to your child also. It is a genetic problem.

After we returned home, we were clueless about what to do. I heard there was a hostel for children with special needs, and we thought of joining him at the hostel because it was challenging to look after him at home. It was a tough decision, but God had other plans for me. This time I had no other choice other than securing admission for him in a hostel.

I was worried about the impact on my younger son, for whom I had lots of hope. Unfortunately, he met with an accident. It was a terrible accident. He was crossing a road while returning from school, and some vehicle hit him. His leg and brain got hit. Both his legs were smashed. One leg was missing. We did everything we could to look after him. He was operated upon five times. It was tough for us financially and emotionally. I had to borrow to pay for his surgeries.

**It was a tough decision, but God had other plans for me. This time I had no other choice other than securing admission for him in a hostel.**

My one child is in a hostel where I cannot go and see him, and the other is in a hospital where he needs constant support for everything.

Here I am, all alone.

My husband was not there as he was going to work to earn a living to run the family. Around this time, I lost my parents too as they were old. As a result, I had no support. I was emotionally and physically drained. I never thought that my life would become like this. I have no one with whom I can share my feelings. All things happened at the same time. For six months, I was in the hospital looking after my second child, and other six months, I was at home looking after them both. I was tired and exhausted.

At this time, Nanda was progressing a little bit. In the hostel, he learnt many things. Earlier, he needed help dressing, eating and all his daily activities. After going to the hostel, he discovered a few things. From there I joined him at AMC special school. There he learnt some sentences and living skills. He is more independent now. He needs some work to be engaged. He learns things very quickly.

After some time, I was not worried about Nanda at all. I was thinking more about my second child, Nagendra. I just wanted him to be alive. He became like a child. I wanted him to walk, eat on his own, do some basic work and be independent. His friends help me a lot at times if there is anything emergency they look after his needs and I finish the job quickly and I come back.

**I feel stuck in one place where I have to wake up, take care of these children, feed them, look after them, and repeat the same. Am not sad that I have to do all this but I hope one day they can do these things on their own.**

If I sit and think it's almost 10 years since I have gone to any function, marriage, festival, not even temples. I have yet to get a day's holiday for myself. Every day I need to take care of these two children.

Now my second child is going to college, so I take him to his college every day, sit there till the evening and after he finishes, pick him back from his college to our home. I thought of going to work to earn some money but I can't leave these children and go. I have been applying for government benefits for a very long time as it helps me somehow. But then I have to take these two children and go, which I cannot do. I feel stuck in one place where I have to wake up, take care of these children, feed them, look after them, and repeat the same. Am not sad that I have to do all this but I hope one day they can do these things on their own.

All I am worried about is what will they do after me? It worries me a lot. Nowadays my husband has gotten fed up with all this. He only helps me to pay my rent nowadays and the little money he gives, that's all. He never supported or cared for my child. I get ration and other things from school, which I manage for my daily life.

I don't know about the future, I have yet to think of it much, but I still want to keep some security or money for them but cannot do anything. When I think of it, I get very much nervous. I hope my second child gets work. He is only physically disabled but not mentally. He is a brilliant and bright child. He needs little assistance, but he works nicely. He loves to work and I pray every day that he gets a job after finishing college.

## 2.4

## The Story of

# Ananyya

Ananyya is the silver lining of the dark clouds that cast a depressing shadow over my life. She is just 15 years old but stands up in my support whenever my parents-in-law or relatives scold me. She has a developmental disability but has taught me many things in life. I am more patient than I was earlier and empathize with parents with a similar disorder. Someday, she will give me the strength to overcome the acute pain caused by my husband, my in-laws and my sister.

I do nurse hopes that Sandeep, my 22-year-old son, will one day become a pillar of strength. My other daughter, Ahalya, is married and lives in a village. Still, my husband has prevented me from keeping in touch with her. Sometimes, I ponder over the question of why God has forced me to endure so many challenges and losses. Then, I concluded that perhaps God was aware I could withstand the pain and that I should find purpose in it.

Every stage in my life has been a struggle.

I was on the threshold of turning 18 when my father asked me to marry his sister's son. I was speechless. I had no idea what marriage meant. For a second, I should get married to lead a happy life. The next minute I felt like I needed to get married. Still, there was nothing much I could do or fight, so I agreed to get married with many hopes for a peaceful life.

I am the eldest of four children from a typical middle-class family. My father, Bhushan, is a farmer. My mother, Aarathi, worked with him. He was an alcoholic. So arguments and fights ensued every day. It was very distressing to me when I was a child. I didn't know from whom to seek support or how to stop this fight.

I was in 5th STD when my parents dropped me at my aunt Ahalya's house because it was difficult for them to take care of four children. It was excellent in my aunt's house without fights and arguments until one day, when one sibling married a man from a different caste. It snowballed into a big issue resulting in arguments, blame games, and gloom in their house.

Such friction in my aunt's house disrupted my studies even though I was about to write my 10th exams. I was sent back to my parent's residence. I could not study further, nor was I satisfied merely doing chores. I was interested in tailoring, so I joined my hometown's tailoring classes, where I learned to stitch blouses and churidar. I still remember earning Rs 40 for stitching each blouse, and I repaid the fee for tailoring classes with this money. I worked for a year, and somehow I was trying to find happiness in my work when my father asked me to get married to his sister's son.

A month before the wedding, my parents left for Tirupati. In their absence, my in-law-to-be arrived out of nowhere. They wanted to advance the wedding by 20 days. I was shocked. I told them to talk to my parents on their return from Tirupati, but they went ahead with the arrangements. My parents arrived a day before the wedding, and arguments and confusion followed. The next morning, I married at a temple. I moved to Bengaluru with my husband, Venkataramana, with new hopes, expectations, and many dreams.

Things were going well. I used to stitch some blouses and earn a little, and my mother-in-law Savitramma used to go for some household chores. My younger sister, Janaki, was accompanying her. My parents were having financial difficulties, so my sister asked me if she could come over and find a job, and she started working with my in-law. She was staying next to our house in a small room.

**Within three months of our wedding, I was pregnant. It was a beautiful moment, but at the same time, I had no idea how to look after everything. My first child weighed 3.5kg, so I had to undergo a c-section, and I was restless.**

Within three months of our wedding, I was pregnant. It was a beautiful moment, but at the same time, I had no idea how to look after everything.

My first child weighed 3.5kg, so I had to undergo a c-section, and I was restless. My parents did not look after me. I stayed in my husband's house for almost 1.5 years, and after that, I went to my hometown with a 1-year-old child and was 3 months pregnant too. I was in my second pregnancy.

I stayed in my home town for two months, but when I was about to leave for Bengaluru, my child had rashes all over his body. He had smallpox. So I had to stay for more days and left after a few weeks. This time it was a different feeling while returning to Bengaluru with the same hopes, but I never thought I would be in for a big shock.

When I returned to Bengaluru, my husband and mother-in-law were aloof. My sister looked a little fat and suspicious. One evening, my mother-in-law said she wanted to talk to me. She sat next to me and said, “When you went to your home town, some things changed here. I wasn’t at home, and your husband slept in your sister’s room. Your sister is in the seventh month of pregnancy.”

I cried, asking her how she could allow an affair with my sister, but my mother-in-law was calm as though nothing wrong had occurred. She said, “you had a C-section delivery, and it looked like you will not have any other child. They liked each other and slept. What’s wrong with that. I don’t think you have to make a big issue. Now let’s call your mother and talk about this. We can’t hide your sister’s stomach, it’s getting bigger, and everyone will start talking. So let’s get her married to your husband.”

I wept for several days. My husband would talk about my C-section delivery whenever I asked him how he could get into a physical relationship with my younger sister. My in-laws called my parents over, told them about my younger sister’s pregnancy, and the wedding took place in another town. Soon, she delivered a baby girl.

**I delivered a boy. He was a little underweight. I tried to breastfeed him. He was tiny and had some breathing issues.**

I was under a lot of stress when my delivery date approached nearer. I went to the hospital on my due date but was sent back as the doctors felt I could wait for some more time. This occurred thrice. I was admitted to Lady Curzon and Bowring Hospital in Shivajinagar when I was almost in my tenth month of pregnancy.

I delivered a boy. He was a little underweight. I tried to breastfeed him. He was tiny and had some breathing issues.

I called my husband and told him to check what was happening with his breathing and to take him to the doctor. So he and my mother-in-law went to meet a doctor to check what was wrong with the child. The following day woke up, and I was waiting for my baby so that I could feed him, but my husband and in-law came with an empty hand. I waited for them to say something, but after what I heard I wished that they never went to the hospital in the first place.

*Me: where is my child*

*Husband – hmmm, looked towards my mother-in-law.*

*Mother-in-law: I don't know what happened. Your child died last night.*

*Me: What? How? What happened? Please bring my child.*

*Husband: We already buried him. He did not survive.*

It was heart-wrenching. How could they do that? I wanted to see my baby's face. I asked the doctor how this happened, and he said he didn't see the baby. I called my husband, but he never took the call. They had gone back home. I stayed for a week in the hospital and then returned home. I shouted at everyone, screamed, and cried, asking what had happened to my baby. They said it died, but nobody said how or what happened. I was devastated. It was in the morning. I was sitting in my room looking after my first child. Suddenly, my husband came and handed me a girl child.

**It was heart-wrenching. How could they do that? I wanted to see my baby's face. I asked the doctor how this happened, and he said he didn't see the baby. I called my husband, but he never took the call.**

I was shocked. I asked my husband, "whose child is this?

My husband said, “you looked very sad after the child died, so I am giving your sister’s child.”

The baby was two months old. “I asked, why are you giving me this child?”

He replied, “look, If people come to know that your sister is pregnant before the marriage, it will be a bad name for your sister, and she can’t handle the child at this age. As you have already lost the child, please think of this as your child and take care of it.”

Three years passed. My first child was 6 years old, and my second child was around 3 years old. My husband was a little good towards me. He was also looking after my sister in the village. He went there for a few days and spent time with me in Bengaluru. They were all good to me.

One night my husband came to me and asked if we should go for a third child. I gave it a lot of thought on it. I had enough pain in my life. Still, I wanted to go with the third child hoping that this would be a companion and someone with who I could share my feelings because my first child was a little innocent. So, I agreed to have a third child.

In a few months, I was pregnant with 3rd child. Slightly my hopes were going down, and my mother-in-law started taunting me a lot and torturing me mentally and physically. One of the other arguments is about what I should eat and what I shouldn’t. I still remember it was around 7 months when my father-in-law was diagnosed with diabetes. Due to his health issues, he got a lot of angry and kept asking to make this food, that food and do this work, that work. There was much less support from my mother-in-law and my husband. At times, they used to beat me. I even lost a lot of weight. Every day was a hassle.

My third baby was diagnosed with hydrocephaly at 8 months of pregnancy. The doctor did suggest getting an abortion or performing an operation. When I told him this, my husband didn't react much. He said he would pray to God and everything would be okay. My mother-in-law said, "you did not perform this pooja or that vratha. That's why you had a child like this."

I cried a lot during her pregnancy. I have to undergo a C-section again. When the baby was born, she weighed less and there was no birth cry. They had incubated my child for almost five days. It was painful, as nobody visited my baby, Ananyya, in the hospital, not even my parents. On the 7th day, my husband came and we got discharged. A few months into post-pregnancy, my baby had some health issues, vomiting a lot and her hands would shake a lot. She used to sleep for long hours, more than a normal child would sleep and cry, and she doesn't drink milk. It was challenging for me to handle the child. When I said this to my family, they always scolded me but never took my child to the hospital.

**My third baby was diagnosed with hydrocephaly at 8 months of pregnancy. The doctor did suggest getting an abortion or performing an operation. When I told him this, my husband didn't react much.**

Two years later, her body started shaking a lot. I screamed for help, but nobody responded. Next to my home, there was a girl who told me about NIMHANS, and with her help, I went to NIMHANS without telling anyone. When I met the doctor, he told me about Epilepsy. That's when I came to know my child had sudden Epilepsy all this time. I felt very bad, she was the only hope I had, but she had been suffering all this time.

She was also diagnosed with an intellectual disability. That night I discussed this with my family. My husband said, "*why is this child still alive?*" My mother-in-law suggested we visit a temple and offer pooja to cure Ananyya's Epilepsy.

My baby girl was missing all milestones. She was crawling when she was three years old and spoke very few words. I needed to visit NIMHANS one more time for therapy. Once again, my mother-in-law told me to go to the temple, not NIMHANS. I was furious and lost my patience. I took my child to Manipal hospital and commenced physiotherapy for her. Ananyya was almost three and a half years when she first started walking.

I felt a little happy.

Near my home, I got her admission to a government school. I wanted to give her a normal life, but God had other plans for her. I was getting a lot of complaints from the school as she was not able to sit or listen to the teachers. Later, one day, when I went for a NIMHANS visit for her regular check-up, doctors told me about the AMC school for children with special needs. It was located next to NIMHANS hospital.

I spoke to my family members about her admission to AMC school. They were reluctant to send her to the school. I stopped listening to them and admitted her to the AMC. This was the best decision I made; after joining there, her behaviour changed. She listens to all teachers, has good sitting behaviour, she is good at writing now. She also learned to share things and was waiting for her turn, fixing puzzles and telling the dates. She was also into games.

**I stopped listening to them and admitted her to the AMC. This was the best decision I made; after joining there, her behaviour changed.**

Every day I take her on the bus. Around 9:00 in the morning, I was holding Ananyya's hand and crossing the road when suddenly, she was pulled away. We fell apart. It took me two minutes to register what was happening. She got severely injured. Some bike came from nowhere and hit my child.

Immediately I admitted her to a hospital nearby. Her back muscle and leg got cramped. Everything fell apart when she almost learnt all the basic skills and became independent. Now, we were back to square one. She needed help with everything, from brushing her teeth and washing herself to using the toilet, feeding, and dressing. She was in pain for a very long time.

**I cannot take help from anybody, nor does my husband help me. Now, only Ananyya stands up in my support when anyone scolds me. This makes me very happy.**

Everybody started blaming me as I was the one who was taking her to school when the accident occurred. So, everyone started scolding me when I was in the hospital with my daughter for several days looking after her. Still, I am really happy that my child is alive. After a few months, she had her first menstruation. It was a very uncomfortable situation for her. She was not able to understand when she had her dates and everything. She comes to me and says she feels wet, and then I take her to the bathroom and see. When I know, she is on her period. I will always be there with her to look after her, especially the first day. She bleeds a lot. I take her to the bathroom every 3 hours and change the pad. After the accident, she cannot bend her back and see down, so she does not know how to transform and clean everything. I do that for her. At times I was angry with God for making her like this because she was a special child. At least she was independent. Now she needs help with everything, and she needs lifelong support. I have met many doctors and am trying to save money to get her prosthetic leg. She can become a little independent in looking after her. It is terrifying to think about what will happen after my demise?

She is the only person who does not give me any trouble. She only asks for the TV and plays on her own. She has grown strong and learnt a lot.

I do not have any regrets or sadness that I have a special child but all my sadness regarding the husband and mother-in-law, as their always scold me. It is tough for me. I cannot take help from anybody, nor does my husband help me. Now, only Ananyya stands up in my support when anyone scolds me. This makes me very happy.

## 2.5

## The Story of

# Somashekar

Patience pays. And how!

Our teenaged-son greets visitors at our place and enquires about their well-being.

Such gestures make us, parents, proud because he is a special-needs child.

We are a big family originally residing in Visakhapatnam, in Andhra Pradesh, with many siblings and other family members.

I was 19 years old when I got married. My husband, Ramesh Reddy, and I had a significant age gap of eight years. He works as a professor in a college.

Two years into our marriage, I gave birth to my elder son, Somashekar Reddy. During the pregnancy, I underwent all the tests and visited doctors regularly. Everything was going as usual.

At my 8th-month test, the doctor suddenly mentioned some child development issues. They didn't say anything. Just told us to come to the hospital as soon as I felt even a little pain.

