

What a wonderful culmination of two decades of working with people with Alzheimer's dementia. *Alzheimer's 911* is an impressive, empowering, and honest book, full of frank and fearless advice and very practical help. Frena draws from her widely varied real-life experience as an Alzheimer's dementia caregiver and walks you through step-by-step. This is a must-read guidebook, covering all aspects of dementia care from Alzheimer's to the many other dementias of age. Her personal anecdotes are both touching and humorous, and she enables caregivers to understand what is really going on inside the person with dementia. I have to say I laughed and I cried and found this book very entertaining, as well as deeply spiritual. This is one Alzheimer's book you don't have to be afraid to pick up!



Raghida Khouri, RN

Frena Gray-Davidson's *Alzheimer's 911* is an indispensable gift to anyone dealing with dementia. With humor, sensitivity and clarity, the author flawlessly offers the two most profound and precious tools to anyone associated with dementia diseases: Hope and Pragmatism.

As most of us have sadly discovered, hope and Alzheimer's are rarely used together in the same sentence; but in her book, Frena makes the compelling and life-saving case that a rich, meaningful life can indeed be an integral part of the Alzheimer's process. And after making that assertion, she provides practical, concrete, step-by-step pointers for how to achieve precisely such a worthy life while on the Alzheimer's journey. . . whether as afflicted or caregiver.

Frena delivers convincingly and wholeheartedly on her promise to not only make your journey bearable, but to teach you that, in fact, the journey itself will bear you up. For any on the Alzheimer's path, I can only urge them to do themselves the ultimate favor: Read, follow and enjoy this book!



Christiane Griffin-Wehr

Author of *Travels in Place: A Journey into Memory Loss*

If you are a caregiver, if you are a friend to a caregiver, you need to read *Alzheimer's 911*. If you are a pastor, you need to keep many copies of this book within reach of your favorite translation of the Bible. When church members find the courage to tell you of their struggles with a family member or a spouse, you will have a poignant, fun, and realistic resource that will guide them and offer encouragement and simple insight into this caregiving adventure.

Frena Gray-Davidson gives us a fresh way to walk through this holy ground of caregiving. She opens a window that does not show a brick wall but a colorful garden of possibility. Frena has led a lively caregiver support group at our church for a number of years. No one leaves empty. When their well runs dry, they show up...again and again.

Alzheimer's 911 turns the horrendous word "victimhood" into "transformation." It offers creative, profound, and simple ways of being on this journey together, no longer as strangers but as friends.

I have known Frena for eight years. When I moved to Sierra Vista, AZ, my mother was in "Alzheimer's Land." I had read plenty of information on medical advances. I was tired of medical advances. What I needed as a daughter was to hear of the soul journey. I needed to hear a fresh perspective on caregiving that related to the heart and not the mind.

This book affirms the goal to be simple and profound as we encounter caregiving. It provides new ways of listening and laughing and thinking "outside the box." She offers candid illustrations of ways we can go about caregiving in fresh and creative ways. She names the ways we have been patronizing out of fear rather than out of compassion and peace.

Frena says it best: "Take the deeper, more profound, more deeply spiritual approach, and live your life in the present moment." Then our mothers, fathers, sisters, and brothers will know they are being listened to as you care for them. And you will know the transforming reality of "God with you" as you do the sacred work of caring for another.

Had I read *Alzheimer's 911* when my mother was in "Alzheimer's Land," I would have said, "Alleluia! This is hope. This is what caregiving is all about!"



Rev. Virginia Studer
Faith Presbyterian Church, Sierra Vista, AZ

The book cover features a central circular graphic with a glowing sunburst effect and numerous butterflies. The title 'Alzheimer's 911' is prominently displayed at the top in a large, stylized font. The background is a dark, ornate pattern with butterflies scattered throughout.

Alzheimer's 911

Help, Hope, and Healing for the Caregiver

Frena Gray-Davidson

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Dedication

This book is dedicated to my caregiving friends in Bisbee:

Myrtle Attaway, ninety-one and counting, who has cared for her parents, her husband, her friends, her many dogs – including her present faithful companion, Star – and blesses us with the best laugh in the world.

And to my dear friends Yvonne Grimm and Nancy Williams, caregivers to beloved husbands.



