

NEWSLETTER KUMI HOSPITAL UGANDA

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DO NOT UNSADDLE YOUR HORSE by Margaret Philips



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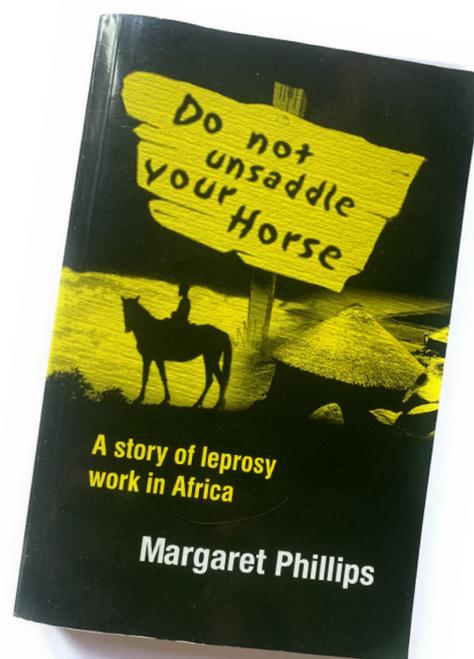
-the notice at the gate made me shudder.

Not even my ten years working with crippled leprosy sufferers in Uganda had prepared me for this level of stigma. Just how was I to begin in my work as Leprosy Control Officer in Lesotho? This is my story: I describe how I grew up during the war, trained and worked as an occupational therapist and became involved with Church youth work. Reluctant as I was to leave England, I went to Uganda in 1965 to replace a close friend at a large leprosy centre. Resources were limited and problems increased with the arrival of Idi Amin. There are tales of some remarkable Ugandans, of the struggle to work in a small expatriate community and of the way God provides in times of trouble. In 1977 I moved to Lesotho, Southern Africa, and the efforts to improve the care of leprosy sufferers are described with many individual stories. The final chapters tell of the problems I experienced on returning home after twenty-one years: seeking employment and adjusting to an affluent society, while still maintaining valuable links and firm friendships from the richness of Africa.

Margaret Phillips

Chapter 5 Where do I fit in?

Chapter 6 Shoes, limbs and Leprosy



Chapter 5 Where do I fit in?

“Mon Dieu! We shall not arrive, C’est terrible!”

The timid little French lady sitting beside me on the plane started to panic. We had been airborne for only twenty minutes when the plane bumped several times and the Captain made an announcement: “Ladies and gentlemen, we have a slight engine problem, so we are turning back to Gatwick for some checks. We are off-loading some of our fuel over the Channel so that we can land. I apologise for the inconvenience.”

“We shall not arrive!” my companion repeated. I smiled at her. “Oh, yes we will,” I said confidently. God had called me to Uganda and I was certain he was going to get me there in one piece. “It’ll be all right, you’ll see.” And of course we did arrive safely. The Reverend Norman Campbell, who was the C.M.S. Representative for Uganda, had written me a welcoming letter in which he had told me to sit on the right hand side of the plane so that I could see the sunrise over Lake Victoria, as we circled around and came in to Entebbe airport from the south. We were far too late for the sunrise because of the delay but it was exciting to be coming in to land. I was met by Norman’s wife, Irene, who had been patiently waiting to drive me the half hour ride to Kampala. Irene spoke about the possibility of some political unrest that week and the reasons for this. It was not the sort of introduction I was looking for. I was feeling strange and wanting to take in what I could actually see, hear and smell. Later I jotted down my first impressions: ‘Looks like Africa! Plants, etc. Banana trees, tall palms, red earth, gaudy flowering trees....’

But-it all seems so strange: the smell, the atmosphere, the moist heat and shrill cry of birds, crickets, etc; the horrid, shabby shops all reddened with dust: the swarms of Africans living in scattered shacks and the contrast of these to the fine Kampala buildings: the realisation that I cannot communicate with these people or understand how they think and live..

I needed time to take it all in but I was five or six hours late and Norman Campbell had made a very full orientation programme for me which, because of the delay, was due to start at once. He gave me a briefing almost as soon

As I had arrived as his big mission house on Namirembe Hill. This included warnings about listening to what senior missionaries have to say, and the importance of having time for people and of simply sharing with them how Jesus helps you day by day rather than preaching at them.

And remember,” he said, “If people annoy you, you probably annoy them just as much.” This last remark obviously highlighted his own experience of living in a small expatriate community. I was later to learn what a sound comment it was. I was allowed an hour to lie down before the evening meal. The Campbells had invited an Ugandan lady who had just returned from studying in the U.K. and now held an important post in the Ministry of Education. It was part of my orientation to meet her because she ‘saw things from the European angle. Most of the discussion was difficult for me to understand and I was too tired to make much effort. I was glad to get to bed.

