

Pam Gantley, nurse: "My experience with CIOMAL in Cambodia"

I first started working with Ciomal in March 2005. At that time I had already worked in Cambodia for almost 5 years. My role with Ciomal was very different to my previous experience in Cambodia. I was moving from a position of advisor to direct line manager.

The centre that Ciomal manages at Kien Khleang is a part of the National Rehabilitation Centre for the whole of Cambodia. There are 38 (official) in-patient beds and 27 personnel working there in addition to myself. We also have linking relationships with the Community Based Team that are also part of Ciomal, the National Leprosy Elimination Programme (NLEP), and the Ministry of Social Affairs (MOSAVY). The whole centre comes under the jurisdiction of MOSAVY there is an on site Director whom Ciomal has a very good relationship with.

When I first visited the centre I was immediately struck by the overall cleanliness and a strong ethos of caring. Both of which were not common in my previous positions. Although I hadn't pursued a management position I found myself quite taken by the centre and thought to myself "Why not! How difficult can it be?" I'd had a lot of ward / departmental management experience in the UK and assumed things would be very much the same. I hadn't considered that I might have to be dealing with plumbing, subsidence and electrical wiring! Thus said it has been a tremendous learning experience for me. Spending time with my grandfather, a builder gave me a good grounding for these problems.

The centre caters to three main patient groups; firstly people who have a "leprosy reactions", this is where the body is dealing with the leprosy bacteria that are dying or being killed off or their bodies cannot cope with the treatments prescribed. People can be quite unwell during this time and it is also the time when the risk of long term nerve damage and thus disability is greatest. The second group is people who need "surgery", either to prevent further disability, to correct a disability or for cosmetic purposes, this group of people are rarely sick but need a rigorous exercise regime and need to stay at the centre because they live long distances away. The final group and by far the most complex group are people who have ulcers, particularly "plantar ulcers". This group of people often need multiple interventions, often including surgery, and are frequently suffering from very low self esteem. Sometimes people have had ulcers for several years and never had any treatment. Because the nerves are damaged they do not feel pain and so tolerate the ulcers. I once came across a youngish man who literally had no skin on the sole of his foot; he had tolerated this for ten years! Unfortunately the time needed to deal with this type of problem can take up to three months and he refused to stay at the centre. The clinical staff tried to find treatments that would allow him to go home (he lived more than one day travel away from the centre and CIOMAL provide travelling expenses) but he declined any support. He went home with no skin on the sole of his foot, we asked the Community Based Rehabilitation (CBR) team to follow him up at home and try to find a way to treat his ulcer but without any success. He will probably end up by going to a place that has little expertise in managing these complex problems where they will amputate his leg. A sad but realistic outcome.

During that first visit I also remember being gripped by fear, "Leprosy!" I looked around and nobody else seemed bothered by this and so I trusted that I would be okay. I'd had no previous personal experience of this health issue and my immediate thoughts centred on my own personal safety. I reflect upon that first thought often, when I'm trying to comprehend the cruelty of stigma.

I had a one month handover from my predecessor before I took on full responsibility for my new role. During this time I made my own assessment of the situation. It was a very "tight ship". It was also very "clinical", similar to a hospital of around the 1960's or 1970's, pristine uniforms, patients in beds and a quietness. This was slightly difficult for me to reconcile, given the fact that the centre was part of the National Rehabilitation Centre. My previous experience of rehabilitation is halfway between institution and home. One of our support workers describes rehabilitation (for himself) as "having a new life".

Hospital settings need to be different, people usually are very sick; they are often a place where people are intentionally disabled so that they can recover from their physical ailments. I wasn't really sure why the centre was like this apart from recognising that clinicians (doctors, nurses, physiotherapists) usually contribute to this, it comes from our training. I also wasn't really sure how to address this. Fortunately it was not something I had to wait too long to find out about. One of the Ciomal expatriates doctors and a very dynamic and professional local physiotherapist attended a training course in Nepal where a very broad concept of disability was introduced.

