Hear our voices
Speaking out so no-one is left behind
The Leprosy Mission, founded in 1874, is a Christian international development organisation working in 32 countries. We are the largest non-government organisation focussing specifically on eradicating the causes and consequences of leprosy. Our vision is ‘leprosy defeated, lives transformed’. TLM in the UK works across 13 leprosy-endemic countries to end the disease and support those affected by it.

Leprosy is classed as a Neglected Tropical Disease (NTD), but it is also a human rights issue and is directly linked to poverty. The associated stigma and discrimination can lead to depression, homelessness, divorce, family breakdown, even the loss of a job or business. That’s why our work goes beyond medical care to include health awareness, early detection, education, rehabilitation, water and sanitation, community reintegration, counselling and psychosocial support, research and advocacy.

Although leprosy-focused, our work includes other marginalised people such as those with disabilities, people affected by other NTDs, or others living in extreme poverty. We are motivated by the example of Jesus Christ, but offer our services to all regardless of background, religion or ethnicity.
The Leprosy Mission (TLM) is recognised across the world for excellence in the areas of leprosy, NTDs and disability. Throughout our history we have pioneered ground-breaking surgical techniques and transformational rehabilitation programmes. But we can only achieve our vision of seeing leprosy defeated and lives transformed through securing increased investment in leprosy work and research, developing new tests and treatments, and challenging discrimination.

Ending discrimination and supporting the inner-wellbeing of those affected improves quality of life and increases the likelihood of people coming forward and completing their treatment. A new early diagnostic test, improved knowledge among health staff, contact tracing and case mapping will help to prevent the spread of leprosy. Formulating an effective vaccine and preventive chemotherapy treatment will give vulnerable people protection from leprosy. Understanding more about leprosy transmission and reaction, including comorbidity research, will improve prevention and treatment methods. We are especially keen to work in partnership with donors, Governments, other NGOs, academia, communities and people affected by leprosy themselves, uniting to achieve the commitments to leprosy elimination promised in the 2012 London Declaration on NTDs and finally see an end to this ancient disease.
**Safia’s story**

“I developed leprosy as a very small child. My family noticed skin patches but there were no medical services where I lived so they didn’t take me for treatment. My hands began to get stiff until I couldn’t bend my fingers any more. I also developed ulcers on my leg, which became infected. My ulcers were so bad that the doctors had no option but to amputate. The toes on my other foot suffered too, absorbing back into the foot. It was a very difficult time.

“I was a grown woman when I was diagnosed with leprosy, and I took a course of multidrug therapy (MDT) to cure me. But because they were afraid of my disease, my family disowned me and my community pushed me out. I was left alone, with nowhere to go for help. I feel very low, miserable and unwanted.”

- Safia is 53 years old and lives alone in the north of Bangladesh.

**Ensuring Best Practice**

Before the Activating and Engaging Government and People in Partnership Project it was assumed leprosy was no longer a problem in that part of Bangladesh, with single figures detected annually. Working through local civil society organisations (CSOs) and media, hundreds of previously hidden cases are now being diagnosed. Raising awareness through schools, newspapers and television has enabled advocacy and government partnerships, ensuring that people affected by leprosy and disability have timely access to relevant, high-quality health services. Government staff, local NGOs and partner organisations are trained in the signs and symptoms of leprosy, and how to treat and manage leprosy and related disabilities.

**Learning for the Future**

Leprosy detection is not prioritised in many countries, which has serious consequences. Safia was diagnosed too late to prevent years of needless suffering; if she had been treated early she would have been cured before disability occurred. Projects which include active case finding, contact tracing and early detection and treatment are vital to slowing the spread of leprosy and other NTDs, and bringing us closer to eradication. Investment in developing an early diagnostic test for leprosy is key – diagnosis often comes years after leprosy is contracted. During this time the disease is spreading and leprosy reaction, loss of sensation and disability all become more likely.

**Investment in research for an early diagnostic test is essential for ending leprosy and preventing further suffering**
Ensuring Best Practice

Salamatou was supported by the Community Empowerment and Leprosy Services (CELS) Project. It aims to improve diagnosis and complication management for people with leprosy and disabilities, including awareness raising and mass screening programmes for new case detection. Because she was found and treated early, Salamatou does not have any disabilities. Local health staff are trained on leprosy and disability, widening coverage and strengthening health systems. There is also a focus on inclusion, forming advocacy groups to restore marginalised people’s agency and independence through livelihood support, rights awareness and hygiene training.