Acknowledgements

Alzheimer's caregiving is a fairly mentorless world, but, thank goodness, there has been Dr. Tom Kitwood, who truly taught that people with dementia are just as real and human as the rest of us and led the ground-breaking Bradford Dementia Project.

And there is the American Alzheimer's Association, the Alzheimer Society of Canada, and the Alzheimer Society of Great Britain – without whose support groups no caregiver would be sane.

In writing this book, I want to thank Dr. Georgia Neff, for invaluable information on the nutritional approach to the dementias, and Dr. Helen Saul, for research and information gathering.

I also want to thank Robert and Cleone Reed for their encouragement to write this book to meet the real inner-journey needs of caregivers.

Grateful thanks also to my wonderful editor, Kate Rakini, for patient help and good guidance.



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Introduction

Are You Feeling Crazy?

So you're dealing with Alzheimer's and it's making you crazy. Well, there's nothing wrong with you. Alzheimer's and most other dementias make most people feel that way at least three times a week. Welcome to the confusing world of dementia caregiving!

Now here's the good news. In spite of everything you've heard, you can make sense of all this. This book will teach you how. You don't have to stay confused, upset, angry, depressed, and feeling helpless. I can't promise you there will never be a day when you don't feel those things. However, if you build your understanding, practice your handling skills, nurture your own inner life, *and* make a really good self-care plan, you will be able to take charge of both caregiving and yourself.

Right now, we can't really fix Alzheimer's. However, it is currently the most researched disease on the planet, so you can rightly hope for a cure to be found literally at any moment. The good news is – you can fix you, and I'm here to help you do that.

Yet caregiving isn't about fixing anything. It's about creating a life you can bear and which, in turn, bears you. From the beginning, we are going to assume that you could make sense of everything in the world of dementia – if you only knew how. I'm going to teach you how. There are things you need to know about Alzheimer's that no one is telling you.

In fact, since the current fashion is to despair about Alzheimer's, any potentially good news tends to be withheld. For example, there is actually a meaningful inner journey going on inside the person who has dementia. There are important ways that a person with Alzheimer's may grow and develop in spite of their disease.

Daily happiness is very possible, even with Alzheimer's. And such happiness is also available for caregivers. It doesn't matter if you didn't want to become a caregiver. It doesn't even matter if you don't particularly like the person you are caregiving. This journey can still lead you to growth, forgiveness, and peace – if you are willing to accept some help.

That, my friend, is where I come in. Nothing you learn on this journey is wasted. Everything will enhance who you are, who you may become, and how you may grow. The whole secret of dealing with Alzheimer's is finding ways to answer the great spiritual question: "How am I being asked to grow?"

Being a caregiver is not a waste of time, even if you don't want to do it. Every task you learn, every dilemma you solve, every tear you wipe away – even if it's your own – and everything you forgive will expand your heart, your soul, and your whole being. It will bring to you a whole range of profound skills and gifts that can be applied to all the situations of your life.

It's okay if you don't believe me now. Just read this book one section at a time. Then try the techniques one at a time. Use the approaches suggested here and see what works and what doesn't in your particular situation.

I've been working with people with dementia for twenty years now. Maybe like you, I never intended to do such work. I was raised in England with parents who were both nurses by profession and, I can tell you, that was on top of the list of work I never intended to do. Caregiving never held any attraction for me. No, I wanted adventure.

So, I became a journalist and worked in Asia as a travel writer and broadcaster, traveling almost everywhere between India and China. Studied acupuncture and Chinese medicine. Practiced Buddhist meditation. Did Tai Chi in Hong Kong for five years with a great martial arts teacher. In short, had the kind of adventures I'd dreamed of.

Eventually I moved to America in search of what shaped the wonderful, lively, heart-centered Americans I'd met all over Asia. And yes, I wanted to grow myself more, too, though I wasn't clear how. But one thing I could have told you then, for absolute certain, was that being an Alzheimer's caregiver would not have been my choice. I never would have picked that as my pathway of development.

However, it picked me. As far as I was concerned, I was only looking to save some rent money when I moved into a shared house in Berkeley, California, to help care for a seventy-nine-year-old woman with a disease I couldn't spell and had never heard of. It was Alzheimer's, of course, and that was such a totally heart-changing time for me and my soul and spirit that I plunged into being an Alzheimer's caregiver for the next twenty years.

