Vagavathali Narsappa, 47, is a hero not only to people affected by leprosy in his home city of Hyderabad, in central India, famous for microchips and minarets, but also to tens of thousands of people across the country. Narsappa has been living with leprosy since he was eight. His fingers were affected and had to be amputated.

“I only have my two thumbs and little fingers.” The disability meant that he could not work. There was a time when he begged on the streets. But the rejection, humiliation and discrimination did not crush his spirit or his love for life.

Currently, the president of India’s Association of People Affected by Leprosy (APAL), Narsappa fondly talks about his wife, Nirmillah. He met and fell in love with her at the leprosy hospital where both were being treated. “We have been together almost 25 years,” says the man who learnt to turn adversity into advantage.

Today, APAL is not only a source of immense support for people affected by leprosy, its presence is increasingly being felt in policy circles within the country and beyond.

Narsappa’s life story reflects the success and challenges posed by leprosy in the WHO South-East Asia Region.

Leprosy is a chronic infectious disease caused by Mycobacterium leprae. It usually affects the skin

STORY HIGHLIGHTS
- Free-of-cost MDT provided by WHO has drastically reduced leprosy cases
- WHO playing a catalytic role in strengthening capacity of leprosy affected people, getting them involved in leprosy programmes
- WHO sets goals of zero child cases and with grade 2 disability by 2020.
and peripheral nerves but also has a wide range of other clinical manifestations. Among communicable diseases, leprosy is a major cause of physical disabilities. Timely detection and treatment of cases, before nerve damage sets in, is the most effective way of preventing disabilities due to leprosy. The year 2000 marked the elimination of leprosy as a public health problem at the global level—a significant milestone in history. Elimination means the prevalence of less than one case per 10,000 population, globally. The elimination target has also been achieved by most of the endemic countries at the national levels by the end of 2005.

However, as Dr Poonam Khetrapal Singh, WHO Regional Director for South-East Asia, says, “Though the prevalence has come down to less than one case per 10,000 population globally, new cases are being reported from more than 100 countries. As per the leprosy statistics published in 2014 by WHO, 215,656 new leprosy cases were detected worldwide. The WHO South-East Asia Region alone contributed 155,385 cases, 72% of the global leprosy case count.”

Significantly, leprosy is not uniformly distributed across the world. More than 90% of leprosy is limited to 15 countries, which report more than 1,000 new cases annually. Even in these high endemic countries, high leprosy prevalence is recorded in certain endemic pockets, usually referred to as ‘hotspots’. Patients having visible deformities in their hands, feet and eyes due to delayed detection, experience stigma associated with disfigurement.

Globally, 13,289 such new cases with visible deformities or grade 2 disabilities were detected in 2013.

One of the biggest challenges in the battle against leprosy is the fact that one in every ten new leprosy patients is a child. This fact needs greater attention, as it can cause childhood disabilities not unlike polio.

Over the last two decades, much has changed for the better. Narsappa talks about lessening stigma and more awareness about leprosy. Then, there was a breakthrough in treatment that dramatically reduced the global leprosy caseload from 11 million to under a quarter million today. In the early 1980s, WHO introduced the multidrug therapy (MDT), which revolutionized treatment of leprosy. MDT offers multiple benefits. The infected person ceases to be infective with a single dose; it is a complete treatment for leprosy; and it reduces the risk of disabilities and consequent stigma. In the long run, MDT reduces treatment costs on the health system.

However, at the societal level much remains to be done. Laws exist in many countries of the WHO South-East Asia Region that discriminate against leprosy-affected persons and their families. These laws impact chances of employment, marriage and other areas.

The WHO is working with governments and leprosy partners to reduce these barriers. Hearteningly, groups such as the Association of People Affected by Leprosy in India are robustly adding their voice to the fight for the rights of those with leprosy to push for an end to this stigma.

**Early detection as a path to eliminating leprosy**

“With the arrival of MDT, we have not seen any more new colonies of people affected by leprosy in the country. That is great news. Now, as a person affected by leprosy, my mission is to work towards zero disability. For that to happen, we need to sustain the momentum by removing misconceptions about leprosy among the public, have early detection and voluntary reporting. School curricula should make children aware that early detection can prevent disability. People affected by leprosy should be made partners in policy making,” says Mr Narsappa who is thrilled that in the colony of people affected by leprosy where he lives, no children have leprosy.
“We are focusing on disclosure of cases to individuals, families and communities. A coming out to doctors and medical staff can only happen when we address the stigma of leprosy. We need to make the public and practitioners partners in leprosy detection, treatment and cure to eradicate leprosy,” says Dr Vijaykumar Pannikar who has worked as a WHO expert for 35 years fighting leprosy and who led the successful trail of multi-drug therapy (MDT).

Now retired, Dr Pannikar continues his work with WHO and partner organizations in what he expects to be the final push. He feels that the global community has overcome the hurdles of developing treatments and ending leprosy is now within our reach.

Since 1995, WHO has provided MDT free of cost in all Member States. Now that the number of leprosy cases has been drastically reduced, WHO is flagging the need for renewed efforts and a focus on “zero” children with deformities and detecting all new leprosy cases before disability.

The last mile in leprosy eradication will need enabling environments where people with leprosy feel enabled to identify themselves and seek treatment.

Leprosy elimination: a WHO flagship

In July 2013, 17 countries came together at the International Leprosy Summit to commit to a global target of less than one case per million by the year 2020 through the Bangkok Declaration.

The declaration recommends measures such as including leprosy-affected persons in the leprosy control initiatives. “The WHO has played a catalytic role in strengthening the capacity of people affected by leprosy. Today, they are more involved in national and subnational leprosy programmes and are better equipped to voice their demands for more funds and human resources,” says Dr Sumana Barua, WHO’s Team leader for the Global Leprosy Programme.

Reflecting the importance of partnering with people affected by leprosy and their families is a WHO set of Guidelines for Strengthening Participation of Persons Affected by Leprosy in Leprosy Service, published by the WHO Regional Office for South-East Asia.

Leprosy declared a Flagship programme for WHO SEARO targeting zero disability among new child cases by 2020

“WHO SEARO has declared leprosy as a Flagship Programme that intends to result in zero disability among new child cases by 2020. There will be a greater focus on the social issue that has prevented leprosy elimination – the stigma that prevents early detection and proper treatment.

The WHO is working with The Nippon Foundation, Novartis Foundation for Sustainable Development (NFSD), International Federation of anti-leprosy associations (ILEP) and the networks of persons treated for leprosy to create the roadmap for the last mile in leprosy elimination.

As WHO fine tunes its upcoming 2016–2020 Global Strategy for Leprosy, the views of Narsappa and his colleagues are being sought in consultation with that of other key stakeholders. The new WHO strategy will aim to detect all cases before disability sets in and will focus on zero disability cases among children by the end of the decade.