When Somashekar Reddy was born, I remember he didn't cry. We didn't know the significance of this episode. He used to take ill frequently during childhood. Fever, diarrhoea, vomiting and many other health problems. He suffered a lot for the first two years. After three years of Somashekar Reddy's birth, I was pregnant with my second son, Suresh. Watching him grow, we realised that his older sibling was not like him in achieving developmental milestones. He was not growing at a normal phase. For three years, we thought he was doing okay. We believed that whatever the delay could be because of his health conditions.

**Until five years, we had no idea he was a child with special needs. We used to not miss any of his appointments with the child specialists in Andhra Pradesh.**

Until five years, we had no idea he was a child with special needs. We used to not miss any of his appointments with the child specialists in Andhra Pradesh. No one mentioned much until we showed the report to another doctor.

*Dr – "Doctors treating him didn't mention anything to you? He has a developmental problem."*

*Me – "No one told me anything, doctor, but when my second son was born, I could see the difference with this boy. I brought him as I had doubts about his milestones and just wanted to ensure everything was okay!"*

*Dr – "Rohini, when he was born, he had a seizure episode. Because of* *that, his brain has not developed fully. He could improve as he grows up.”*

Doctors said that development will occur up to 18 years of age, and at that time in life, he may be like others, or he may not be. They didn’t mention his intellectual disability but told me he has special needs.

For five years, he was home. And he was crying about everything. Worried about what to do with Somashekar Reddy, we offered pooja at all temples. We went on a pilgrimage to every place suggested by friends, hoping that poojas and visits to various temples would help him.

I never cared that it would be difficult for me handle two children. Even if those rituals required me to wake up at 4 AM, I was ready to do it. Anything to get our boy to be like other children. We even put him on homeopathy treatment for some time. About Rs. five lakhs was spent looking for a cure.

We came to Bengaluru, a new city with new hopes and experiences. I needed to learn the local language to manage around and communicate in the locality. But I didn’t want to give up for our son’s sake. If the situations demand me to learn new languages so my son can get good medical treatment and care, I would happily do it!

**But I didn’t want to give up for our son’s sake. If the situations demand me to learn new languages so my son can get good medical treatment and care, I would happily do it!**

Suresh was also at the age to be starting school. So, when we admitted Suresh to school, we sent his older sibling with him too. He was not sitting in one place in school and was constantly crying. Every time I met teachers, I used to hear a list of complaints about our son made in class. Once, the principal called us and asked us to visit NIMHANS and talk to the doctors.

With the help of my husband’s student, we got to know someone in NIMHANS to help us to reach out to specialists. My friends and other parents who came there recommended a special school in JP Nagar. We enquired there, and they demanded Rs 35 000 for just admission apart from additional expenses. It was an expensive school.

Then we secured admission at AMC, a special school next to NIMHANS. I saw many children who were in that school. Some were older than our son and were like small children. Some were lost, some couldn’t talk, and some didn’t walk. Watching many children in the school, I realised our son was much better than others.

I took solace in that he could have been in a much more complex, worst situation, but he is not. My husband, too, feels sad but doesn’t express much to anyone.

My mother, Sumathi, keeps reminding “ *Rohini, we have a huge family, and everyone loves Somashekar Reddy. Someone will take care of him in future. You don’t worry and lose your health too!*” Sometimes these worries have slowed my blood pressure, and I sweat profusely. The doctors also said I should not take too much stress. But the thought, ‘*who after me*?’ bothers me every day.

**My mother, Sumathi, keeps reminding “ Rohini, we have a huge family, and everyone loves Somashekar Reddy. Someone will take care of him in future. You don’t worry and lose your health too!”**

All our relatives are in Andhra Pradesh, while we are here by ourselves, trying to build our life, giving the best in everything for our children. I need someone to support me in Bengaluru. At times, it is scary to think about how we are going to stay here. Because handling Somashekar Reddy was very difficult before he started attending a special school. Travelling with him would be an adventure. We frequently travel to Visakhapatnam to meet our families. My husband usually books the train ticket as it is easy and comfortable to travel.

Every time we got on the train for a long journey of almost 21 hours, I could not sleep because Somashekar Reddy needed me to be there with him. He would cry during the trip. My husband and I would try to distract him and take turns looking after him and Suresh. It took us an extraordinary amount of patience to put him to sleep and get some rest for ourselves. It would disturb other passengers around us as well. While some understood our position and helped us, others spoke ill behind our backs. Such incidents hurt us a lot.

In Bengaluru, few would talk about our son's health problem negatively. But they see things in a very different manner. Before sending him to school, we were not able to handle him. Once a guest visited our house in Bengaluru, and we were all having lunch together. Our son went and poured a glass of water onto their plate. It was so embarrassing. That person was kind enough and understood that Somashekar Reddy was a special child. But how could I expect that everyone would be like them?

I cannot forget this incident in our old apartment in Bengaluru. Somashekar Reddy had this habit of walking in the corridor and standing in front of the windows or doors of open houses. He doesn't do anything but stand there. I will calmly take him aside and distract him with something else. He stands for a while and returns when he is on his own. The neighbours were also quite welcoming, they would give him a smile, and he would smile back. But there was one neighbour in the same corridor. I don't know what happened, but one day, our boy was scared to walk in front of that house and didn't want to go out if he had to cross that house. It was weird, but I took him that day. He was hiding behind me as soon as he saw the window open. I needed clarification. This went on for a couple of days, and one day, I noticed that the house owner took out the stick when he saw our boy and was staring at him angrily. I was furious with this person scaring my child, who did nothing. I called the family out and scolded them for their behaviour. I don't understand why people are so quick to judge that these children with special needs are the ones that will harm them. It hurts parents like me that our children are seen as a threat.

**I don't understand why people are so quick to judge that these children with special needs are the ones that will harm them. It hurts parents like me that our children are seen as a threat.**

When Suresh goes out to play with neighbourhood kids, they accept him but sometimes avoid him. They don't want him to be there at all. Their behaviour hurts me a lot. I would ask both Suresh and his brother to play together sometimes. They both have adjusted together very well. Somashekar Reddy loves to spend time with his father. Every evening, my husband has taken the kids for a walk since the lockdown. My husband's classes would start in the morning at 8 AM, and before that, I rush with breakfast and lunch and get Suresh ready for his online courses. Our elder son was upset that he didn't have any way to get the phone like Suresh. I would take him out to another room and engage him with something. Sometimes he would sit on the balcony and watch other children playing on the road.

In our native town, it is another story! Some would make nasty remarks: " *what type of sins have you committed before his birth to* *have such a child?” Looking at Somashekar Reddy, they would ask Suresh,* too, is a special child?

I get very irritated and frustrated. I also feel sad hearing people talking like this. Nowadays, he learnt to hug people to greet them. Close family members like my mother and in-laws were okay, but I sometimes feared other people’s thoughts. He is a grown-up teenager now. And people may feel uncomfortable. Not everyone knows he is a child with special needs. That thought makes me sad.

But there are incidents with Somashekar Reddy which have given me immense happiness. To handle him, we must be patient, and he taught me to be more patient. Once, we dropped him off with his grandmother (my mother) for a week. When we returned to pick him up, she remarked, “*How are you looking after him all alone in Bengaluru? For just a week, I found it difficult.*”

**Listening to her made me feel that I have done something that is not just everyone’s cup of tea! It gave me a lot of satisfaction.**

Listening to her made me feel that I have done something that is not just everyone’s cup of tea! It gave me a lot of satisfaction.

After joining AMC, we have seen a lot of changes in our boy’s behaviour. Now he listens to what we say. When anyone comes home, he greets them and asks about their well-being. These small achievements make me very happy. All I wish for his future is for him to be more independent. And for me to find a way to secure his future after us.

### Theme

# 3

# INVOLVEMENT OF ALL FAMILY MEMBERS

## 3.1

## The Story of

# Maran

"It's going to be hard, but hard does not mean impossible", goes a proverb.

Quite literally, Maran realized life could be hard or even harsh sometimes, but never impossible. He struggled hard while caring for his ailing wife, Selvi, and Ramana, a child with special needs.

Maran lost Selvi, the family's pillar of strength and Ramana's caregiver, to Cancer. His debts spiralled because he had no money for two square meals daily for his son and himself. He and his son were held captive for a day and assaulted by friends who helped him with loans to meet his wife's medical expenses. One day they waylaid him and snatched his motorbike and mobile phone. Maran was about to lose the rented shelter but found a way to rebound, restart his life, and gradually repay some of his debts.

His cup of woes began to overflow with the announcement of a nationwide lockdown in March 2020. He was an employee in the construction industry, while his wife was a homemaker who cared for Ramana. Construction work came to a grinding halt, so Maran lost his job, and the sole source of income dried up during the most critical phase of his family.

During the lockdown, the couple visited a doctor because Selvi was ill. The doctor prescribed a list of medical tests. Maran was devasted when the doctor read out the results of these tests: she was diagnosed with terminal Cancer. In disbelief, he rushed his wife to another hospital, harbouring hopes that the results listed at the end of the first round of medical tests were inaccurate. Much to his disappointment, the diagnosis was the same.

Accompanied by his wife's sister, Karpagam, also a resident of Bengaluru, Maran rushed from one hospital to another for more tests and treatment of Selvi. In the process, he borrowed Rs one lakh from his friend for medical tests and treatment. He also borrowed from relatives and friends residing in his village. While some doctors recommended more medical tests, others felt treatment should commence immediately.

One doctor, however, was brutally frank with his diagnosis. He called Maran into his cabin to break the bad news.

Doctor: Mr Maran, do you know your wife has end-stage Cancer? At this point, whatever treatment we give her, we can't assure you that we will be able to save her.

Maran: Doctor, please do something to save my wife. Please treat her because she is the pillar of our family. We are not well-to-do people, but she must be protected at any cost.

Doctor: There is nothing we can do, Mr Maran. You have already spent a lot of money on her treatment. Take her home. Spend the last few days with her. She will be able to survive only for another 10 to 15 days.

The doctor was spot-on, for Selvi passed away less than a fortnight after returning home from the hospital. She left behind a distraught husband and a youth with special needs who, incidentally, realized that his mother would never return as she had reached God's abode.

Maran and Ramana were depressed and lonesome as they had no one's shoulder to weep on. After performing the last rites, he returned home and sat beside Ramana, and both wept for hours as the house was deserted, and there was none around to console them. He was clueless about how to earn money to clear the debts and who would be Ramana's caregiver. How to be in the role of a caregiver and encourage the youngster, devastated by his mother's demise, to continue speaking in the manner taught and trained by Selvi?

The situation was turning from bad to worse for Maran and Ramana. He was running out of money to feed his son and himself, and his friends who lent him money showed up at his door, demanding repayment. Occasionally, Karpagam would bring some homecooked food for them. She was selling flowers to earn a living and offered some financial support, too. Soon. Maran was left with money sufficient to buy bread and tea for Ramana.

On a Sunday morning, Kamalesh, the son of the owner of Maran's modest dwelling place, locked the home and demanded that he pay the rent due for seven months. He rushed to plead with the owners, Mr Vetri and Mrs Vasanthi but found they were away in their native village.

In sheer desperation, Maran called team ENRICH at AMC, where Ramana had enrolled ten years ago. He explained his debts and how the owner's son demanded the payment of rental dues. Team ENRICH sent out an SOS to well-wishers, friends and others. In three days, Rs. 12,000 was raised through crowdfunding, which helped Maran offer a part of the rental dues to the owner.

During a recent conversation, Maran said, “If you ask me what made me survive those dark days, I don’t know what it was. Maybe it was my son. He cannot talk, and he is like a child. Now all he has is me. He understands my grief or not, I don’t know. But he is with me. I will take care of him no matter what happens. I don’t want to let him go. I want to secure his life and need help and guidance.”

Maran tried to return to work, taking Ramana along, but the sound of machines at the construction site would upset his son. The boy would play games on the mobile phone for a couple of hours but start crying, forcing his father to take him home. One day, those who lent him money waylaid Maran and Ramana snatched the motorbike and mobile towards interest on the outstanding amount. The father and son duo were forced to travel to construction sites in buses, but Ramana again threw tantrums en route.

When the school at AMC reopened for the academic year 2022, Maran was relieved as he could drop his son off and travel to the work site. With regular income, he managed to repay Rs 70,000 out of the loan amount of Rs three lakhs and secure his motorbike and mobile phone.

Ramana, aged 22 years, came to AMC first a decade ago. His parents enrolled him in regular schools once he turned five, although they realized he had missed developmental milestones. The school turned the boy away because of his learning disability. Selvi took up the responsibility of locating a special school for Ramana, attending meetings with teachers and seeking their guidance on his ailment. She spent a lot of time at AMC, along with Ramana, training him to respond to queries or talk in monosyllables with parents and teachers. She was adept at balancing domestic work and the responsibility of providing extra support to Ramana. Undoubtedly her sudden demise meant a significant loss for Ramana and a break in the training schedule.

Maran has sought the help of AMC's staff to revive Ramana's pension. The pension amount would make a significant difference to the family and ward off people demanding repayment of loans. He intends to save a small portion of his salary for his son's future and establish a small-scale business where the father and son could work together. "I see the future with him," quips a battle-scarred Maran.

## 3.2

# The Story of Nivin

**Family as a unit:**

As a social worker, I endeavoured to reach out to distressed families.

But when I found a crisis staring in my face, I looked within our family for support. And sure enough, my husband, Devan, an electrician, and elder son, Vicky, who repairs electronic gadgets, never let me down. Such support from within the family made all the difference while we grappled with the health problems of our little son, Nivin.

**Initial shock**

When Nivin was born in 1999, he had a cleft palate and a hole in the heart. We were a young couple with a six-year-old son and were excited to welcome another child to our family. But when the doctor gave us this news, we felt depressed.

We did not know what to do. I started to cry at the misfortune that my child was facing in life. It was the time in my life when everything was falling apart. But we had our family. They were the most significant support to us.

Some suggested offering prayers in the child's name and saying God will solve Nivin's health problems. It gave us all strength to face the first few years of caring for Nivin. Next, we visited our family doctor to get another opinion about our baby boy's condition. *"You have reached out at the right time, Alisha. Don't worry. He is still young. And often, these holes in the heart get closed on their own. After that, you can get surgery for the cleft palate. Think of this as a sign from the Lord," remarked the doctor.*

**Family support made all the difference!**

As a family, we thought it would be emotionally, socially, and financially challenging. But Devan and Vicky offered enormous support. We had to frequently visit the hospital with Nivin, and the fear that anything could happen anytime made us stay hyper-alert with our baby.

Devan never once kept himself away from supporting me. He encouraged me to pray and accompanied me during all hospital visits. Vicky was a very young child. I don't know if he understood our situation, but he would stay quiet and follow us everywhere we went. Even as a child, he helped me with many things in the house when Nivin was not well or we had to go for another of the doctor's visits. After a few years, with prayers and medical attention Nivin's hole in his heart closed automatically. Soon, we sought an appointment at Bowring and Lady Curzon Hospital and got his cleft palette operated on. They had to stitch him from his upper lips on the right to the inside of his mouth. It was scary when the doctor explained the enormity of the operation. I felt really anxious thinking about how my little one will endure this pain?

Nivin's survival is like a big miracle to us. And we were hopeful whatever the delays in his milestones would be okay as and when he is growing up and is healing. We were not ready to give up that he could not have a life like his brother. When he was around six years old, we secured admission for him to a regular school with high hopes that he would be like any other child his age. He will learn to talk slowly and lead an everyday life.

It took us 11 years to come to terms with Nivin's condition. He is still not able to talk. Just mimics action. We then understood that having him in the regular school is hampering him more than helping. We started looking for a special school to help him become as independent as possible. From the school, we learnt that the government supports children like Nivin with benefits like pension, disability card, NIRAMAYA scheme - medical insurance. I also saw many parents needing help accessing these benefits as they needed to figure out where to go. I came forward and started to help them with whatever I could.

**When he was around six years old, we secured admission for him to a regular school with high hopes that he would be like any other child his age. He will learn to talk slowly and lead an everyday life.**

I told myself, *"God has given us this child because he is sure we will be able to care for this child."*

It felt like God knew us; it was destined that we, in this birth, would be helping our son and other parents in need and thus find meaning in our life.

