

**Book Journeys Author Interview - Oct 03, 2013**

**Dr. Angela Lauria with Carrie Knowles, author of *A Family History of Alzheimer's: The Last Childhood*.**

*"If you feel you have a book, a memoir, a book that you want to write, you need to write it."*

~Carrie Knowles

Angela:

Well, hello, everybody, and welcome to Book Journeys Radio. I am your host, Angela Lauria, I am the founder of the Author Incubator and creator of the Difference Process for writing a book that matters. We were actually off last week, because, last week, I hosted my biannual "Free Your Inner Author Live" workshop. We had a – a dozen people cranking out memoirs, fiction books, a couple of self-help books, we had coffee table books, just really a – a variety of books that are being created to help make a difference in the world, and – workshops are so fun, because the people who attend are in the middle of this creative process and they're ... highs and lows and challenges, and – a lot of people don't get to the other side of that, so the reason we do this show is to show authors in transformation that there is a light at the end of the tunnel, was a time when all of our guests felt like they may not finish their book, and today's guest is probably no exception. Her name is Carrie Knowles. Carrie, spells her name c-a-double r-i-e, and Knowles is k-n-o-w-l-e-s. Carrie is the author of a memoir called *A Family's Story of Alzheimer's: The Last Childhood*. I was excited to do this interview, because Alzheimer's definitely affected my family. My grandmother had Alzheimer's, I was very close to her, and I think stories, memoirs and other peoples' experiences can really help us through those processes, so Carrie, thank you for being here and tell us about your book!

Carrie:

Thanks for having me. Well, I've been a writer, professionally, for the last forty-five years, and in the early 1990's our family – we were – confronted with the fact that, probably, our mother had Alzheimer's, and like so many families we had let it go to a crisis before we were willing to really come to the idea that, in fact, she had Alzheimer's. And then, once we began that journey with her, and also, she was very complicated – we didn't have durable ..., lots of things happened, and we found ourselves on a real roller-coaster of going to doctors, trying to take care of her, realizing that what was wrong with her was bigger than we thought it was, and just the moving through the medical system, through the care system, and also our own emotional – devastation from the disease itself. One time, when I was up, trying to help my siblings unravel everything that was going on, and – get us on a good path, my two brothers and my sister – held a powwow and came to me and said that, "There's nothing – there's nothing about the impact of this disease on the family, and you ought to write it."

Angela:

Mmm.

Carrie:

And, because of their encouragement, I did that. And so, that became .... Yes.

Angela:

And – and so, what was your – what was your wish for the book, what was your – did you – envision how this book would be in the world?

Carrie:

Well, I think that what – my wish was sort of a collective wish with my siblings, that I could create a book that could take you through the stages of Alzheimer's, more importantly the decisions that the family would have to make, and put a real face on those decisions. It's one thing to read a pamphlet that says, at some point, they'll have to put your mother in an – assisted living, or an Alzheimer's wing, and – and it's really quite another to make decisions to do that – to make a decision for somebody else's life. How to – going to live, is a much harder decision than you might think it is, and so I wanted to give a face to it, all my siblings were incredibly generous in terms of exposing themselves and the struggles that we all went through, and were one hundred percent behind me doing this and pushing me to do this. And so, it – it's a pretty intimate book about one family's struggle with these decisions.

Angela:

Mmm.

Carrie:

Our father was ... by this time, and we have a stepfather who didn't really like us very much, so he was very much out of the picture. He wasn't a partner for us, and he wound up, unfortunately, dying – right at the point that we were beginning to wrestle with the idea that something was terribly wrong with Mom. And so, in – what we wanted to do was to say to other people, "Look, these are hard decisions, and you haven't failed just because –" I – I think it was very – to us, it was very destructive w – when we would watch these Hallmark kind of movies that would have – and I don't mean to say anything negative about Hallmark, but – of – if you just love enough, the person will come back to you and be well, and, of course, that's a false message, and it's not true, and it makes everybody else feel like a failure. So, that was ...

Angela:

Mm-hmm. So, when you got the idea, when you came up with the idea – to get this book written, how long, from the time you – "We should write a book –"

Carrie:

Right.

Angela:

– until you had it – finished and printed in your hand – what was that whole process like for you?

