

An Indian Approach to Helping Lymphoedema Patients

Tim Maiden, a former Cosyfeet Podiatry Award Winner, describes his recent trip to Kerala in South India, where he studied local methods of treating lymphoedema patients and assisted in their treatment.

Podiatry has given me a great opportunity to work in countries that many people will only visit as tourists, and has allowed me to integrate a little more, and get a sense of the raw issues that the people cope with every day.

I have recently arrived back from India after a period of time working in several medical clinics there. For me India remains a place of mystery and intrigue, while I accept that it has been demystified a little in recent years following increased international media coverage of its domestic news. Terrorist attacks, call centre complaints and sports all form prominent issues in the nation's media profile and have given a very negative slant to a country with so much diversity.

With time seemingly more precious I have found it difficult to visit any country without having a 'meaningful' purpose there. I found the perfect excuse to visit India following a conference last year, where I attended a lecture by Professor Terrence J. Ryan, Emeritus Professor of Dermatology at Oxford University. Professor Ryan asserted that podiatry should be playing a more proactive role in the treatment of lymphoedema. Professor Ryan is the overseeing consultant working with an organisation called the International Association for Dermatology (www.IAD.org.in). The group is based in Kerala, Southern India with links in other states and provinces.

Podiatry in India is a relatively new concept although schemes have been running to educate a new workforce of podiatrists at dedicated training camps. I saw this trip as an opportunity to learn and to help with education, advice and treatment of lymphoedema, whilst exploring one of the most diverse places in the world. The experience from start to finish was daunting but almost every step was exhilarating.

India is a country with a population of over 1.3 billion people, where there is a huge chasm between rich and poor. It is the largest democracy in the world and yet countless people die there on a daily basis for the lack of the basic needs to survive. Millions wake up on the streets on a daily basis unable to attain work due to the social stigmas associated with many diseases that only the poorest seem to acquire.

India is a country that people seem to love or hate. For me, I love it. I find the bright, vivid colours, the deep fragrant spices of the market places, the rich tapestry of social dynamics and the mix of fauna on most streets absolutely enthralling. I have had a mild obsession with the country since childhood, and have admired heroes, both real and fictional, including Ghandi and Tendulkar as well as characters from Kipling's books. So it was with passion, excitement and some fear that I boarded a flight and headed to IAD in Kerala.

IAD is a not-for-profit organisation that has seen over 2000 patients for treatment of Filariasis at Kasaragod, and educated many more at its clinics in Kerala, Kanartaka and Andhra Pradesh. It

conducts rigorous data collection in a broad range of areas enabling it to double up as a research clinic, regularly upgrading protocols effectively and investigating new treatments. Each site location is vastly different from the others, whether these are differences with the species of mosquito and disease, socio-economical, educational, geographical or of climatic conditions. Despite these huge differences the treatment protocol remains the same. In addition, all IAD patients have joined the scheme to improve their health, and are united in their desire to help themselves to end their chronic and often desperate suffering.

The focus of IAD is to help reduce swelling, treat and educate on reducing the swelling of lymphoedema and the causes of this. More specifically IAD is working to reduce the morbidity factors associated with Filariasis. The treatment takes place over several weeks and includes counselling of the patient to help educate and manage expectation, followed by consultations from doctors specialising in Allopathy, Ayurveda and Homeopathy, with physical treatment and ongoing education after this. Furthermore there is a 6-week follow up when the staff will visit patients in their homes to confirm that no complications have been witnessed.

The WHO defines Lymphatic Filariasis (LF) as follows:

“Commonly known as elephantiasis, this is a disfiguring, disabling disease, usually acquired in childhood. In the early stages there are either no symptoms or non-specific symptoms. Although there are no outward symptoms, the lymphatic system is damaged. This stage can last for several years. Infected persons sustain the transmission of the disease. The long term physical consequences are painful, swollen limbs (lymphoedema or elephantiasis). Everyday work becomes difficult due to frequent infections. Hydrocele in males is also common in endemic areas.”

Many of the practitioners working with IAD have been patients themselves and have the additional understanding of what patients are experiencing. IAD hosts weekly study days, plus weekly lessons following treatments, where staff are often educated about new ideas or given practical explanations of what can be achieved in certain cases.

All of the staff at IAD are so grateful for outside interest in what they are doing, and get such a kick out of educating others and doing something of such benefit to society. IAD has esteemed visitors, predominantly from Europe and the US, who attend to treat, learn and teach. As the targets are the healing of patients and data collection, results are achieved quickly and effectively, with an atmosphere of progressive easy freedom and meticulous note taking. There is a refreshing sense of optimism in each of the staff and patients. With the rigorous audits and assessments, the treatments are especially concise, clear and coherent. Limited funding is available, so staff have learned to turn a car tyre into a shoe, for instance, or use locally sourced or natural products. Such practices instil you with a fresh zest in podiatry practice.

