

## **Victoria Diehl Testimony, DG Tedros Roundtable April 28, 2021**

Hello from Costa Rica! I am grateful for the opportunity to testify about my personal experience with palliative care. Many thanks to the IAHPD and the cosponsoring organizations for raising the voices of family caregivers in global policy.

My family and I live in San José, Costa Rica. A little over a year ago, my 75-year-old dad, Thomas Diehl was diagnosed with stage 4 adenocarcinoma of the left kidney, with metastases to the prostate and lung.

It all started last January when I noticed he was very concerned about blood in his urine. We immediately took him to the hospital where they carried out diagnostic tests and exams diagnosing a carcinoma in the prostate and metastatic lung adenocarcinoma in the left kidney.

The day I had to break the news to him, it broke my heart. My dad has been an incredibly positive person, and that day he had to change his perspective on life. Watching him going through what was a period of uncertainty and fear was one of the most painful moments I have ever had to experience.

The physicians at the public hospital that diagnosed him told us that he was not a candidate for any curative treatment and sent us home. They suggested palliative care as the best option for him.

Dad's symptoms began to worsen. He became completely dependent for his daily activities and personal care, needing someone with him all the time. Since I am the only one of his daughters who lives in Costa Rica, I became his main caregiver. But I was working and needed the income. This is when Dr. Carlos Acuña, who runs an NGO that advises patients and caregivers on how to access palliative care in Costa Rica told me about the law called "Benefits for caregivers of people with illnesses in terminal phase". As a contributor to the Costa Rican Social Security Fund, I can apply for a caregiver license – making it illegal for an employer to fire me for as long as my father needs my services. In return, I receive a financial subsidy that is a proportion of my salary.

Costa Rican Social Security palliative care team started doing home visits and adjusting their frequency, according to my father's needs. They also gave us access to the palliative line, which takes calls 24/7, 365 days a year. We can contact my father's care team, ask them questions, and receive advice and support. From the first moment we have felt great professionalism, empathy, and humanity among those in charge of my father and my family: Dr Acuña, Dr Valverde, the nurse Auxiliadora Conejo and the psychologist Sandra Ayales. During every visit they take the time to address our concerns as a family, making the home visit a time when he can talk about his fears, worries, and doubts.

The team also helped us to access the medical equipment my father needed: a walker, bathing chair, wheelchair, and hospital bed, as well as pain control medications such as morphine.

The Palliative Care Unit gives us telephone and videoconference support, guiding us through crisis episodes.

All this has been possible thanks to a strong public policy supporting palliative care and an integrated health system that gives all the Costa Ricans, like my Dad, the opportunity to have the best quality of life possible during serious illness. I am not saying everything is perfect. As the disease has progressed, Dad's symptoms and his suffering have also increased. Despite being a health professional, as the main caregiver I constantly worry about having this responsibility on my shoulders and I am afraid of making

mistakes and cause him suffering. So, we have some good days and other not so good days when fear and worry invades our home.

Although this is a difficult time for us, I cannot imagine **not** having all the support, the guidance, the medications, supplies and excellent care that I mentioned in this testimony. This has enabled me to take care of my father in the final stage of his life and return with love and affection everything that he has done for me. This is the minimum all patients with serious health related suffering are entitled to and should be part of Universal Health Coverage.

Thank you so much for everything