What's the difference between you and me? Am I, unlike you, a perfect caregiver unruffled in any way by the problems of caregiving? Oh please, let's get serious here! Ask anyone who knows me and they'll tell you the word "perfection" does not describe the average day of being me.

However, there probably is an important difference between you and me, and that is exactly what allowed me to learn what I have learned. The difference is that I had never heard of Alzheimer's before becoming a caregiver. That meant I had no preconceptions about it, leaving me free to be open and inventive. Nor have I been related to the people I've cared for. In my first experience, I had never met Hannah when she was healthy, so I wasn't upset by her losses. I also had three other helpers in the house, so I wasn't alone with the issues of caregiving.

When I began being an Alzheimer's caregiver, I went to several workshops and seminars. I found them largely useless. They seemed to be about brain cells, drugs, DNA – and despair. I knew I couldn't learn anything helpful in all of that. The nearest real help that I found was in the caregiver support groups offered by the Alzheimer's Association. For the first time I experienced real caregiving being talked about by real people actually doing the job, just like me. Unlike me, they were also dealing with sadness, loss, and the pain of watching someone they once knew become a completely different person.

I realized right then, in my first support group meeting, the essential

difference between family caregivers and myself. It was like the difference between Fred Astaire and Ginger Rogers. You know the joke – she had to do everything he did, but wearing high heels and dancing backwards. In caregiving, I'm Fred Astaire and family caregivers are Ginger Rogers. That doesn't mean, however, that many of the things I learned can't be very useful to you. Because of my lower stress level and my lack of personal grief and pain, I was able to learn what I can now pass on to you.

It also helped that for the previous fifteen years in Asia I spent long periods of time in Nepal, Indonesia, India, and Hong Kong. Each one of those cultures was new to me when I arrived for the first time. I had to learn something of the language, the customs, and the lifestyle of each place in order to manage daily life at all.

Everywhere there were kind people willing and ready to help me get to know their world. I loved Asia and it was a very magical time in my life. Those experiences helped me understand that learning about Alzheimer's was going to be like learning about any other new culture. All my instincts told me that I should learn about Alzheimer's from the person I was caring for.

I knew I shouldn't listen to most so-called experts, especially if they only peddled hopelessness and despair. No, I knew intuitively that the Alzheimer's expert in our house was an elderly woman living in the midst of the disease – in Alzheimer Land, as I soon thought of it. There was no point in going to seminars that didn't empower me. Instead, I spent my time hanging out with a seventy-nine-year-old German Jewish refugee in Berkeley, California, and she became my Ph.D. in Alzheimer's.

The first year I didn't even realize how much I learned. My view of what was going on was so profoundly different from the mainstream medical view, and still is, that back then I doubted my own observations. It took me nine more years to understand what a wonderful teacher she had been, she and the others I cared for in those years. In that first decade, I had plenty of time to try out the many things I'm going to share with you. In the second decade of my Alzheimer's and dementia work, I began teaching families and professional caregivers what I had learned. It was, and is, all about developing relationships with people with dementia.

That, you see, is the heart of our struggle. How do we create a

heartfelt relationship with someone made new to us because of an illness? An illness, moreover, that has changed this person into someone we don't want that person to be? No one wants someone close to them to change into a person with Alzheimer's or a similar dementia. Not only is the disease challenging enough as it is, but our society hates and fears it.

Caregivers are not being encouraged to learn the possibilities that still remain, which leaves us stuck with nothing but loss. If we liked this person before, how can we get over the change in them? If we didn't like this person much before, how on earth do we get over ourselves? Even worse, how do we make a heartfelt relationship with ourselves when we may not like ourselves as caregivers? If we are confused, grieving, angry, and distressed by demands, which promise to be endless, how can we find ways to like ourselves? These feel like insurmountable problems.

We can only change ourselves with tools, time, a willingness to grow, and the acceptance of a real but very different relationship in present time with this person who has dementia.

So in this book, we'll start with the easiest item – the tools. Then we'll get to some other useful things. Let me warn you – when it comes to dementia, there is nothing that always works. What works on a Tuesday afternoon may not work on a Friday morning, this week. Next week, who knows?

