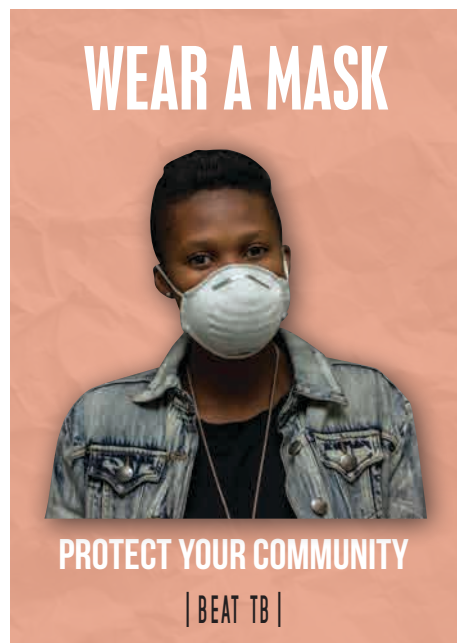


TUBERCULOSIS

addressing the issue in the community

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Above and below: These posters have been produced by the design team for distribution in the community. If you or your organisation would like to use these posters, contact Bronwyn Slater at g11s4801@campus.ru.ac.za or Danielle Vorster at g11v2819@campus.ru.ac.za.

Hospice is here to help

JAMIE-LEE DORMEHL

Hospice has a bias associated with it. People who should go to Hospice for help and support avoid going because of the stigma, attached to it.

Previously, Hospice's motto was "helping the dying live until they die..." This is no longer their motto. Instead Hospice now grants patients palliative care; an approach intended to improve

the quality of life of patients and their families who are facing problems associated with life-threatening illness. Quality of life improves when an individual's experience and expectations change.

At Hospice they aim to prevent and relieve the suffering of patients. They strive for total care; to identify the illness at an early stage and grant patients an impeccable assessment as well

as treatment of pain and other problems, physical, psychological and spiritual.

Health providers at Hospice aim to create open and honest communication with their patients. There should be a mutual respect between the patient and the nurse.

Information is made available in words that are clearly understood by the patient in order for a mutual agreement of care and treatment options to be made.

It would be beneficial for the Grahamstown community as a whole to dismiss the negative ideas associated with Hospice and come to realise that they are not only there for end of life care but also for the prolonging of it.

Hospice aims to walk down the road of illness with their patients ensuring the best possible outcome and aiming to celebrate life and give support.



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I will do you proud

Mandisa defies TB to spread a message of hope throughout the Grahamstown community

JAMIE-LEE DORMEHL

She has a voice full of tension and optimism, and a smile that creates an everlasting glow.

Mandisa Shannon de Bruyn radiates positivity as she says; “I’ve made it through, I am still here”. The 35 year old widow who survived Tuberculosis has given her life to the Grahamstown TB Care Society for three years, spending her days counselling patients with TB at a local clinic in Grahamstown.

Raised by her grandmother in Grahamstown, Mandisa has moved around trying to make ends meet; from Grahamstown to Johannesburg to Bloemfontein. But she always comes back home to her family and friends in Grahamstown who provide her with the support she needs.

She married Alvin Barry-John de Bruyn in 2008 and the couple have two children; Lee-Anne, 5 and Randall, 4. She also has a third dependant; Mbaso, 9, who lives with her grandfather.

“I had a very challenging year,” says Mandisa, as she describes her daughter Lee-Anne’s first year of life which was spent in hospital. Unaware of how, or why, both Lee-Anne and herself contracted TB, Mandisa considers herself lucky to have detected it early. She just knew after experiencing a non-stop cough that sounded like nothing she had ever heard before, that there was something wrong.

Unlike other people who may experience weight loss and night sweats as well as other symptoms, Mandisa and her daughter only experienced a “different” cough and got tested early enough to prevent the symptoms from getting worse. After about three days of the initial treatment Mandisa said she felt better.