Learning for the Future

Salamatou’s story demonstrates the importance of active case finding in preventing the devastating effects of leprosy. Many people ignore their symptoms because of fear or ignorance, or because they can’t afford the time or money to visit a doctor. Active case finding, accompanied by awareness raising initiatives, is a vital tool in the fight to see leprosy defeated and lives transformed. People are found, treated and spared from avoidable physical and emotional suffering. Communities are strengthened and become more inclusive, and new generations grow up knowing that leprosy can be cured.

Active case finding and contact tracing drastically reduces rates of leprosy, disability and stigma

Salamatou’s story

“I was married with five children when I began showing symptoms I didn’t understand. I didn’t visit a doctor because I was always busy with my children. I hoped it would get better, but it didn’t.

“When TLM Niger health workers came to my community looking for cases of leprosy, I was diagnosed with the disease and began MDT. But my husband was afraid of catching it, so he divorced me and left me and our children alone without support.

“The health team visited regularly to check my health and make sure I was taking my medicine. I was getting better but my community treated me very badly. So, with the support of TLM, I began to educate my neighbours about the truth of leprosy, that it’s easy to cure. Nobody should be abandoned or left out because of leprosy.

“Happily, my community’s attitudes changed and now I am accepted. My husband came back and we have a sixth child, we are very happy together.”

Salamatou lives in Tillabéri, Niger.
Anisha’s story

Anisha has lymphatic filariasis (LF), a parasitic disease which causes swelling of the legs. It is spread by mosquitoes and caused by microscopic worms. Sadly, there is no complete cure. Like leprosy, it can lead to stigma, disability and lack of opportunities.

“My legs swelled when I was pregnant, we thought it was a pregnancy symptom. After my child was born my right leg went down, but not my left. The doctor gave useless injections, and a traditional healer’s herbal salve caused a serious infection.

“Eventually some medical field workers diagnosed my LF and alerted TLM Bangladesh, who made sure I received treatment. Even so, I now have severe elephantiasis and my skin is thick and hard.

“But I will not let this ruin my life. I help my husband to grow rice, potatoes and jute. The self-care that I was taught has healed the ulcers on my leg and TLM designed shoes for my swollen feet. I will do all I can to remain hopeful and independent.”

- Anisha lives in northern Bangladesh.

Ensuring Best Practice

TLM Bangladesh is conducting cross-NTD work on leprosy and LF and staff are trained in managing both conditions. In other countries our partners are addressing different NTDs including soil-transmitted helminths (STH) – intestinal worms spread through soil. Over 94 per cent of new leprosy diagnoses are in areas co-endemic for leprosy and STH. TLM Nepal’s Mycobacterial Research Laboratory is investigating the implications of leprosy and STH co-infection for leprosy reaction and other immunological complications. Leprosy reaction is the primary factor for developing neuropathy and disability and affects up to 50 per cent of leprosy patients. Understanding more about this will inform better treatment of leprosy and other NTDs.

Learning for the Future

Similar to leprosy, people with other NTDs often have reduced mobility or suffer high levels of discrimination and rejection. They also need to learn self-care techniques to keep the skin clean and avoid infection and ulcers. WASH (Water, Sanitation and Hygiene) is a vital element for managing leprosy, LF and many other NTDs. Pioneering cross-NTD work reaches more people, improves cost effectiveness of government health programmes and reduces the suffering of the most vulnerable. Trained staff can recognise a wider range of symptoms, enabling more accurate diagnoses and earlier treatment. Further research into co-infections of NTDs is essential for improving treatment.

Integrated NTD approaches and innovative research are vital for cost effective treatment and prevention of leprosy
Learning for the Future

A major obstacle to defeating leprosy is the lack of preventive options – even vaccines currently in development will not completely protect against leprosy. LPEP is a promising tool to reduce leprosy prevalence. When given to contacts of people recently diagnosed, it is shown to significantly reduce their chances of developing leprosy, especially if they had a childhood BCG vaccine. Thoroughly tracing contacts also uncovers new cases of leprosy. Further research on chemoprophylaxis and changes to methodology, such as giving LPEP to all households in a leprosy hotspot, could increase its impact, preventing many thousands of people from developing leprosy. WHO has endorsed LPEP as an effective prevention method.

Improving tools for leprosy prevention and scaling them up is essential to end leprosy transmission.

Ensuring Best Practice

Leprosy spreads through close contact. Although MDT is effective, active transmission continues, with a high proportion of child cases. Leprosy Post Exposure Prophylaxis (LPEP), given as a single dose of rifampicin, reduces the likelihood of contacts developing leprosy. Ram and his family took part in the LPEP Programme run by TLM Nepal, Partnership for New Life and the Leprosy Control Division of the Government of Nepal.

