

No Need to fear

breaking the stigma of leprosy



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PUBLISHED BY
People's Forum for Change
(Leprosy People Association Trust)

Acknowledgment

I wish to express my gratitude to Reverend Joshua whose vision and encouragement has been instrumental in my writing of this book.

I will always be indebted to Reverend and all the staff of Kaveri Kala Manram whose hospitality I have enjoyed for the past 2 years. You all continue to inspire me!

Thank you Ranjan and Vanni Hope for helping me make this connection.

Thank you to Leprosy Mission England Wales for your ongoing support and encouragement.

Last but not least, thank you to all the leprosy affected people who have taken the time to share their personal and inspiring stories with us. Their courage and bravery gives strength not only to people affected by leprosy but to *anyone* who feels discriminated and disheartened.

FOREWARD

Kaveri Kala Manram is an organisation that is dear to my heart. One could say that this organisation in many ways found me, as if by complete chance or even destiny. As a 2nd generation Sri Lankan; born, brought up and educated in Australia and working as a medical registrar in an inner Sydney hospital; an opportunity arose to work for 1 year in a clinical research role at the Peradeniya Teaching Hospital. It was only after moving that I heard about this organisation called KKM.

The main reason I was interested in KKM was due to its involvement in leprosy. Leprosy was something that I only came across at school after reading historical literature. Leprosy was not even taught at medical school because of how exceedingly rare it is in the contemporary world. Then to find out, to my utter amazement, that leprosy was still an ongoing issue in the Northern provinces of Sri Lanka; only inspired me to find out more.

Over the year I spent in Sri Lanka, I intermittently visited KKM headquarters and became accustomed to the work of Reverend Joshua. The years of hard work and dedication by him and his team was next to phenomenal. Starting from grass roots interventions, KKM has been able to thrive into an organisation that has supported tens of thousands of disadvantaged people. The unique aspect of KKM is that it is able to sever the patriarchal, caste-driven system and provide the psycho-social support for people affected by leprosy. Ultimately treating people for what they are: humans.

From a medical perspective, I personally believe that we all have a lot to learn from the way that KKM runs its holistic social programs. It is not just about treating the disease process with medications and nutrition. It is also about alleviating the stigma, casting aside the discrimination, providing opportunities, uplifting the community and most importantly fostering dignity and self-worth.

This short compendium of stories highlights the work KKM has done for leprosy over the past few decades. There are no better authors that can track the journey of KKM and the impact that it has made on impoverished communities in Sri Lanka inflicted by the ravages of leprosy. The journey you are privy to is short of amazing.

This organisation only exists due to the hard work of the people that work at KKM. Working office hours from 9am to 5pm, day in and day out, in tropical heat with only vadais and Sri Lankan kopi for sustenance is no easy feat. Believe me, I could not even last an afternoon!

The KKM office is a flurry of activity with the goal of ‘love for all of humanity’ in mind. The youth that work for KKM instil absolutely all their energy and really personify a quote of Mahathma Gandhi’s, “Be the change you want to see in the world.” This book in many ways is recognition of the efforts of these countless young adults under the guidance of Reverend Joshua, for their hours of toil, sweat, miles, meetings, translations, videos, proposals and hard work put into KKM.

Now it is time for you, to sit down, relax and absorb the stories of this great organisation.

I hope you enjoyed this read as much I did.

**Yours Sincerely,
Dr Varan Peranathan**

Introduction

I am excited to share the stories of some courageous people who have transformed their lives after contracting leprosy.

To many of us, leprosy is a disease consigned to Biblical times! Leprosy conjures up images from long ago of a highly contagious, crippling disease, a life sentence for its victims who are covered and hidden from the rest of society.

Is it still around?

Really??

These are common responses I hear when leprosy is mentioned. My response was certainly no different...until 2 years ago.

Up until 2017 my only exposure to leprosy was an innocuous few words read in a medical textbook.

It is one of the many infectious diseases transmitted by bacteria. In the case of leprosy, the offending bacteria are called *Mycobacterium Leprae* (M Leprae).

