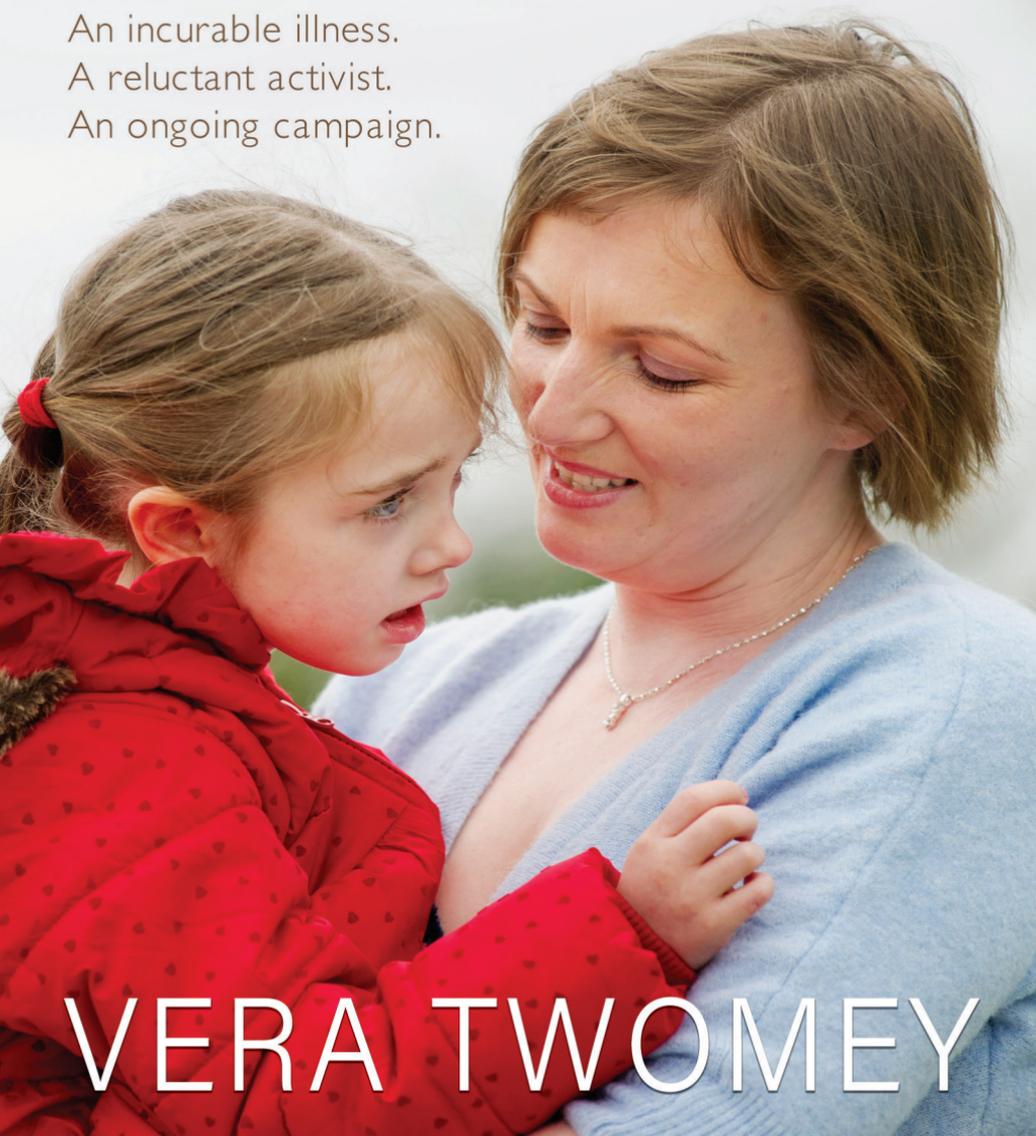


for Ava

An incurable illness.
A reluctant activist.
An ongoing campaign.



