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**TB CARE II**

# Changing Lives of MDR TB Patients

## TB CARE II Bangladesh



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# Forward

*The TB CARE II* project Bangladesh is a USAID supported project to help the National TB Control Program (NTP) increase universal access to TB services. Improving management of Multi-Drug-resistant TB (MDR TB) is a special focus of the project. It is estimated that there are 3,800 MDR TB cases annually in Bangladesh. A large proportion of these cases remain undetected and untreated, potentially increasing the risk of infection in the community.

It is not possible to combat the threat of MDR TB without a synchronized effort to expand national capacity both for diagnosis and treatment. To this end, the TB CARE II project started two new interventions in 2012. The introduction of Gene Xpert technology has been helping a large number of suspected patients with correct and faster

diagnosis of drug resistant TB. The community based approach for management has significantly reduced treatment delays by shortening hospital stays and allowing the patients extended time at home to complete their treatment. These efforts resulted in a substantial increase in the enrolment of MDR TB patients in treatment in less than two years.

This booklet titled ‘Changing Lives of MDR TB Patients’ has been prepared to highlight the impact of MDR TB on patients and their families and to demonstrate the achievements that have been made in improving systems of care. The stories epitomize the trials and tribulations that transpire in the lives of MDR TB patients. We hope these stories will generate awareness about MDR TB and inspire readers to join our fight against TB.



# Follow the Treatment, Beat the Disease

*For Ruhul Amin,* it all started in 2009 when he began to experience a persistent cough and fever, typical symptoms of TB. At first, he tried taking some medicine following the advice of a local pharmacist. When this did not work, he was referred to a local NGO clinic for a sputum test and was diagnosed with TB. Unfortunately, Ruhul's TB did not respond to the routine treatment or the follow up extended therapy. After additional diagnostic tests and waiting for several months, he got the report diagnosing him with MDR TB. This is a severe form of TB for which irregular taking of anti-TB drugs is often the cause.

In yet another setback, Ruhul's treatment initiation was delayed due to a shortage of beds at the hospital. He was put on a waiting list with many other patients ahead of him. In the ten months he had to wait to begin treatment, his condition deteriorated from bad to worse. In the early part of 2012, he was transferred to his home to receive

*Ruhul won his 20 month fight against TB and is now leading a normal life.*

care under the home based model established by the project in this area. The project supports a DOT provider who administers drugs and provides other clinical support to the patient on a daily basis. The small monthly allowance given for nutritional support helps Ruhul to maintain a balanced diet so that he can stay strong and fight the disease. Most of all, receiving treatment at home has allowed him to get continuous care and mental support from his family members, reinforcing his strength and ability to fight the disease.

The long wait for correct diagnosis and treatment delayed Ruhul's recovery and ruined him financially. He lost the small business he used to operate, and had to



borrow a large sum of money against his village home to support his family and pay other treatment related costs. Despite all these adversities, Ruhul never lost hope and strictly adhered to the treatment regimen. He won his fight against the disease after 20 months of treatment. On August 5, 2013, the senior consultant of the Chittagong Chest Disease Hospital formally declared him cured of the disease. Ruhul has started his small business again and is leading a normal life. He acknowledges that the patient-centered support provided by the project throughout the treatment period was critical in his being able to beat the disease.

# Vocational Training Helps Shovo Akter

*Life has not been easy* for 18 year old Shovo Akter. Over the past few years young Shovo has had to undergo the difficult treatment of her MDR TB while simultaneously trying to care for her 18 month old daughter. Originally diagnosed with TB three years ago, she completed her treatment hoping she had been cured. After a short period of time, however, her symptoms returned.

Shovo lives with her mother in Narayanganj, a crowded bustling trade city near Dhaka. They share a small shanty room in a slum area. She depends on her mother for everything: the care she needs, food, and shelter.

After being diagnosed with MDR TB, Shovo stayed at the hospital for the first eight weeks of treatment. Living at the hospital without her daughter was difficult, but allowed her to get used to her treatment regimen and resulting side effects, and to receive hands-on care during the

*Being able to add some extra income to the family brings a sense of confidence and an urge to live that is so very important in beating this disease.*



most difficult periods. At the hospital, she also received hands-on training showing her how to cut and sew dresses, and even learned a new embroidery technique called 'karchupi.' The TB CARE II project introduced this training to help impoverished MDR TB patients gain vocational skills that they can use to generate some extra income during and after treatment. The training is also intended to be a diversion, helping the patients adapt and adhere to their complex treatment.

Now, a DOTS provider visits Shovo at her home every day to provide treatment and psychological and emotional support. She is happy to be home and is making gradual progress. She has also found a way to use the vocational skills that she gained at the hospital to improve her economic situation: doing embroidery work for neighbors' dresses. Being able to add some extra income to the family brings a sense of confidence and an urge to live that is so very important in beating this disease.

# The Journey to Cure a Migrant Worker

*TB knows no border.* Sukur Ali is an MDR TB patient from Gazipur near Dhaka. He first contracted TB while living in Malaysia, a popular destination for Bangladeshi migrant workers. Living conditions for these workers are extremely poor and Sukur was forced to share a room with 25 other laborers. In 2011, he started to cough, and also began experiencing fevers and night sweats. He also began to lose weight due to a sudden lack of appetite, making him too weak to continue his job. He returned home almost empty handed, leaving behind his dream of improving his family's economic situation.

