

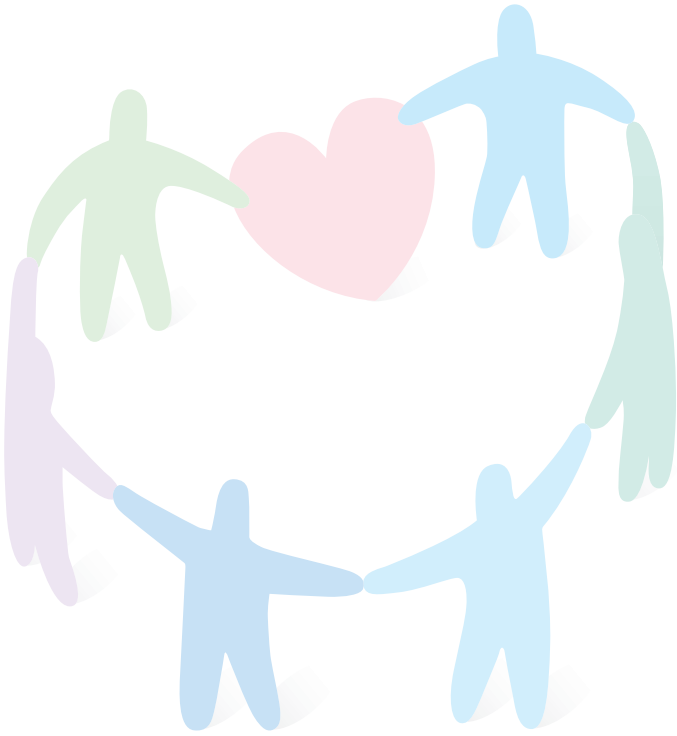
Let me wipe your tears and touch your heart...

*A memory of volunteers working with people affected by
TB and TB/HIV in Thailand*



Printed by : TB/HIV Research Foundation, Thailand and The Research Institute
of Tuberculosis, Japan Anti-Tuberculosis Association (RIT-JATA)

Supported by : The Mitsubishi Foundation, Japan.



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Let me wipe your tears and touch your heart...

The World Health Organization (WHO) recommends "*empower tuberculosis (TB) patient and community including patient involvement in TB care and prevention*" as one of the six global stop TB strategies. This book provides the evidences to support the effectiveness of this strategy by presenting some of the patient volunteers' best practices and the volunteers' most inspiring experiences in caring for people with TB and TB/HIV in Chiang Rai, Thailand. The patient volunteers who contributed to this book had or are still living with TB, HIV or TB/HIV. Most of the patients and patient volunteers are people residing in rural villages. They only had the opportunity to complete their education at a primarily level or in a few instances they were able to attend secondary schools. They are all what we would consider low income earners who are struggling with life's basic needs from one day to the next. This struggle is even further compounded by their illness. Although the volunteers' social and economic status seems to be so poor, it is their heart and spirit that is incredibly rich.

One of the patient volunteers suggested the title for this book "*Let me wipe your tears and touch your heart*" after he read the following stories:

- a stubborn elderly TB patient,
- an elderly TB/HIV patient who was left alone,
- an adolescent with TB/HIV who attempted suicide,
- a TB/HIV drug user,
- a TB/HIV migrant couple from Myanmar
- a TB/HIV prisoner
- a transvestite TB/HIV patient
- a TB/HIV patient experiencing sexual abuse

These patients were not only physically suffering from virus, bacteria and illness, but they also encountered social, economic and psychological difficulties that often left them feeling hopeless, depressed and at times with little or no motivation to live. They were discriminated against by the community and by their own families. These trying circumstances often led them to an interruption in their TB-treatment. However, the patient volunteers depicted in these stories turned these patients' crisis into opportunities. Many of the patients in the end were cured from TB and thus empowered to live. Some of the patients became volunteers themselves. Although a few of the patients died during the course of their TB treatment, as a result of the volunteers dedication all of these patients died with a measure of dignity that they had never known before.

We sincerely hope that after reading the stories in *“Let me wipe your tears and touch your heart”*, the readers will have a better understanding of the psycho-social difficulties which people with TB and TB/HIV are encountering and will appreciate the volunteers' vital role in TB and HIV care and prevention.

Importantly, as a result of wiping the patients' tears, the book shows us that the volunteers' pride and happiness was born through *“giving” and not by “receiving any financial or material incentives”*.

The following pages tell us the stories of people who have such a little voice, but in the face of so many obstacles, an undeniably great spirit in the Thai society...

Note to the readers

In the traditional Thai culture, most people in the community show respect based on age. Even in instances where the people have never met they may still address each other as if they were relatives. For example, in this book some patients may call the volunteer uncle, brother or even sister and the volunteers may call the patients or patient's family members as grandmother/father, mother or sister depending on the age and gender of the patients or the volunteers.

Abbreviations

ARV = antiretroviral drugs (medicine for people with HIV)
TB = tuberculosis
TB/HIV = tuberculosis with HIV co-infection



The pride of being
a transvestite volunteer

“He isn’t a doctor....just another HIV-infected person. Why should I listen to him?”

Volunteer Somchai is a well-built man in his thirties who is kind, likes to look his best, and is attracted to a person of the same sex. He recounts his volunteer’s experience about how sometimes people with HIV would reject his advice and counseling. Sometimes he overhears patients who don’t accept him make comments on his voluntary service such as *“He isn’t a doctor....just another HIV-infected patient. Why should I listen to him?”* But never has Somchai let this comment put down his will for voluntary service. He sticks to the principle that there is always a problem and an obstacle to everything. If we get caught in this too much, we’ll lose the will to work. In the case where we have a strong will, such a comment won’t affect us. Although some patients and families do not accept him and his role as a volunteer, many have named him **“a transvestite doctor”**. Somchai takes this as an acceptance of his role as a volunteer by these many people.

Volunteer Somchai learned of his HIV positive status around seven years ago. For over four years now, he’s volunteered at the hospital working with HIV patients. As a volunteer, he helps educate people living with HIV and antiretroviral (ARV) treatment, as well as, tuberculosis and TB drugs. He also assists these patients in managing the drugs and makes home visits to keep them motivated. Somchai himself has never had TB but he used to get seriously sick from HIV complications. He was so ill that he thought he would succumb to the disease. Today, Somchai is on ARV and volunteers to help look after over 400 friends who have HIV. Somchai visits around 100 patients at their home. Among these patients, one patient has especially impressed him. Somchai considers this patient a “Fighter” and shares with us this patient’s story.

