

A paradise for leprosy patients | Management: Past an...



Management of the Valley of Hope

In the Valley of Hope, the residents were not only patients but also the administrative staff, teachers, medical staff, policemen, cooks, fire-fighters, laundry workers, postmen, lawn care workers, sanitation workers, carpenters, electricians; and drivers, amongst others. Here, in this lush Arcadia surrounded by hills, they live a self-contained and for the most part a secluded life, far from the madding crowd. This utopia for leprosy sufferers started out as an ideal healthcare model as envisioned by Earnest Travers, a British doctor.



Inmates that have been isolated at Pulau Jerejak, Penang. (photo courtesy of Culion Museum, Philippines.)

In the 1920s, leprosy was still an incurable disease and was so dreaded that the leprosy sufferers would try really hard to keep their condition secret by way of hiding. If a child has contracted leprosy, his family would pull him

out of school and keep him at home. As a measure to prevent the spread of leprosy, the British government enacted the Leper Enactment Act in 1926, which mandated the notification and segregation of leprosy patients in Malaya. Once a patient was found to have contracted leprosy, they would be taken away to one of the various leprosy camps in the country, such as the Penang's Pulau Jerejak, Johor's Tampoi; and Selangor's Setapak, amongst other places.



Dr Ernest Aston Otho Travers (1866-1934)

When Dr Ernest Aston Otho Travers¹ (1865-1934) was serving as a medical officer in the Setapak Leprosy Camp, he saw the poor facilities and the overcrowded, subhuman living conditions in the camp and began to mull about ways to improve the situation. In 1923, at the 5th Biennial Congress of Tropical Medicine held in Singapore, he introduced the idea of a “self-supporting community.”² His bold and forward-thinking

vision was materialised by Dr Gordon Ryrie, the first Medical Superintendent of the Sungai Buloh Settlement.³ The Valley of Hope, officially opened on 15 August 1930, was then the largest and best-equipped leprosarium in the British Commonwealth.

The 570-acre colony, much like a little country, is a self-contained community and has every facility one can imagine – hospital wards, housing, a marketplace, a school, a community hall, a recreational field, a prison, a mosque, a Hindu temple, Chinese temples, churches, and a variety of clubs and associations. The settlement even introduced its own printed currency for internal circulation.



The chalets in Valley of Hope were planned in clusters so virtually it formed a settlement of a village concept. (photo by Dr Lim Yong Long)

The emblem on the notes was a kingfisher, the early inhabitant of the stream that flowed through the settlement. . (photo courtesy of Sungai Buloh Settlement Council)

In the past, the Medical Superintendent was the settlement's supreme leader, who made all the final decisions. The Lay Inmate Superintendent, on the other hand, helped the Medical Superintendent to manage the settlement, the inmate workers and also any recruitment-related affairs. All lower-level managerial roles, with the exception of the Medical Superintendent and part of the medical staff, were undertaken by the patients.

A comprehensive inmate worker system



Dr Lim Kuan Joo (photo by Lian Ling Siong)



Patients who were in better condition were recruited to work as nurses and dressers. (photo courtesy of Kong Kwai Thong)

The comprehensive inmate worker system has been in place since 1930. Dr Lim Kuan Joo who served as the Deputy Director of the settlement from 1976 to 1985, said that the management system was already well-established by the time he assumed office. Hence, he did not introduce a new system or create any new positions. There has however, been a steady decline in the number of inmate workers as many patients had since retired or have passed on.

Dr Lim stated that all inmate workers received an allowance from the government, and the Lay Inmate Superintendent was the best-paid position. When an inmate retired from a position, another worker higher in seniority would take over their job. If the position was one that was open for all inmates, then applicants must go through an interview in the administration office. As the Deputy Director, Dr Lim would make the final hiring decision, after taking into consideration the advice of the then Lay Inmate Superintendent, Mokhtar Bin Haji Karim, and Hospital Administrator, Michael Phang.

