

From: Rebecca Baldock

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Hello, hope you are all ok and have not been too badly affected by the flooding.

Last night there was a party for the leprosy patients. A couple of people from Joanne's church had given her some money which they decided to use to buy meat and sodas for the patients on the leprosy ward (Joanne is my physio colleague from Ireland). People with leprosy get all their treatment and food here free, as they are supported by the German Leprosy Mission. However like with schools and other institutions the food is very basic. In the community these people are still often very poor so again wouldn't have a great diet. They were all very excited about their party and set up a committee to organise what would be brought and how the food would be prepared.

Social do's here are always quite formal. A program is written down as to what will occur. There's an opening prayer then introductions to who people are, and different speeches. Last night after everyone had eaten, many of the people got up to say thank you for the evening. It was very touching. Two of the people had been young Leprosy patients when the hospital opened in the 50's. They reported that over all the years no one had ever given the patients a party.

Before reading up on Leprosy, my impression of it came from the Bible and the film "Robin Hood Prince of Thieves". I had a image of people with a disease that turned skin flacky white and caused fingers to just fall off.

Leprosy is in fact a bacteria that affects mainly peoples skin, nerves and eyes. It is spread from a untreated infectious person through droplets from the nose, which are then inhaled by a person with a poor body defence system. Leprosy can be cured and a person who is on medication for a week is no longer infectious. However the damage that has already been caused by leprosy is irreversible. Leprosy mainly results in things like patches on the skin, loss of sensation and sometimes poor functioning of certain muscles - due to nerve damaged.

Before reading the next paragraph take a few moments to imagine a world without pain. Think about all the times we take painkillers ...

This abstract is taken from "The Gift of Pain" pg 3-5 by Philip Yancy and Paul Brand. It's a very sad, but good illustration of the gift of pain. Don't read if you are squeamish

"Tanya was a four year old patient with dark, flashing eyes, curly hair, and an impish smile. I examined her at the national leprosy hospital in Carville, Louisiana, where her mother had brought her for a diagnosis. A cloud of tension hung in the air between the little girl and her mother, but I noticed that Tanya seemed eerily unafraid. She sat on the edge of the padded table and watched impassively as I began to remove blood-soiled bandages from her feet.

Testing her swollen left ankle, I found that the foot rotated freely, the sign of a fully dislocate ankle. I winced at the unnatural movement, but Tanya did not. I resumed unwrapping the bandages. 'Are you sure you want these sores healed, Young lady?' I said, trying to lighten the atmosphere in the room. 'You might have to start wearing shoes again.' Tanya laughed, and I thought it odd that she did not flinch or whimper as I removed the dressings next to her skin. She looked around the room with an expression of faint boredom.

When I unwrapped the last bandage, I found grossly infected ulcers on the soles of both feet. Ever so gently I probed the wounds, glancing at Tanya's face for some reaction. She showed none. The probe pushed easily through soft, necrotic tissue, and I could even see the white gleam of bare bone. Still no reaction from Tanya.

...I asked her mother about the foot injuries. 'They began as soon as she learned to walk' her mother replied. 'She'd step on a nail or thumbtack and not bother to pull it out. Now I check her feet at the end of everyday, and I often discover a new wound or open sore. If she twists an ankle, she doesn't limp, and so it twists again and again. An orthopaedic specialist told me she's permanently damaged the joint. If we wrap her feet for protection sometimes in a fit of anger she'll tear off the bandages. Once she ripped open the plaster cast with her bare fingers.'

Tanya suffered from a rare genetic defect known informal as 'congenital indifference to pain' She was healthy in every respect but one: she did not feel pain. Nerves in her hands and feet transmitted messages about changes in pressure and temperature - she felt a kind of tingling when she burned herself or bit a finger - but these carried no hint of unpleasantness. Tanya lacked any mental construct of pain. She rather enjoyed the tingling sensations, especially when they produced such dramatic reactions in others.

'We can get these wounds healed' I said ' But Tanya has no built-in warning system to defend her from further injury. Nothing will improve until Tanya understands the problem and consciously begins to protect herself'

Seven years later I received a telephone call from Tanya's mother in St. Louis. Tanya, now eleven, was living a pathetic existence in an institution. She has lost both legs to amputation: she had refused to wear proper shoes and that, coupled with her failure to limp or to shift weight in standing (because she felt no discomfort), had eventually put intolerable pressure on her joints. Tanya had also lost most of her fingers. Her elbows were constantly dislocated. She suffered the effects of chronic sepsis from ulcers on her hands and amputation stumps. Her tongue was lacerated and badly scarred from her nervous habit of chewing it.'

Tanya's particular problem occurs rarely, but such conditions as leprosy, diabetes, alcoholism, multiple sclerosis, nerve disorders, and spinal cord injury can also bring about the strangely hazardous state of insensitivity to pain. Ironically, while most of us seek out pharmacies and doctors in search of relief from pain, these people live in constant peril due to pain's absence."

Like my earlier images of Leprosy - it was originally thought that leprosy caused peoples flesh to be rotten and just rot away. Dr Brand discovered that this was not true. The reason that these patients get awful sores and ulcers and often have amputations, is purely because of the damage caused to the nerve and the loss of sensation it brings. These people no longer feel pain in their feet or hands, for example - they have nothing to tell them that the pan they are touching is too hot, so they get burnt. That their shoes are rubbing, or that they have stepped on a nail etc. These wounds then get infected, and if they do not heal can cause them to have to have amputations. In effect they are destroying parts of their body unwittingly because they can no longer feel. Most of the people treated in the hospital are old leprosy cases. They have been cured of their disease years ago, but they still get ulcers and wound problems due to the damaged nerves.

There is still much stigma against leprosy in the community, which will ultimately be as a result of fear. A lot of the work done with these people now, is not only treating them for their wounds, but also educating them on ways to care for and monitor their skin. For example most leprosy patients would get special shoes made, to make sure they are wearing shoes, but also so they are made from soft leather which is less likely to rub and cause blisters. We also have an occupational therapist who works with them to help them socially and economically in the community. He's taught a few of them to make clothes. And many of them now have pigs which they look after and can make a income from the pigs they produce. This not only helps them financially, and to be able to stop begging, but also gives them some respect in the community

Interesting facts about Leprosy

Your Vaccination against TB also gives you immunisation against Leprosy, and it is said to give a greater immunisation against Leprosy then TB

It affects people with a very poor body defence system, which is only about 5% of the population.

In the past it was found on every continent. Now it is only found in three continents, Africa, Asia and South America

If you are interested in reading more about Leprosy. It is worth reading a book about Dr Paul Brand, who dramatically changed the treatment of people with Leprosy and what is known about the disease.

Ten Fingers to God - by - Dorothy Clarke Wilson His autobiography

Or

The Gift of Pain - by Philip Yancey and Dr Paul Brand

Love Becca

Prayer points

Please pray for people with Leprosy as they continue to struggle to be accepted in the community

I've just had a school friend here at Kagando for 3 weeks, which has been great. She's now about to travel round Uganda with one of her uni friends for another 3 weeks. My parents are also preparing to come and visit in two weeks time. So please pray for safe travels and for a good time to be had by all.