

Annual Report
**Palliative Care Services &
International Collaboration of
Palliative Care
In Union Territory of Lakshadweep**



**Lakshadweep Institute of Palliative Medicine
An Organ of Thanal Charitable Organization
SR.NO.557/2009
Kavaratti Island
UT of Lakshadweep**



*"I shall be born in India again and again
With all its miseries and wretchedness
I love India best"*

Rabindranath Tagore

LAKSHADWEEP is a group of scattered islands located in Arabian Sea. It is most exotic place to call them the coral paradise of India. There are 36 islands with 32sq.km area. Out of 36 islands only 10 are inhabited and the population is around 60,000. Lakshadweep is one of the calmest places with sandy beaches, warm breezes and peaceful atmosphere.

BUT the reality has another different face; the lives of people are in perils of diseases. The burden of diseases is quite large in number compared to the population. The non communicable diseases like diabetes, hypertension and cancer are common in almost every household and the sequel render them as bed bound or disabled. There are numerous cases of stroke, cancer, end stage renal disease, heart failure and neurological disorders. They always want cure, but there is none.

WHEN the palliative care started the scenario has improved gradually. It's a care rather than cure and it requires some skills and humanity. Thanal charitable organization, a charity foundation was marking its own history by introducing the palliative medicine, the new branch of modern medicine.

K.Abdul Hameed Moulana

THANAL CHARITABLE ORGANIZATION

Origin & Evolution

FIVE years back Thanal was doing charity works such as treatment aid to poor patients, feeds to hungry, free cataract surgeries etc. Finally Thanal realized that these services can be gathered under an umbrella namely palliative care. The team made visits to houses of patients and cleaned their wounds. Thanal provided rations for monthly livelihood.

THE patients are neglected because of ignorance, the team used to identify the patients who really need the care and take the nurse or doctor to the scene for professional management. It is memorable of one patient with bed sores over both hip and sacrum. He had an open wound in the back; it was so opened as to see the respiratory movements of lungs. if he was not cleaned and dressed for one day the family wouldn't sleep in that house because of that stinky wound.

WHEN the team began to visit daily for wound management, the family got assured and the patient was discharged off with his spiritual pain.



Donating Wheel Chair to Patient

THANAL Charitable Organization is one of the NGOs in Lakshadweep which always dedicated to uplift the poor and disabled. The credit of pioneering home based palliative care services in Lakshadweep rests in the hands of this organization.

Barriers to Palliative Care

Patients and their families are often unaware that pain and other sufferings can be overcome with palliative care.

Doctors, nurses, and pharmacists have limited knowledge of the practical application of palliative care reducing the likelihood of pain relief or palliative care access

Availability of pain and palliative care medicines is limited. The uninterrupted supply of medicines is one of the goals because many of the patients spend around Rs.5000 per month to get the medicines from mainland.

A large number of patients needing palliative care are bed-bound and can be effectively cared for only with home visits, facilities for which are not available within the existing government system.

The geographical isolation of islands and distance between islands make the services difficult. The transportation services are few in peripheral islands.

Role as NGO

The role of Thanal is pivotal in palliative care. This NGO assists the palliative care by following procedures

The palliative care is a holistic approach, to make it holistic it needs more professionals from various fields.

The identification of volunteers and their training is huge responsibility

The social matters like family disputes are being managed

The educational support to family is another concern of NGO. The social organizations can bargain with reputed institutions.

The financial support to patient and family. The best way to get support is likely to be the NGOs

PAIN & PALLIATIVE CARE CENTRE LAKSHADWEEP INSTITUTE OF PALLIATIVE MEDICINE

“You matter because you are you. you matter to the last moment of your life and we will do all we can, not only to help you die peacefully, but also to live until you die”

Cicely Saunders
Founder of Modern Palliative Care

The Beginning

When there was an urgent need for a doctor – nurse team to sustain palliative care services in Lakshadweep, Dr.Ali Azher just completed his graduation and joined the palliative care. Dr.Ali Azher and Br.Ahammed Khafi were sent for palliative care training in Trivandrum Institute of Palliative Sciences (TIPS) an organ of Pallium India Trust.