During my time at IAD I met and treated a wide range of patients. The following three stand out in my mind.



Very happy patient, still
unable to reduce ankle
oedema



Oil massage taking place



6 week follow up, unable to
afford footwear



Bilateral bandaging



Family life for stigmatized
ladies



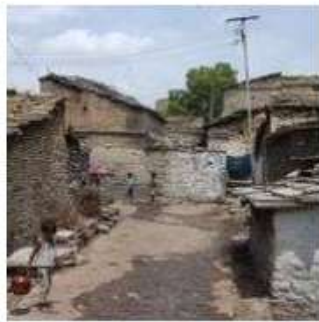
Concordant patient but
problems from low quality
bandaging.



Patient made bandage
protection



Long term effect of LF



View of a rural village



Stagnant water in rural village

Case study 1

This 36-year-old gentleman had suffered from LF since his early teens and had no other known medical conditions.

The limb of the patient was not grossly enlarged, however, there were signs of swelling in relation to the contralateral limb. Several days a month the patient was too ill and incapacitated by his sickness and cellulitis to work, causing a reduction in income and trouble maintaining a household.

Initially, when the patient presented, he had several open lesions on his legs, following self-treatment using the heated Neem seed. The patient also had scarring from a failed lymphoedema liposuction which would often break open through dryness.

The Neem tree is a plant seen to have 'mystical' properties and is regarded as the 'go to' treatment for most conditions. With limited education about their condition, lack of medical assistance and consequent frustration, sufferers frequently listen to any suggestion that may help. In this instance the patient was told by a neighbour to heat up the Neem seed and lacerate the leg to drain the lymph, but in this case further infection ensued without any benefit.

The liposuction highlights the importance that healthcare professionals understand the condition before commencing treatments, while good firm education could have assisted in reducing incidence of infection.

Despite a general widespread campaign for taking medication, the patient was previously unaware of the medical significance due to a lack of understanding and an inability to miss work to attend the clinics at the requested appointment times.

(The helpers employed to distribute medications in the villages are usually paid such low salaries that many are forced to work other jobs, and thus frequently no one is present to hand out the medications. So long journeys are not always met with reward, leading to disillusionment and lack of immunity.)

The patient was suffering from major gaps in levels of knowledge and education of the condition (In the majority of cases education turned out to be the best treatment.) Following education and counselling, the patient learnt the importance of taking the medications and ceased to suffer from illness associated with his LF. He also understood how to reduce the risk of infection. In addition, it was of benefit for his family to understand the clinical situation, both to enable them accept it, and to educate others in the neighbourhood, leading to a reduction in stigma. The patient also benefited from the compassion shown by the staff at the centre, and he reported a much higher quality of life in the review at the end of the two-week period.

Case Study 2

This 52-year old gentleman had suffered from LF since his 20s, however it was suspected that he had contracted the disease far younger. He was an agricultural worker in the paddy fields of southern Kerala and as such spent long hours in the breeding grounds of the mosquito. Under

such circumstances it is very difficult for workers to prevent infection without taking medication. Unlike other cases we saw, the patient has a bilateral infection which has caused swelling in both legs.

He had sought treatment previously, taking western medication in the form of antibiotics each time he contracted an infection, however this was not sustainable as he had to travel over an hour on public transport, or walk several hours to attend a local government hospital to collect antibiotic medication. The legs continued to increase in size with more and more recurring infections. He had ultimately become unable to work due to weekly infections leading to bed rest for three days, which had in turn made the limb increase in size still further, reducing his mobility.

The patient was unable to afford regular medical attention as no one else within the household worked. His three children were all of school age. His diet was very low in calories and he lived near water systems of stagnant water in a hut without glass windows or much more than a wooden plank for the door. So even if the patient were to use smoke to deter future mosquito attacks on the family, the chances of total prevention are fairly slim. Using expensive repellent was not an option.

The patient heard about the scheme set up by IAD from a friend who had undertaken the treatment previously. (A group of fellow sufferers have now formed a close relationship and spend many days and evenings each week together. They also work actively in the community to raise awareness among others. This is a far cry from the experience of many others living several hours' walk from the centres.) Patients are required to travel in on a daily basis for two weeks until treatment is completed. They then continue self-treatment at home with their caregiver or solo.

