

The Hidden Storm: an emotional journey with type 1 diabetes

INTRODUCTION

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The Hidden Storm begins when the life of Manuel gets hit by an invisible storm in the form of type 1 diabetes; the intruder is silent, invasive and hard to manage.

Manuel's story is not just about diabetes: it deals with what it means to grow up emotionally with a chronic illness that makes you different. And how that difference, with the right support, becomes a companion not an enemy.

Whether you are a parent, a caregiver, a person with type 1 diabetes, or someone seeking to understand this peculiar disease, I hope these pages bring you some clarity to face your hidden storm.

The story started a morning of 1999. He was seven. The three siblings kicked off their day like any other school morning: getting dressed, brushing teeth, filling backpacks, having breakfast before leaving: the usual chaos of getting kids out the door in time. But something wasn't right. Manuel was crying in his room; his little brother had teased him for wetting the bed again. He hadn't had accidents in years, and now they were happening several nights in a row. He was confused. So was I.

That morning, he dressed quietly, only to notice his favorite pants hanging loose around his waist. He had lost weight without trying. He looked pale. And even though he'd just woken up, his body was exhausted. At school, he forced a smile when he saw his friends, but he didn't have the energy to run after them. He was constantly thirsty, running to the bathroom. In the afternoon, I took him to the doctor. I knew something was wrong but didn't expect our lives to change with a single blood test. The result was clear, and terrifying: Manuel had type 1 diabetes, or T1D.

The pediatrician sent us to the children's hospital. It felt like being dropped into another universe with a new vocabulary and a constant worry. When the diagnosis was confirmed, a team of specialists greeted us, and we began the process of stabilization and education. Manuel spent five days in the hospital learning to understand his body with diabetes, while us parents were finding out what lay ahead to keep our child alive.

Manuel was never left alone and that's when he met Rufus: a big stuffed dog with floppy ears and a friendly face. Manuel decided that Rufus also "had" diabetes. Somehow, this stuffed animal became the companion Manuel needed: a quiet presence who understood, never judged and was always there.

With time, we adapted. I learned to work with diabetes, not against it. I made room for grief, fear, frustration and a new routine.

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What this book offers

The Hidden Storm draws on my dual perspective as a mother and a therapist to offer what is often missing in the conversation about diabetes: the emotional side of medical care.

While treatment and technology safeguard the body, this book turns to the inner landscape of living with T1D, including the emotions and everyday struggles that shape our lives. The book shows how feelings ripple into our routines, influencing how we eat, sleep, work, and connect with others. Medical care is indispensable, but so too is personal care: when emotional well-being walks hand in hand with treatment, life with T1D becomes not only manageable, but also more meaningful and fulfilling, lightening the heavy weight of the disease.

Over the years, I have listened to the stories of people with T1D, from toddlers to retirees, from newly diagnosed individuals to a veteran “pro” at managing his condition. *The Hidden Storm* brings together stories from people of all ages and geographic backgrounds, weaving together a common human experience through time. As a person ages, needs associated with T1D evolve while self-care remains indispensable. Consequently, certain themes may reappear across different age groups, underscoring how each stage of life uniquely reshapes diabetes care.

The book is divided into four sections:

- **Section I: diabetes uncovered** introduces the disease and offers essential knowledge for the journey ahead. The early days of T1D bring a steep learning curve: the hospital stay, new routines and unexpected changes. Alongside these adjustments comes an emotional roller coaster that many families experience and don’t always understand. This section helps anticipate what those first weeks and months may feel like. The three sections that follow can be read independently, simply begin with the one that speaks to your age group or the stage of life you are most curious about.
- **Section II: childhood with T1D** explores what life with T1D looks like for children and their families. From school days and playtime, to illness, sports, camps and social life, I address the emotional weight that a diagnosis brings. The section closes with two testimonies from children and one from Opal, mother of Tomy, diagnosed at just two and a half years old.
- **Section III: adolescence with T1D** dives into puberty, hormones, peer pressure, identity, body image, mental health, and the unique challenges faced by girls, including eating disorders. The testimonies of three young women share some memories of their teenage years spent juggling with T1D.

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- **Section IV: adulthood with T1D** brings its own milestones, especially for people recently diagnosed. Today, nearly half of all new diagnoses happen after age 20¹. This section explores how diabetes intersects with work, love, sex, pregnancy and the process of aging. It concludes the book with the testimonies of three men diagnosed in their 30s, 40s, and 50s, who share their experience and their search for emotional balance.

The power of testimonies

The Hidden Storm is built around Manuel², Allan, Arthur, Beth, Carolina, Charles, Eduard, Isabella, Jeremy, Juliette, Leila, Opal, Sofia, Tomy, Tadeo, their families and myself. Each name represents a lived reality with struggles and successes.

The Hidden Storm brings some answers to difficult questions: testimonies and my experience with Manuel offer snapshots of what life with diabetes looks like. You will meet Manuel and Rufus again and again through these pages and you may recognize yourself at times.

If you are a parent freshly thrown into the world of T1D,
If you are a teenager struggling to balance independence with T1D,
If you are navigating early adulthood, pregnancy, parenthood or loneliness with T1D,
This book is for you.

Throughout interviews, one message echoed: “*I am not my diabetes.*” Some participants stated how important it was to be called a “person with diabetes” not a “diabetic person.” The word *diabetic* carries shame or stigma for some. However, not everyone agrees. Juliette insists to use the phrase “I am diabetic”: although she is not her disease, she argues that using “I am diabetic” confirms that she has type 1 diabetes. It is a way to distinguish T1D from T2D, two different diseases.

This is the book I wished I had at the time of my son’s diagnosis.

¹ Leslie R.D. & Al. October 18, 2021. *Adult-Onset Type 1 Diabetes: Current Understanding and Challenges*. <https://diabetesjournals.org>.

² Names are changed to respect confidentiality.