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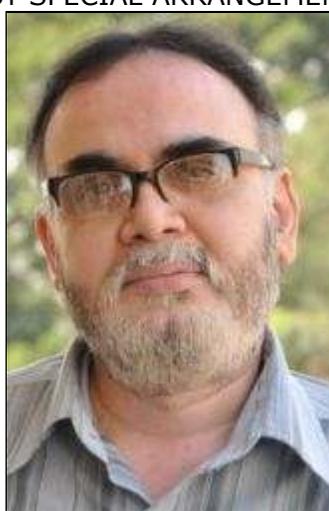
A landmark order issued by the Tamil Nadu government seeks to remove the stigma attached to the skin condition called leucoderma.

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BY SPECIAL ARRANGEMENT



K. Umapathy, secretary of the Leucoderma Awareness Movement-India.

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MANICKAM (name changed), at 45, was one of the most sought-after caterers in Coimbatore. His delicious preparations were so popular that many of his clients did not hesitate to alter the dates of their functions to suit his convenience. His fortunes, however, did not last long. There was a sudden 180-degree shift in the attitude of his clients when his skin began to lose pigmentation. They stopped placing orders. Manickam slipped into a severe depression and committed suicide when he was 51.

Manickam is just one of the several lakh victims of the social stigma attached to vitiligo, a skin condition which is commonly known as leucoderma. The disorder is characterised by white patches on the skin. Though not all those who suffer from vitiligo take the extreme step of ending their lives, some of those who get demoralised by the way they are treated by the rest of society often cut themselves off socially and confine themselves to the four walls of their homes.

The exact cause for vitiligo is not known but it is widely accepted that it occurs when melanocytes, or pigment-producing cells, die or are unable to function for a variety of reasons, including autoimmune or genetic disorders. There are other theories too, such as that melanocytes destroy themselves, causing depigmentation. Some experts attribute the skin condition to a combination of genetic, stress, autoimmune and environmental factors. It is more of a cosmetic condition than a disease, they opine.

Although it is a cosmetic skin problem, persons affected with vitiligo undergo a psychological trauma that has an adverse effect on the quality of life, especially in countries such as India where people are dark-skinned. According to experts, vitiligo occurs worldwide with an overall prevalence of 1 to 2 per cent, and its incidence ranges from 0.1 to 8.8 per cent in different countries. The highest incidence of vitiligo has been recorded among the people of the Indian subcontinent. The plight of those afflicted with vitiligo is made worse in India by certain religious beliefs associated with the condition.

Ancient Sanskrit texts mistakenly refer to the disorder as sweta kushta (white leprosy), a variation of leprosy. In many other Indian languages also, similar terminologies have been used from time immemorial. These misnomers have virtually pushed vitiligo-affected persons to the edge. But now there is some good news for them. On December 27, 2010, the Tamil Nadu government issued a landmark order making it clear that the terms ven kushtam and ven kuttam – both meaning white leprosy and hitherto wrongly used as the Tamil equivalents of vitiligo – should be abandoned forthwith.

The government order (G.O.) has been issued against the backdrop of a sustained campaign launched by the Chennai-based Leucoderma Awareness Movement-India in different parts of the State to create public awareness regarding the disorder. The Director of Public Health and Preventive Medicine has endorsed the views of the organisation in this regard. Accepting the contention that the misnomers ven kushtam and ven kuttam have given rise to misconceptions such as vitiligo is akin to leprosy, is hereditary or is contagious, the government has directed the authorities concerned to hereafter refer to vitiligo as ven pulligal (white spots). According to the State's Principal Secretary (Health), V.K. Subburaj, the government's decision is aimed at creating public awareness about vitiligo, allaying the grievances of affected persons and ensuring that medical personnel use the correct terminology.

Welcoming the unique G.O., K. Umapathy, secretary of the Leucoderma Awareness Movement-India, told Frontline that the Government of India, other State governments and administrations of the Union Territories should come forward to emulate Tamil Nadu so as to remove the mental agony of vitiligo-affected persons and their kin. Describing the G.O. as a "great beacon of hope", he said it would go a long way in creating public awareness. "It lights up the lives of crores of the affected population in the country. We deem it a recognition of our 15-year-long just struggle for some recognition and relief," he said. Copies of the English version of the G.O. would be sent to the Union Health Minister and Chief Ministers of all States and Union Territories, pleading for issuance of similar orders, he said.