Carrie:

Well, it's a long process, because I think we were knee-deep into the whole process of – the situation with our mom before I started working on the book, and it was very wonderful, I got a grant from a North Carolina arts council to write the book, so it gave me a little time off for – from – commercial type of writing, and writing for newspapers and magazines, in order to take time to work on the book, but the book sort of follows over a – a long and bumpy journey of keeping track of what was going on with my mom, and also, since I had written a lot of non-fiction in my professional life, nutrition and other – lifestyle issues, I also wanted to incorporate real research in it, not just say, "This is hard," but give people real – medical research along the way, so there was a lot of research that was going on, and, plus, at the same time, we were caring for our mom. So, I don't know, it probably took me five or six years – let me say it was very difficult to get a publisher. As you can imagine, during the early days of –

Angela:

Yeah, let me just – right, so it's – right, that's a good point. So, let's just talk – let's break it down into actually writing it versus getting it published.

Carrie:

Well, that's – well – well, because it was published in two different ways. ...

Angela:

Mmm! Okay. ...

Carrie:

Right. Well, initially, the – the book – i – it probably took me six years to write the book, and so, I was in the middle of what was going on with my mom – five, six years, and I couldn't find a – a big New York publisher who would take it, because – everybody said, "Oh, this is a sad book – and it has such a sad ending!"

Angela:

Mmm.

Carrie:

"We want a happy book about Alzheimer's!" And I would ...

Angela:

... Nicholas Sparks, I guess, managed that, so – right. (sighs)

Carrie:

Yeah. Yeah, that was really unfortunate – that – that’s the kind of book that makes you crazy if you’re an Alzheimer’s caregiver, ‘cause – you can’t kiss ‘em and love ‘em, and that’s to – makes them remember who you are, and that’s okay, that’s another story. So, it was originally published by a very, very, very small press. And – so, that’s why I said it was – a two-part thing, and very shortly after the small press published the book, they went bankrupt.

Angela:

Oh, no.

Carrie:

And I actually had to go to court to get the book back. So, I got the book back, and then – by then, more things had happened in our lives, and so, I went back into the book and – wrote through to the stage we were in then, and – found a New York publisher, Random House imprints, Three Rivers Press, which is part of ... imprints at Random House, they purchased it. And, once again, I had to change –

Angela:

So, tell us that – tell us process, how did you sell it to them? Did you go through an agent, did you write a book proposal, tell us – ha – what that whole story looked like.

Carrie:

Well – a – a writer – a – a fellow writer, who had read the book and just knew me a little bit loved the book and he went to his agent, Regina Ryan, and she took it to Three Rivers Press and got it sold to Three Rivers Press. And then, I (chuckles) – it’s kind of, like, I don’t know how it could have gone from bad to worse. It was wonderful for it to be published by Random House, except for my editor – I’m gonna tell you the worst stories in the world, you think Alzheimer’s is a bad story. (laughs) My publishing ... this book, it just seems doomed – and everybody kept saying, “ Ha, we’d really like you to write a happy ending to this book,” and I’m “... sorry, about that.”

Angela:

Yeah.

Carrie:

So, we went to Three Rivers Press and I had a – a first editor, and we had done all the edits, and blah, blah, blah, was ready to go, she went on vacation, she came back from vacation and I – lost her job. And then, my book was turned over – no, no, no, my book was then turned over to a new editor, and she was a brand-new editor with Three Rivers Press, very nervous, very brand new, and she decided she had a different idea for how to organize the book from my first editor did at Three Rivers Press. So, I rewrote the book again, and – to satisfy this editor, and actually, I – I’m very pleased with the way it turned out. I thought she

had some good ideas. That was great, and then, the week before my book came out, she had – probably a mild nervous breakdown, and she left Three Rivers Press.

Angela:  
Great!