Let me introduce you to M Leprae:

- They are elongated, rod shaped bacilli.
- M Leprae prefer to live in the warm, sun drenched, tropics.
- 95% of the human population is genetically *unsusceptible* to M Leprae.
- An infection by M Leprae results in skin lesions and nerve damage, and in advanced cases physical deformity.

However today, leprosy is completely treatable and curable.

Medication is supplied free of charge by the World Health Organisation and usually needs to be taken for 6 to 12 months.

Interestingly, people affected by leprosy stop being contagious within 3 to 5 *days* of commencing treatment!

So why is there so much hype?

Why do people fear leprosy?

Why do many still ostracize and shun people who contract leprosy?

We still hear many stories of people affected by leprosy being discriminated at work, some even losing their jobs. Some people are abandoned by their spouses or divorced as soon as the diagnosis is disclosed. Some are shunned by their family members and others are banished from their community, long after they have been cured.

Prejudice and discrimination develop when there is fear and misinformation. This prejudice can persist and exist for decades.

I wish to share the heart-warming accounts of people who suffered from leprosy and have successfully emerged from it. You will see how they all harnessed the support and guidance extended to them and used their courage and determination to **not just ‘go’ through a difficulty but ‘grow’ through their difficulty.**

These stories of people affected by leprosy capture their resilience and tenacity in the face of insurmountable odds. Their success stories are empowering not only for people affected by leprosy, but anyone facing discrimination.

But first, let me relate the account of the compassionate and courageous Reverend Joshua, who was determined to lend a helping hand to a community afflicted with leprosy. It is estimated that nearly 40% of this community had signs and symptoms of leprosy, many with significant deformities.

Chapter I

How do you engage a community facing discrimination?

Where do you begin?

Reverend Joshua is eager to share his journey.

Exactly 20 years ago, in 1998 when Sri Lanka was embroiled in a civil war, Reverend Joshua recalls seeing a news report about residents in a refugee camp struggling to get access to drinking water. This camp was in a very remote part of Chulipuram, called Kattupulam. The location of the camp was only about 3 kilometres from where the Reverend was working at the time, so he decided to pay them a visit himself.



On enquiring about their circumstances, he was informed the only common well for the refugee camp was being deliberately contaminated with hair and oil by neighbouring villagers.

The camp residents explained they were being despised and discriminated on two accounts. Firstly, they felt it was because of their cast and secondly because many of them were suffering from advanced leprosy. Reverend noticed an even **more** debilitating factor – the residents themselves lacked self-esteem, were disheartened and resigned to their fate. He realised their own

convictions were holding them back, so he resolved to motivate them to change to a **better version of themselves**.

Reverend's appraisal of the situation revealed that since they were refugees, a relief organisation had provided them with temporary huts. The men were fishermen by trade but were unable to go fishing due to the security restrictions imposed at the time. They

could do labouring jobs but the surrounding community did not wish to employ them. A school was located at quite a distance from the camp and some children were seen



to walk back and forth but were not enthusiastic about pursuing an education. Many in the camp had advanced leprosy. New cases were being discovered. Compliance to treatment was poor. Some with visible, advanced deformity appeared to use it as a means of getting sympathy and aid.

He shared the **vision** he had for them. He promised them if they wished to change and were willing to work towards improving their current plight he was prepared to come back once a week to guide them. *They agreed!!*

Reverend decided to use a nutrition programme as a foot in the door. The nutrition programme cost Rs1, 000 /- month. This was started with a loan at a local shop.

Reverend formed 4 women's groups comprising of 10 to 11 women in each group. Initially he gathered them once a week in a common location and discussed what they could do to look and feel better about themselves.

He recalls setting simple tasks for them to accomplish every week. One week he would request the ladies to present themselves in washed clothes. The next week they were also asked to comb their hair. The third week he would suggest they also apply powder on their faces! Within a month, the women themselves could see the metamorphosis in the overall appearance of the community.

Reverend then turned his attention to improving the dwellings. Again with the intention of making the transformation come from within, he suggested the weekly meetings should be held in peoples' homes. Reverend's secret mission brought about the intended improvement. Each week, 4 ladies, one from each group, would set out to tidy up her house and clean up the surrounds in preparation for the meeting at her home!