He smiled and said: “We had to accommodate to their suggestions. The high-level inmate workers are allocated fine, government staff quarters. Sometimes if we offered a place to A but not B, they would get very upset and make a big fuss about it.” High-ranking inmate workers would get to stay at one of the spacious, detached bungalows, which were located on the main road at the East Section. The bungalows also used to be the living quarters of the British senior medical staff.

Dr Radhiah Mustafar, the current deputy director of the National Leprosy Control Centre, said that the inmate workers are not registered civil servants under the Public Service Department, so they have a separate pay structure. They are not entitled to the benefits and welfare reserved for civil servants, such as a certain amount of annual leave, and must gain the management’s approval if they wish to take a day off.



Dr Radhiah Mustafar (photo by Lian Ling Siong)

Though the inmate workers had relatively lower pay and no annual leave, their working hours were quite flexible. Except for those working on 8-hour shifts in the hospital wards, many inmates in other positions only needed to work for a couple of hours a day.

“We don’t expect them to work for the whole day because they are just patients. If the Lay Inmate Superintendent wants you to trim the grass, you

just finish your part and go home,” said Dr Lim Kuan Joo.

The all-important identification “card”, the medical treatment board



Each patient is given a Medical Treatment Board upon admission. (photo by Tan Ean Nee)

When the patients were first admitted, they would usually be admitted to the West Section wards to undergo a full body examination. Each patient would be given a *papan* (medical treatment board), which is sort of a permanent identification that contains the particulars of a patient, including the date of admission, registration number and medical records. The *papan* would be withdrawn at the time of discharge.

After being treated in the West Section wards for a period of time, patients who required minor care and supervision would be assigned to the East Section chalets. Before moving into the East Section quarters, the patients must present their *papan* at a store in the East Section in order to claim their daily necessities and utensils: such as a bed frame, bed boards, mosquito net, beddings, mug, plate, pot; and a straw mat. Should any of these items break thereafter, they can even bring them to the store and exchange for new ones. In addition, the authorities would also give out two pairs of shoes and a bolt of fabric every year.

The patients received great care and welfare in every aspect of their lives during the segregation. Meals were provided for all inpatients whereas recovered patients living in the chalets were given a specific amount of fresh cooking ingredients. Rationed food was available for self-collection every morning at the ration distribution shed.





In the early years the British authorities even distributed food rations to the staff and patients, according to a resident's job, race and any special dietary



Inmates are allowed to marry in the settlement.
(photo courtesy of Lam Tow)

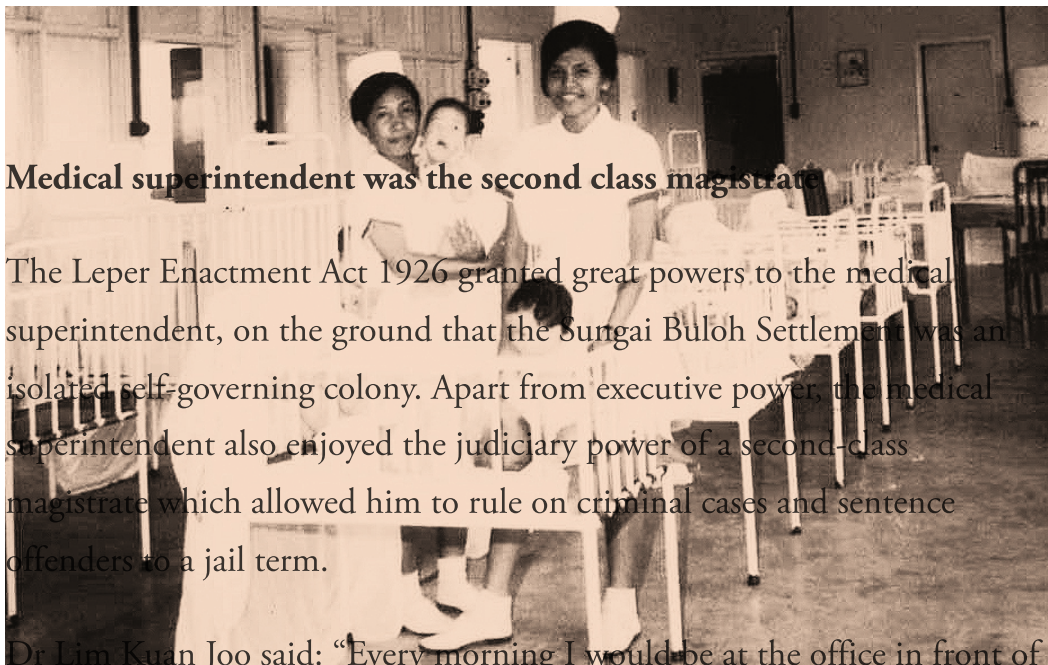
requirements. The food rations were divided into eight classes: ranging from Diet No.1 to Diet No.8. For instance, Diet No.8 was provided exclusively for the medical superintendent and senior officials; lower-ranking staff was entitled to Diet No.4, whereas

