ABOUT THE BOOK
Rosie loves Jack. Jack loves Rosie. So when they’re separated, Rosie will do anything to find the boy who makes the sun shine in her head. Even defy her parents’ orders and run away from home. Even struggle across London and travel to Brighton on her own, though the trains are cancelled and the snow is falling. Even though people might think a girl like Rosie, who has Down syndrome, could never survive on her own.

Introducing a strong and determined protagonist with Down syndrome, debut author Mel Darbon gives readers an underrepresented but much-needed point of view with a voice-driven, heartfelt story of finding your place in an often big and intimidating world.

Q: Rosie Loves Jack is your debut novel. How did you settle on writing for young adults after working in theater and as a teacher?

A: For as long as I can remember I wanted to be a writer. I read constantly as a child and I loved that writers could take me to other worlds and experience different people’s lives. I wanted to be able to do this myself. Of course, life doesn’t always work out the way you want it to, and it took me some time and a stern word from my children until I finally put pen to paper. It felt like I had come home, and everything I had learned working in the theater, where stories are brought to life, and working with inspirational young people was invaluable for my writing and hopefully made it much richer.

The reason I settled on writing for a teenage audience was because I’ve always loved that age group. At this age you are finding out about the world and your place in it and who you want to be as an adult, which is exciting and motivating. Teenagers are free from the lethargy that creeps into our lives as we get older—they keep us on our toes! It seemed natural for me to begin my writing career with them.

Q: Is Rosie Tremayne based on a real person or real experiences?

A: Rosie is based on a real person, although she is also my invention and an amalgamation of different teenagers who I know. I was lucky to work with a group of very compelling young people a few years back, who all had Down syndrome. One of them, a girl called Rosie, was feisty, funny, and fiercely independent. I always wanted to write her story and share the voice that she so wanted to be heard. In my MA course in Creative Writing, she popped back into my head for a character workshop we had to do. She wouldn’t let me go after that and I knew it was time to introduce her to the world. Her voice guided me through the story.

Some of Rose’s experiences are based on real ones that I was told about by friends or the young people I worked with, and some are based on my brother’s experiences as a person with a developmental disability. For example, there is a scene where Rosie and her boyfriend Jack are in town getting something to eat from McDonald’s®. While they are there a group of children mimic how they speak and throw food at them. Sadly, this is a true story.

Q: How did your experiences growing up with a brother with Autism influence Rosie Loves Jack?

A: Growing up with my brother had a huge influence on my writing. As a child there was no indication that anything was wrong with him, which caused confusion.
when he had his meltdowns. One day, when I was nine years old and my brother was five, we were out shopping in town when he had a major tantrum, shouting, kicking, and screaming. Several people came up to us, not to offer help, but to berate my mother, telling her that she was a disgrace, that my brother’s behavior was disgusting, and that he ought to be put away.

I couldn’t understand why some people were so judgmental. I wanted to tell them to “put on my brother’s shoes” for a moment and try to comprehend what it was like to be him, locked in a world that made no sense to him, where even in his sleep he’s tortured by his dreams and is unable to let us know when he’s in pain. I wanted to use these experiences in my book *Rosie Loves Jack* to highlight what it is like to have to deal with injustices such as these, sometimes on a daily basis.

But I also knew that I wanted to write my book so people could see that life with a developmental disability is definitely not unworthy; we need to look beyond disability to ability. My brother’s life has fueled my desire to help dispel any myths about disability because I want to make it clear that when you have a brother like mine, the positives far outstrip the negatives. My brother has taught me compassion, kindness, patience, and the ability to empathize. My character Rosie became my agent to demonstrate this, through her journey to find her boyfriend and her autonomy.

Q: *Why did you choose to have a main character with Down syndrome instead of a different developmental disability?*

A: This is something I am asked a lot and it isn’t surprising considering I have a brother who is profoundly autistic. I wasn’t ready to put my brother in a book just yet. I felt a huge responsibility to honor him and his life but knew that with his very limited language it would be difficult to navigate this as an inexperienced writer. I was nervous I wouldn’t get it right and that I would feel I had let him down. Working with young teenagers with Down syndrome made me realize how much of an inspiration they are. I got to know them as individuals and work with them in college and on their work placements. I became close to them all and realized that one girl in particular, who became my character Rosie, would be an incredible ambassador for demonstrating what we both wanted to say, that just because someone has difficulty communicating doesn’t mean they have nothing to say.

