

Foreword

If you have picked up this book, chances are you are either professionally involved with the elderly or dealing personally with someone who has lost the ability to remember. Or perhaps you are looking ahead at the frightening possibility that you may, one day, be among the forgetful.

Over four years ago, I watched helplessly as a wall suddenly descended in my husband's brain, cutting him off from his past and from the life we had shared for 35 years. Coping with this apparent catastrophe took all my attention and energy and it was a while before I could even begin to consider the future, and even longer before my curiosity and need would allow me to read.

Since that time I have reached out hungrily to everything that would help me understand what had happened to us. I've attended courses, visited care homes, started groups for elders suffering loss, and, most important of all, witnessed my husband coping with the reality of what had happened to his rich and creative mind.

When I first read *Deeper into the Soul* I almost wept with relief. Here is a book that speaks in one clear voice embodying all the voices I have sought in so many different directions. All the pieces of what I have been struggling to learn are here: information, understanding, communication skills, and, above all, a deep, encompassing wisdom to lift our experience from the mundane to the profound.

If you are a researcher, a hospital worker, a teacher, a caregiver, this book belongs on your desk or at your bedside. The creative, engaging format reflects the experience of the authors in teaching their philosophy and administering care homes. With each page leading the reader into an ordinary, recognizable question, they offer us four perspectives embodied and illustrated in characters who speak either from what they know or desperately wish to know. The Student-Intern asks our questions, the Psychologist offers us information, the Physician provides the science, and the Sage moves us above the obvious to the inspirational.

As I have learned, forgetfulness has many facets—physical, emotional, practical, spiritual—pushing everyone involved with it to search for

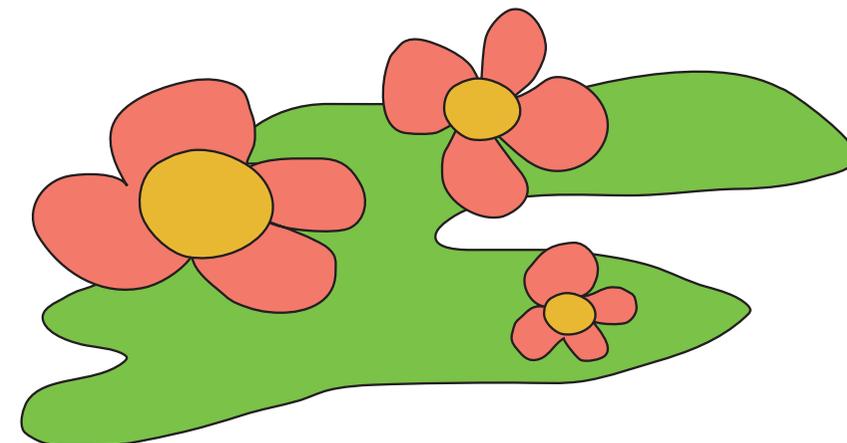
something beyond simple survival. Every day is filled with challenge, whether you are dealing with someone you just met or your spouse of many years. When the man I love and know intimately asks me if I am his mother, when he forgets the way to the bathroom, when he doesn't know the day or the year or his age, I have to find something inside myself and him that will move us from this tragic winter into the land of warmth and possibility.

When we are with this forgetful person we may be asking why this long, seemingly empty, silence or this string of disconnected words, how to respond to him or her, or, most vitally, where to look inside ourselves for the peace and compassion we need to face and accept this mysterious other. *Deeper into the Soul* offers us a new perspective: clear, accessible, and inspiring.

When we wobble off-balance, shock-struck, we need something to hold us looking up, a life preserver thrown from above, and, under our feet, a magnet firmly embedded in the earth. This book manages to cradle us safely between the two.

Deeper into the Soul will push you further than you meant to go, surprising you into a smile of pleasure, a buzz of new learning, a challenge to your usual interpretation of meaning. Best of all, it will engage and enlarge your heart.

Elizabeth Bugental, Ph.D., MFT
Author of *AgeSong: Meditations for Our Later Years*



[F]rom ancient Egyptian to modern Eskimo, soul is a highly differentiated idea referring to a reality of great impact.

Anthropologists describe a condition among “primitive” peoples called “loss of soul.”... Until he regains his soul he is not a true human. He is “not there.” It is as if he had never been initiated, been given a name, come into real being.

Other words long associated with the word soul amplify it further: mind, spirit, heart, life, warmth, humanness, personality, individuality, intentionality, essence, innermost, purpose, emotion, quality, virtue, morality, sin, wisdom, death, God. A soul is said to be “troubled,” “old,” “disembodied,” “immortal,” “lost,” “innocent,” “inspired.” Eyes are said to be “soulful,” for the eyes are “the mirror of the soul”; but one can be “soulless” by showing no mercy...