“Had I not met you.....I would have killed myself”

Khumta is in his forties, likes to look his best and is sexually attracted to men. He’s the youngest son of the family, and after his parents died, he moved in with his sister. Khumta was only able to complete primary school. Before having a TB disease and HIV co-infection, Khumta was a singer in Pattaya, Thailand’s famous coastal city known for its beach resorts. He got HIV from having sex with men without protecting himself. Volunteer Somchai met Khumta for the first time at the hospital. Khumta’s appearance struck him—he looked very thin, weak and hopeless. At the hospital (in the presence of the nurse and volunteer), his family seemed to be very caring to Khumta. But things turned out strikingly different when Volunteer Somchai visited Khumta at home. Somchai was struck by the fact that Khumta was left lying alone in a small bamboo hut with a thatch grass roof. He had an old mattress and a mosquito net, and there was a dog that kept him company.

The first thing Khumta said to Volunteer Somchai was:

“I want to die. I don’t want to live”

“Please take it easy... Is there anything I can do? I’m here to see whether you’re taking the TB drugs or not, and whether you had any problems after taking the drugs or not.” Said gently Volunteer Somchai

Khumta repeated the same sentence:

“I want to die. I don’t want to live”

Volunteer Somchai showed his concerns while talking to Khumta. Khumta finally revealed his story.

“Before I was sick, I would return from Pattaya and helped my sister harvest the rice. She welcomed me, and I lived and ate with her, but when I contracted TB with AIDS, she started to despise me and acted very differently towards me. She asked me to move into this hut all alone, so it’s a good thing the dog keeps me company. I don’t want to live anymore. My father and my mother already died. I am alone. I want to kill myself.”

Khumta’s eyes were teary. That moved Volunteer Somchai emotionally and could have made him cry if it weren’t for the fact that being a volunteer, Somchai was there to help encourage patients not to make them sadder. Being a transvestite, they seemed to get along well and became quick friends. Volunteer Somchai commented on Khumta’s situation with words of encouragement...

“Don’t think too much. If your sister does not care about you, let it go. When you’re over TB or getting better you can find a job, or move somewhere else and help yourself. But for now, you must focus your will power on curing the disease”.

The first home visit made Khumta emotionally and mentally better, especially when he heard of a future plan for home visits by volunteers. Volunteer Somchai and other volunteers would take turns to visit Khumta at least once a week. A transvestite’s style of talk that Somchai used was very helpful with Khumta. He chatted about issues that were not related to the illness, teased, and joked. This made Khumta realize that Volunteer Somchai was a friend who shared the same problems with him. Volunteer Somchai shared his personal life experiences before and after HIV infection with Khumta. Friend talk during the home and hospital visit helped keep Khumta motivated, and no longer made him feel lonely, despite being deserted by his sister.

The pride of being a transvestite volunteer

Although Somchai isn't a doctor or a nurse, he has helped save lives through his role as a volunteer. This is echoed in Khumta's words to his friend, Somchai:

"Had I not met you.....I would have killed myself"

These heart-felt words were from the heart of the patient Khumta and continue to inspire Volunteer Somchai to work as a volunteer, and make him proud of being able to help people. Volunteer Somchai was happier when Khumta got better, and he helped find Khumta a job in a laundry shop where he earned his own living. One year after the cure of the first TB, Khumta had another TB attack. This time Khumta needed a different treatment regimen—he needed an injection apart from tablets. Khumta was admitted to the hospital for the first period of his treatment. He called Somchai to visit him at the hospital, and Somchai did so willingly. The first period of his treatment, Khumta felt hopeless because he needed a daily injection. Somchai was there to keep him motivated and going:

"Just hang in there. You've had TB before and you've managed to get over it and return to work. Hang in there with the tablets and injections, you will be over it soon and can work again. Use your will-power, and keep going."

Khumta was given an injection everyday, so he had to fight. Volunteer Somchai, who told him to fight, praised Khumta for his courage to battle the illness and find solutions for the problems he faced. Khumta lived almost 10 kilometers away from the hospital, and did not have a relative who could take

him there; neither did he have the money to pay for transportation for his daily injection. Finally, Khumta bought a second-hand bicycle for less than ten US dollars, and rode it to the hospital everyday.

“Sometimes I was almost out of breath. If I was short of breath, I stopped and then started again because I wanted to get over the illness”

Where there is a will, there is a way... Finally, Khumta and his bicycle reached the goal—his TB was cured after 9 months of treatment. Not only did his volunteer friends support him emotionally and mentally, they also found him a new job. Khumta trained himself to make brooms, and made this his living.

I will volunteer until I'm no longer standing

Somchai said with ambition, he believes that being a volunteer must begin with loving to give and share with other people. He is proud that his volunteer work entrusts him to help people and share his good will with others. ***Somchai commits himself as a volunteer until he's no longer standing, or at least until he is no longer needed...***





Refusing TB treatment for fear of rape

*A moving experience of a female volunteer and
her sympathy for another woman*

Saipin- a twenty-five year old mother of one contracted HIV from her husband. After this she suffered complications due to TB, pneumonia and other opportunistic infections. Her husband disappeared and was nowhere to be found after discovering that he had contracted the virus leaving Saipin no other option then to take her five year old son back to her home upcountry where without access to medication her condition worsened.

She continued with her TB treatment while receiving antiretroviral drugs but then she missed two of her monthly appointments with the doctor. Youpa, a volunteer worker for people with HIV, herself a former TB patient conducted a home visit to find out the reason why Saipin had not been able to keep up with her appointments. Volunteer Youpa found Saipin and her son in a small dilapidated hut that looked as if it would collapse at any moment. The hut had only one room barely sufficient to shelter the mother and her son. The hut had been built and provided for by Saipin's relatives who were also kind enough to cook her some simple meals that they would usually put on the ground outside the hut. They never entered the hut for fear that they might contract TB from Saipin.

“Please, I don’t think I want any treatment. Just let me die. Whenever my condition improves... he rapes me. Even though he knows I’m sick, he does these bad things”

Saipin pleaded with Volunteer Youpa in tears, despondent at the kind of fate she seemed to have been dealt.

