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Iago’s Legacy: Loving Without Limits Changes Everything

This is Iago’s story: a child born without eyes and with a severe hearing impairment, who passed away three years ago. But it is also his parents’ story: Javier and Elia fought for his life and happiness from the very beginning, facing countless challenges with inexplicable joy. Their son changed their lives.

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This is Javier and Elia's story, and it's about how, when you choose to love and embrace life, what might seem tragic turns into a gift. And like all great stories, this one, too, is marked by light and darkness, tears and laughter, hardship and perseverance.

They had to navigate a difficult pregnancy, take in completely unexpected news, face a daunting diagnosis, resist constant pressure to abort, and fight to give their son the fullest life possible, pouring out all the love they had so that, despite his many limitations and the uncertainty of how long he would live, he could be the happiest child in the world.

This is also Iago's story: the little boy who gave back love a thousandfold; the boy who taught his parents to live in the present without fear of the future, to hold nothing back for tomorrow; the boy whose laughter could stop time. Iago stretched their hearts so wide that now only God's love can fill them.

Pregnancy at a difficult time

Javier is from Toledo, and Elia is from Santiago de Compostela (although she also considers herself Toledan, since she moved there at the age of six.) They met in 2008 and got married in 2011, when they were both thirty. That same year they moved to Pamplona, where they began the adventure of married life.

Elia and Javier were not particularly fond of children. They admit they had never imagined themselves becoming parents at that point in their lives. On top of that, Elia struggled to find work for two years, right in the midst of the severe financial crisis after 2008.

Javier is a professor, researcher, and scientist at the University of Navarre.

Elia has a degree in Environmental Science. Despite all her efforts to adapt her CV to the job offers she saw and to improve her qualifications, she couldn’t land a job. This left her frustrated and disheartened: “I felt lost, aimless, not knowing what my role was.”

Then came the news of the pregnancy. “It wasn’t the ideal time, but when I saw the positive test result, everything changed. I threw myself wholeheartedly into motherhood.” Elia began taking great care of herself, pouring all her energy into living out this new mission as best she could.

An unexpected discovery at the second ultrasound

The early check-ups were all normal, but during the 20-week scan, something caught the gynaecologist’s attention. The doctors told them the baby was a boy, but then lingered unusually long on the baby's face. They asked Elia and Javier to step outside while they consulted a colleague, because they had noticed something that wasn't quite right.

"We waited outside and started thinking: well, maybe he has a cleft lip or something like that. Maybe it's nothing, a false alarm. Let's see what happens… We were in shock." After several tense minutes, the other doctor arrived, and they were told the news: the baby's eyeballs were not visible.

A painful diagnosis

Shortly afterwards, tests confirmed that the baby had a severe eye malformation. The doctors didn't know whether he would be able to see or if other complications would arise, so they suggested terminating the pregnancy. "They told us we had the option to end the pregnancy. We said NO without hesitation,” Javier recalls.

“There was no need to look at each other to decide what to do: we both said no, immediately. There was no decision to make. It wasn’t a religious response; it was something natural, instinctive: to protect your child’s life, to care for him and love him. We are this child’s parents. Our mission is to help him live, no matter what,” Elia adds.

Pressure to abort

From that moment on, the pressure to abort became a constant at every check-up. “They kept insisting we were still within the legal window, that we still had time to terminate the pregnancy. At one point, we pointed out their misuse of the word ‘terminate’… We told them that to interrupt something means you pause it with the intention of continuing it later. But what they were offering us was to end our child’s life. And for us, that was simply not an option,” Javier explains.

The doctor’s reply was: “Well, maybe your child won’t be able to see.” Elia remembered thinking: “Is that a reason to get rid of him? First of all, he said *maybe*, so it wasn’t even certain. And even if it was true, not being able to see wasn’t the worst thing in the world. That’s what I thought at the time.”

“I thought of the ONCE [the Spanish National Organization for the Blind], and of so many people who are blind and live full, happy lives. Should they not be here just because they can’t see? And inwardly, I kept thinking: well, if he can’t see, we’ll deal with it. Maybe he’ll need thick glasses. So what? I only saw solutions. I didn’t see a problem so huge that it could justify ending our child’s life.”

