Lymphoedema treatment for sufferers in Uganda: a charitable experience

Jane Board, 02.01.26

Abstract

This narrative is written by, and from the perspective of, a member of a team of four Lymphoedema Practitioners (LPs`) who, in September 2025, travelled to Uganda to work alongside the executive team of the Lymphedema Warriors Association Uganda (LWAU). The objective of the two-week trip was to provide lymphoedema treatment and self-management techniques to sufferers of all forms of lymphoedema in two treatment locations (camps) in Uganda.

To provide context, the report will commence with a background summary concerning access to treatment for lymphoedema sufferers in Uganda in conjunction with a global health programme instigated by the World Health Organisation (WHO).

It will describe the subsequent formation of LWAU, and the organisation's strategy in the recruitment of volunteers with experience to treat lymphoedema. It will also describe the kindness and generosity of the hosts to the LPs` staying in their home that was also extended to patients.

The report will recount the types of lymphoedema and total numbers of patients treated by the team in both medical camps, including the causations of lymphatic filariasis (LF) and podoconiosis.

It will conclude with a summary of the author`s experience, the challenges faced by LWAU, and the opportunities ahead for the organisation through projects underway.

Background

In 2000, the WHO launched the Global Programme to eliminate Lymphatic Filariasis (GPELF) a neglected tropical disease (NTD) as a global health problem by 2030 (WHO 2025).

Lymphatic Filariasis (LF) is caused by filarial worms that are spread by bites from infected mosquitos. The worms that produce millions of larvae `nest` in lymphatic vessels of humans and obstruct lymph flow resulting in lymphoedema. Symptoms are painful and profoundly disfiguring and include significant swelling of the legs, breasts and genitals, infections and gross skin changes of elephantiasis and papillomatosis (Sightsavers 2000). Uganda is estimated to have a population of 51.5 million people. In 2021, as part of the GPELF programme, of the 13.7 million sufferers identified to receive mass drug administration (MDA), 13.3 million were treated with preventative chemotherapy to interrupt disease transmission (WHO 2023). Included in the GPELF programme was a recommendation for minimum packages of care to manage

lymphoedema and hydrocele (scrotal oedema), with services being made available within primary care systems in all areas of known patients to manage morbidity and prevent disability (MMDP) (WHO 2025). More recent LF data specific to Uganda could not be found in the Global report on neglected diseases 2024 (WHO 2024) or retrieved from the Uganda Ministry of Health website.

The Lymphedema Warriors Association Uganda

There has been notable success within the MDA programme in reducing the overall prevalence of LF infection in Uganda, but implementation of the approach to MMDP has been less of a priority (Sightsavers 2020). Some 5 years later Bagonza et al (2025) report many rural communities in the country to still have untreated LF and a lack of access to treatment and self-management. In 2022, and in response to unmet need, LWAU, a non-profit organisation run by an executive team of volunteers (table 1) was established with the objective of empowering all lymphedema sufferers residing in Uganda through education, support and advocacy (Kushaba 2025, www.lymphedemauganda.org , 2025). A continuing poor health system and absence of local health care professionals with lymphoedema training have resulted in LWAU`s annual, worldwide recruitment of volunteers via social media. The objective is for volunteers to provide treatment in two medical camps in Uganda for sufferers with all types of lymphoedema. For the second camp of 2025, three LPs` from the UK, and one from Australia (table 2) responded to the call to provide treatment in Kampala, Uganda`s capital city, and Busiriba, a village in the Kamwenge District, Western Uganda. The LPs` (the team) did not know each other.