We have seen improvement in his behaviour. Before in our neighbourhood, people would see Nivin and gossip about him, that he is violent and stuff like that! But he is such a sweet child. He likes to mingle with people. But because he cannot talk to express himself, he makes sounds to express his emotions. When he is happy, sad, or angry… we, as a family, are used to it. But in the beginning, it was scary to other people.

I remember one incident. We have been staying in a small rented house in our building for the past 30 years. About five years ago, we had a new neighbour. They were bachelor boys, two of them. They were sceptical about having Nivin right next to their home. When they were shifting, Nivin would stand there, giving his cheeky smile. For first-timers, it would be weird to have an adult behave like this. We didn't know this was where Nivin was going because he knew everyone around the neighbourhood. We leave him free to go wherever he wants, but he should have someone with him and come back before dark. And sometimes, our friends near our house call us and say that they saw Nivin wandering alone towards the main road and sometimes they would bring him back home.

**Every day they would find Nivin leaving for school, and they began to greet and talk with him. Now, if they don't see Nivin for a day, they would come and ask me about him. "It feels very boring, aunty, without Nivin around," they said.**

When I learned that our new neighbour was unaware of Nivin, I told them that Nivin has special needs and loves to mingle with people. Slowly the boys started to interact with Nivin. Every day they would find Nivin leaving for school, and they began to greet and talk with him. Now, if they don't see Nivin for a day, they would come and ask me about him. "It feels very boring, aunty, without Nivin around," they said.

Soon Vicky, too, stepped in. He is interested in repairing electronic gadgets. Now Vicky makes Nivin join in doing this. Even if that is only like picking up some screws and wires. Nivin started to enjoy this time with his brother. As the teachers guided us, even I gave him small household tasks and kept him engaged all day. Devan also suggested that he come home early in the evening from work and take Nivin around the neighbourhood. Like this, we practised the routes to help Nivin reach home. After some years, everyone in our community knows Nivin and loves his company.

I send Nivin to buy biscuits, milk and some house items with the exact amount of money, as he will need help to do the math. He will go to the shop in our neighbourhood and ask for the items using his fingers. When there are many items, I will call the shopkeeper, tell them the list, and request them to send them through Nivin. This way, all of us in our family are trying to make Nivin a contributing member of our family.

### Vicky's narration

I am Nivin's elder brother. All our childhood, he tagged along with me. When I was young, too, it wasn't enjoyable. I was very angry with my mother and father because they cared more for him. I did not understand why he was still not talking though he was growing older. My parents sent Nivin and me to the same school. It was around our 4th or 5th grade, and my brother and I went to school together. All the children would make fun of me because of my brother. They would call me names, making me very angry and sad. I was angry, don't know what or who. Maybe I was angry with God because he gave me a brother like this.

One day, when walking back home, I saw some older boys bullying a boy younger than them. That young boy suddenly looked like my brother. He is also vulnerable! And anyone could harm him like these boys here. What will Nivin do? How will he protect himself?

That day I don't know what got into me. I just ran to save that boy. And then, after that incident, I don't know what happened. He had been the brother I always never wanted. But after that incident, he was no more a brother. He was like my own son. He will always be my first priority in my life.

**He had been the brother I always never wanted. But after that incident, he was no more a brother. He was like my own son. He will always be my first priority in my life.**

I see my parents tensed about Nivin's future. On many occasions, I have reassured them that Nivin will be under my care until I am alive.

## 3.3

## The Story of Ankita

**Peace.**

The mere mention of this word triggers emotional reactions in this family of a toiling mother, two young and educated sons, and a sister with special needs. The void created by their father, who walked out in a huff to live by himself in a dilapidated building, is discernable.

Maya's dream of a blissful married life remained a mirage as her husband, Avinash, proved to be an abusive and violent life partner. Her woes increased when her first pregnancy ended in a miscarriage.

Later, the couple was blessed with two adorable baby boys, Advik and Atharv, but peace between them remained elusive. Given the financial position and the responsibility of raising two little boys, Maya opted for contraception without informing Avinash. A year later, her husband forced her to get rid of the contraceptive device after days of arguments and scenes of violence.

Maya recalls her subsequent pregnancy: "All through the pregnancy, it was a challenging lifestyle. I had to care for my boys, myself, and my unborn life. I was working in the garment industry and earning some money. My husband was not sharing his responsibility in bringing up the children. He was physically around but never offering any help. We would have arguments on the same issue, and he would go away for a few days and return when he calmed down."

Ankita, their daughter, arrived in 2006. "Ankita is our favourite daughter, including my husband, though he does not live with us anymore. I don't know what upset him so much that he walked out on us. One day, Advik saw him and called out, trying to talk, but he walked away. Later, Ankita told me she noticed her father and spoke with him. He asked her about her school and how she was."

The daughter was three-years-old when her mother noticed she had a high fever. She was rushed to NIMHANS when, for the first time, doctors informed Maya that Ankita was a child with special needs.

The disturbed mother nursed hopes of a recovery. She sent Ankita with Advik to the Anganwadi school. She would spend the day with her brother and come home with him while the mother carried on with her work at the garments unit. A few years passed, and Advik finished his primary schooling, and he had to change the school for his high school. This made Ankita go to school alone without her brother.

This was when her special needs became evident. Maya was summoned to the school by Ankita's teacher.

*Teacher: Maya, I want to talk to you about your daughter.*

*Maya: Tell me, madam, what about her? Is she doing well in school?.*

*Teacher: Maya was at least doing minimal tasks when Advik was here.*

*But since your son joined another school and Ankita is coming alone, she has become very lonely in the class. She is not able to pay attention in class. She sits quietly and alone and does nothing. I understand this is very hard for a parent to hear. She is a slow learner. But I allowed her to stay here because you requested us a lot.*

*Maya: I understand, madam. She will be okay when she is around children of her age. She will learn things like them. And with the support of her brother, she will overcome anything that is bringing her down.*

*Teacher: She can still learn and lead an independent life Maya. Don't lose hope. There is a school for children with special needs. Enquire about it and enroll Ankita there as soon as possible. She is really a sweet child. I hope God will help you find a way. Don't worry.*

Maya was shattered as her sons were very young to understand the problem with Ankita. She was in a quandary about sharing the pain with relatives as her husband refused to return home and support their daughter.

After a short while, Maya took Ankita to NIMHANS for a check-up and some medical tests. One doctor recommended that she seek admission for Ankita to a nearby school for children with special needs. "That afternoon, I walked along with Ankita towards that school. It was an empty road, and I was sceptical that there was a school anywhere. After entering the premises, I saw many students with special needs. Some could not walk, and some were lost in their own world. I also saw a few students laughing with their friends and

**That afternoon, I walked along with Ankita towards that school. It was an empty road, and I was sceptical that there was a school anywhere. After entering the premises, I saw many students with special needs.**

looking like any other normal children of their age. I was hopeful that our daughter would improve,” recalls Maya.

Ankita was admitted to second standard in the school, and her training commenced. She settled in the new school within a week and told her mother she loved the time spent there. She was promoted to third standard post-summer holidays, but the school was closed due to the COVID lockdown.

By then, Adivk and Atharv had finished their education, and Advik even secured a job with an impressive pay cheque in an IT company. One day, he told Maya “”*Ma, you have toiled enough to bring us to where we are today. Now we will take care of you and Ankita. You rest and relax now. Don’t worry about anything.*”

An emotional Maya remarked, “My sons are my strength. They were there to support me and protect me from the beginning. I want these three children to always stay happy and support each other. My only worry is how Ankita will manage without me in the future. Advik and Atharv would not give up on their sister, but how will their spouses accept her? We can only sometimes expect they will be okay to have Ankita and take her. I am just worried about my girl.”

**My sons are my strength. They were there to support me and protect me from the beginning. I want these three children to always stay happy and support each other.**

Advik allayed his mother’s fears, saying, “ Ankita is my favourite. I am 25 now and a working professional. And she is like a child to me. She will always be my little girl. She was always silent since we were young. I was nine when she was born. It was like having an angel in our house. Atharv and I love our sister a lot. Sometimes when I see another brother and sister, I feel despondent. I have a sister. But I don’t know how it feels to have an average sister. I heard my friends say they fought with their sisters, shared a secret with them, planned a surprise for each other's birthdays, and many things. I lost them all. But again, I am not sad about having my sister, Ankita. She may not be doing all these, but she would never leave me until we were alive."

**This youngster requests the government to train children with special needs for gainful employment in small-scale industries. Such training would help them earn their wages and lead a dignified life.**

He recalled the challenging but sweet moments of taking his younger sister to school and teaching her everything he learnt, the walk around the colony etc. He also learnt about his sister's special needs through the internet and how to make such children more independent. "Then, I started interacting with her school teachers and helped my mother and brother understand. It was a long process, and since that day, we have been involving Ankita in all our activities. She is my sister, with or without her special needs, and I want her to be treated as one of our family members rather than thinking that she cannot do anything," he said.

This youngster requests the government to train children with special needs for gainful employment in small-scale industries. Such training would help them earn their wages and lead a dignified life.

## 3.4

## The Story of

# Vydehi

Shalini’s life is the classic example of a sense of fulfilment even as she surmounted emotionally stressful challenges and coped with abrupt changes in lifestyle as the caregiver of Vydehi, her daughter with special needs.

She bore the brunt of some of these changes on the domestic front, all unanticipated, as they impacted the behaviour of Vydehi. She was trained to live an independent life. Vydehi turned overtly attached and dependent on her father, Raja, owing to the demise of her aunt Subhadra and her grandmother Uma’s transfer to a special care facility. Besides her younger sister, Triveni married and went to the USA with her handsome husband, Tarun.

With all these changes at home, Vydehi withdrew from others, did not sleep well, and had her first seizure in April 2021. She was hospitalized, and upon her return, there were not only drastic psychological and biological changes, but she also grew lazy and stubborn and demanded attention. “We are unsure whether these changes are happening because she is taking pills or because of her biological or psychological changes. We feel we are stuck in the middle of the road. We are not sure where this road will lead us, " Shalini laments.

The family--Shalini, her husband Raja, a retired official, and Vydehi--plan to move to their village farmhouse and start their life afresh. "If something happens to us, we know that our neighbours or even her sister will take care of Vydehi. At the same time, we are teaching her to become independent so that one day, she will be like she was before. We are doing our best and leaving the rest to God, " remarked Shalini.

Looking back, Shalini bemoaned how Vydehi excelled in Yoga and Bharatnatyam dance before the negative changes in her behaviour set in. She arrived in this world with Down Syndrome. The doctor informed Mr Raja about the ailment immediately after the birth. Mr Raja, however, did not have the heart to break the news to his wife.

At birth, Vydehi was chubby and weighed three kg. A few days after their return home from the hospital, Shalini found the infant's face did not appear normal. She shared her opinion with her husband, and he immediately sought an appointment with the doctor. The following morning, they drove to the hospital along with the infant. The doctor examined the baby girl, looked at Raja first, and turned to Shalini to break the bad news that Vydehi was born with Down Syndrome.

Down syndrome? What does that mean? The doctor explained that Vydehi was a child with special needs. A child with special needs? The doctor explained, " Your child will be slower than other children in achieving developmental milestones. Her speech and motor will be delayed. There is no treatment for this; You parents are the ones who need to teach her everything more than 10 times to make her understand and learn the skills."

Shalini took several days to recover from the shocking news conveyed by the doctor. Despite being in a state of confusion, she started reading books to learn everything about Down Syndrome. The mother followed up by learning more about teaching motor skills through new books. She also met the doctor once a month to learn how to teach basic skills to her daughter.

Shalini was reluctant to take the baby to social events or family functions until the doctor advised that exposure would help Vydehi. She was around 4 years old when her motor skills and speech were similar to those of a three-year-old. The doctor appreciated her development and suggested that the couple have a second child.

The doctor's suggestion resulted in more confusion, but he convinced them that the arrival of the second child would help Vydehi. The second baby girl arrived in about a year, and the couple christened her Triveni. Sure enough, Vydehi's behaviour changed for the better in her motor skills and speech after Triveni's birth.

The couple enrolled Vydehi in Bharatnatyam could when she was a six-year-old and evinced interest in attending dance classes. She was focused and learnt every bit of it with much compassion and dedication. She grasped every Mudra and stance quickly. She was disciplined and practised and followed the guidance of the teacher said. She was a very enthusiastic girl.

Encouraged by her enthusiasm, the parents decided to showcase Vydehi's talent in competitions and cultural events. Her teachers were proud of her performances as she won some prizes and received certificates of participation. A moment of quiet pride for the parents was when the parents of other children approached and asked them how Vydehi could perform like an average child.

Soon, Vydehi was enrolled in a special school where the mother of another child with special needs taught Yoga. Every morning after the prayers, she taught Yoga to all the children. One day while Shalini was dropping Vydehi to school, the Yoga teacher met and told her that Vydehi was doing very well in Yoga classes. The teacher felt the girl should join a Yoga School near their residence.

Vydehi excelled in Yoga and Meditation at a Yoga school near her home. "The best part of admitting her to this Yoga school was that she maintained a perfectly healthy diet and was physically fit. Her face was glowing. I also started practising Yoga with her in the evening. I found some relaxation while practising Yoga. There was this one competition in which she wanted to participate. And she practised Yoga along with meditation very intensively. Then she also started working on her diet. She stopped eating non-vegetarian dishes. Her intake of liquids was more than that of solids. She performed with more Bhakti. She was so disciplined and followed all the rules. She won the medal in that yoga program. She was becoming a more independent adult and actively involved in many activities. She won competitions in advanced Yoga and was leading a very enriching life. Then after a while, she started teaching Yoga to children. Her behaviour was like any other ordinary woman of her age. We can say it was her golden time," reminisced Shalini.

Soon, she started behaving like an adult and decided the dress and matching accessories daily. She, however, had to quit teaching at the school as the parents of some of the children complained to the principal that they were not comfortable with a person with special needs teaching Yoga. Vydehi's distraught parents had little choice but to lie to her that the school was moving to a distant part of the city and coaxed her to quit the job.

Shalini decided to keep her engaged at home by teaching Vydehi knitting, bead-making and some household activities. She was independent and helped her mother with household chores.

At this juncture, Triveni's wedding was held. It upset Vydehi as her younger sister would live in a different country. She did not talk to Triveni for some time, but her younger sibling explained that their mother did everything for their good. She advised Vydehi to listen to their mother.

On the day of Triveni's wedding, the parents were relieved to see Vydehi greet all the guests and participate in all rituals. Vydehi soon attained adulthood and started exploring herself. She started leaning on her father and often tried to hug him. One day she told Shalini she was keen to get married. "I was surprised. I asked her, are you earning any money? She said NO. Next, I asked whether you knew how to cook? She replied NO!

Do you wash vessels or clean the house? She again said NO!I said that only if you do all these things will you get married. If not, you cannot," Shalini said, adding it was a challenging conversation with her daughter.

Just when the parent felt at ease about Vydehi, her aunt's demise, the relocation of her younger sister and grandmother significantly impacted the young woman. "Some days, she is perfect. She wakes up early, does some yoga, helps me with household work, and takes her tablet. The next day, she woke up at 10 AM and didn't like to eat anything the whole day; she looked restless and didn't respond to anything, so we needed to force her to take a tablet. We are unsure whether these changes occur because she takes pills or because of her biological or psychological changes," added Shalini.

Despite all the challenges, changes and uncertainties, Shalini's sense of fulfilment as a caregiver of Vydehi seems immeasurable.

## Theme

## 4

# COMMUNITY ACCEPTANCE

## 4.1

## The Story of

# Rani

The community did not understand our special needs child.

Sometimes, destiny uproots a family and moves the hapless members away from a judgmental and insensitive neighbourhood.

I can vouch for such a change because it occurred in our family.

So, let me narrate the episodes which forced us-my wife, Janani, my daughter with special needs, Rani, and myself, Rajesh, to move to Bengaluru from our village, Nagenahalli, near Ranebennur.

We are a family of three brothers and a sister afflicted with polio on her left foot. I was seven years old, about three years younger than my elder brother, Ranganna, when we lost our father, Kumaraswamy, to cancer. I dropped out of school after 3rd standard to support my mother, Devaki, with the flour mill left behind by my father. My mother remarked once, “Rajesh, we are not earning enough money from this flour mill.”