That's why you need a whole repertoire of approaches, skills, tricks, and devices in your box of tools. You need flexibility and ways to bribe, persuade, and manipulate. You need to grow a kind understanding of yourself and also of this person you caregive. Also – trust me on this – you really need to come to a place of secure love for yourself and others. Love is going to be your greatest management tool.

We do Alzheimer's caregiving just one day at a time and, some days, just one hour at a time. That's how we make it work. You'll succeed by developing new skills every day and trying them out repeatedly. Flexibility is your lifeline, and rigidity will break you in health and heart and will profoundly affect the one you care for.

So, let's find a way out of the craziness and into the light. First, we have to get on the Alzheimer's bus, where we'll start by throwing away almost every assumption our society makes about Alzheimer's, because

they really aren't true.

For example, did you know that our modern Alzheimer's disease of today is not actually the disease studied by Dr. Alzheimer, nor is it much like the disease that was named after him by his director? He was not studying the dementia of old age, but something then called "pre-senile dementia."

We also assume that Alzheimer's disease affects people in ways it doesn't. We commonly describe people with Alzheimer's as empty and gone away, and it is widely assumed that nothing positive could possibly be going on within this disease. Even professional care people think this way.

They need, instead, to ask themselves whether their patients have gone away because there is nothing worth being present for. My experience of Alzheimer's is that people are present and reachable as we love and accept them for being exactly who they are. In that place, there are all kinds of activities they respond to and ways they can express themselves.

The heart and spirit of a person does not get Alzheimer's and may even recover from former wounding through the course of their disease. We assume their behaviors demonstrate dementia and that therefore they are meaningless disease symptoms. We don't see these behaviors as meaningful communications.

We create our own problems with dementia by choosing to see it as a battle of conflicting interests – our normal thinking versus the abnormal thinking of the person with dementia. That is how we start to make ourselves crazy and the person we care for lonely.

Listen to any medical description of Alzheimer's and all you hear is medical jargon about disease process. You don't hear much about people. Yet, it is only in looking inside the disease that we can find the person. It is only in finding that person within that we can find answers, for both of us. No one is a disease. A person is a person and may have a disease, which complicates living, but it does not dehumanize them. Be very suspicious of anyone who thinks that way, because they neither truly know people with dementia nor have answers for you. We would have known a great deal more about how to help, support, and reach people with dementia well before now if they had not been devalued.

Our main job is to learn how to be good caregivers. Until we care for ourselves as caregivers, we never successfully grow to the task. Instead,

we'll become those angry, over-stressed, resentful people so often found in Alzheimer's caregiving. Much of this overall negativity comes from the inner being of the caregiver, not from the illness being dealt with.

On the whole, we have not asked dementia caregivers to learn the disease. We have not asked them to learn about themselves as caregivers and to take on the task of dealing with their own emotional and spiritual growth.

That is what this book asks of you. Learn the disease, discover yourself as a caregiver, and take the necessary steps to transform that within you that needs to be changed. Don't worry if you don't yet know how. That's why I wrote this book, so you can shorten your own distress period by learning from my mistakes. You'll also have many opportunities to learn from your own mistakes. And, I promise you, with your more flexible attitude, you'll have a lot more fun than all those people terrified of Alzheimer's.

Our society almost gloats about how overwhelmingly awful it is to be an Alzheimer's caregiver. I know many who have managed the task with grace, humor, and resilience – which doesn't mean they managed every single day with all of those qualities. Here's a starter list for growing yourself:

- Have the willingness to get to know the disease.
- Show openness to re-learning this person who now is affected by dementia.
- Practice the ability to sit in the present moment with this person.
- Develop the patience to take life slowly.
- Nurture compassion and love for someone on the dementia path.
- Cultivate forgiveness – of yourself, of others, and especially of the person you care for.

We caregivers can easily become addicted to problems, especially once we get tired, overwhelmed, upset, sleep-deprived, and emotionally drained. It's like any other addiction. We know where we are, what it feels like, and how familiar it is, so we put up with the pain of the addiction

rather than take the challenge to grow and heal.

This book is about how caregivers can, and indeed must, grow spiritually and emotionally, in order to heal and free ourselves from pain in our caregiving lifestyle and to bring the best to the one we care for. It centers solely on the caregiving issues and the caregiver. It is a book about walking the caregiver walk in companionship with one who needs us. Once you learn that, you will have a much better time and so will the one you care for.