The next task embarked on by the Reverend was to empower each woman to bring Rs5 or Rs10 to the meeting. He noticed some ladies even started bringing in Rs100. Each group opened a bank account and deposited this money. At the end of one year each group was able to boast a saving of Rs20,000 to Rs25,000. Reverend said his intention was two-fold. One was to instil the concept of saving and the other to exhibit the power of unity.

Dr Preman from the UK and Grace Bunker, a missionary and teacher at the Uduvil Girls College, heard of Reverend's efforts and offered their support.

While Reverend continued to guide and empower the women this way, he noticed the youth in the community were becoming accustomed to him. Reverend estimates about 150 youth were in the refugee camp at that time. With the war still ongoing, there was no television or radio. As a means of entertainment, he encouraged the youth to stage a drama every Saturday. Parents were invited to be the appreciative audience.

Always working with the bigger picture in mind, Reverend ensured the storylines imparted messages on health and hygiene, caring for the environment, moral values, empowering ourselves to take the initiative, and on not blaming others for our misfortune.

These subtle messages delivered in an entertaining and non-threatening manner by the youth brought valuable changes to a previously demoralised community. They also helped the community gain a better understanding of leprosy and how to manage it.

By the year 2000, having heard about the incredible contribution imparted by Reverend to this community afflicted by leprosy, officials from The Leprosy Mission trust India, supported by The Leprosy Mission England and Wales (TLMEW) came to meet



him. They requested Reverend to draft a letter of his concept in English and post it to them so they could render financial assistance.

Reverend says he had 2 challenges. One was the fact that the document had to be in English, and the other was a lack of time as he was still working full time for the Church. Reverend recalls after receiving 3 reminder letters from India, he finally managed to formulate his concepts in 2003, and received some much needed funds.

The TLMEW, who forged an association with Kaveri Kala manram (KKM), has stood by and supported Reverend Joshua and KKM for the past 15 years. Reverend's work has been greatly enhanced by the support rendered by this organisation.

In December 2004 the Tsunami struck. As part of the emergency response and rehabilitation, ACT international offered to build 50 homes for Chulipuram residents. This was an unexpected but highly needed windfall for this disadvantaged and neglected community.

By 2005, along with the villagers' own saving scheme and donations from well-wishers, there were sufficient funds to



purchase a small plot of land in Chulipuram. Again Dr Preman, along with Anne Watson, an Adelaide Nurse offered their support.

On this plot, four small homes were built. Iyngaran who was one of the beneficiaries of this housing scheme, came to see me with his wife Kamalarani to share their story which appears further on.

The work of Reverend Joshua in this community has been instrumental in building their belief and resilience for a brighter future. Reverend's actions are an inspiration to us all and show that even a village with high levels of poverty and leprosy can thrive and prosper.

Chapter 2

How may a child react to a diagnosis of leprosy?

What would be her perspective?

What bias may she encounter?

How would she overcome prejudice?

Miriam came forward to share her story.

Miriam was the first born child of a young couple. Her mother was 19 at the time. Born in Chulipuram, the family was displaced to Mullaiteevu when Mirium was only a year old. Mirium's younger sister and brother were born when the family were living in Mullaiteevu.

When Mirium turned 9 displaced families were being relocated to Chulipuram. Her father left the family during the relocation, so Mirium's mother returned to a



camp in Chulipuram with her 3 young children in tow. Soon after her return, Mirium recalls attending a medical camp organised by Reverend Joshua. A pale, numb patch on her left leg was noted by the examining doctor. A biopsy was taken and she was referred to Jaffna hospital. Mirium recalls being told it was imperative she

take some tablets continuously for 6 months and if she was not compliant, serious deformity of her hands and feet could ensue. She says she took the tablets religiously as she feared the consequences. Her treatment was completed before she turned 10 and she was completely cured. Mirium thought no more of it.

At the age of 11 Mirium moved into Vasantham Jennifer Girls' Home. One day one of her best friends suddenly started moving away from her. Initially puzzled, she later realised it was because of her past diagnosis of leprosy. That was the very first time she says she became aware of how others may react to her history of leprosy.

Young Mirium recalls informing Sutha, a lady caring for the children in the home. Sutha started counselling and educating the children in the home. It was a long and lonely 4 to 5 months before the classmates gradually started befriending her again.