“Keep your spirits up, Saipin. You can tell me what’s happened. I came by for a home visit to find out what is wrong with you and your health. Why have you been silent and why haven’t you kept up with your appointments at the hospital?”

Volunteer Youpa spoke in a gentle voice and gently touched Saipin's hands

"From the time you paid me that first visit I understood what you told me. I believe that people with AIDS can be cured from TB. I looked to you as an example and I took heart for the fact that, like you, I too, could be cured of the disease. You told me to be patient and to get well for the sake of my child. I took the medicine as you had advised me. I started first with those tiny tablets..."

She was now sobbing uncontrollably.

"So what happened to make you stop taking your medication and miss the hospital appointment for two whole months?" Asked Volunteer Youpa.

"After three weeks of medication I became stronger. I regained my appetite and gained some weight. I looked much better and because of that my step father abused me...he raped me. I don't know why this fate has befallen me. I have been seriously sick, yet he could still assault me sexually."

Saipin could not stop crying

Volunteer Youpa couldn't help feeling distressed as Saipin cried her heart out. She felt the pain of what the other woman had been through and had to fight back the tears so as to appear calm, all the while stroking Saipin's back to console her. As a volunteer, Youpa assessed Saipin's condition and saw that it was necessary to send her to the hospital so that a doctor could make a diagnosis and recommence the TB treatment. Saipin looked tired, seemed to be

breathing with great difficulty and was running a high temperature. Her life would be threatened if she continued to go untreated. Volunteer Youpa had a motor-cycle but she knew that putting Saipin on her bike would be dangerous since in her condition Saipin could easily fall off. So, Youpa placed a call to another volunteer friend. The three of them rode together on the motor bike with Saipin in the middle between the other two. Volunteer Youpa thought to herself defiantly that she wouldn't mind getting arrested for illegally carrying three passengers on a motor cycle.

Luck was still on her side since Saipin was able to get safely to the hospital and once there she was hospitalized. In spite of having a great number of responsibilities back home Volunteer Youpa was concerned about Saipin. She devoted her time to caring for Saipin, keeping her company during her hospital stay, making sure she bathed, washed, trimmed and combed her hair, clipping her nails so that very soon Saipin looked much better than she had before.

“You’re not a relative of mine yet you have cared for me in ways that even a relative of mine could not do. They never showed any concern, they even looked down on me....”

It gave Volunteer Youpa such pleasure to hear these words that came from the depths of Saipin's heart. She was very pleased to see Saipin fresh and clean and feeling so much better after having been through such abuse and emotional turmoil. She paid several visits to the hospital and saw how happy those visits made the young patient. Volunteer Youpa herself felt personally gratified seeing the happiness in Saipin's eyes. The two of them were in no way related. Their acquaintanceship was based on tuberculosis and AIDS and Youpa's role as a volunteer.

Aside from tending to Saipin's physical and emotional needs Youpa also tried to contact Saipin's family members to ask them to care for the patient and her child. Realizing that Youpa herself had cared for Saipin without any reservations the relatives soon became more accepting and were less prone to shun her TB and more willing to accept the responsibility of caring for their family member. It was also through Volunteer Youpa's efforts that Saipin found a way of dealing with her step-father's sexual abuse. Youpa was very proud of all she had accomplished as a volunteer.

In spite of having only a few years of schooling and making an honest living as labourer and a vendor she could still play a part in helping a woman who had suffered so intensely. Volunteer Youpa had helped her patient to get the care and acceptance they deserved from patients and their family members.



3

“...Having a problem
and then killing yourself?
...You didn't deserve
to be born”

*The Challenges and the encouragement from
a volunteer to an adolescent patient*

Meechai is among many thousands of children in the province affected by the HIV endemic. In many cases their mothers and fathers have already died and the AIDS virus was passed on to them. His father died when Meechai was 8 years old, and four years later, his mother died. After the death of his parents, Grandfather Kampan was the only person in Meechai's world. Grandfather Kampan, who is almost 70 years old, has been the only person that Meechai has held on to, and the only person who has looked after Meechai. Grandfather Kampan never would have thought that he would still be working at this age, not for his own living, and especially not for his grandson's living. He believes he's already old enough to leave this world, but because he still has Meechai, Grandfather Kampan must fight for his grandson, who he loves and adores.

Being there until the mother died... being here until the son was cured

Somyos was a volunteer who learned of his HIV positive status more than 10 years ago. He later volunteered to care for people with HIV. Volunteer Somyos is happy helping these patients in his district. He uses a self-sufficiency principle conveyed by Thailand's King as guidance for his living. He dedicates his spare time from farming and construction to work as a volunteer in his village. His volunteer job involves campaigning about public awareness HIV/AIDS, and reducing stigmatization among people living with HIV. Volunteer Somyos knows Meechai's family very well. Suksri, Meechai's mother, was also infected with HIV and worked as a volunteer with Somyos for many years. Unfortunately, Suksri contracted a drug-resistant type of TB. Although Suksri complied very strictly with her TB treatment (because she was so concerned about Meechai), she lost the battle with the disease and died.

“Brother Somyos, can you please look after Meechai? I’d like him to get a good education..”

This was always repeated by Suksri every time Volunteer Somyos visited her at home. He still remembers Suksri taking medications for drug-resistant TB. Suksri had to take the pills that were bigger than a tamarind seed—and she took five pills each time. Because she was concerned about her son’s future, she tried to swallow these big pills. The effort she gave to swallowing the pills was even more than that given to swallowing food. She desperately wanted to hug her son, but she didn’t want him to contract TB from her. She was just lying and watching him from a distance. Despite all the efforts to cure TB, Suksri died after one year and nine months of TB treatment.

“Brother Somyos, can you please look after Meechai? I’d like him to get a good education..”

These were the last words he heard from Suksri before she died. After her death, Volunteer Somyos stopped by regularly at Meechai and Grandfather Kampan’s. One day, Meechai felt sick with TB. He was lying on the mattress looking like a corpse. His body was very thin, and looked like a skeleton wrapped with skin. Besides having HIV and TB, Meechai had diarrhea. He could not eat, because every time he ate he would vomit. Volunteer Somyos thought that Meechai would die and felt sorry for Grandpa Kampan, who alone attended to Meechai’s needs. All Volunteer Somyos could do was to visit Meechai more frequently. Although Somyos did not have much money, when he visited Meechai and Grandpa Kampan, he tried to buy them something just to keep motivated.