Diet No.1 was for the average patient. The hierarchy-based food rationing system continued until it was abolished after the country's Independence.

Before then, patients who wished to get married only needed the approval of the Medical Superintendent's office. Married couples could get a bigger cooking pot and apply to move to the Marriage Quarters. However, after post-Independence, the patients must register their marriage at a marriage registration centre located outside of the settlement, so as to have their marriage legally recognised.

If the patients were to have a child, they must leave their newborn baby in the Babies' Home for a six-month care. Within those six months the parents were only allowed to visit their baby once a month. In addition to that, the baby would be sent away at the end of the sixth month, either to adoptive families, orphanages or convents, unless the parents have a relative or friend who was willing to take their baby into their care. As a result of this rule, many descendants of the patients were thus separated from their parents.





Medical superintendent was the second class magistrate

The Leper Enactment Act 1926 granted great powers to the medical superintendent, on the ground that the Sungai Buloh Settlement was an isolated self-governing colony. Apart from executive power, the medical superintendent also enjoyed the judiciary power of a second-class magistrate which allowed him to rule on criminal cases and sentence offenders to a jail term.

Dr Lim Kuan Joo said: “Every morning I would be at the office in front of the Council’s hall, listening to Lay Inmate Superintendent Mokhtar’s report. After that I would deal with the issues. I would **try** my best to solve them all. You see, I was also a second-class magistrate and I had the power to release prisoners.”



Police force cum fire brigade and time keeper. (photo courtesy of Ahmad)

He said the Valley of Hope was a very special place, pretty much like a small country with its own fire brigade, police force and prison. The settlement authorities encouraged the residents to grow plants around their chalets and even allocated land for them to farm chickens and goats. The

once sizeable farm, closed down a long time ago, is now part of the medical faculty of Universiti Teknologi MARA.

Besides that, he said the patients also drove the government's vehicles themselves. Every Friday the driver would drive the settlement's truck to restock supplies at the sundry shops and food stores in Petaling Street.



JAL plane crash survivors return to thank Sungai Buloh hospital staff and inmates for rescuing them.

(photo courtesy of Dr Lim Kuan Joo)

In fact, the driver of the Valley of Hope was a hero to the Japan Airline plane crash in 1977. Dr Lim Kuan Joo recounted that a Japan Airline aircraft crashed into a jungle near the Sungai Buloh Settlement. The ambulances could not access the crash site and only four-wheel-drive vehicles could cope with the bumpy jungle trails.

Chief Steward Kok Hoe Hua was the one who arrived first at the site and rushed the survivors to the hospital with the settlement's four-wheel-drive car.

Two of the 10 crew members and 43 of the 69 passengers survived the plane crash. The Sungai Buloh Settlement even vacated two hospital wards to treat the survivors. In 1978, the plane crash survivors visited the settlement personally to thank all the leprosy patients and medical staff for their timely help and care.

