

LIFE

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HEALTH P.6

Meanwhile in India the stigma of leprosy rarely improves

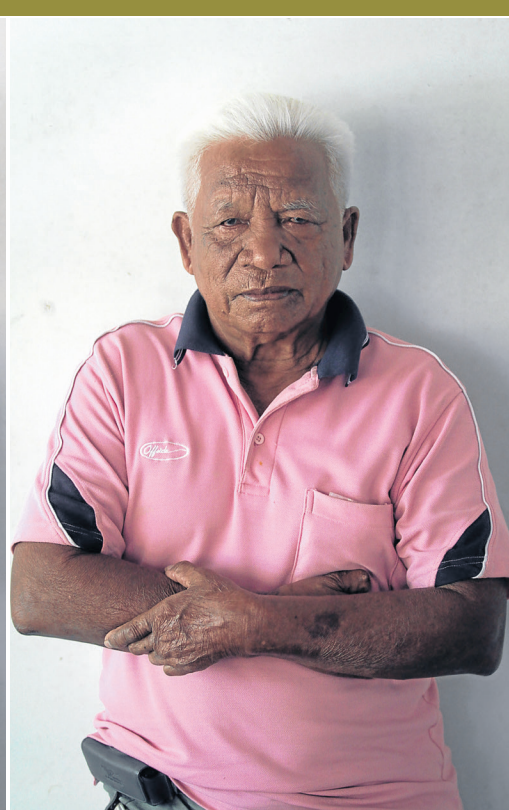
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Boontham Sukkasem.



La-ied Ditsaru.



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THE LEPROSY MISSION

A new lease of life for the Phud Hong Colony

STORY: ARUSA PISUTHIPAN PHOTOS: JETJARAS NA RANONG



Anong Kerdhung.

In Thailand, there are more than 500 registered leprosy patients, not to mention the unregistered, according to figures in 2012 from the Department of Disease Control's Rajprachasamasai Institute working under the Ministry of Public Health to prevent and monitor the prevalence of leprosy in the country.

And because leprosy — an infectious disease caused by a bacterium called *Mycobacterium leprae* — has been believed to be a sin-cursed illness making lepers a target of social disdain due to physical deformities and the lack of limbs in most cases, most lepers choose to live in colonies — a sanctuary where patients, as well as relatives are allowed to live like a community.

There are 12 leper colonies in several regions of Thailand. Phud Hong Leper Colony is one of them. Located in the southern province of Nakhon Si Thammarat, the colony was founded in 1947 with an objective to provide an asylum for people falling prey to the sickness where they can live without being looked down upon. Most of the lepers at the colony are above the age of 60. All of them have had medical treatment and are no longer contagious. There are almost 150 lepers living in the colony with their

relatives. Some members of the 155 families, especially those who work to earn their living outside the colony, are still forced to deal with social outcasts and discrimination.

Inside the leprosarium, lepers feel they are safe from social bias. But in fact they struggle to live in loneliness. Unlike orphanages or homes for the elderly, no one ever wants to visit leper communities for fear of being infected. The colony thus has hardly any visitors who would give them the much-needed support.

In the past, leprosy was thought to be easily transmittable from one person to another, making those suffering from leprosy a disgrace among themselves and their families. Yet today, people's attitudes towards patients have changed and turned somewhat positive. Despite that, patients at Phud Hong Leper Colony still have to live with a financial strain given the 100 baht daily allowance they receive from the government, which is not enough to put food on the table.

To shed light on physical, emotional and financial deadlock lepers are forced to encounter, *Life* talks to seven lepers at Phud Hong Leper Colony about what they have been through and how they wish the society's attitudes towards them to change.

BOONTHAM SUKKASEM, 61
Lottery vendor

Boontham Sukkasem was diagnosed with leprosy when he was 15 years old. Suddenly his classmates showed signs of hatred after they became aware of his disease.

"Back then I did not know if leprosy was curable. Neither did I know where to turn to for medical treatment. So I did not do anything, only kept the worry to myself," recalled Boontham.

Boontham admitted that today, fortunately, people's attitudes towards lepers have changed considerably. The Persons with Disabilities' Quality of Life Promotion Act, which was enacted in 2007, has helped the physically impaired enormously in terms of better social benefits. Yet Boontham still thinks that what the disabled need the most is the chance to be treated like the able-bodied, especially in terms of job opportunities.

"People with disabilities are the first group of people that society chooses to neglect," said Boontham. "But when it comes to social welfare, we are the last group that people think of. But the disabled also need compassion and care. And most importantly, we need to be given the same rights as normal people. After all, lepers or not, we are all humans. And we must help each other."

LA-IED DITSARU, 77
Unemployed

When La-ied Ditsaru was still in school she was pinched hard by a friend of hers, and she remembers feeling no pain. Not long after that she realised she suffered from leprosy and was consequently forced to leave school.

"I moved into Phud Hong Leper Colony in 1948 and have stayed here ever since," said La-ied. "Back then people felt lepers were disgusting. When we patients hailed public transportation on the road, we never got picked up."