He helped feed Meechai and gave him TB drugs, and he would often spend more than half a day with both the grandfather and the grandson. Because Meechai didn't like taking the pills, Grandpa Kampan and Volunteer Somyos had to crush the pills into powder, dissolve them in water and feed them to Meechai. Fortunately enough, the TB that Meechai had was not a drug-resistant TB like his mother had. He gradually recovered, and was successfully cured. Because he is a teenager and often thinks about himself, Meechai cannot accept the fact that he has HIV, and has to take medicine for the rest of his life.

*“Uncle Somyos, I can just use this rope to hang myself, can't I?”
Asked Meechai despairingly.*

“We all were born to learn the fact that getting ill is natural to being human—sometimes serious, sometimes mild. Once we're born, we have to fight. We human beings must fight, and we must face everything. But if we think about killing ourselves when we have problems, then we'd have been better off not to have been born.”

Volunteer Somyos' words worked. They reminded Meechai of the fact that his mother and Somyos were also sick but chose to bravely fight the disease. Although his mother died, she had put everything she had into fighting the disease. Volunteer Somyos, on the other hand, showed that his life was worth living by helping others. He deserved praise.

Meechai is 17 today, and he is still living with HIV. He is preparing for an entrance examination into a technical college so that he can fulfill his own and his mother's dream to become a foreman. Volunteer Somyos is watching and supporting him in making the dream come true....



4

Volunteer without borders
...Myanmar or Thai,
they are all patients

“All volunteers...you should use the patient toilets at the end of the building. Don’t share the staff toilet”

A hospital worker, announced very loudly to the HIV-infected volunteers who were there to help with the hospital’s HIV clinic. The announcement was loud enough for all the patients who were waiting for the service to hear. An experienced volunteer like Sopa understood very well that stigmatization and discrimination against people living with HIV was still common among public and health personnel. Sometimes, the hospital staff’s discriminating words and behaviors discouraged some volunteers from working, and made them leave the job, but for Volunteer Sopa, she loved her volunteer job. Sopa knew that she had HIV almost 20 years ago. She has had many episodes of opportunistic infections but survived them. Sopa works on campaigning about HIV knowledge among people at risk, such as inmates. She also gives counseling for HIV testing, and antiretroviral (ARV) treatment at home and at the hospital. She has been a volunteer for 12 years, and has helped many people living with HIV, as well as, TB patients who have HIV co-infection.

Sopa, or Aunty Sopa as called by her friends, has witnessed inspiring and heartbreaking stories about patients from her volunteer job. One of those inspirations is a story of Oo Saw and Ma Khai, a Myanmar couple who illegally traveled to and worked in Thailand many years. Volunteer Sopa still remembers clearly her first home visit to the couple who are both infected with HIV.

“I’m very worried, Oo Saw doesn’t take the pills. He said he has an allergy and feels a hot flush after taking the pills. I’m also not well, but I have to put up with these pills because I want to go to work, get money to buy food....and get money to go to the hospital next week.”

Ma Khai spoke slowly in Thai with her Myanmar accent. Volunteer Sopa understood very well what Ma Khai said. In front of her, Oo Saw was very thin, and there was a sign of drug allergy on his skin. He was lying in despair, and not wearing clothes because he felt hot. Ma Khai was also thin and looked tired. Her eyes were filled with worries and stress.

“We live here alone, and don’t know who we can call for help. We have to pay for the hospital because we are not Thai, and we don’t have a Thai ID card.” Said Ma Khai sadly with little hope.

Volunteer Sopa understood very well about the illness and the worries this couple was facing.

“Please, calm down. We volunteers will try to help you. But Oo Saw, you must have the will power to overcome TB. The first two months, you may not feel very well because you have to take four drugs. But after two months, the doctor will decrease the drugs to two. TB will be cured if you continue taking these drugs for six to nine months. You don’t have to take these pills for the rest of your life, so you must not give in. Look at this patient in the photo, he has HIV and used to have an allergy with TB drugs and almost died. He’s cured! Oo Saw and Ma Khai will be cured like him.”

Sopa showed the couple a photo of a volunteer who used to have TB. The couple looked at the photo with interest, and started to regain their will power.

“The next time you can’t pay the hospital costs, you go to the social workers and explain to them your situation. The hospital will find a solution for you.”

Volunteer Sopa regularly visited the couple at their home and asked them to join a self-help club for people living with HIV in their village. More importantly, Sopa convinced the other members to empathize with this Myanmar couple, and give the couple 400 Baht (13 US\$) per month as a living allowance. Even though they weren't Thais, they also suffered from HIV and TB. The money paid for the living allowance came from the municipality fund for people living with HIV within the village. Volunteer Sopa's efforts resulted in Oo Saw and Ma Khai emotional and financial support from Thai people, who also lived with HIV. They had hope for cure, and were accepted into the self-help group. They attended the meeting with Thai friends, which shows that they are sisters and brothers regardless of being Thai or Myanmar.

Volunteer Sopa was very proud that she had helped Oo Saw to cure his TB, and return to fishing and selling the fish at the market. Ma Khai returned to work in the restaurant to wash dishes, like she did before she fell ill. Sopa was very proud that she successfully convinced her Thai friends at the club to support the Myanmar couple with a living allowance without discrimination against race and class.

Volunteer Sopa was a village woman who only finished primary school education. When asked what she wants in her late forties, her answer was:

“What I have today is enough. For the rest of my life, I want to do good things for our friends who have HIV. I’ll do anything good, if I have the opportunity. I’m happy as I am, and I sleep well when I help people, and give something to others”.

Although, a volunteer like Sopa is denied the use of hospital staff toilet, she is proud that she can do something good for people with HIV and TB with HIV co-infection. **The most important thing is, she also helps create a social space for poor people.**





“Never been chased away!”

*The volunteer’s strategy to caring for a stubborn
elderly TB patient*

“Go away!”