Some inmate workers became public servants





The inmate workers received their superiors' recognition and acknowledgement for their diligence, commitment and dedication. Lim Thiam Chye, who served as the settlement's supervisor from 2003 to 2012, and Dr Lim Kuan Joo praised the inmate workers for their selfless devotion. Lim Thiam Chye remembered the inmate assistant nurses so well that he could name and praise each and every one of them. "They were very committed workers. I really appreciate these recovered inmate workers for their exceptional dedication and contributions to all the patients."

He said that the "healthy scheme" was already in place before he joined the Valley of Hope. The scheme was to select healthy and non-disabled ex-patients to work as formal public servants, so that they were eligible for the public sector's pay and pension benefits. Most of the ex-patients recruited became assistant nurses.



Nurses who had passed the exams would be promoted to be government servants. (photo courtesy of Ng Sai Moi)

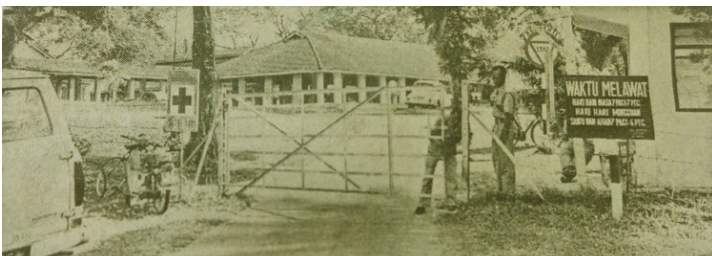
When Lim Thiam Chye was the supervisor, he would go around and inspect the hospital wards every day. The inmate workers who worked as the assistant nurses never gave him any trouble. He said that the leprosy patients had wounds that were difficult to heal, so the nurses gave great care to them. They knew each and every case very well and kept a detailed record of all patients' conditions and whereabouts. They took their job seriously and showed a very good attitude at work.

Since 1996, he said the settlement's five service areas: cleaning, ground maintenance, linen and laundry, engineering, and biomedical service has been outsourced to Radicare (M) Sdn Bhd, a concession company. Hence, some of the inmate workers such as the janitors, sanitation workers, lawn

care workers, ward attendants, and other staff have been reassigned to other positions.

Dr Radhiah joined the Valley of Hope since 2010. She said that after giving the inmates a body check-up in 2012, the settlement authorities found out that many of them were no longer fit to work because they had become frail and elderly with blurry vision. So, the inmate workers were requested to retire from their positions. Their work allowance was around RM145 before retirement and they can still receive a pension of RM100 per month after retiring. The monthly allowance for a small number of inmate workers who are still active at work has been adjusted to a range of RM200-RM250. As for the assistant nurses who had been registered under the Public Service Department, they are entitled to the benefits and welfare for civil servants.

Curfew in the settlement

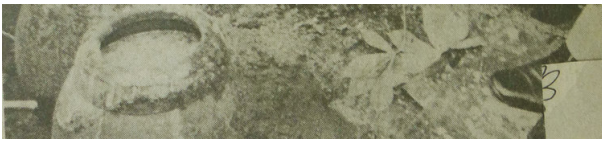


Tight security at East gate during curfew. (photo courtesy of Sungai Buloh Settlement Council)



Suspects of the illegal samsu distilling activity. (photo courtesy of Sungai Buloh Settlement Council)





Settlement Council)

The settlement was a closed community during Dr Lim Kuan Joo's term as the deputy director. The current site of Sungai Buloh Hospital used to be a part of the colony and the main gate was the Gurkha Gate. Some Nepali mercenaries who came here to seek treatment in the early years, built the Gurkha Gate before they returned to their country, to show their gratitude to the British military. One must pass through this gate to enter the leprosarium. Inside the settlement, the West and East Section each had a gate of their own. The entry restrictions were gradually loosened since the 1960s, so the inmates could slip off to work and outsiders could also sneak in for a movie or business dealings. However, the sensational "Samsu Case" broke out in the settlement in 1979 and led to a total lockdown.