Carrie:

So, my book was published by a national publisher without any support, she hadn't done any publicity for it. So it came out with no publicity, and the – I wound up – through just my own perseverance, and also the – the need. It came out 2000 with Three Rivers Press, at a point when many, many people across the country were struggling with the same thing our family had struggled with, in big numbers. And so, I wound up, with the help of – of bookstores – booking myself up and down the eastern seaboard – bumped from one bookstore to another, on my own, completely on my own. And then, a firm that was involved in hospice and life care for Alzheimer's patients asked me to start speaking for them, and so I traveled around the country, and I did a lot of work for – a lot of speaking engagements for medical personnel, as well as for family members, and I did that for about three years, until I was just – exhausted from .... It was really quite interesting, because, when this book came out in 1990 – I – I mean, in – in 2000, what was significant about it – when it – when it came out – Three Rivers Press, when it – I mean, I'm sorry, when it first came out in the end of the 1990's – was that doctors assumed that, when you brought your loved one to the doctor to say, "I think something's wrong," they counted that as the beginning of Alzheimer's, and the same week that my – the first book was a very, very tiny press – came out, somebody had sent my book to a friend of theirs who – Dr. Webster Ross, at University of Hawaii, and that same week, he published a paper in the American Medical Association Journal about the failure of family members to recognize the first seven years of Alzheimer's. And he called me and said, "If I had your book, you would have saved me ten years of research."

Angela:  
Wow.

Carrie:

He said, "You understood what it took us ten years to figure out, that –" many, many years go by, and those early stages, with doubt, confusion, embarrassment, whatever – denial – that great river of denial – yeah, yeah, ...

Angela:

Yeah, we had it all. We thought my grandmother had some – weird new sense of humor, or something.

Carrie:

Right, and often, doctors will say, "Oh, it's probably a vitamin deficiency, so give her more vitamins and she'll be okay." So – the work that I did with this book really became quite

important with the medical profession as well as family members, because it talks about what was going on –

Angela:

And that wasn't really intentional?

Carrie:

No. I – I didn't realize until we were – halfway under water with it, how much the medical profession didn't understand about this disease.

Angela:

Shocking.

Carrie:

And there's something about how they would – and –and I remember, i – it was just in the book, when we finally got my mom into the Chelsea Methodist Home, in Michigan, which, by the way, is a wonderful, wonderful place, and our family owes them a great debt of gratitude for – of gratitude for how kind they were and how much care they gave our mother for the ten years she was there. But – what was im – important was – in an – in an early time conference with them – they said, "Gosh, your mother just – seems to be advancing so quickly, so soon!" And my sister and I just looked at them and said, "What are you talking about?" And they said, "Well – she just – the onset of Alzheimer's was just – three months ago when she came to us," and we looked at them and we said, "What are you talking about?" And they said ...

Angela:

What gave you that idea?

Carrie:

Right. And we said, "This has been going on for seven – at least seven years," and they said – they kind of looked at us – and they laughed and they said, "Well – I mean, really, what makes you think she had Alzheimer's seven years ago – that's kind of ridiculous," and we began to tell them the story, and they went, "Oh, my God – what you've lived through," and the – their perception always was – which was quite interesting – of families, that they would just – put people – put their loved ones into the Alzheimer's unit and drive away as fast as they could, and they thought that they were callous and horrible people without realizing that, in fact, they were exhausted, stretched to the limit, and completely burned out by the time they got to that point, when they took a loved one to an Alzheimer's unit. So, a lot of what I did was help staff – medical staff understand just what the family members went through before they got to their door.

Angela:

Mm-hmm. Absolutely. So, as you were writing this, over the – five years or so, what were some of the hardest parts to write? What were some of the challenges that you faced?

Carrie:

Oh, gosh. Well – I – I – let me just complete with the book. Because I didn't get any support from Random House, it then went out of print, and then, just recently, I bought the book back out as an e-book, and, on my own, with additional chapters that include just how do you deal, after the death, and so that's – I – I really encourage people to – to get the e-book, because it's – that's another story in and of itself. I think the most difficult issue was beginning to understand, for myself as a writer – because, I – I was – that's what I am, what I have been – all of my adult life – w – where – where was the arc? Where was – how did this story – how did all the pieces fit together? How do you talk about the family, and Alzheimer's, and the – w – what's – w – what's the connection here? And I really struggled with trying to make a – a systematic whole of the book, so that people of – a – almost like you would with a novel – w – where's the arc, where's the story, where's it going? And I began to realize – my siblings and I talked a lot, and – and one of the things that came out of our discussions, which I think many other people have said to me, "Thank you, thank you for saying this," it's – when your loved one loses the memory of you, your memory, your life with that loved person, gets locked up. There are points in which you wonder, "Were you crazy? Did this really happen?" You lose that validation, and I think about – when people get together at family events, how – everybody talks about, "Do you remember when?" "Do you remember when this happened, and Uncle George did that?" And there's this wonderful sharing, and r – recreation of those memories, and when that gets cut off, when those memories get lost from your loved one, you're really left wondering, yourself, were those memories real?