VERA TWOMEY

for Ava

VERA TWOMEY



MERCIER PRESS

The greatest achievement in life is to lose fear.
When you are no longer afraid, you are free. Once
this happens you will achieve any goal, in time, with
focus and determination.

Vera Twomey

Foreword

I've had the privilege of meeting many remarkable people in my role as a public representative in the Irish parliament; however, occasionally someone truly inspiring crosses my path. Vera Twomey most certainly falls into that category. As much as this is a book about dealing with a child's terrible illness and fighting for medical justice, it is essentially a book about a mother's love and devotion to her daughter. It isn't until we're tested that a person learns what they are capable of and how strong they can be. This story teaches us profound lessons about friendship, solidarity and the human condition.

I first met Vera and her husband, Paul, in May 2016, in Leinster House. They had come to highlight the desperate situation they faced regarding their daughter Ava's health and how they were committed to doing anything they could to alleviate her immense suffering. Vera's impassioned plea struck a chord and after listening to her speak I knew that something had to be done in terms of legislation for medicinal cannabis. That meeting would start the process and the development of a deep friendship that helped bring the issue to the national stage.

Vera's campaign to gain access to medicinal cannabis for Ava has captured the public's imagination and they readily took this extraordinary family's plight to their hearts. Her dauntless will and determination in taking on an obdurate establishment was both inspirational and moving. The narrative that played out was one of institutional resistance and inherent conservatism, within both the political and medical spheres, in relation to access to

medicinal cannabis. Her sheer devotion and commitment to Ava drove Vera to anything and everything in securing the necessary treatment.

Vera's fight for Ava is one no family should ever have to endure. Their enormous sacrifice will hopefully make it easier for others in the future to avoid the monumental obstacles that were placed in their way. I am more confident than ever that access to medicinal cannabis will happen in Ireland. It is inevitable. The winds of change have fundamentally altered people's awareness of its enormous benefits.

History will show that it was one woman, exhibiting incredible courage and conviction, who took on the system, won the right to obtain access to medicinal cannabis for her daughter, and paved the way for so many who will benefit from her heroic struggle. Vera always said to me, 'Gino, we need somebody inside and outside the parliamentary gates to win.' I'm glad to have played a role in the past few years, but ultimately it is people like Vera Twomey who have begun to open the gates for the many people who may benefit from the use of medicinal cannabis to help alleviate their pain and suffering.

On that afternoon in May 2016, when I first met Vera and Paul, I didn't realise what lay ahead, much less its significance. Since then I have developed a deeper awareness and appreciation of the courage exhibited by so many carers and ill people living in Ireland. Their courage is infectious and, together with dogged persistence and solidarity, we can move forward to success. Now that is something truly worth fighting for.

GINO KENNY, TD

PROLOGUE

A Normal Day

'I have sadness in me, I have anger in me,
I have heartbreak in me.'

– Ellen DeGeneres

It was early in 2016 and just a normal day, or as normal as it ever gets when one of your children suffers from a serious, chronic illness. Ava's epilepsy had long since taken over our lives. Every waking moment was consumed by it. I operated under constant fear and tension, waiting for the next seizure. It was coming, though you never knew when – but as sure as day it was coming. We had reached a stage where Ava was having several seizures almost every day, with over twenty on a bad day. They may have varied in extent and severity, but each one was an agonising experience, full of pain and terror.

I was in the kitchen that day, doing the washing and chatting away with my mother, Katty. The door between the kitchen and sitting room was open, so I'd occasionally snatch a glance at the children playing, to see that they were okay. You know yourself – when it's quiet, it's usually time to investigate what they're up to.

The constant illness had sapped the strength from my six-year-old daughter. Ava had been out of sorts over the last few days, with another ear infection that raised her temperature,

along with other alarm bells for an impending seizure, like how her previous night's sleep had been very disturbed. The family needed to be vigilant. Being sleep-deprived had become part of daily life, as we monitored Ava through the night for seizure activity.

Bang.

A cry of distress came from the sitting room.

I rushed in, with my mother following right behind.

