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## **Estefanía: “There are many kinds of hope”**

Estefanía is a pediatrician at a public hospital in Chile. In her work, she ensures that children with non-oncological terminal illnesses receive the best possible quality of life. This goes beyond managing physical symptoms and includes emotional and spiritual support for the patients and their families.

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One of the places she visits her patients is Casa de Luz, part of Fundación Casa Familia, the first pediatric hospice in Latin America. This facility welcomes children with terminal illnesses and their families, providing the palliative care they need through an interdisciplinary team.

In addition, Estefanía teaches in the pediatrics department at the Universidad de los Andes, where she works to advance social pediatrics, which focuses on the holistic well-being of children.

Her daily life in this specialty is unpredictable, alternating between calm days and moments of intense activity. Her experience in this field has led her to profound reflections on life and suffering. “I’ve learned that the dignity and worth of a human being don’t depend on their abilities,” she says. For Estefanía,

pain, though hard to accept, is deeply meaningful: “It reminds us of our fragility and invites us to trust more fully in God.”

Estefanía, a supernumerary of Opus Dei, finds her strength by ensuring she takes care of herself and in her faith. She loves dancing as a way to relieve tension, but what matters most to her is nurturing her spiritual life.

In the interview below, she shares her experiences, reflections, and the impact of her work on the families she supports.

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**What led you to work in palliative care?**

Honestly, it wasn't something I actively pursued. After completing my residency, I was offered a

position in oncology. A few years later, I began working with NANEA patients: children with special health care needs. Then, in October 2022, when the Universal Palliative Care Law was enacted in my country (previously it only covered oncology patients), the hospital invited me to launch this new universal palliative care unit.

**How would you describe your day-to-day work supporting patients and their families during such delicate moments?**

We are available 24 hours a day, seven days a week, 365 days a year. Each day is different.

We aim to keep the children at home as much as possible. We train parents to manage everything they can at home and provide home visits and video calls as needed. We also care for hospitalized patients, children at the Casa de Luz hospice,

and some in children's homes. Our work takes us everywhere.

Broadly speaking, our role involves two things: symptom management (both physical and emotional) and emotional-spiritual support for the children and their families. We ensure that our children have the best quality of life possible and that parents know they are not alone in this journey.

**Is there any experience or patient that has especially impacted you?**

Every one of my patients has touched me in some way. Each child and their family has a special story that leaves a mark on the soul: stories of great pain, but also of resilience, love, selflessness, and unconditional care. We form close and deep bonds with most of the families, which often continue through the period of mourning.

Some of the most impactful experiences have been with babies diagnosed prenatally with conditions deemed “incompatible with life.” Thanks be to God, these babies were not aborted. Sometimes, months later, they pass away in their mothers’ arms, surrounded by love.

**How do you handle the emotional challenges of your work? What helps you keep going?**

I’m hypersensitive, but I think that’s an advantage because it allows me to connect more deeply with the parents. That connection is essential for building trust, which enables me to help them better.

I find comfort in knowing that my work makes this stage a little less difficult for the children and their families. My greatest consolation is the belief that this isn’t the end; that these children are made for heaven

and go directly there, to a place without pain or suffering.

That said, I've experienced burnout episodes that have taught me the importance of self-care. To take care of others, I have to take care of myself. While self-care is essential, the most important aspect of doing my work well is nurturing my spiritual life. I try to begin and end each workday in the hospital chapel, spending some time in prayer. I see myself as just an instrument. God is the one doing the work.

**How do you convey hope and comfort, especially when the end is near?**

Contrary to what people might think, palliative care doesn't mean "there's nothing left to do." There may not be hope for a cure, but there are many kinds of hope: we have the hope of living the remaining time as fully as possible; the hope of a peaceful

death; the hope of parents and families finding a way forward; the hope of finding meaning in what they are experiencing; and the hope of life after death.

Offering hope and comfort to my patients and their families is an essential part of my work. I always do so while respecting their beliefs and values.

### **What do you think people outside the hospital should know about palliative care?**

People should know that palliative care is about life, not death. It's not just about relieving physical pain but also addressing emotional, social, and spiritual needs. Palliative care isn't only for the final days; it should begin from the moment a diagnosis is made.

## **How do you see the impact of your work on the lives of patients and their loved ones?**

I believe our work has a profound impact. We help families cherish meaningful moments together at home.

Losing a child or sibling is one of the most painful experiences a person can go through. I think we make this process a bit easier. For parents, knowing they can call us anytime brings relief from their burden and stress. They can reach us during emergencies, especially in the final stages, or contact us with less urgent questions.

We also provide them with tools and resources to face the progression of the illness and, eventually, the child's death, with dignity and love.

Previously, these children often passed away in hospitals or

emergency departments. Thanks to our program, they can pass away at home, without suffering, surrounded by their loved ones. This also helps the family experience a healthier grieving process.

## **What have you learned over the years?**

I've learned so much from my patients and their families. Perhaps some of it I already knew in theory, but now I've seen it firsthand. I've learned that the dignity and worth of a human being don't depend on their abilities or their "usefulness" to others. Every life is worth living; no life is more important than another.

These children are an immense source of love. I've also learned that human beings are capable of incredible love and sacrifice, of truly unconditional care.

Most families want and can care for their sick children, but it's an incredibly difficult and sacrificial task that they can't do alone. They need resources, but more importantly, they need support and companionship. Those things are still far too scarce in most cases in our country.

**Is there any personal reflection on the meaning of suffering that you would like to share?**

I believe that suffering, although difficult to understand and accept, has profound meaning in human life. First, I think it reminds us of our fragility and invites us to trust more fully in God. Suffering also allows us to develop a deeper empathy for others. When we experience suffering, we are better able to empathize with, accompany, and console others enduring it, creating

bonds of solidarity and compassion that enrich us as human beings.

In palliative care, we talk about “total pain” because suffering is not just physical. We are spiritual beings, with both body and soul, embedded within a family and a community. This perspective is well understood in palliative care.

From the perspective of faith, suffering is a participation in Christ's suffering, an opportunity to grow in faith and love—never a punishment. As Cicely Saunders, a pioneer in palliative care, said, “Pain is only unbearable when no one cares.”

**What role does the medical and nursing team play in creating a supportive environment for patients?**

Creating a supportive environment for patients and their families is essential. This is why our approach is

holistic and multidisciplinary. We coordinate care with other specialists, hospital units, and other sectors of the healthcare system. We rely heavily on the indispensable collaboration of psychologists and social workers, as well as volunteers and foundations that provide significant assistance.

### **Where do you find inspiration in such challenging situations?**

As a great palliative care specialist once said, when you work to alleviate suffering without any ulterior motives and with a genuine attitude of service, you experience the joy of caring for and accompanying others. It's so true. I'm inspired by the dedication and love with which families care for their children.

It's also inspiring to see that we can genuinely alleviate suffering and be a channel through which God shows

his love and comfort. Jesus clearly shows his special care for children, the poor, the sick, and the suffering. So I work with God's favorites!

### **What are the main barriers or challenges you see in the practice of palliative care?**

As physicians, we are trained to cure and save lives. Death is often seen as a failure. No one wants a child to die, but we cannot deny that some illnesses are incurable. Changing this perspective is not easy. When healing is not possible, our duty is to care for and accompany the patient.

We must learn to focus on the person, not just the illness, and understand that success is not always about prolonging life at any cost but rather about living as well as possible and dying well.

It is harder to have hope if you do not believe in a God who loves you,

who has a wonderful plan, and who shows us that this life is not the end, because there is life after death.

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