Angela:

Right.

Carrie:

And that sense of loss, and the – the every day, constant sense of loss, and – and the exhaustion doing that. Yes.

Angela:

So, what – so, one of the things I think that was unique about your experience in writing the book is that you have had other people that – shared these memories in different ways.

Carrie:

Right.

Angela:

And one of the things that comes up with memoir authors is, they feel like they're telling their version of the story, but other people might not agree with it, they might have perceived it differently. Were there challenges where you saw a story one way and your siblings saw it another way?

Carrie:

Sometimes, but I think, more generally, we – we talked about what I was writing about – all the way along it, and I – I'm very –

Angela:

Mmm. It sounds like there was a collaboration.

Carrie:

In a way it was, and – our work – I'm very proud – w – we've got an exceptional family – we were very – n – not a wealthy family – we were unable to hire outside help – we were on our own. We didn't have any aunts or uncles around us to support us – we were, really, four siblings on a rocky ship on our own trying to see our way through it. In addition, our mom just – as one doctor said, he'd never seen anyone who exhibited all of the symptoms of Alzheimer's, and we just laughed and said, "You know, we needed material." And so, we got it. But I – I was nervous when the book came out, what my siblings would think about it, and they were very proud of it, and very grateful that I had done it.

Angela:

Mmm.

Carrie:

And ... I had told the truth about who we were and what we did and I – I really respect them, and I respect – th – their generosity and also, we were lucky that we could work cooperatively, for the most part. Yup.

Angela:

So – excellent. So, what – obviously, one of the highlights for you is – sharing this experience, in a way, with your siblings. Were there other things that have come out of having written this book that have been – positive experiences for you that wouldn't have happened without this book?

Carrie:

Oh, I got to meet so many people, and talk with them and make them feel not alone. It was a wonderful experience, it continues to be a wonderful experience. I still get e-mails from people who have discovered the book and – it's – it's – it's – it makes me feel very good that the book might – was successful in that way, it – it really did what we hoped it would do, which was help people.

Angela:

Yeah. ...



Carrie:

I have this funny experience – I had a very funny experience, I was in Chicago, on the west side of Chicago, speaking one night, and it was a big audience – there were a hundred or so people in the audience. And I looked out in the audience and half of the audience were nuns, and I thought, “Wow, this is unusual.” And I realized that there was an old convent on the west side of Chicago. And at the end of my talk, all the nuns lined up and stayed – each walked up and gave us a little pocket change to this one nun who was the mother superior of the convent, and at the end of the talk she came over with this handful of – nickels, dimes and quarters and bought one book and told me that they would share it with their order, and then it would go to their sister order, and then it was gonna go to Canada to their sister order –

Angela:

Wow.

Carrie:

– and I thought, “That’s so wonderful, but my children need to go to college.”

Angela:

Yeah, that one book, so many people.

Carrie:

So many people on one book.

Angela:

It’s like a little library, yeah.

Carrie:

Right. A little traveling – like the traveling cat story, but it was just my book.

Angela:

Yeah, there you go.

Carrie:

Yup. So.

Angela:

So, you mentioned speaking, had you done speaking on this topic before, or did having the book open up that opportunity for you?

Carrie:

Having the book opened up that opportunity for me, yes, mm-hm.

Angela:

And how did that – what was that process like? A lot of people that are working on books would like to ... one, and especially with memoirs, they have a story – that it – it's gonna be (sneezes) excuse me, sorry about that, it's gonna be hard to get speaking engagements, it's a memoir, it's – I don't have the same credentials as – an Alzheimer's doctor would have. So, how did you – what was your journey?

Carrie:

Well, because it wasn't from a medical point of view, it was from a family member's point of view –

Angela:

Right.

Carrie:

– the – it was pretty easy to then step into – speaking with families, and then – a – and also, from going to bookstores and speaking at bookstores, it was very curious. There would always be one or two doctors who would be standing in the back of the room, and they would wait 'til everybody else had left, and then they would come up and ask questions, and that's – how I got to then be asked to speak to medical personnel, because they would say – “Could you talk to our staff?” or whatever.

Angela:

Wow.