Q: *Tell us about your approach to writing about a character with Down syndrome. How would the story differ if Rosie didn’t have Down syndrome?*

A: I thought very hard before deciding I would write a book featuring a character with Down syndrome. It is a difficult area to cover unless you know what you are talking about; even though you can research any topic in great depth, it’s never the same as if you truly understand or experience something for yourself. It is an especially sensitive area, so a lot of writers might hesitate to embark on a story with a character such as Rosie, for fear of getting it wrong and misrepresenting them. There were challenges that presented themselves, so I had to ensure that I was respectful and considerate before I even began writing. And despite having a lot of experience with people with Down syndrome, I still did thorough research.

I realized I wanted to write a love story that demonstrated how my character Rosie is a teenage girl first, and not just a person defined by her Down syndrome. I wanted Rosie to help the reader understand that human emotions don’t discriminate between those who are able and those who are disabled. Rosie is an individual who shares the same universal desires to love, and to be loved and accepted without limitations. It is the universality of these desires that connects Rosie to her reader.

It became evident that I had to make sure my character was simply part of the landscape and focus on Rosie’s ability and not disability. I had to make her a fully rounded individual and not just a channel to display her disability. As an author I needed to bear in mind that it is not the child with a learning disability who prevents themselves being fully included in society, it is the barriers in society that do that.

Rosie is a typical teenager consumed by her love for Jack and she has the same hopes and aspirations as anyone else. Rosie doesn’t see her Down syndrome as a shortcoming and wants to be treated equally. I avoided stereotyping Rosie by dismissing her Down syndrome as my starting point, which then meant I avoided any obstructions.

I was confident I could portray a realistic picture of Down syndrome, as I’ve personally known people with this condition for many years and learned that there are varying levels of capabilities. Basically, I treated Rosie like a normal teenager, then considered the common characteristics of a person with her condition. It soon became apparent that your average sixteen-year-old might be more streetwise and confident alone in London,
but might also be just as vulnerable and gullible; Rosie, because of her innocence and trust, is much like a typical teenager because they think they know it all and think they are therefore infallible.

Ultimately, I think that the differences for my story, if Rosie didn’t have Down syndrome, are not as big as it might at first seem. She is above all else a teenager, and many of the young people I have spoken to in schools have said, “Rosie is just like me,” which is what I wanted. A neurotypical teenager might be more worldly wise, they might not take everything so literally, and their speech patterns might be a bit more sophisticated, but not necessarily as poetic. They might be more self-aware and probably more self-obsessed, because that’s how the media programs them to be, but it certainly doesn’t stop them from being just as kind and sensitive as Rosie.

Q: Why did you choose to write this book with first person narration? What are some of the challenges of writing from this perspective?

A: I wrote Rosie Loves Jack with first person narration because I really wanted my reader to see the world through the eyes of someone with Down syndrome. We hear all the time that children need to see the world they live in reflected in the books they read and yet books are still often exclusive in some ways. It isn’t just important for those children who are disabled to see themselves as the protagonist, the hero, but for all children to see every type of representation. My aim in having a character such as Rosie was to enable young people to put on someone else’s shoes and truly understand what life is like for that other person. From that comes empathy, understanding, acceptance, and the realization that we all have value and deserve to be heard.

Using first person narration presented specific challenges. I had to consider the view of the world from someone with Down syndrome. Many people with Down syndrome have incredible empathy and are very in-tune with the feelings and the needs of others—something I witnessed when I worked at Henley College and through knowing a friend’s daughter who has Down syndrome. Alongside this comes a very innocent view of the world that is lived in the moment. I had to be constantly aware of this, yet at the same time show how easily it is possible for any young person to be fooled into believing that a person is good and trying to help them, when in fact they are being conned, or even, as in Rosie’s case, being lured into a very frightening situation. I had to be aware of this balance between Rosie’s worldview and a more streetwise teenager who would probably navigate getting lost in London more easily, but in their own way wouldn’t cope any better than Rosie did in the grooming house.

Q: How did you pick Jack as Rosie’s boyfriend?

A: I wanted someone like my brother, who looks neurotypical and yet has a developmental disability, to highlight the difficulties of a hidden disability. He was an invention in my head but his character and looks are loosely based on people I know. All my characters become real people to me, and I believe they actually exist in the world! I know them inside out, right from birth, even my minor characters. The events in people’s lives are what make and shape them, so to me it is all important to do this—then they come alive.

