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EVERYTHING I'VE NEVER SAID

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Teachers' Notes

Written by a practising teacher librarian
in context with the Australian curriculum
(English)

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SYNOPSIS

Ava thinks like any other eleven-year-old girl. The problem is, she can't share her thoughts with anyone, not even her family, because she is locked inside her own body. Rett syndrome makes it impossible for Ava to communicate – she can't talk, nod her head or point her fingers. Her greatest wish is to find her voice, especially to tell her family how much she loves them.

Everything I've Never Said is a tender story of hope, persistence and friendship. It is also an important story that shares the obstacles faced by people with disabilities, as well as the families and friends who love and support them.

THEMES

- Relationships
- Hope
- Disabilities/Rett syndrome
- Persistence
- Communication
- Love

WRITING STYLE

Everything I've Never Said is told in first person, present tense through the narration of Ava, an eleven-year-old girl who understands everything but who cannot share that understanding with others. Through her perspective, readers feel her sense of frustration and helplessness, particularly when various efforts to seek help so often hit dead ends. The text offers personal and detailed insight into the challenges, doubts and emotions experienced by Ava and her family, allowing the audience to feel a true sense of empathy and connection with Ava's situation. The language is tangible, realistic and engaging. The inclusion of Ava's thoughts and coping mechanisms make this a unique and very powerful text.

STUDY NOTES

- The prelude of *Everything I've Never Said* immediately positions the reader within Ava's confined world. Discuss the style and language features of this introduction. Why has the author chosen to start the novel in this way?
- Discuss the opening scene at Nic's high school performance. How does this scene capture the limitations placed on Ava and her family because of Rett syndrome?

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- Why does Ava describe herself as 'Nic's biggest secret'? Why does she feel this way? How must this feel for Ava?
- Discuss how Ava feels when her family '[talks] like [she's] not in the room' (p. 4). Why do they do this? Why do you think the author has drawn attention to this?
- Discuss the ways in which Ava uses her eyes to communicate. Why do you think Nic and Kieran best recognise this, rather than her parents?
- When Nic has friends over, it seems that Ava is often removed from the house or confined to her room. How do you think Ava feels about this?
- Discuss the relationship between Ava and Nic. How does it develop throughout the course of the novel? In what ways is it similar to and different from the relationship you share with your siblings? How does this relationship differ from the bonds children have with their parents?
- What triggers stress in Ava? How does she respond to such distress? Why do you think she responds in this way? What are your stress triggers? How do you react? Why has the author gone to such lengths to share this component of Ava's condition?
- In what ways do Ava's parents misjudge her tastes and abilities? Do you ever feel that your parents don't quite understand you fully? Discuss with a friend.
- What does Ava mean when she says, 'I've met a million Bellas before, and I know I've a better chance of making friends with the willie wagtails than with someone like her' (p. 27)? How did you react when Ava pulled Bella's hair, saying, 'I'd do it again in a flash'? How does this make you re-evaluate your own behaviour around people with disabilities? How can you avoid being a 'Bella'?
- How would you describe the relationship Ava has with her dad? How is this affected by his stroke? Give examples from the text to support your ideas.
- Why does the author decide for Ava's dad to have a stroke? How does this help readers to better understand Ava's experiences? How does this allow Ava to feel empathy for him?
- Create character portraits of Mum, Dad, Nic and Ava. What are their strengths and weaknesses? Give evidence from the text to illustrate your thinking.
- Discuss Samantha Wheeler's use of figurative language throughout the text and its contribution to the reading experience. Examples include:
 - o Not talking is like being trapped underwater (p. 6)
 - o Nic has stormed down the hallway and slammed her bedroom door, which sounds like a train hitting bricks (p. 7)
 - o Nic's curls jump out of her head like springs from a mattress (p. 8)
 - o The towel scrapes like sandpaper (p. 9)
 - o My heart clatters like goanna claws on concrete (p. 25)

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- o Mum's breathing hard, like she's trying to control a volcano inside her (p. 32)
- o Her voice sounds small, like a mouse is caught in her throat (p. 53)
- o Mum walks around like a piano's landed on her shoulders (p. 59); My shoulders feel suddenly heavy. Like I've got my own piano bearing down on me (p. 65)
- o Mum dashes from room to room, like a ball trapped in a pinball machine (p. 59)
- o Mum strokes my hair like I'm a cat, and I pull my head away (p. 75)
- o The prac student is watching us like we're in a snake enclosure at the zoo (p. 99)
- o Everything that touches my skin irritates, like it's made of scratchy steel wire (p. 160)
- o Their long hair is dead straight, like uncooked spaghetti (p.164)
- o I'm like a terrier with a bone (p. 183)
- o I feel like a buffalo is sitting on my chest (p. 189)
- o The 'yes' and 'no' squares are like Christmas presents waiting to be unwrapped (p. 190)
- With reference to the front cover, discuss the description on p. 37 of Ava's swimming lesson. Why does she feel 'almost like a mermaid' when in the water? How is this exemplified later in the text when Kieran takes her swimming? In the role of Ava, write a reflection that shares your love for the water.
- Why does Ava relate so well to the book her dad always reads her, *Little Ginger*? Why, although it is too juvenile for her, does she still like it when he reads it?
- Why are Ava and her mother anxious about the idea of the respite house? How, when they finally do visit Rosie's Cottage, are they surprised to find it nothing like they imagined?
- Why doesn't Nic want Ava to go to Rosie's Cottage? Was this a surprise to you? Why?
- Why is it that Nic understands Ava's likes and dislikes more than her parents do? Why has the author decided this to be the case?
- How did you feel when Ava made friends with Aimee? How do scenes such as them having manicures and bowling help exemplify the importance of friendship?
- Why does Nic often feel as though she doesn't exist? Is she justified in feeling this way? Discuss.
- Ava paints when at school. Create a series of paintings that reflect Ava's feelings at various flashpoints during the novel.