Carrie:

And so – so – I would – so, it was – it was very gratifying to feel as though I wasn't only helping family members, but I was also helping people who were going to be helping family members – better understand the situation. I have to say it was pretty exhausting, because it's such an emotional issue –

Angela:

Yeah.

Carrie:

– and – people came with – I remember one woman – oh, my gosh – she had cared for her mother and father, who both had Alzheimer's. She was presently caring for her husband's father, who had Alzheimer's, and her husband's great-aunt, who had Alzheimer's, and her husband's great-aunt and her husband's father were living in the home, and she was caring for them full-time. And I thought, “You are a saint.” And the issue for family members – when you think that the – the title of the book is *The Last Childhood*, because, from onset to death, the trajectory, we now understand, is seventeen years. And so –

Angela:

Oh, wow! I did not know that.

Carrie:

Right. ... Right. So – and – you can look it up in the literature, and they'll say, "Now we understand, from onset to death is seventeen years," but the first seven years are those mucky years, in which you aren't sure, but some odd things are happening, and then the seventh year – the sixth, seventh year, usually there's a crisis –

Angela:

Mm-hmm.

Carrie:

– and that crisis is a car wreck, or somebody wanders in the middle of the night and gets lost and ... find them, or some other very alarming – undeniably bizarre incident happened. And then –

Angela:

We had a kitchen fire in our family.

Carrie:

Yeah. Right, right. And – th – there were – so – for the most part, m – people who become parenting-averse, they are – become – full-time caregivers for the last ten years. That's a long time –

Angela:

Yeah.

Carrie:

– and for many people, particularly women, it means that many women wind up having to quit work because they – you can't leave an Alzheimer's patient alone – you can't do that.

Angela:

Right.

Carrie:

So – it becomes a full-time job.

Angela:

So, what advice would you have, especially to somebody, maybe they're a caregiver, but somebody who feels like they're busy – with caregiving or with their life, but they still want to

write. What advice, based on your experience, would you give them to help get their book done?

Carrie:

Well, I think you have to – whether you are a caregiver and – whatever. You – if you feel you have a book, a memoir, a book that you want to write, you need to write it, and you need to also be forgiving of yourself, and you need to – set a – set a plan – to write one hour, or two hours a day that a – are yours to – to have, but to know if something comes up, measles, mumps or whatever it is, that you forgive yourself and move on to the next day.

Angela:

Yeah.

Carrie:

You have an hour to write and you keep going. And – it's the same advice I would give anybody who wanted to write any kind of book, that you just – if you think about it, if you – if you wrote two pages a day, and you took your birthday off and Christmas and Easter and Halloween and every weekend, at the end of the year you'd still have six hundred pages.

Angela:

Some book! Right.

Carrie:

Yeah. You'd have a book. Right.

Angela:

Right.

Carrie:

And – when y – and – y – when you edit it, you might wind up with three hundred pages that you love and like, but you still have a book.

Angela:

Right.

Carrie:

And – I – I'm one to talk, because my – my last two books, which are both novels, *Lillian's Garden* and *Ashoan's Rug* – I did them – not exactly together, but worked on them over the last ten years – going from one to the other at different times when – when things were working in one book and not the other. So – it takes me ten years to write a book, sometimes, and so, it's – I – I – I – I'm not too hard of a taskmaster, and I tell people ...

Angela:

Yeah, I like that story. I think that's a great – place to leave people, is with being gentle with yourself as a writer and knowing your book is gonna come out when it's ready –

Carrie:

Yup.

Angela:

– and there's not – there's not a fire, sometimes taking care of your mom is more important than getting your pages in.

Carrie:

Absolutely.

Angela:

And – that doesn't mean it won't get done eventually.

Carrie:

Right, right. It won't. And it – it will happen.

Angela:

So, Carrie Knowles is – Carrie Knowles is the author of *A Family Story About Alzheimer's: The Last Childhood*. You can learn more about her at [carrieknowles.com](http://carrieknowles.com), that's c-a-double-r-i-e-k-n-o-w-l-e-s.com. Carrie, thanks for – for being with us here on Book Journey.

Carrie:

Well, thank you so much for having me. It's been a pleasure.

Angela:

Terrific. And we will be back next week, we're here in – here in the Book Journeys Radio, where we are changing the world one book at a time.