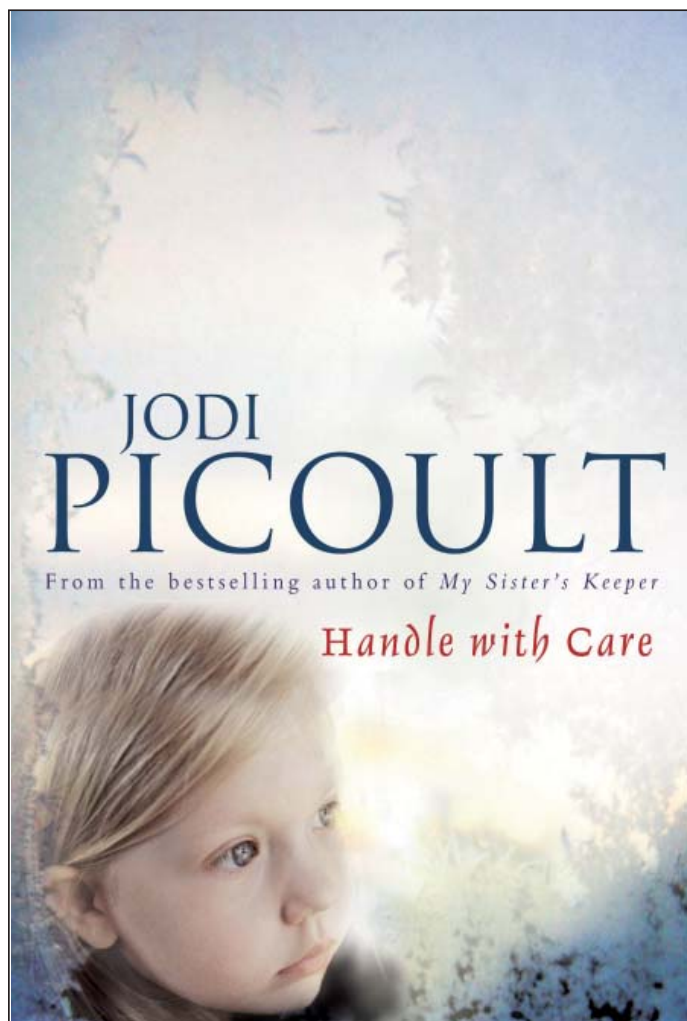


ALLEN & UNWIN



# READING GROUP NOTES

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## About the Book

Willow O'Keefe is born with osteogenesis imperfecta, or brittle bone disease, which means she will suffer hundreds of broken bones as she grows, and a lifetime of pain. As the family struggles to cover medical expenses, her mother Charlotte decides to file a wrongful birth lawsuit against her obstetrician for the compensation which might ensure a lifetime of care for Willow.

But it means that Charlotte has to say in a court of law that she would have terminated the pregnancy if she'd known about the disability in advance. And the obstetrician she's suing isn't just her physician - she's her best friend.

Handle with Care is an absorbing narrative which also questions the basis of medical ethics and of personal morality. What rights do parents or doctors have to terminate a life? How disabled is too disabled? As a parent, how far would you go to save someone you love?

## About the Author

Jodi Picoult is the bestselling author of fifteen novels. She grew up in Long Island and then studied creative writing at Princeton. Following her graduation she had a series of jobs including as a technical writer for a Wall Street brokerage firm, as a copywriter at an ad agency, as an editor at a textbook publisher, and as an 8th grade English teacher - before entering Harvard to pursue a master's in education. She married Tim Van Leer, whom she had known at Princeton, and it was while she was pregnant with her first child that she wrote her first novel, *Songs of the Humpback Whale*. Jodi and Tim and their three children live in Hanover, New Hampshire with a dog, a rabbit, two Jersey calves, and the occasional Holstein.

## A conversation with Jodi Picoult about *Handle With Care*

**What led you to OI as the topic for this book? Did the idea of a wrongful birth suit come first or second? Talk about the research required for writing this novel.**

The seed for *Handle With Care* began with an article I read about wrongful birth – a mother in New York who had recently won a multi-million dollar settlement suing her OB/GYN after her son was born with severe chromosomal abnormalities. It was clear from the article that she loved this child dearly – but that in order to give him a better lifestyle, she needed to tell the world she would have aborted the foetus, if given the chance. That moral conundrum got me thinking: what if her child had not been profoundly mentally disabled, but just physically disabled? What if her child could hear her in court, saying that she wished he'd never been born?

