

## Project Hamrahi report – Asha Kiran Society, Odisha

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Our trip to India began in Guwahati, Assam, where we attended the 27th International Conference of Indian Association of Palliative Care. I was invited by Dr Davinia Seah to attend the conference along with Dr Bethsheba 'Sheba' Eicher and Sister Korobi Curtis (RN), the palliative care team members from Asha Kiran Society (AKS), Odisha.

After the conference, we visited AKS, which is about a 5-hour car ride from the nearest major city of Vishakhapatnam. AKS is a non-profit organisation which serves a population of about 50,000 people over about 400 square kms. About 90% of this population is illiterate, with about 50% of the population from scheduled tribes (indigenous people whose status is formally recognised by national legislation), and 20% from scheduled castes. There are about 40 beds in the general hospital with a community outreach program to over 220 villages. We spent about a week at AKS, understanding their health care system, going on home visits and providing education to the staff.

On the first day of home visits, I visited a young female patient with Sister Korobi. She had neurological deficits secondary to a stroke from alcohol abuse. Korobi had visited her the week before, and she needed assistance with her personal hygiene. We demonstrated and encouraged her to do daily exercises which included standing up and down with the aid of the tree in front of her as a support. This was problematic as it was difficult for her to follow instructions due to her neurological deficit.



All of the communication was through her young daughter who had left school to care for her mother. The young girl was overwhelmed with no other supports available. Caring for her difficult mother often felt burdensome, and she often viewed her mother as a liability.

We then drove an hour to another village where we met a female patient with paraplegia. She was lying on the ground with only a thin piece of cloth that divided her from the hard earth. Korobi had visited two weeks ago, and the purpose of this visit was to attend to her personal hygiene.

Her main carers were her son and daughter-in-law who would leave the home early in the morning to attend to the fields. Their return was not until late that afternoon or evening. Unfortunately, she would have to wait for the arrival of her son and daughter-in-law to return home to administer her medication. Her daughter-in-law would often be frustrated by the seemingly never-ending tasks of caring for her mother-in-law.

I felt an overwhelming feeling of powerlessness in being able to care for this woman. The level of her dependency on others was so great. I had no answers to the many questions that were running through my mind. As we repositioned her in the sun. I sat and held her hand and she smiled. There were no words I could use to express my feelings of sadness. As I walked away, I looked back and waved goodbye. We met the local community health worker and expressed our concerns about the lack of support for this lady. It would be another week before Korobi would be able return.



Korobi's tireless efforts to improve the lives of her patients is remarkable, but it feels like a tiny drop in a big ocean of need. It is hoped that Korobi's presence in these villages will open up a dialogue between herself, the community health workers and the local people. Despite her visibility in these villages, it can take a very long time to build a trusting relationship amongst the village people.

My experience of palliative care in India was insightful, because it was imperative to see it through a different lens. What I gained from my experience is how palliative care can differ due to the cultural context, how it needs to be delivered to tailor to the needs of the people. One has to be open and flexible to different values in order to demonstrate effective palliative care.