During the following week I was taken to many different places in and around Kampala by various people, most of whom were C.M.S. missionaries.

These people impressed me. They all had such worthwhile jobs and they were very dedicated. I felt first there was very much the newcomer.

First there was, Namirembe Cathedral, the Uganda Bookshop and the smart little museum. Then back to Mengo Hospital for the official opening of a physiotherapy pool, donated by the Rotary Club. I heard about the many polio clinics that were being set up around the country by Mr Ron Huckstep, a consultant orthopaedic surgeon. He was doing great work in registering hundreds of polio victims, straightening up their contracted limbs and getting them to walk with simple callipers and wooden shoes. "There's a long waiting list," one of the physios told me. "

"Well, begging is more profitable if someone is seen to be very disabled.

A beggar who can only crawl will do very well on a Friday when Moslems are supposed to give alms."

Ron Huckstep was clearly involving the physiotherapists in all his plans and it seemed that his enthusiasm was infectious.

I was taken to Makerere University, a large Catholic mission at Kisubi, which included a secondary school, and to several rehabilitation projects that provided training for disabled people in agriculture, tailoring, leatherwork and so on.

Then on my first Sunday the enthronement of a new Bishop was taking place and it was suggested that I should go. I felt rather self-conscious as I made my way up the hill to the Cathedral. I was a white person on my own in the midst of so many enthusiastic Ugandans all dressed in their beautiful, Sunday best clothes.

People with tickets had to be in their places early. I had no ticket. I stood watching the important people arrive: Dr Milton Obote - the President of Uganda, numerous Bishops, the Archbishop... As the service started edged up the steps of a side door. There were so many police around that I didn't like to push in.

Two or three children wriggled inside and two women, begging to enter, do so.

Then a policeman turned to me: "You go in if you can find somewhere," he said, "but there are no seats." I smiled gratefully and squatted beside some Ugandan ladies, one of whom offered me two grubby handkerchiefs on which to sit.

There was a printed service sheet with the English version of the hymns beside the Luganda, so I was able to join in. The retiring Bishop was handing over to the new Bishop Nsubuga- 'his brother'- and his words were translated into English. It was quite emotional. Then came the Communion. 'How can they manage with so many people? I wondered: but it all happened in an orderly way and there was a great feeling of awe and oneness. Shelters had been erected outside for food for the invited guests. I wandered up again in the afternoon and the festivities were continuing in an atmosphere of revival.

My orientation continued the next day with visits to various offices in Kampala with Irene, to apply for my driving permit among other things. We continued to Mulago Hospital to talk with the staff of the orthopaedic workshop and then drove back to Mengo hospital to see the physiotherapy department in action. Finally we went to a slum area of the city -a real shanty-town – with shacks, squalor and crime. Groups of men were sitting around beer pots drinking through long tubes. “Most of these people are from up-country,” Irene said. “They come to the city thinking the streets are paved with gold, but there’s no work for them and they end up as thieves. They often drink right through the day and then there are arguments and fights at night. It’s very sad.”

I tried to take it all in, but how glad I was when Jane arrived. She was sympathetic when she saw the programme I had completed. “They made you do all this! You must be exhausted. Kumi is very different to Kampala so a lot of this is irrelevant anyway. “It was interesting though,” I said, but from the way she spoke I realised that I would need even more orientation when I reached the Leprosy Centre. I hoped it would be of a more gentle nature. ed to have arrived. We went shopping together for things I would need, including cutlery, cups, saucers and plates.

“It’s important to o have a design you really like,” Jane said, “Even if it does cost a bit more. I was reluctant to spend so much, but I obediently chose some attractive crockery. Later I realised that her advice had been good. It is important to have some items of daily use that you really enjoy when you are living in a very basic way.

We collected my driving permit and when Jane had finished all her other jobs and picked up two boys who had been admitted to Mulago Hospital for surgery, we set out for Kumi. “I’ll drive to Jinja and then you can do the next bit to Tororo,” Jane said. “That part isn’t so busy.” We passed a forest area with enormous trees, huge coffee and tea plantations and open savannah with boys herding small groups of cattle. The drive gave us the chance to talk while the two boys in the back seat were silent and wide-eyed at all they were seeing. We shopped for fruit at road-side stalls, buying quantities of tangerines, oranges (all green skinned), a big stalk of little fat bananas as well as a few pineapples. The journey took us due east, but at Tororo we turned north, passed Mbale and completed the last thirty miles to Kumi on a narrow but smooth tarmac road.