She says that the first two months of treatment were the worst, but she did not experience any side effects. Mandisa had to walk daily for 30 minutes to the clinic for the first two months of treatment.

Mandisa says that a mistake a lot of patients make is the delayed diagnosis of TB.

Leaving the treatment for too long can have detrimental repercussions on patients’ lives as well as on the lives of their families.

Patients wait until it is too late and they are too weak to be treated. Not only is Mandisa familiar with the benefits of early treatment, she is living proof.

She is also familiar with the detriments of TB, having used her pay cheque to travel to Johannesburg at the end of June 2013 in order to visit her ill husband who had eventually agreed to take the same TB

treatment.

Arriving at the hospital where Alvin was at 2pm on 4 July, Mandisa was 10 minutes too late... She was too late to see her husband for the last time — too late to say goodbye.

Mandisa lost her to the disease, leaving his son Randall with a memory of his daddy “sleeping” in a box. He could have survived; everyone can survive if the correct procedures are followed.

Unfortunately, many TB sufferers are ashamed of the stigma which surrounds it and thus avoid going to hospital for treatment. Talk in parts of Grahamstown is that it’s the government’s fault, for placing TB in the same category as HIV. The truth is that one can have TB and be HIV negative; and vice versa.

Alvin was extremely stressed as he worried about young Lee-Anne who had been very ill. He lost his job and struggled to provide for his family, all external factors which contributed to the severity of the illness, sapping the strength of his immunity system and making him vulnerable.

People “outside” are far too judgemental says Mandisa; “they judge too hard”, but she has grown strong and does not care what people think of her or say to her.

“I am me, I am living for me and my children, I believe in me,” says Mandisa. People should not allow others to stigmatise their life. Mandisa aims to find people who are “running away” from the medication and explain to them that this is uncalled for and dangerous. Using her own struggles and success with TB as motivation, and the story of her husband as a cautionary tale, she hopes to get a few converts to the medication.

Making morning porridge used to be a task she shared with Alvin, Mandisa says; and now it’s hers alone. This fact and many other difficulties motivate Mandisa to read and learn more about TB in order to teach other people about it. She uses her opportunity as a counsellor at the clinic to “show something” to people. She practices as a motivational speaker allowing people to experience a practical example.

“This is me,” she says with a smile, “I am me.” She is an extremely positive person who acknowledges that people are sometimes unable to imagine the hardships she has been through. “Life is good,” she says, “I’m enjoying my life.” Overcoming difficulties one day at a time, Mandisa stretches her heart out to others. She now lives for her children, hoping that one day when her husband sees her again, he will be proud.

Life after Tuberculosis

Mandisa de Bruyn is a survivor of Tuberculosis, an inspiration to all TB patients. Kendal Quicke documents how Mandisa inspires others.





“I’ve made it through. I’m still here.”

1: Mandisa gives an example of the medication that TB patients take in the first week of diagnosis. Mandisa was diagnosed early and made a full recovery.

Photo: Kendal Quicke

2: Mandisa de Bruyn stands outside her work in the Joza Township, Grahamstown. Mandisa is a TB survivor. **Photo: Kendal Quicke**

3: Mandisa speaks to a patient with TB at her work. Mandisa counsels people with TB, encouraging them to take the full course of treatment in order to recover.

Photo: Kendal Quicke

4: Mandisa embraces her daughter Lee Anne who, like her mom, is a TB survivor.

Photo: Kendal Quicke

5: Mandisa looks at a photograph of her late husband in her home. Her husband passed away on 4 July 2013 from TB.

Photo: Kendal Quicke





Nandi Mandla behind the front gate of her home in Grahamstown. Because of the stigma attached to Tuberculosis, she feels ostracized, spending most of her time at home. **Photo: Megan Fischer**

Keeping strong in the face of stigma

ANDREW TOMBS

"Sometimes I feel frustrated and angry. It feels like I'm trapped in something, that my life is being put on hold."