Table 1

The Executive Team: Lymphoedema Warriors Association Uganda:
Lawin Kushaba, Founder and Secretary
Lipson Nuwagaba, Strategy and Partnerships Lead
George Ssejjemba, Media and Communications Officer
Irene Nabirye, Administrative and Operations Coordinator
Fredica Bugema, LWAU Partner. Director of Rural Health Promotion & Poverty Alleviation Initiative (ruhepai.org)

Table 2

The Lymphoedema Practitioner Team (the team):
Michelle Basford, Advanced Occupational Therapist – Lymphoedema, Allied Health, Sunshine Coast Health, Sunshine Coast University Hospital, Australia
Elaine Spaine, Lymphoedema Nurse Specialist, Solar Care, Isle of Man, UK
Rita Serra, Lymphoedema Specialist Practitioner / MLD Therapist, London, UK
Jane Board, Independent Lymphoedema Nurse Practitioner, Eastbourne, UK

The LPs` preparation

With contact facilitated through the British Lymphology Society (the BLS), the UK charity for lymphoedema professionals (www.thebls.com), the team undertook preparation for the visit via social media / whatsapp. Whilst each of us had been informed by LWAU of the logistics of the trip, there remained a level of anxiety generated from a `fear of the unknown` because none of us had undertaken such an experience before. Nevertheless, we wanted to help because we knew of the absence of a structured care system in Uganda meant affected individuals often struggled to access treatment, leading to complications such as infections, reduced mobility and economic hardship (Kushaba 2025).

The LPs` were pleased to discover their clinical backgrounds to be underpinned by the main pillars of lymphoedema treatment (the BLS, 2025). Travel vaccination, visas, lymphoedema treatment materials and uniform clothing were the topics of discussion. We quickly discovered the extent (and unexpected cost) of travel vaccinations (e.g. yellow fever, cholera, rabies and anti-malarial medication) because we were scheduled to undertake work in remote villages. Not all of us required a working visa. We established our need for a uniform comprising of long sleeve tops, trousers and robust footwear for protection against mosquitos. Essential to our travel preparation was the securing of lymphoedema materials to enable our treatment of patients e.g. bandages and compression garments. We had been informed by LWAU of their reliance on imported goods because of the absence of supplies within Uganda. Time was therefore spent in the gathering of material goods in our home countries, with some posted via shipping, but most to be carried in our suitcases. All the airlines used by the team provided a generous luggage allowance, and because we had become aware of the shipped goods being subjected to additional (unnecessary) charges by the Ugandan custom agency, we exploited these allowances to the full. Extra hands, provided by

husbands / partners were needed to help carry our luggage to the airport check in departments!

Kampala Camp

The first camp was based in Kampala, the home of Kushaba Lawin (LWAU founder) and her parents, and the centre of operation for the executive team of the organisation. It was to be the main accommodation for the team`s period of stay in Uganda. A single room extension became the base for the planning and delivery of patient treatment and equipment storage. The room was simply furnished and quickly filled with the team's suitcases full of bandages and compression garments! Our accommodation was comfortable. The weather averaged a temperature of 30 – 32 degrees centigrade. Access to a water supply for washing was erratic, frequently necessitating the use of cold water from jerry cans that were routinely replenished by our hosts. We quickly learned to manage with minimal water whilst appreciating the luxury of instant hot water from taps in our home countries! (We always had access to bottled water for drinking and teeth cleaning).

African Culture

Typical of the African culture, was the hospitality of Lawin and her parents, and the extent of it. Their kindness and generosity in feeding not only the team, but patients who had travelled far and who were frequently provided with overnight accommodation was both amazing and humbling. Clearly, not part of our treatment packages in the UK or Australia! Based on African cuisine, the food was simple and nourishing. Rice, meats, carrots, greens and bananas and other fruits formed the basis of the menu, and with wonderful tastes because the food was fresh and unprocessed. Dishes such as Ugandan Matoke and Chapati were also cooked and provided the sustenance needed for the work in hand!

Also typical of the African culture was time keeping and what amusingly became known between the team and our Ugandan hosts as the "ish" (to some extent / sort of). Timings were very flexible, unlike in our home countries, where the team were used to scheduled appointments for events. At the Kampala camp, patients arrived when they did and sometimes along with other people requiring treatment who would sit in with the appointment. The LPs` adjusted to the relaxed time keeping surprisingly quickly because we were able to spend time with each patient free from the pressures associated with set clinic appointments and `running late` in our home countries. However, from the perspective of information confidentiality, the team never quite got used to the attendance of other patients in the same clinic space. It highlighted the rigours of our GDPR training!