I was now seeing the district of Teso for the first time. It s evening and it looked golden as the sun stretched its beams across the flat savannah grassland. Little thatched homesteads snuggled in among the long grass. Boys ambled home with their cattle. We gave wide clearance to the few cyclists, for they behaved as if no other traffic used the road; it was certainly different to the busy streets of Kampala. We reached the small township of Kumi as the Indian shopkeepers were lighting up their dukas (shops) with candles and lamps. I was glad to have arrived.

The 200-mile journey had taken us four hours. Jane showed me to a Guest House, close to hers, where I was to stay. I was at once rather sick, so she packed me into bed, arranged a mosquito net over me and left me to fall into a hot and fitful sleep. The next day I felt poorly. I potted about but spent most of the day sleeping. However, on the following day I had recovered sufficiently for Jane to show me around. "The Centre is very spread out," she explained. "My house is two miles from the children's compound where we have 300 children with leprosy. Then five miles further on is the adult part of the Centre at a place called Ongino. That land was given because it was considered to be unhealthy. It's low lying and there are a lot of mosquitoes. A house is being built for you down there where most of the other expatriates live but it's not finished so you will be in the Guest House for some weeks yet."

So we set out for 'unhealthy Ongino'. It was Saturday. We went to see the hospital and some of the patients. There was a relaxed, happy atmosphere and the patients were laughing and chatting with Jane. "What are they saying?" I asked her.

"They say that we look like sisters and they are very pleased to see you. You must greet them: 'Yoga' is what you say. It means 'Hello', 'Good morning', 'Good evening, or anything like that, so it's easy."

I was surprised at what I was seeing. I had thought the patients would be locked up and crouching in corners of dark buildings but here they were enjoying a spacious compound. Yes, many were very crippled, but the place was attractive with whitewashed buildings and gay flowering trees. We had coffee with Kay and Eric Johnson. Eric was a LEPRO worker (Leprosy Relief Association) and he and Kay were from Yorkshire. As Farm Manager, Eric had built up a special herd of cattle by crossing Red Polls with the local Zebu. He had cleared many acres of bush and erected miles of fencing to form paddocks. It was a tremendous contribution not only to the Centre but also to the district. It showed what could be achieved with sufficient effort even in such an unlikely place as Ongino, Eric had Bougainvillea trees to the area and the Centre boasted over a hundred varieties. He had planted large orchards with all kinds of citrus fruit trees, pawpaw, guava and pineapples and he had pioneered bee keeping. All this helped greatly in the fight against the stigma associated with leprosy.

Kay Johnson was a nurse but she was fully occupied with her three young children as she was teaching the two elder ones at home.

They were all very much at home in Uganda, playing happily with the local children and enjoying the freedom of outdoor life. Bobby, the eldest, was an enthusiast for any sort of wild life. "Would you like to see my stick insects?" he asked me.

Kay laughed. "I'm sure she wouldn't! But why not bring the monkey to show her. He's much more fun." The monkey had been found injured somewhere and he was being looked after with the best possible care and attention.

He was duly displayed and admired. The expatriates totalled nine adults and Maurice and Janet Lea headed the team.

Maurice had left a thriving general practice in Devon to become a C.M.S. missionary at the age of fifty. He had been Medical Superintendent at Kumi for twelve years, so he was somewhat of an authority on leprosy. Janet was a social worker, but she was involved in a host of different jobs, ably supporting Maurice and together they acted as mother and father for the younger expatriate staff. They were very loving and caring. "Don't worry how long it takes you to get used to the place," Maurice said to me, and I knew he meant it. It wasn't easy though. I wanted to make my contribution so badly and everything was new to me. I couldn't see where I fitted in. "Will you be happy here?" one of the Leprosy Assistants asked me after I had given a talk at the Christian Fellowship meeting. "Yes," I said firmly. I could still be sure of that. I knew God wanted me there and I just had to work through the strangeness and find my place. In a way it was an anticlimax. My preparations in England had gone so very well that at times I had almost wished for something to go wrong so that it would seem real, but now I was struggling and I didn't like it. After a few weeks I became sick again. It was late on a Saturday night. I vomited so much that I became desperately weak. I decided that I must get to Jane's house before I was too feeble to walk there. Jane was wonderful. She turned out of her bed and made me comfortable in it. Then she called Dotty, her neighbour, who was the children's nurse and one of the LEPRO workers. Dotty Jordan, a very blunt person who always said exactly what she thought, was from London. She had a great deal of experience of medical work in Africa and was somewhat older than Jane and me.

