

Interview with Heather Cariou, author of *Sixtyfive Roses: A Sister's Memoir*

Today, Tyler R. Tichelaar is pleased to interview Heather Summerhayes Cariou, who is here to talk about her new book, "Sixtyfive Roses: A Sister's Memoir."

Heather Cariou was born, raised and educated in Ontario, Canada. As a child, she dreamed of becoming both a writer and a ballerina. When she learned the fates of the Bronte sisters, Emily Dickinson and Sylvia Plath, she chose ballet over writing, and trained for a time at the National Ballet School of Canada. She fantasized that fans would someday drink champagne from her toe shoes, a la Anna Pavlova. Seeing Elaine Stritch as "Mame" in 1969 changed all that, and she decided to become an actress. But ultimately writing drew her back. Today, she is a founding member of the Galaxy Writers Workshop in New Jersey, and sits on the Board of the International Women's Writing Guild, to whom she owes her life as a writer. Ms. Cariou is proud to count the following authors among her mentors: Ted Conover, D.M. Thomas, Sally Bingham, June Gould and Eunice Scarfe. Heather emigrated from Canada to New York City in 1983, and now lives on the Hudson River in New Jersey with her husband, stage and screen actor, Len Cariou. She is currently co-producing the feature film of "Sixtyfive Roses" with Eva Longoria and UnbeliEVable Productions. Besides her memoir, "Sixtyfive Roses" she is working on a novel.

Tyler: Welcome, Heather. I'm glad you could join me today. To begin, will you tell us about the title of "Sixtyfive Roses" and why it was chosen in case some of our readers have not yet guessed?

Heather: My younger sister Pam was diagnosed with Cystic Fibrosis when she was four, and couldn't pronounce the name of her disease. She told people she had "Sixtyfive Roses."

Tyler: Who is the audience for your book?

Heather: "Sixtyfive Roses" is not simply a book about Cystic Fibrosis. It's about fighting for your life and your dreams against the odds, so in that sense it's really a book for anyone and everyone. It's for all readers who love a good story well told. I wrote it for every kid who stands in the shadow of a sister or brother, for every parent who ever walked the floor through the night with a sick child, for every friend and neighbor who wonders what the family down the street is going through. Whether it's illness, addiction, abuse, or financial crisis—sooner or later everyone faces some kind of obstacle, and I hope the story of "Sixtyfive Roses" will comfort and inspire those who are facing such challenges.

Tyler: Tell us about your sister and what her struggle with cystic fibrosis was like for her?

Heather: Pam had a terrible physical struggle with her disease; she lived a great deal of her life at the precipice of her mortality. Her physical struggle was therefore at the root of a great spiritual struggle. In order to live, and live well, she had to place her spiritual and mental focus above her illness, even as she was forced to deal with the grinding physical realities of it. Dying was not her greatest fear; she feared not making the most of the life she'd been given. Truthfully, I can't say exactly what having CF was like for her. In some ways she was a very private person, and she also tried to protect us from the worst of her pain and fear. She was funny and feisty, compassionate and serene, wise beyond her years. She loved unconditionally, she bore her pain stoically.

Tyler: Where do you think that strength came from?

Heather: Pam always said her strength came from the love of her family. She also had a great faith in God, a deep spirituality, and I think she had faith in herself from which she drew strength. She was capable of great joy as well, had a terrific sense of humor, and that definitely sustained her. Doing things she loved, like working with children, and drawing on the beauty she saw in the world around her gave her strength. She had a gift for seeing the beauty in everything. As a young woman, she was also very inspired by the writings of Viktor Frankel.

Tyler: Heather, in the book you mention that you promised to die with your sister, Pam. You were only six-years old at the time. Do you think you understood about the disease then, and how did your relationship with your sister and with the disease change as you grew older?

Heather: I understood what was right in front of me, what I saw in terms of her physical struggle: her terrible cough, her difficulty breathing, her extreme thinness, the many trips to the doctor and hospital. I also understood that my parents were fearful, so I had a pretty clear picture that something big was at stake. Both my sister and I had to fight in our own ways toward understanding and acceptance of her diagnosis and prognosis. I focused a lot on the darkness surrounding us, and she focused on the light. I was pre-occupied with the thought of dying, but she taught me how to live. Her illness ultimately bound us together more than it pushed us apart. Since her death, I've come to see how much of a teacher and spirit guide she really was—and remains.

Tyler: Heather, most siblings have spats between them. Was your relationship with your sister different than between most siblings because of the disease?