That led me to osteogenesis imperfecta. Also known as “brittle bone disorder,” it is a genetic bone disease characterized by fragile bones that break easily. It's caused by a mutation on a gene that affects the body's production of collagen in bones. It affects 25-50 000 Americans – the range is large, because mild cases of OI often go undiagnosed. There are eight types of OI, ranging from lethal at birth to mild with few symptoms. A person with severe OI might experience hundreds of fractures and have a reduced life span. Other symptoms include short stature (people with severe OI are approximately three feet tall), hearing loss, curvature of the spine, respiratory failure, and loose joints

and muscles. Physically, it's a very difficult condition – but mentally, people who have OI are one hundred percent normal. Many kids with OI are even brighter than their able-bodied friends, because they do so much reading when they can't run around after a break.

For research, I tried to walk a brief way in the shoes of a parent whose child has OI, by visiting multiple families with kids who were afflicted by the disorder. The first girl I met with OI had Type I – a milder form – but had suffered nearly fifty breaks in her eight years because her parents wanted her to live as normal a life as possible. Rather than having her walk on her knees or restrict her activities, they allowed her to do what she wanted... knowing that it would lead to broken bones. I remember asking Rachel what it felt like when that happened. "It feels like lightning under my skin," she said, and I realized then that the pain these kids feel is just what you or I would feel if we broke a bone, it just happens much more frequently for them.

From Rachel, I moved on to meetings with kids who had Type III OI – the most severe type you can get that isn't lethal at birth. I remember the flash in five-year-old Hope's eyes when the waitress at the restaurant mistook her for a toddler, due to her size; the pain in Jonathan's mom's voice when she talked about how she used to think about just leaving him and running away, because she was so afraid she'd be the one to cause another break. During a visit with Matthew, his mom asked me to take him out of his car seat – and I panicked. What if I was the one who snapped a bone this time? This, I realized, was what these parents went through on a daily basis.

The kids I met who have OI were all sweet, bright, engaging, adorable – and much more than the sum of their disabilities. This was best illustrated in the case of a young woman who became my technical advisor for *Handle With Care*. Kara Sheridan is a paralympian who swam in Athens for Team USA in 2004, who is currently a PhD student in clinical psychology, and is busy planning her wedding. She also has Type III OI. When I asked her what she wished people would know about OI, she said it's a challenging and painful condition, but it doesn't mandate a tragic life. The moments she's cherished the most have come about because of her condition, and are just as important a part of OI as the medical difficulties. She also pointed out that no child has OI alone – it affects families, friends, and loved ones by default.

Many people shy away from a child in a wheelchair – but when you spend time with kids who have OI, you are not struck by how different they are from able-bodied children... you're struck by how similar they are. They giggle, they flirt, they tease their brothers. They tell knock-knock jokes and whine about long car rides and hate broccoli. But they also know about things regular kids don't: splints and braces and Pamidronate infusions and spinal rodding. And when you watch them interacting with their parents, you realize that these mothers and fathers are just like the rest of us: willing to do whatever it takes to give their child the best life possible.

Even if that means lying to a judge and jury.

And suddenly, it's a lot harder to tell whether that's blatantly wrong... or impossibly right.

**The characters in your books are always layered and complex, as are the issues that plague them. How do you create a character like Charlotte that readers can love and hate at the same time?**

Well, for me, it's a lot harder to create a flat character who's either all villain or all hero. Most of us are a combination, aren't we? Charlotte's the best kind of character – one who is doing something that looks unpalatable, but for all the

right reasons. In this way she reminds me a bit of Nina Frost from Perfect Match. You want to hate her – but can you really say that if it were you, you wouldn't at least think about doing the same thing she does? Charlotte's tragic flaw, in my opinion, is that she is so single-minded in her pursuit of making Willow's life easier that she neglects the rest of her support system – her friends, and her family.

**How did you choose the recipes that appear throughout the book? Do you believe in the significance they hold for Charlotte? Are you a baker yourself?**

Before I got married, I was lucky enough to have a roommate who became one of my best friends. Now, Katie works at the Smithsonian organizing special events – but prior to that, she went to culinary school. When I knew that I wanted Charlotte to be a baker, I turned to her and asked for help. Charlotte, as a baker, would believe that the sum of the ingredients is so much more than its parts – this is true for her when it comes to Willow, too, who is so much more than a litany of moments where she broke a bone or had a surgery or was sidelined to recuperate. I do bake (too much, if you ask my husband, who is constantly cursing me for a pan of brownies cooling on the stove that he is compelled to eat) – and often I have been struck by the metaphorical language of baking. I wanted Charlotte's cookbook to be a collection of these terms, with accompanying recipes. So one day I emailed Katie a list – words like weeping, hardball, blind baking – and asked her to create recipes that might involve each term. I have to admit that rarely is my fact checking process so delicious... I got to bake, and road test, every recipe in the book.