Q: How did you decide to depict Rosie’s speech patterns and Jack’s spelling? Why did you choose to differentiate between Rosie’s narration and the occasionally jumbled way she speaks to others out loud?

A: Rosie’s voice and language were central to my novel. I needed to convey the essence of the way she spoke, without making it hard to read. Many people with Down syndrome have anatomical differences in the mouth and throat region that affect feeding, swallowing, and oral motor skills. They can also often have poor muscle tone in the mouth area, so speech and language difficulties range from mild to severe, depending on the person. Sometimes I ran Rosie’s words together to indicate this, and to also show how Rosie’s thoughts could tumble over each other when she was anxious, stressed, or simply over-excited. I also had to show her personal outlook: an “orange-segment moon” or hair like “fuzzy, blond ropes,” for example.

It was important to me that I establish the lyrical voice inside Rosie’s head. Rosie might not be able to articulate everything she wants to, but this does not mean that she cannot do that internally. My thoughts on this came from living with my brother, whose language skills are that of a three-year-old, and yet he is capable of very complex statements. At nighttime when he is asleep, he shouts out constantly and it was while lying in bed listening to this that I realized how much more coherent he could be in his sleep, and it set me thinking, “How do we know what anyone with a cognitive impairment might actually be capable of expressing inside their minds?” It was an important lesson to learn. Rosie’s lyrical voice in her head came out of this and
I was delighted that my sensitivity reader, someone with Down syndrome who was hired to read and assess my manuscript, felt that I had gotten Rosie’s voice exactly right and that at times she felt that Rosie was herself, in the way she spoke and how she saw things.

For Jack’s spelling I decided to make his level of ability at the stage where a child is learning to read and write using phonetics. He didn’t need sophisticated language, as with a child’s view of the world, it is simple but often beautiful. Jack is able to express himself more easily through his artwork—his pictures paint what is going on inside his head. Like Rosie, you have the balance of some words simply put or expressed juxtaposed with a much more complex way of thinking.

Q: Where did the idea of Jack writing postcards to Rosie come from?

A: It was an idea that came to me when I was deciding how Jack would be able to communicate with Rosie having smashed his phone. Jack is much better at expressing himself through his artwork, so postcards were an ideal way for him to do this, as well as write some short sentences. Also, Jack knows that Rosie can read but at times finds it difficult, so it was his way of helping her understand what he was saying. I wanted it to demonstrate his love and care for her.

Q: What is the significance of the little blue butterfly that visits Rosie and Jack?

A: The little blue butterfly is Rosie and Jack’s good luck charm—their special butterfly that watches over them. There is a scene in the book where Rosie remembers when she and Jack go to Chester Zoo and a tiny blue butterfly lands on her hand and then on Jack. They decide it’s significant for them and it must be good luck. After the visit, Jack gets his mother, who makes jewelry, to design a tiny, blue enamel butterfly brooch for Rosie, to watch over her always, which is why the butterfly helps keep her pushing on to find Jack. It is a symbol of their love for and devotion to each other.

Q: Rosie is treated very differently throughout the story by the variety of people she encounters. Did these interactions come from personal experience?

A: Yes, the majority of these interactions came from personal experience throughout my childhood, both good and bad. Times have changed and people’s attitudes and the understanding of someone with a developmental disability have changed too. People with Down syndrome, for example, are much more present in society, in schools, and in the media than they once were, so the fear and stigmas of the past are slowly being eroded. But we do still have quite a way to go. A couple of summers ago my parents decided to pop out in the car with my brother, only to find that there was a neighborhood street party going on further down from them. They were the only people who hadn’t been invited—because of my brother. My parents were devastated, and my brother would have loved, if not actively joined in, just sitting watching everyone and enjoying the atmosphere. I was heartbroken for them and it demonstrated that people still make unfair choices and judgements for people like my brother. And I knew it was important to show situations like this in my story.

Q: You cover very serious topic like sex exploitation and homelessness. Why did you choose to make these part of Rosie’s story? And why are these topics important to include for a young adult audience?