This incident left an indelible mark on Mirium's young mind. What she resolved at the time is what makes her precious. She decided one day, she herself would work towards leprosy awareness so that other young children with leprosy would be spared the pain of rejection.

You will see later how Mirium, now a vibrant young lady of 27 years, successfully worked towards this goal.

Chapter 3

Could children face discrimination in educational institutions?

What can be done to rectify this?

Felicia shared the story of how she at 25 and her younger sister Jancia aged 12 yrs were diagnosed with leprosy at about the same time. Jancia was boarded at a hostel at the time. When staff at the hostel discovered she was consuming leprosy medications they made her leave the hostel and go back home.

The local Public Health Inspector (PHI) had to then intervene and educate the hostel authorities. Once assured she was not contagious, Jancia was readmitted to the hostel.

Children who were in the refugee camp in Kattupulam, Chulipuram had an extra burden. Schools in Jaffna were reluctant to accept children from this camp. To help overcome this discrimination, Reverend, with the help of



Jennifer Smith from England established a Home for 10 boys [Vasantham Robert Boys' Home] and 12 girls [Vasantham Jennifer Girls' Home] and managed to provide them with an alternate pathway to be admitted into Jaffna College.

Elilen was a young boy who grew up in Vasantham Robert Boys' Home from the age of 7. Elilen shares his story.

Elilen's mother contracted tuberculosis and his grandmother had advanced leprosy with deformity. His father deserted the family.

He says his mother was a daily wage earner, doing labouring jobs. If there was no work for her for a few days then there would be no income on those days for the family. These were incredibly difficult times for them.

Elilen and his 2 younger siblings had no financial means to attend school until Vasantham Boys' Home took him in at the age of 7. He can still picture his very first encounter with Reverend. On the day he was selected, he says he cried bitterly at the thought of being taken away from his mother and siblings. However once he got to the boys' home, he can still remember the blue soap dish, a red bucket and some fresh clothes given to him by Reverend. He beams that this was the very first time he 'owned' something!



Elilen fondly remembers Suba from the Girls' home coaching

him in his studies and giving him a sound grounding. With no need to worry about where his next meal was going to come from, he could now direct his full concentration towards his studies.

Elilen thrived in Jaffna College. He played hockey, cricket, football, basketball and athletics for the school and earned the All-Round Sportsman of the Year Award.

When he sat for his A' Levels, he made the school proud by scoring the highest marks for Jaffna College in his year! He scored an A and an A+ for Media and Psychology respectively. He weighed the pros and cons and decided he could serve his community better if he chose to study Psychology at university.

Elilen entered Jaffna University in 2017 and is in the second year of a four year course in Psychology. He continues to be passionate about his studies. He also continues to excel in sports, winning 4th position out of 180 in the Inter Island University Marathon.



Thayarani also volunteered her story.

She is the oldest of 5 children. Thayarani's grandmother, all of her father's 8 siblings and more than half her cousins were affected by leprosy.

Born in Kattupulam, Thayarani's parents were also displaced due to the civil war, when Thayarani was only 2 years old and her



younger brother barely a month old. By the time she reached 7 years she recalls her family could return to Chuliuram but not to Kattupulam. She remembers living in a

thatched hut. The following year another family permitted them to stay in their larger house. When she was a teenager, the family moved to Paandavattu, another remote community in Chulipuram. Her father was able to purchase a piece of land and they built a mud hut.

After the Tsunami, the family received funds from a charitable housing scheme to build a better home for themselves in Paandavattu.

With her father working as a fisherman and mother only getting sporadic labouring work in the fields, 16 year old Thayarani lacked financial assistance to pursue her education. At this juncture, she was accepted into Jennifer Girls' home, and with financial help from TLMEW she studied for her A' Levels.

In 2010, at the age of 21, Thayarani joined KKM. She says it was at this time that she learnt about the signs and symptoms of advanced leprosy. With this knowledge, she became aware that many of her extended family members' hand and foot deformities were due to advanced leprosy. She realised she could assist them if she gathered further information to treat and manage leprosy.