One day, we were forced to sell the flour mill to pay off loans for my father's treatment. We took up odd jobs to help meet the family's daily expenses. I encouraged my siblings to study well, and they passed Class X even as they took up odd jobs to repay the debts. Owing to my curiosity about electronic and electrical gadgets, I learned how to repair fans, televisions etc.

My elder brother Ranganna and I married sisters belonging to one family. My wife, Janani, was a good human being who supported me tremendously during my arduous journey.

She also worked with me in housekeeping.

Our sister, Ragini, delivered a cute baby with special needs. My wife and I took care of them, and due to the many people in the house, I had to take some more loans to look after everybody. It was during the delivery of her second child that my sister developed complications. She and the newborn baby passed away despite undergoing treatment in a local hospital for about a month and a half. This tragedy haunts me even today.

My wife and I were taunted every day by the people of our village because we delayed the repayment of money borrowed for our sister's treatment. Janani was extremely upset and went away to her mother's place. She returned and stood by me to clear all our debts.

Our first baby girl, Rani, arrived soon. She was adorable. We were relieved as there were no complications during the delivery. She was slightly slow with her development milestones, but we did not think it was unusual. She was around three years- old when my wife was pregnant with a second child.

I returned from work one evening when my wife rushed to say that Rani was down with a high fever. I went to the room to check, and she started moving her body involuntarily. We were clueless; we didn't know how to react or what to do. This was the time when she had her first epileptic attack.

For a long time, people in our village did not kindly treat our daughter with special needs. When she went to a regular school in the village, the teachers forced her to sit near or outside the door, saying she was mentally ill and incapable of understanding anything in class.

As usual, my wife and I went to work. I had a tiring day but came home early. I called my child but did not hear any response; instead, my wife responded that Rani was missing. We searched the entire house, enquired with our neighbours, and looked around temples and nearby places but could not find her. My wife and I were shattered, we begged everybody if they had seen her, but nobody responded. We were praying to all Gods to help us find our child.

**For a long time, people in our village did not kindly treat our daughter with special needs. When she went to a regular school in the village, the teachers forced her to sit near or outside the door, saying she was mentally ill and incapable of understanding anything in class.**

One small boy came to us and asked whether we searched in the cowshed because Rani liked to play there. We rushed into the cowshed and screamed her name. We heard a slight murmuring sound. When we went further, we found her.

My heart sank when I noticed her hands were bound and her mouth plastered with a cloth to prevent her from calling for help. With tears rolling down our cheeks, we picked her up and freed her limbs and mouth. She looked terrified.

That night, I decided to move out of our village and travel to Bengaluru to start my life afresh. I had to take care of three children, so before proceeding with the family, I moved to Bengaluru to work as a painter for a few days.

A person I knew helped me get a job in the Nuclear Medicines Department (NMD) at Kidwai Memorial Institute of Oncology in Bengaluru. After working there for a few months, I brought the salary home to pay the rent. Then I asked my wife and daughter to move to Bengaluru and searched for a school for Rani.

During this period, we had two more children. I requested my elder brother to take care of them in his home in our village. I send him money every month to meet the expenses of these two children.

Since 2005, I have worked at NMD in the same hospital where doctors tried their best to save my father's life.

I still think my daughter is God's gift. We moved to Bengaluru because she was ill-treated by people in our village. I earned more than I used to in the village. Whenever I return to the village, I try to take some stationary items and give them to people in need. I try my best to help people in some way. I also encourage teachers to treat children with care and respect.

Our daughter is now 20 years old, attends a school for children with special needs, and does her own work. She is a much-disciplined child. We get a disability pension in her name; I deposit that amount in her account so that if something goes wrong, I want her to have some savings in her name. I will protect her till my last breath.

I pray to God to give me the strength to take care of her, and I hope someone can marry her and stay with us. My sincere request to people in the world is not to harm these children with special needs.

## 4.2

## The Story of

# Yamuna

Yamuna's life was a one-in-million saga of extraordinary sacrifices.

She walked out of her marriage and changed many jobs to earn enough to provide food and shelter to her sibling with special needs, Yadav, 16 years younger than her. A sudden cardiac arrest cut short her journey, marked by remarkable sacrifices. The love and affection she showered on him were the same as during his childhood in their village.

Her lifetime wishes of securing safe accommodation in a hostel for Yadav, however, could not be fulfilled owing to her sudden demise, but it brought the larger society into the picture to care for the life of her younger sibling. Yadav's elder brothers, who had neglected him once Yamuna left their village, arrived to take care of him. Only time would prove whether Yadav was cared for by his brothers as much as his sister did or allowed him to lead the life of an orphan.

Yamuna's life mirrors the many challenges caregivers face while trudging the path with a person with special needs. She made several sacrifices as Yadav's caregiver and passed away without ensuring permanent shelter for her younger sibling. Her sudden demise, however, opened a window of opportunity for the community to rush to his rescue and take care of him.

Initially, Yamuna's journey as Yadav's elder sister was marred by jealousy because their mother, Kamalamma, cared for and spent more time with him during their childhood. She was also intrigued by their mother's reminders that Yadav would require help and support for everything and that he was different from her two elder brothers.

Gradually, she took a liking for Yadav because he was the youngest child in the family and accompanied him to school. She was also under the impression her elder brothers would take care of Yadav while she would wed and leave their village sooner or later.

Their joyous journey to school and back was cut short when Yadav's father, Muddappa, felt the boy would not be able to learn much and could instead help him with odd jobs. So, he would take the boy around and give him tasks like arranging chairs or fetching water, towels and other things.

Just when Yadav got used to accompanying his father, Muddappa passed away. Yadav was extremely upset about his father's demise because he enjoyed going everywhere and helping Muddappa. "Forty years ago, we didn't know why he was the way he was during his childhood. We have a better understanding today. We thought Yadav was different from others and would be like this. Some children are bright, and some are dull; Yadav fell in the latter category," Yamuna had recalled before her demise.

With their father's death, Kamalamma took up the responsibility of raising Yadav. Yamuna's elder brothers got married, and the new additions also meant changing opinions and perceptions about Yadav. Unfortunately, their mother did not live long, creating a void in Yadav's life with the loss of an important caregiver.

Yamuna felt Yadav's elder brothers would take over the role of caregivers and moved to Bengaluru to pursue a course in teacher training and to take up a career in teaching. She, however, found life extremely tough and expensive in the city. On returning home from school, she held tuition classes for some children to earn extra money and maintain a decent lifestyle.

Yamuna was in for a rude shock when she returned to her village after a gap of four years to spend a couple of days with her elder brothers and Yadav. She felt she was no longer welcome, with everyone in her family pretending to be courteous and merely making enquiries about her welfare. She maintained a calm and relaxed demeanor as her main intention was to meet and spend time with Yadav.

Her younger brother rushed out upon hearing about her arrival. He quizzed her about their late mother like a child who did not understand the concept of death. Yadav appeared weak and unkempt. Yamuna hugged her brother and wept for a significant amount of time.

The following morning Yamuna ventured out to meet her neighbours, in particular Vimala, who had called often to complain that Yadav was neglected by his elder brothers and their spouses. Vimala told her how Yadav was forced to live in a dirty storeroom without sufficient air, light, food, and clothes. Yamuna realised Yadav's innocence was misused by her elder siblings. Obviously, they did not honour their promise to the parents that Yadav would be looked after well after their death.

While the thought of Yadav being ill-treated by their elder brothers and spouses constantly haunted her, her younger brother repeatedly asked whether she would leave him in their village. She boldly decided to take Yadav with her to the city. Much to her surprise, her brothers did not express any concern about how Yadav's stay on the same premises would affect her life.

Soon, she received marriage proposals from eligible bachelors. Yamuna told them they should allow Yadav to live in the same home after the wedding. While most refused, a widower, Rangaraju, with a child from his first wife, agreed to Yamuna's rider.

Life was blissful for Yamuna and her soulmate for a while, but minor issues cropped up about Yadav. One day, Rangaraju shouted at her about Yadav and even suspected their relationship.

The result: Yamuna took a bold step to end the marriage. She moved out along with Yadav as she was financially independent and was receiving a decent salary as a teacher at an Anganwadi. Many eyebrows were raised about her choice of her younger brother over her husband. Yamuna was resolute in her decision. She felt if she did not help her brother with special needs at this juncture, she would regret missing such an opportunity all her life.

To add to her woes, the Anganwadi, where she was employed, closed down as there were very few children, and many opted to go to public schools. Left with no money, she decided to pursue a new career as a midwife in a hospital. The experience she had gained while assisting her mother in their village helped her find a job quickly. Besides, she also took up the housekeeping task for a few of the medical staff members at the facility.

While her elder brothers did not step forward to offer any help or support, doctors who gave her the housekeeping task came to her rescue. They found Yamuna a proper place to reside. The small rented house was far from the hospital, so Yamuna scouted for another job. The experience gained as a midwife helped her to cater to the needs of young mothers and their newborns. In addition, she also worked as a support nurse in the labour rooms during the birth of babies.

Soon, the word spread about Yamuna's efficiency in caring for newborns, giving them a bath or cleaning them. So, she was hired by many young mothers to care for babies till they were four months old. For the ageing Yamuna, it was as though she was tending to her favourite God, Lord Krishna, just as Yashoda did.

Yamuna also earned some extra money selling homemade. Pappads, pickles, and some south Indian snacks. She made them at home in the afternoon while tending to newborns in the morning.

Despite all her sacrifices and career switches to earn sufficient money for Yadav and herself, she was tense about her younger brother's future. The question of "Who after me" haunted her all the time.

Her sudden demise at age 68 meant a wish unfulfilled: a permanent shelter in a hostel for Yadav. Would Yadav, aged 52, get the same care and attention from her elder brothers that he received from Yamuna and lead a life with dignity in their village?

## Theme

## 5

# GOVERNMENT SUPPORT

## 5.1

## The Story of

# Nandini

Like all starry-eyed brides, I was optimistic about a blissful life in my husband's place. I, however, had no dreams of worldly life but good education for our children so they could lead a comfortable life.

When I married Pramod, working in the police department in our picturesque hometown, Kodagu, there were celebrations galore. Soon, we moved to the police quarters in, Bengaluru.

Another round of celebrations followed at my in-laws' place and my mother's place when I gave birth to our bundle of joy, Pranav. When our baby boy was around 12 months old, it occurred to me that he was not reaching developmental milestones.

We took Pranav to the hospital for a complete medical checkup. On completing various tests, the doctor said, "Kalyani, this baby will not be able to develop like an average child."

I became pregnant after four years; this time, it was a girl, Nandini. She was a silent child until four months of age. She, too, was slow in reaching her milestones. Both the children, by then, had episodes of epileptic seizures. Both were diagnosed with moderate intellectual disability with epileptic attacks and attention deficit disorder.

As Parents, we were devastated. Now, it dawned on me God had other plans, far from my dreams of a comfortable life for the children and parents. My husband was worried about how we would take care of both of them in Bengaluru without the support of our family. People around us expressed their sympathy and optimism, saying that the children would be alright when they grew up and look like normal children.

Handling two children with special needs was challenging for me. After talking to the doctor, I realised that my children need extra support and care to grow. So, I started to teach my children to stand with the help of a chair and walk using a 3-legged traditional walker. I used to take them both on walk morning and evening. It was at the age of five Nandini took her first step.

Owing to their epilepsy attacks, I had to visit the hospital frequently. In Bengaluru, we had none to help. My husband would leave for work and would be back only by night. I was managing the kids all alone. It was horrifying, me alone with two toddlers who needed support. We had to take a bus to reach the hospital. It was the time when both the children were not able to walk yet. I had to carry them.

**Handling two children with special needs was challenging for me. After talking to the doctor, I realised that my children need extra support and care to grow.**

We offered pooja at several temples and knocked on the doors of many hospitals to seek a cure for our children. We had spent enough on our children in the beginning days, which stressed me out. My husband and I decided to let Pranav reside in our hometown and Nandini with me here in Bengaluru and place her in an Anganwadi. We used to get complaints from her teachers, saying she was pinching and scratching other children in the room. They are finding it difficult to handle her. It was not like they were terrible with my child. They used to like her a lot and talk to her when she was going there.

Later I shared this problem with one of my friends, who suggested I visit AMC. I felt depressed when I enrolled Nandini at AMC school for children with special needs. I was shocked to see many children with special needs arriving at AMC.

**Once Nandini started training at AMC, her behaviour was hugely different. I saw the change, and I knew this would help Pranav, who is in our hometown. So, we decided to bring Pranav back to Bengaluru.**

Once Nandini started training at AMC, her behaviour was hugely different. I saw the change, and I knew this would help Pranav, who is in our hometown. So, we decided to bring Pranav back to Bengaluru. He was already nine or ten years of age at that time. He was not making eye contact with any of our family members, but he used to react to whatever we said.

We took him to doctors in Madikeri. They said he would not grow up as an average child and asked us to get treatment in a care facility in Wilson Garden, Bengaluru. We didn't know where to send him.

All my family members advised me that taking care of Nandini and Pranav alone would be challenging. But I wanted to give my children an opportunity to learn and have the best options for life. I am a mother, and looking after my children should not be something I was running away from my responsibility. I convinced my parents and my husband and told them I would get back to them if things didn't work out or if I needed support. I told them I wanted to take this risk and see how things would turn out. Unwillingly they accepted. And Pranav came back to Bengaluru to stay with us.

As expected, there was a change in Pranav's behaviour. Before, it was tough for us to make him sit in a place, but after going to AMC school, he learnt to stay in a class. He was not toilet trained properly, but slowly in school, he understood. He started to involve in household work. Even though it is minimal, he still does things that are possible in his capacity.

It will be around noon when the kids are back home. I would give them lunch and put them to bed. Until 5 pm, they would sleep well. I would finish the other household work and wake them up by that time. Then all three of us would take a walk to a field that was near our house. Both Nandini and Pranavl were not mingling with other children playing there. They would get into fights as one of them would have fought with those children. And some other children there didn't want to play with my kids.

**After joining AMC, they could mingle with other children and play with them. They would imitate their actions. Now even the neighbouring kids are willing to let Nandini and Pranav play with them.**

After joining AMC, they could mingle with other children and play with them. They would imitate their actions. Now even the neighbouring kids are willing to let Nandini and Pranav play with them. After the children started to go to school, we faced financial difficulty. Initially, when Nandini came to school alone, I dropped her off and picked her up. But when Pranav joined AMC, the expenses mounted—increased spending on their medications, hospital visits, and many other things added. We also arranged an autorickshaw for the kids to travel to school. But we were managing somehow for the sake of our children. We borrowed small amounts but cleared them soon after my husband's salary was credited. It was not like we were drowning, but managing children and other family needs was a bit overloaded. I wanted to support my husband, who was the only earning member. Once the children went to school, I would get some time for myself. I used that time to stitch clothes and make alternations or other minor tailoring work. I want to learn this better and add some income to support my husband.

It used to get very difficult to handle Pranav. Every day was difficult. Once, we went to a relative's marriage; Pranav was very young, around ten years maybe. He was running around here and there, and he just got missed getting hit by a jeep. At that time, all the people were talking about many things about my child. It hurt me so much. Whenever we went to any function, people talked without knowing about my children's condition. Some people also show pity, saying this shouldn't have happened to us. All those things hurt me a lot. I cry and console myself during those times.

During the COVID lockdown, Nandini and Pranavl were staying home, and there was no one else with me to manage them, nor I had time to do something else. And in the pandemic's peak, Nandini was not well, and we had to get her to the hospital. My husband was also in essential service, and I feared he might get the virus. In turn, the kids who fall in the vulnerable category would catch it.

During those days, I was on edge all the time. I don't know what happened to me. Even a phone call and any sound would unnerve me. Every day my parents would call from Kodagu, and my husband would call sometime during the day. I used to get a lot of negative thoughts, and staying alone with the kids amplified it. My husband then suggested visiting Kodagu and the kids, as other family members would also care for the children.

The doctor treating our children advised us to visit a psychiatrist and a counsellor. Initially, it felt unnecessary, but later my family suggested it, and I started taking medicines.