"We'll get you sorted," she declared good humouredly, "We can just make a night of it." I was still being sick but she bustled around finding tablets and drinking water. It reassured me to realise that she and Jane would stay with me till I was able to settle down and sleep. Over the next few days no one appeared to be concerned that I was so poorly, neither did they suggest that I had malaria because I was taking the wrong prophylactic tablets. Eventually I obtained a supply of Paludrine, and once I had recovered, that saw me through the whole of my time in Uganda without another attack. The house that was being built for me at Ongino was nearly finished and just before Christmas I was able to move in. Jane had drawn the plans for it and I realised now that it would have been hers had she not been moving to Addis Ababa. 'So this is the house the Lord had for me while I was hunting for one in Ryarsh', I mused. 'How good the Lord is!' I felt it was rather like getting married. Someone took me to Mbale to show me where I could buy some more household goods: a pressure cooker, an egg poacher, a kettle, an iron, curtain material and material for uniforms as well as some groceries.

Janet came to chat with me, expressing her concern that I might find it difficult to manage on the allowance I was receiving, as it was so much less than my previous salary. "No, I'll manage," I assured her. "I've always been careful with money and these expenses won't be repeated." As with most new houses there were various things that did not work properly and these proved difficult for the builder to put right. It seemed as if some of the workmen had never seen a flush toilet before - (all the older staff houses had outside, 'deep-drop' latrines). They were delighted that it worked when one man stood on the seat pouring water into the tank above as if that was what had to be done every time it was used. Some of the light switches were a bit odd but I didn't want to make a fuss. "You will need a houseboy," Jane told me. I was reluctant to agree to this but Jane went on to explain that it was kind to give the local people work. She had employed a young man called Elimilech for seven years. "I had to teach him everything - how to wash and iron, make the bed and cook, but he is really useful now. Perhaps he will agree to work for you when I leave. It's much further for him to cycle - eight miles each way, I suppose - but we can ask him." Elimilech agreed. He was used to receiving regular payment and feared being redundant. Over the years he had used his meagre wage wisely. He had managed to pay the bride price for his wife and build a little homestead and he was very proud of these achievements as well as his small son, Oumujal. We visited him at his home one day and his wife served us with tea, bananas and roasted groundnuts in their spotless mud and grass roofed house. For a few weeks I employed a young man called Gerefasio as houseboy. He had never worked in an expatriate's house before and he was very slow and careful. Someone had obviously warned him not to move things and one day I noticed that he had polished the floor round a pair of sandals. I patiently spent time with him every day explaining what he had to do.

Janet arranged for a boy who was on holiday from secondary school to help me learn Ateso, the local language. "You must use him as an informant," she said.

"Don't expect him to teach you - let him answer your questions."

She produced an Ateso grammar book, a dictionary and some other simple books.

I met Christopher in the cool of the church at 3.00 in the afternoon on most weekdays. It was really hot at that time of day and an effort even to walk there.

I decided I must get a bicycle to save my energy and soon I was the owner of a sturdy 'sit up and beg' machine which proved very useful.

It was strange preparing for Christmas at the hottest time of the year. In addition to Jane's main duties she was organising nativity plays, the first of which was to be performed by the children before they all went home for the only holiday they were allowed to have during the year. The wide veranda of a large staff house on the children's compound acted as a stage and I helped Jane paint a backcloth which depicted an African bush scene which, we hoped, would make the story

more relevant. I felt so grateful that the birth of Jesus took place in such humble surroundings and under conditions which these children could fully understand. Excitement reigned as the children prepared their few belongings in tin cases or bundles and collected their bus warrants for going home. The medical staff were always worried about letting them go for fear that they would not return to continue their treatment. "And just you remember to come back," Dotty Jordan warned a lanky teenager who lived a particularly long way from Kumi. "Term starts on January 25th and no later. If you don't come back for treatment you will finish up with hands like this -(she demonstrated a clawed hand), and a twisted face (another ugly demonstration), so just you remember..."

The little group of youngsters who had gathered for this impromptu lecture moved off with some stifled mirth. They were well used to Dotty's outbursts and did not take them too seriously; but hopefully the chance of free education would ensure their return, even if the need for swallowing tablets under supervision did not have the same lure. Schooling at any other school required fees which many families could not afford. Jane was now free to turn her attention to the play for the adult patients which was performed annually by the staff. The patients came from a variety of tribal areas and at least three languages had to be incorporated for everyone to understand a little of the Christmas story. The performance took place outside after dark, with sufficient lighting for everyone to see what was happening and enough darkness for the actors to disappear when they needed to. The colourful costumes, carefully kept from year to year, the rhythmic singing and the serious attitude of the staff as they entered into their parts, all combined to make the evening very special. The patients' faces were just visible in the darkness. They were watching keenly, eyes agog. 'I wonder how many of them have never heard the story before,' I thought as I watched one patient leaping joyfully back to the ward on his crutches at the end. 'Has he really understood? I hope someone can explain the real meaning if he only saw it as a bit of fun.' On Christmas morning crowds of people flocked to our church. Activities were organised for the patients after the service so that they did not get to the inevitable beer pots too early in the day and cause trouble by getting drunk and thereby disturbing the expatriates who had their own (very English) supper party in the evening. "I think you've only just realised you're in Africa," Maurice said to me as we all munched our way through turkey and Christmas pudding. "Don't worry how long it takes for you to get to grips with the work." Forty days had passed and I still had not really discovered what my contribution would be. Every morning I had been with Jane in the occupational therapy workshop and in the physiotherapy department, but her time was rapidly running out and soon I would be on my own. How was I going to manage?