Numkala works in the LPEP Programme and has been a community health volunteer for 23 years. “Many women’s husbands stop them from visiting the health post. I don’t get paid but I want to educate people and support these women and children to get treatment. We are committed to finding and treating everyone with leprosy, giving their contacts medicine to prevent disability and making our villages leprosy-free.”

Ram’s story

“When I lost sensation in my little finger, I didn’t know what was happening but I knew it wasn’t normal. My condition got worse until I couldn’t feel my fingers or the palm of my hand. I also had tingling sensations all over my body. I became afraid when I developed red patches on my skin, I didn’t know where to find treatment.

“Fortunately, I heard about a leprosy prevention programme happening close to my village. My whole family were checked and I was diagnosed with leprosy. I was shocked and scared. I didn’t like talking about it, but the counsellor helped me process my feelings and motivated me to take treatment.

“My diagnosis led to 20 of my family and friends taking medication to prevent them from contracting leprosy. I am very thankful for this.”

■ Ram lives with his wife and children in a small Nepali village close to the Indian border.
Economic empowerment

Thein’s story

“When I was 10 I lost sensation in my hands and feet, they became stiff and I couldn’t move them. I was diagnosed with leprosy and began MDT. But after three months I had severe leprosy reaction [a type of allergic reaction to dead leprosy bacteria] and couldn’t hold things or feed myself – I was bedbound and ached everywhere.

“As my health improved I became a farmer, but my disabilities made it hard and I often injured myself because I couldn’t feel my hands or feet. Once I stepped on a spike and didn’t notice, and the injury became infected. I also have some sight loss. Eventually I had to give up farming. I didn’t know how to support my family, I felt so useless.

“After Cyclone Nargis came [in May 2008], a rapid response team connected me with TLM Myanmar. I received a self-care kit to help me care for my hands and feet, and a microcredit loan for a basket weaving business. I make 30–40 baskets a week, with a good profit on each. I have money to care for my child. I feel much better, even with my problems.”

Thein lives in Yangon, Myanmar.

Ensuring Best Practice

TLM Myanmar is the leading disability-focused organisation in Myanmar with a network of 18 Disability Resource Centres. These provide disability services, livelihood support, and seek to include people affected by leprosy within the disability movement, and people with disabilities within mainstream society. This includes supporting the establishment and capacity development of the Myanmar Federation of People with Disabilities. Activities are being scaled up through partnership with BRAC, a leading microfinance provider, and Enablement, a specialist community rehabilitation NGO, all funded by the DaNa Facility.

Learning for the Future

Disability-friendly livelihood support is necessary to ensure that everyone has a chance to meet their potential and earn a good living. This inclusive development model involves people with disabilities at every stage of project design and implementation. It includes development of business plans, appropriate and accessible training, follow-up support, removal of attitudinal and environmental barriers, and soft loans. Further investment is needed to develop microfinance products which will help new livelihood and agricultural initiatives to succeed, as well as focusing on creating barrier-free marketplaces and provision of assistive devices.

Disability should not be a barrier to earning potential – livelihoods projects must be innovative, relevant and individually focused.
When people with disabilities are empowered they can live fulfilled lives, become agents of change and support sustainable development.
High-quality assistive aids enable dignity, mobility and fullness of life

Ensuring Best Practice

Chanchaga Orthopaedic Workshop invests in innovation to improve mobility and quality of life for people affected by leprosy and disability. Its excellence is recognised by the Nigerian Army, which has commissioned prosthetics for injured soldiers.

Chris is the assistant senior technician. “I was working with the Nigerian National Youth Service Corps when I met a leprosy patient who had a below-knee prosthesis from Chanchaga. I was very impressed by him and by the excellent work and craftsmanship of the workshop, so I applied to work there.

“I feel inspired by the work here, and proud to be a part of it. I care about each of my patients, and take joy from helping them. I am always asking, ‘What can I do to improve the life of the patient?’ What we do here impacts lives: it is about love, passion, and care for people who are vulnerable.”

Learning for the Future

TLM’s skilled, dedicated staff are always seeking new ways to serve and enable people affected by leprosy and disability. This may mean providing complicated prostheses, or simple adapted tools and cutlery which can be used by people without fingers. Innovation is key, learning from individual patients about how to improve their lives and then developing the tools to make it happen. In India, we are developing 3D printing to produce low-cost, high quality assistive devices such as protective footwear and prostheses. Further investment is needed but the initial signs are that this ground-breaking technology will revolutionise the way we serve people with disabilities.