In 2012 The Leprosy Mission funded Thayarani's three year university course in Visual communication.

In 2013, she accepted the offer to go to India for a 3 month course in a leprosy hospital.

Thayarani says her dream is to continue her social service rather than secure a Government job. She says

she will always be indebted to The Leprosy Mission England Wales. She hopes to continue to spend her years ahead 'rendering service and helping others'.



Chapter 4

What challenges may people affected by leprosy face in their career?

What impediments may they face to their economic development?

How have some managed to overcome such obstacles?

I shall share 2 success stories here. One is how Mirium fulfilled her childhood dream of working in leprosy awareness. The other is the story of Iyngaran, who was in one of the 50 families in Chulipuram to get a home after the Tsunami.

I'm sure you will remember Mirium who was diagnosed with leprosy at the age of 9 and at that time vowed to work in leprosy awareness. When Mirium turned 18, she joined the organisation Kaveri Kala Manram and says she gathered as much information as she possibly could about leprosy.

Miriam was a natural at dance and drama and managed to impart her knowledge to village children in a very interesting and entertaining manner. To her delight she noticed she was able to attract children and found they would readily confide in her. She says she always speaks to them with love and not with authority.

At the age of 22 Mirium was sent to India for a 6 month course in Madurai and Chennai to work in various hospitals and gather vital knowledge about caring for people disabled by advanced leprosy. She was very proud that she travelled all by herself.

Miriam has worked with passion and enthusiasm at KKM for the past 9 years and now proudly holds a well-earned title of Project Officer of The Leprosy Association.

Iyngaran was born in Kattupulam, Chulipuram. His father was a stone breaker earning Rs25 per day and his mother worked as a labourer and gardener earning Rs10 per day. He is one of three



siblings. Some

members of his family had leprosy. His

parents' meagre income was barely

sufficient for food let alone clothes. Having

only one set of clothes, Iyngaran says he felt

too ashamed to go to

school wearing the same clothes day in, day out. He skipped school quite often and says he had not learnt to read or write when he stopped attending school altogether in Grade 4. He recalls feeling so frustrated one day that he threw away his school books in a lake and called it quits. With nothing to do he started roaming the streets aimlessly.

Only when he was 14 or 15 years he says he taught himself to read as he says he needed to figure out the bus destinations!

When Iyngaran was 18 years old his family got displaced due to the war. At 20 he ended up in Vavuniya and at 25 years he married Kamalarani. Three years later they were able to return to Chulipuram but not to Katupullam. They built a temporary home and lived in it. Two years later they were able to return to his birth place, Kattupulam in Chulipuram. He recalls this place was a

neglected forest by the time he returned. Iyngaran and his wife cleared a piece of land, built a temporary tent and moved in with their 3 children who were 5 years, 3 years and 8 months old. He became acquainted with Revered Joshua when he helped the Reverend clear another piece of land. They discussed the needs of their community and over time developed a close friendship.



When the Tsunami struck in December 2004 and post Tsunami relief homes were being offered, Iyngaran says his family missed out on the first round of 25 homes as they did not own any land. Before the second round of 25 homes was to be allocated, Reverend had bought a piece of land and divided it into four. Iyngaran's family was lucky to be given one of the quarters and thereby qualified for a funded home.

Iyngaran was working as a Rural Development Society (RDS) officer at this time. He attributes most of his success to Reverend saying many of the men resorted to alcohol and left the family responsibilities to their wives. He feels he too could have gone 'astray' if not for Reverend.

By 2006, Iyngaran's family had a home and a well and 8 coconut trees. He recalls Reverend gifting him a mango tree that still stands on his property.

Iyngaran says he initially worked as a mason, was then involved in constructing a man-made lake in Pallai. He was later involved in working on a farm where he first planted tapioca then eggplants and later onions. His crops flourished and as he became more and

more successful, he was in a position to employ farm hands. Today he is pleased to be in a position to offer work for 20 to 25 men on his land. Last year he even managed to purchase a tractor to transport his produce and workers.

Iyngaran does credit Reverend Joshua for his success. He states that knowing the Reverend would come periodically to enquire about his progress, kept him motivated to strive and achieve more and more.