It was on 27th march 2013; the palliative care in Lakshadweep has been officially inaugurated. This day is remarkable because the budding of corals ensued that day. The palliative care centre has been officially inaugurated by Prof. Dr.M.R.Rajagopal, Director and Chairman of Trivandrum Institute of Palliative Sciences (TIPS) on 27th march 2013. We started our work in a rented office.

And on 27th march 2014, we have inaugurated our own office in Kavaratti. The foundation stone has been laid for the hospice in the future.



Our New Office Building

POLICIES

Now the palliative care centre has more than 80 patients with family and they are getting around the clock services. The palliative care centre aimed at following three tenets

Improving the quality of life by reducing the pain, sufferings and medications

Allowing natural death to happen in home with end of life care

Building bridges with various international organizations

KEY ACHIEVEMENTS

The drugs controller of Kerala state has approved our need for morphine and upgraded our institution as **RECOGNIZED MEDICAL INSTITUTION.**

The supply of Oral Morphine for terminally ill patients.

The uninterrupted supply of Palliative Care Medicines

Around the clock services

International Collaboration with Australasian Palliative Link International (Project Hamrahi)

Trained Doctor & Nurses (The very first in UT of Lakshadweep)

Trained Volunteers (A great achievement in public)



Our Team with Foreign Delegates

STATUS OF PATIENTS



Mrs.Kadeeshoma was in distress and disability when she was victimized by stroke. She was not able to use latrines because of her immobility. She was always covered with urine and dirt. The palliative care team has taken care

of this patient, they catheterized the patients, they used to clean her and they give education and awareness to family. Now the things are quite normal as the family affairs change.

A 12 yrs old female child, sumayya has been paralysed for 10 years. She has got cerebral palsy at the age of 2yrs. she is having vomiting and aspiration in almost every week. The family struck with grief, they never knew what to do. They were sent back to home by all health facilities. When palliative care team started to attend the needs of family, they got relief and happiness. Thanal has provided a water bed and used to provide food kits and toys on special occasions.

Mr.Sayed Poo, a humble man with extreme patience and hospitality. He is end stage renal disease with pulmonary edema and stroke and cataract of both eyes. When we saw him he was swollen and he had big non healing ulcer on his right foot. It was actually a burn. He was taken care and it took 7 months to heal the wound. Br.Khafi managed to get the home every day and cleaned the wound. Once



A Healing Touch by Khafi

he took maggots from this wound now he is completely healed. Currently he is on hemodialysis and doing well.

Another blind patient, we usually taken care of her; she fell during late hours and she got fracture neck of femur. This patient was evacuated to Cochin for surgery. When she returned, she developed a big bed sore over the sacrum and the surgical wound itself infected and filled with pus. It was a kind of oozy and stinky. The daily wound management was prescribed and it took three months to heal the wound.

So many patients may complain of severe symptoms, once they saw the palliative care team all symptoms will subside. That link, rapport, is must for palliative care. It's a care, rather than cure for soul and body.

DEATH OF THE PATIENTS

“In life, you try your best to hold tight to your dignity,
In death sometimes others have to hold onto it for you.”

The centre has aim on the death of patients. The team knows about the death of the patients. They are given the very basics of end of life care. They are encouraged to keep the patient at home. The centre promotes following principles

- ✿ The residential aged care and end of life care
- ✿ Allows natural death to happen
- ✿ Bereavement support to the family





“You must be the change you wish to see in the world.”

Mahatma Gandhi

Contacts:

Mr.K.Abdul Hameed (Moulana)

Chairman & Director

Phone: 9495877410

E-mail: thanallak@gmail.com

Dr.Ali Azher

Medical Superintendent (Palliative Care)

Phone: 09447983105

E-mail: aliazhermuhammed@gmail.com

Br.Ahammed Khafi MK

Nursing Tutor (Palliative Care)

Phone: 09447331571

E-mail: khafkamk@gmail.com