Chapter 6 Shoes, limbs and Leprosy

I had never been very good at finding work to do when everyone around me seemed to be doing all that was needed. During my occupational therapy training I had received a very poor report of my three months' hospital practice at King's College Hospital in London. There were too many students for the size of the department, so I hung back and allowed my colleagues to deal with the patients most of the time. My report said that I was either lazy or I was not interested in the work. Fortunately my college did not take these remarks too seriously, as I had a generally good record. When there was no one else to do the work, then I was able to plan and apply myself to the task, getting fully involved and seeing progress. So it was that when Jane left for Ethiopia, I had to take responsibility and begin to learn. In this chapter I deal with the nature of my work and explain about leprosy and its complications in some detail, including its long history that contributes so greatly to the widespread fear of the disease. I learned mostly by working with the patients and trying to understand their problems. The workshop had two rooms, the larger of which was used for weaving. This was not a traditional craft but it was suitable as an occupation for even the most crippled patients. Colourful table-mats, cushion covers and small towels were produced and sold to visitors. The smaller room was for shoe and limb making. Several patients were employed there and they received a small wage for their work. Most of the shoes were made out of old motor car tyres, the soles being cut from the tread and the straps from the sides. The straps were stitched in place to form simple sandals. Artificial limbs were made out of wood and leather and were very heavy. This part of the workshop did not enthuse me. It was dirty and primitive but I knew it was an essential part of the hospital and needed to be developed.

My other duties included the supervision of the physiotherapy sessions that were held in another building, where one or two patients, trained by Jane, taught simple hand and foot exercises to the patients who needed them. Then there were health education groups to organise so that the patients could learn about their disease, how treatment would help them, how to recognise the early signs in other members of their families and how to prevent complications occurring, especially if they had suffered nerve damage and had loss of feeling in their hands and feet. When I arrived at Kumi I had not received any instruction about leprosy, nor had I had time to do any personal study, so I was not only ignorant - I had some completely wrong basic ideas about the patients. I once asked Jane about some clinical details and referred to the patient concerned as a 'leper'. Jane, who was usually so placid and gentle, gave me a very angry response: "You must never call patients lepers," she declared. "If you do, it implies that there is no cure for the disease and that they are labelled as having leprosy for life."

I soon got used to calling them leprosy patients and, like Jane, always cringed when uninitiated visitors used the word 'leper'. Leprosy is a fascinating disease, despite the terrible deformities suffered by patients who do not receive treatment soon enough. It is one of the oldest diseases known, being present in India in 600 B.C. There are documents, which clearly describe the skin and nerve signs, and chaulmoogra oil was used as a treatment. The disease was spread to the west by armies of Alexander the Great around 327 B.C. It was called 'Elephantiasis', but it was clearly what we call 'leprosy' today. Somehow, after this, the term 'leprosy' became confused, because in the Old Testament the Hebrew word "Tsaraath" is used. This word is more or less untranslatable, but the root meaning is 'collapse', 'strike' or smitten by God'. Various stories in the Old Testament show that leprosy was considered to be a punishment from God for someone who had committed a serious sin. Leprosy is dealt with in great detail in the book of Leviticus, Chapters 13 and 14. The diagnostic signs are given and hardly any of them are seen in the disease we call leprosy today. It seems that all the unsightly skin conditions, including mould and fungus, were grouped together as "Tsaraath". The confusion continues today: I was to experience many occasions when someone suffering from a severe skin condition, which in no way resembled leprosy, would be sent to the leprosy workers, often by other health staff, who tended to be scared of that type of patient. Whatever it was that was called leprosy in Bible times (and I shall continue to call it leprosy for lack of another word), it was obviously greatly feared. When Miriam was struck down with leprosy, as a punishment, Aaron said, as he begged God to forgive her, 'Let her not be as one who is dead.' (Numbers 12 v10). Leprosy could only be cured by God, so it was a priest who diagnosed it and he also had the job of ceremonially cleansing the person if healing took place.

