

# Sue Varvel's Sabbatical to India and Sierra Leone



## **Introduction**

In spring 2007, Iain Rennie's Director of Nursing, Sue Varvel, took a sabbatical from her role in an effort to make a difference to the lives of people with life-threatening illnesses in the developing world.

Thanks to an education grant from University College Hospital where she trained, Sue spent 7 weeks in India and Sierra Leone sharing her expertise in palliative care with communities, and says her life will never be the same after her experience.

Sue said: "When I first decided I wanted to take a sabbatical in another country, I contacted our umbrella organisation 'Help the Hospices'. They suggested I plan a trip to Sierra Leone, where there is the greatest need. I was then approached by an organisation in India also requiring help and I was able to plan 2 weeks at the beginning of my trip to support that organisation. It took a year to plan my visit, and I know that my time there will always be a part of me - it's in my soul."

In this document Sue tells the story of her emotional and inspirational trip, in her own words and pictures.

## The First Leg

Having prepared for this trip for several months I finally departed for Delhi on Tuesday 13<sup>th</sup> February 2007. I was totally unsure of what I was going to but strangely not scared. The first shock was arriving to a frost. I hadn't bargained for that and knew that I wasn't prepared with my packing! Oh well - I'll have to sort that later.



Driving to my accommodation was an absolute shock to the senses. Busy roads - cars everywhere, beeping their horns constantly. Then the dirt and mess, and rows of tented homes, filled with shoeless people with little or no possessions. I knew there would be poverty but was not prepared for what I saw.

I was cosseted in a conference centre for accommodation. The conference I was taking part in was on the same site so I felt safe. This, I came to realise, was important travelling on my own. I had been invited by an organisation called CanSupport - a community palliative care team based in Delhi. They were holding the conference which was to take place over 2 days followed by 2 workshop days which I was taking part in also.



## Hospice at Home in India

I started my stay by meeting the teams. CanSupport is a charity providing palliative care across Delhi divided into 5 teams based in the North, South, West (2) and Gargoon regions of the city. The teams are each made up of a doctor, nurse and counsellor who travel together with a driver to the patients. They meet on Thursdays to discuss the patients, difficult situations and to have some training. This is a lengthy but necessary process as the work is intense and complex.



I spent the following day with a team in West Delhi visiting patients. I was amazed at the conditions in which they work. The slum areas are difficult to access and then it's even more difficult to find actual addresses. Travelling anywhere takes long periods of time sitting in queues of traffic, all adding to the frustrations of the day.

The team carry medication and if the patients are poor they are given it for free. It is accessed in 2 ways - buying and recycling from other patients!! Nothing is wasted. Monitoring medication is difficult. Many patients and carers are unable to read, or understand instructions, so taking medication regularly is a touch and go situation! Morphine is licensed here but only orally in tablet form. There is a stigma associated with it so encouraging patients to take it is another problem to be overcome.



The most common cancers are head and neck in men due to chewing tobacco and cervical cancer in women so many of our visits involved dressings to fungating face and neck wounds - very distressing for the patients and their families. I had managed to beg some free charcoal dressings from a drug company as they are impossible to get in India. Seeing them put to good use was wonderful.



## The Conference

The conference was hard work, I had 5 sessions to do which felt scary beforehand but was, in fact, an uplifting experience. Doctors and nurses attended on the first 2 days and were keen to learn - writing furiously and asking many questions. The last 2 days involved social workers, volunteers and nurses - all wanting to know more. Nurse teaching in India is not interactive - it is based on old-style teaching methods and the nurses, although keen to ask questions, are not keen to work in a workshop environment. This day was more of a challenge!



The last 2 days of my stay were spent again with the teams. On the last day I visited South Delhi and had the most interesting day of my stay. The homes we visited were particularly poor. Many half-dressed children were running around barefoot. As we entered the first house of the day I took a photo of some children. As soon as I did this lots of children ran up shouting "acostie, auntie" wanting their photo taken too. Everyone liked their photo taken - including the patients who, however ill, posed for me with their families.



As we left this house we were approached by some young men who wanted us to visit a friend who was ill. They had seen our car with its insignia. We followed them to another house where we found a very ill, frightened 24 year old man with lymphoma. He had spent his money on a hospital stay for tests and now could not afford to return to the hospital for treatment. It is possible to access a Social Worker in Delhi who can get some financial aid for patients such as this but it will only cover a small part of the treatment which is a great shame as this disease does respond well to treatment. I felt so sad for him and his family - especially as he was the same age as my eldest daughter.



We had a few more visits but the most poignant was the last one of the day who was a 52 year old man with prostate cancer and bone metastases awaiting radiotherapy. This was the only house I visited where the atmosphere was uncomfortable. The patient and his wife had travelled from East India to get treatment and were staying with relatives. They had left their children at home and were missing them and were not made to feel very welcome. After a while they both started to cry. We all felt helpless as there was nothing we could do. Two family members stayed hidden in the kitchen - refusing to enter into any discussion. All that could be done was to attempt to console them. We all left feeling dreadful.

The weather by now was getting hotter - as hot as an English summer - and I was grateful to be leaving before it got much hotter. I did get a day off! I went to Agra and visited the Taj Mahal - an amazing, peaceful place in amongst the trauma and poverty elsewhere.

