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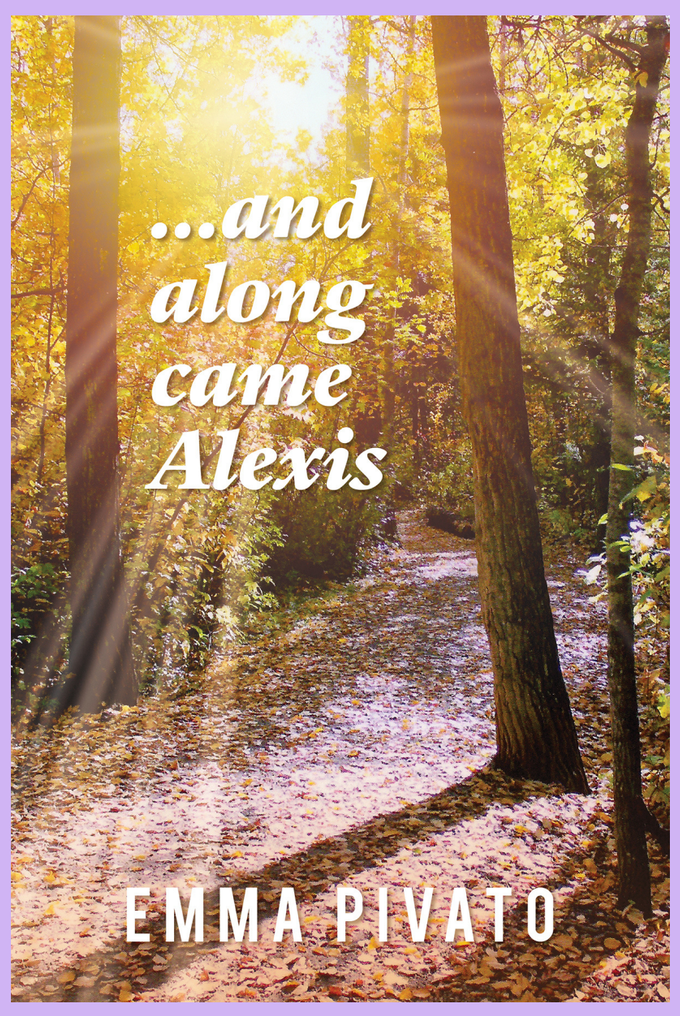

Non-fiction | Disability advocacy

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...And Along Came Alexis

A MEMOIR BY

Emma Pivato

A rich perspective on disability advocacy and a mother's deep love for her disabled daughter.

...And Along Came Alexis is a book about choices and consequences. The author's youngest daughter, Alexis, was born in 1978 with multiple disabilities, including blindness, an intractable seizure disorder and spastic quadriplegia. The choice to keep her at home despite medical advice resulted in a limiting of career opportunities for her parents and educational and other enrichment opportunities for her siblings. However, it also introduced the family to a whole community of earnest and interesting people dealing with similar challenges that they would never have known otherwise, and it provided rich perspectives on a different way of living. As for Alexis, she thrived far better than had been predicted and developed into a sweet, trusting person with a clear sense of self and an appreciation for the people in her life. The book describes the story of her life to date from her mother's viewpoint: its victories and setbacks, its grim moments and its funny moments. Overall, it is a positive story, demonstrating what is possible, even under very challenging circumstances.

Keywords:
disability; family life; non-verbal; blindness; quadriplegic; seizure disorder; caretaker; advocacy; parent advocacy; parenthood; motherhood; disability rights

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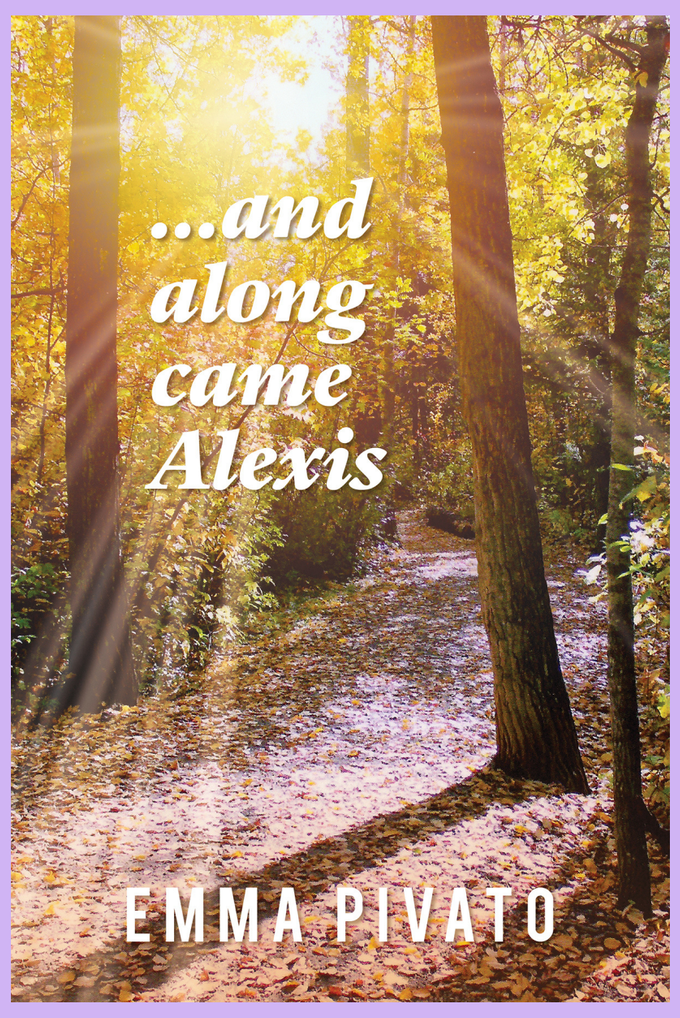

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Author Bio

Emma Pivato spent her formal career working as a psychologist in various settings and teaching in a graduate program at Athabasca University. She also did some writing along the way, first an edited work, *Different Hopes, Different Dreams* (1984, 1991), Alberta stories about families having children with developmental disabilities. Later she published some academic and literary articles dealing with topics ranging from philosophical to practical — the development of a specialized wheelchair, for example. In 2013 she published her first Claire Burke mystery novel, featuring individuals with disabilities and other characters with various personality quirks. The 8th volume in this series will be out soon and the 9th is underway. But in the last few years her focus has been on putting together the present memoir, *...And Along Came Alexis*, which describes the numerous joys and challenges that Alexis and her family have experienced together. Her website is emmapivato.com.

Excerpt

I just did not believe that a mother should be asked to make daily evaluations of her child. .... Time to explore other options, I thought. But first I did a little self-exploration. By that point I had made the acquaintance of several other mothers faced with the challenge of raising a child with severe and multiple disabilities. I could not help comparing myself to them. Some were so hurt and angry that they blamed the system and everyone who crossed their path for what had happened to their child. But others seemed to be quietly accepting this new path in life and just focusing in on how they could follow it most efficiently for the greater good of their disabled child and the rest of their family. Measured against them, I found myself neither as angry as the former nor as noble as the latter. I wanted out from under but not at Alexis' expense. Was there any way I could make that possible? Could I have my cake and eat it, too?