Kampala treatments

Our assessment and treatment of patients was a challenging experience at times. Unscheduled patient appointments frequently undermined the team's preparation. A majority of patients also attended with no medical documentation, because their access to health care elsewhere (if at all) did not facilitate the sharing of written medical communication. We became reliant on the verbal information provided by each patient and tried to ensure two members of the team participated in questioning to uphold safe practice. It was helpful that English was the first spoken language, but many patients needed encouragement in sharing their medical history, perhaps because of shyness, uncertainty about us, or their lack of exposure to the concept of information sharing.

All types of lymphoedema routinely referred to our clinics at home, were also seen and treated at the Kampala camp e.g. breast cancer, venous insufficiency and trauma. We did not witness patients with lymphoedema in the end stages of life, although one lady presented with bilateral leg oedema following a course of radiotherapy for the treatment of cancer. Of significance and key to the team's clinical learning was the attendance of two men (30 and 54 years old respectively) with LF who had previously received physical treatment from LWAU, and lymph node transplant surgery undertaken by Professor Aung in September 2024 (see below).

The signs and symptoms of LF required time for processing by the team. (Photographs never quite prepare for what is physically seen). The younger man had apparently also undergone chemotherapy treatment as part of the GPELF programme but was unable to convey the detail of his medication. Clinical examination revealed the presence of a soft non pitting oedema, with no skin changes affecting his right thigh. The removal of an unclean retention bandage from his right lower limb revealed a gross shape distortion in the lower limb and foot, generated by extensive papillomatosis and deep skin crevices. The toe digits needed to be determined from the papillomatosis, and wounds that were to require dressings identified from deep skin crevices (PHOTOGRAPH). Amazingly, there was no evidence of wound or skin infections. Care was taken with washing the leg and foot, using an antiseptic wash in a bowl of water to douche, then drying carefully using sterile gauze dressings. Non adhesive dressings were applied to the clean open wounds, followed by the application of a lymphoedema bandaging regimen. The 50 year old man presented with similar symptoms but less severe when compared to the younger man. The same treatment was undertaken as of the first man. In the absence of treatment follow up, both men were supplied with bandages and wound dressings to enable self-care. (We did not undertake examination regarding the presence of hydrocele).

With regards to lymphoedema materials, it was at this point that the team became very aware of the potential shortage for treating patients at the second camp. It was a scenario we had anticipated in the days of our preparation, now very real and

compounded by the unknown number of patients who we were yet to see. Not only the bandages to be used directly by the team, but also a supply to enable patients to self-care.

Travel

Ably driven by George or Lipson (table 1), we travelled as a large team to our second camp at the village of Busiriba, in the district of Kamwenge, Western Uganda, situated at an altitude of 1, 437 metres above sea level. The team consisted of the LPs`, the executive team of LWAU and trainee healthcare workers known to the organisation who attended so as to enhance their clinical practice.

Our travel was not direct. From the outskirts of Kampala we drove to the Isingiro district near the Tasmanian border to treat two patients in their homes. Lipson then took us to visit an empty, former school building donated to LWAU. He wanted to show us the ground breaking project of LWAU; to achieve a fundraising goal of $90,000 for the furnishing of `East Africa`s First Lymphoedema Rehabilitation Center -Uganda` (Building Hope: East Africa's First Lymphedema Rehabilitation Center – Uganda – Lymphedema Warriors Association Uganda (LWAU)). Whilst there was much work to be done, it was exciting to see, and we were grateful to be shown (PHOTOGRAPH)

We then travelled on to Kazo where we were kindly hosted for 3 nights by Fredica (table 1) for our daily travel to Busiriba. Whilst some roads were constructed with tarmac the majority, especially those in the rural areas, were no more than mud tracks, with very uneven surfaces. Nevertheless, it was revealing to see a large part of Uganda, including areas of poverty; the huts and villages, expanse of plateaus, forests and banana plantations. Also, a marked change in the colour of the soil, from beige / brown to rusty orange/ red because we had entered a mountainous region

As we approached the health centre on the first day, we were greeted by a `sea of colour`, generated from the flamboyant clothing worn by the ladies sitting on the grass verge near the building. Apparently, many of the men and women attending for treatment had travelled on foot overnight. There was no café or shop to obtain beverages. It was a humbling experience.