Once home, a sputum test confirmed his TB diagnosis, and Sukur was initiated onto treatment. He continued regular TB treatment for five months, but he could not recover from the disease. When the extended treatment also failed, he was sent for additional tests, leading to a diagnosis of MDR TB. After a few months at the hospital, he

*Sukur is now happy and relieved to be able to undergo treatment at home.*

came back home to continue his treatment under the supervision and guidance of a DOT provider supported by the TB CARE II project. The small financial allowance he gets for supplemental nutrition and transportation costs has been extremely helpful for him. The project staff also helped him get a monthly ration of 30 kgs of rice per month from the local government. In a statement referring to the sputum collection and transportation system established by the project, Sukur said: "I am glad that I no longer need to go to Dhaka for any follow up tests. I go to the nearby upazila to give sputum sample."

Although the delay in proper diagnosis of TB, two treatment failures, and living with extreme economic hardships had diminished his will to survive, Sukur is now



happy and relieved to be able to undergo treatment at home. A few months back, Sukur's wife was also diagnosed with MDR TB, and has since started treatment with support from the project staff. While he feels sorry for his wife, Sukur remains confident that they will both defeat the disease and return to living a healthy life.

# Khokon Rises from the Ashes

*TB is a debilitating disease,* causing financial and emotional strain on patients who often times come from the most vulnerable populations. This was the case for Khokon, an MDR TB patient from Chittagong City, who has been fighting TB for the last four years. According to Khokon, “TB almost ruined my life. I lost my small business which was going quite well. My friends and even my close family members abandoned me because of my disease.” Luckily, he is doing much better these days as he continues treatment at home with the support of the TB CARE II project.

Khokon was 23 when he was diagnosed with TB in 2009. He started the standard TB treatment that lasted for eight long months. After this time period, and to his utter dismay, he learned that his disease had failed to respond to the treatment. Upon further investigation, he was diagnosed with MDR TB. Fortunately, he was

*Khokon is now free from any major complications and getting better every day.*

almost immediately admitted to the hospital and started treatment right away.

The prolonged illness made Khokon physically weak and mentally depressed. Additionally, he was financially broke having lost his small business which was his only source of income. Afraid of infection, his friends and family members stayed away, leaving him alone to fight for his life. It was at this time that the TB CARE II team began to assist Khokon, and with their guidance he was able to see a new hope for survival. He was released from the hospital and continued treatment at home under the supervision of a DOT provider who visits every day to help with his daily medication,



treatment adherence, side effects management, and other follow up clinical support.

Khokon is now free from any major complications and getting better every day. He acknowledges that poor patients like him won't be able to beat the disease without the treatment and nutritional support offered through the project. He is trying to start his business again and believes that sometime in the near future he will also regain his friends and relatives.



# Kawser Is Back on His Feet

*Md. Kawser was one* of the first three patients enrolled in the community based MDR TB program introduced by TB CARE II in Narayanganj. Prior to his diagnosis, Kawser was a marginal farmer living a quiet and healthy life at his village home in Mymensingh. His struggle with TB has entirely changed his life and livelihood. He currently lives in Narayanganj with his wife, a garment factory worker, son, and parents.

Three years ago while living at his village home, he was diagnosed with TB after a sputum test done at the local upazila health complex. He started the standard TB treatment and was hoping to get cured soon. Unfortunately, he showed no improvement after five months on treatment. Kawser was referred to the Damien Foundation TB Hospital in Mymensingh for further investigation and management. He was diagnosed with MDR TB in June 2011, but the treatment could not be initiated for another

*“It might not be possible for me to deal with the complications of the disease and adhere to treatment without the project’s support.”*

four months due to a limited number of beds reserved for MDR TB patients at the hospital.

Kawser has been receiving MDR TB treatment under the home based care system supported by the TB CARE II project. In one conversation with the DOT provider who supervises his treatment on a daily basis, Kawser said: “It might not be possible for me to deal with the complications of the disease and adhere to treatment without the project’s support.” The DOTS provider comes every day to administer drugs and



check his progress. “Without the monthly allowance,” he said in a low voice, “I would never think of eating any nutritional food in my present economic situation.”

Kawser has completed 20 months of treatment and is doing very well both physically and mentally. He is no longer infectious and is happy to live with his wife, son, and parents while on treatment. He has started a tea stall and feels good that he is once again earning an income to support his family.

# Nasima Akter Beats TB Against All Odds

*Nasima has been fighting TB* for the last five years. She also has diabetes. Separated from her husband, she along with her 7 year old daughter live with her mother and younger brother in Narayanganj. She is also fighting to get back her 5 year old son who was taken away by her husband as a result of her disease.

Nasima had no knowledge about TB when she was first diagnosed five years ago. She underwent treatment but did not complete the full course, which is one of the main causes for developing drug resistant TB. After a few months of apparent recovery, she relapsed and started to feel sick again. Her treatment was extended, but was still unsuccessful in improving her recovery. After further clinical investigation, she was diagnosed with MDR TB. Upon receiving this diagnosis, her husband chose to abandon her, taking their 5 year old son with him. She has not seen either of them since they left.

*Nasima now fully understands that she must complete the entire course of treatment in order to be one hundred percent cured.*



Nasima started treatment of MDR TB at the National Chest Disease Hospital in Dhaka. After two months at the hospital, she was happy to come back home to complete the continuation phase of the treatment. The DOT provider, a health assistant from the local hospital, visits her at home every day to administer the drugs and provide counseling for treatment adherence which is so critical for successful treatment. The DOT provider and the local project staff are also vigilant to ensure that she is keeping her diabetes under control.

Nasima is nine months into her treatment. The follow up TB tests were negative, which means she is no longer infectious. Nasima now fully understands that she must complete the entire course of treatment in order to be one hundred percent cured. She looks forward to the day when she will have a job so that she can earn some money and bring back her beloved son to live with her.



*Learn more about TB CARE II and the challenge of TB in Bangladesh at:*  
[tbcare2.org](http://tbcare2.org)