Historically disability is usually considered to be about "physical impairments" this concept included "activity limitations" and "participation restrictions", thus encouraging service providers to think more holistically about disability. Over the past three years 6 people have attended this training programme, including myself and it has brought about a tremendous change in the centre and how disability is being understood. The physiotherapy team had already recognised the importance of knowing whether a person can safely perform ordinary activities of daily life – going to the toilet, eating, sleeping, playing – but were unsure of how to incorporate this into their daily work. Most of the patients were to remain on "bed rest" to prevent any disability or problems with ulcers. The first step was to encourage safe and healthy activity. We recruited 2 "support workers" to assist with this. Both are young healthy people living fairly ordinary Khmer lifestyles and both had received treatment for leprosy, both of them have some degree of physical disability but it is not very evident and both of them look after themselves so that they do not experience further disability. They are great role models who have real understanding of some of the difficulties and obstacles faced by people who have been treated for leprosy.

An area for "activities" was made available and an old computer was put in this area. This is a non-clinical area, pictures have been put on the wall, sometimes it's quite a messy room, with pens and papers all over, it also get quite noisy! The walls are covered with pictures and photographs and it's a very well used space. I once found one of the cleaners in there she was sticking small leaves onto a tree on the wall, when I asked what she was doing she said she had some family problems and each leaf represented one of her worries. She was very quietly unburdening herself. Apparently this was the "worry tree". No one was ever told how this room should look or what should happen in there. It was just "the activity room".

The centre had a literacy programme that was quite formal, the teacher stood at the front and shouted instructions to the students (ranging from young teenagers to middle aged adults) it worked but it was quite a formal approach particularly given the difference in age groups and literacy needs. One of the first things I noticed after the activity room started to be used was that literacy classes had taken on a very different shape, newspapers and magazines had replaced the primary school readers that were being used, mathematics had been introduced and it had all become quite a noisy activity! I heard a tremendous noise one day and enter the room to find four youngish men, 16-22 yrs, with their faces covered in red and blue pen! They were playing a word game where the winner got to write on his opponents face! Everyone was laughing and enjoying learning to spell words.

This area became quite popular and brought a new set of challenges with it! As a nurse my first response is usually to protect people. This often results in restricting people's behaviour. The clinicians, including myself, were confronted with the reality that people are active and will put themselves at risk in order to be active. Health education now needed to address this and move from a "one way suits all" approach to a more individualistic approach. The physiotherapy team have taken this on with great courage. Having to be creative and think outside of what they learnt in their training. One young man had had surgery on his right hand which due to nerve damage had lost function and resembled a claw. After the surgery and an intensive exercise programme he had straight fingers and was able to grip larger objects like a cup. He was very pleased with the result, particularly the cosmetic appearance he decided that he would like to have the same operation on his left hand. When he returned several months later it was noted that his right hand had started to reclaw. When this happens it is often felt that the surgery had failed or the patient was lazy and not doing his exercises.

This young man worked in a Karaoke parlour and so was inserting music CDs into a machine all day. While he was preparing for his surgery on his left hand he put some CDs into the computer it was noted that the way he inserted the CD, using his right hand was completely opposite to the exercises he needed follow, and this very simple, but regularly repeated activity, was actually causing his hand to reclaw! The physiotherapist spent some time with him and figured out a way that he could insert a CD into a machine whilst at the same time improving the function in his right hand and reducing the clawing. I have been very fortunate to witness many of these experiences where very subtle things can actually make a real difference to a person's life.

The stigma that comes with leprosy is comparable to nothing else, where it comes from is unclear. Ciomal and NLEP have raised the general public's awareness regarding leprosy and although increasing numbers of people are less afraid it remains a huge problem. When "new" patients arrive at Kien Khleang they are not hard to identify. Typically they appear to be very isolated, faces are often expressionless, they avoid eye contact and very rarely smile. Sometimes they have been excluded by their community and other times they have excluded themselves. Young people drop out of school, marriages have fallen apart, some people have attempted suicide and often people have moved frequently. The isolation that people must feel I really cannot imagine. One fifteen year old boy is so isolated and self conscious that he can hardly speak. Sometimes fixing people's hands and feet has very little impact if the person remains isolated and has very little self worth.

