

Teacher
Notes

**CHAZ
HAYDEN**

TEACHERS NOTES BY MEGAN BEIT
WALKER & BOOKS

THE FIRST THING ABOUT YOU is a young adult novel which explicitly looks at life with a disability through the eyes of Harris Jacobus, a 15 year old boy with Spinal Muscular Atrophy. Spinal Muscular Atrophy (commonly referred to as SMA) is a rare genetic condition where the body doesn't produce the protein needed to send messages from the brain to the muscles. This results in decreased muscle function and atrophy which affects every muscle in the body including those required for breathing and feeding. Most people with SMA require ventilation whilst sleeping, help in transitioning to different pieces of equipment, feeding support, and extra respiratory care to keep the lungs clear.

Harris and his family have just moved across the country in order for his father to pursue a new job. This means a new school for Harris and his brother and the challenge of interviewing a new nurse to tail him and help with everyday activities. In the past, Harris' mother has performed this role for him and we are told of the various problems that they have encountered, mostly due to prejudiced views of disability. Through a chance meeting the family hires Miranda, a nursing student who previously attended Harris' high school. Miranda helps Harris navigate the school and his relationships with his fellow classmates.

The book looks at how other people view and treat those with a disability, often informed by assumptions based on stereotypes.



CHAZ HAYDEN

Chaz Hayden is a debut author who, like his main character, was diagnosed with spinal muscular atrophy as an infant and spent his childhood in and out of hospitals. *The First Thing About You*, he says, is "not just about disability but about friendship and love and all the things that a young person hopes to experience". Follow him on Instagram and Twitter: @TheChazHayden.

MEGAN BEIT

Megan Beit lives on a property in rural NSW and is a teacher with over ten years' experience of teaching both primary and secondary students in Canberra. She is a mother to three children, the youngest of which shares a diagnosis of Spinal Muscular Atrophy with the author of the novel and the main character in the text. Disability advocacy is a strong focus in her life and in her teaching practice. Megan is passionate about creating equal opportunities for those with a disability and developing further understanding of what is needed to improve access and inclusion in the wider community.

THESE TEACHER NOTES ARE FOR:

Secondary students, years 9-12

KEY LEARNING AREAS:

English

THEMES:

Acceptance

Diversity

Advocacy and ableism

Inclusion

CURRICULUM OUTCOMES:

YEAR 9

- Investigate how evaluation can be expressed directly and indirectly using devices, for example allusion, evocative vocabulary and metaphor (ACELA1552)
- Interpret and compare how representations of people and culture in literary texts are drawn from different historical, social and cultural contexts (ACELT1633)
- Explore and reflect on personal understanding of the world and significant human experience gained from interpreting various representations of life matters in texts (ACELT1635)

YEAR 10

- Understand how language use can have inclusive and exclusive social effects, and can empower or disempower people (ACELA1564)
- Compare and evaluate a range of representations of individuals and groups in different historical, social and cultural contexts (ACELT1639)
- Evaluate the social, moral and ethical positions represented in texts (ACELT1812)
- Analyse and evaluate how people, cultures, places, events, objects and concepts are represented in texts, including media texts, through language, structural and/or visual choices (ACELY1749)
- Identify and analyse implicit or explicit values, beliefs and assumptions in texts and how these are influenced by purposes and likely audiences (ACELY1752)

SENIOR SECONDARY CURRICULUM

- How responses of readers and viewers can range from empathetic to critical. (ACELR004)
- How readers are influenced to respond to their own and others' cultural experiences (ACELR037)
- The power of language to represent ideas, events and people in particular ways (ACELR038)
- How cultural perceptions are challenged or supported (ACELR039)
- How literature reflects cultural change and difference (ACELR053)
- How ideas, values and assumptions are conveyed (ACELR058)



DISCUSSION POINTS AND SUGGESTED ACTIVITIES

BEFORE READING:

DISCUSSION POINTS:

- Think about the words ‘disability’, ‘advocacy’ and ‘inclusion’. What do you think these words mean and what do they look like in context and in action?
- Stereotypes: List as many high school stereotypes as you can, as per the table below – what visual clues do you have that lead you to make certain assumptions?

STEREOTYPE	PHYSICAL ATTRIBUTES	PERSONALITY TRAITS	SOCIAL STATUS	HOME-LIFE
e.g. Jock	Wears sports gear	Good at sports Not good at English and Maths	Is popular, “gets the girl”	Parents don’t pay too much attention to what he gets up to. Has a house in the suburbs, maybe owns a largish dog, like a Labrador.

WHILE READING

FAR (PAGES 1-86):

This section of the novel introduces us to Harris and his family. They have just moved from California to New Jersey. We see Harris attending his first day of school with his mother as his nurse and the issues they face with accessibility of the curriculum and the physical space. He does, however, connect with Zander, a younger student who seems to know the lay of the land at school. He also meets and is intrigued by Nory, a girl whose mother has passed away. After a meeting with a nurse from the agency, Harris has a less than desirable day at school with her and begins to despair. When visiting his brother Ollie’s school, they are connected with Miranda, a nursing student who is keen to learn what she can and relates well to Harris. She seems very capable, requires little training from Harris’ mother, and he appreciates the way she speaks plainly with him.

