

ONE DAY SOON

CRISTY BURNE

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YEAR LEVEL: Y4-8

ABOUT THE BOOK

What if one day soon never comes?

When Alex's parents receive a message that brings shocking news, his whole world is turned upside-down: Alex's uncle has been diagnosed with a genetic form of Motor Neurone Disease. The ripple effect is immediate – it means his dad has a fifty percent chance of carrying the fatal gene. And if Dad has the gene, Alex has a fifty percent chance of carrying it, too. But even as Alex grapples with mortality, he discovers the unexpected joy, deep love and impromptu dance parties that come from living closer to death.

Told in verse, *One Day Soon* is a story of how, ultimately, a few special moments can matter most.

ABOUT THE AUTHOR

Cristy Burne is an award-winning, internationally published author working on the intersection of story, science, technology and creativity. Cristy is a trained scientist and has worked for twenty years as a science communicator and as editor of CSIRO's *Sciencetriffic* magazine.

Cristy's books have been shortlisted for the WA Premier's Book Awards and the Wilderness Society's Environment Award, won the WA Young Readers Book Award, and been recognised as Notable by the Children's Book Council of the Australia. Cristy is the author of junior fiction favourites *To the Lighthouse*, *Beneath the Trees*, *Off the Track*, and *Into the Blue*, and co-author of *A New World Rises: Tales of a LEGO® Future*. She is an exciting and inspiring presenter specialised in combining science with creativity. Expect the unexpected!

THEMES

- Family
- Illness
- Motor Neurone Disease (MND)
- Genetic testing
- Death
- Hope
- Verse novel

AUSTRALIAN CURRICULUM OUTCOMES

- Y4-8 English
- Y4-8 The Arts
- Y4-8 Health and Physical Education
- Y4-8 Science

USEFUL WEBSITES

- Author's website: <https://cristyburne.com/>
- MND Australia: <https://www.mndaustralia.org.au/>
- Luki and the Lights: <https://globalneuroycare.org/full-movie/>



CLASSROOM IDEAS

Discussion questions

1. Before reading, activate prior knowledge by discussing what students already know about Motor Neurone Disease (MND). The MND Australia website has resources to support discussion of MND with children.
2. What is a prologue? What is its function in a novel?
3. *One Day Soon* is a verse novel.
 - a. What is a verse novel?
 - b. Why would an author choose to write in verse?
 - c. Do you like this style of writing?
 - d. In a verse novel, standard punctuation and formatting is not always used. What effect does this have on the reader?
4. Alex picks up clues that something is wrong with his uncle before his parents tell him. Do you think kids are more observant than adults give them credit for?
5. What do you think Alex means when he says, **'the kind of talking adults do so they don't have to listen, and they don't want to hear'** (p. 17)?
6. Nonnie makes pikelets, Rohan's favourite dish, when the family is worried about him, even though he is not there to eat them (p. 17). Are there any foods you like to make or eat that make you feel connected to loved ones?
7. On page 25, Alex's parents reveal Uncle Rohan's diagnosis. Use five adjectives to describe how Alex and Archie feel about this news.
8. What do the following words and phrases from the story mean? Search a dictionary or online to check.
 - a. symptoms (p. 27)
 - b. life expectancy (p. 27)
 - c. clinical manifestations (p. 27)
 - d. prognosis (p. 28)
 - e. progressive (p. 28)
 - f. untreatable (p. 28)
 - g. fatal (p. 28)
 - h. inherited (p. 56)
 - i. genetic mutation (p. 58)
 - j. familial (p. 62)
 - k. vital (p. 65)
 - l. mutation (p. 92)
 - m. coercion (p. 143)
 - n. dignity (p.143)
9. When Alex looks up MND online, he feels like he learns too much (p. 29). What does he mean by this? What would have been a less confronting way for Alex to discover more about MND?
10. When Dad gets back from visiting Uncle Rohan, he discusses some of the adjustments they have to make to support Rohan as his muscles weaken (p. 43). What other adjustments do you think they might have to make?
11. Consider the councillor's advice on page 56: **'Don't keep secrets. Children are smart. If you don't tell them what's going on they'll assume the worst, so it's better that you tell them the truth.'** Do you agree or disagree with this advice?
12. At the funeral, Alex experiences a mix of emotions. List the different feelings Alex has and explain why each one might be happening.
13. Throughout the story, the metaphor of elephants is used. What do the elephants represent? Why might an author choose to include such a metaphor in their writing?
14. The novel's ending is left open, with the reader not finding out if Alex's dad has the gene mutation for MND, and therefore not knowing if potentially he also has the gene. How did it make you feel to end the story without knowing? Why do you think the author chose to keep this open?
15. *One Day Soon* is an example of a coming-of-age novel. What does this mean? Can you think of any other coming-of-age novels or movies?
16. *One Day Soon* is based on the experiences of the author's family. What value does lived experience bring to a work of fiction?