Brief details of each patient were taken by members of the LWAU executive team, whilst they waited to be seen. (In all, 112 patients were assessed and treated). The working room used by the team to treat patients had no access to running water or electricity. The internal floors and surfaces were very dusty. The pace of the team`s work was both frenetic and exciting. Speed was essential because we wanted to treat each attendee. Patients were escorted into the working room for individual assessment and treatment with an LP. The temperature averaged 30 degrees, with minimal ventilation. Time constraints meant that the LPs` communication with patients was limited to a smile, asking of their name and a gentle handshake before a short, prompt assessment and

treatment. (The patients always smiled back). The team assisted each other when patients presented with complex symptoms; from deep, arterial wounds, to exposed bones caused by the mishandling of a scythe whilst harvesting crops. We worked in to the early evenings, using the torches on our mobile phones to provide light. By the end of each day, our uniforms and plastic aprons were dishevelled and dirty from sitting / crouching on the floor. Our hands were hot, grubby and sticky from copious applications of hand sanitiser and disposable gloves in the absence of soap and water.

All forms of lymphoedema were seen at this camp too, with treatments frequently modified in respect of our dwindling treatment supplies and our desire to hold some stock for patients still waiting to be seen. Whilst the usage of donated, second-hand short stretch bandages was an ethical challenge for the team (we always used new), it was the only available option to ensure bandaging and compression garment treatment for all patients with a clinical need. (The second-hand materials were always clean and unstained).

Time to converse with patients was very limited because of the volume to be treated. However, we were able to glean that many worked in their `gardens`, growing crops such as carrots and bananas. Invariably, the patient cohort were older in years and seen to be wearing ill fitting, flimsy footwear. Many presented with oedematous unclean feet, with widened forefeet and skin changes affecting their toe digits (nodular in formation); indicative of Podoconiosis, a non-filarial type of lymphoedema (PHOTOGRAPH). The condition is often associated with environmental factors and lack of hygiene (Masete et al 2024). The same authors report the risk of Podoconiosis from long term, barefoot exposure to alkalic red clay soils formed from volcanic base rock in environments of high altitude and rainfall. The penetration of mineral particles through the skin causes inflammation and fibrosis of the lymphatic vessels and the subsequent development of oedema in toe digits, feet and limbs (Masete et al 2024). Unfortunately, the volume of work prevented counting of the numbers considered to have presented with podoconiosis. The prevalence of podoconiosis in Uganda could not be retrieved from a literature search. Masete et al (2024) cite a limited clinical suspicion and the absence of a positive diagnostic test to contribute to the underestimation of the prevalence of podoconiosis in Uganda. However, the same authors undertook a population based cross – sectional survey of 7 districts in Uganda and were able to report that of the 10,023 participants sampled, 187 had clinical features of podoconiosis.

In the limited time that we had with patients suffering from pedal oedema, we stressed the need for foot and limb washing, being mindful that some sufferers did not have direct access to water. Unfortunately, our reduced material supplies meant not all patients could receive the compression garments they clinically required. Some were treated with lymphoedema bandaging, or of their toe digits instead.

Educating on self-management techniques had proven to be difficult on the first day at Busiriba because of the numbers of patients needing to be treated. On the second day, to address the issue and facilitated by LWAU, the LPs` presented a group session on self-management techniques for patients who had gathered outside of the health centre (approximately 112). In addition to advice and demonstrations surrounding skin care, simple lymphatic drainage and exercise and mobility, a session was also requested on lymphoedema bandaging. Lymphoedema bandaging was not regarded as a self-management treatment component by the LPs` because of the variances required to accommodate individual clinical need. Nevertheless, the LPs` understood the need for patient instruction in this instance because of the absence of local lymphoedema care.