Wandee, a female prisoner in her sixties said curtly dismissing Montha a single, pretty inmate-volunteer in her thirties. Volunteer Montha brought TB medicine to Wandee who had been placed in an isolation room due to her infectious TB.

“Oh...grandma...You haven’t taken your medicine. How can you expect me to leave?” Volunteer Montha replied gently.

“Leave me alone, I want to die. Just let me lie here on my own and die.”

Wandee continued to scold Volunteer Montha.

“What are you lingering here for?...Haven’t I told you to leave me alone, Can’t you see I want to die? Nobody wants to come near me. They see how I get these injections everyday. My buttocks hurt so badly I can no longer walk. No one wants to come near me for fear they’ll get sick like me.”

Wandee complained bitterly at her fate while keeping up with her attempts to chase Volunteer Montha away. If this had been some other volunteers they might have been offended with someone as quarrelsome as Wandee. The prison nurse had assigned Volunteer Montha the task of caring for Wandee for fear that the depression might drive Wandee to suicide like other elderly inmates who had jumped off the building to end their lives. Instead of feeling angry Volunteer Montha could only take pity on the woman she came to regard as her own grandmother. Wandee was suffering from her second tuberculosis episode.

She was so weak, pale and skinny and had endured so many injections that she could hardly walk any more. It was no wonder that she lacked the will to continue her TB treatment since none of her relatives had ever once been to visit her in prison.

*“Grandma...Let me massage your buttocks with some balm, O.K?
Once you feel stronger I’ll take you for a walk.”*

Volunteer Montha took out the balm and began to massage the area where Wandee had endured the painful shots.

*“I was once a TB patient here like you. It was such an ordeal.
I could hardly get up and move about. Each time I took the
medication I would feel like throwing up. I didn’t even have any
injections and yet it felt terrible at the beginning.”*

It seemed that Volunteer Montha’s real stories and her gentle massage began taking effect. Wandee calmed down and stopped attempting to chase Montha away. She also took her medication obediently.

Patients’ smiles are empowering to the volunteer

In spite of their difference in age, Volunteer Montha and Wandee soon became firm friends. Throughout the six months of her TB treatment Montha noticed a big change in Wandee. From a moody woman who kept to herself for fear that the other inmates would shun her and one who refused TB treatment she became a patient who accepted the medication given to her each day on a regular basis so that soon she was cured of the disease. The injections caused her such pain she was unable to walk but with the encouragement she received from Volunteer Montha she would hold on to the railings, propping herself up to stand and eventually she could walk normally as she had done before she became ill.

Soon enough other inmates in the prison came to talk with her. Volunteer Montha felt proud that she had played a role in Wandee's recovery. She had regained her strength and now had a social life. Each time she flashed a smile at her on the occasions the two would meet in the prison Montha would feel so heartened and feel this was so rewarding for a prison volunteer like her.

Because of a mother and child's love...Montha became a volunteer in the prison!

Volunteer Montha's story could come straight out of a novel – no extremes in terms of sentiment leading to jealousy and envy, but rather a deep bond of love between a mother and daughter who found themselves incarcerated together in jail. From the age of twenty-one Montha had been imprisoned and had served eleven years of her thirty-five year sentence on charges related to amphetamines. She could vividly recall what transpired on the day of her arrest:

“Please sir, my daughter was not in any way involved in this matter. I merely brought her along on an outing. Please sir, she knows nothing at all about this.”

Maria, Montha's mother pleaded loudly with the policemen who were ready to put her and her daughter in the police car. The officers seemed to believe what Maria was saying since, in all earnestness, Montha did not seem to have any knowledge as to what had taken place.

“Would you like to go home?”

Asked the police officer, who could pass as Montha's own father

“No sir, no. I can't leave my Mom. She often gets sick. How can I possibly allow her to go to jail all on her own. I must go with her. I'll miss her so much.”

Upon hearing this Maria broke down and cried for what she had done. Montha had learned that her mother got HIV from her new husband which meant that she frequently had to see the doctor for treatment. The daughter was adamant about never wanting to part from her mother and to leave her to fend for herself whilst in prison. Maria had taken the risk of becoming a drug pusher thinking that she was HIV positive and death was therefore imminent. She had hoped to make a good amount of money so as to ensure that Montha and her younger siblings would have enough for their studies. Ironically her daughter never got to finish her education and ended up spending time in prison with her mother. The young woman recalled how her mother was constantly in tears and how the fate that had befallen them took a toll on her physical and emotional well-being. Eventually she also succumbed to tuberculosis which took her life a year after she had served her jail sentence. Montha felt gratified that she had been able to be at her mother's side up until the last days of her life and this marked the beginning of her mission as the prison volunteer many came to regard as an inmates' angel.





A gentle smile for
everyone...
even for a patient
who was going to die:

The elation of a female inmate volunteer

If Chanthra, the thirty-six year old female volunteer were to walk down the street like any other women, she would definitely cause the heads of young men to turn. With her fair skin and beautiful eyes accentuated by long lashes she can carry her body like a model on a catwalk. However, the last time Chanthra actually walked the streets was eleven years ago. She has spent the intervening time in detention together with thousands of other female inmates in very congested settings. Chanthra is serving a thirty-three year sentence on charges of possessing amphetamines.

Engaging in the amphetamine trade...due to HIV infection

Chanthra was an upcountry girl with a vocational school education who was employed in a shop in her province making only enough to live. She married a man close to her in terms of social status. She was pregnant after two years of marriage. The day she describes as an ominous one came when she went to the hospital to begin ante-natal care. She was informed by the nurse that her blood tests revealed she had been infected with HIV—the same one people knew as the deadly AIDS virus. That was in 1995 and she had seen some of her neighbours and co-workers, married couples who were her contemporaries, die after having AIDS symptoms. The news from the nurse came to her like a death sentence and she couldn't help but think of what would happen to her and to the child who would be born orphaned; she wondered who would care for the baby since both she and her husband did not come from well-to-do families. Prior to that there had been several occasions when she had been propositioned to sell amphetamines but she couldn't bring herself to take on something that she knew was illegal. But after she learned she was HIV positive and realizing that she was about to die and leave her child orphaned, Chanthra decided to become a drug dealer in the hope that the compensation of hundreds and perhaps even

thousands of dollars on which to live would ensure a comfortable life for the child. Chanthra was caught and sentenced to imprisonment. To this day all she has are a sister and her father. Her husband and baby, both HIV positive, died while she was serving time in jail.