Reverend of course gives the credit back to Iyngaran, stating, what KKM did for Iyngaran is 25%, what Iyngaran did for himself is 75%.

Whichever way you look at it, Iyngaran's life is a resounding success.



Chapter 5

What role may spirituality play in the recovery of people affected by leprosy?

Miriam explains how she received solace from her faith. Her mother was a Christian and her father was a Hindu. Miriam chose to follow her mother's faith. As most people do when a major



health issue comes our way, young Miriam too looked up to the heavens and pleaded ‘Why me?’

She recalls the priest was very comforting. He had counselled and consoled her advising her to look at a bigger

purpose for her life. She finds the thought that God had chosen her for this career steeped in service was empowering.

Elilen recalls religion per se did not play a large role in his life. He says Reverend Joshua was the most influential person in his life. He says Reverend's “actions speak louder than his words” and he hopes to one day emulate Reverend's philosophy.

Chapter 6

What is Kaveri Kala Manram (KKM)?

How did they begin?

What are they doing now?

What hopes do they have for the future?

KKM is a cultural organisation that was formed 20 years ago.

The aim was to use traditional arts and theatre to foster social and environmental justice, particularly for leprosy affected families. Initially KKM was composed of youngsters from Kattupulam, the community that first benefitted from Reverend's rehabilitation programmes.

Over the years, this organisation has grown and flourished as more and more beneficiaries joined Reverend in his mission. Reverend's nieces and nephews and



other well-wishers have also thrown in their support.

KKM has now expanded to four offices, the original remains in Chulipuram in Jaffna, and the other 3 new offices are in

Pallai(Hope Farm), Kilinochchi (House of Hope) and Malayalapuram (supported by Vanni Hope).

Reverend Joshua, the founder of KKM, and his troupe have touched and enhanced the lives of tens of thousands of people. KKM employees



continue to be involved in caring for people affected by leprosy and promoting leprosy awareness in Sri Lanka. These diligent staff visits remote schools and isolated communities to impart their knowledge about leprosy through street drama, storytelling, leaflet distribution, power point presentations, and discussions.

New cases are brought to light through the field work of KKM as well as through contact tracing of known leprosy patients. Once identified, KKM staff will inform the local Public Health Inspectors and if necessary accompany people to the skin clinic for a biopsy. If the biopsy confirms leprosy the hospital will counsel the patient and supply monthly treatment cards of medication.

KKM becomes involved again in supplying nutritious food packets and ensuring medication compliance. They provide support and valuable counselling when needed.



KKM then continue their association with people affected by leprosy and their families, as they assess their living conditions and their means of livelihood and if needed help secure funding

from overseas organisations. Deserving families are helped through the construction of a well, provision of plants, chickens, goats etc. The Leprosy Mission England Wales provides vital funding and so do many other organisations such as Vanni Hope, Carers Foundation, American Education Fund, Blossom Trust and Rotary International.

KKM and its Executive Director Reverend Joshua's view for the future is to form and support an organisation that utilises leprosy affected individuals to effect the changes needed to transform their lives and eradicate leprosy.

Chapter 7

What life challenges could people face?

How could they deal with them?

Felicia talks about being abandoned by her husband when her leprosy was diagnosed.

Let me share the hardships faced and surmounted by this courageous lady.

When Felicia was just 18 years old her mother and younger brother died. Her father moved on. Felicia was left in charge of her other younger brother and younger sister.

When her brother was 14 years old, he developed some skin lesions and skin sores. He was taken to hospital and diagnosed with leprosy. Felicia was married and had a 2 year old daughter by this stage. When contact tracing was done it was discovered that Felicia who was now 25 years old and her 12 year old sister also had leprosy. All three siblings commenced medications for 1 year.

Felicia recalls, three days into her treatment she developed fever and shivering and needed to be hospitalised for 3 days. She was advised these were side effects of her medication and that the side effects would be less severe if she consumed nutritious food. She says KKM became involved and provided her with the nutritious food. With that and the ongoing monthly counselling she says she managed to complete her therapy.