As we go forward, I want to share the story of how I first learned Alzheimer's from an expert living within the disease. An essay about this journey, "A Life in Alzheimer's Land," is interspersed throughout this book. I suggest that you, too, might find it helpful to journal about your own experiences of learning, struggling, and growing into the task of becoming a caregiver – especially the journey to relearn who this person has now become, hidden within dementia. So, let's go.

A LIFE IN ALZHEIMER'S LAND

I met Hannah and liked her immediately. She was sitting on a battered sofa and, when I sat down beside her, I held out my hand to her.

"Hallo, Hannah," I said. She took it between her own and held onto it. Her skin was soft and dry against mine and she looked at me out of light blue eyes, not old like the rest of her. She smiled. It started in her eyes, spread to her mouth, and slowly travelled until it filled her whole face with pleasure. I could feel the same big smile on my face. Then we both laughed. We had connected.

"It's so good that you came," she said, as if she had been waiting especially for me. Hannah welcomed me effortlessly into her heart. She was a dignified woman with a graciousness that survived her losses. Her understanding of the world around her was fractured and it gave her a bizarre charm.



chapter
1

Starting Your Journey

I want to start by pointing out that I use the terms Alzheimer's and dementia interchangeably. Not only because Alzheimer's is actually one form of dementia, but also because, right or wrong, I have concluded that it is likely that we use the word Alzheimer's far too often. As I detail later, there is ample reason to note that causes have been found for the development of many dementias. Therefore, there is little reason to assume they are Alzheimer's dementia, when so far that remains a dementia of unknown cause, origin, and treatment.

Mine is not the usual view and I only come to it through observation of real people and their lives. I do not dissect brain cells or autopsy brains. I observe people with dementia, their lives, and the events of their lives and find they often have common pathways. I was the first observer ever to draw attention to the pattern of early serious deprivation in childhood among those later diagnosed with dementia.

At this point, I am the only person I know to suggest the use of digestive enzymes to improve brain function through more efficient absorption and distribution of nutrients – again based on personal observation. I may also be one of the few to suggest that the behaviors of dementia are meaningful communications rather than meaningless symptoms.

Agreeing with me doesn't matter. What matters is that you take

your own learning in hand and trust your own observations while being with and caring for your person with dementia. You are your own expert and what you see is what you see. From what you see, you can make a care plan that works for both of you.

So I use Alzheimer's and dementia interchangeably for two reasons. One, because we lack the knowledge and genuine evidence to differentiate the dementias. Two, because our problems as caregivers are, for the most part, essentially the same, no matter which dementia we are dealing with. There may be subtle degrees of difference between the dementias, but the greater and more important differences for caregivers involve the usual range of idiosyncrasies between human beings. Everyone does dementia in his or her own way and that's what we have to learn. We have to learn each individual person and how their needs communicate themselves to us, if we are paying attention.

Family caregivers of elders with dementia often get stuck when they don't want to admit that life has changed and will never be the same again. Be willing to learn what the usual, normal, average symptoms of dementia are. See how they apply to your person. That way, you will save yourself tons of frustration, anger, resentment, and negativity. Even if you even slightly suspect that your mother or your mate is doing certain things to annoy you, a person who wanted to stay sane would be wise to attribute them all to dementia. Give it to the disease rather than the person.

One thing you can know for sure. If a person can get up in the morning with the sure intention of doing certain things to make you crazy, they don't have dementia. So if your man or your mom is driving you crazy, it's just by happy accident, not by successful intention. The other really important part of getting to know dementia is that people really can grow and develop even in the midst of their losses.

Getting to Know Dementia

I have observed that people with Alzheimer's have almost invariably had difficult childhoods and have often grown up to be fearful, wounded, anxious, secretive, or angry. They were wounded long ago and such wounds can hurt forever. People get very used to their own pain and

discomfort and do not realize that the wound is not in their hearts. The wound is centered in their defense system, and that comes from the mind, *not* from the heart.