Picking up her TB medicine from the spittoon in order to take it once again

In the eleven years she has been imprisoned Chanthra has developed TB twice. Chanthra is regarded as a star patient who takes the instructions of her doctors very seriously. The prison doctors impressed upon her how important it was to keep taking the TB medication. Failure to do so could result in resistance to tuberculosis drugs that was no longer treatable with any medication. She recalls how in the first week of treatment the medicine made her so nauseous that she threw up several times after taking the tablets given to her. Still, she would pick up the medicine from the spittoon and swallow it again so as to complete the prescribed dosage. Having experienced first hand the pain and agony of being an HIV and TB co-infection patient Chanthra could relate very well to other patients and decided to become a volunteer and care for other female inmates who shared the same fate that had befallen her.

A smile for everyone – even patients who are going to die

Volunteer Chanthra had felt she had to endure such a depressing life but she came to realize that at least she had a father and sister who loved her and were genuinely concerned about her, waiting at home for the day when she would complete her imprisonment. So different was her case from that of Malee, a younger inmate who also had HIV and TB co-infection.

“I don’t want any treatment. Just let me die.”

Malee mumbled as she lay there, her eyes bereft of any feeling whatsoever.

“Be patient and accept the treatment and you will be cured like I was. Time passes by very swiftly and soon we can go home to our families.”

Volunteer Chanthra tried her best to soothe Malee’s feeling..

“I have nobody left in my life. Nobody wants me. My family doesn’t consider me to be their relative. My parents have both died. There’s nothing worth living for.”

Her sobs nearly brought Volunteer Chanthra to tears.

“Just look at our fellow inmates. Once they realize I have TB and also that I have been infected with that deadly disease... they shun me.”

Malee’s tears continued to stream down her face. Volunteer Chanthra spent more time consoling her and Malee finally agreed to take the medication that Volunteer Chanthra had carefully crushed and mixed with water before feeding it to her.

“At least you have me by your side and I promise you we’ll be friends forever.”

Volunteer Chanthra held Malee's hands flashing a sweet and gentle smile.

Not only was she administering the medication to Malee, but Volunteer Chanthra was also doing her laundry and helped wash her body even at times when Malee suffered from diarrhea and could not take herself to the toilet. Sadly, though, in spite of the excellent care she received Malee's life ended in prison. She died peacefully from complications arising from HIV and TB **her eyes fixed on Volunteer Chanthra smiling at her the same way she had from the start of her TB treatment until the last moments of her life.**

Volunteer Chanthra was determined to help patients who were going through the same health problems she herself had endured. Her selfless care and concern filled her with an inner peace and joy that she could not explain. All she knew was that she was most heartened to see others cured of the disease and living a normal life as she did. Even when some of them succumbed to the disease and died the way Malee had done she was still at peace with herself since they had not died feeling hopeless and abandoned. She had been able to administer to their needs and to offer comfort and solace even in their dying moments. Chanthra would offer prayers each day in the hope that she would be given the chance to one day care for her ageing father in the same manner that she was doing for strangers in the prison.

Let us hope that the fervent wishes and prayers of so gracious a person as Volunteer Chanthra are one day granted....



7

“Adamant” I’m not going
to let you go.

*The volunteer’s caring strategy for
a TB/HIV drug user patient*

“What the hell are you talking about? Don’t you dare come into my house and talk about such things...what’s all this about...I don’t know what you’re talking about.”

Suthep, a middle aged man in his forties, still found the strength to shout all this in spite of his condition during a visit from Sompong, an HIV volunteer from a neighbouring village. He was there to explain to Suthep about the antiretroviral drugs that allows people with HIV to live longer.

“I can stop talking about that today if you don’t want to listen to me. I can come by again next week.” Said Volunteer Somphong.

Suthep’s mother, Malai, learned that Volunteer Somphong himself was a person living with HIV who volunteered his services to other villagers suffering from AIDS. In spite of having been so ill at one point, he was able to survive the disease and could assist other patients in the village. Malai appreciated this while on her part she had practically given up trying to convince her ill tempered son who was also addicted to amphetamines to go to the hospital. She had learned that her son had contracted HIV when he had suffered an accident a few years back and a blood test yielded the result. Suthep, however, did not know that anyone other than his family members were aware of the results of that fatal blood test.

“Please help us, Sompong. I don’t know who else I can turn to. I know that Suthep has AIDS and I’ve been telling him to hurry up and see the doctor. Nowadays good medicines are available and he won’t have to die like his sister did. His wife also tried to talk to him but that got him so angry he started to beat her up. Things get even worse when he takes drugs. You can help by talking to him. Please,... please...please help us.” Pleaded Suthep’s mother.

Volunteer Sompong felt very sorry for Malai. He could empathize with the kind of pain a mother like her would feel. She was desperate not to lose another child from the two children she had. Two years ago Suthep's younger sister had died after suffering the same disease. She had left behind her orphaned children who had become a burden to their grandmother. Her life now was filled with stress and she often felt desperate. Volunteer Sompong was filled with pity and was very pleased to help Malai and her family. Hence, a week passed by and when Volunteer Sompong visited Suthep in his home Sompong brought up the subject in their conversation.

“Honestly, how much does a tablet of those amphetamines you take cost?” “Seven dollars for one tablet”

Suthep's answer paved the way for Volunteer Sompong to say what was on his mind.

“Seven dollars?!! My dear friend, don't you know that these pills you pay so much money to acquire are damaging for your body? How can you pay the money you earn in a day for such things? Do you know that the medicine the hospital gives us doesn't cost a cent and it can also cure us of our symptoms? Think carefully and take your pick. Something that costs you so much money and kills you or the one that costs nothing and can treat our disease? Use your judgment, friend. You've got kids to think of, your mother and yes, your wife. Who's going to care for them if, God forbid, something happens to you? Just think about it...”

Volunteer Sompong left Suthep with those words to ponder.

The struggle to choose between amphetamines and anti-TB medicine

Volunteer Sompong never thought his parting words with Suthep would have instant results. He was awoken the next morning by the sound of someone calling his name at his front door. It was Suthep, his eyes all red from having cried so much, he dropped to the ground and said,

“Help me, please. I think I’m going to die. I can’t take it any more. Take me to the hospital. I want some of those medicines...that’s it for me with those drugs.”