However, within a week of Felicia's diagnosis of leprosy, a Public Health Inspector had visited her home and discussed leprosy with her husband. She feels the PHI may have misinformed her husband who became anxious about the illness and abandoned the family. In spite of this added strain, Felicia recollects, in her 4th month of treatment, she had agreed to travel to Colombo with KKM and deliver a talk in front of a large audience about how leprosy affected her and her siblings.

Brave Felicia says her motivation for this was the desire to help other leprosy sufferers by bringing their plight into the spotlight.



Chapter 8

The Leprosy Association, who are its members?

What is their vision?

How do they contribute?



KKM decided it was time to change a society that was viewing people with leprosy simply as victims. The time had come to empower leprosy affected persons to be totally committed and work together to dispel the myths about leprosy and work to eradicate leprosy from the entire island!

With this in mind, The Leprosy Association was formed in 2017.

All office bearers of this Association – President, Vice president, Secretary and Treasure are all selected from individuals who **have had** leprosy. 90% of the membership is to be composed of people who have been affected by leprosy. Only 10% of the membership is to be composed of people not affected by leprosy.

73 year old NahamaniAya is the charismaticcurrent president of the



Leprosy Association. He was diagnosed with leprosy at the age of 69. He was married and had 4 children having lost two children during the war. They lived in a village called Tholpuram. NahamaniAya recalls being 'heartbroken' at the diagnosis of leprosy. He says he kept wondering how he got it and why he got it.

He remembers within 3 days of commencing his medications, two KKM staff visited him in his home, counselled him about leprosy and provided him with nutritious food packets.

About 3 months into his treatment some neighbours became aware of his diagnosis. Once word got out he found his job suffered. He was a salesman and his sales plummeted. He says he contemplated suicide as he felt humiliated and devastated by the behaviour of his community.

He recalls KKM workers provided valuable counselling and the hospital staff commended him on his compliance to treatment. This gave him the courage to go on, but he still felt the need to move away from Tholpuram to Mullaiteevu where he stayed until he completed one year of treatment.



Now he is pleased to report he is the President of The Leprosy Association, the head of The People's Forum for Change and a member of the Leprosy Awareness committee!

Amarasinghe is a 38 year old gentleman, married with two daughters. He recalls, in 2013, when he was 33 and his youngest daughter was merely 4 months old, his family were displaced from

Embilipitiya to a forest land in Bohasveva.

The family cleared a portion of the land and built a temporary



dwelling with items they could forage in the forest. Two years later, Amarasinghe says he noted a patch on his left elbow that was biopsied and diagnosed as leprosy. He appreciates the counselling he received from his doctor who advised him not to be afraid and assured him if he took his medications for a year and remained compliant, he would be cured.

Initially startled by his diagnosis, Amarasinghe resolved to complete the course of medications. Within a few days into his treatment he started feeling very weak and tired but says the symptoms improved when he was given nutritious food. Within a few months the patch started clearing and he felt encouraged.

His vision however deteriorated so he changed his profession from being a driver to a labourer.

A Public Health Inspector (PHI), who came to review him, inadvertently disclosed his illness to his neighbour. Once word got around his community, he says his daughter was expelled from her school and the family were pressured to leave the



community. Amarasinghe says he felt devastated, hit rock bottom and contemplated suicide.

Fortunately he disclosed his predicament to another newly appointed PHI who spent time educating and counselling the community. Once reassured, the community permitted Amarasinghe's family to stay on.

Through this PHI, KKM also became aware of Amarasinghe and his leprosy. About 4 months into his treatment, KKM built a tube well on his property, helped him complete his government funded home and provided him with coconut and pawpaw plants. KKM also spend time raising leprosy awareness in his community and in the local schools.

Amerasinghe proudly says he was always a community minded person with leadership qualities. After his struggle with leprosy, he is even more committed to becoming a village leader.

His enthusiasm has empowered him to organise a few community functions, including the New Year celebration this April that was attended by 80 community members.

He has also held the post of Vice President of The Leprosy Association since 2017.

Amerasinghe is now a leader of a community that nearly banished him, he claims, tongue in cheek!

Chapter 9

What dreams do people have?

Do they manage to live up to their dreams?