The disease took away her life as a student so today La-ied sees the importance of education. She believes it is crucial that relatives of the patients receive an opportunity to go to school so that, after graduation, they can work for a better living standard for the family.

"Suffering the disease, I had no choice but to quit school. So I have no knowledge to earn myself some income. But I want people outside the colony to understand that lepers and their relatives are like everyone of us. Especially our children or grandchildren, they need to be educated so that they can stand strong for not just themselves but also their parents or grandparents who suffer leprosy."

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Stigma hinders efforts to combat leprosy in India

Despite government's declaration of 'cure', many believe true extent of disease hidden

NIRMALA GEORGE

AP

At first, Ashok Yadav ignored the patches of pink skin on his arm. But when pale sores erupted on his body and he lost sensation in his fingertips, a doctor issued the devastating diagnosis. Yadav had leprosy.

"What followed was like a nightmare," said Yadav, who has lived in Kasturba Gram, a leper colony outside New Delhi, since his diagnosis 30 years ago. "I lost my job. My parents felt I would spoil my sisters' chances of getting married. My family felt it would be better if I left home."

The stigma of leprosy endures in India, even though the country has made great strides against the disease, which is neither highly contagious nor fatal. Now the number of new annual cases has risen slightly after years of steady decline, and medical experts say the enormous fear surrounding leprosy is hindering efforts to finally eliminate it.

People continue to hide their diagnoses from families and loved ones out of fear they will be ostracised. Employers regularly turn away people who have had the disease, even if they've been treated and cured. Many struggle to get driver's licenses and other routine documents. Even the disease-free children of leprosy patients are shunned.

"We face a thousand indignities every day," said Neelawati Devi, a longtime resident of Kasturba Gram. Some 10,000 people live there, including the children of leprosy patients.

"Our children face taunts and slights when they go to school," said Devi, holding out her hands, the stubs of her fingers wrapped in gauze bandages. "But we want

them to get an education and get jobs. Their future should not be ruined."

Public health centres across the country have launched campaigns describing leprosy as the world's "least contagious communicable disease". Health workers are trying to spread the word that leprosy is not hereditary and does not spread through normal contact.

But the deformities that are the hallmark of leprosy contribute to the fear surrounding the disease, a chronic bacterial infection that often lies dormant for years before attacking the body's nerves and slowly causing numbness. Hands and feet eventually claw inward and serious injuries often go unnoticed because no pain is felt. Often fingers and toes are lost due to injuries and sores. Scientists believe it is spread through droplets from coughing or sneezing during prolonged contact with someone infected, but they are still not completely sure.

Also called Hansen's disease, leprosy has been curable since the 1940s thanks to antibiotics, and the worst physical deformities can be avoided if it is caught in time. About 95% of people have a natural immunity.

Worldwide, the number of new leprosy patients dropped from around 10 million in 1991 to around 230,000 last year as countries intensified efforts to fight the disease. In India, hospitals and clinics began treating patients with a combination of drugs that effectively kills *mycobacterium leprae*, the germ that causes leprosy.

In 2005, India declared victory, with health authorities reporting less than one case for every 10,000 people. But pockets of the country continue to have problems with leprosy, including in the central state of Chhattisgarh, Maharashtra in western India and Bihar and West Bengal in the east.

According to the Health Ministry, during 2012-2013 India detected 134,752

new cases of leprosy, slightly more than the 127,295 cases reported a year earlier. India accounts for 58% of newly diagnosed leprosy cases in the world, according to the World Health Organization. The disease also remains a problem in Brazil, China, Indonesia and East Timor.

C.M. Agarwal, the Health Ministry official in charge of the country's leprosy campaign, says the rise in cases is the result of

an intensified campaign against leprosy, meaning health workers are reporting cases that otherwise would have gone unnoticed.

But some activists disagree. They say that after India's 2005 declaration, the leprosy programme was merged with the country's public health scheme and scarce resources were reassigned for other urgent causes.

They also say the problem might be worse than anyone realises because of

leprosy's long gestation period. "The incubation period can stretch from five years to 15 before the first signs become detectable. And by then, many others could become infected," said P.K. Gopal of the National Forum of Persons Affected by Leprosy, a nongovernmental organisation working with leprosy patients.

The government is stepping up its fight against the disease, assigning additional

health workers to 209 districts seen as high endemic areas in 16 states. But that won't end the pain and stigma that leprosy brings to patients and their families.

"Our children shouldn't have the shadow of leprosy hanging over their lives," said G. Venugopal, one of the elders at Kasturba Gram, as he sat outside his home under Delhi's weak winter sun.

"They often face taunts in school. People are cruel. They will say, 'Oh, this is the son of a leper.' Then the children say they don't want to go to school and we have to push them," he said. Gopal, who has worked with leprosy patients for more than 40 years, said the stigma persists "because it's very difficult to change people's attitude over a short period of time."

"As things are, the fear of leprosy is so great that people refuse to come forward for treatment. This has had an adverse effect on the success of the leprosy programme," he said. Venugopal has been working with nongovernmental agencies to lobby the government to expand the disability allowances that some leprosy survivors get. "They pay us a monthly allowance of 1,800 rupees (970 baht), which is a pittance," he said. The money does not even pay for the bandages that leprosy patients use every day on their sores, said Uttam Kumar, another resident.