These are the words of Nandi Mandla*, a sufferer of Extreme Drug-Resistant Tuberculosis (XDR – TB) which has rendered her "trapped" and deaf. Mandla's story is one of disappointment with a system that was meant to protect her.

Early in 2012, Nandi started experiencing symptoms of Tuberculosis (TB), which included weight loss, a loss of appetite and the presence of a persistent cough. At the time she had thought that her symptoms were those of the 'flu, and not of TB.

Mandla decided to get it checked out, but found that the two doctors she went to were unable to diagnose her, and the day clinic merely gave her medication for her 'flu'. With her symptoms persisting, she decided that the next step was to go to the Themba Hospital to get tested for TB. Mandla tested positive for TB.

She was immediately started on medication, but after a month she was told

that her TB had mutated to Multidrug-Resistant TB (MDR – TB) and as a result she was transferred to the Marjorie Parrish TB hospital in Port Alfred, where she was to receive her new treatment for MDR – TB.

This is where the system started to fail her. The ambulance driver sent forgot to pick her up, which resulted in her having to wait two more weeks without proper medication. She was then put into an overcrowded ward.

"I remember asking the nurse if one of the patients was meant to be in there with us, as she seemed a lot worse than us.

"The nurse then admitted that she was meant to be in a different ward, but there were problems with space so she was kept with us." Mandla believes that it was due to the fact that she wasn't at Marjorie Parrish earlier and the unmonitored presence of the pre-XDR – TB patient, that she progressed from MDR – TB to XDR – TB and subsequently became deaf.

"The doctor was never there. If you got sick today and you needed some kind of pill, you would go to the nurses' room and ask for it. But you would then get told that the doctor needed to sign for it, and

she'd only pitch up two weeks later." To Mandla, the experience at the hospital made her feel like she was nobody: "You were just a sick person there, all you had to say was yes, yes, yes.

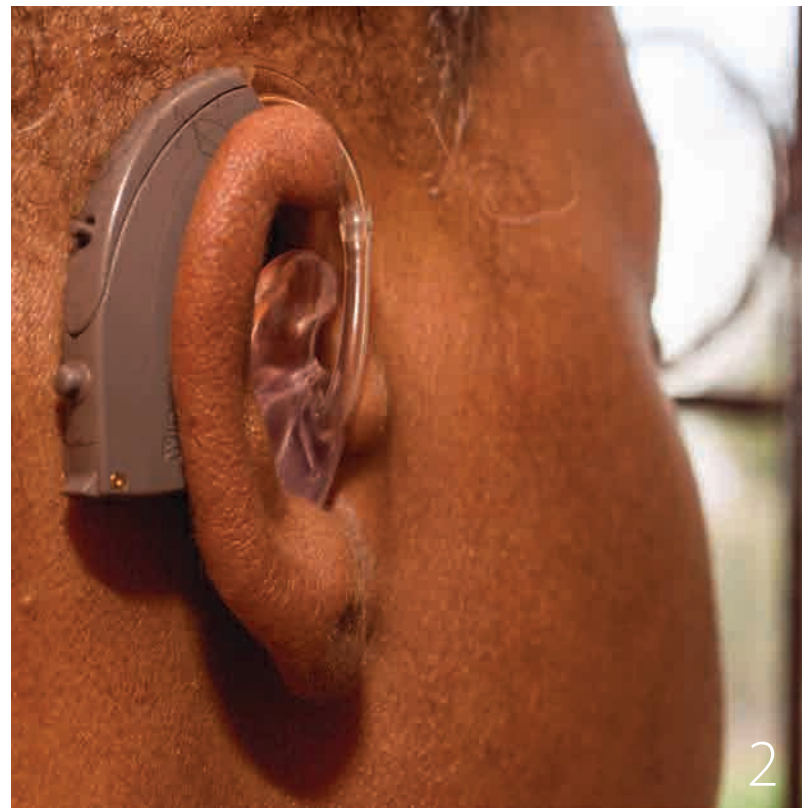
"You don't want to send your family member to such an institution."