Looking back at how things have turned out, I am delighted with a few things I have experienced with my children. It was the day I decided to bring Pranav back from our hometown and send him to school here. I am glad I took that decision. He did not recover, but he evolved as a better person and learnt to do many things in his capacity. Now he also initiates activities like folding small clothes when I ask him to. Both of them are toilet trained. Nandini will go and play with a girl in our neighbourhood.

**It was the day I decided to bring Pranav back from our hometown and send him to school here. I am glad I took that decision. He did not recover, but he evolved as a better person and learnt to do many things in his capacity.**

We had put a lot of effort into making the kids learn to walk. I had to train them day in and out. Now when I see Nandini and Pranav walk around, and get up to help them, they refuse to take the help and try walking independently. I feel thrilled seeing these. I have witnessed a bit of normalcy in all these little milestones, making me very happy.

Even though I am alone in Bengaluru with my children, I have very supportive neighbours. There are times when I want to go out somewhere. They have come forward to help me out. I left the children with them and went out to finish small errands. When he reached the age of around 18 years, he had to shift to the workshop from the special school. But we could not afford to pay extra for his workshop and auto for travel. Both my husband and I then decided to make him stay home and send Nandini to school.

There is always this thought about why this happened to me. I believe in Astrology. But my husband has no faith in astrology.

Whenever I talk about visiting astrologers, he does not accompany me. He has accepted that nothing will change our child's condition.

To add to our problems, Pramod was diagnosed with diabetes.

He told me a couple of times about the stress in his job. He worries about our children, too, about securing their future. If they were like other children, they would have gone to school, college, tuition, and watched TV. It just makes him sad, and he consoles himself. A couple of times, we have thought that until we are there, we will take care of the children and later, we can plan to admit them at a hostel. We have yet to make up our minds because of many of our life's uncertainties.

**During one of my visit to AMC one of the staff heard my story and sympathetically asked what would help you in your situation?**

During one of my visit to AMC one of the staff heard my story and sympathetically asked what would help you in your situation? It was a very good question because it gave me an opportunity to reflect on my life and gave me an idea to think about my child future.

Let me share with you what would make me stronger.

Firstly – I wish I had someone continuously to support me, guide me for many medical and other problems. Such a handholding will take away the negotiating the challenges single handedly

Secondly – Support from the government where there are various schemes available could have been made available without me and my husband having to run around to get that. I am hopeful that my children will be included in the family pension scheme and given to my understand which is possible. Such a support for their lifetime would allow for a well wisher to take care of them when am not there. The help from AMC and my family has been vital. I also wish similar help could be provided by general community to understand my situation, reach out for help and mostly not to think of my child as abnormal.

In short am looking for practical support, acceptance, and feeling of security for my children

### 5.2

## The Story of

# Aarati & Aarav

Babudom.

Everyone has had the misfortune of dealing with Government officials who sit behind large desks and talk down.

Everyone? Alas! Even a single parent with a child with special needs was not spared. And for no fault of hers.

“Is it too much to expect from the Government,” asks a harried Aarati after one bitter experience about her son Aarav’s disability pension. Instead of making them run from one office to another, shouldn’t the Government hand over financial assistance at the doorstep to the child with special needs or the parent/guardian? she queried.

Another question on Aarati’s mind: Doesn’t the Government trust parents/guardians of persons with disability?

The reason for her angst was a prolonged argument with the local Postmaster on Aarav's disability pension and his threat to withhold the amount.

A nationwide lockdown was announced in March 2020 to contain the number of Covid-positive patients, but it also meant an abrupt disruption in the delivery of disability pension by the postman to Aarav's home. His mother was under the impression that a new procedure would be announced on the disbursal of financial assistance to children with special needs.

One year later, in 2021, Aarati received a notice from the Postmaster to update Aarav's account with the latest KYC details. Upon visiting the Post Office, she was quizzed by the Post Master as to why the disability pension was not withdrawn. She explained to him that before the lockdown, the amount was handed over to their doorstep. And with a 90 per cent disability, it would be impossible to get Aarav to the Post Office every month.

To her shock, the Postmaster said the disability pension should be withdrawn within three months, or it would be suspended.

**Postmaster:** There is a procedure for the withdrawal. If the pension money is not withdrawn for three months, the pension will be suspended.

**Aarati:** Even if the pension is suspended, it is not your right to stop it because it is the right of the child to receive financial assistance.

**Postmaster:** if you are not taking the pension every month, it shows that you have other income sources and are not dependent on the pension amount.

**Aarati:** Of course, I have another source of income. How can I manage my son's expenses with Rs. 2000 (disability pension)?

**Postmaster:** The Government is giving you a pension to purchase medicine and other requirements for the account holder.

**Aarati:** Sir, whatever it is, you cannot question whether I am using his pension money.

**Postmaster:** No, ma'am, we cannot do that. We have the option to suspend the pension in that case.

**Aarati:** So, give me another option: withdraw the pension money.

**Postmaster:** Give me a letter saying it is impossible to bring your son to the Post Office every month and request for change in the authorization for withdrawing the money by the parent or guardian of the PWD.

**Aarati:** I will give you the letter just now, along with the

disability card and other necessary KYC documents.

**Postmaster:** I will put this request to process. Please come after ten days. We will have to see how to give the money in instalments because Rs. 40,000 is accumulated in this account.

**Aarati:** Sir, I am also willing to apply for an ATM card.

**Postmaster:** How will a child with a disability use an ATM card? We do not give such children ATM cards.

The amount was essential for Aarav's future but had to be retained in the Post Office account. So, Aarati thought of linking his bank account with the one in the Post Office. This would help in direct credit of the pension to his bank account.

Her elder son, Abishek, an IT professional, resides in Germany. She is unsure whether he would relocate to India to care for Aarav after her demise.

Abishek visits his mother and brother twice a year and stays connected with them over the phone.

Aarati married Narasimha, a well-settled man in Bengaluru, soon after completing secondary education and lived as part of a joint family. The couple was blessed with Abishek.

Six years later, Aarav arrived in this world. To the proud parents, everything about the baby boy appeared normal until ten months of age. However, Aarav was diagnosed with Intellectual Developmental Disability (IDD), and the percentage of disability was assessed to be 90 per cent.

A plethora of questions swarmed Aarati's mind: What would happen to their son now? What could the couple do to make Aarav an ordinary boy? How to take care of a child with special needs?

She, however, could not devote much time and attention to Aarav as she had to attend to many people in the joint family. The couple hoped the medicines would help even though multiple seizure episodes continued.

With the children growing up, the couple decided to part ways with the joint family. While Aarati became a caregiver for Aarav, her husband continued as a working professional. "My elder son was going to school, and I had to give attention to him too. I remember getting more and more frustrated with every little thing. I did not even have a moment for myself. Looking after everything for Aarav, his brother Abishek, my husband, and other household activities was exhausting," lamented Aarati.

Soon, differences cropped up between Aarati and her husband. She wanted to enrol Aarav in a residential school, but her husband opposed the idea. Misunderstandings and clashes on one issue or the other escalated between Aarati and her husband. Once their elder son

Abishek left for Germany for higher studies, Aarati decided to walk out of the marriage.

For Aarati, Aarav has proved a constant companion for many years now. " A mother with her son, who is severely disabled, is no joke to live alone in this society. But God has provided a roof and food for both of us. It terrifies me to leave him in any residential care now. I don't know how much he understands what is happening in our lives, but he smiles and makes me smile regardless of anything in the world," she remarked.

Aarati learnt about the disability pension scheme and visited the Post Office to open an account and link her son's pension to this account. She used the pension money for his medicines and small expenses, saving the rest for his future. The thought of "what about Aarav after my demise" weighs heavily on her mind.

This thought prompted her to save a significant amount for Aarav's future, but she got furious with the indifference of the Post Master and the lack of a well-devised system to hand over the pension amount on time and at home to children with special needs.

## 5.3

## The Story of

# Rashmi

Living in poverty but clueless about how to knock on the doors of the Government for help.

This was the predicament of Rashmi, a single parent of Vineeth, a child with special needs, who was keen to secure her son's future. "I tried to get support from the Government, but there needs to be proper guidance. Nobody is there to help me out. The feeling of what after my demise is increasing day by day. Covid has taught me uncertainties can occur at any time. I wish there were government facilities to take care of my child when I am no more, some assurance or money to deposit in his name," rues Rashmi.

She had heard about loans for persons with special needs but needed to know which organization or official to contact. The urgency to make Vineeth financially independent weighed heavily on her mind after those 21 traumatic days in the ICU of a hospital in Bengaluru during the pandemic. She served tea for a living near hospitals and bus shelters at night when she tested positive for COVID and was hospitalized. Her daughters, married and living in Tamil Nadu, refused to care for Vineeth though she pleaded with them when confined to the ICU. “If only the Government can take care of him, I can die peacefully,” she said in an emotion-choked voice.

Rashmi has resolved not to give up her efforts to ensure Vineeth’s financial independence by setting up a tea stall for him with her savings.

This mother of three migrated from Tamil Nadu to Bengaluru when her husband, disturbed about Vineeth’s ailment (Down Syndrome), dumped the family and married another woman. She was married to Shashi Kumar, an employee of a tea stall in a village in the neighbouring state. The couple was first blessed with two daughters, Mallika and Kalaivani, who enrolled at a Government school near their home.

One evening, Rashmi was cooking dinner when Shashi Kumar walked into the kitchen to chat with her. “I wish we had a baby boy. I am not very happy with only girl children. I want to have another child, and I like that to be a boy,” he told Rashmi. It set off a minor argument as she felt no parents could have a son or a daughter as and when they desired. Ultimately, she gave in to avoid more disputes at home. She also felt their son would take care of them during old age.

Much to the delight of the couple, in particular Shashi Kumar, a baby boy arrived. He was christened Vineeth. The father took great care of the baby boy, but Rashmi noticed a problem with the infant: Vineeth was missing his developmental milestones. So, the couple took their child to a doctor when he was 18 months old.

The doctor immediately diagnosed the ailment as Down Syndrome. Neither Rashmi nor her husband could not decipher what it meant nor how to pronounce it. The doctor explained the infant would require support throughout his life, and his developmental milestones would not be similar to normal children.

Another shock left the couple heartbroken: the doctor recommended immediate surgery as Vineeth had a hole in his heart. Rashmi and Shashi Kumar rushed to a hospital in Chennai to meet specialists in medicine the following day.

After completing all medical tests, the doctor asked the couple to meet him in his chambers.

**Shashi Kumar:** Doctor, please tell us our child can be operated upon. He will be okay, right?

**Doctor:** I am sorry to say this, but your child has Down's syndrome; because of that, there is a hole in the heart, and usually, as they grow up, the hole gets closed. Now we cannot perform the operation.

**Shashi Kumar:** Down Syndrome? What is that?

**Doctor:** – The child will have slow development and will not be like other children.

Following the meeting with the doctor in Chennai, Shashi Kumar gradually began distancing himself from Vineeth. Soon, he even ignored Vineeth though the toddler longed for his father.

Faced with many physical health issues of Vineeth, the couple arrived in Bengaluru to meet doctors at Narayana Chikithsalaya Hospital, but with little success. The couple applied for a pension for the boy.

Shashi Kumar's attitude towards his wife and children worsened over the next few months. He would scold them even for mistakes. One day, the couple had a big argument with Shashi Kumar, demanding a healthy baby boy. He even threatened to send Vineeth to a HelpAge home or a place for the needy. He walked out, saying he would disown his wife and children and marry another woman.

That night, Rashmi wept and could not catch a wink of sleep. The following morning, she and the children moved to her parents' place and lived away from Shashi Kumar for a few months. One day, her neighbour broke the news that her husband was set to marry another woman. She rushed home to find Shashi Kumar waiting with a bunch of papers. He thrust them into her hand and sought a divorce. "I am getting married to a girl who can give me a healthy son. I don't want you to live here anymore and leave this house immediately," Shashi Kumar told Rashmi even as she collapsed weeping profusely.

She took the help of her cousin living in Bengaluru and moved to the city with her children. She supported her children with money earned from selling tea near hospitals and bus shelters. Soon, her daughters passed Class X (Tenth), but she could not enrol Vineeth in a school for children with special needs. One school demanded a fee which she could not afford, but a teacher informed her about AMC.

The following morning, she took Vineeth to AMC and enrolled him. She would drop him at AMC in the morning and pick him up in the evening. The boy was learning well at this school. With the help of money saved over some time, she got her daughters married to grooms recommended by her cousin. This cousin had initially helped her and her children move to Bengaluru.

When she felt she would be in a position to devote more time to Vineeth, a nationwide lockdown was announced in March 2020. Neither could she earn her living serving tea nor send Vineeth to school. Overnight, the boy turned stubborn and spent his time outdoors rather than practising writing on worksheets given at the school. He was socializing with children in the neighbourhood, but Rashmi was worried he could catch the COVID infection.

She prayed that Vineeth's school would reopen soon while stepping out at night to serve tea and earn a living. At this point in time, she tested positive and spent three weeks in the ICU of a local hospital, but she tensed up about the welfare of her son.

Rashmi's relative agreed to take Vineeth to his estranged father, but Shashi Kumar demanded money to take care of the boy. Ultimately, he was given shelter in a hut in the village and served some food once Rashmi agreed to pay the amount demanded by Shashi Kumar.

Despite such ordeals, Rashmi could not get any help from the Government for her son with special needs. Nor was the information accessible on procedures to seek the help and support of the Government.

## Theme

## 6

# SELF CARE

## 6.1

# The Story of Akshay

*"Everybody has a chapter they don't read out loud"*, goes a saying.

This is true for me.

I was 18 when I married my uncle, Anand (my mother's brother), aged 32.

I was definitely not happy with this alliance, but I had no choice as my parents had decided about it. I was a healthy person at the time of my wedding.

I was pregnant within two years of the marriage. In my seventh month of pregnancy, I suffered from high blood pressure and was admitted to the hospital. I spent the next three months in the hospital because of fluctuations in my blood pressure. I was happy that there were no issues at the time of the baby's delivery. I had an expected delivery. I had a baby boy. We named him Akshay. He was healthy at birth.

As he started growing, I felt he was slow. He was not walking even though he was around three years old. I got worried and told my husband that we should meet the doctor in NIMHANS to check if anything was wrong. He didn’t come with me. So, I went alone with my child.

The doctor said there was nothing wrong with Akshay. “Rajini, yours is a consanguineous marriage (wedding of close relatives), so there could be some issues with the baby. He will take more time to reach the milestones,” was the doctor’s diagnosis.

This diagnosis made me very sad.

Akshay was the only child I had. And I felt lost. Once I reached home, I shared my conversation with the doctor with my husband, but he didn’t take it seriously. After a period of silence, Anand said, “ we will have another child.”

We already have a child with developmental issues, and Anand suggests that we will have another child. I was speechless. I was not agreeing with the thought of having another child. Every day my husband and I fought about this issue of another child.

This resulted in physical and mental health issues. I was stressed all day, which raised my blood pressure again, and I started treatment every day. One day I had a major fight with my husband, and I stepped out of the home holding my baby in my arms.

I stayed with my parents. In the first few days, it was difficult for all of us. My parents were not happy that I left my husband, particularly my mother, but that didn’t stop me. I needed to do something to look after my child. So, I started working as a housekeeper and looking after my 4 years old baby. It was challenging. I was crying every day with no support from anyone. I was afraid of stepping out of the house as my neighbours stared at me as though I had committed a blunder. Some of them even taunted me and spoke ill behind my back.

Soon, I was haunted by a wide range of thoughts. I had sleepless nights too. I even had suicidal thoughts, but my mother changed. She became supportive in looking after the child whenever I went outside. When Akshay had pain in his feet, my mother used to oil massage his feet daily. I was looking after all the household work and managing everything with the amount I used to earn.

On one occasion, one of my cousins came to visit me. We spoke for an hour, sharing all my misery with her. Being a religious person, she suggested some rituals to improve my life. I usually don't believe in such things, but somewhere within me, I had hopes that something good could happen. I found peace after commencing the rituals.