According to The Valley of Hope Pictorial History Book, 10 drinkers died a collective death in Semenyih, after consuming illicitly distilled rice wine. A group of police raided the settlement and found 372 gallons of samsu in one of the chalets, with 25 gallons bottled and ready for distribution.

The Ministry of Health was furious about the case and it pushed Dr Lim Kuan Joo to take tough measures – an immediate curfew that strictly banned all outsiders from entering the leprosarium and a compulsory deposit of RM500 had to be paid to the Council by all truck drivers who needed to access to the settlement to deliver goods and flowers. If the truck drivers were found to be involved in illicit activities, their deposits would be forfeited. Otherwise, they could claim the money back when they stop their business dealings with the settlement.

Dr Lim Kuan Joo admitted that the new policy was unpopular but it couldn't be helped. It was a necessary measure at that point of time because the inmates' illicit distilling activities had already tarnished the reputation of the settlement.

He went on and said: "The inmates' horticultural business was very hot at that time... The Council received a good sum of deposit and the interest

earned from that made the Council wealthy. With that money, we were able to offer more to the patients.”

The National Leprosy Control Programme was introduced before Dr Lim assumed office. When the Council gained better finances, he decided to give transport and meal allowance to outpatients who travelled to the settlement for medical consultation. Later, he even upgraded the allowance for bus fares to cover taxi fares so that it would be more convenient for poor patients to make follow-up visits. Moreover, Dr Lim would also make a pay-raise request to the Ministry of Health on behalf of the inmates when public servants get their increments every five years. Hence, in the eyes of many inmates, he is a kind and respectable doctor who cared very much for the patients’ benefits, despite of his strict and impartial management style.

Compulsory segregation abolished in 1969

The year 1969 is a watershed in Malaysia’s leprosaria control history. That was the year when the National Leprosy Control Programme was implemented, first in Peninsular Malaysia, and later extended to Sarawak in 1974 and Sabah in 1985. The programme is the government’s effort to control leprosy through early case finding and effective treatment. The 40-year-old compulsory segregation policy was officially axed under this programme and leprosy patients could just visit any public hospitals or clinics in the country for medical consultation and treatment.



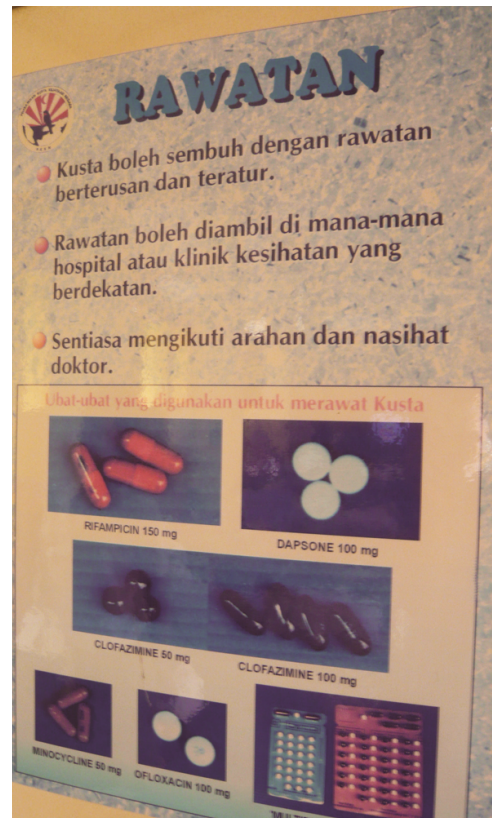


Following the implementation of this new programme, the Sungai Buloh Settlement was renamed as Pusat Kawalan Kusta Negara (PKKN), or in English: the National Leprosy Control Centre (NLCC). Besides managing the settlement, it was given a new mission to promote the National Leprosy Control Programme. The title “Medical Superintendent” for the head of the settlement has also been changed to “Director”.

