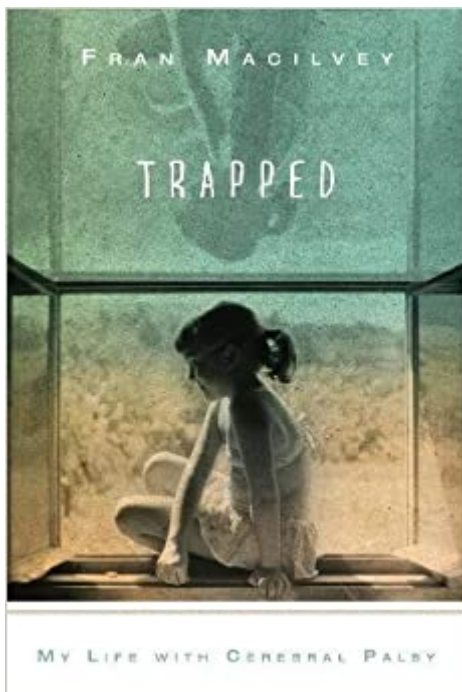


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# Trapped: My Life With Cerebral Palsy



## Synopsis

The true story of one woman's life with cerebral palsy. Living in the Belgian Congo with her husband in the 1960s, Fran's mother became pregnant with a daughter. However, right after she gave birth in the hospital, she felt strange. Unbeknownst to anyone, another daughter was on the way, but before anybody responded, an hour had passed. Because of the delay, Fran was born with cerebral palsy. Growing up with her siblings in Africa, Fran always felt different. When everyone else was playing and having fun, she would watch and wish she could join in. After the family moved to Scotland and Fran grew older, her hurt turned into anger, self-hatred, and suicidal depression. Then one day, someone looked at her and saw a woman to love, and that was the start of her journey to self-acceptance. Fran has written the painful truth about her life to help readers understand how disabled adults really feel. In her revealing account, she shows just how hard it is to maintain the appearance of a "normal" life. More importantly, out of her million and one mistakes have come lessons in real acceptance, peace, and joy, which she would like to share with her readers.

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## Customer Reviews

"Trapped is an ideal firsthand account of the unique and largely unknown world of disability.

Disabled people deserve to be recognized as human beings. Many more will be, thanks to Fran

Macilvey's exquisite prose. This puts us all in her debt." —Dr. James

MacDonald, a playwright with cerebral palsy and an Associate Research Fellow at the University of

Exeter

Fran Macilvey was born premature and disabled in the Belgian Congo in 1965. Returning to Scotland in 1972, she spent eight years at boarding school, then qualified and practiced as a solicitor for ten years before returning to her first passion, writing. Apart from *Trapped* she has written two further books drawing on her experiences with disability. She lives with her husband and daughter in Scotland.

It had some boring spots which I skimmed over. Other parts were more interesting. I found she complained a lot and wasn't the nicest person by her own admission. I have a friend that is in the same situation as the author. The friend has a million things to complain about but she NEVER does; in fact she's always thankful for what she does have. Perhaps that gave me a slanted view of this book.

This book is a strikingly honest memoir telling about the author's life with cerebral palsy. Coping physically with a disability is challenging enough. Add to this coping with the emotional part. Add to this the problems interacting with other people without disabilities. What do people without disabilities know about what it feels like to live with disabilities? The answer is: very little! And this is where the interaction problems begin. People are cruel, people are tactless, people are inconsiderate, and people are ignorant. Not all people are. There are people who are kind and helpful, yet they are, quite often, a bit at a loss when it comes to interact with a disabled person. How should one act towards someone with a disability? Should one pretend not to notice? This is silly. The disability is too obvious. Should one ask for how long the person has been like this? Sounds a bit tactless, doesn't it? Or should one ask whether the person had been in an accident? This is what I have occasionally chosen. Yet I would always feel bad right after, realizing that the disabled person would probably have to answer this question several times a day, 365 days a year, and this for decades. I would always be relieved when the person replied that it was an accident. Then, I could inquire about the accident and listen empathetically how the accident had happened, what injuries had been suffered, what progress had been made, etc., etc. It was always a bit embarrassing when the answer was that it was a birth defect. This came occasionally with a look, saying: "O.k., now you know that I am a genuine cripple. Are you feeling better now?" And this is the reason why I, like so many