**The next day I went to AMC and saw many other children like my child. That's when I felt my child was much better than anyone here.**

Akshay was almost 7 years old but never went to school. None admitted him with a common complaint that he was hyperactive and did not follow the instructions. There was a neighbour with a child who was slow in development. They talked about a special school and gave me the address to visit.

The next day I went to AMC and saw many other children like my child. That's when I felt my child was much better than anyone here. At least my child is healthy. I think God has given me a gift compared to other children. Then slowly, Akshay was also improving. I felt happy, felt like everything was under control. Now I didn't have to argue with anybody. It was only me, my child and I was delighted about the support I was getting from my parents.

I think God had other plans for me. My happiness doubled when my sister brought an alliance. Initially, I was not okay with getting married again because I had not yet overcome the trauma of my first marriage.

With all these doubts, I went to talk to Madhukar, the person my sister introduced. I still remember that was the happiest day of my life. I never thought I could trust one more person in my life, and the first time I felt that good human beings exist.

The first thing that Madhukar said was, “I know all about your life, and I am marrying you because of your child. I am happy to look after you and your child.”

I didn’t know what to say. Madhukar also said, “ I think God made me wait till these years, and I think he sent me to you. It’s definitely God’s grace.” I felt so happy and thought it was God’s grace.

I got married. My happiness increased because Madhukar was very supportive. He gives me some time to be alone, where I can go out and spend time with other people I know. He looks after Akshay with all love and affection. I had blood pressure and stress. After marrying him, my stress levels decreased. I could manage everything with the amount I was getting. He is a driver and earns a sufficient salary to look after us but I never stopped going to work. I worked hard to save some money for Akshay’s future.

**Once, AMC had a workshop for parents and they spoke about self-care. That is too difficult for me, like how can I do all these activities.**

Once, AMC had a workshop for parents and they spoke about self-care. That is too difficult for me, like how can I do all these activities.

I need to look after everything, and I shared about self-care with my husband. He encouraged me to practice walking every day. Every day, I walk to work, and at night after dinner, I go for a walk. This time is so precious to me. I feel so good after walking. At times, my husband also joins me. It has become my favourite part of the day.

I struggled with sleep due to people talking about my child and me. Now nobody talks behind me. At least I am not even worrying about that now. Because now, I have a family of my own, an excellent, caring, supportive husband and my child Akshay who is slowly learning and talking. I am happy with his progress. So now I don't have any issues, I get very good sleep, and now I don't compromise on my sleep. I get eight hours of sleep no matter what.

My faith and belief in God have increased. I am very thankful that he sent me all these people in my life. Everyone taught me different things in this life. I take that as an opportunity to learn and overcome my hurdles. The one thing that I learnt is that I need to believe in myself and look after myself so that if only I am healthy, then only I can give a better life for my child.

So, now no compromising on my health. I have started interacting with other people with special needs children. Now, whenever I feel stressed, I talk to them and being connected makes me feel that I am not alone. Whenever I need something, I can ask for help. Now I feel much more relaxed and stronger mentally and physically.

### 6.2

## The Story of

# Arjun

His neighbours were curious.

Why would an electrician make frequent visits to the stationery shop nearby?

For Shiva, the electrician, charts bought at this stationery shop were of immense value.

His wife, Kamala, and he first helped Arjun, their six-year-old son diagnosed with cerebral palsy, recognize all family members, close and extended. A picture of each kin was pasted in a book, and their names were written under respective photographs to help the boy recognize them. It took an enormous amount of patience as the child with special needs took a long time to learn how to place his family members.

Once Arjun could recognize his kith and kin, a variety of charts came in handy for Shiva and his wife to teach the boy about everything under the Sun: flowers, fruits, birds, and even parts of the body or interiors of their home. The couple was overjoyed when Arjun started speaking a couple of words. "I remember the conversation we (his wife and himself) had at that time. We realized from our experience raising our child during the first six years that we are the best support for Arjun. And if we are the best support for him, we must live as long as possible. So we decided, along with taking care of our son, we needed to take care of our health. " recalls Shiva.

It was a wise decision. Shiva followed a regimen of brisk walking for 30 minutes and Yoga, particularly Surya Namaskara. "It always gives me energy for the entire day. I relaxed with the help of Anuloma Viloma Pranayama every day. I practiced no matter how busy my schedule was. On hectic days, I used to take Arjun out for a stroll, only to be at the receiving end of strange glances from passersby," he said. Besides Arjun,

Teachers at a special school taught the need for self-care among parents of children with special needs. They also got suggestions on the question that weighs heavily on the minds of couples like Shiva and Kamala: "What (about the child with special needs) after us?"

This piece of advice by teachers during a workshop held for parents has helped Shiva and Kamala bond better and understand each other's concerns during strolls in the morning. "We plan to make things better for our children and ourselves, so we can live longer and be around for Arjun. Some minor changes in our daily routine will help us lead a healthy, calmer, and confident life," remarked Shiva.

Besides Arjun, 22, the couple has another son, Aananda, aged 16.

Arjun was eight-months-old when doctors diagnosed him with cerebral palsy. At that time, the couple was in Kamala's parents' home in Anekal, a bustling town about 30 km from Bengaluru. The infant could not roll over or move his feet. He was rushed to

Parijma Hospital in Wilson Garden, Bengaluru, from Anekal.

It was a day-long visit to the hospital. Doctors advised the couple to bring the infant to the hospital twice or thrice a week for physiotherapy, which could help him walk. And once the physiotherapy treatment commenced, the couple would spend an entire day shuttling from Anekal to the hospital in Bengaluru and return home in the evening. "Each visit would cost us hundreds of rupees. We were not financially well off; I was the sole earning member of the house. Taking a few leaves at work resulted in a break from work for the next four years. I had to quit my job because my wife was finding it challenging to handle the child and take him to physiotherapy and doctor appointments," rued Shiva.

With treatment at Parijma Hospital proving expensive, the couple reached out to doctors at NIMHANS for Arjun's treatment. It did not work. Shiva and his wife spent a lot of time on travel between Anekal and Bengaluru.

As a last resort, the couple moved to Shiva's place in Mysuru and commenced treatment for Arjun at JSS Hospital. The doctors at JSS Hospital suggested surgery to help Arjun walk and a speech therapy session. The doctors were of immense help when the couple explained the treatment was beyond their means. They agreed to perform the surgery at a concessional fee.

Shiva considers the couple's arrival at JSS Hospital the turning point at a time when some of their relatives had coaxed them to perform special pooja and rituals instead of medical treatment. Shiva and Kamala tried Ayurvedic medicines to help Arjun walk but in vain.

Ultimately, the couple agreed to surgery on both feet of Arjun at JSS Hospital. Kamala's father, Venkatarama, helped meet the medical expenses as Shiva had quit his job and could not afford to pay for Arjun's treatment.

On their return to Anekal, Shiva chanced upon an article in a local newspaper on techniques to be employed by parents to teach children with special needs. That's when he frequently visited the stationery shop to purchase charts and teach Arjun with the help of pictures.

Though the couple had come to terms with the fact that Arjun would take more time to walk and talk, some relatives suggested moving him to a hostel or a daycare facility. Shiva, who had returned to work, was uncomfortable moving his child to a hostel. His wife and his parents found one soon in Bengaluru. They left to check out the hostel only to return without Arjun, who was accommodated there. "That night, all of us cried and didn't eat dinner. In the hostel, Arjun was also calling to go home. He did not eat anything since he was left there," said an emotional Shiva.

At the behest of elders in the family and a gynaecologist familiar with the medical history of Arjun, Shiva and Kamala decided to add a newborn. Another baby boy, Aananda, was born without any complications. He was six years younger than Arjun and achieved all his developmental milestones like any average child.

Much to the delight of Shiva and Kamala, Aananda's arrival helped Arjun improve his communication skills and gait. Arjun started to initiate activities and imitate his younger sibling.

The couple felt the best method to cope with barbs, and caustic remarks made by insensitive people would be to speak more often about the child with special needs. "Nothing seems more important when it comes to my son. I started talking to people. Some of them sympathized, some empathized, and many blamed us, our past life, our Karma, our misfortune, and whatnot. I did find many others who helped my wife and me understand our son better and help him. I also saw people who accepted me. It was not easy to listen to the judgemental views of everyone around us. The more I started to talk about it, the more I was making peace with my life," he added.

Shiva and his wife, however, are concerned about Arjun's future. "Aananda does say he will take care of his brother. But our anxiety will persist till our last breath," remarked Shiva in a voice choked with emotion.

### Theme

# 7

# PERSONAL GROWTH

## 7.1

# The Story of Rakesh

*The significant aspect of the Rakesh-Padma story is the exceptional commitment of the mother and the growth of both Rakesh and his mother, Padma.*

All parents worry about the future of their children. This is true with us as well.

To the relief of my husband Venkatesha and myself, our elder sons Rakshith and Rohith are leading their life to the full.

My growth pangs began during my third pregnancy, or to be precise, the day Rakesh arrived in this world. When I talk of growth, it is a unique and rich experience. It is an extraordinary feeling that a mother with a God's child endures because there is as much pain as the feeling of fulfilment.

A God's child?

Let me tell you all about Rakesh.

It was a proud moment for us and everyone in India when he won the bronze medal in gymnastics at the Special Olympics held in China in 2007.

This achievement, however, is not the reason for my description of Rakesh as God's child.

He arrived as a premature child. That's not all. Much to our anxiety, he missed one milestone after another—he did not respond to sounds nor even look at us. He did not roll over. He was just three months old when he was diagnosed with Down Syndrome.

DOWN SYNDROME?

What does it mean?

This question bothered us when we heard this diagnosis. Still, we were confident that Rakesh's ailment could be cured with the help of medicines. We, however, were shocked when doctors explained that there was no medical treatment or growth like his normal siblings. We could teach him some skills to keep the boy going for the rest of his life.

The world around me crumbled. I wept for many days and even many months.

Why me when everything was going suitable for the family? This single question repeatedly disturbed my thought process.

I am a helpless woman. Should I blame obsolete technology for not indicating a pre-natal flaw? I would have opted for an abortion because we were parents to two healthy children.

I would sit idle, looking at my child, wondering what went wrong.

Then, I would return to daily chores to try and overcome the heartache. Those were challenging times.

Gradually two things happened. First, I accepted that Rakesh was God’s gift. Second, I thought, how am I going to make him independent?

One crucial source of support was accurate information provided by the medical team. During my visits to the hospital, I was informed about various seminars and programs organised at NIMHANS. I found all the available resources, like social workers and psychologists. I connected to other parents with special children and learnt from everyone. This support gave me strength and helped me know what to teach my child. Visiting NIMHANS has opened more doors for my child. We didn’t have more therapies or awareness about the condition then. Without the help of NIMHANS doctors’, I would not have been able to be in position to teach my child to be independent. In particular, they were administering behavioural therapy every Tuesday. Those things helped me a lot in the journey of caregiving. I was perturbed, so I learned everything the doctors told me. I learnt to be more patient and understand that my husband and I must be involved if we want the child to develop better.

**Gradually two things happened. First, I accepted that Rakesh was God’s gift. Second, I thought, how am I going to make him independent?**

*My approach towards independence of Rakesh:*

I decided that I would do my best. I will make Rakesh as independent as possible. I chose not to hold him back from society. I wanted him to be part of society and urged the community to accept him.

This was not easy, as the community needed to be more supportive. The community/neighbours maltreated my child. My neighbours in the building were scaring my child a lot. Whenever any other child screamed or made noise, they thought it was my child and scolded him when I was not around. My child used to shiver and urinate and never came downstairs. I learned that my child is not going downstairs because of them. One day, I chose to speak to them and ask what if you had a special child? Would you treat him like this? Ever since this episode, I did not worry about these neighbours. I calmly took him to parks and for yoga and pranayama classes.

I never hesitated to take Rakesh to social gatherings. I made sure that my child could experience everything like any other child, which will help him nurture his skills and explore his strength.

*Gradual empowerment of Rakesh.*

He went to school till 6th STD but was inferior in his studies. I then chose to enroll Rakesh in a special school. He learnt many things at this school. I noticed his exceptional talent. He was keen on sports, so I signed him up for gymnastics and table tennis. All these activities were new to me. This is an opportunity to learn all these activities and support Rakesh.

**I never hesitated to take Rakesh to social gatherings. I made sure that my child could experience everything like any other child, which will help him nurture his skills and explore his strength.**

You will be surprised to know that I got fully involved in all the activities we signed up for, Rakesh. With the help of one teacher, I took him to China to represent India at the Special Olympics held in 2007. He won the bronze medal. It was a proud moment for us to witness his achievement in gymnastics.

### *Another shock*

Our family was struck hard by a tragedy at a time when everything was going well. I was settling, accepting the child, making more progress, and moving ahead. My husband, the sole breadwinner and best source of support passed away. I was bedridden for some time because of the shock. Venkatesha always encouraged me and shared the responsibilities like taking Rakesh to gymnastics. At the same time, my elder son used to take him for a walk. As a family, we were all involved in the caregiving journey. Rakesh was also very close to his father. He was despondent. He used to recollect and talk about every moment he spent with his father.

**I, however, enjoyed the special relationship with Rakesh. In a way, it was closer than my other children. I also grew up with Rakesh as an evolved person.**

That's when I worried about what would happen to him after my death. So, to train him to live alone even after my demise, I remained stronger and started sending him to home school for 15 days to stay there and work on his own.

I made him aware of death and marriage and why he couldn't get married or have children. I also taught him how to behave with everyone in my absence or his siblings' absence. Thus, Rakesh was trained to move forward in life one step at a time.

As a woman, I lost the opportunity to live an expected life and witness the wedding and the regular family of one of my sons. I, however, enjoyed the special relationship with Rakesh. In a way, it was closer than my other children. I also grew up with Rakesh as an evolved person.

I tried becoming stronger. I was never worried about what my family thought about having a special child or what others would say. I never considered discussing or explaining it, but I faced many problems with neighbours and other communities.

“When I believe in God, my willpower to face anything is tremendous. I don’t follow any particular rituals. I chant some hymns and light lamps. I think more about being kind and honest and follow dharma in life. My mother Radha always says to help people in need and be truthful on your part. She is spiritual and says that spirituality is a powerful tool that allows one to face challenges in life. I have seen other parents getting separated on the arrival of a special child. But I think you should be happy to have a child like Rakesh because these children are not like others who take to drugs or other bad habits. These children are innocent and obey us all the time.

I am happy to have a God’s child in Rakesh.

## 7.2

## The Story of

# Chandana

The striking aspect of this family is an unfortunate medical episode, the acceptance by parents, the challenges of a growing girl and learning the caregiving experience to emerge as evolved persons.

Our journey as caregivers of our daughter over two decades has been arduous. By sharing our first-hand experience, we wish to motivate other caregivers not to lose heart as they would eventually emerge as evolved parents. Patience, encouragement, motivation, following the advice of healthcare professionals and attending group meetings for awareness are the watchwords we discovered during the journey.

**FATHER's narrative:**

I worked in KPTCL, and my wife, Jaya, was a lecturer at Government College. So, we were working parents. Our child was taken care of by my mother, Sharadamma. Now we are retired, our younger daughter is married, and we are three of us in the family. We are a loving and caring family.

### Shock

My wife, Jaya, was around eight months into her pregnancy when there was a sudden fluctuation in her blood pressure (BP). She was admitted to the hospital. I was worried about my child and my wife. The doctor said he wanted to talk to me.

He said, “Prakash, your wife is okay now, but there is something else you need to know. The delivery must happen today, as there is the danger of the child dying in the womb.” I was not sure what to do or say. All I knew was that the baby’s arrival was not around the corner. We did not have much choice. We agreed. My wife had a C-section, I was not sure whether I heard the birth cry, but I remember our child was kept in the incubation ward for 15 days. It was a girl. She was underweight when she was born, but she was healthy.

**Joining her in other regular or continuing here might disturb other children in school. We decided to enrol her in a special school.**

After 15 days of protected care, Chandana was united with her mother. At that time, the doctors indicated that the child might have problems. This was related to her being born before the due date and other medical issues.

I was despondent, knowing that my child would not have a normal life and needed guidance throughout her life. We accepted whatever God gave us. We decided to look after her no matter the child’s condition. Until around three years of age, we took her to different hospitals. We believe that she is living a better healthy life because of God. We christened her Chandana.