Dr Lim Kuan Joo assumed office as the Deputy Director seven years after the new programme came into force. “Segregation used to be compulsory according to the law, but after 1969, we want you to go home. However, we do have a special unit to handle patients who have nowhere to go. We will admit the patient if it’s really the case, but we do not arrange involuntary admissions anymore. We will look into the cases and conduct appropriate social surveys. If the patients really have nowhere to go, we will take them in. As for inmates who wish to leave the settlement, we will just let them leave.”

In response to the question of whether most recovered patients choose to go home or stay, he answered instantly: “Go home? How? They have been there for three or four decades and are out of touch with the outside world. Even their own relatives might reject them because of the discrimination against leprosy patients. So they have nowhere to go.”

Now, three decades after the introduction of the National Leprosy Control Programme, Malaysia’s leprosy control policy is nothing like before. Lim



The Multi Drug Therapy, introduced in 1980s could effectively cure leprosy. (photo by Tan Ean Nee)

Thiam Chye, who was involved in organising the National Health Conference in 1992, said that leprosy became curable after the multidrug therapy (MDT) was introduced in 1982. Since 1987, the National Leprosy Control Programme has been fully incorporated into basic medical and healthcare services and leprosy patients can just go to any of the government hospitals for treatment. Hence, by the time he joined the NLCC in 1989, it no longer admitted new leprosy cases.

He said that the centre had gradually transformed into a general hospital with its own emergency department, ambulance service, outpatient department, and general wards. During his time, it was mainly serving the residents in Kuala Selangor, Petaling and Gombak district, and functioning just like other district hospitals.

Management transferred to Sungai Buloh Hospital



The Sungai Buloh Hospital was built to accommodate the growing population of patients from Klang Valley. (photo courtesy of Sungai Buloh Settlement Council)

Today, the Valley of Hope has developed into a neighbourhood with a big general hospital, inpatient wards and living quarters for former leprosy patients, and university premises. The 130-acre Sungai Buloh Hospital was completed by the end of 2005 and officially opened in September 2006. In

2008, the management of NLCC was officially transferred to the new hospital.

Dato Dr Khalid Ibrahim, who assumed office as the Sungai Buloh Hospital Director in 2007, said, “I think this is necessary because the patients have decreased. The government streamlined the management to optimise manpower and efficiency and we do find it more effective this way.”



The buildings in the background belong to University MARA. These new structures have changed the settlement's landscape. (photo by Tan Ean Nee)

In 2007, the government uprooted the recovered patients who were living in the East Section chalets and started bulldozing the 111 chalets and a prison in the East Section in late August, to make way for Universiti Teknologi MARA's medical faculty. The Sungai Buloh Settlement Council and the residents, led by the Council's Acting President Lee Chor Seng, protested against the demolition plan and gained media attention and public support. Unfortunately, their attempt to save the historical buildings was unsuccessful, but it opened the public's eyes for the first time to the beauty of the Valley of Hope.

According to Dr Radhiah, when she first joined the settlement in 2010, there were six female wards (Ward No.48-53) in the West Section and 10 male wards (Ward No.82-91) in the East Section for former leprosy

patients. Later, in the same year, NLCC received funds allocated under the 9th Malaysia Plan to refurbish four old wards and build a communal home. After the construction was completed the female patients in the West Section were relocated to the four newly-refurbished female wards located next to the East Section's male wards.

The West Section wards have now become a step-down ward in the Sungai Buloh Hospital to make more beds available for the hospital. Patients who are in more stable conditions are transferred here from the Sungai Buloh Hospital, to receive inpatient care.

The demolition of the East Section in 2007 destroyed the inmates' homes and left them with emotional trauma. However, in general, the management of the Valley of Hope has been upholding a humane approach since its establishment to provide great care to the leprosy patients. The inmates are given free room and board and medical care for life. Since the food rationing system was abolished in 2011, the chalet occupants receive a daily food allowance of MYR21 (around MYR 600 per month). Dato Dr Khalid said in the interview that considering the rising prices, he will make his best efforts to adjust the food allowance to MYR 25 a day.