Miriam's dream, after enduring the pain of being rejected by her primary school friends, was to one day work with and care for people affected by leprosy and to work for leprosy awareness. She succeeded in doing this as soon as she turned 18 years. She has been a valued employee of KKM for the past 9 years and has recently been appointed the Project officer of The Leprosy

Association.

Miriam says she has derived a lot of pleasure and peace of mind from her service oriented work.

Elilen's says his lifelong dream is to emulate

Reverend

Joshua! He too wants to extend a helping hand to financially disadvantaged children in his village. He explains that many children would have the potential to excel either academically, in sports, in music or in arts. These talents may never surface if the child is not given the opportunity. Elilen also wants to use his psychology training to understand people's thought process and figure out exactly how to motivate them.



Felicia, who was abandoned by her husband as soon as her two younger siblings and she were diagnosed with leprosy, has soldiered on for the past 4 years, supporting her daughter and younger brother and sister. She is now self-sufficient, working on her land. She too holds a position in The Leprosy Association – she has been the Secretary since 2017.

Iyngaran, having grown up in a refugee camp with meagre possessions, dreamt of financial stability and of the opportunity to serve his community. Once owning next to nothing, he is now a land owner and an employer. Iyngaran together with his wife Kamalarani now focus on giving other disadvantaged community members a helping hand.



Amarasinghe's dream was to become a community leader again after his struggle with leprosy. You would have read about his achievements earlier – he has successfully organised many community events and has been holding the title of Vice President of The Leprosy Association since 2017.

NavamanyAiya who said at 69 years he felt heartbroken and even suicidal has turned around in 4 years to be the President of The



Leprosy Association and is working tirelessly to spread leprosy awareness.

Isn't it heart-warming to read the narratives of people, who once struck by a devastating illness have not only managed to get back on their feet but have even managed to fulfil their dreams and are functioning as exemplary citizens in their community?

Chapter 10

What lessons did I learn from my 2 year encounter with people who conquered leprosy and their support network Kaveri Kala Manram, guided by an incredible visionary Reverend Joshua?

**** Outstanding leaders go out of their way to boost the self-esteem of others.***

As you would have gathered, when Reverend first set out to work with the leprosy affected villagers, all he took with him was a heart filled with compassion and a resolve to make a positive impact on the lives of the downtrodden. Initially spending one day a week (his only free day, Saturday) with them, he empowered these people to start transforming themselves. Amazingly the techniques he harnessed were so basic yet profound. He ensured the changes started at the grass roots and it had to come from within!

****Once someone's self-esteem is restored, it is amazing what they can accomplish.***

You would have read how people who were once in the depth of despair, some even suicidal, when diagnosed with leprosy, battled to conquer both the disease and its stigma in the form of people's prejudice.

What I certainly did not expect to see was, how after their victory, they harnessed their new found courage and fortitude to go that extra mile to serve their community! The enthusiasm and dedication of these people to serve other members affected by leprosy is truly amazing!

****With the right attitude and a guiding hand we can all turn our life challenges into opportunities.***

When we encounter a loss in life, a really catastrophic loss - it could be our health, finance, relationship or career, we are bound to hit rock bottom.



We must *not* let this be the end.

Some *may* manage to pick themselves up, however most will need a helping hand. This support could be as simple as a kind word, an empowering conversation or a guiding hand to point the way.

Hitting rock bottom can give one the opportunity to pick oneself up and move forward in a *brand new* direction.

Let us lead a life with purpose.

If a fellow man should feel his life is a struggle, and is ready to throw in the towel, let us be the one to lend a helping hand. Let us be the one to help someone *rewrite their story!*

Let me finish with this quotable quote:

If you look beautiful it is God's gift to you

If you live your life beautifully it is your gift to God!

The participants' of these stories have been edited with their permission in other names, and some are their own names with their agreement.

Ostracised, discriminated and abandoned – within this book are the stories of how members of a community affected by leprosy were able to overcome the obstacles of society's ill-placed prejudice. Within these pages are the experiences of those people who were once affected. The stories they have shared provide us with a window into their world. We are taken on a journey that delves into the crux of the leprosy issue– stigma. Stigma has haunted this community from the moment they are diagnosed, all the way to adulthood.....until now. This is an eye-opening piece about how we can all play a role in shaping a better future for a discriminated community.