We got her admission to a regular school next to my wife’s college. The first day at her school went well. After a few days, they called us and said they could not handle my child. She was not yet toilet trained and could not eat or dress independently. Her ADL still needed to be developed. Joining her in other regular or continuing here might disturb other children in school. We decided to enrol her in a special school. Near my house, there was a special school named Manonandana special school.

We are from Andhra Pradesh, and we speak Telugu at home. For our child's language development, we started talking in Kannada and learnt some more Kannada.

It was our first day in Manonandan. There were many special children over there. When we saw them, the first thing that came to our mind was that our child was in better condition.

Chandana is quite stubborn, and we sometimes have to raise our voices. Sometimes she understands when we scold her and improves her behaviour. Soon, we had our second daughter, Sadhana. She has influenced Chandana a lot.

**Initially, she was a little shy while talking to newcomers. But now she is not scared anymore. She mingles with everyone and greets them nicely.**

**Community response**

We were never worried about what people said. Wherever we went, we used to take Chandana along. There were mixed reactions everywhere.

Initially, she was a little shy while talking to newcomers. But now she is not scared anymore. She mingles with everyone and greets them nicely. She is well adapted to the people.

Challenges of growing up in Chandana.

Our second daughter got married. It was a very delightful yet sad moment because our elder daughter could not get married and have a life of her own.

One day when we were all watching TV, Chandana came and asked, “papa, why am I not married yet?” I did not know how to answer her, and then I replied, “we have yet to find the right person for you.” It did not stop there; whenever we asked her to do some work or if we didn’t get her what she liked, she screamed, “find me some boy. I will also get married and leave the house. I don’t want to stay here.” Then, we had to soothe her and told her about what marriage is all about:

“Marriage has responsibilities. You have to cook, clean, wash vessels, go to work when there is no money, and take care of other people. If you are ready to do all this and see you doing all this, we will get you married.”

She didn’t ask this question again. It was good to talk with her frankly and explain the realities of life.

It is common to think that they don’t understand; they have no emotions. This is not true. If we try to make them understand and be patient, everything will work smoothly. This approach worked well with Chandana. She never talked about marriage and family.

**She didn’t ask this question again. It was good to talk with her frankly and explain the realities of life.**

Nowadays, she watches the television and is fond of watching movies. She tries to imitate the actors. She has also become a quieter and more independent girl.

### Our worry about her future

All our worries are now what happens after our demise. Sometimes I feel that Chandana could also have a married life and settle in life, which would be much more relief for us.

### Gift of God

When I look back to the day when I heard my child is special to the current situation, there are many things that we have learnt from her. We learned to care more, turned more compassionate, and provided more attention because we have her.

For every parent, we wish to state: we all need to accept our children and be more patient with them. All they need is pure love and care, it's a God's gift to us, and we have the responsibility to take care of this child no matter what happens.

### 7.3

## The Story of

# Kriti

A child with special needs as God's gift to her mother?

Well, strange are the ways of the Lord Almighty, who restored peace, freedom and a sense of security in her mother, Sita, through her daughter with special needs, Kriti. The mother experienced as much pain as a sense of fulfilment in raising her daughter. She does not mince words, declaring: " Kriti is the best gift God sent me. She was an angel who gave me my freedom, supported me when I fell, held me when am sad."

Sita considers Kriti her lifelong companion because of her unpleasant marital life with her husband, Ramanath. Her elder daughter, Mala, is married and lives with her husband, Vasanth, in another city. "I will teach Kriti all the skills to lead an independent life in return for the changes she ushered in my life," vows Sita.

The youngest and most pampered child in a family of six, Sita discontinued her studies after failing Class X. All her siblings were good at studies. Still, some of her elder sisters married when they were just 15. The family moved places as her father, Rangappa, was a Sub-inspector of the police. She was interested in tailoring or beautician courses and was popular among her colleagues. Unlike her elder sisters, a wedding was never on her mind.

At 21, her father broached the topic of her wedding, saying, "I am getting old, and you know I have a heart problem too. I don't know how long I will live. I want to see you with your family before anything happens to your mother or me." He also gave her a choice to pick her husband from among many relatives.

**So, holding on to many dreams, I stepped into the phase of married life," she recalled.**

Her mother, Revathi, recommended Ramanath, her nephew (sister's son), an engineer employed in Bengaluru. Sita agreed to the proposal and looked forward to moving from Hosur, a town, to Bengaluru, a dream city for many. "There are abundant opportunities to live the life I was dreaming about. I always wanted to learn something, like tailoring, become a beautician, open my parlour, and so many other ventures. I was looking forward to my future husband holding my hand and supporting me in living my dreams. I knew the person I was marrying. I would see him when I visited my grandmother's house during vacations. So, holding on to many dreams, I stepped into the phase of married life," she recalled.

Life was terrific in Bengaluru. Her husband would call to ask whether Sita had her breakfast and lunch, how she was doing, and whether he could bring home anything of her choice. Such calls later became a nightmare for Sita because he quizzed her on her routine and her conversation with neighbours or visitors showing up at their place. He also turned possessive and stopped her from stepping out alone for shopping or even visiting relatives. Her dream of turning into a beautician fell apart. “He didn’t even like the word parlour. Every day, we quarrelled. We realized that we had divergent views and thoughts. Suddenly, I felt helpless. I had to ask him for every penny, even groceries and vegetables,” she lamented.

The silver lining was her first pregnancy. She had an expected delivery, and the baby girl, Mala, was adorable. She lived with her parents for a couple of months post-delivery, with her husband visiting her frequently. Soon, she was pregnant again but decided to abort the foetus with the help of some tablets as she wanted to be financially secure before the second child. Her decision to abort triggered a major quarrel between the couple. “I felt like a bird in a golden cage because my husband would not let me step out. I wanted someone to open the cage and set me free,” remarked Sita.

Four years later, she was pregnant again and delivered a baby girl, Kriti, who was a tad underweight at the time of her birth. She was later diagnosed with Down Syndrome and intellectual disability. “During the initial days, she was different from other babies because she slept a lot and did not cry much. I still remember when every time I took her to a monthly check-up in the hospital, all the doctor used to say was that she would be alright, don’t worry. I often saw the doctor calling some of his interns and showing our baby, talking about something using gestures. I was perturbed as some of the neighbours also said our baby looked different and did not make eye contact with anyone. I took her to St. John’s hospital when she was a year old for a Chromosome test,” she recalled.

Sita has several questions to quiz the doctors who met the couple after the Chromosome test.

She asked:

Is our child okay?

Will she have normal development?

Will she grow?

Will her speech be normal?

The doctors set at rest all fears, saying the baby could be slow in achieving development milestones but eventually achieve normalcy. Kriti’s speech was delayed, but she started crawling around in her pink dress and stood up one evening.

At four, Kriti was admitted to a regular primary school and moved to another school a year later. A teacher advised her parents to seek a doctor’s opinion and secure her admission to a school for children with special needs.

Someone close to Sita’s husband told the couple to consult doctors at the Indira Gandhi Institute of Child Health. The couple met Dr Mahadevappa. The first question he asked was how much the couple had spent on the child’s treatment. Next came the advice, “Your child is different from others. She has an extra “ X” Chromosome in her body, which means she has Down Syndrome. Now you can only do a little to make it better. However, she will develop if you start working on her basic skills and give her extra attention and training.”

**The doctors set at rest all fears, saying the baby could be slow in achieving development milestones but eventually achieve normalcy.**

While Sita was walking Kriti for speech therapy one day, an old lady suggested she visit a school on the road next to the Indira Gandhi Institute of Child Health. She noticed a school called AMC after three unsuccessful attempts. Kriti was admitted to AMC after teachers enquired whether the child knew basic skills like using the toilet. “Every day, I used to drop her off and stay there for the day for a few months. There I saw a lot of other children with special needs. I got a chance to meet a lot of other parents who have children with special needs. I had found a new family here, made friends, and learnt a lot from them. Listening to different parents’ stories and struggles made me accessible and strengthened. I was able to empathize with them. I shared my sadness and feelings with them. It relieved the pain I was keeping for a very long time, “ reminisced Sita.

**Now I have Kriti for a lifelong as a companion. She is definitely God’s gift,**

She was offered the task of making candles at a workshop attached to AMC and thus earned some money. My husband opened a joint account in a bank and took all my salary from me. He used to get me everything, but he took freedom too. This didn’t stop me from what I wanted for my heart. No matter what happens every day, I work there to earn some peace where I work, and I can also look after my child there. So it was a happy place for me,” she added.

When the elder daughter got married and left for her husband’s house, Sita was worried about how she would live with her quarrelsome husband. “Now I have Kriti for a lifelong as a companion. She is definitely God’s gift,” vows Sita.

## 7.4

## The Story of

# Anil

Keep your face towards the Sun, and all the shadows will fall behind you, goes a famous saying.

Perhaps, Anita practised this saying to perfection as she battled various problems- from abject poverty in her childhood to a troubled marriage and a child with special needs- in her life.

Life in the quaint mining town of Kolar Gold Fields (KGF), known by its nickname “Little England”, 100 km from Bengaluru, was not easy for her poverty-stricken family. Her father, Doreswamy, a carpenter, earned meagre wages adequate to feed six children, his wife, Ponnamma, and himself just one meal a day. He saved the rest to pay the school fees of his children.

The fourth child in the family, Anita, wanted to study, unlike two of her elder sisters who dropped out. She was all set to join a pre-university course (PUC) when she suffered the first jolt: her father suffered a massive heart attack and passed away. Her elder brother took up their father's occupation to save the family from going penniless.

She moved to Bengaluru to work as a stenographer in a private firm. Good marks secured in IInd PUC and a typewriting certificate helped her net the job with a decent salary. Her salary was sufficient for the hostel accommodation, two younger siblings' education, and an elder sibling's wedding. And whenever she was in distress, she visited the church nearby to pray or read the Bible. Her father's advice was constantly ringing in her ears: "No matter what happens, work and eat food from your money. Whenever problems crop up, leave them to God. Never depend on others for help."

**Her father's advice was constantly ringing in her ears: "No matter what happens, work and eat food from your money. Whenever problems crop up, leave them to God. Never depend on others for help."**

Anita was content with the role of a sheet anchor for her family. She almost chose to remain single when a distant relative met her at the hostel with a proposal to wed his son. Her mother was informed about the proposal. "She was happy and told me to get married like my sister and brother. Why do you have to be alone? If you get married, someone will be your companion," recalled Anita about her mother's reaction.

Soon, the young man, Prakash, showed up at the hostel and proposed to her. "I was speechless for a few minutes. Then, we spoke for a while. He told me we could share the struggle. I will be there for you. I was married at 23 years. I came to my parents-in-law's house with just three sarees. They made me feel so happy and at ease on the first day. I got to eat three meals every day. It felt amazing. I am still thankful to my husband and mother-in-law, Vasantha, for giving me this life," said Anita in total gratitude.

She found a job and struck a work-home balance when she tested positive for pregnancy. Her neighbours triggered a rift between her mother-in-law and Anita with taunts that she came without a dowry or that her late father did not own a house in KGF. Vasantha, who always praised her daughter-in-law for managing work and home, took those taunts seriously. She vented her ire at Anita, and so did her husband. Around this time, her baby boy arrived, but the situation did not improve. "Nobody was taking care of my child. They were not happy with me. My mother-in-law tried many tricks to send me out of the house and tortured me, but I didn't leave. Suddenly, I felt lonely and had suicidal thoughts," she lamented.

**My mother-in-law tried many tricks to send me out of the house and tortured me, but I didn't leave. Suddenly, I felt lonely and had suicidal thoughts," she lamented.**

Anita stopped herself from sharing some poison with the newborn, thanks to her late father's advice never to give up. The problems increased when she quit her job, unable to manage the pressure at work and the newborn at home. She met her spiritual guide at the church and unburdened herself in his presence about her problems. He offered his support and counselled Prakash about her issues and concerns. The couple buried their differences and decided to have a second child.

The news of her second pregnancy upset her mother-in-law. She accused Anita of carrying someone's baby, not of her son. At one point, even her husband accused her of adultery, leaving her shattered. She was ill-treated and beaten up during her eighth month of pregnancy. When she collapsed, her elder child, Praneet, ran to their neighbour's house, requesting help.

An elderly woman rushed to her rescue and scolded her husband. "She does not set out of the house. How can you accuse her of adultery? How can you assault her when she is in the eighth month of pregnancy?" were the questions hurled at Prakash.

Next, she escorted Anita and her little son back to KGF. Curious about her unannounced arrival, Anita's mother quizzed her about why she was accompanied by her neighbour. She meekly replied she could not manage the little boy and her advanced pregnancy. She did not utter a word about being assaulted by her husband and abused by her mother-in-law.

A month later, her second baby boy arrived, and her mother called Prakash to share the good news with him. He came two weeks later. He remained silent when her mother asked about his delayed visit. His silence prompted Anita to reveal her husband and mother-in-law's torture and how they accused her of adultery. Ponnamma told Prakash she would take care of Anita and her grandchildren and not allow them to return to Bengaluru. Prakash's friends came over after some time and convinced Anita to move back to Bengaluru with her children.

The first sign that Anil was a child with special needs surfaced when he was almost four years old, and Praneet was seven. He was screaming and crying all the time at a function organized at Praneet's school. A lady among the guests walked across and advised Anita to consult a doctor about Anil. A year later, she realized Anil could not speak even though he was five years old.

Anita met a doctor at NIMHANS. He diagnosed Anil with moderate intellectual disability with secondary symptoms of ADHD. The doctor explained the boy would be a slow learner and his milestone would be delayed. Obviously, she was depressed but tried to teach him something at home besides sending the boy to a speech therapist. She taught him about colours, vegetables and fruits every day. “I am often grateful to God because even though he gave me a child with special needs, he gave everybody a healthy lifestyle and food. That is the plus point of having a child with special needs,” she explained.

**A lady among the guests walked across and advised Anita to consult a doctor about Anil. A year later, she realized Anil could not speak even though he was five years old.**

The problems did not end, as her husband was upset about their special-needs child, who walked around with footwear and a broom. Soon, the neighbours complained about Anil walking away with their footwear and dropping them elsewhere. Anita and Prakash had to pay the neighbours to purchase new footwear. This problem also escalated the friction with Anita’s in-laws. She convinced her husband to move out of the joint family to avoid more issues within and outside, owing to Anils’s odd behaviour.

The couple and the two boys moved to a small rented place. Soon, Praneet took up a job, and his salary provided additional money for the family. Anil attended a regular school but was hyperactive and often troubled other children. His parents were told to admit him to another school, but his admission to the new school meant his mother had to remain on campus the entire day.

One day at the new school, the teachers rushed to Anita, saying Anil had gone missing through the main gate. The three hours were traumatic for her as she looked for the boy everywhere and even lodged a police complaint. As the search continued, she noticed a boy walking backwards near a bus stop. She raced towards him. Much to her relief, it was Anil. He had left the school and was waiting for her at the bus stop.

A few days later, a friend informed her about a school near Kidwai Memorial Institute of Oncology. The following day, she rushed to AMC and requested teachers to enrol Anil. On admission, Anita was told by teachers about tablets for hyperactive children. He was advised to take eight tablets every day because of his age.

At this school, Anil learnt many new subjects, much to the relief of Anita and Prakash. One teacher enquired about Anita's education and work experience and whether she would take a job next to the school. The school was looking for an extra hand to help parents of children with special needs with applications for disability cards, pensions or Niramaya cards sanctioned by the government. “ I said I was happy to do it. I started working there. Many of them used to come to tell their stories to me. I saw many people struggling to get a small pension amount for survival. I was really grateful for my life after listening to everyone's stories. After filling out those forms, a few people used to pay me some money, Rs 10 or Rs 20. That was my salary. I didn't have a regular salary job. Sometimes with the amount I get, I use it for people struggling to leave, so I give this money to those people so they can get some cash for themselves. I was thrilled doing it. This all happened because I had Anil in my life. He was an

**At this school, Anil learnt many new subjects, much to the relief of Anita and Prakash. One teacher enquired about Anita's education and work experience and whether she would take a job next to the school.**

extraordinary gift. I wouldn’t have known about the disability world if not for him. I learnt to be more patient. I learnt to be grateful and helpful to people, “ recalled Anita.

