

Discussion Questions

1. In Jacob's speech at the Prader-Willi Syndrome fundraising gala he says, "I have Prader-Willi Syndrome, but I AM Jacob Zavitz!" It can be a challenge for people living with disabilities to be recognized as themselves, and not through the lens of their disability. How has reading *I Am Full* shaped how you think about the challenges of living with a disability? Is the author successful in presenting the complexity of living with a disability without defining Jacob by his condition?
2. In the prologue Dan Yashinsky says that his son Jacob is the closest thing to a superhero he's ever known. How do you feel about describing people living with disabilities as courageous?
3. Death and diseases such as Alzheimer's and dementia can give us the responsibility of becoming the "storykeepers" for our loved ones. Are you the storykeeper for someone? Has *I Am Full* encouraged you to become a storykeeper?
4. Dan Yashinsky tries to recreate the narrative voice of his son Jacob. What are the artistic and ethical challenges of this approach? Why do you think he chose this approach? How do the poems, letters, and other texts from Jacob's life help bring him to life for the reader? What moments in Jacob's life stood out to you the most?
5. What are your thoughts on Dan Yashinsky's approach to handling grief through storytelling? Do you think this approach can be therapeutic for others dealing with loss?
6. *I Am Full* doesn't follow a strict chronological order. Is it a challenge to read a book without a conventional plot or suspenseful story arc?
7. The author has said he thinks of the book as the saddest and funniest of books. Do you think the mix of humour and tragedy does justice to the memory of Jacob? Were you surprised to be laughing (if you did) in a book about remembering a loved one?
8. Jacob's brother said, "My brother's death is the least interesting thing about him." How do you understand this statement in the context of your own experience of grief?

FREE BOOK CLUB DISCUSSION GUIDE



I AM FULL
STORIES FOR JACOB

Dan Yashinsky

Print ISBN: 9781773241272 • \$19.95

EPUB ISBN: 9781773241289 • \$9.99

Jacob Evan Yashinsky-Zavitz lived his life with enormous courage and humour, dealing every day with the intense hunger known as hyperphagia that accompanies Prader-Willi Syndrome (PWS), a genetic condition that affects one in 15,000 people. In creating a rich and meaningful life for himself, he also became a wise advocate for people living with PWS and people with other disabilities.

Jacob died tragically as a result of injuries from a car accident at the age of 26. In his grief-journey, his father began to gather Jacob's poems, speeches, letters, notes, and his own record of Jacob's sayings and doings—a whole book's worth of "Jacobisms." A West African proverb reminds us that "A person is not dead unless they have been forgotten." Becoming Jacob's legacy-bearer, his storykeeper, was Dan Yashinsky's way of finding meaning in the face of heartbreaking loss.

I am Full is Jacob's story

Questions for Dan Yashinsky

I Am Full is a deeply personal work. How did you balance the personal with the universal themes of love, loss, and resilience?

I have spent time with traditional storytellers from many different cultures, and one thing I observed is that they always want to feel their stories will be useful to others. Even when their stories are tragic and almost impossible to speak aloud, the idea is that others may learn from your experiences. This impulse made me want to write about Jacob, and to share his stories with others. For a long time I didn't have any idea how to do this, or even if I had a right to give voice to his life-experiences, especially given the heartbreaking circumstances of his death. But slowly, episode by episode, I became Jacob's chronicler. For me and others who loved him, Jacob was a true hero, one of those rare human beings who embody courage and humour and compassion in the face of great challenges. My belief that his stories could give others some comfort, wisdom, and laughter, too, slowly overrode my initial doubts about whether I could or should write about his life.

What was the process like for you to gather and create the texts for this book, especially in the midst of grief?

I've always kept a journal, and many pages of it are devoted to the sayings and doings of our two sons Natty and Jacob. I'm also a packrat, and have kept everything they ever wrote, drew, photographed, etc. As the idea of *I Am Full* coalesced, and as I began to try and write in Jacob's imaginary voice, I ransacked my journals and my family archives for material. The book came together over a period of a few years, moment by moment, episode by episode. I can't say that being a storykeeper is any kind of antidote to the acute pain of grief, but at least it draws a frame of meaning around the unbearable loss. Being responsible for keeping a loved one's stories alive gives purpose to surviving their death. About the writing itself, because I chose not to write it as a chronological record or biography, I felt free to string the pieces together by theme, echo, and feeling. I also crowd-sourced friends' responses to the book as it evolved, and often learned new things about how to order the episodes from people's comments.

How did your storytelling background influence how you chose to tell Jacob's story in I Am Full?

Death, loss, grief... these happen on the other side of language. They overwhelm our voices and vocabularies. Losing Jacob as the result of a car accident that I caused added to the unspeakable weight of this tragedy. But a storyteller is trained to believe that words matter, language matters; above all, that a story told and heard at the right moment can make a difference in the world. In the first months and years after his death, it began to dawn on me that the story of his life is so extraordinary that the need to share it is far more important than my own private sorrows and hesitation. His older brother Natty had heard some of the writing at a public reading I did, and he encouraged me to keep at it. I also asked permission from other family members. It was Natty's encouragement that made it possible to honour his little brother with this offering in the form of a book.

In the book, you mention being guided by Jacob's imagined voice. How has that imagined presence helped you navigate your grief?

I should mention that Jacob was a very funny boy and a very funny man. Revisiting his life brought much laughter and even hope in the darkest of times. The book also includes a lot of his own writing: poems, letters, speeches, etc. Connecting to his voice – both in my imagined form and in his own writings – has been a comfort on this long grief road. I continue to dream of him almost every night, and I remember him every day, and – as everyone knows, who carries the voice and stories of a loved one – these daily and nightly rememberings are a small way to not fall over the edge of despair. Honoring our loved ones, giving voice to those who can no longer speak, is an important reason not to succumb to our own silence.

What do you hope readers take away from Jacob's story, especially those who may be unfamiliar with Prader-Willi Syndrome?

I hope that everyone who lives with a disability, including Prader-Willi Syndrome, is reminded of the ways that their lives are rich, meaningful, wise, and even funny. I also hope the book gives courage to everyone who cares for people who live with a disability. My own experience as a parent of a child with Prader-Willi Syndrome made me understand that Jacob was – and continues to be – a great teacher. He taught me about living with a difference, and about acceptance, and about how we need to care for each other. It's because of what I learned from Jacob that I won't perform in a space that isn't fully accessible. He himself was a passionate advocate on behalf of people living with PWS and other disabilities. It has been wonderful to hear from readers who say that Jacob's stories gave them new hope that their own children will be able to lead rich and meaningful lives.

Has your storytelling practice changed since Jacob's death?

Within two months of his death, I went back to my job as the storyteller-in-residence at Baycrest Health Sciences. I went back to telling stories with people in palliative care, psychiatry, and dementia programs. Bringing stories into that extreme environment was probably the best way to reenter the working world while still in a state of acute grief. My listeners were themselves going through trauma and loss, and gave me the welcome and love I needed. In the following years, I've sought out stories of beginnings and becomings, creation myths that talk about how we become human. For the last couple of years I've told these stories with my partner, dancer/choreographer Annemarie Cabri. Telling stories since his death, I'm always aware that there may be someone in the audience who is also suffering terrible loss. Perhaps the stories will be a lifeline, or at least a reminder that they are not completely alone in their grieving.