Heather: Yes and no. In families battling childhood chronic illness, parents quite rightly have to put their energy and focus into the disabled child, while the well children are generally expected to develop compassion and independence beyond their years. Most well-siblings have a very complicated love/resentment/guilt/grief cycle going on. And as you suggest, the sibling relationship can be challenging enough without an illness, addiction, special talent or disability thrown into the mix. It is true that in *any* relationship these issues will change the dynamic, for better and for worse. For us, it was almost a good thing that regular sibling spats occurred, because it was so “*normal*.”

Tyler: Tell me about the process of writing “Sixtyfive Roses.”

Heather: The emotional revisiting of certain memories was excruciating. There were days when I would write a paragraph, then lie down on the floor and cry for two hours, then get up and start writing again. Sometimes I had to stop writing for several months and then come back to it. I knew I didn't want to write a “my sister was an angel” book, so I made myself confront the underbelly of the experience, which I thought would be most worthwhile to me, and to my readers. I also studied my craft as a writer long and hard. I wanted to write a book that had *literary* value. I attended writing workshops, read hundreds of memoirs, had my work critiqued, and rewrote and rewrote. I actually worked on the book for almost twenty years, through a number of drafts, learning and growing both as a person and a writer with each attempt. What helped me most was finding the International Women's Writing Guild. I owe my writing life to them.

Tyler: Did you find it difficult being the healthy child? Did you feel guilt, and did you wonder why your sister had cystic fibrosis and not you?

Heather: These questions are very much at the heart of the story, and the short answer is yes. The longer, more complicated and interesting answers are in the book—in fact, the answers to those questions required a book!

Tyler: Your parents founded the Canadian Cystic Fibrosis Foundation as a result of your sister's illness. Will you tell us how they dealt with your sister's illness and how that led them to this effort of creating a foundation?

Heather: My parents were very young when Pam was diagnosed, in their early twenties, an age when they still possessed that wonderful, innocent belief in life and their ability to prevail. They were uncomplicated, very honest and direct, and dealt head-on with the diagnosis and everything that came after. They just wouldn't take no for an answer, and refused to believe that nothing could be done for children with C.F. Looking back, they remind me of Margaret Mead's quote: “A small group of thoughtful people could change the world. Indeed, it's the only thing that ever has.” Writing about that time of their lives was actually quite fun. It's astonishing what they accomplished.

Tyler: How have your parents reacted to your writing “Sixtyfive Roses”?

Heather: They are very proud. My father has hand sold over 300 copies. People in my hometown should duck if they see him coming! However, they certainly don't agree with everything I've written. My mother said she felt at first like "the Emperor's new clothes," exposed and naked. But the amount of mail we've received praising my parents has put those fears to rest. The most important thing to tell you about my parents, is what happened when I gave them what I thought was the final draft. My mother said it was wonderful writing, but they thought I was holding back for fear of hurting them. She told me I had to rewrite it, stand in my own truth, and they would find a way to deal with it. It took great courage for them to give me that gift, which had the effect of changing me as a writer, a daughter and a woman. This is why I begin and end the book with, "Pam said tell the story. Mother says tell the truth." The book that came out of that rewrite has been described as brutally honest, but that's apparently what readers like most about it.

Tyler: For people not familiar with cystic fibrosis, will you tell us about how the disease progresses? Is it common for people to live for many years with it, such as your sister did, living for twenty-two years?

Heather: Cystic Fibrosis is the most common life-threatening genetic disease of children and young adults. The average life expectancy is currently thirty-seven years. My brother Jeff, who also has CF, will be forty-seven this Christmas. When my sister was diagnosed in 1958, however, the mortality rate before the age of six was close to 100%. Having CF is like drowning from the inside. It also disables the pancreas. Over time the stress of repeated infection in the lungs can debilitate the heart and other organs as well. I don't want to get too graphic—for most people with CF, it's a nasty, progressive, relentless disease. There are several hundred mutations of the CF gene, so the range and severity of symptoms, as well as life expectancy, can vary greatly from person to person. Many patients have lung transplants, and the outcomes there can also differ significantly.

Tyler: Heather, will you tell us more about your brother? Are his experiences similar or in any way different from your sister's? How is your relationship with him different?

Heather: I have two younger brothers, one healthy and one with CF. They don't have a good relationship with each other, and though I do have what I consider good relationships with each of them, both are still somewhat distant with me. However, I know that we all love each other. In part, this was the cost of what happened with Pam. The pain is just too great for them to stay close, I guess, at least in the way I'd like. And guys are guys too, if you know what I mean. They just deal with things differently, but don't get me started...