If you don't actually believe this right now, that's okay. It's a fairly radical idea and one that I learned entirely from people with dementia. I always thought my feelings, defenses, and wounds were, of course, centered in my heart. Being with people with dementia for so long, I noticed that as they lost their relationship with reliable memory and the meaning of their own feelings, they often became very different people.

At first, they found peace, and then they moved to joyfulness, a sense of play, and even into a sort of blissfulness. Our deepest heart-centered feelings are always joy and love. When mind can no longer control the gates of the heart with fear or anger, people can then enter the sacred space where absolute love and joy reside. Alzheimer's and the other dementias can open the heart in a whole new way as memory and early training loosen their hold. People can become happy, unworried, less fearful, and much more loving. It is not at all uncommon in the progress of dementia. It is one of the blessings.

So, learn everything real about dementia, and then pay close attention to the one you care for. In your journal, note specific effects of different elements of daily life. This will help you understand how to manage both your lives better. For example, if you see that your mother gets agitated if pushed to hurry, you'll know to leave plenty of time to get ready for a doctor's appointment. If she becomes very sensitive to rain or wind, as many elders with dementia do, you'll know to avoid taking her out in such conditions, if possible. This way, you'll avoid exhausting struggles.

You, and you alone, are the real on-the-spot expert on the person you care for. You are the one who can sense when something has changed. You are the one who knows what makes that person comfortable or uncomfortable. Be prepared to stand up for what you know when necessary. That means you stand up to doctors, to social workers, to siblings, to everyone who assumes they know more about your person than you do. No one is as expert on your person as you are.

What Alzheimer's Looks Like

The Invisible Phase

This is my term for that period of months or years when only the person afflicted is aware that something is wrong with their memory and thinking processes. No one outside this person has any idea of their inner struggle, unless they talk about it – and most people don't. The stress and difficulty of this time of isolation and fear may show outwardly in any of the following ways:

- Emotional changes – becoming depressed, outbursts of anger in someone previously even-tempered, accusations, fearfulness
- Habit changes – not interested in former hobbies, reluctant to socialize, begins drinking heavily
- Changes in appearance – unkemptness, poor choice of clothes, doesn't seem to care about appearance, looks less organized
- Problems at work – no longer carries out duties well, can't follow through on projects, falling standards, inability to manage
- Cognitive problems – can't seem to follow a rational discussion, can't grasp a concept, can't balance a checkbook, can't organize medications
- Memory issues – which may be concealed from others

This is often a very secretive phase where trust issues are paramount. The person doesn't want anyone else to know there's something wrong, often because it is hard to understand what exactly is going on. Nothing feels right, mentally or emotionally. I suspect this phase can go on for years before the issues become outwardly visible as what is usually called the early stage.

The Early Stage

This is dementia as it first looks to outsiders and covers a range of problems. The visible early phase sees an intensification of all the memory, functional, and social issues, which become increasingly stressful for the individual trying to deal with them at the same time that the ability to do

so is declining.

This is the point at which family members begin to be concerned. They see that Mother looks less clean, neat, and well dressed, that her hair is no longer so well looked after, that some of her behaviors are odd. She puts salt into her coffee instead of sugar and yet drinks it down without apparent response.

Normal household tasks get ignored and left undone, or are done incompletely, inefficiently, or oddly. Nothing seems to be proceeding smoothly any more. Emotional outbursts may continue. Accusations may be made, against neighbors, family members, bank tellers. Everything is someone else's fault.

Shopping, eating, and driving may all be being done poorly. The refrigerator is full of ice cream but not much food. The stove isn't used for cooking. Family members begin to question if something is wrong and whether they should intervene. Both answers are YES.

Disruption of daily life continues – pots are left to burn on the stove, sleep habits change, things are put away in strange places or lost indefinitely, car accidents happen, or people get lost while driving in familiar territory. This whole period of time, which might be a couple of years, has everyone feeling uneasy, unsettled, and unable to decide what to do. This is when the first family council should take place.

Re-Learning the Person with Dementia

People with dementia change. That is inevitable. Exactly how a person changes is almost totally individual and this is another learning task for you. Note those changes so you can make allowances for them and plan around them.

For example, people who used to be very outgoing and gregarious no longer seem to want to go out. When you try to make them, they seem to withdraw in the crowd. We can guess – and guessing is a very valid part of observation, by the way – that because these people can no longer process information and deal with social contact successfully, the old sense of enjoyment has gone. Instead, they feel alone, fearful, and incapable in a social scene. Caregivers deal with this in different ways. Some will still try to make their person social, thinking that this helps retain abilities.