Like many others in Kasturba Gram, Kumar was thrown out of his home because neighbours objected to having a leprosy patient in their midst. Kumar, whose bandaged feet are the only sign of his ailment, spent months on the road before finding a refuge in the warren of one-room tenements in Kasturba Gram.

"Here we are all anonymous yet we are all fellow sufferers," Kumar said. "Everyone has their own sorrows, but our pain is the same."



Leprosy patient Satnarayan Singh, 86, sits outside his shop at a leper colony in New Delhi, India.

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THE LEPROSY MISSION

AMART TOMAN, 75
Oil palm farmer

Amart Toman was infected with leprosy when he was only eight years old, following a rash and numbness on his right knee.

"It was a combination of feelings — sadness, doubt, worry — when I first knew I had leprosy. I think this disease is the one people do not want to suffer most," Amart recalled, crying.

As a child, Amart was still lucky his peers did not pick on him. However, he decided to relocate to Phud Hong Leper Colony to prevent himself from being an object of ridicule among people around him.

Today Amart earns his living on an oil palm plantation. And he wishes to assure society that leprosy is not easily transmitted like many people have misunderstood.

"I have children and they do not suffer leprosy," Amart said. "At the plantation where I work, people treat me as normal. They eat with me and sometimes we party. So as long as patients try to stay healthy probably by having regular exercise and being strong, I think we can live and work like normal people."

UBON RAKSASRI, 75
Unemployed

Once surrounded by her classmates, at 12 years of age Ubon Raksasri was left alone after everyone at school knew she had leprosy.

"My friends stopped playing with me. And finally my teacher told me to leave school," Ubon recounted.

The disease deformed her hands and stole her left leg eight years ago, making her look like a disabled person and a social pariah. No public transportation wanted to allow her to get aboard as they were afraid other passengers were to be infected.

Today Ubon wears a prosthetic leg, enabling her to walk and live her daily life more comfortably. But she said that the artificial leg must be removed when she stays home for wearing it all day is likely to cause wounds. Consequently, what she needs the most is a wheelchair so that she can travel short distances without having to crawl.

"People may call us the disabled. But we are not nasty."

PARD SAEWONG, 82
Unemployed

When Pard Saewong was only five years old, he knew he was different.

"I was not like any other kids because I had leprosy," said Pard.

The boy was asked to leave school when he reached the second grade — the same time the symptoms began.

Pard's face was severely deformed and so were his limbs. The disease destroyed his hands and deprived him of both legs. He conceded that such physical disabilities have made it almost impossible for him to work and earn some money.

Pard admitted that it was himself who left the disease untreated for so long that parts of his body were badly affected and that he feels deeply sorry. Yet despite such impairment, the disease has long been under medical control and he is certain that it is no longer spreading.

"Admittedly life is difficult without legs and hands. But even though I lost parts of my body, I never lost my spirit. Today I can cook and take care of myself to some extent. I think as long as lepers remain emotionally strong and do not succumb to sickness, we can live without being a burden for society regardless of our physical deterioration."

ARKOM PRASONGSILP, 84
Unemployed

Learning he suffered leprosy was the saddest thing that has ever happened to Arkom Prasongsilp.

"It was when I was 13 years old and one day I discovered some red skin rashes. I was then urged to visit a medical professional at a local health clinic," he said.

After his diagnosis, Arkom lived with his family for many years before he decided to move to Phud Hong Leper Colony in 1991 as he hoped the colony would allow him to live a new life without having to worry about how others would feel towards his ailment.

Today Arkom is still required to pay a medical visit once every three to four months to keep his age-related complaints at bay. And he wishes that people outside the leper community look beyond physical deformities that lepers have no other choice but to live with for the rest of their lives.

"Things people see — crooked noses, limbs being amputated and so forth — are just the physical side of the whole story," he said.

"Inside we lepers are also human — the sick ones who need mercy instead of alienation. The misbelief that leprosy is easily transmittable is no longer true."

ANONG KERDHUNG, 53
Shoemaker

Unlike many lepers, Anong Kerdhung was diagnosed as falling prey to leprosy when he was 22 years old. And that was probably an age old enough for him to know how to cope with the sorrow.

"My friends knew nothing about my disease back then and it was probably because I always stayed at home after the diagnosis so I hardly faced social discrimination from others," said Anong.

Today Anong's job at Phud Hong Leper Colony is of great importance — a person most lepers cannot live without. "I am the colony's shoemaker," he explained. "Many lepers suffer leg deformities. As a result, they need shoes that fit perfectly, as they would not be able to walk properly."

These days Anong makes and repairs one or two pairs of shoes a day. He does not charge his leper neighbours directly for the work but he receives some monthly wages from the Don Bosco Development Centre, which also helps take care of lepers in the colony.

Anong can be a symbol of determination and independence — solid proof that lepers are not necessarily of no use. In fact, if they keep their spirits up, they can be beneficial and productive for the community they live in.

"I think a larger number of people outside the colony know that leprosy is no longer transmittable. And this is a very good sign."



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