Recovered patients at the ward are provided with 3 meals a day and given free life treatment. (photo by Mango Loke)

He said, “We used to provide ingredients for them to cook but since they are now old and no longer able to cook for themselves, we have replaced the rations with a cash allowance of MYR 21 per day. Meanwhile, recovered patients who are registered with Malaysia Leprosy Relief Association (MaLRA) are also entitled to MYR 300 allowance per month. This is funded by non-governmental organisation, and not the government. As for the ex-patients who are not entitled to the MaLRA allowance – those without a *papan*, will be referred to the Welfare Department.

Dato Dr Khalid Ibrahim said that there were 12 ex-patients who were not eligible to receive MaLRA’s monthly allowance because they had long been discharged from the settlement and no longer had their *papan* with them. However, with the government’s recommendation, they could receive financial assistance from the Welfare Department.

Initially, he said that the Ministry of Health allocated land for recovered patients living in the chalets to do some gardening as a measure to improve their physical and mental wellbeing. Today, the inmates are running a horticultural business with the land to earn extra income.

Besides that, the settlement authorities are also covering the maintenance and utility bills for the chalets. Dr Radhiah stated that “the government has promised to take care of the patients’ welfare by providing comfortable homes for them to live in, and providing free maintenance service, electricity and water supply.”

By October 2016, there were 138 recovered patients in the NLCC, with 73 living in the chalets and 65 staying in the East Section wards. Dato Dr Khalid Ibrahim explained that all these inpatients – 28 females and 37 males – were no longer threatened by leprosy. They were staying in the wards because of old age or other health conditions such as hypertension, heart disease, and asthma, which requires inpatient care.

Dr Radhiah says that both the male and female wards have two doctors respectively, and a matron going on ward rounds. The wards run in three shifts a day with two nurses on duty in each ward at all times. She says that

the East and Central Section used to have a clinic each to provide easier access to healthcare services for the chalet residents. Following the decline in the number of recovered patients, the settlement authorities have closed down the East Section clinic but kept the one in the Central Section, and moved the East Section residents to the Central Section for easier management.



Every Tuesday and Thursday, there will be a doctor at the Central Clinic to give consultation and treatment to the residents. (photo by Mango Loke)

Today, recovered patients still come to the Central Clinic early in the morning – either by motorcycle or on foot – to get flu, cough, fever and other common ailments treated. Some hypertension and diabetic patients also visit the clinic regularly for follow-up care. The clinic has a friendly atmosphere. Zaitun, a soon-retiring old nurse and other healthcare workers, know the recovered patients’ cases so well that they can immediately tell their appointment dates if the patients have forgotten about it. The wood furniture made by the settlement’s carpenters also adds a touch of homey warmth to the clinic.





(photo by Mango Loke)



Dr Radhiah says that every Friday morning, the NLCC will send a medical team of doctor, nurses and medical care providers to make home visits. The team provides treatment for immobile or critically-ill ex-patients and check on their medication compliance as well as personal and home hygiene. The medical care providers will clean and dress the ex-patients' wounds, if there are any.

Furthermore, the NLCC will perform screenings for recovered patients on a yearly basis, to check if there is any signs of a relapse. If the bacterial test result comes back positive, the patient will receive medical treatment.

When asked why the government gave special care to leprosy patients, Dato Dr Khalid Ibrahim said that there is a historical factor behind this policy. In the early years, the leprosy patients had gone through so much before any effective drugs were developed. They had been forcibly segregated and placed in special colonies. So, it is the government's humanitarian efforts to provide proper care for these patients as a form of compensation.

“These recovered patients have been living in the settlement for so long – some came here at the age of 7 – this is already their home, their life, and everything. They are elderly, infirm, and bodily disabled because of leprosy, so I think it is better to keep them here.”

From 1930 to 2017, the Valley of Hope has been through numerous changes, which makes it so different from what it used to be. Still, the humanitarian spirit that has been nurturing the settlement remains ever present in the valley.

Interviewed by Chan Wei See & Wong San San

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