

So, what do you know about leprosy?



Surely nobody suffers from leprosy these days? It's mentioned in the Bible!

Sadly yes. Leprosy (Hansen's disease) is still rife in many countries. It's still a 21st-century disease, devastating people's lives right now.

But I don't know anyone who has it!

That's because we on the Isle of Man are too healthy and well fed. Leprosy is found in the poorest countries of the world. According to the World Health Organization (WHO), there are more than 200,000 new cases of leprosy diagnosed globally each year, 202,185 in 2019 falling dramatically in 2020 to 127,396 due to less new case detection and fewer countries reporting on new cases as a result of the Covid-19 pandemic.

What's being done to eradicate this disease?

The Leprosy Mission Isle of Man, (through its parent charity in the UK) is part of a global organisation leading the fight against leprosy, having as its strapline "Leprosy Defeated, Lives Transformed". Projects are supported in 10 countries across Asia and Africa (Bangladesh, Ethiopia, India, Mozambique, Myanmar, Nepal, Niger, Nigeria, Sri Lanka and Sudan).

So, what causes leprosy?

Leprosy is a bacterial disease. It's spread by moisture droplets passing through the air from someone with leprosy but hasn't started treatment. It's usually associated with poverty, malnutrition, overcrowded living conditions and poor sanitation, all of which help lower a person's immunity and make them more likely to catch the disease. It's not hereditary.

Is Leprosy contagious?

No, despite a longstanding belief to the contrary you can't get leprosy by touching someone. It's only mildly infectious.

What are the symptoms?

Leprosy affects nerve endings, particularly in the outer body extremities like hands, feet and face. This reduces sensation, so pain isn't felt. Imagine walking on broken glass, or burning yourself whilst cooking or ironing and being totally oblivious to what's physically happening to you. Because the bacteria multiplies slowly, symptoms of the disease can take a long time to develop - around five years on average but sometimes as long as 20 years.

Are there any complications if you have leprosy?

If treated early, it's unlikely the disease will cause permanent disability. But if left untreated, it progresses and the nerve damage spreads. Lacking sensation in their hands and feet, people with leprosy can injure themselves. And these injuries can lead to ulcers, infection and permanent disability.

Leprosy can also cause muscle paralysis, resulting in clawed fingers and foot drop. This makes it difficult for people to walk or use their hands.

The condition can also damage nerves in the face, causing the eyelid muscles to stop working. As the eyes are no longer protected by blinking, they are easily damaged, leading to sight loss and blindness.

Is there a cure?

Yes, there is! A cure has been available since 1982. Multidrug therapy (MDT) is a combination of three drugs taken daily for six or 12 months, depending on the severity of the disease. Sadly, although treatment stops leprosy progressing, it can't reverse disability. However, a clawed hand, dropped foot or damaged eyelids can be restored with surgery. Custom-made protective footwear can reduce the chances of injury and stop ulcers developing. Unfortunately, some disabilities caused by leprosy are too severe for surgery to have much effect.

Surely if there's a cure, that's it, isn't it? What's the problem?

If only it was that simple. Hard as it may be to understand from a Western perspective, the myth persists that people with leprosy have brought it upon themselves by being "bad".

So much so, that anyone showing symptoms, both children and adults, are treated as outcasts and can be thrown out of their families, villages and schools. Many people lose their jobs and struggle to find new employment.

Small wonder then, that if anyone suspects they may have symptoms, they try to hide it for as long as possible. But the longer a diagnosis is delayed, the more permanent damage is likely to be. Ignorance, superstition, stigma and discrimination lie at the heart of the problem and these have to be tackled before this disease is eradicated and consigned to the history books.

Is any progress being made in improving the situation?

Definitely. The Leprosy Mission is making progress in all countries where leprosy still exists by:

- ❖ Working with local health services to enable early awareness, diagnoses and treatment of the disease
- ❖ Challenging cultural misconceptions
- ❖ Trying to reduce major disability resulting from delays in diagnosing leprosy by working with hospitals, health centres and leprosy affected people themselves to improve treatment and self-care
- ❖ Partnering with Human Rights Organisations and those with leprosy themselves to end stigma and discriminatory practice against those with the disease
- ❖ Improving the fabric, services and facilities of hospitals, health clinics and centres
- ❖ Establishing vocational training centres and providing employment opportunities
- ❖ Helping to start up self-help groups and local cooperatives so those with leprosy can earn a living and become independent.

Diana, Princess of Wales, was Patron of the Leprosy Mission up to her death. Photos of her touching people with leprosy did much to counteract misunderstanding and ignorance that leprosy can be caught in this way. Novels like "The Island" by Victoria Hislop, about the former 'leper colony', Spinalonga on Crete, have also help throw a spotlight on this disease.

Has Covid-19 caused a problem?

Yes, it has. We all have personal experience of what it's like to feel isolated, cut off and unable to meet up with family and friends because of Covid -19.

For those with leprosy, this can be a normal way of life for them. We've heard how mental health problems have increased in the western world because of the pandemic. Almost half of people affected by leprosy face mental health problems such as depression and anxiety. Some have considered taking their own lives. Covid has just exacerbated the situation.

Some quotes from Head of Programmes at the Leprosy Mission, Sian Arulanathan:

- ❖ “Devastatingly, this is a human time bomb waiting to explode. As ever, it is people living in Leprosy-affected communities that will be hit the hardest”
- ❖ “Social distancing and isolation is an almost impossible task in densely populated areas”
- ❖ “For those living hand to mouth, it is difficult to blame a labourer for being tempted to work with a sore throat. If they stay at home, it is very likely their family will not eat that day....”
- ❖ “There are so many issues our teams are addressing currently. This includes finding solutions to practical problems like how to stop people congregating at water pumps. It is very hard to self-isolate and undertake frequent hand-washing when you do not have running water to your home...”

Coronavirus means it's going to be harder for The Leprosy Mission to achieve its aim of “Leprosy Defeated, Lives Transformed”.

But how can the Isle of Man make a difference?

The good news is it already has.

For the first time, residents of three disadvantaged communities in Nigeria's Federal Capital Territory Abuja are able to see a doctor locally and receive medicines free of charge. The life-changing Wheels that Heal project has been made possible by a grant from the government of the Isle of Man and donations from the people of the Isle of Man.

It enabled The Leprosy Mission to buy a van and to kit it out with ramps, steps, awnings and partitions. Medical equipment has been purchased including thermometers, weighing scales, blood pressure monitors and blood sugar testing devices. The mobile clinic is stocked with dressings for leprosy-related ulcers and a range of medicines.

The Leprosy Mission has provided two specialist doctors to staff the mobile clinic. The charity has worked closely with the Nigerian government which has supplied two nurses and a pharmacist to help. This mobile health clinic touring communities affected by leprosy, disability and terrorism has been welcomed with open arms.

So, yes, we on the Isle of Man can make a positive difference 😊

How can I find out more?

Leprosy Mission Isle of Man contacts are:

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