The doctors believed Elia and Javier didn’t understand the seriousness of the situation, which is why they kept insisting, telling them over and over again that the baby might also have other, more severe conditions linked to the blindness. And the only solution they offered was abortion. This is when Javier and Elia experienced a deep sense of loneliness and abandonment. If they wanted to move forward with the pregnancy, they would have to face the consequences on their own. They remember it being one of the hardest moments of their lives.

Elia was tormented by questions: “What did I do wrong? I take care of myself, I don’t smoke, I don’t drink, I exercise. Why, if I’m a healthy person? Why this punishment? Why me?” In that difficult moment, her faith was tested: “I felt abandoned by God.” But over time, that changed: “I realised that *I* was a gift for Iago. God had chosen me to be his mother.”

The battle begins

Iago was born in May 2014, premature and with multiple complications. After the delivery, he was admitted to the neonatal ICU. Elia wasn't able to hold him in her arms. “They just told me: ‘He’s very weak.’ Despite everything, I was happy, radiant, because my son was alive. The doctors had painted such a bleak picture during the pregnancy that we didn’t know if he would even be able to breathe when he was born. We didn’t know if he would die right then, if he’d survive a few minutes, a few hours, or how long. So when I saw he had been born and was alive, I was just happy.”

Little by little, they discovered more issues: deafness, heart problems, hormonal and growth issues. In spite of his faith, Javier felt overwhelmed. “I knew that God squeezes but doesn’t choke. But I felt we were right at the limit.”

Even so, they decided to trust. “On the cross, Jesus also asked, ‘Father, why have you forsaken me?’ But then He said, ‘Into your hands I commend my spirit.’ That was what we learned.” And that’s what sustained them.

But everything changed with Iago’s birth. They went from feeling abandoned and alone during the pregnancy to experiencing the support and help of many people, associations, and institutions that did everything they could to give Iago the best possible quality of life: the staff at ONCE, the Early Intervention Center, the school, various therapy centers… They're deeply grateful to all of them. "There are so many people who give everything for you, and everything for your child," Elia says. "But there's a total lack of information. No one tells you any of this during pregnancy: not about the financial support, nor about the people who will be there to help you raise your child."

Hardship and triumph: turning the tide

Iago's life was a challenge from the beginning. His health was fragile and his development very slow. He spent the first four months of his life in the hospital. "They told us he was deaf too, but we had the feeling he could hear, and in fact, later tests proved us right. With hearing aids, he was able to hear relatively normally."

As a mother, Elia began to feel overwhelmed. "At first, all I could see were problems. I kept thinking about everything Iago wouldn’t be able to do.” But one day, she had a change of heart: “Suddenly, everything flipped. I thought: maybe this child has a mission here. Maybe he isn’t a punishment for me; maybe I’m a gift for him. It was like a surge of energy, and it completely changed the way I saw things.”

Living in the present without fearing the future

During a cardiac arrest and hospital stay in which Iago nearly died, they decided to live in the present and stop fearing the future. “We realized we had to enjoy each day. We didn’t know how long Iago would be with us,” Javier explains.

“That was one of the greatest lessons we learned from him: not to worry or hold anything back for tomorrow, which we didn’t even know he would see. To not withhold a single kiss, a single hug, or a single 'I love you!' That's why Iago was so happy: because he was surrounded by so much affection. And all the love he received, he gave back a thousand times over," Elia adds, moved.

A joyful child

Despite his limitations, Iago was happy. As his father wrote in an obituary published in the Diario de Navarra: "What stood out most was his smile, sometimes crooked, sometimes wide, revealing a chaotic but adorable set of teeth. Without wanting to sound cliché, it was a contagious smile. Once, in the supermarket, a girl of about twenty looked at him with a kind of strange, even hostile expression. Then Iago gave her one of his smiles, and that scowl melted into a look of tenderness that blended with the joy that radiated from Iago."

They know people who, because of outside pressure, ended their pregnancies — and that decision weighs on them for the rest of their lives. “One time, while waiting for the pediatrician with Iago, a woman came up to me in the waiting room, saying how adorable he was and how happy I seemed with him. She told me she hadn’t had her baby because the same diagnosis had been made during pregnancy. She just assumed we hadn’t known about Iago’s condition. When I told her that we had, she broke down and started crying.” Elia tried to console her as best she could. In the middle of that waiting room, completely unexpectedly, she came face to face with the burden, sadness, and wounds that abortion can leave in a woman’s heart.