A: Rosie is part of our real world where these issues are there for us to see. I felt that any young person out in London by themselves and unsure of where to go is vulnerable, not just someone with Down syndrome, for example—though Rosie has an innocence and naivety that a lot of sixteen-year-olds might not have. But at sixteen you think you know it all, which can make you as vulnerable as someone who is as naïve as Rosie. It seemed a probable progression in the story that this could happen to my character and I felt I could use it to highlight these issues—because there will always be predators and although most of the time it won’t end like Rosie’s journey did, it can and does happen.

Sexual exploitation often hasn’t been thought of in the context of applying to a young person with a disability, until it was at the forefront of the news in the British media. People listened with horror to these terrible stories of abuse, but after the initial period of shock, the story faded away, kept within the parameters of the television and got left for others to sort out on their own, as it was too awful to even think about.

My daughter works with young girls who have been groomed. I was shocked to discover that the larger percentage of these girls had a developmental disability. As an author I can allow my reader to explore difficult topics like this in the safety of a book, in a setting where the reader can ask questions or teachers can use it to open a discussion which sheds light on the situation. I hope that young people will find this valuable.
Sexual activity for people with a developmental disability is something that’s rarely ever discussed in a good, healthy, loving context either, as it’s sometimes seen as a taboo subject. If characters like Rosie were represented in more books and films, on television, and in advertising, then they would be seen as the human beings they are with the same emotions and desires, but also suffering the same terrible abuses. If people with developmental disabilities were more visible there would be more open discussions.

I was very conscious of the risk of raising too many issues and thus failing to do justice to any one of those issues, but I was also aware that Rosie is part of a world where these concerns are there for us to see, be it eating disorders, homelessness, sexual exploitation, or addiction, to name a few. And Rosie’s journey is a reflection of life. In Bath, where I live, the number of homeless young people is shocking. For Rosie to find a safe haven with a young homeless person seemed logical after she had been dumped by the river in London—and a very likely scenario. There is an unwritten rule amongst the homeless community to look out for each other. My inclusion of Tom, the homeless boy, wasn’t a device to raise this topic, he just happens to be there at the right time and right place, but, as a writer, there is nothing wrong in sowing small seeds of awareness on such matters, which could stimulate a dialogue that is productive. Through that knowledge come understanding and compassion.

Q: Which part of Rosie’s story is your favorite? Was there a scene we didn’t get to read that you wish made it into the final version of the book?

A: One of my favorite scenes is when Rosie is on the underground heading to Victoria and she stops to listen to a busker, who she asks to sing her special song. It’s a moment where Rosie disappears into her own head as she listens, and it is a very lyrical passage. For me it was a perfect moment when we understand the way Rosie thinks and feels in comparison to the Rosie we witness in the outside world and all that she has to deal with. It was also an important scene for me because Rosie dances with a lady who it turns out has a baby with Down syndrome. This lady has assumed that Rosie needs help navigating her journey, but she is moved to tears when she understands that her assumptions are wrong, and it changes the way she sees everything herself.

Actually, no, there wasn’t a scene I wish had been included, though I would have liked to have made the scenes longer in the grooming house, so that I could develop the relationship between Lisette, the teenager who is responsible for Rosie in the house. I had to hold back on that though, as it would have interrupted the pace too much and halted the momentum.

Q: Why did you choose to end the story with Rosie still in the hospital?

A: I chose to end the story at the hospital because it left the reader wondering what happens next. In many ways the loose ends are tied up because Rosie and Jack have been given the chance to be together again and, very importantly, Rosie has found her autonomy. I have left it open as to what happens next, so that the reader can decide. Perhaps we need Jack’s side of the story first before we journey further with Rosie and Jack.

Q: What do you hope readers take away from Rosie Loves Jack?

That they’ve read a great love story that entertains them, and they can relate to. I hope they take away a book with a character that stays with them and might raise healthy discussion on some of the issues presented in it. Perhaps they may look at the world through different eyes and understand more than anything that just because someone has difficulty communicating doesn’t mean they have nothing to say, and by putting on someone else’s shoes they take a step towards empathy and understanding.

ABOUT THE AUTHOR

Mel Darbon spent a large part of her childhood inventing stories to keep her autistic brother happy on car journeys. She won’t mention the time spent with him standing by level crossings waiting for the InterCity 125 to go past, as she wouldn’t want to be labelled a train spotter. Life took her in many different directions working as a theater designer and freelance artist, as well as teaching young adults with learning disabilities and running creative workshops for teenage mums. She lives in the UK with her husband and their dog, Alfie. Rosie Loves Jack is her debut book.