Hospice y Cuidados Paliativos para Niños con Enfermedades Terminales en los Andes de Perú: Amor, Dignidad y Compasión al Final de la Vida

Mónica Pfeiffer, End-of-Life Doula, Thanatologist, Palliative Care passionate
Founder and Director of Casa Khuyana Association (*building the first pediatric hospice in Peru*)

How Palliative Care found me

Peru is a centralized country, and only in Lima, the capital, are there specialized hospitals and qualified doctors, so in the provinces there is no early detection of complex diseases. Many children are diagnosed when the disease is very advanced and there is little or nothing to do. In 2012 I started the Ronald McDonald House Charities Foundation in Peru, a wonderful organization that marked the beginning of my path. It was then that I faced death that was being handled in a crude and unhumanitarian way. At RMHC we offered families emotional support and well-being while the children lived with us. However, when they were hospitalized and reached the final stage, there was not much we could do. The public health system is cold and depersonalized. During the six years I was there, I witnessed the death of many children. The majority died in pain and without company, due to the rules and bureaucracy that exist to this day in public hospitals. Many children confessed to me that they knew they were going to die, and what they wanted most was to spend their last days at home, with their loved ones, even though it was in those poor and remote communities in the interior of the country. I felt that there should be a more humanized way to accompany and care for patients during the end-of-life process, and that was when I first heard about Palliative Care and the Hospice philosophy. I knew that even when it was not possible to cure, it was always possible to care and accompany with love and compassion. Then I became passionate about Palliative Care and decided that one day, I would build a hospice for children. I made the doctors Elisabeth Kübler-Ross and Cicely Saunders my teachers, and I decided to prepare myself for that dream that has become my life mission.

Casa Khuyana: a door to heaven in the Andes of Peru

In 2021 I founded the Casa Khuyana Association and in 2022 we began to build the first pediatric hospice in Peru, in the province of Calca, Cusco, protected by the mountains surrounding of the Sacred Valley.

"If we cannot add days to a child's life, we will give life to their days".

Hospice Circle of Care



Statistics & Facts

- In Peru, every year 1,800 new cases of cancer are diagnosed in children under 18 years of age.
  - *40% - leukemia*
  - *18% - tumors of the central nervous system*
  - *18% - lymphomas*
  - *24% -other causes*
- The survival rate of Peruvian children with leukemia is between 20% and 40% (the lowest in this region of South America)The INEN in Lima (National Institute of Neoplastic Diseases), annually receives 700 patients under 14 years of age, of which 75% come from the provinces.
- The city of Cusco, despite being among the top 25 tourist destinations in the world, has high poverty rates, especially in rural communities. That is why, when a child is evicted from the hospital and sent home "to have quality of life," the family finds itself at a crossroads, since at home they do not have the minimum resources to offer well-being to that child.



Biography

Monica Pfeiffer, Communicator and Project Manager, always knew she wanted to work with children. In 2012 she started the Peru chapter of Ronald McDonald's House Charities. Monica became passionate about Palliative Care and decided that one day she would build a children's hospice, a place full of love and compassion for children with fewer resources to live during their final process with their families. Monica decided to prepare for this great dream and became certified as an End-of-Life Doula and Thanatologist, and she also studied Palliative Medicine for Children and Adolescents. In 2021 she founded the Casa Khuyana Association and is currently building the first Pediatric Hospice in Peru. Mónica is also a Reiki practitioner and is an active member of the ALCP (Latin American Association for Palliative Care).

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