In the New Testament leprosy is mentioned fifteen times and the Greek word *lepra* is used. This is another word that is difficult to translate but its root meaning is 'to husk, scale or remove the bark'. No diagnostic signs are given, so it is not clear whether what we call leprosy today was included. In the accounts of healing, leprosy and mental illnesses are the conditions that are singled out, probably because they were the most feared. The fact that Jesus actually touched someone with leprosy is very remarkable. He treated everyone as a human being no matter how repulsive their appearance. In Mediaeval times the stigma towards leprosy worsened. The sufferers were often given over to the care of Monks. In England many old churches still have squint windows, through which the 'lepers' could see something of the service from a particular place assigned to them.

In southern Europe there was a special 'Lepers' Mass'; the person was brought in 'as one dead' and the priest would read the rules he had to follow, including, 'I forbid thee to go abroad without thy leper uniform'. It was not until 1847 that leprosy was clinically defined, (that is, leprosy as we know it today), and it was

separated from all other skin conditions. Then in 1874, a Norwegian doctor, named Hansen, discovered the leprosy bacilli. At this stage the disease should probably have been renamed after him, but it wasn't. Countries in the Americas do try to call it Hansen's Disease, but most of the world stays with 'leprosy'. And so the battle with stigma goes on and on. No real cure was found until 1941 when dapsone (a sulphone drug) was discovered in the U.S.A. This was a real breakthrough. The drug was cheap! Its use meant that leprosy sufferers need no longer be isolated in asylums but could be treated as outpatients. The leprosy bacillus is probably spread by droplet infection although there may be other ways in which it is passed on. At one time it was thought that babies who were carried on the back of a mother who had the disease would catch it because their cheeks rubbed up and down on the mother's bare skin, but this was never proved. Whatever the mode of spread, about 80% of the population has an inborn immunity so that most people do not develop the disease even if they have been in close contact with an infectious sufferer. When people do develop leprosy, the amount of resistance they have in their bodies determines the type of the disease. With no resistance the bacilli spread throughout the body, affecting the skin and, later on, those peripheral nerves that lie close to the surface of the body. When the patient has some resistance to the bacilli, the signs are more localised, resulting in a few skin patches but damaging the nerves much sooner because of the 'fight' which the body puts up against the bacilli. The first type of leprosy is known as lepromatous and it is contagious and difficult to diagnose in the early stages.

The second type, known as tuberculoid, is not contagious and much easier to recognise. In between these two types is borderline leprosy which is contagious and often the most difficult to treat because of the possibility of 'reactions' of the body to the bacilli, which, if not properly managed, lead to nerve damage.

Treatment with dapsone was for a minimum of two years for tuberculoid leprosy but the lepromatous patients were supposed to take the drug daily for the rest of their lives. When I arrived at Kumi in 1965, dapsone was the treatment for all the patients. Over the years it had been very effective, particularly as the majority of sufferers in Uganda had the tuberculoid type of the disease. It was much later that problems of resistance to the drug threatened to undermine its success.

Dr Wiggins, who was British and had been a director of Medical Services in the Uganda Government, established Kumi Leprosy Centre in 1927. Prior to his initiative, leprosy sufferers were supposed to live in 'camps'. The 'unhealthy' land at Ongino was provided when it was decided to separate the adults from the children. Other leprosy settlements in various parts of the world were set up around this time on sites that were also considered to be unsuitable for: any other purpose. Carville, a big leprosy establishment in Louisiana, U.S.A. was built in a heavily polluted area that had the highest rate of cancer in the whole country.

A centre in the west of Uganda was built on an island in Lake Bunyoni, a most beautiful place but quite impractical as far as administration was concerned. The Misses M. Laing and A. Kent, C.M.S. missionaries, succeeded Dr Wiggins. Miss Laing was a large and powerful woman by all accounts. Mr Enabu, one of the older African staff members was himself a patient during those days. "It was very difficult to get enough food for all the children," he told me. "So if there was a shortage she would go with a bodyguard of four strong men and some of us older ones and dig up people's shambas (gardens). And no one dared to argue with her!"