We visited the patient at the review stage following a successful treatment during which the limb had reduced by several litres since his initial visit to the IAD. The leg was weighed for size using the (picture) method of measuring the displacement of water in the water-filled bin. No infection has presented since following the routine instigated by IAD and the skin integrity and discolouration has continued improving.

The issues that the patient faces are the cost of the bandaging and of the Ayurvedic treatments. The costs seem low to us, but not to the patients. European produced bandaging is much better in quality than that produced locally. This imported bandage is only available via IAD, and the organisation has significant costs in the distribution of supplies to the patients in some of the more distant villages. (We discussed the use of places of worship as meeting places for distribution of medicinal supplies, but found out that both IAD and the villagers would have to pay for this benefit, irrespective of religious beliefs).

The quality of life for this patient has improved considerably in the six weeks since treatment began, and with the education he has received, the likelihood of a relapse is greatly reduced. Yet with his potential inability to afford the ongoing costs of treatment, the future for him is unclear. The patient has subsequently had each of his children immunized against the condition, allowing them to have a better future ahead.

Case Study 3

In complete contrast to the other two case studies, the subject of this study is an 18 year old boy from a wealthy business family in Mumbai. Sufferers of LF do not usually come from such an economic group, and this boy suffered the additional stigma of having a condition normally associated with poverty, and therefore being very unusual within his social and family circle.

The patient had been hoping to attend university but was achieving poor grades due to absenteeism for fear of attending school. He visited the Kasaragod clinic for two weeks following years of different treatments and a worsening condition. He had no other medical conditions but his LF had led him to struggle with walking and finding footwear. In addition, he could only wear shorts or specially tailored trousers. The patient had suffered from LF since the age of three and the condition had been misdiagnosed many times as he did not fit the usual demographic.

The boy's life had been affected dramatically due to the social stigma surrounding the condition. His understandable and natural fear of rejection had led to this boy being marginalized by society. Even the boy's mother appeared unable to see her son as a fully functioning human being. The boy's mother appeared apathetic toward him, perhaps as a result of self-shame. I became involved with the case during the second week of treatment, and the difference in him was remarkable. Following conversations with caregivers they noted that both the mood of the boy and of his family had improved substantially. Upon further conversations with the teen, he appeared optimistic about returning to his home town for university. The patient was fortunate enough to have enough money to have specially customised footwear made: a situation we attempted to rectify with limited success. (Any ideas for low cost footwear would be very welcome.)

My time with IAD was refreshing, stimulating and fun. It was especially rewarding to see work that was being done to reduce stigma through education, and also the remarkably successful outcomes of treatments for patients with LF using a combination of Allopathy, Ayurveda, Yoga and Homeopathy.

Although IAD is one of the three internationally recognised centres with a thorough treatment protocol, we were constantly forced into thinking outside the box due to the huge financial constraints of being a non-profit organisation (NPO). Working with enthusiastic practitioners, many of whom have suffered from the conditions we were treating, made the whole process fun, and at times challenging.

Treating people who lack the benefits of health education or income, whilst making a positive impact to the lives of sufferers, is very rewarding. Filariasis affects approximately 120 million people worldwide in 81 countries. It is a disease that poses a risk to over 1 billion people, with 20 million people last year being diagnosed with the condition in India.

My fears about going to many developing countries surround the possibility of catching a disease through living in communities of sufferers, but these cases are very rare and the benefit that we can provide to people with debilitating chronic conditions is huge. I hope to return to IAD this year to volunteer my skills and experience again. There are so many issues that podiatrists can help with there, especially those with a few years' experience in the NHS, as the structure and management skills acquired would be of benefit. Private podiatrists with an inquisitive mind would also be of great value, as they would have to think outside the box on an hourly basis

there. I would implore all podiatrists to experience voluntary work of this nature. It would help you remember why you became a podiatrist in the first place, and breath fresh life into your practice.

I would like to thank the people who had visited IAD before me for their assistance and advice, Dr Cross for tolerating my erratic emails, Professor Ryan for his introductions and advice, Bailey's Instruments and Cambridge CCS. A heartfelt thank you also to IAD, who made my nine week stay so wonderful, stimulating and thought provoking.

If you have questions for Tim Maiden, he can be contacted at tim.maiden@gmail.com.

Cosyfeet's annual Podiatry Award assists one person each year to further their professional knowledge and skills. The £1000 award is open to any podiatrist or podiatry student who is planning voluntary work, a work placement or research, whether in the UK or abroad. It is designed to assist with travel and living expenses. To find out more about the Cosyfeet Podiatry Award see www.cosyfeet.com/award or email prof@cosyfeet.com.