**During the course of the trial, Amelia develops an eating disorder and starts cutting herself. Did you see this as the natural progression for her character? Were these types of behaviour in siblings of disabled children something you found to be common while conducting your research?**

While doing research with a child psychiatrist about adolescent bulimics I learned that cutting is very common for those girls. Apparently, bulimia involves a lot of self-hatred...and cutting figures into that. Siblings of disabled children aren't always like Amelia, thank goodness – I'd hope that their families do a better job of including them than the O'Keefes do. For Amelia, having a sibling with a disability is compounded by the fact that she feels she's failed her sister (in Disneyworld, for example) and that there are very high stakes in that household for being a child who isn't perfect (which would be Amelia's interpretation of her mother's lawsuit).

**Having created multiple narrators, is there a character that you connect with most, or that you feel represents your own voice?**

I had great sympathy for all of the characters in this book – each of them has a valid point to make, in my opinion. So I'd have to say that at different times, I sided with each one!

**Your narrators share their stories as though they are telling them to Willow. Why did you decide to construct the novel this way?**

I have always wanted to write a book in the second person narrative voice, but it's tricky and calls for the right kind of story. Because the whole book revolves around Willow, I wanted her to feel present and accounted for - hence the structure. Plus, given the behaviour of these characters, they deserved to explain themselves directly to Willow. But I also wanted the reader to feel viscerally what it's like to be at the centre of this kind of controversy: and that second

person narration also helped foster that sense that the characters are “talking to you”.

**As the author, do you ever feel as though you’re taking on the role of the jury? How did you decide what the ruling of the wrongful birth suit would be?**

I like to think of my reader in the role of the jury, actually. It’s my job as writer to present all sides of the story and then, based on the evidence, leave you to decide what was wrong and what was right. As for a ruling here, it wasn’t as important to me as the final twist of the book – but in order to have that final twist, I had to first have the jury rule a certain way...and that’s all I’m going to say before I give it away!

**Why did you decide not to share Willow’s perspective until the end?**

Because the reader serves as Willow’s “stand-in” for the book – since the characters are explaining themselves to “you” it makes you part of the action, and therefore part of the judgment of their behaviour. And yet after hearing everyone’s explanation about the wrongful birth issue, I felt the reader also deserved to hear directly from Willow to see how everything had affected her.

**You’ve said before that you know how a book will end before you write the first word. Was this also true for Handle with Care? Do you ever change your mind about an ending as you get deeper into the story?**

I do know the ending before I write a single word, and I did here too. I will tell you that I think Handle With Care is the saddest book I’ve written – and coming from me, that’s pretty dire! I never wavered on the ending, however, because there’s a bit of a morality lesson in there as well – it’s a real “be careful what you wish for” moment.

(Interview from [www.jodipicoult.com](http://www.jodipicoult.com))

## Discussion Questions

1. Charlotte and Sean are faced with a very difficult decision when presented with the option of suing for “wrongful birth.” How did you feel about the lawsuit?
2. Sean is angry and wants to get payback for the way he and his family were treated by the authorities in Florida. What is your initial reaction: to do so or forget about it?
3. How does Amelia deal with her position in the family: being a pre-teen, having low self-esteem, and being the healthy sibling of a very ill child?
4. All the characters in the book are telling their stories to Willow. Willow doesn’t have a voice until the end of the book. What effect does that have on the telling of the story?
5. How do you think the insertion of recipes provides further insight into the story and into Charlotte’s character in particular?
6. Discuss the different ideas about mothering that the author presents in this book. At what moments do certain characters fail or succeed at being a mother?

7. Discuss the roles that honesty and deception play in this novel. How do the characters lie to themselves and to each other?
8. What do you think Charlotte and Sean's different approaches to the case say about their love for their child?
9. How does Amelia show her compassion for Willow?
10. Why do you think Marin thanks her birth mother for revealing the truth about her conception? Discuss Marin's reaction to what she learns.
11. How do you feel about the ending? Why do you think the author chose to write it this way?

## Recommended Reading

My Sister's Keeper Jodi Picoult

Change of Heart Jodi Picoult

The Rest of Her Life Laura Moriarty

Red Dress Walking S.A. Jones

Things Without A Name Joanne Fedler