Inner wellbeing and holistic support

Edem’s story

“T developed skin patches as a teenager, but didn’t know what they were. For six years I used herbal treatments, with no effect. One day I pierced my foot by stepping on a nail and went to hospital, where I was diagnosed with leprosy. I didn’t believe it because nobody that I knew had leprosy.

“My wife and I are farmers, growing maize and corn. This became very difficult work because I found it hard to move around. I got sand and soil in the ulcers on my feet which irritated them. I also had serious eye problems and completely lost my sight in one eye.

“Eventually I went to Chanchaga Hospital and started taking MDT. This changed my life – I was given free treatment, protective footwear, crutches and a new wheelchair, which has restored my independence and will help to avoid future injuries. Without this care and support, my life would be so much worse.”

Edem lives near Minna, Nigeria, with his wife, five children and foster child.
Ensuring Best Practice

Ruth is the passionate and dedicated patient counsellor at Anandaban Hospital, and a qualified psychologist. She supported Mahendra during his time at the hospital. “Leprosy is a stigmatising disease and often leaves the patient feeling that they are a bad person and cursed by God. At Anandaban, we don’t just treat the physical symptoms of leprosy, we treat the psychological aspects too. We try to build up courage and self-esteem through group discussions and by individual and family counselling sessions. A big part of the counselling is telling people the truth about leprosy. It's a lengthy process, but it is very rewarding.”

Learning for the Future

Leprosy, disability and NTDs can negatively impact mental health. Rejection, self-stigma, lack of employment opportunities and loss of family support systems can take a serious toll on a patient’s wellbeing, leaving them isolated, vulnerable and depressed. Too often, leprosy-affected people lose hope for the future, feeling worthless and useless, even attempting suicide. But investment in counselling, peer support and awareness raising will restore hope and purpose.

Mahendra’s story

“I first noticed symptoms when I was eight but I was scared, so I tried to pretend it wasn’t happening. Eventually I couldn’t hide it any more, I developed ulcers so bad that I couldn’t walk. I had to stop playing football and going to school, all the things I loved. My parents took me to various hospitals but I wasn’t diagnosed with leprosy until I was 10.

“I was confused and angry, and my father was furious – he abandoned and disowned me, saying, ‘Let him die – it is not worth him living if he has leprosy’.

“I had nowhere to live and no support. Eventually I was referred to TLM’s Anandaban Hospital but my wounds were so bad, the only option was amputation. Nobody visited me and I became depressed and hopeless, crying all the time. Thankfully Anandaban gave me counselling and a custom-made prosthetic so I can move around independently and care for myself. TLM gave me hope for the future. My idea is to open a small shop, but I worry that people would not shop there because I’ve had leprosy.”

■ Mahendra is 16 and comes from Dhanusha, Nepal.

NTDs need holistic treatment that includes a focus on mental-wellbeing to restore hope, confidence and purpose.
Meaningful inclusion can only be achieved through empowering women and girls, and challenging gender-based discrimination.
Ensuring Best Practice
The CREATE Project, funded by the European Union, is working in 18 districts across four states of India. CREATE provides skills training and access to employment, and mobilises individuals to understand and attain their rights. Working through community groups, it empowers people affected by leprosy and disability to promote inclusive development, advocate for disability rights and challenge injustice. This is done in collaboration with local government, self-help groups, Disabled People’s Organisations and other NGOs to ensure inclusion and to build advocacy and support networks. Advocacy for social justice is ongoing at local, district, state and national level.

Learning for the Future
Globally, millions of people still face discrimination resulting in injustice and exclusion. Leprosy is one of the world’s most stigmatising diseases, preventing people from accessing treatment, securing employment and exercising their rights. India is just one country with legislation which actively discriminates against people affected by leprosy. There has been some recent success in repealing this legislation, and TLM Trust India is supporting a Private Member’s Bill within India’s parliament to overturn the 119 discriminatory laws, but there is still a long way to go. Leprosy cannot be eliminated until harmful laws are repealed and people affected by leprosy are empowered to claim their rights. Investment is needed to ensure that the voices of people affected by leprosy and disability are heard and acted upon.

Political commitment to equal rights, at all levels of government, is key to achieving inclusion and social justice
Inclusion for all

Pankaj’s story

“I was diagnosed with leprosy as a teenager. MDT cured me, but children at school refused to sit with me and even the teachers treated me badly. My eye problems and clawed hands made it hard to write, so I began studying from home. I felt discouraged, but I was determined to succeed. With hard work, I graduated from college with a History degree. I also had eye surgery and reconstructive surgery at TLM’s Naini Hospital, which made life easier.

