

# where there is a will...

## The story of Berenice

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Based on a  
true story



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**CHATTY, PORT ELIZABETH, NELSON MANDELA BAY - 3 FEBRUARY 2014**

Dear.....

We have never met each other but I would like to write this letter to you because I know how it feels to have TB. I too had to take the TB treatment for six months and I am now completely healed.

In this book I'll tell you my own story. I felt just like you. I was afraid that I will be pushed away. There are many people who believe that we can infect them. That is not true. If we take our pills it kills the germs before they can get to other people. This is true even if you have HIV with your TB.

I am so glad that I tested for HIV and continued with my TB treatment. The worst time was after the first two months of treatment. I felt so much better and then I started to think that I do not have to take treatment anymore. It was a blessing that I could be cared for by a DOT supporter near my home. She was very good to me, I could talk to her about my problems and I could trust her completely. The clinic trained her well. The daily record of treatment helped me to check how soon the treatment would finish. Talk to the sister at the clinic or to the DOT supporter when you feel like it. Do not keep your problems to yourself.

I hope these six months can pass soon. Do not stop until you have finished the treatment. The risk is too great that your TB could become worse. I hope and pray that it will all go well for you!

With many greetings

*Berenice*

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## **TO ALL TB SUFFERERS**

This picture book is based on a true story.

Paid lay actors were used throughout this novella. No assumption should be made about the health status of all persons portrayed in this novella. The TB nurses portrayed are actually based at the health facility concerned. All actors are thanked for their diligent participation.

Any resemblance to actual TB patients is purely coincidental.

This is Berenice with her four young children...



They live in the Chatty area of Port Elizabeth in Nelson Mandela Bay



Berenice has become very depressed...

She has had a nagging cough that will just not go away and now she feels life is getting too much for her.



She is impatient with her husband...

You are late again, Charles. Where have you been?

Why did you become so bad-tempered lately? You did not even greet me!



She is impatient with the children...

Ryan! Chris! You are making a terrible noise! Stop it now! Katie! Shaney! How many times have I asked you to take off your school uniforms?



These kids in this small house make me crazy... they fight all day, they mess in the house. I do not have the strength to handle it all!



So what do you expect me to do? I work all day!

Later, when they were calmer, Charles started listening to his wife...



I have no more energy. I'm so tired that I am unable to do the things I could easily do before. I just cannot get rid of this annoying cough. I'm exhausted!

Just look at how much weight I lost...

My goodness, and I did not even notice!



Later than night...



What is wrong Berenice? Look at how much you're sweating again!

I'm sweating and it's not even a warm night! What makes me sweat like this, Charles?

Berenice was thinking all night about what might be wrong with her ...



I remember Vanessa's mother also became so thin and weak, she had TB. I can surely not have TB? Also, my Uncle Cedric... he became thin and weak, but he had both TB and HIV! I cough so much, just like them ... maybe I should go to the Chatty clinic so that they can examine me there, just to be sure.

**Berenice decided to rather go to the clinic to find out what was making her feel so bad.**



**You say you have already used medicine for the cough. It sounds like you may have TB. Let me examine you and then we do a sputum test to see if you have TB. We can also do a quick HIV test, if you agree. So let me do these two tests, it will not take long.**



**Nurse Adams, I do not know what's wrong with me. I feel so tired and weak. I sweat so much at night that I can't sleep properly. And this annoying cough just does not go away... it makes me so tired that I am losing my appetite and my weight. I am also very worried that this may be HIV!**

**While she waits for the result of her HIV test...**



**This is very bad... Vanessa's mother died of TB! ...and Uncle Cedric, also passed away. What if I'm HIV-positive? Oh no! I am going to die!**



Let's go outside into the fresh air so that you can cough some sputum into this bottle.



Outside the clinic, Berenice coughs and gets a sputum sample into the bottle.

Remember to take a deep breath and cough as hard as possible to loosen the phlegm in your throat. That's it, thanks Berenice!



well, your HIV test is negative, so keep it that way. OK? And now your sputum sample is ready for TB testing at the laboratory. Please come back tomorrow to get your TB results, will you Berenice?



But a week passes by before they speak to each other again, when Nurse Adams goes to look for Berenice and finds her at her sister's house.

Berenice, you did not come back to the clinic for your sputum test result. That's why I came looking for you. What happened?

Nurse Adams, what are you doing here?

I do not always have taxi fare to get to the clinic! Besides, I thought that since I do not have HIV, I can't also have TB, not so? So, my sister and I went to a faith-healer's church to be cured of this tired feeling. That's why I did not come to the clinic.



Berenice, your TB result is positive, so you have TB. We must start your TB treatment immediately! Many people pray for healing from TB Berenice, and that is good, because you will need all your strength to complete the TB treatment. Many faith-healers encourage people to pray and also to take their medication.