Soon, her elder son, Praneet, attained marriageable age, and the couple set about scouting for a young bride. Anita felt her niece, Varshini, her elder brother’s daughter, would be the best match. She knew about their family and Anil being a special-needs child and would be compassionate about him. Much to their delight, Varshini agreed to wed Praneet. So, everything went well at the wedding.

Meanwhile, Anil was growing up and attained puberty. He started exploring his body. Prakash and Anita wanted to discuss this problem with family, friends or doctors when one episode almost resulted in the family split, with Varshini turning indifferent towards Anil.

**Much to Anita’s surprise, she found Varshini avoiding Anil and trying to ignore him. Her change in attitude upset Anil and resulted in behavioural changes, including aggression**

One evening, Anil was missing, and everyone in the family was concerned about his whereabouts. Just as all members were looking for Anil, a tensed Varshini rushed downstairs. She refused to talk to anyone about her frightened look. A little later, Anil was found upstairs.

Much to Anita’s surprise, she found Varshini avoiding Anil and trying to ignore him. Her change in attitude upset Anil and resulted in behavioural changes, including aggression. Anil even suggested that he and his parents move to another place because of Varshini’s growing indifference towards him. At one point, he used abusive language against her.

Anita decided to speak to her elder son to sort out this problem. She told Praneet that if Anil proved troublesome for the young couple, the parents and the special-needs child would shift to a new place. Praneet broke his silence: Varshini found Anil standing naked upstairs in the evening when everyone was looking for him. He had used the bathroom upstairs, wet his pants, and stood naked while waiting for his clothes to dry. "I felt depressed because she kept all this to herself. She could have at least shared with me. I tried to talk to her, but she didn't listen. It was tough to handle this situation as I didn't know whom to approach for help," was Anita's lament.

She observed Anil's behaviour and found he spent more time in the toilet, and when he stepped out, his pants were wet, and he appeared exhausted. She also found some injuries near his private parts while giving Anil a bath and dressing him.

Anita reached out to her friend Sudha, a mother of a special-needs child. Her child is a bit older than Anil. She, too, spoke about being uncomfortable dealing with a similar problem with her son. "We share our sadness and console each other. She has been of critical support to me. It was challenging for me to talk about this to my elder son or my husband and seek their help. God supported me through such challenging times. When times get tough, I go and read the Bible. It takes a few minutes, and I am at peace, and it calms my mind. Reading the Bible helps me forget all the pain," added Anita.

Much to the relief of everyone in her family, Anil stopped his odd behaviour. Varshini, too, dealt with him with patience, and the issue was sorted out. "I believe in prayers; prayers are essential regardless of my religion. As I pray, God helps me find a solution to all my problems. I visit the church very often. When we pray in the church, we first pray for the aged, disabled people, people who are hospitalized, and people who are suffering. Then we pray for our family. As a family, we serve the aged and those living in homes for the poor and needy. On Anil's birthday or special occasions, we donate to such homes instead of wasting money through celebrations," Anita said.

Anita often rushes to pray to God and seek the strength to deal with problems. Her prayers always end with one request: a peaceful death for herself and Anil. "I don't want him to live here. That's the only thing I ask God: take my child and me to you."

**Her advice to caregivers:** Difficulties and obstacles are part of the caregiving experience. Please maintain faith in God and find some meaning that will help you sail through the journey. I will give my best until I can and pray daily to God to give me more strength to help people beyond my capacity.

She firmly believes Lord Almighty would lead caregivers down the right path. "I will ask them if they need support; I will bring my friends and pray together and thus support them. I tell them that you are not alone. We will support you. It gives relaxation."

## 7.5

## The Story of

# Nikhat

Some disconnections will bless your life.

In Nikhat's case, one disconnection helped her wriggle out of a troubled marital life.

She was all set to attempt another disconnection-- this time a permanent one from the world and all her problems--but was stopped in the nick of time by her infant's gentle touch. She discovered a shining light in the eyes of Zayan, her baby boy with special needs that stopped her from using her saree and the ceiling fan to end her life. "Would you not live for me, Ammi" were the unspoken words as Zayan touched Nikhat's feet the second time to clear the dark clouds hovering in her mind.

It was the last time the thought of ending her life ever crossed her mind. She decided to walk the extra mile to provide Zayan with a comfortable life and agreed to her father, Aftab's suggestion to marry again. She is looking forward to a new home where Zayan will receive the love and care of a doting father. "As my mother said, Allah gave me this child as a blessing. But Allah also put me through a tough test. I have passed the test. I will fight all battles on Zayan's behalf and live to make his life comfortable," vows Nikhat.

**Allah also put me through a tough test. I have passed the test. I will fight all battles on Zayan's behalf and live to make his life comfortable,**

A few days later, this single parent, with Zayan in her arms, walked around looking for a special school for children with special needs. She discovered one such school and secured a job in the tailoring section to be close to Zayan throughout the day. "I am an earning member of my family," she declares with pride.

Born in a family of four brothers and three brothers, Nikhat nursed ambitions of donning the uniform of a police officer after graduation. She ended up as a school teacher and not a police officer because she did not match the criteria of height and knowledge of fluent English. Her life as a college student was much fun as she was part of a group of eight young women. Often, she penned the lyrics of the late Lata Mangeshwar's famous song in the notebooks of her classmates:

*"Phool Jeevan main gar na khilein to*

*Kaaton se bhi nibhana padega*

*Zindagi pyar ka geet hai*

*Isse har dil ko gaana padega"*

On completing three years as a teacher, her father, Zameer, an autorickshaw driver, raised the question of her wedding. His nephew (sister's son) was found to be the ideal match. "Maybe everyone would say marriage is a turning point in their life.

It was a turning point for me too. But not in the way I was expecting. I was looking for love and companionship from my husband, but he was not what I expected of him," was her lament.

Her husband, Iqbal, belonged to a large family of six brothers and four sisters. In his family, household chores were never-ending. It felt like the daughters-in-law in that house were treated worse than maidservants. Cook, clean, and repeat. That was all the daughters-in-law did every day. Her mother-in-law, Kausar, was never short of taunts and barbs. Some of the insults haunt Nikhat even after a decade of separation from this family.

**It was a turning point for me too. But not in the way I was expecting. I was looking for love and companionship from my husband, but he was not what I expected of him**

Soon, she was pregnant. None except her sister-in-law, Khadeeja, cared about her health. She accompanied Nikhat to the doctor for monthly tests. The doctor advised Nikhat to put on more weight and stick to a diet rich in fruits and vegetables. The doctor felt a healthy diet and rest would ensure the growth of the foetus and normal delivery.

One episode during the fourth month of her pregnancy harmed Nikhat's health. At her sister-in-law's place, there was a quarrel between the couple and the families. They called her parents-in-law and continued the argument. When they returned home, her father-in-law, Abdul Haleem, vented his anger and frustration by slapping Nikhat twice. It hurt much, and she could not hear anything from her left ear for some time. “All these things were happening in my husband’s presence. He did not try to stop his father or support me,” she sobbed.

A distraught Nikhat called her mother, Afreen, and explained the ill-treatment and assault. She gave her two options: “Ammi, either you allow me to come back home and stay with you or I will throw myself on a railway track and end my life.”

Her mother immediately asked her to return home, and Nikhat left with whatever she could pack into her suitcase. The neighbour, an autorickshaw driver, rushed to her rescue and offered to drop her at her mother’s place.

A few days later, her inlaws called to enquire about her welfare. Her father replied in a brusque manner that he knew how Nikhat was humiliated and assaulted and vowed never to send her to live with her husband and inlaws.

Four months later, her husband visited a couple of times to woo her back from her parents’ home but was unsuccessful.

Iqbal: *I want to talk with you.*

Nikhat: *I don’t want to talk with you. If you’re going to talk, you talk. I don’t want to speak with a husband like you.*

It was her eighth-month pregnancy, so he visited her continuously for eight days to persuade her to return to his place. He even tried to take her for a walk near the beach, but she disagreed.

As a last resort, he took her to his house. She stayed for a night and was dropped back at her parents’ place by Iqbal.

“That was the last time I saw him. After that, Iqbal never came back, “ Nikhat recalled.

During the ninth month of her pregnancy, Nikhat’s mother took all precautions. She provided her with nutritious food and frequently escorted her to the doctor for tests. She was rushed to the hospital after one false alarm of labour pain. Zayan arrived in this world.

Nikhat said, “We didn’t know about his health condition. He was slow in his development. My mother was his primary caregiver when he was born. She was so enthusiastic about doing everything for him. We didn’t realise there was a delay in his development milestones. I was also malnourished, and we thought because of that, he would slowly be okay. Later, when we got to know his special needs, I felt my life was falling apart. First, it was a bad marriage. Now, a baby boy with special needs.”

Her mother continued to provide all support. She told Nikhat: “Whatever Allah gives us, he does to test, and we have to pass these tests to get his blessings. Zayan is one such blessing for you. He’s God’s child. We will be with you. We will look after him along with you.”

Nikhat felt her mother had spoken the truth. “Indeed, Zayan was a blessing. I started to work soon after and left him with my mother. She would take care of him until I was back. Life was getting back on track. A couple of years after Zayan was born, we lost our mother. My strength, my support. She was everything. I felt like I was left midway in an unknown place, without anyone to guide me. Everything was so dark. I remember times I could not look at Zayan and help him with his needs. He had just learnt to sit around four years of age. I had to quit my job and remain with him. My father supported me, but it would never be as a mother would.”

Nikhat’s expectations of her new life partner: “I want a man who is willing to accept my son along with me. Even if I am not there, I want him to be there for my son and give him the love of a father. Whatever else Allah has for me in life, I am ready to face them all (challenges).”

## 7.5

## The Story of

# Kavin

Back in the 1980s, Mary and Joseph took some bold decisions. They tied the knot though they belonged to different religions and had a significant age gap of 18 years.

That's not all.

Mary, aged 32, and Joseph chose to have the baby despite being alerted by the doctor during pregnancy that their bundle of joy would miss developmental milestones and suggested the option of an abortion. A couple of months later, the doctor felt the baby boy would not pull through because he arrived early in this world (during the eighth month of pregnancy).

The couple believed that showing all love and affection to Kavin would help the infant overcome health problems, but they were in shock. A day after his birth, the newborn was diagnosed with Down Syndrome. "We thought it was some defect and didn't know what it was. We didn't know how this journey with Kavin would be," recalls Mary.

After 22 years as a single parent and caregiver for a child with special needs, Mary has discovered a new meaning in life. She expects perfection in only some things. Amid many twists and turns, including the demise of her husband, a complete downslide in the family's fortunes, and an abrupt end to Kevin's education in a special school, Mary sees her son in every child. She has turned humane and compassionate. She believes Lord Almighty will respond to her prayers for support for Kevin.

While narrating her experience, Mary said that she and her husband were well-educated and visited many libraries to borrow books and update themselves on Kevin's ailment. "We started reading many books to learn how families' looked after children with special needs. This gave us a much broader perspective of caring for Kavin. We showed more interest in the upbringing of this child, and we saw that even the doctor was very supportive of our efforts to make this child independent.

We had our mother with us. She told us to do many things so the child would be alright. But I told her about his condition and what needed to be done. We never shied from taking Kavin to social events. We gave him all the exposure to life like an average child. Like-minded people and our close friends were very close and interacted with Kavin," she reminisced.

Describing it as an "everyday learning process," Mary said even now, she updates herself on Down Syndrome by surfing the internet. She's more alert after one of her friends spoke about the drastic impact of hormonal imbalance among people with Down Syndrome.

She was educated in a convent, so Mary enrolled Kavin in a similar school. "Many people didn't know about a child with Down Syndrome. There was little interaction at that time. We used to meet parents of children with special needs and share our experiences.

Kavin was quite shy and more disciplined than the other children. He was adorable at that young age, and many parents would approach us. We shared our experiences and information from the books we had read," said Mary.

As Kavin's caregiver, Mary had to drop her plans to pursue higher education overseas. Instead, she looked forward to opening a Montessori for children so that she could keep Kavin, too, engaged in preschool activities. Mary also shelved this proposal because Joseph was not okay with the idea. Instead, she joined as a teacher at a local school in Bengaluru.

She, however, had to give up her job as a teacher and take care of Kavin following the demise of Joseph in 1999. Kavin was only 11 years old when his father died because of multiple organ failures. "Joseph was very fond of Kavin, and our son was also close to his father. But when his father got very ill, he was not fond of loud sounds. Kavin was introduced to Music by his half-brothers, Aiden and Charlie. Whenever his father was resting and the Music was played, he used to get really angry. Once, he lashed out and slapped Kavin. After that, Kavin was a little fearful and distant from his father. After a few days, Joseph was extremely ill and was first admitted to Mallya Hospital and later to St. John's Hospital. Kavin did not see his father during the last ten months of his hospitalization. We lost every asset as we had to pay all medical bills in the hope that we could save Joseph," she lamented.

When Joseph breathed his last, Mary allowed Kavin to witness the cremation, saying his father had taken the path to heaven and would not return. The boy could not understand the concept of death, so Mary took Kavin to the hospital every day for a month to help him realize that his father was no more and would not return.

She took up a part-time job for a living while simultaneously attempting to make Kavin as independent as possible. She enrolled the boy at AMC.

School experience: Mary and Kavin were naturally sensitive, so they would get upset about minor issues. It took a while for Kavin to adjust to the school environment and become independent. Once, Kavin was shaken when the staff at this school said they would not be allowed to commute by bus if the bus fee was not paid. Mary consoled him, saying she would remit the fees.

Kavin was in the habit of hugging someone during birthday parties or other celebrations. It was his style of sharing the love of affection, but some at the school misunderstood it.

It was this girl's birthday, and he hugged her. The girl used a coconut crust and beat severely. When Mary received Kavin that evening, he was in bad condition. She rushed him to the doctor, who said the boy was not bitten by an insect but beaten by someone and gave him a certificate to support his diagnosis. Kavin never spoke a word about whatever happened in the school.

Mary visited the school and talked to Kavin's teacher. "If you want to make this child normal, you can beat him however much you want. If not, what is the reason he got hurt? I am also a teacher. I don't beat normal children. How could you do this to my child," she argued with the teacher.

Kavin did not want to go to school after this incident.

Mary said, "Now I keep telling him not to worry about anything. It doesn't matter what happens. We have to move on. You have to accept it and smile again and have fun. The fear was evident before, but now it is not there."

She was keen to see him return to school, which would help her return to work. She, however, could not because schools were closed during the lockdown announced to check the spread of COVID positive cases. One of Kavin's half-brothers helps Mary and Kavin with money. Still, the mother needs additional money when her son wants something. "In the end, it is that feeling that I have given him some comfort in life," added Mary.

# About AMC

AMC was started in 1960 by Dr. D. L.N. Murthy Rao, then Director of All India Institute of Mental Health, Bangalore (now NIMHANS). AMC is a one-of-a- kind institution providing lifelong support for 120 – 140 individuals with Developmental Disability Disorders (DD). AMC is working with the goal to improve the quality of life of persons with developmental disabilities and their families. The wide range of services offered at AMC are provided free of charge, as 90% of the beneficiaries are from low socio-economic background.

**Mission**: To promote development, independence, economic sufficiency, community inclusion, self-determination of persons with IDD; Empowerment of their families through coordinated services of training, research, technical assistance and dissemination activities. AMC has the following facilities: special school, multi-category vocational training center, sheltered workshop, day care center and Samruddhi, a programme to support families. The other free services provided are: supply of uniforms, shoes, bags; milk with multi millet porridge, vitamin supplements; nutritious lunch everyday; transport facility for everyday commute; outdoor activities like visit to exhibitions, fairs, picnic, etc. and yoga and training in painting, dance and music.

## The Association for the Mentally Challenged

Near Kidwai Cancer Hospital, Off Hosur
Road,Bangalore, Karnataka 560029

enrich.amc@gmail.com
www.amcin.org