When these two ladies left in 1948 there were 300 children at Kumi and 800 adults at Ongino. Most of the staff at Ongino were patients and they were all accommodated together in wards, which were locked at night to prevent trouble. An English doctor, Harold Wheate, arrived later the same year and two Ugandan Medical Assistants joined the staff, Jesse Ndahura and Onesimus Busimo. To this day wards are named 'Laing', 'Kent', 'Ndahura' and 'Busimo' - a well-deserved honour, as conditions were very tough in those days. As I struggled to get rid of my preconceived ideas, I began to see the patients as special individuals. I longed to know what made them tick - what they thought about the hospital - what they talked about all day. They seemed usually to be appreciative and to have a good sense of humour. The contrast between the appearance and attitude of a patient on admission and after a few weeks was often very remarkable. Many of them were very poor and they had often travelled a long way to reach us. Even the meagre food supplied at the hospital improved their appearance, which was surprising as our food budget was less than half that spent on local prisoners! Some of the patients occasionally complained about the monotony of beans and maize meal, but they were given meat or fish on special occasions and the women would often gather the leaves of wild plants to cook as vegetables. The patients referred to me were always those who had loss of feeling in their hands or feet because they had started treatment too late, or had suffered reactions. The loss of feeling was due to damaged peripheral nerves and these not only give feeling but also control muscles. So many of my patients had clawed fingers or 'dropped foot' deformity - (the patient being unable to raise his foot at the ankle when walking). Loss of feeling in a person's hands is a terrible handicap. All of our patients liked to cook, whether they were allowed to do so or not, and the local saucepans had no handles and were always gripped at the hot rim. Everyone used tin mugs for tea and these were handled without thought. Burns were very common. The challenge was to convince the patient of the cause. One morning I found a patient with a blister the size of a tennis ball on her hand. "How did this happen?" I asked her. "It came by itself," the woman replied. "It wasn't there yesterday. The leprosy is eating my body". Hands were also damaged when hoes and other tools were gripped too tightly because the person could not feel how much

strength he needed to apply to prevent the implement from slipping from his grip. This was especially dangerous if the patient had clawed hands, when excessive pressure was taken on the fingertips. Some patients had no fingers at all. They had continually injured their hands and neglected the wounds because there was no pain. Their injuries had become infected causing bone absorption. Sometimes one or two shortened fingers remained and there were fingernails at the tips. This proved that the fingers did not 'drop off' - a view that was widely believed by local people. I once heard Dr Paul Brand, the famous leprosy expert, tell a story about a group of Indians who were gathered around an open brazier in a city street, roasting maize cobs. One of the cobs fell into the fire and there was no way of rescuing it. Then someone spotted a leprosy sufferer with badly crippled hands standing nearby and she was called to assist. Without hesitation the woman put her hand into the fire and picked up the cob. Burns would have resulted - a horrible price to pay for a charred maize cob that she would certainly have been allowed to eat. What a terrible thing it is to be robbed of that precious gift of PAIN! Most of our patients arrived barefooted, often with ulcers on the soles of their feet, - hence the need to provide shoes. Because they felt no pain these ulcers were often unnoticed or badly neglected. No one normally looks underneath his feet if he feels no pain. The damage was usually due to the wasting of the soft tissue on the sole of the foot, so that there was nothing to cushion the bones against the hard ground when the patient took pressure in walking. It was easier to tell the patients that thorns and sharp stones caused the trouble but some of them seemed to think that the leprosy was responsible and that the damage would occur whether they followed our advice and wore sandals or not. Foot ulcers had to be healed before the patient was allowed to walk freely. This meant using crutches or a wheelchair if one was available, and plenty of bed rest. We soon discovered that the ulcers would heal faster if the patient's leg and foot were put in plaster of Paris incorporating an iron walking bar. The patient then had the advantage of being mobile, but other patients often complained that the smell after some weeks was quite disgusting. They were right, but the treatment did work, helped by the maggots that took up residence inside the plaster. Tyre shoes were not ideal, of course, even when they were lined with sorbo rubber, which we could obtain fairly cheaply from Bata Shoe factories in Kampala or Nairobi. The patients preferred not to have the lining, because tyre shoes which were made and sold in local markets had no lining and to avoid stigma it was better if their shoes looked like market shoes. We had to persevere relentlessly with our teaching, but I began to realise that some of the patients with loss of feeling in their hands and feet actually felt that these parts did not belong to them and they disowned them. Sometimes they wilfully tried to destroy themselves. Even in the 60s it was possible to rejoin a hand that had been completely severed from the forearm in an accident victim. However, when such patients were

carefully observed in the months following the surgery, it was found that many of them mentally rejected the part and some requested that it be removed because it no longer felt part of them - it felt as if it were stuck on because of the lack of feeling. This is what our leprosy patients must have experienced too.

Old motor car tyres were, actually, quite difficult to obtain in Uganda.