Tyler: Heather, if your sister were here today, what message would she want to give your readers?

Heather: She'd want readers to know that they can't control life by being afraid of it; that when they cannot change their circumstances, they are challenged to change themselves, (and that's where their power truly lies); no matter what their circumstances, they must remain open to the joy and beauty that can be found in each and every day; they must learn the difference between giving up and surrender; they must never give up. She'd want everyone to practice forgiveness and say I love you out loud and often.

Tyler: I was very impressed to see that Celine Dion wrote the foreword to your book. Will you tell us why she agreed to do so and how it came about?

Heather: Celine is the Celebrity Spokesperson for the Canadian Cystic Fibrosis Foundation. She lost her niece Karine to CF. I sent the manuscript to her through the Foundation, and she agreed to write the foreword, partly, I think, because 5% of proceeds from sales of "Sixtyfive Roses" goes to Cystic Fibrosis research in Canada and the U.S.

Tyler: Heather, what has changed for people with cystic fibrosis compared to when your sister first contracted it? Is there greater hope for people today?

Heather: There are always reasons to be hopeful, more so today than ever before. Treatments are better and constantly improving, and research is ongoing. We're on the brink of some exciting breakthroughs, I believe.

Tyler: Will you tell us about your other writing projects? I understand you're working on a novel now?

Heather: I'm so excited to be writing a novel—and even more excited that my agent thinks I can, and flat out demanded that I do it! It's a whole new adventure, another learning curve, and right now I'm enjoying it. I'm also involved as co-producer of the movie of "Sixtyfive Roses" with Eva Longoria and UnbeliEVable Productions.

Tyler: Do you think you would have been a writer eventually even if you weren't inspired to write this book about your sister's illness?

Heather: Absolutely. Pam was right; it's what I was meant to do. I've never been happier in my own skin than since I became a writer.

Tyler: A lot of people want to be writers. Will you tell us a little about the path you took to get there and especially why you credit the International Women's Writing Guild with your achieving that goal?

Heather: I'm so glad you asked that! One of my mentors from the IWWG is June Gould, who wrote a book called "The Writer in All of Us." I believe there is a writer in all of us, or at least a story that we own and live by. Some people call the act of writing therapeutic, but I'd rather use the word healing. I think everyone who has the inclination to write should do it. Often in writing our own story we find out how much of a myth we've created, and that we have the power to change how we view it and ourselves at the centre of it. It's a worthwhile pursuit. In the fine novel "Fugitive Pieces," by Canadian writer Anne Michaels, a character says, "Write to save yourself, and some day you'll write because you've been saved."

However not everyone has the temperament or ambition, the patience and persistence, to be a *writer*. And there's a difference between the act and the art of writing. I found the International Women's Writing Guild in 1984, just as I was beginning to work on my memoir. This was no coincidence, by the way. The Guild is very special because it is open to all women worldwide, without portfolio. It believes in the personal growth and empowerment of women through a connection to the written word. I attended their week-long summer conference, held at Skidmore College, and have returned every year since. The women there have taught me, believed in me and held my vision for me when I could not. They would not let me fail. There is incredible permission in that place, and women are granted a voice they often can't raise in their everyday lives. There is a huge emphasis on process, as opposed to other writing conferences I've been to where it's all about result. Every year I re-create myself there, fall in love with myself, strengthen my voice as writer. And I witness other women doing the same, even if they have no desire to publish. Even if all they aspire to is writing more deeply in their journals. So once I found the Guild, and came to terms with the idea that I wasn't cheating on my actor-self by becoming a writer, I was like a horse let out of the barn. Someday I'll have to write the story about writing the story.

Tyler: Thank you for joining me today, Heather. Before we go, will you tell us about your website and what additional information may be found there about "Sixtyfive Roses: A Sister's Memoir"?

Heather: I've got a great website, if I do say so myself! www.sixtyfiveroses.thebook.com It has lots of photos that aren't in the book, inspirational quotes, links to resources, reviews, video of Pam. Of course my favorite page is "What Readers Are Saying." My email address is on the back of the book; I love hearing from my readers, and I answer every letter. I also have a great time doing Book Club appearances in person or by Skype. Go ahead, invite me!

Tyler: Thank you, Heather, for the informative interview. I'm sure your sister would be very proud of you, and I hope your book brings attention and hope to those who have cystic fibrosis.

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