other people, quite often, look away when I see someone with a disability. When I do this, I also feel bad, and I am sure that the disabled person, who in most cases will notice that I look away, will feel bad, as well. I have not yet found the right way to act towards people with disabilities. The only disabled person I ever felt comfortable with was a 3-miles-up-the-road neighbor, whom we met several times at a barbecue party held by one of our neighbors. This man, who was severely disabled from birth and sat in a wheel chair, had such dazzling humor that we laughed with him for hours every time we met him and completely forgot what he looked like. (Then, some 6 years ago, when we wanted to invite him ourselves and asked someone for his full name and phone number, we learned that he had been in a fatal car accident, only few weeks earlier, while we had been out of town. It was assumed that he had suffered a seizure before he crashed into another car. We are still mourning this man. I wish we had invited him earlier.) Then, there is also the question when to offer help or assistance.

• I have a bad back. This is why I use an electric cart at Walmart,cs and also at the supermarket. It happens, quite often, that when I look at shelves pondering what to take, someone offers me help. This is so kind and well-meant. But it is also annoying because I don't need any help. I can get out of the electric cart when I need to. I only use it to avoid backache. So let's face it: It is a problem for both sides, the disabled person and the not-disabled person. I wish someone came up with a perfect solution. And I bet, so does Fran Macilvey. For Fran, not only the physical problems are difficult to cope with from early childhood on; the emotional and interaction problems are, too. Even loving family members hurt Fran's feelings. The parents claim to treat Fran the same as her siblings. But do they really? No, they are not treating her the same. It is not possible to treat her the same. And wherever and whenever Fran is treated the same, she is bound to over-exhaust herself or stay behind on family walks and hikes. Understandably, Fran gets annoyed when she can't keep up and they leave her struggling. Yet she also gets annoyed when someone offers her an arm to lean on. She wants to be self-reliant. For her family members, offering help is a "damned if you do, and damned if you don't" situation. And Fran absolutely refuses to use a wheel chair. The book starts with Fran telling how she keeps struggling along on the side of walkways, so not to get knocked over by joggers or other people who are in a hurry, yet she is, nevertheless, falling, hurting herself and/or landing in dog poop. When reading this, my first thought was: "Why on earth doesn't she use a wheel chair?" This is because I didn't mind using a wheel chair when my back problems were at their worst. And this is probably because I was brought up NOT to be self-reliant. Throughout my

childhood and teenage years, my mother insisted on doing everything for me, and while I found this annoying, it didn't bother me enough to fight it. (Not that I was a submissive child; I just chose my battles wisely.) My mother did not wait on me hand on foot with the purpose to spoil me; she did it because she wanted everything done her way, not allowing the slightest difference from her routine. My husband was brought up the opposite way. So when we discussed Fran's desire for self-reliance, my husband fully understood it. We eventually came to the conclusion that a compromise might have been best, that is, walking short distances on suitable trails and sidewalks and using a wheelchair for longer distances and on crowded walkways. This would be our choice. Yet Fran's choice was and is different. Fran is stubborn, which is part of being resilient. She, quite often, insists on doing things the hard way. And she occasionally comes to regret it. Growing up, Fran experiences anger, self-hatred, and depression. While this is understandable, it had never occurred to me that someone born with a disability might have such emotions. I would have expected an accident-victim to feel depressed, but I had always thought that a person who had never known a normal life would be used to his or her condition. This shows how ignorant "normal" people can be. To my excuse: I have never experienced chronic anger, self-hatred, or clinical depression. And I have also never cared too much about what people would think of me. (If they liked me, fine. If they didn't, not like me, too bad.) So one might allow me (and people like me) some mitigating factors. Reading this book, my heart went out to Fran. I felt so sorry for all her physical and emotional suffering, especially the painful surgeries that were supposed to "make her better" but never did. (This reminded me of the old pilot wisdom: "If it ain't broke, don't fix it.") And I was so happy for Fran when, towards the end of the book, she finally found true love and, quite unexpectedly, even came to experience the joys of motherhood. Throughout the book, I admired Fran's resilience and her ongoing struggle to lead a life as normal as possible. The book is eloquently written, yet first and foremost, it is written with staggering honesty. Fran Macilvey not only tells what it is like to live with a disability, she discloses her most private thoughts and emotions. In other words: She bares her soul. There were a few things I did not like about this book: The reader never learns why Fran's parents split up and whether they got divorced or only separated. I also would have liked to learn why Fran never pleaded with her mother to take her and her sister out of this terrible boarding school, where beside other hardships, she never even got enough to eat. There didn't seem to be any real need for this boarding school. (I also attended such an awful boarding school for 1 1/2 years. So I could well relate to