It is a valid point of view, although not one that I share. Usually people with dementia need less stressful lives in which they are not forced to confront their growing inadequacies. As a caregiver, you are free to make your own care plans for the person you look after. Just don't think you can hold back the disease, because you can't. People often tend to lose interest in what they once cared about and I'm not sure we can, or even should, do much about that.

Although people would like to think it's really true that you can retrain a brain affected by dementia, there is no real proof of this. After all, Nobel prizewinners have Alzheimer's. Observers can easily confuse the pleasure of getting attention with joy in the activity. My observations are that people can be distressed by mental exercises that are too complex. I've seen people slap themselves or beat on their own heads when tormented to carry out intellectual or, even worse, memory tasks. I don't support it.

Maybe, instead, we caregivers need to help them find new rewards. There are many other kinds of satisfaction and amusement available to people with dementia. Perhaps we should look at activities based upon the non-intellectual – creativity, painting, gardening, pets, music. Learn to pick up on any cue that this person mentions from their own life.

Better to learn what works for this person now so you can replace losses with other kinds of reward. The brain has now changed and, with it, the personality. We usually can't move people back to being who they were once they are no longer that same person. We may be able to evoke their former being from time to time, but we can't force it.

Instead, our task is to find that which more suitably meets their needs and helps them to be happy. Many people with dementia become much more at home in their own hearts and may become more emotionally open and available. That openness and availability is where we should try to evoke responses. If we insist on holding onto who this person once was, everyone is left lonely and bereft. This is a center of crisis for many caregivers.

The increasing emotional openness of the person with dementia can be a profound challenge to family members who were more comfortable with reticence and avoidance. It is, however, their own chance to become more emotionally open and available to themselves. It can also be one of

the great and curious gifts which dementia has to offer caregivers, if they have the courage to accept it.

Be Prepared

You never know what's going to happen, so be prepared with your care package of necessary information on the person you look after. This should include their Medicare card, any other medical insurance information, social security card, list of current medications, list of current medical conditions, copy of Power of Attorney for Healthcare, copy of Advanced Medical Directives, personal doctor's name and telephone number, and any other relevant papers.

Never give these to anyone and never leave them with anyone. If someone wants to copy down the information, at the hospital admissions desk, for example, stand there and wait for the papers to be returned to you. Hospitals can easily lose your paperwork if you give them a chance. Have a spare copy of the medications list so you can allow an ambulance crew to take them to the hospital if they are answering a 911 call at your house. Put everything in a folder that fits into an easy-grab plastic bag and keep it by the telephone. That way, in an emergency, you can grab and go. Remember to keep everything updated.

If you think that one day you might choose to place your elder in long-term care, do your homework well in advance. Visit likely places in your area so you know what they look and feel like. Note down any that you like the look of and check out their latest state inspection report, which by law they are mandated to keep available for reference for any visitor or official. When you get home, go online and look up their state licensing and check past reports and any citations they've received, since this will help you in your assessment. Small geographical issues – slow flowing water from a washbasin – are not important, but issues of abuse, neglect, and poor care conditions are very important.

Caregiver Toolkit

Usually in Alzheimer's and similar dementias, the emergencies for caregivers are internal – that is, how bad you feel, how angry, how agitated,

how sad, and so on. So this is a simple start-up toolkit for you, to help you through the moments and hours when things seem too overwhelming. Do *not* disregard the usefulness of such tools because they look too simple. Caregivers usually tell themselves a *very big lie*, which makes self-help almost impossible. They internally tell themselves that the way they feel now cannot be healed or helped until the problem is over. They then have a sense of personal hopelessness and the guilt of thinking they are wishing for the death of the person they care for.

We need help when we need it. In every moment you can choose to change yourself. You can pick calmness instead of agitation, love instead of anger, breathing instead of tensing. There are a number of extremely simple ways to de-stress the moment and that de-stressing is the key to your peace of mind. You can indeed solve your particular internal problem, the stress you feel, in every moment. You have power to make that choice at any time. So, discipline yourself to make that choice instead of choosing to perpetuate your stress.