DISCUSSION POINTS:

- This section of the novel introduces the theme of ableism and touches on how we often change our behaviour when speaking and interacting with disabled people. Assumptions are made about disabled people’s intellect and they are often ascribed the role of educating the non-disabled community.
 - *A girl with brown hair held back by a green headband swooped in next to me and reached for her locker, bumping into the back of my wheelchair which was barely in her way...I would rather someone tell me to get out of their fucking space then pretend I’m not a burden. This girl did the next best thing and just went about her business.* P. 14 *Nory: I’m taking honors*” Harris: “Same. I may be in a wheelchair, but I’m actually pretty smart.” Nory quickly looked down at her desk and then back at me, trying to find her words. “Oh, I didn’t mean it like that”. P. 25 *Mr Bavroe asked me to tell the class about my disability. I wish I could’ve told him that inclusivity was not making someone feel uncomfortable for the enrichment of others.* P.11

Sometimes there is a line between making suitable adjustments and treating someone ‘like everyone else’. How can we determine what is appropriate (respectful)?

Interestingly, Harris assumes that Nory doesn’t understand football when he texts her – what underlying prejudices is he evincing and what connections can we draw with ableism to other forms of discrimination such as sexism?

- The book often uses metaphors and symbolism to help the reader make connections with the characters’ feelings. Can you find other examples in this section?
 - *“After a few bites of New Jersey pizza, I didn’t see what all the fuss was about. If that claim to fame was crap, what were the odds Hersey’s nurses would be any better?”* P.5
- Harris uses colours to help identify strategies to talk to people.
 - *“I thought about colors a lot, actually. Especially when I was about to meet anyone new. It was always the first question I asked them. A person’s favourite color says a lot about who they are,”* P.8

Do you agree with Harris or is this just another form of stereotyping and potential prejudice?
- Language is an important feature in discussing disability. The book criticizes words like ‘differently abled’ when describing a disabled person. There have been different terms used to describe disability, with changing perspectives regarding what is respectful. Why do you think this is and what can we do to ensure we are being both respectful and inclusive without causing division?
- Consider the quote:
 - *“The problem was that everyone had something wrong with them. My something wrong was obvious and difficult to overlook, while most people’s were hidden.”* P.41

What do you make of Harris’ claim – is it accurate or simplifying a more complex issue?

NEAR (PAGES 87-206):

Harris begins to find his place at school. He goes to the mall with Zander and makes new friends on the football team. As Harris is a keen watcher of sports and has grown up watching his brother play, he excels at understanding the mechanics of the game. He is offered a viewing position at the front of the school game and offers knowledgeable advice to the players which they are impressed by. He is determined to fit into this group and starts sitting with them at lunchtimes. With help from Miranda, he builds on his relationship with Nory and ends up going on a date with her. We learn that when Miranda was a student her best friend died under strange conditions. Her relationship with her boyfriend, Brad, sounds borderline controlling/abusive with Miranda having no other friends and needing to 'check in' with Brad on a regular basis.

DISCUSSION POINTS:

- Mr Bavroe is alluding to something Miranda has done in her past, but the statement has wider significance. How is this applicable to the themes of ableism, advocacy and inclusion?
 - Mr Bavroe: *"History may not be the most exciting subject, but it's important... Learning about our past mistakes means we can make better decisions today,"* P.97
- When Harris decides to sit with the football team (despite Zander being aghast that he doesn't have an invitation) he begins challenging the stereotypes presented by cultural norms, specifically that of *Mean Girls* which is referenced several times over the novel. While sitting at their table he surprises them all with his knowledge of football and suggests impressive strategies. Why does the book allude to *Mean Girls* and what parallels can you draw between the two texts?
- When Harris is finally assigned a laptop as part of the inclusion plan for him, it is archaic and heavy. He knows that his Mum will be furious but when he raises his concerns with the receptionist she states how difficult it is going to be to talk to the principal about a better option.

This is an important piece of evidence for how advocacy and inclusion can be tokenistic and how the individual has not been listened to. What steps should the school have taken to ensure they are not simply ticking boxes when suitably adapting equipment for Harris?

- We begin to see hints that Harris is changing – particularly after Miranda helps him lie about how he got his disability; from a dirt bike accident rather than being born with a genetic disease.
 - *"I thought I was cool and interesting- at least, that's what Miranda had been telling me. But maybe it wasn't actually true,"* (p.184)
- Do you think these are positive changes for Harris? Why or why not?

CLOSE (207-291):

Harris begins pushing the boundaries of his newfound confidence while also losing faith in his relationships with Zander and Nory. He questions whether Nory is indeed interested in him romantically and feels held back by how 'safe' Zander seems. After convincing his parents to let him go to a party he has too much to drink and Zander calls Miranda to help clean him up. The friendship/professional relationship between Miranda and Harris begins to blur. She sneaks into his room one night and confides in Harris the reason for her best friend's death. They both struggled with substance abuse and Miranda saw her friend unconscious and just left her. After attending a concert with Nory and Miranda, Harris develops a respiratory condition. Miranda offers Harris a vape and after struggling for breath she calls an ambulance in a panicked and guilty state.