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- Kieran seems to be the first carer to ever worry whether Ava likes him. Why do you think the author dresses him in a Superman t-shirt? What is her message about people like Kieran?
- How does Ava manage her behaviour differently once Kieran comes into her life? What strategies help her to do this? How does this show Ava's strength of character?
- Why does Ava enjoy attending the disco so much? Why hadn't she been to something like this before? What does this tell us about the virtues of safe risk-taking?
- Why is communication such an important tool? How does Ava feel once she is finally able to share her thoughts with her family and friends?
- Discuss the significance of the title of the novel. In small groups, discuss what Ava would say to the important people in her life such as her parents, Nic, Kieran and Aimee. In addition, what would she say to characters such as Wendy, Mel, Bella, Jin-Soo and Hayley?
- How do Ava, Kieran and Nic exemplify the importance of persistence and perseverance?
- What does Ava mean when she says, 'You just have to learn how to listen' (p. 99)? Do you ever feel as though people don't listen properly to you? How would you rate yourself as an effective listener? What tips would you give others about being good listeners?
- In the role of Nic, write a series of diary entries that share your experiences throughout the novel. Show her growth throughout these entries.
- Why doesn't Ava need 'words, or eye-gaze, or anything' to wish Nic a happy birthday and to say 'I love you' (p. 211)?
- What role does Kieran play in *Everything I've Never Said*? Why is his character crucial to this story?
- Invite occupational and speech therapists to speak with students about their jobs and the important ways in which they help people like Ava.
- At the end of the novel, Mel does Ava's hair. How is something seemingly so simple such a poignant inclusion to the novel?
- Create a visual representation that reflects the importance of Ava's eyes in *Everything I've Never Said*.
- What message is *Everything I've Never Said* sharing about the obstacles faced by families supporting loved ones with disabilities? What could be done to make this easier?
- In the role of Ava, create and perform a monologue to share the things that you want to say to your family – everything you've never said.
- Visit the following websites to find out more about Rett syndrome:
 - o www.rettaustralia.com
 - o www.rettsyndrome.org

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AUTHOR MOTIVATION

When my youngest daughter was diagnosed with a rare disability called Rett syndrome in 2011, we were prepared to tackle it head on. We went to all the therapists, did all the exercises. But the everyday challenges of living with a frustrated young person unable to communicate soon became too real. Screaming, aggressive behaviour and lashing out were the norm. In the confusion and chaos, it was easy to believe that our girl had no thoughts of her own, and no ability to make choices. So many people would look at her and say we should give up, it wasn't worth it, there was nothing inside.

But one look into our daughter's eyes told us there *was* something inside. Something special and marvellous and *her*. Imagine if you couldn't say you were hungry, or cold, or didn't like the song on the radio? You'd be frustrated too.

I was motivated to write this story to show that no matter how people look on the outside, it's what's inside that counts. Inside we're the same. Afraid of the dark. In love with a pop star. Amused by videos of cats. And we're a little bit different too. We have different strengths, different abilities and different values. We only need to reach out to find a treasure trove of difference to celebrate, and I hope this story will help us all to be brave enough to reach out.

As a postscript: since I began this story six years ago, technology has advanced enough to make equipment like the eye-gaze device described in Ava's journey more and more accessible to people with communication challenges. With its help, we hope in the very near future to give our daughter a chance to say everything she's never said.

ABOUT THE AUTHOR

Samantha Wheeler studied agriculture, worked with dairy farmers, and taught science before writing her first children's book in 2011. Five novels later, her stories have been shortlisted for the Queensland Literary Awards, Speech Pathology Australia Book of the Year Awards, the Readings Children's Book Prize, the Wilderness Society Environment Award for Children's Literature, and commended in the Royal Zoological Society of NSW Whitley Awards. When not writing, she spends time with her husband, pets and two beautiful daughters,



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the youngest of whom has Rett syndrome. Samantha hopes her stories will encourage everyone to speak up for what they believe in.
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