

Ask the Author... *Ann McLane Kuster*

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The Last Dance

Facing Alzheimer's with Love & Laughter

By Ann McLane Kuster w/ Susan McLane

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\$15.00, 224 pgs, soft, 5.5" x 8"

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1. Could you describe some of the emotional stages you and your parents had to deal with during the course of diagnosis and treatment?

In the beginning, everyone had to overcome their denial and come to terms with the reality of my mother's decline. For some this was harder than for others. My mother led the way with her candor. Over time we learned to be open and honest about our feelings of loss and false hopes for the future. Our "Fridays with Susie" and writing The Last Dance helped my mother and I explore the "role reversal" in our lives and our emotions about the changes in our family. Reading my mother's life story helped my father, and then my siblings and the rest of our extended family, come to terms with their own aging and with her Alzheimer's disease. One by one, we learned first to offer our support and then eventually to ask for and accept the support of others, including family, friends and finally our whole community.



2. How has humor played a role in the way your immediate family has dealt with your mother's disease and the way everyone has reacted to it?

The title of our book, The Last Dance: Facing Alzheimer's with Love and Laughter, embodies my mother's indomitable spirit and character. Although she has led a charmed life, my mother has experienced and learned to overcome adversity. Susie is known for her optimism and sense of humor about life's travails. She left college at age 18, pregnant at the end of her freshman year, to marry my father and move to England where my oldest sister was born. Over the next eight years, she had five babies and two broken legs (at the same time!). Raising five children under age seven (with only one car in the family), my mother learned to cope by making life fun - teaching ski lessons to the whole neighborhood, picking apples for homemade applesauce, tapping sap in the back yard to make maple syrup, and throwing birthday parties for our special day of the year.

Then during her 25 years in the New Hampshire Legislature, my mother's humor and charm helped her overcome the constraints on women in her generation. Her optimism and good cheer turned into leadership qualities essential to building coalitions and engaging allies in her quest to promote women's rights, provide support to the mentally ill and to needy families, and protect our natural environment.

Now her sense of humor helps us all to cope with her decline by finding joy in life's simple pleasures - singing songs, sharing stories, savoring smiles. Over time, we have learned to laugh together through our tears, as we find the humor in every day life. Even now, when my mother cannot walk, or even talk, the "essence of Susie" shines through in her laughing eyes and expressive face.

3. What has been the biggest surprise in your mind about how your father has dealt with the care of your mother? Has he changed and in what ways?

The book is dedicated "to my mother, Susie, for showing us the way home and to my father, Malcolm, for learning to walk on water." Everyone has been amazed and impressed by my father's patience and kindness, as he helped my mother get through the long days and nights ("24/7") of her struggle. I learned that my father had to come to his own conclusions each stage of the way. Although he was resistant to the changes at first, once he accepted the next step, he became an authority and even an advocate for the accommodations in their lives. When she began to have difficulty walking on her own, I suggested a wheelchair, but he couldn't accept the limitation on her independence or on their mobility. He held her arm firmly by the elbow and remained convinced that they could manage just fine. Eventually, he bought a wheelchair and took it everywhere they went, but he still encouraged her to walk with the railings around their house. When she could no longer manage to get around on her own, he finally came to terms with her move to the nursing home. Over time, my father has opened his heart and his mind to the changes in his life, which in the end has made our family closer than ever before. We visit and talk with each other more openly and more often. He sees my mother every day, sharing his love as her husband, rather than her burdens as her caretaker.

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4. What would you say to health care providers about Alzheimer's Disease? How important is it that you get a loved one to the correct health care provider and how does one find that doctor?

Dr. Robert Santulli, an Alzheimer's specialist at Dartmouth-Hitchcock Medical Center and researcher at Dartmouth Medical School, wrote that The Last Dance "should be required reading for health care professionals who work with people with (Alzheimer's) disease, or their families." We all hope that my mother's open approach to aging and Alzheimer's will lead patients, families and health care providers to be more candid about the decline at an earlier stage in the disease, when families and caregivers have the opportunity to look beyond the illness and appreciate the person who is afflicted. Alzheimer's has such a bad reputation for anger and frustration. We hope that facing the inevitable decline at an earlier stage with patience and understanding will help those afflicted and their families to avoid negative feelings of hurt and harmful attitudes that may be caused by fear and frustration.

We would definitely recommend a complete evaluation by competent and experienced medical providers who can distinguish between the various signs of aging and the many types of dementia, including Alzheimer's disease. Consult the Alzheimer's Association in your area for more information and for specific recommendations. There are important break through medications that can provide positive results early in the process, buying critical months for patients and their families to face their future together. We hope our story will be a positive resource that will help you avoid misdiagnoses and misunderstandings about the impact of aging and Alzheimer's in our lives.

5. You've said that each family dynamic is unique and so is the way that family will deal with Alzheimer's. How did your family come together individually and as a whole to accept the disease and then assist your mother and each other?

*For each person, our perception becomes our reality. In the beginning, I was more aware of my mother's memory loss because I spent more time with her and I heard from those in our community who expressed their concerns about her. My siblings were living their own busy lives, focused on their families and issues in their own lives. Then my parents began to share my mother's story more openly with family and friends, first with our "Fridays with Susie" and then our book *The Last Dance*. As time went by, my siblings and our extended family realized that my parents' world was changing day by day, week by week. Each in their own way, my sisters and brothers came to terms with my mother's decline and offered their support. One by one, they began visiting and calling more often, bringing food and good cheer, cleaning out my parents' house, putting up railings, and doing whatever they could do to help my parents accommodate the changes in their lives, both physically and emotionally.*

6. How has your family helped your mother to pass on her legacy?

Every member of our family will pass on my mother's legacy in their own special way. My siblings and I all care passionately about our communities and the future well-being of our country. We volunteer on political campaigns and actively support our favorite causes. One sister served for many years on the school board, while another served in the NH Legislature. We have all volunteered for numerous charitable organizations, from mental health and child welfare agencies to community theatres and environmental causes.

Four of Susie's granddaughters marched in Washington last spring to protect women's reproductive rights, while another studied in South Africa and observed their elections last year. All of her grandchildren love to travel and care deeply about the state of the world and our future well-being. My older son and another cousin are both pursuing their dreams in ski racing, training and competing with their grandmother's competitive drive and optimistic spirit. Everyone in our family loves the natural world and enjoys our family time and traditions together. We are all delighted and honored that my father, Malcolm McLane, will be awarded the Lifetime Achievement Award by the NH Business and Industry Association, and I am especially pleased to be awarded the Marilla Ricker Award by the NH Women's Bar Association for leadership in the legal profession. Each in our own way, we will carry Susie's torch and promote her causes.

To request a media kit & interviews contact: Deidre Randall, BlueLine Publicity/Peter E. Randall Publisher, LLC.

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