Volunteer Sompong was overjoyed with what he heard and the news that greeted him that morning. He rushed his friend off to the hospital and the tests confirmed what he and Malai had suspected all along – Suthep had AIDS and there was the further complication of TB. He soon underwent treatment and his condition gradually improved. A month passed by at which time Volunteer Sompong received a call from Suthep’s wife, Dalin who was hardly able to hold back the tears of sorrow as she spoke.

“The TB medication made him much better. What happened though was that he went back to those drugs (Amphetamines) once his physical condition improved. He sold everything we had –our pick-up truck that is our only means of making a living. When I told him off he got so angry he started throwing things at me. I can’t take it any more. It’s better if we just split up. I only pity Mom and those kids. What are they going to live on?”

“Calm down, Dalin. Tell me-- now that Suthep’s gone back to taking drugs, is he still taking the TB medication?”

Volunteer Sompong questioned her with much concern about the situation.

“He has been taking it but only because Mom and I take turns forcing him to. He sneaks into the bathroom to take those horrid drugs though. When I find out what he’s doing we get into another big fight. He’s even tried to hit me. I can’t take it any more. I think this is it. I’m leaving him...”

Dalin looked as if she had given up.

“Take it easy. I’ll pay him a visit and see what I can do.

Volunteer Sompong got on his bike and headed straight for Suthep’s place. On the way, he stopped by at Mr.Wim’s house. Everyone in that neighborhood knew that Mr.Wim was the main supplier of amphetamines there. Volunteer Sompong tried his best to plead with Mr.Wim asking him to stop selling Suthep the drugs for the sake of the man’s health. This endeavour was based on the premise that without anyone willing to sell the drugs Suthep would find it harder to maintain his habit and addiction.

Amphetamines vs. the hard working volunteer

Volunteer Sompong made the decision to devote more of his time to Suthep during the time he was undergoing TB treatment. He understood the immense challenge Suthep faced in trying to kick his amphetamines habit. Thai people

often refer to amphetamines as “Ya Ba” or the drug that makes you mad or crazy, recognizing just how difficult it is for the addict to stay in control when under it’s influence.

“The doctor’s now given you TB and antiretroviral drugs. Can you make me one promise, friend?”

Volunteer Sompong faced Suthep earnestly,

“You’re the one who saved my life. Of course I’ll listen to you.”

Suthep replied with equal earnestness.

“Listen to me, Suthep. If you dare take any of those drugs while you’re on this TB treatment the drugs will just kill off the TB medication and you’ll never get cured. If you can’t break that habit and quit the drugs there’s no point at all. We’ll have to start all over and increase the dosage for a year. What’s worse is if your body resists the medication then you’ll need to get daily injections for months and months. You must promise me never to go back to those drugs and I will give you my word that I’ll visit you every day, mornings and evenings, to make sure that you’re taking the medicines for TB and also for AIDS.”

Strangely enough, it seemed that these words and warnings of the consequences worked this time. Suthep could sense the sincerity on the part of the volunteer who kept his promise tirelessly visiting him day after day. They weren’t related and yet the volunteer showed such care and concern for his well-being. This gave Suthep the encouragement he needed for him to refrain from taking drugs and concentrate on the nine months of TB treatment. Initially, he did suffer

terribly from withdrawal symptoms and he'd turn violent and start attacking his wife. But each time that happened Dalin would reach for the telephone and call Volunteer Sompong over to help take care of the situation.


Happiness of a dedicated volunteer

“If it weren’t for a volunteer like you in my life I would have died a long time ago. That or I might have ended up in jail. What would have happened to the kids or my Mom, I don’t know.”

This was music to Volunteer Sompong’s ears. Hearing words which came straight from the heart of someone like Suthep. It filled him with pride that he had helped Suthep to get cured of TB therefore preventing his mother, wife and children from contracting the disease as well. These days, each time this volunteer walks into his local market the people he once helped, including Suthep who has survived AIDS and tuberculosis and their families who are now able to resume their daily trade and business, happily offer him their goods like fish and vegetables. It is gratifying indeed that Volunteer Sompong has played a major role in helping this patient and his family.

Who could know that just fifteen years ago, Volunteer Sompong who is regarded as a hero in his small community nearly succumbed to the AIDS virus himself?

Who could know his family members refused to take him to the hospital for treatment and they doused the bicycle he used with boiling water?

It didn’t matter who knows or doesn’t know. **All he knows is that he will continue volunteering his services to the community and to those suffering from HIV and tuberculosis until the day he breathes his last breath...** 



Fear of TB, forgetting the motherly care

*A story of a volunteer who brought back the gratitude
to the motherly love*

“Mother Kaewta, Mother Kaewta....anybody home?”

“Excuse me, anybody home? Mother Kaewta, are you in?”.

Sakda, an active volunteer for HIV patients, came to visit Kaewta, an HIV-infected woman in her fifties, and about the same age as his mother. Volunteer Sakda was shouting in front of her house, but nobody responded. The whole house was very quiet, as if nobody were there. He was about to turn back and leave, but suddenly he heard a cough behind the closed door. Sakda knocked on the door and opened it with a greeting.

“Is Mother Kaewta in?”

He stepped back from what he saw in front of him. Alone, Kaewta was lying there in a dark room. She was very different from the Kaewta he had first met at the hospital HIV clinic. The first time they met, Kaewta was in her second month of antiretroviral (ARV) treatment. Then, she looked fit and gained some weight, and she was so happy that she was going to survive AIDS. But after taking ARV for three months, Kaewta started to cough a lot, she had a fever and lost weight. The doctor told her that she had TB, and had to have TB treatment as well as ARV. Before continuing the conversation, Volunteer Sakda opened the window to let the air circulate and the sunlight to come in. Kaewta had lost so many kilos that she then weighed just above 30 kilos or something. She was lying there alone, next to the mattress where there was a dish of rice, water and bottle of medications. It seemed Kaewta hadn't touched any of her food or medications.

“Mother Kaewta, are you alone? Where are your children?”