“I’ve suffered terrible discrimination. I was fired as a teacher, a job that I loved and was good at, when the school found out I’d once had leprosy. I’ve been refused entry to places of worship and I’m often denied a seat on trains and made to sit by the toilet. I was even thrown off the disabled section of a bus when the conductor realised I’d had leprosy.

“I am now the president of a leprosy people’s organisation because I feel passionately that leprosy-related discrimination needs to end – too many people are still being denied their basic rights.”

Pankaj lives in Uttar Pradesh, India.

Ensuring Best Practice

TLM trains people like Pankaj to be Leprosy Champions, using collective advocacy to obtain rights and challenge injustices. This becomes more effective when people affected by leprosy are included by other organisations, particularly disability groups which have sometimes excluded them.

Suraj is president of the influential disability network Uttar Pradesh Vikalaang Manch, with a membership of 223,000. UPVM’s aim is to help people with disabilities gain dignity, self-esteem and equal rights. It collaborates with disability networks across India, promoting inclusive education and access to social security. Since working with TLM, UPVM now includes leprosy-affected people and advocates against anti-leprosy laws. Suraj personally wrote to the Chief Minister of Uttar Pradesh urging him to ban the use of the word ‘leper’ as a discriminatory term.

Learning for the Future

Even in places where disability inclusion is improving, people affected by leprosy still face discrimination. Despite various global agreements, including the UN Convention of the Rights of Persons with Disabilities (UNCRPD) and the UN Principle and Guidelines on the Elimination of Discrimination Against People Affected by Leprosy and their Family Members, discrimination persists. Achieving the aims of UNCRPD will depend upon all people with disabilities, and others, working together to ensure its complete and effective implementation. Mainstreaming leprosy into disability work is key to ensuring that no one is left behind; that all people have the opportunity to live full, dignified and purposeful lives.
Ensuring Best Practice

For the first time in Sri Lanka’s history, the interfaith leprosy programme is bringing together religious leaders from all major faiths to end leprosy. ADT’s partnership with the Ministry of Health has grown significantly, enhancing the government’s focus on leprosy. ADT is now reaching out to faith communities, schools and prisons and will continue to expand its awareness work. The Ministry of Health has recognised the effectiveness of the interfaith approach and is keen to implement this model in the treatment of other diseases.

Learning for the Future

Religious leaders have a powerful voice and influence over their communities. Working with and through them is crucial to spread awareness of leprosy and NTDs, to begin to break down social barriers, and to challenge exclusion and discrimination. Interfaith activities are not just helpful in addressing leprosy; in a country fraught with religious conflict they are also building peace and co-operation in communities, as differing faiths unite for a common purpose.

Engaging religious leaders in raising awareness and challenging deeply ingrained beliefs about leprosy is essential to ending leprosy and related discrimination.

Working for unity

“I used to think social work was irrelevant, and the church fellowship I lead didn’t want to be involved. But after talking to other religious leaders about leprosy, I realised that this was part of my ministry. I joined the Puttalam interfaith leprosy programme and now co-ordinate some of their activities. We are building better community relationships as well as addressing leprosy – different religions are working together, rather than fighting.”

Pastor Gershan (pictured second from the left) is a Pentecostal minister in Sri Lanka.

“I knew I had to be a part of this initiative. The Qur’an is specifically concerned with health; cleanliness and healthiness are equal to trust in God in our religion. If someone is suffering from illness the Qur’an says we should help. If we help anyone it is good, but more blessing is received if we help the marginalised.

“One issue is that Muslim women wear a hijab, so leprosy symptoms may go undetected. I therefore want to raise awareness and include leprosy within Friday prayers at my mosque. I am also a principal of one madrassa (Muslim school) and plan to speak about leprosy in all the madrassas in my district.”

Imam Abdullah Mohammed Ali (pictured far right) became a member after attending a national leprosy conference arranged by Alliance Development Trust (ADT), a local TLM partner.
TLM works with local organisations and fosters close links with Government, the local church, other NGOs and leprosy-affected communities to make sure that our projects and programmes are inclusive, sustainable and effective. We are dedicated to reaching the poorest and most marginalised, ensuring that no-one is left behind.

TLM is a member of numerous networks and works through many strategic partnerships to share learning, engage in joint advocacy activities and co-implement programmes. We recognise that we cannot defeat leprosy and transform lives alone; partnerships are essential to multiply our impact. As part of our dedication to growth and improvement, we are always open to new relationships with partner organisations to ensure the best possible outcomes for those affected by leprosy and the communities in which they live.

**Holistic treatment**

**Inclusion**

**Research and innovation**

**Stigma and discrimination**

**Economic empowerment**

The names of some individuals in this booklet have been changed to protect their identity.

Some of the partner organisations that TLM works with: