

THE IMAGE OF CEREBRAL PALSY IN THIS COUNTRY WILL FOREVER BE LINKED TO THE NAME OF LLUÍS SERRA (2000-2009). THE BOOK *Quiet* (2008) HAS HELPED GENERATE A MOVEMENT TO RAISE OUR SENSIBILITY REGARDING A CONDITION WHICH, UNTIL RECENTLY, WAS AS UNKNOWN AS IT WAS STIGMATISED. ALL OF THIS BECAME POSSIBLE THANKS TO THE WILL OF MÀRIUS SERRA, LLULLU'S FATHER, TO EXPRESS HIS EXPERIENCES.

## "The great legacy which Lluís left is that he has changed my perspective"

Sergi Rodríguez



Pep Herrero

Màrius Serra, escritor

### What is *Quiet*? A book for you or for others?

It would be nice to be able to say that it was born out a desire to consider others... but it would be a lie. That always comes after the event. I understand writing, even more sharply in this case, as a response to a need. In my case the need to express through narrative, the tool available to me as a writer, the experience I had been living through for some nine years. I was thinking less about the reader and more about myself. In truth I had considerable doubts about how this book would be read. As soon as it was published, right from the initial reactions I realised the many interpretations that could be made of it, and that many people identified with it.

### How do you look back on that nine-year experience, now it has passed?

With my heart on my sleeve, as the best years of my life. I hope there will be plenty of good ones still to come, and I have no intention of living in the past, but every thought and memory of that time is filled with very intense joy and pain. Obviously there is a process which begins the day that the world falls in on you. Soon anguish and suffering begin to alternate, although now one appreciates aspects which previously were completely invisible. Every hospital discharge, for example, was a party like no other from me. That is the bittersweet feeling I aimed to express in the book. The contrast between pain and joy allows you to appreciate things much more intensely. Only in the dark is the light at its brightest.

### What range of emotions did you experience with your son Lluís?

The first was vertigo, like a sudden rush giving you the feeling you've lost your bearings. A simple fact creates an abyss which disorients you, as if you had emigrated to a different country. You have no point of reference. And precisely because of that you learn to view things differently. In my case I experienced it as a challenge: switching the GPS back on to get a fix on this new territory. I soon realised that I was looking at the same things as before in a different way. It was not a change of scene, but of perspective. I felt very well prepared, though, thanks to the obsession I had always had with reading and writing, in which observation and imagination are fundamental. I suddenly saw myself as a writer holding on to a wheelchair, who had become a filter for viewing the world. Behind someone as special as my son I realised that there was a privileged viewpoint through which to see the reactions of the human race, because the huge fragility of a person who does not correspond to any of our values as a species (is not two-footed, does not hold his head up, has no verbal coherence...) provokes curiosity, fear, tenderness or rejection.. always very extreme reactions. I didn't change my strategy in any way, though; I continued doing what I had been doing, while realising that I was also part of that vertigo.

### You never wanted to stop living a normal life. Can you explain?

In our case it was always like that. When he was just five weeks old he was admitted to hos-



pital, and we never emerged from that dynamic. There was never a clear diagnosis, but we could already see that there was a problem. A five-week-old child doesn't walk, doesn't do anything... and that situation, to a degree, lasted nine years. Lluís was always a newborn baby. Many people, when they become parents, stop going on holiday, taking aeroplanes... while others jet off to Thailand; it depends on your own personal approach. We had always travelled a lot, and this new situation led us to reaffirm the need to try to carry on doing the same things as we would have done if Lluís hadn't had that problem. To begin with the logistics were the same as with any small child, but as he grew up it became more complicated. Nonetheless, wheelchair and all we ended up making it to Canada and Hawaii. It also helped that, in the initial years, despite the epileptic attacks, Lluís had no health problems: he never caught cold, he was a peaceful child... Later, when hospital admissions became questions of immediate necessity, we travelled closer to home. We experienced unforgettable situations which to a degree alleviated the pain and the impotence caused by seeing that he could enjoy life with a low level of perception.

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**As a parent, what are the main improvements in treatment or care you would hope to see in the future?**

Deep down, more dialogue. You need to receive information to live with a situation like that. In our case, right from the fifth week the Vall d'Hebron General Hospital the Nexa Foundation was suggested as a possible way forward. In other cases the condition reveals itself over time, and that generates great uncertainty. Maybe the administrative procedures need simplifying, with better coordination between public agencies. You have such a complex and changing state of mind, and all the basic paperwork seems mountainous. We were living through this just as the Dependent Persons Act came

in, and the fact that the details just weren't being made clear led to considerable frustration. And then he needed a special school, because an ordinary school cannot cope, in physical or educational terms, with a cerebral palsy sufferer. There needs to be a clear policy from 0 to 6 years, and above all from 0 to 3. When Lluís was less than one year old he began to go to a centre every day, where we were given information.

**What has the social perception of this condition been like?**

One of the most shocking things that happened to me after I published *Quiet* was all the messages I received from people telling me about children or elderly people with paralysis who were never taken outside the home. In the countryside, some people even had them in the cattleshed, with the animals. It is a phenomenon perceived very differently by the over 60s. It used to be a taboo. You only have to look at the way the language has evolved: from cretin to spastic, from retardation to palsy... I think that my experience, if Lluís had been born earlier than 2000, would have been quite different. He was born into a world with plenty of trained professionals, he ultimately benefited from the Dependent Persons Act... I don't deny there are plenty of good intentions, but there is still a paternalistic undercurrent in the provision of care. And that is often not the best thing for parents facing this problem.

**How did other people react in daily life?**

What I most recall is a highly fragmented and irrational fear. Some people look one way or the other fearfully, trying to avoid anything they would not want to happen to themselves. Others looked with the fear of not knowing how to deal with the issue, not being up to it. The clearest and most obvious reaction came from children, who would come up to Lluís and ask "What's up with him? Doesn't he speak?". It is a very widespread and at the same time understandable fear. But it also shows how ill-prepared we are to deal with situations of catastrophe or failure; we don't even have the words. I found it very difficult to pretend with people who were aware of my situation and would ask: "How are things? Does he let you sleep?". It was a difficult situation. In most cases you would end up making up your own



narrative to give people depending on the situation. I found that explaining it to other people helped to explain it to myself, and that giving expression to my situation cast light on my fear of the unknown, because his illness was never given a name. Often you would have to predict the reaction of others; with older people at times you would end up having to console them, because they would become sad and cry. It was like a dark joke. Others would trivialise it, and say “it’ll pass” or “he’ll grow out of it”, as if it were a common cold.

### And what about the treatments?

That is a very delicate issue. There are people who go to medical conferences, who keep their finger on the pulse... Bertín Osborne, who also has a son with cerebral palsy, says that he has taken him off the medication because he has started following an alternative treatment. We were also offered that. Normally they are expensive, they come from the United States... It puts you in a horrific ethical dilemma: am I doing enough for my child? And we took him to public hospitals, private centres, to three doctors... This particular treatment has aroused considerable doubts among the medical community, because it places the parents in the role of therapist: you have to over-stimulate your child, do some really tough exercises, which the mother normally deals with, for hours every day, and monitor the situation. If it doesn't work, which is generally the case, people accuse you of not having done it properly, or not having spent enough hours on it... It puts you in an unreasonable situation. Obviously you want to fight for your child and you are very vulnerable to any message coming out of alternative medicine. And there are people who exploit that.

### Did you expect the response and interest which the book aroused?

That was totally unexpected. I even had real doubts as to whether to launch the book in public. Although I am very engaged with the media, with this book I didn't know what face to put forward, given the degree of emotional involvement. And above all I didn't want to present myself as a victim. I must say, though, that my counterparts in the press dealt with it wonderfully right from the start. That assuaged my fear. And it started to become a



real phenomenon. Over the past 15 months I've received some 3000 e-mails from people telling me their stories, stories which have really struck a chord with me. And then I had the idea of staging a charity concert which I organised over four months via the blog *Mou-te pels quiets* [Get moving for the still ones]. That helped raise the profile of cerebral palsy, the forgotten disability, and generate a new sensibility. I feel very proud that I did that. Lluís died one month and ten days after that concert, and the fact that I had organised it, and also written a book about his life, was really important from a personal perspective. It was a totally different way of experiencing the grief. Now, on balance, there are more sweet than bitter memories, and we will always have that with us. Lluís left us a legacy the trust fund in his name, the lift we had installed at home for him and which we will use when we are old... but his true legacy is that he changed my viewpoint and allowed me to see things that I would probably never have seen.

**Màrius Serra** was born in Barcelona in 1963. His biography reveals an issue which is a constant in his work: how blurred the boundaries between reality and fiction are.

“Everything I relate has happened to me in one way or another. And I have used all of those elements to create a fictitious jigsaw,” he says. He graduated

from the University of Barcelona in 1987 with a degree in English language. That same year he won the El Brot Award for his work *Amnèsia*. In 1989 he began working extensively in the press, radio and television, while also setting up a word game magazine, *Més*. He has a weekly puzzle and crossword section in *Avui* and *La Vanguardia*. He is also a member of the editorial board of *verbalia.com*, a word game and literature website. His key works include *Ablanatanalba* (1999) and the collection of stories *La Vida Normal*, which won the City of Barcelona Award in 1999. His essay *Verbàlia* won the Serra d'Or and Lletra d'Or Critics Award (2001). More recently, in 2006, his novel *Farsa* received the Ramon Llull Award. In 2008 he wrote *Quiet*.