The reason so many don't do this is because they are addicted to stress. Addiction to stress is like any other addiction. No one in the caregiving world ever talks about this, but caregivers quickly get addicted to stress because it brings instant energy, albeit long-term harm. The energy of stress is a free drug with terrible side effects.

I'm not denying that caregiver life is genuinely stressful, but Alzheimer's caregivers have been notably unwilling to learn better coping skills. Everyone working with them notices this and wonders about it. I have come to the conclusion that it is the addiction to stress that feeds this reluctance. And this addiction probably has a great deal to do with the fact that many caregivers die before the person they are caring for. So here are five de-stressors:

1. Breathe

Sit down and take ten deep breaths, slowly in and slowly out. Each breath should go all the way from your nose down to below your naval, moving your belly in and out each time. Do this regularly throughout a stressful day. Notice how very shallow and tight your breathing is when you are stressed. This starves your body of oxygen and makes you feel worse and do worse. Using this tool can profoundly change your moments.

Don't believe me? Try it and see. Breath is your lifeline. When stressed, we take in too little air, too seldom. This is a great gift you can give yourself in any moment.

2. *Walk away*

If the person you care for has become agitated or angry or is just plain driving you crazy in that moment, turn around and walk away. Sit in the garden, lie on the sofa, run a hot bath, pick up a book, play the saxophone – anything that shows you that you are in control of the boundary of your life in this moment.

Even if you have to stay in the same room, you can give yourself the gift of doing something you want to do instead of something you don't. You can mentally walk away. A bonus from this is that the other person often calms down in response to your calm.

3. *Don't argue*

You can never win an argument with a person who has dementia. Do you know why? Because they have dementia! They are injured irrevocably in their cognitive ability to make sensible arguments. So save your breath. Breathe for yourself instead; then walk away so you can think about why you're trying to force your opinion on a person with dementia. Usually it is because you are angry, which they pick up and return as stubborn resistance.

4. *Be absurd*

Sometimes our own zaniness is what keeps us caregivers sane, so be absurd. Waltz the cat, bark at the dog, dance around the house. On the whole, people with dementia do not have a whole lot of judgment about our silliness, and that can be very freeing. Try it and enjoy it.

5. *Apologize*

Let's suppose you lose your cool and express anger at or about the person you are caregiving. A few minutes later, it is very likely that this person will have totally forgotten. That is the time to apologize honestly.

For example: "I'm really sorry I got mad at you. I shouldn't have done that. I just didn't get enough sleep, and blah, blah, blah."

It is very usual for the person with dementia to say, "Oh no, you never lose your temper," or something gratifying like that, because these

incidents are not stored in their long-term memory. You get let off the hook for bad behavior and, even better, you are often absolved totally by this person you look after. So next time you lose it, say you're sorry and see what happens. In the immediate moment, you'll feel better for apologizing and, in the long-term, it is rather like absolution – a great comfort. It's one of those quirky little bonuses of caring for people with Alzheimer's. So, enjoy!

Five short problem-solvers – can they really work? You'll have to try them to see for yourself, but here's the reason they often work. When we feel that some aspect of caregiving is a constant, on-going, unbearable, problematic issue, we become stuck in our position. Once we get stuck, we find it impossible to unstick ourselves and it becomes a vicious circle. Doing any of these five things breaks the cycle. Once we break the cycle, everything can change for the better.

A LIFE IN ALZHEIMER'S LAND

I had been told that she had no short-term memory but that did not mean much to me until I saw how it affected Hannah. Every time I left the room, even for a moment or two, she would greet me afresh each time I returned.

“Oh how nice!” she would say, “I’m so happy to see you.”

She did not remember I had been sitting next to her a few moments before, talking with her. I enjoyed the warmth and friendliness of these greetings, of which there must have been more than a dozen on my first afternoon with Hannah. I thought it was delightful. I especially enjoyed it when she said, “I shall never forget you!”

Hannah was a big-boned woman with silvery-white hair, a patrician profile that must have taken years to grow into, and a ready smile.

It was easy to feel affection for her right from the start. Like many others who have lived in extremity, I am drawn to those who survive life on the edge and do it well. There could be no doubt that Hannah was living on the very edges of her intellect and yet she seemed very full emotionally.