Then on to Sierra Leone!



## Next Step

My first thoughts were thank goodness I had been to India first! Arriving in Sierra Leone was a real culture shock. Even the airport was an experience! This is the poorest country in the world - with no electricity or running water. Although I had witnessed poverty in India it was just part of the whole culture - wealth exists in its extreme too, together with 'normal' living. So it didn't prepare me fully for Sierra Leone - poverty everywhere with no supportive infrastructure.



My task was to build on the work started by Sheila, Ruth, Jacqui and Esther all of whom had either visited before or, as in Esther's case, was still out there with her husband's work. Esther very kindly helped me settle in - it was a culture shock and it was clear that great work had already been done, and Esther had an established role so I was unsure what my role was to be. The first few days were spent visiting the communities - Esther driving! I was shocked at the living conditions and the fact that there really wasn't any running water or power.



## Project Management

My personal project was to develop the dispensary - to write protocols and policies and to train the staff further in the managing of the dispensary and the use of the drugs.

This was the first major step in structuring the use and storage of medicines with a view to applying for a morphine licence at a later date. Drugs are so difficult to obtain - even simple medicines sometimes can't be bought and supply is often hit and miss. Drugs are bought through pharmacies in Freetown. The reality is the quality and standard of each drug is questionable and even if morphine is obtained it will almost certainly only be in powdered form.



A major achievement for me was in the later stages of my visit I was able to obtain a stronger pain relief medication - this will improve the care considerably for patients.

During my stay Esther, the team and I started to visit the local 'displaced communities' - introducing the palliative care service via the Paramount Chiefs. These are often self-appointed leaders who oversee and support these communities, many of which arose during the war. Thousands of people fled the rebel invasion and set up initially small tented communities to provide safety until the war ended.



The communities grew larger and larger and were more substantially built, and are now small townships. The poverty within these communities is immense.



The first community we visited formally in this way was Grafton. We were inundated with people needing care - the difficulty was assessing and treating those who had palliative care needs. We had to turn many away. We were, however, able to help many and start a regular visiting programme to give care and support patients and their families. This is hospice at home!



Although there is cancer in Sierra Leone the main problem is HIV/AIDS and much of the work is identifying those who may be positive and getting them tested to establish the next steps. Testing for HIV and for other illnesses such as TB is free. However transport to test centres costs, and this often stops patients going for testing. Also the drug therapies are free but need to be collected on a regular basis, so many patients don't complete their treatment, which creates a vicious circle. People still die of things like TB, cholera, diphtheria and polio. Vaccination programmes are up and running but accessing patients is also a problem - poor roads, transportation and not

knowing where the population is. They seem to be about 60 years behind us with climate problems and war added in!

## The Saddest Day

My saddest day was visiting a lady who had no home but was 'borrowing' a room used to keep sheep. She had no money for food, no clothes other than those she had on and no possessions. The community was helping her a little but it was clear that this was rather under sufferance. I was able to give her some money. 10,000 Leones - which is about £2. She was so grateful - I felt dreadful. This money would last her 2 weeks. She cried and embraced me and I felt incredibly humble. We were able to take a food package to her the next time we visited.



Our next visit was to an 11 year old boy who we had been nursing for about 3 weeks. We were not able to establish his diagnosis but it was clear he was very ill. We thought maybe some form of leukaemia. This morning we arrived to check his medication and found that he had died. The family were devastated and were wailing inconsolably. They were already preparing for burial which happens straight away. The mother, who was 7 months pregnant, was inconsolable. I was able to use my support skills - there are some things that cross the language barrier including maternal feelings and emotions. But this was a sad day.



I had been anxious before my trip that I would be sad all the time and was worried that I would be ineffective because of my own emotions. However that was not the case. I had a lot of fun and the people are happy, and content. They know no other life so expect nothing. Unlike home, where everyone wants more! The children have no toys to play with. On one of my visits I found some toddlers playing with baby birds - holding the beaks and pulling the wings. I was horrified but it was understandable.



The language spoken was mostly Krio - a form of Pidgin English. I managed to learn enough to chat with the team and to ask patients questions to assess their problems.

*"Ow di bodi?" means "how are you?" (how's your body?!). Equally "ow di sleep?" means "how did you sleep?". It did work mostly!*



I learnt a great deal from this experience. I used assessing and examining skills I hadn't used for years. It was comforting to know I knew some things!! I really enjoyed teaching the nurses and setting up the dispensary was a major and wonderful achievement for me personally.

The ongoing issues for the team are great - money for drugs and fuel for the vehicles to enable the nurses to visit when needed is in short supply. A 'debate' on my last day while trying to buy more essential medication resulted in the medication being declined in order to pay for repairs to the generator. I could see the point but the frustration was immense. The team have worked hard to raise their profile and develop the service and are becoming well known in the communities - I hope to be able to support them in the future by fundraising here in England and I am busy collecting dressing and equipment to send out when someone is visiting. Another problem is that there is no recognised postal service! We do take so much for granted.



I will never forget my visit - I learnt so much from the team and the people and I believe I have forged a link so hope to return one day!