Volunteer Sakda asked with concern

“Since the doctor told me that I have TB, my son left me alone in this room. He does not come near me. He is afraid of getting TB from me. He comes in just to leave some food, and then rushes out. I am so pitiful. If it were my neighbors, I wouldn’t mind at all. But this is my son...he deserts me.”

Said Kaewta bitterly

“What about your daughter?”

Volunteer Sakda was wondering because he knew that Kaewta had two children.

“Before, when I did not have TB, she visited me everyday, but now she only comes here once every three or four days. When she comes, she doesn’t stay long, and doesn’t come near me, especially when I cough. I’m left alone and eat alone all day and all night. I won’t survive. I’m dying. My children dislike me and desert me.”

Said Kaewta hopelessly.

“I’m here today to see whether you’re taking TB and ARV drugs everyday and whether you have any problems”.

“I’m dying. Taking medications won’t help.”

Said Kaewta hopelessly.

“Don’t feel so hopeless, Mother Kaewta. I know someone in this village who had AIDS and TB, and almost died. His eyes were all yellowed and almost died, but he took the medications, and was cured in the end. Now, he is living a normal life, and also is a volunteer. So Mother Kaewta, you must have a will like him, so you can be a volunteer too.”

Volunteer Sakda's words seemed to work. Kaewta looked more hopeful after hearing of the patient who survived TB and HIV. She tried to eat and take medications because she wanted to be cured.

Bringing back the gratitude to motherly love

Volunteer Sakda quickly managed a meeting with Kaewta's son and daughter at their place. Sakda didn't blame them at all during the meeting.

"It happened, that I visited your mother to see whether she took the medications correctly. I believe she is feeling hopeless that she won't survive TB. In fact, TB can be cured. Even though TB is infectious, there are ways to prevent it. More importantly, it is curable but the patient must complete TB medications. I know a person who was even worse than your mother, but his TB was cured. We must help to look after her. I'll try to visit her every week. I am concerned about her. She feels hopeless, and she's afraid that she's dying. But I think she will survive, if she continues to take her medications and eat."

Volunteer Sakda spent time talking about TB treatment and prevention, as well as, care of patients, and the benefit of room ventilation. It seemed Volunteer Sakda's effort worked because there was an obvious change in Kaewta during the second visit.

"My children treat me much better, they're not like before. My daughter comes to see me everyday. She puts the mattress and pillow out in the sun. My son is more relaxed when he's around me. He helps prepare medications for me, and watches me while I'm eating. Before, he would rush out after giving me the food and medications... I'm feeling like taking medications and eating."

Said Kaewta.

Volunteer Sakda was very glad that he was an important part of the process that finally brought the son and daughter back to the care of their mother. They did not forget to return the gratitude to their mother.

The young volunteer who mentored a volunteer who is his mother's age

Volunteer Sakda kept his promise—he went back to see Kaewta every week. He was happy that Kaewata was cured from TB, and was fit enough to go back to work. Other villagers came to her for advice about the illness, and she finally decided to disclose her HIV status to the villagers. *She is now one of the leading volunteers for her community.*

Today, volunteer Sakda earns less than the national minimum wage, so why is he so happy? Here is his answer:

“Working as a volunteer is like making merit. I feel very good helping other patients. Wherever I go, people greet me, ask me how I am, and they sometimes call me ‘doctor’. This is enough for me. It makes me happy to hear that, even though I’m not a doctor. I’m proud that people respect me, even though they know that I’m not a doctor.”



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TB/HIV Research Foundation (THRF)



**Global Wisdom and Local Participation
to Fight Against TB and HIV/AIDS**

Registered in Thailand # 222/2545

Tuberculosis and HIV/AIDS are global health emergencies and Thailand is not spared. In 1992, a group of Thai and Japanese doctoral students carried out their multi-disciplinary dissertations on tuberculosis and HIV/AIDS in Chiang Rai, the northern most province in Thailand. They soon realized the importance of research in providing knowledge as an effective tool for prevention and control of the diseases. After having worked in the field for more than 10 years in close collaboration with the Research Institute of Tuberculosis, Japan Anti-Tuberculosis Association, they firmly believe that successful prevention and control programs require not only research but also human resources development and technical collaboration at community, national and international levels.

The Foundation was officially registered in Thailand in June 2002 as a non-profit organization, with the aim to drive research on tuberculosis and HIV/AIDS forward. It has since been conducting and supporting biomedical, health and social sciences research on tuberculosis, HIV/AIDS, and other related problems. It has also supported human resources development and provided consultations in the fields of tuberculosis and HIV/AIDS.

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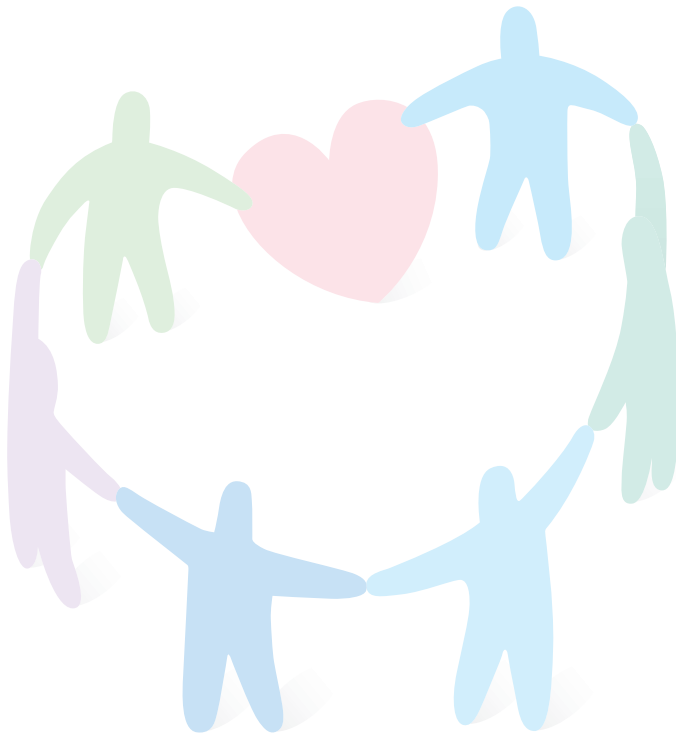
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***This book tells us that as a result of wiping the patients' tears,
the volunteers' pride and happiness was born through
"giving" and not by "receiving any financial or material incentives".***