The activity room is a place where people's confidence can grow. Being able to practice things in a safe and understanding environment builds people's confidence. One middle aged man was a painter until his right hand became too disabled to paint. He lost his income and moved in with his sister. Each time she was out of the house his brother in law would speak harshly to him. Whilst at Kien Khleang he learnt to paint with his left hand, and was very good. He had found some of the self worth that had been lost, and has sold some of his paintings locally. The down side is that people put all their trust in Kien Khleang and so are at risk of becoming institutionalised and can easily become an isolated community. To overcome this we have forged strong links with other community facilities and service providers. Many of these are with general disability associations and health services. We do not provide everything under one roof; people have to leave Kien Khleang to access certain services. This has been a challenge as ignorance has no restrictions. Trying to support and encourage people to do what "ordinary" people do is very difficult, particularly when the doors are often closed because of fear and ignorance. In addition to this a small budget has been set aside for social activities. Every 2 weeks one of the support workers plans a social

activity. Usually going to the cinema, or riding along the river in a tuk tuk, stopping and having a snack, sometimes going to a cultural place, but most importantly being with other people. A small sports area has been created at the back of the centre where people can play table tennis or badminton. Sometimes the neighbours join in or some of the children on their way home from school. These activities breakdown barriers and enable people to be less isolated and participate in everyday activities. The embarrassment and shame that people experience is lost in the excitement of the activity. One lady who had no hands was being teased by the staff regarding the Khmer New Year party. She was asked who she was going to dance with. She replied that she wouldn't be dancing because of her hands. (Hands are a very important part of Khmer dancing). The physiotherapists secretly arranged for a cosmetic pair of hands to be made. This was the best Khmer New year present she had ever received. When she put on her new hands she appeared to grow taller. She spent the whole party dancing and showing off her red nail varnish!

The past three and a half years have been a very fulfilling part of my life. Not only have I been able to work in an environment that is almost instantly rewarding, I've also had the opportunity to see the clinical staff grow into their professional roles. Previously there were a number of international advisors who worked with the clinical staff, training, encouraging them to develop professionally and take on responsibility, developing guidelines and practice standards and generally pointing people in the right direction. The Cambodia health service is still only ten years old and the rehabilitation services are even younger. Still there comes a time when people need to start to do things themselves and take on the responsibility for their own development. I had the additional opportunity to experience this transition first hand. Again things were not always easy and certainly didn't always go smoothly but with the departure of each international technical advisor I was able to witness this growth, particularly amongst the clinical staff. Sometime picking up the pieces, sometimes reminding people, but generally ensuring that the resource and support have been available for people to do their jobs to the best of their ability. In addition to this the Kien Khleang staff have been confronted with having to share their own unique knowledge and expertise.

The centre that Ciomal supports is the only centre of it's kind in Cambodia. It is the only place that people who have ulcers on their feet can go to where they are not told that they need to have their leg amputated. Healing wounds, providing advise or good quality footwear and giving health education are the first interventions that are provided in Kien Khleang. The increasing number of people who have nerve damage to their feet with the only option of amputation has necessitated service providers to look at available alternatives. The staff at Kien Khleang have been asked to share their knowledge and skills at a number of workshops and training events. They have done this in a very professional manner, preparing presentations and training sessions with very little experience of this in the past. I have enjoyed seeing them grow and also gain confidence.

As the time comes close for my own departure I am very pleased to be handing over to Bou Sophal. A very committed member of the Ciomal team who has been with the programme for 14 years. I decided 2 years ago that I would move on and although I'm not regretting my decision I am absolutely sure that I will miss the centre and the staff very much. With Sophal's extensive experience in leprosy management and the fact that he is Khmer I couldn't wish for a more appropriate replacement. I wish him the best of luck. I'd also like to express my thanks to Ciomal and the NLEP for supporting me in this very pleasant posting.