17. This story is told in the first-person from Alex's point of view.
 - a. How does this affect what information you can access?
 - b. Does this point of view influence how you feel about Alex?
 - c. How would the story be different if told from another character's point of view, or from the third-person point of view?

Creative Writing

1. Consider how Alex introduces himself and his brother on page 9. He is able to convey a lot of information in few words. In a similar style, introduce yourself and any siblings in under 50 words.
2. Stephen Hawking is one of the most well-known people to have lived with MND (p. 31). Research his life and write a biography that includes key life details and important achievements.
3. On page 40, the author creates a metaphor about time: **'time flips and gasps, a fish out of water, now still.'** Write your own metaphor that describes time as if it is stretching or slowing down.
4. Choose a character, other than Alex, and create a series of diary entries exploring an event from the story from their point of view.
5. Write a review of *One Day Soon* including a brief synopsis, your opinion of the story, a star rating and a reader recommendation.

The Arts

1. Alex and his class initially groan at the idea of dancing at assembly (p. 20). How do you feel about performing at school? What type of performance is your most/least favourite?
2. Create an artwork to explore one of these lines from the story:
 - a. **'At school there's an elephant in every room and I'm carrying it alone'** (p. 67)
 - b. **'It sure feels good to take a breath in the sunshine'** (p. 71)
 - c. **'The air is heavy with silence'** (p. 87)
 - d. **'I don't want to be the kid who is 50 percent dying'** (p. 171)
3. Music becomes a source of comfort, distraction, unity and remembrance for Alex's family.
 - a. How does the family use music to help them cope with their grief?
 - b. In what ways can sharing music (singing, playing, listening) bring people closer during difficult times?
 - c. How can music help people celebrate the life of someone they miss?
 - d. How does the author use music as a symbol of connection or healing?
 - e. What message do you think the story is sharing about the power of music?

Health and Physical Education

1. What strategies does Alex use to help him cope during difficult times? Which strategies seem most effective?
2. What small successes or moments of strength or hope can you find in Alex's story?
3. How do Alex's experiences in the book help him develop resilience and shape who he is becoming?
4. Alex chooses to share his worries with some people, like his teacher, but not with others, like his friend Bima. In what ways can talking to a trusted friend or adult support someone during difficult times? How might choosing *not* to tell certain people also protect a person's wellbeing?
5. How can people express big emotions in safe and healthy ways?
6. How might learning about a genetic risk influence a young person's identity, choices or future goals? Why do you think the family were required to meet with a genetic councillor before undergoing any testing?
7. Despite losing some independence as his physical condition deteriorates, Uncle Rohan finds ways to maintain his identity. What actions, choices or relationships help him maintain his sense of identity?

Science

1. On page 71, Ms Robbins says, **'everything is science.'** What do you think she means by this? Do you agree?
2. Explain what Alex means when he says, **'so even if Dad has the gene maybe he'll lean to the other side of the curve'** (p. 166). What 'curve' is he referring to? What is Alex's hope?

3. MND can sometimes be linked to genes that run in families, like Alex's family. A genetic test can show whether a person carries a gene that increases their risk. Some people want to know this information, while others prefer not to find out if they carry the gene.
 - a. Why might someone choose to be tested for a gene linked to MND? What are some possible benefits of knowing your genetic risk, even if there is no cure?
 - b. Why might someone decide *not* to be tested? What worries or problems could come from having this information?
 - c. What guidelines or rules help decide who can have a genetic test, what they can be tested for, and how the process must be carried out (for example, counselling, consent and privacy)?
4. Draw a picture to communicate the information in the chapter titled, '**how genetic mutations can cause illness**' (p. 93).
5. Design a modification or device to support someone with MND who has reduced ability in a specific function (for example, gripping, walking, speaking or swallowing). Explain what problem it solves and how it would help in daily life?