DISCUSSION POINTS:

- Harris begins to break down stereotypes with his new friends on the football team. They feel comfortable asking him questions about his disability, although sometimes the questions are a bit awkward. What role does humour play in breaking down barriers?

- Different people in our lives take on various responsibilities and relationships. For example, a mother's role is very different to a friend at school. What type of responsibility is Miranda given and does that affect her relationship with Harris? Do you see her relationship with Harris as a professional one or a personal one? Should there be implications for her as a trainee nurse? If Harris was your child how would you feel? Do you think Harris' needs and opinions should be prioritised, given he expresses a preference for a nurse who is more of a 'friend' than an 'employer'?

LOST (292-324):

Harris has a stint recovering in hospital and Miranda disappears, unable to be contacted. Harris tries to send her messages and says she was not at fault for his illness but to no avail. Harris' mother resumes the role of full time carer for him. This takes a toll on her relationship with her husband, with the two arguing about the laptop and that not all teachers were giving him accessible homework. The parents have a meeting with the principal and the teacher involved and a compromise is reached. Harris learns Zander has a brother with autism and realizes he never asked many questions about his home life. This leads him to think about other people in his life and he has an honest conversation with his brother.

DISCUSSION POINTS:

- This section of the novel draws connections between Harris' problems and the different characters in the book and their struggles (mainly Ollie and Zander). While the circumstances are different, the way in which we can include and support each other is remarkably similar. What lessons can we learn here and what strategies can be used to navigate sensitive topics with our community?
- Throughout the novel there are a lot of indirect clues that suggest Harris has low self-esteem and wants to be thought of as cool, confident and attractive to the opposite sex.

The characters of Miranda, Zander, Nory and even Lex (the football captain) play a role in Harris breaking into this unknown territory. At this stage of the novel, we see Harris begin to accept himself after spinning out of control. Learning his own boundaries and taking control of them is empowering to him. Do you think he would have reached this point without the input of those around him? Does it make the risks he took (and Miranda) worth it?

- Consider the below quote. What realisations is Harris making about his own behaviour?
 - *"That was my relationship with Miranda. She'd taken me places I'd never have been able to go on my own, but I'd fallen way too hard, way too many times. At some point, I needed to stop blaming the bike and start blaming myself for getting back on. At some point, I needed to remember where I'd started,"* P.323
- After returning back to the 'table for lost souls' Harris states that he feels it belonged to them. What is symbolic about the 'table for lost souls' and what is the significance to Harris?

APPROACH (325-342):

Harris apologises to Nory and the two have a new understanding of each other. They begin a romantic relationship.

DISCUSSION POINTS:

- Harris reflects that he was making progress with his own personal growth
 - *"For the first time in a long time, I wasn't thinking about Miranda. I was closing the distance between who I'd been and who I wanted to be. And even though it felt like I was leaving something behind, that was okay. That's how it had to be."* P.335
- Do you think he would be where he was now if it wasn't for his experiences with Miranda? Can you think of difficult times in your life that have also helped you grow into the person you are now?

- When talking to Nory, Harris states that before moving to New Jersey his wheelchair was what defined him. He was now starting to realise otherwise. What does this reveal about Harris' character journey?

ARRIVE (343-354):

Miranda shows up at Harris' house much to the surprise of the family. She asks to talk to Harris in private. She apologises for what happened and offers to come back as Harris' nurse. He declines as he knows what once was could never be again and he has learnt all he could from her.

DISCUSSION POINTS:

- This chapter is interesting because we see a complete role reversal between Miranda and Harris. In the beginning, Harris needs Miranda to help him with his basic needs and to fit in at high school. At the conclusion of the book Harris realises he is figuring out who he is meant to be but he doesn't like the 'lie' he becomes when he's around Miranda. She, however, needs him to fulfill some kind of purpose in her life by being someone to care for – to fill the void that her friend Kaylin left. Harris respectfully ends their friendship. During our lives, people enter and leave for different reasons. What lessons do you think Harris learnt from Miranda? Do you think he did the right thing by leaving her when she needed him?
- Harris and Nory convince Zander to move tables, leaving the 'lost souls' table in order to make different memories. What do you think their new table arrangements say about their perspective on school and friendships now?

AFTER READING

DISCUSSION POINTS:

- Think about the words disability, advocacy, and inclusion. What do you think these words mean and what do they look like in context and in action? Revisit the work you completed before reading the book. Has your understanding changed?
- Stereotypes are featured predominantly throughout the novel. Do you think they have a place where they can be used effectively? How are they problematic or used in a derogatory way?
- What action will you take after reading the novel to shift opinions towards the disabled? What are some small things you can do now to support equal opportunities for all?