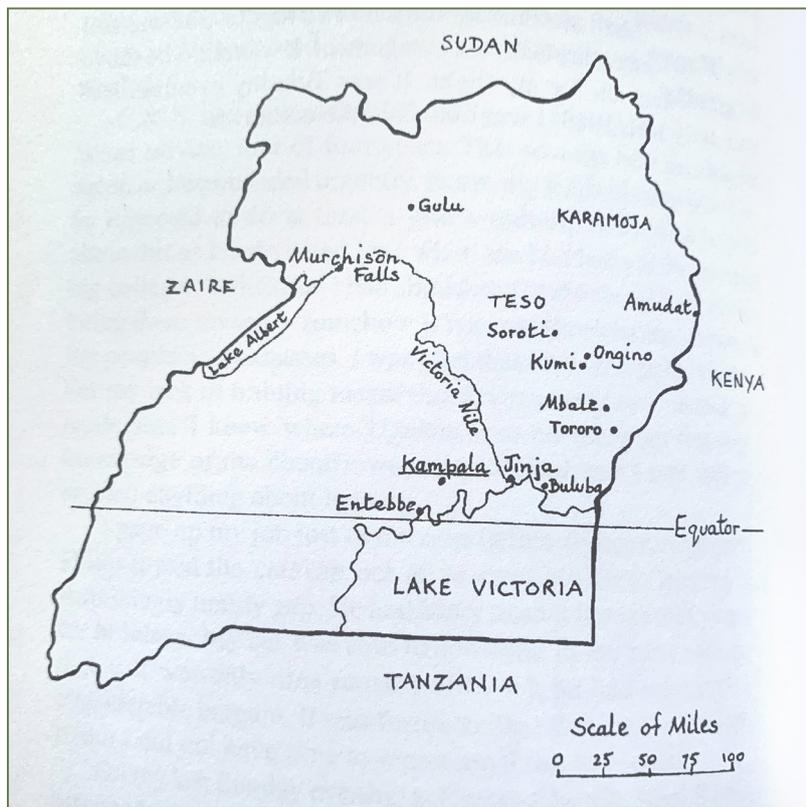
I frequently visited the garages in Mbale, our nearest town, which was 30 miles away, to see if they had any to spare. Often I returned with tyres that were too heavy or which had wire mesh in the tread and these were no good for shoes.

Soon the garages were expecting payment for the tyres. I remember an occasion during my first leave in England, when I was driving through the outskirts of a town and suddenly spotted an enormous heap of old tyres that were, presumably, going to be burned. I felt exasperated at the waste - but how could they be transported to Uganda? When the foot ulcers were healed there was usually deep scar tissue and as this was often at places where the foot bends in walking the ulcer often developed again. Just before Jane left, a Lancashire clog maker, Dick Turner, came to show us how to make wooden shoes that would enable the patients to walk while the foot was held as if it were in a splint. He arrived at Entebbe airport carrying two clog-making knives, which measured about four feet in length, and experienced some difficulties in explaining their use to the customs officials.

Under his directions two small, low benches were fixed to the floor of a spare storeroom and the knives were mounted on these. The clogs, made of musisi wood, were made to fit exactly the sole of each individual patient and as they walked they 'rocked over' because the sole was tapered towards the toes.

These shoes proved useful until the scar tissue had lessened and the patient could use flexible shoes again. Sometimes there were patients who had such severe ulcers on their feet that the only option was to amputate the leg below the knee. It was always a last resort and some patients took a long time to agree, always hoping that somehow the foot would improve. For others it was not a difficult decision. I remember one man who had been brought from a far away village, travelling on the back of a bicycle for several days. Under filthy bandages we found two inches of the tibia bone protruding from badly infected flesh. He had no foot and he looked desperately haggard and ill. He was glad to have his amputation as soon as antibiotics had cleared the worst of the infection. After a few months he was quite unrecognisable; he had put on weight, he was smiling and walking well with his artificial limb. The most primitive artificial limb was a 'peg-leg' that was made from a piece of broom handle mounted on a sort of three sided box into which the patient knelt, with his (usually short) stump protruding behind. A small foot was added and leather straps held the knee in place over a padded surface. This contraption was unsightly but very practical. If it got broken he would usually be able to find some way of fixing it. Only when it was completely worn out would he need to return to Kumi. As time went on an effort was made to produce limbs

that were more cosmetically acceptable. These had leather sockets into which the stump fitted and some even had carved toes on the foot with painted toe nails! The patients who made these limbs showed initiative but they had never received any training and they were not of a high enough educational standard to be accepted for any relevant course. I needed vision, bright ideas and some clear planning to develop the work, but at least I was discovering priorities, accepting the challenge and beginning to feel at home. I was also getting to know some very remarkable people.





The Kumi Hospital logo is a leaf branch and fruit of the Hydnocarpus Wightianus or chaulmoogra tree. Chaulmoogra Marotti seed oil has been widely used in traditional Indian medicine (Ayurveda) and Chinese medicine. It entered early Western medicine in the nineteenth century before the era of sulfonamides and other antibiotics for the treatment of several skin diseases and leprosy. Chaulmoogra is given intravenously and might have calming- and fever-reducing properties and activity against skin disorders.

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