We returned to the camp at Kampala for the final days of our stay and the treatment of more patients. It was a pleasant surprise to meet Professor Aung, Program Director, Deggendorf Institute of Technology, Germany. A certified plastic and aesthetic surgeon, including micro and lymphatic surgery, Professor Aung undertakes humanitarian work through his liaison with LWAU. We heard about lymph node transplant surgery and his undertaking of online consultations for severe cases managed by the LWAU team. Unfortunately, our timetables did not coincide to enable the team to witness lymphatic microsurgery.

Prior to our departure, a meeting for debriefing and review was arranged by the executive team of LWAU with the LPs` . Many of the aspects recognised by the team had been highlighted in Lawin Kushaba`s recent article (Kushaba 2025) e.g. the challenges associated with sustainable funding, material supplies, logistical constraints and limited local healthcare expertise. Nevertheless, it was good to hear about projects underway e.g. the development of partnership collaborations with local and international stakeholders, and the long-term plan to advocate for government policies to integrate lymphoedema management into national health programmes (Lawin 2025). Also, the development of a database management system for the collection of patient demographics and the structuring of patient treatment and appointments was underway.

Conclusion

It was a humbling and amazing experience for me. Humbling because of the gentleness of the Ugandan people suffering from lymphoedema, regardless of the cause. To see or hear the simplicity of the lives they lead day by day and their gratitude for the treatment given.

In consideration of being unknown to each other prior to the camps, the camaraderie and mutual trust within the LP team in our working and living together was amazing. From the learning of new diagnoses and collaboration with patient treatments to the

sharing of dry shampoo, chocolate biscuits and paracetamol tablets for headaches. (Elaine, Rita and Michele; thank you so much!).

Humbling and inspiring also, was the passion and drive of the executive team of LWAU who worked (and continue to do so) tirelessly to provide a lymphoedema service as best as they can with the challenges they continue to face, but also with hope for the future. I know I speak on behalf of the LPs`, in thanking them for their kindness and hospitality to us and in wishing them for every success in the future.

References

Bagonza A, Gibson L, Kabiri L, Bezalel C, Narahari SRB, Franks PJ, et al. (2025) Exploring barriers to accessing treatment for Lymphatic Filariasis through a socio-ecological lens in Buvuma and Napak districts, Uganda. PLOS Neglected Tropical Diseases. https://doi.org/10.1371/journal.pntd.0012747

Kushaba L (2025) Lymphedema medical and surgical camp report: addressing neglected tropical diseases in Uganda.

Lymphedema Warriors Uganda Association www.lymphedemauganda.org (online November 2025)

Masete, I., Simpsonb, H., Matwalec, G., Mutebid, F., Thieleckee, M., Nuwahaf, F., Mukonea, G., Deribeb, K., and Davey, G. (2024). Podoconiosis in Uganda: prevalence, geographical distribution and risk factors. In *Transactions of the Royal Society of Tropical Medicine and Hygiene (2024)*. Vol 118, Issue no:12, pages 790 - 798

Sightsavers (2020). Lymphatic Filariasis in Uganda: knowledge, attitudes and practices. Research Summary. https://research.sightsavers.org/wp-content/uploads/2020/10/Uganda-LF-research-summary-October-2020.pdf

British Lymphology Society (2025). What is lymphoedema? Treatment https://thebls.com/pages/what-is-lymphoedema (online November 2025)

World Health Organisation Regional Office for Africa (2023): Country Disease Outlook: Uganda, Universal Health Coverage, Communicable and Non communicable Diseases

https://www.afro.who.int/sites/default/files/2023-08/Uganda.pdf (online November 2025)

World Health Organisation (2024): Global report on neglected tropical diseases 2024.

https://www.who.int/publications/b/70237 (online November 2025)