Ava was lying on the sofa, her torso stiff as a poker but her arms and legs jerking uncontrollably. She had a fixed, far-off look in her eyes. She wasn't in the room any more; the seizure had her.

I needed to control my worry and, to be honest, keep myself from panicking. You go into automatic pilot mode when a seizure strikes; you tell yourself, 'Keep calm, you know what needs to be done, just do it.'

While my mother stayed with Ava, I ran back into the kitchen. Reaching up, I got the rescue medicine, Buccolam, from its appointed place, high up in the press. It's powerful stuff and not to be used lightly. It may stop a seizure – though not always – but either way it would leave Ava zonked out for several hours afterwards. No, it wasn't to be used lightly at all. Still, it was all that was available.

My mother told me, 'Twenty seconds, Vera', as I hurried back into the sitting room. We still had time; it might stop of its own accord. You had to wait five minutes before administering the rescue medication, so it was an agonising waiting game, kneeling beside Ava, praying for it to stop. After five minutes she exclaimed, 'Vera, it's not stopping.' She was right; if anything the seizure was growing in intensity, with more powerful muscle

spasms. It was time, so I gave Ava the medicine, hoping it would halt the attack.

Afterwards, I looked up at my mother. 'What do you think, is it easing off at all?'

She looked down at me with a pained expression. 'No, Vera, she's not coming out of it. I think it's nearly time to phone for the ambulance.'

You needed to wait to see if the rescue medication would work before the next step: the emergency ambulance call. But my mother was right; we were at that stage now.

I made the call.

Whoever answered the phone on the other end recognised the number. 'Hello, Vera, is that you? Is Ava having a seizure again? How long? Okay, we're on our way.' The call-outs were so regular that there was no need to provide an address.

I had a few short moments to phone my husband, Paul, who was at work, with the bad news and try to organise things for my mother, who'd mind the rest of the children. I also rushed to put some essentials in a bag for the looming hospital stay.

The ambulance arrived from Macroom in less than fifteen minutes. Ava was still seizing. Working quickly – we were well used to the procedure by now – she was gently lifted into the ambulance and off we sped. About twenty minutes later, we arrived at the hospital in Cork city.

So here we were, back in the Cork University Hospital (CUH) Accident and Emergency room again. How thoroughly sick of that room I was. Some of the most upsetting, distressing moments of my life have taken place there. The doctors and nurses surrounded Ava, trying to stop the attack. 'How about if we try phenytoin?' suggested a junior doctor.

‘But doctor, that takes half an hour to have an effect,’ I protested. I’d been through this process so many times.

‘Yes, oh, yes, that’s right, Mrs Twomey, it does. Have you experienced this before?’

‘Yes I have, too many times, and that one isn’t suitable; it’s never worked quickly enough for Ava.’

While this discussion was going on the seizure stopped as suddenly as it had begun. It had lasted about forty minutes from beginning to end. It had been a bad seizure, powerful. Another shocking day, but far from the worst.

Ava looked wretched and completely exhausted lying in the hospital bed. As I gently held her hand and stroked her hair, trying to give her some comfort from the pain or at least let her know she wasn’t alone, I wondered to myself: how did my family end up in such a terrible predicament?

Much more importantly and more urgently, I strove to think of a way to alleviate her suffering and give her a chance at a better, healthier life. As I held her hand, I silently assured her, ‘Ava darling, I promise we’re going to make it happen.’



To what lengths would you go to give your sick child the chance of a better life?

When Vera Twomey's daughter, Ava, is diagnosed with Dravet syndrome, a rare form of epilepsy that causes frequent and often life-threatening seizures, the family's life is thrown into chaos. As prescribed drug after prescribed drug fails, and the medical system all but gives up on her daughter, a potential new treatment comes to light: medicinal cannabis. Illegal in Ireland, Vera vows to do whatever it takes to ensure that her daughter gets access to this potentially life-saving treatment. Whether it's protesting and campaigning across the country, walking hundreds of miles to the country's seat of power, breaking the law, or even confronting a government minister face to face – Vera Twomey will do it all, for Ava.

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