Phương and An go to the doctor by Paul Mason

with illustrations by Amelia Darmawan
A children’s book about tuberculosis

Written by Paul Mason

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My mum is no longer able to communicate with others, because she has advanced dementia. She can’t walk, she can’t talk, and she no longer recognizes once familiar faces. I have many questions that I will never get to ask her. But, sometimes life presents me with answers to questions I never even knew I had.

As a young child, I remember asking my mum what she wanted to be when she was my age. “I used to want to work with children who were taken to the mountains because their bodies were weak and they needed the healthy air. But, when I finished school, I moved to Australia and they no longer had such places for children, so I became a nurse instead.” She told me. I never knew what these mountain retreats for sick children were, and I never knew why they had been abandoned either. At the time, I hadn’t thought to ask.

After starting research on tuberculosis at the Woolcock Institute, I read several books about the social history of tuberculosis. It was through these books I learnt that the mountain retreats my mum referred to were sanatoria, and the children were most likely tuberculosis patients. These retreats were increasingly abandoned in the 1950s because antibiotic treatment had proven effective. In the 1960s, when my mother entered the workforce, they were no longer to be found.

Tuberculosis was largely eradicated in developed countries due to successful screening programs, effective monitoring, and good medical infrastructure. However, the infectious disease continued to afflict people in developing countries. Despite an effective cure, not all people with tuberculosis were accessing health resources, nor were they always able to complete a lengthy antibiotic treatment program. While the disease was largely forgotten in the first world, it was still devastating the lives of unseen populations in the third world. Multidrug resistant strains of TB found ripe conditions for breeding among people with inadequate and incomplete treatment, and those co-infected with HIV. The disparity between low-income and high-income countries grew with tuberculosis rates under ten per 100,000 in developed countries and in their hundreds per 100,000 in developing countries.

My mother was born in Indonesia, later went to school in Holland, and then migrated to Australia as an adult. I don’t know if she ever learnt the word for tuberculosis in English, her second language. It’s a question I will never get to ask her. However, through the guiding hands of fate, I am blessed to learn that I am working in an area that my mother had once hoped to work in herself. My mother’s condition is not currently curable, but tuberculosis is both preventable and curable.
In 2013, the year I first started research on tuberculosis, an estimated 550,000 children developed tuberculosis and at least 80,000 children died of the disease. Tuberculosis remains an important contributor to global child mortality. I hope this children’s book can help educate children and their families that tuberculosis is treatable and that they should help support those who become sick with the disease. While interviewing patients with tuberculosis in 2014, I noticed that many of them did not have a high level of education. Furthermore, many of them did not have a very good understanding of tuberculosis infection, despite having visited a doctor and specialist healthcare staff. Putting together an educational resource that can be understood by the largest number of people possible is important.

My colleagues and I had the opportunity to pilot this children’s book with a hundred school children in Ca Mau, the southernmost province of Vietnam. On a quiz with ten comprehension questions about the content of the book, no students got more than 2 questions wrong. In fact, fifty percent of students got every answer correct. So, this was an excellent indication that this book is an effective tool to learn about tuberculosis. I hope that copies can be published in many languages and can be distributed to children living in vulnerable communities around the world.

I thank Professor Guy Marks, the Woolcock Institute, and the NHMRC Centre for Research Excellence on Tuberculosis for giving me the opportunity to work in this area. I want to make special mention of Amelia Darmawan who shared her artistry, as well as Kerstin Baas, Alicia Wong, Malin Andersson, Lucy Williams, and Todd Decker for helping fundraise for the project. I also thank all the people who have accompanied me along this journey: Libby Gleeson and Euan Tovey, Stephen and Maria from Eiffel Hot Bread Shop Revesby, the beautiful Puneet Singh, Dinh Thi Nhung my research assistant and collaborator, the staff of the Woolcock in Vietnam, the clinicians and laboratory staff at the Centre for Social Disease Prevention in Ca Mau, the National Tuberculosis Program in Vietnam, members of the International Union Against Tuberculosis and Lung Disease, representatives from the StopTB partnership at the World Health Organisation, and all the people who have donated their time or money to make this children’s book a reality. Together I hope we can reduce the global impact of tuberculosis.

Paul Mason
Sydney, Australia
Thursday, 24 March 2016
Three friends, Truc, Phương and An, like to play together.
When they go bike riding, Phương is very quickly breathless and An very quickly becomes tired. Sometimes they cough.
Phương has an occasional cough and wheeze that can become really bad.
An has night sweats. An has a cough that lasts more than a month. An loses weight. An no longer keeps up with Phương and Truc when they ride bikes.
Phương and An go to see a doctor.

Their doctor listens to their chest to hear how they are breathing.
Sometimes a doctor will also use other tests such as a Chest X ray, a blood check, or a sputum smear. The doctor does not always have to use these tests.
The doctor says that Phương has asthma. Phương talks with the doctor about managing asthma.
Medical treatment for asthma allows Phương to play once more.
An has tuberculosis and goes in for treatment. An’s dad goes in for treatment as well.
Family and friends help support An’s family while they are away for treatment.
“I am sad that An is sick but I am happy that An can take medicine to be cured. I am looking forward to riding my bike with An.” Says Truc.
Truc and Phương call An on the phone.

Truc and Phương write letters, emails and phone messages to An.
After a short period of time, An feels better. An stops coughing but An still needs to complete several months of treatment.
An completes the tuberculosis treatment. Completing the treatment means that An’s illness will not return. An’s dad also completes the treatment.
Other families go in to be tested for tuberculosis, but they are not found to have tuberculosis disease. Tuberculosis will be less likely to spread to others if:

1) more people are checked for tuberculosis
2) people with tuberculosis disease are treated
3) people with tuberculosis disease complete their full treatment
Hygienic behavior helps to prevent the spread of the germs that spread tuberculosis disease.
Now that An has been treated for tuberculosis and Phương’s asthma is being managed, the three friends can play together.
“All kids' books have the power to entertain and to educate but this one can actually save their lives.”
Deborah Abela, author of *Ghost Club* and the *Max Remy Superspy* series

“More than a million children are infected with TB every year. It is important to recognize that TB is everybody's concern, including children. This book allows children to know about TB in a simple, kids-friendly format.”
Dr Isaac Chikwanha, Médecins Sans Frontières

"Educating children about their health is one of the best pledges families and nations can make. This book is a great contribution towards that more than commendable goal."
Diego Armus, author of *The Ailing City: Health, Tuberculosis, and Culture in Buenos Aires, 1870–1950*

“A beautifully written and illustrated children’s book that educates children about the symptoms, diagnosis and treatment of tuberculosis. This book will help to encourage children with TB and their families to seek treatment, and decrease the stigma associated with this disease. “
Dr Jennifer Ho, Woolcock Institute of Medical Research, Vietnam

“May children everywhere be charmed by the story of Truc, Phương and An. Paul and Amelia’s delightful rabbits have a very serious message for all of us: with the right medical care and help for patients young and old, TB can be successfully treated. Read this book and if you need to, let the doctor be your friend.”
Helen Bynum, author of *Spitting Blood: The History of Tuberculosis*