She lost her hearing as a result of this lack of care, as she was being given the wrong dose of Capreomycin for her weight and wasn't properly monitored. She also points to her hand where she was scarred from the misapplication of an IV drip that made her hand swell up to twice its size, and gave her extreme pain in her arm.

She admits that it is difficult living with TB. But she still manages to keep a positive attitude. Mandla believes that TB is a problem and, like all problems, can be solved.

"There is a stigma present. There is pity present. But if you have the right support system, you can get through it. If people could just be more aware, it will be solved."

* Nandi Mandla is a pseudonym used to protect the patient's identity.



1: Nandi Mandla holding up her Terivalidin medication. Terivalidin is one of the 28 pills she takes per day. **Photo: Megan Fischer**

2: Mandla has Multiple Drug-Resistant Tuberculosis. She lost her hearing due to her being given too much of the drug Capreomycin. **Photo: Megan Fischer**

3: Mandla's Tuberculosis medication. After being diagnosed with multi drug resistant Tuberculosis, Nandi has been on treatment for eight months now. **Photo: Megan Fischer**

4: Although Mandla's eyesight has not been affected by her Tuberculosis or treatment, it is not uncommon amongst TB patients to have their eyesight affected. **Photo: Megan Fischer**

5: Holding her mother's hand for support. Mandla's mother lives with her and helps her around the house. **Photo: Megan Fischer**



Min'emnandi yokuzalwa

The editorial team would like to thank those involved in making this birthday party a delight

JAMIE-LEE DORMEHL

Lee-Anne de Bruyn turned five on Monday the 14th of October 2013.

Many of her previous birthdays had been spent battling Tuberculosis in hospital.

Having met Lee-Anne when interviewing her mother (Mandisa Shannon de Bruyn) about their struggles and successes with

TB, Kendal Quicke and myself came to realise it was soon to be Lee-Anne's birthday and that her mother was unable to provide her with a party to celebrate her life. A life that is worth being celebrated; a life that has overcome many challenges for such a young age; a life of a little princess.

After being positively moved by Mandisa's enormous heart and her optimistic approach on life regardless of the hardships she and her family had been through, we decided to take it upon ourselves to give Mandisa the opportunity to give Lee-Anne a celebration to remember. On telling Mandisa our intentions she asked us if this was a dream.

On 13 October 2013 we hosted a hugely successful party at Mandisa's home in Joza. A party that would not have been the same without the kind-hearted community members

of Grahamstown who assisted with donations and sponsorships. Everybody who attended the party was grateful for the effort which had been put into the party.

Scoobedu Jumping Castles kindly donated Lee-Anne and her friends with a jumping castle for the afternoon which they played on enthusiastically for as long as possible. Home Industries donated a beautiful large pink cake for Lee-Anne to blow her candles out on. Checkers was kind enough to provide rolls for the hot dogs and boerie rolls.

Tip Top Butchery gave us an enormous discount on *wors* and viennas.

Vineyard and Buddy's Liquor Store donated cans of cold drink to the party. All of this made a substantial difference in the success of the party. And a great success it was. Rhodes University SRC sat alongside us in the Kaif as we were granted with extremely generous donations from the students at Rhodes University, without which the party would not have been possible. We were bowled over by the giving hearts of the students. The party was a huge amount of fun and was enjoyed by everyone.

A huge thank you to everyone who helped us in making someone's dream come true.



The cake at Lee-Anne's party was sponsored by Home Industries situated in Pepper Grove Mall. **Photo: Kendal Quicke.**



Lee-Anne and her mother Mandisa De Bruyn stand in front of the jumping castle in their garden in Joza Township. Both mother and daughter were thrilled about the event.

Photo: Kendal Quicke.



Kendal Quicke, Jamie-Lee Dormehl, Mandisa and her two children Randal and Lee-Anne pose for a photograph at the end of a happy fun filled day. **Photo: Kendal Quicke.**