The movement would now intensify its awareness campaign, Umapathy said. He recalled the tireless campaign spearheaded by the Leucoderma Awareness Movement to remove the misconceptions regarding vitiligo. Himself a victim of the social stigma, he initiated the campaign after some socially conscious doctors helped him understand that vitiligo was not a disease and was not contagious. Only a small percentage of cases, around 12 per cent, have a family history.

He was delighted when he came to know that the first Prime Minister of India, Jawaharlal Nehru, had ranked vitiligo as one of the three major medical problems the country was facing, the other two being leprosy and malaria.

Convinced that the social stigma could not be removed without creating public awareness about vitiligo, Umapathy launched the movement in 1995. To begin with, the movement targeted the youth, particularly school and college students, to carry forward the message. After getting due sanction from the authorities concerned, Umapathy and other activists of the movement addressed brief meetings in educational institutions highlighting facts about vitiligo. Students also took a pledge at such meetings.

The movement has also released a documentary on the disorder and distributed over one lakh CDs on the disorder. As part of his endeavour to create awareness, Umapathy wrote a book, Venpulligal: Pirachanaigal, Theervugal (Leucoderma: Problems and Solutions), which answers several questions people may ask about vitiligo.

Apart from organising awareness programmes, the movement has initiated measures to provide treatment with herbal medicines. Marriage counselling is available on appointment at the clinic run by the movement at Tambaram on the outskirts of Chennai.

The movement has enrolled about one lakh affected persons in Tamil Nadu as members, apart from having around 60,000 members in other States. "We have been asking stigmatised people not to allow vitiligo to decide their future. We also cite the life of the King of Pop, Michael Jackson, as the best example to convert the challenges before

them into opportunities," he said.

According to him, women with vitiligo bear the brunt of the antagonism. If young women develop the skin condition before marriage, their chances of getting married are remote, and if it develops after marriage, they are pushed into a quagmire of marital problems, often resulting in divorce and ostracism. People with vitiligo face hurdles in education and employment too. Even if only one person in a family has vitiligo, the social stigma affects all the other members. "We appeal to people not to subject vitiligo-affected persons to embarrassment by staring at them or discriminating against them as their self-esteem falls steeply and they develop a sense of being rejected," he said.

Experts belonging to different streams of medicine, including allopathy, ayurveda and siddha, differ on the efficacy of therapies for the condition. However, all of them agree that therapy takes a long time and that patients should be mentally prepared for that. Dermatologists say that allopathy offers therapies such as topical steroid therapy, psoralen photochemotherapy, depigmentation, skin grafts, micropigmentation and melanocyte transplants. Ayurveda and siddha offer herbal and natural treatment.

Though there are people who are sceptical about the efficacy of allopathic treatment for vitiligo on the grounds that it has serious side effects, dermatologists point out that such problems can be avoided and managed if medication is properly followed up with the help of experts.

Dr V.R. Janaki, former Professor and Head of the Department of Dermatology, Madras Medical College, said there was a time when there was little scope for treatment. "Now we have many options, and treatment is available to the common man." According to her, phototherapy is widely practised and is freely available at all government district headquarters hospitals. "Now the Medical Council of India has made it mandatory for any institution having postgraduate courses in dermatology to install phototherapy units."

Welcoming the G.O., she said that the medical fraternity as a whole, apart from dermatologists, should play a key role in creating public awareness. She also pointed out that World Vitiligo Day was observed on May 19 every year as part of the awareness campaign.

Dr V. Vijay Kartik, a Chennai-based consulting dermatologist and venereologist, said, "Apart from steroid creams, other creams such as topical calcineurin inhibitors are also used now and they are showing good results. Grafting procedures have been done in Chennai for the last 25 years, while depigmentation is done very rarely." Affected persons should shake off their inhibitions and come forward to undergo treatment, he said.

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