An ordinary child

Iago won everyone over with his love and tenderness. “His hugs were unique. They filled your soul,” Javier recalls. At school, his classmates accepted him completely naturally. He was just one of them. “They would let him smell their sandwiches, help him in games. They even voted him the most handsome in the class,” he says with a smile.

They were advised to send him to a special education school, but he passed all his first year of primary school in a mainstream school. Iago was a fighter. He survived five cardiorespiratory arrests, although after the fifth, there was only time for his family to say goodbye.

“The first few years were very tough,” Javier remembers, “but then the boy grew, and he started going to school like any other child, where he had his friends, went on field trips, went down the slide… always with immense limitations, but just like any other child. I remember his last birthday. We celebrated it at a farm school with nearly all of his classmates, and you could see how they treated him. It was really moving because they did it with complete naturalness, knowing he was one of them, just another friend, but also aware that he needed different things than the others, that you had to speak to him differently, more slowly, treat him with more affection."

The family grows

In 2018, when Iago was four, his sister Gabriela was born. "We went from being parents caring for a severely disabled child to being a family of four, almost like any other. Gabriela is an exceptional girl, very bright, and she benefited from living with a very special brother for four years. She began signing when she was just eight months old, and her linguistic maturity and sensitivity to others are still evident today."

"In the parents of a child with a disability," Elia says, smiling, "you can really see that we are capable of being deeply happy because we give so much love and receive even more. That's the only secret. Society pushes you and makes you believe that to be happy, you have to travel, go to the cinema, have spending power… and it generates this kind of stress about living as many intense experiences as possible to feel fulfilled. And now, when I look back, I realise how misleading that is, and how truly happy we've been."

A legacy of faith and love

Although doctors told them Iago would die within weeks of birth, he lived for eight and a half years. And not only that: he lived those years with a joy few people achieve, even over decades. Throughout his life, Iago taught his family and everyone who knew him the unconditional value of life.

“Iago changed our lives for the better,” says Javier. “It’s true that we haven’t been to the cinema in eight years, that we haven’t travelled (we used to be great travellers), that we don’t have a social life anymore… but those things are tiny compared to all the good he brought us. He changed our lives for the better. He made us better people.”

Throughout those years, Elia couldn’t work. Her life was dedicated to her son. Now, she wants to work in something that reflects what Iago taught her: helping other children with difficulties, other people in need.

Iago’s time on earth was short, but his impact was lasting. “Every life is valuable. Loving without limits changes everything.” Javier and Elia sum up his legacy in these words: “Iago came into this world with a mission: to teach us how to love truly and to trust in God.” His story transformed his parents’ faith. “We discovered that happiness doesn’t depend on everything going your way, but on loving what God gives you.”

Death isn't a full stop: it’s a comma

The hardest moment came a month later, when they returned home and his room was empty. They were a family whose whole life revolved around Iago: his needs, his schedule, his therapies… He filled everything. And suddenly, they had to start moving again, without that central gear. The emptiness was enormous.

“At first, I thought the worst thing that can happen to a person is to lose a child. It seemed like the greatest tragedy anyone could face. But over time I’ve come to realise that’s not true; death is part of life. I think the real tragedy is that there are children who are not loved by their parents.” When Iago died, Elia developed a deep thirst for God. “Iago made my heart so big, that now only God can fill it,” she concludes.

“The void he left has gradually been filled by a strengthening of our faith and its expressions. Even though we are convinced that the love for a child with a disability transcends faith and religion, and can be experienced by anyone, we couldn’t have processed our grief without the support of our Catholic faith. We deeply admire those parents who are able to go through a healthy grieving process without relying on religion or the belief that they will be reunited in the future," reflect Elia and Javier.

"Today, our whole family still feels Iago very close to us. The pain is there every second of the day, literally, but so is the joy of knowing that now he is the one who looks after us and is preparing a place for us beside the Father," they say. When asked how many children they have, they reply, "Two."

"We only speak of Iago in the past when we refer to his disability: we had a son who was deaf and blind. Now, we have a son who is guiding us by the hand to a place so beautiful that our eyes are not yet ready to see it."

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Listen to the story in Spanish here:

Prelatura de la Santa Cruz y Opus Dei · Un vida que lo cambió todo: la historia de Iago