Fran's story is suffering at this place. Yet in my case, it was the only way to go to high school until my parents were able to rent a flat in Munich.) I found some parts of the book too sketchy and other parts more detailed and explicit than necessary. And there were a number of lengthy complaints that had very little to do with Fran's disability. Most of us not-disabled people will have also experienced cruel teachers, nasty coworkers, unfair superiors, long waiting times in hospitals, inconsiderate nurses, inapt doctors, and inedible hospital food. With certain changes, this book could have been a 5-star rating on my scale. Notwithstanding the shortcomings I found with this book, I strongly recommend everyone to read it. There will hardly be another book that allows the reader into the brain and body of a person forced to live with a disability. We who are able-bodied or only have a bad back, bad knees, a bad shoulder, and/or a few other not-so-very life-impeding ailments need to learn what life is like for disabled people and what we can do to, possibly, make life a little easier for them. And one last word to the author: Fran, please tell me how I should act when, next time, I come across someone with a disability. Don't tell me to just say, "hi" as I normally don't say, "hi" to strangers. So this wouldn't be natural behavior. Should I smile? Yet couldn't it be that the person takes my smile for charity? And how should I act when I meet a disabled person at a social gathering? There it would be normal to say, "hi", yet at what point, if at all, should I mention the disability, and what can I say that's neither hurtful, nor annoying, nor tactless? HELP!

"Trapped" is the writer's incredibly powerful story of life with debilitating cerebral palsy. Fran's journey has moments of humor, surprising in her honest, almost out of body, observations of the difficulties she faces each day. At other times, her story is so painful it is hard to read, hard to accept such a journey. Despite the darkness and pain in her journey, Fran sees mirrors of her own life in the limitations we all experience - the limitations and the fear and self-disgust we feel when unable to accomplish a desired goal. Her perspective is both internal and self-aware while being a true observer of human nature. "Trapped" is an important work, a revelation and a blessing. Fran herself is a gift to all of us.

Fran's writing is so poignant and vivid that as a reader, you find yourself feeling every emotion and living her story with her rather than just reading about her. Her courage is inspiring and what a message of hope she gives to us all! Fran allows us the privilege to walk with her from childhood all

the way through to her adult life as a wife and mother. Along the way, we both feel her pain and rejoice in her triumphs. And in the end, we celebrate with her. By far, my favorite part of the story was near the end where Fran so beautifully describes the growth she has made in how she views herself. "I realize now that there is nothing I can do to make myself ugly... I can punish myself, push myself and hate myself. Yet nothing I do to hurt myself makes any difference to the truth: my soul knows I am beautiful, even when I forget, or try to kid myself that I am the world's worst person." You ARE beautiful Fran!! Inside and out! May you never forget it!!!

I really enjoy reading a good biography or memoir and I was particularly interested in this book after seeing all of the glowing reviews. I was a little surprised when the book actually exceeded my expectations! This is one of those books that really draws you into the story and allows you to see the real person, for better or worse. I admit I knew very little about Cerebral Palsy before I read this book, which is one of the reasons I picked it up. I feel like I now have at least a greater appreciation for the disability and for those I see with similar circumstances. It's a good reminder that everyone has a story.

The book was interesting and the reader feels both admiration and sympathy for the author, who suffered a lot but made a good life for herself in the end. A brave and thinking person. Still, I would have liked to know some specific things that changed her outlook. What experiences or what philosophies pushed her in the right direction? The change seemed sudden and rather vaguely accounted for near the end of the book.

Fran MacIlvey's wonderful book offers readers a precious gift, one that does not shrink from revealing the painful truth about the realities of growing up disabled in an otherwise able-bodied family. This she achieves in succinct, engaging and beautiful prose, without a trace of self-pity. From the arresting opening chapter to the inspirational finale, Fran's story reminds us of the simple truth we knew along but keep forgetting: love and kindness to oneself and others is the answer. In a world of shallow distractions, the hard-won wisdoms that Fran courageously re-discovers for herself have much to teach us all. Highly recommended.

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