

Just When U Think U Know What You're
Talking About . . .

Along Comes Grandpa

Caregiving Resources for People in the Real World

Sue Salach

Just When U Think U Know What You're Talking

About . . . Along Comes Grandpa

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Published by Wheatmark™

610 East Delano Street, Suite 104, Tucson, Arizona 85705 U.S.A.

www.wheatmark.com

Salach Senior Services, Inc, Streamwood Illinois

Publisher's Cataloging-In-Publication Data

(Prepared by The Donohue Group, Inc.)

Salach, Sue.

Just when u think u know what you're talking about-- along comes Grandpa : caregiving resources for people in the real world / by Sue Salach.

p. : ill. ; cm.

ISBN: 1-58736-666-5

1. Older people--Care--United States. 2. Caregivers--United States. 3. Aging parents--Care. 4. Adult children of aging parents. I. Title. II. Title: Along comes Grandpa

HV1461 .S25 2006

362.6/0973 2006929255

Dedicated to Grandma and Grandpa Salach



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FOREWORD

I HAVE BEEN WORKING in the healthcare industry for almost thirty years in many different capacities: medical receptionist, medical assistant, oncology nurse, hospice nurse, and managing physician practices and most recently, senior housing. Through all of these years, I have read more books and journals than I can count regarding caring for seniors, caring for caregivers, self-help guides for families, resource guides, and the list goes on. This is one of the first books to address caregiver needs and issues in one concise story.

It is the story of a relationship between two very different generations, separated by almost sixty years, which at times is funny, heartfelt, sad, and moving, and at all times honest. Sometimes it is painfully honest about how difficult it is to be the caregiver, the family member, the cheerleader, the doctor, the nurse, and the care coordinator. We are all those things and more when we assume the role of caregiver for a loved one. Unfortunately, the relationship changes and we no longer get to be the granddaughter, wife, mother, father, or husband when we assume the caregiver role.

Each family member has a role in the caregiving, whether he or she realizes it or not. Some are supportive and involved; some are passive and uninvolved; and unfortunately, some are long-distance armchair quarterbacks. These are the relatives loaded with advice on what you are doing right and wrong and how they would do it if they lived closer or

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didn't have a job from which they could not take time away. Thank God for friends and spouses that are there to lend a hand or a listening ear or to "grandpa-sit" when the need arises.

When a parent ages and begins to have health problems, the dynamics of the entire family change. Some families are torn apart by the illness and some are brought closer together because they share in the caregiving. When families work together, their relationships remain strong and supportive. When families are all over the map on the game plan for Mom or Dad, unfortunately, the result is that too many times it is the last time they speak together or communicate for years, or forever, because someone was mad over something that was said, or done, or not done.

I remember taking care of a senior that was very near death and she told me that her wish was that her children wouldn't be so angry at each other and would stop fighting. She said this was the only thing that made her sad. The day she died, the atmosphere in the home was very tense. The children were all there, but they were bickering over bills and money and how many days they had missed from work, while their mother lay dying in another room. I wish I could say that this was a rare occurrence, but unfortunately, it is not.

There are so many more resources available today than when I first began in healthcare, and in some ways, I think all of the choices can complicate matters even more. Years ago, families took care of their loved ones. They took them into their homes and cared for them as their parents and grandparents did for them as children. Today we hire caregivers, Geriatric Care Managers, and home health agencies, or utilize retirement homes, assisted living communities, and nursing homes to take care of our loved ones. How do we find them? How do we know which is best for our loved

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ones? How do we take care of a loved one at home when we work sixty hours a week and are raising children and just trying to keep our heads above water? Sue's story takes us through the continuum from caring for Grandpa in her home, to hospice care in the nursing home. Along with her story, she shares valuable insight and gives great advice and information on how to access resources during the caregiving process—the things she learned on the journey that she shares with us. I remember teasing her after she kidnapped Grandpa from the Psychiatric Unit. I told her that he was a great teacher and she sure was learning a lot about the healthcare system. While I was trying to lighten the mood and make her laugh, it was true. Grandpa was a great teacher. Sue has now become the teacher and she is imparting all of the knowledge she learned through her triumphs and successes and failures along the way.

For those of us in the healthcare profession, a word of advice: Be the daughter, or granddaughter, or son, or husband, or friend. We forget to take off our clinical hat and just be the family member. You cannot be an objective healthcare professional as the caregiver of a family member or loved one. Someone and something gets lost in the process. We are less likely to ask for help because we think we know it all or that people will think less of us because after all, we are nurses, doctors, and technicians, and we have special training. The sad thing is that we usually don't realize the mistakes we have made until it's all over. Professionals have a difficult time grieving. We have been trained on how to terminate and let go after losing a patient, and that is how we can do what we do every day. However, when this is not a patient, when it is someone we love, a part of our life, a part of us, we can cheat ourselves by trying to be the professional and not the one who loves this person. When we do this, we end up dealing with grief and loss issues years after we have lost

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our family member because we never took the time to acknowledge what we were feeling along the way as a child losing a parent or a husband losing a wife, etc. Sue teaches us this through telling her story so candidly and openly.

Sue's endearing story makes the reader feel that it is OK to laugh, be angry, or feel guilty, to be frustrated, tired, sad, hopeless, and to feel all of these things at the same time, or go through the stages a little at a time. However, the most important message from this story is that we all get through it and we need to forgive ourselves the mistakes we made along the journey. We are all human, and that's life.

—Jan Hutchinson, RN

INTRODUCTION



The Reason for the Journey

I HAVE FOUND THAT there are several reasons for my journey as caregiver. First and foremost, I think that my educational and career journeys were specifically designed to lead me to care for Grandpa. Although I wasn't even close to being perfect, I was lucky enough to have access to the right people and resources to help me. I think that I needed to learn what it means to care for someone who is elderly—talking about it and doing it are two very different things. I had to experience what it means to see someone you love struggle with an aging body, and how to get them the care they need. I had to learn how to utilize the resources I am always sharing with other caregivers. You can have all of the resources in the world, but if you don't know how to apply them, they are useless.

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My experience with Grandpa has really changed my entire perspective on the role of a caregiver. I had to experience how overwhelming it is to try to meet the needs of an older adult who needs more care. I had to live through the times when I just wanted to curl up in a fetal position and pray to God that someone would magically take over and help Grandpa. I have to say that being a caregiver has humbled me and made me realize that I may have misjudged other caregivers I have met through my work in the geriatric field, thinking, why don't they do this or that. I really had no idea what they were going through when I gave advice to these family members trying to find out how they could get help for their loved ones. On an educational and career level, I sounded very authoritative in my advice. I am sure that some of those people I spoke to went home and felt even guiltier because they didn't know how to help, or even cursed me for making them feel overwhelmed by all that they still needed to or hadn't even thought of doing for their loved one.

I also feel that this journey was exactly what I needed to write this book. If I had written it before my time caring for Grandpa, I would have written a more candy-coated book of what everyone should do to care for their loved one, one of those self-help books that make you feel even more inferior than you did before you sought the help.

My hope is that now, with my education, career, and caregiving experience, I have written a book that is realistic in every sense of the caregiving experience. I hope that this book will reach out to you as I admit my faults openly and honestly, like a gaping wound with the bandage removed. I hope that you will find some sage advice in the "Tips" area of each chapter and that they will be useful guidelines for you as you go through your own journey. I hope that my "learn from my mistakes" storytelling style will help you avoid some of the many pitfalls that await you as you try to

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make the right choices for your loved one. I also hope that when you are finished reading this book, you will take what you learn and pass it on to your family, friends, and neighbors who are caring for a loved one.