I have TB? But I don't have HIV? Don't these go together? Nurse Adams what am I going to do? I do not want to die of TB, my children are too small, they still need me, who will look after them if I die?



TB is curable Berenice, even people with HIV have had their TB cured when they complete their treatment. You need not die! To cure TB you need to take the full six months of treatment, or your TB could become much worse. Fortunately, you can choose a trained treatment supporter to assist you to take your daily medication at home! That should make it easier for you, not so? Berenice, let's go back to the clinic together to start your treatment and you can choose a treatment supporter.



Berenice meets Charmaine, her treatment supporter...

I'm so happy that Nurse Adams suggested that I take my TB treatment at home with your support.



Yes, I will be happy to support you to complete your treatment. In fact, as part of a special project I will need to take a photo of you taking TB treatment each day.

Back home, Berenice is still shocked and very scared. She wonders how she'll manage... her cousin, Ingrid also had TB. Ingrid prayed and completed her treatment. The faith-healer also encouraged her to complete the TB treatment.



So Berenice also prays to God for strength and guidance...



After the prayer she felt better. She is now determined to get treatment and get better.



I trust Nurse Adams, she allows me to talk about my fears and reassure me. I'll take the clinic's treatment and I'm glad that Charmaine will be my DOT supporter to help me take my treatment at home.

Berenice remembers Nurse Adams' advice on a healthy diet and that she should eat fresh vegetables regularly and perhaps even start her own vegetable garden.



I will cook fresh vegetables and a little meat or fish for my family's meals every day. You know, healthy eating is not that expensive ... besides it will be good for Charles and the children as well. I can start my own vegetable garden and Charles and the children can also help me.

When Charles got home, Berenice told him everything...



Don't worry, you will be better again, my darling! The children and I will help you in the house. Six months is not that long; you are soon going to be cured of TB and be well again!



They talked until late and Berenice was happy that her husband supports her. He even told her the story of his cousin, Clarence, who started TB treatment at Chatty clinic. But Clarence needed to go to Cape Town when he got a construction job there. The clinic helped him by arranging his treatment through a treatment supporter at a Cape Town clinic. He completed his TB treatment there and was cured.

The next day Berenice told her neighbour, Thandi, that she has TB and will have to take treatment every day for six months. Thandi's response really shocked her!



TB is contagious Berenice, and I am pregnant!! I don't want my family to get TB. Please stay away from us! Go to a faith-healer rather! Why believe in medication, don't you believe and trust in God for healing?

At the clinic the next day Berenice tells Nurse Adams about her neighbour's reaction.



Nurse Adams, can I infect other people? Will my own family also get TB?

It's really a pity that people react and label others. That's called "stigma". Don't worry, Berenice! TB is curable and as long as you take the pills every day, you cannot give anyone TB. The pills kill TB germs before they can get to other people. And I have taught you how to cough into your elbow, that's just good manners. Since no one in your family has any TB symptoms, and you remain on TB treatment, they cannot get infected from you.

Berenice reassures her neighbour after her visit to Nurse Adams at the clinic...

You should not be afraid of being infected, Thandi. Nurse Adams says that the pills kill the TB germs before they can spread.



Wow, Berenice! I am learning so much from you. I did not know that people with HIV can also be cured of TB! So they only need to take TB treatment every day? No, my friend, I will try to support you where I can. I am so sorry about my reaction. Please forgive me?

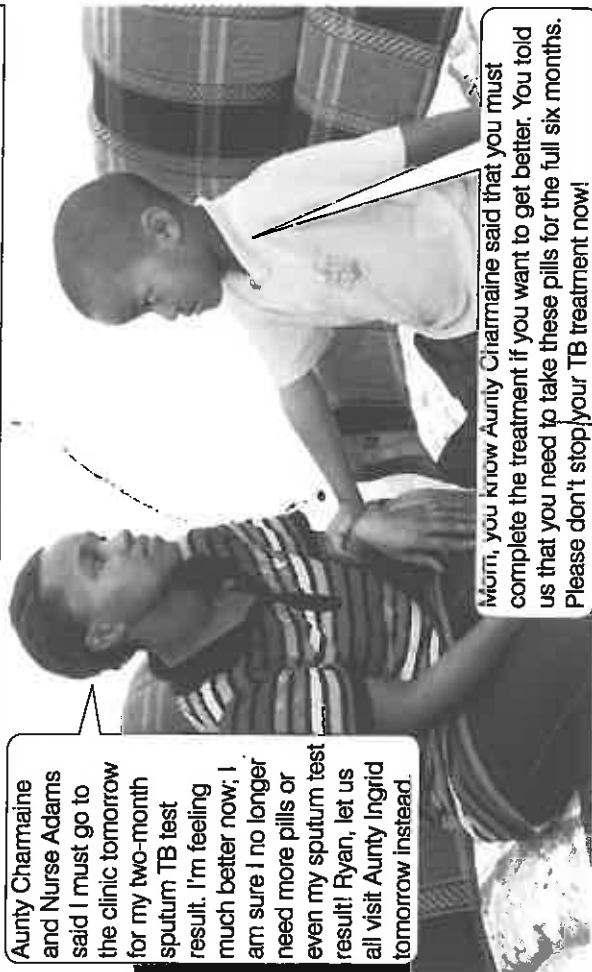
Berenice leaves Thandi as she needed to buy some fresh vegetables..



It feels like everyone is watching me. Do they all know that I have TB? ... do they think I also have HIV? I feel so ashamed. I have to get better. If they know I have TB and see me get cured, that will be a good thing. Nurse Adams says that everyone can be cured of TB, so long as they take their medication.

**Two months later... after giving sputum at the clinic for her second TB test...**

Aunty Charmaine and Nurse Adams said I must go to the clinic tomorrow for my two-month sputum TB test result. I'm feeling much better now; I am sure I no longer need more pills or even my sputum test result! Ryan, let us all visit Aunty Ingrid tomorrow instead.



Mom, you know Aunty Charmaine said that you must complete the treatment if you want to get better. You told us that you need to take these pills for the full six months. Please don't stop your TB treatment now!

**Berenice is so proud of Ryan for caring, so she goes to the clinic where she gets good news...**



Berenice, you were smart to take your pills every day for the first two months. I saw the DOT Supporter's report of the photos that were taken when you took treatment. The outcome of your second sputum test is negative! It shows that you are getting better, but you must still keep taking your pills in order for you to be healed completely.

From now on, you will drink fewer pills. You can still take them from Charmaine.

Yes Nurse, I want to get well for the sake of my family. Having Charmaine's coming to the house has helped me greatly.



**In the following months Berenice continued to take her pills every day. Her family insisted that she gets a lot of rest and helped her with the housework.**



Three months later...

I'm so glad I did not have to go all the way to the clinic every day and stand in a long queue. It was so much easier to take the pills. I'm glad I did not give up! Thank you for your help Charmaine!



Well Berenice! Now there's only one month's treatment and a final sputum test to go! Can you believe we have come this far already?

One month later...

Berenice visits the clinic again the day after her final sputum test at Chatty Clinic.



Congratulations, Berenice! The outcome of your final sputum test shows that you do not have TB anymore. This is your last treatment. You are cured of TBI!

That night Berenice shares the good news with her husband...

Charles, I'm healthy! Nurse Adams says my lungs are completely clean. I'm done with the pills because I am cured of TBI!



Great! Let's celebrate and have a party. We will invite everyone who helped you to recover.

They invited Thandi, who helped to look after the children when Berenice had to take her pills or had to rest ... and Charmaine, who supported Berenice and helped her to finish treatment and some other friends.



I will visit Nurse Adams tomorrow. She must tell all her new TB patients that TB can be cured! If Berenice can be cured, then anyone can be cured!

## HERE IS YOUR TREATMENT SUPPORT CALENDAR

Write down the date you started with your treatment, also write the day you think you will finish the treatment.

Put crosses over a finished week. This will help you to check your progress and it also makes time to go by unnoticed.

Keep it like that!! You will get better.

I started treatment on (date): \_\_\_\_\_

|         |         |         |         |
|---------|---------|---------|---------|
| WEEK 1  | WEEK 2  | WEEK 3  | WEEK 4  |
| WEEK 5  | WEEK 6  | WEEK 7  | WEEK 8  |
| WEEK 9  | WEEK 10 | WEEK 12 | WEEK 12 |
| WEEK 13 | WEEK 14 | WEEK 15 | WEEK 16 |
| WEEK 17 | WEEK 18 | WEEK 19 | WEEK 20 |
| WEEK 21 | WEEK 22 | WEEK 23 | WEEK 24 |
| WEEK 25 | WEEK 26 | WEEK 27 | WEEK 28 |
| WEEK 29 | WEEK 30 | WEEK 31 | WEEK 32 |

I finish treatment on (date): \_\_\_\_\_

Name: \_\_\_\_\_

## ACKNOWLEDGEMENTS

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This educational booklet/novella is based on a true story similar to that of most TB patients. The persons depicted in this photo-novella are lay-actors whose demographic characteristics are broadly representative of the communities they reside in. No assumption or inference of their actual health status should be made based on their appearance in this story.

**LAY ACTORS:**

|              |                     |
|--------------|---------------------|
| Berenice:    | Semondelay Conradie |
| Charles:     | Vusumzi Limba       |
| Nurse Adams: | As herself          |
| Charmaine:   | Chané Bell          |
| Thandi:      | Thokozile Buyaphi   |
| Ryan:        | Keanu Conradie      |
| Chris:       | Mathew Petrus       |
| Katie:       | Fatema Sanud        |
| Shanay:      | Asyatu Sanud        |

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