— James Hillman

Acknowledgments

We would like to thank the individuals and organizations without whose help this project never would have been successful.

Our work is inspired by the work of Arnold and Amy Mindell, who first applied process-oriented techniques to communicate with people in comas; by our many students, interns, and volunteers at Pacific Institute, who keep sharing with us their amazing encounters with people with forgetfulness; by the work of Naomi Feil, who with her validation method pioneered a new approach to working with people with dementia; by the teaching of Max and Ellen Schupbach, who model for us how to work with awareness and have awareness work on us; and by the many elders living in our AgeSong Institute Senior Communities and elsewhere, whose love and care for us make this journey worth taking.

The need for a different manual for caregivers, one that would introduce a new, more respectful approach to people afflicted with what standard medicine calls dementia and Alzheimer's, was born from our work with the elderly in senior care facilities created by AgeSong and supported by the vision and work of Pacific Institute's gerontological and mental health programs.

Dr. Doris Bersing, the director of Pacific Institute, was a central, supportive force behind the work, and we greatly appreciate her passion for our project. Special thanks go to Elke Tekin, our brilliant sister, who was involved in planning the first draft of the manual; her commitment to a better life for our elderly remains an inspirational force driving our work.

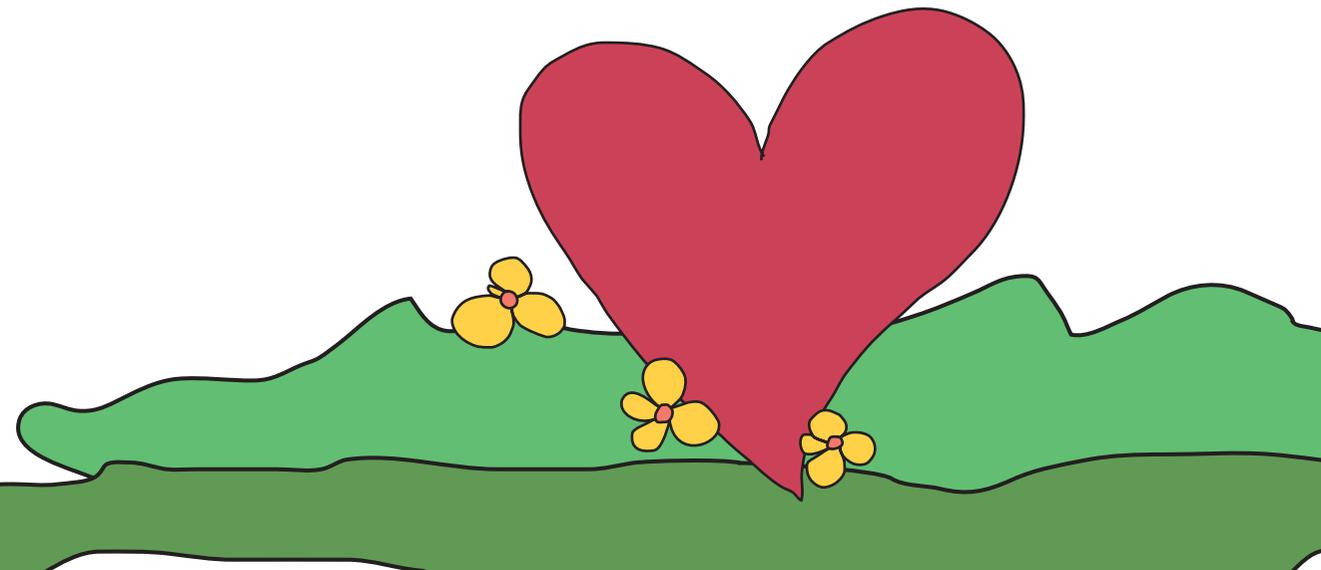
A big thank you to Piotr Orlik for working with us throughout the whole process; his creative mind and talents were responsible for creating the graphics and cartoons in our book.

We are grateful to Steve Boga, whose editing eye and enthusiasm for both writing and the elderly helped us move the project forward, and to John Levy for looking at the manuscript and helping this book be more organized and structured.

Without the dedication and tireless work of our AgeSong Institute Senior Communities caregivers and staff, who inspired us with their gifts, this work would not have been possible. Appreciation also goes to Zen Hospice of San Francisco, whose approach to being with the dying so much mirrors our approach to forgetfulness here and to the Blue Mountain Center of Meditation, the work of Sri Eknath Easwaran, and to their many wonderful students, teachers and practitioners—their dedication to changing this world to a more loving, accepting and heartfelt place is exemplary and inspiring.

We are thankful to the Institute of Applied Social Sciences, University of Warsaw, and the Kosciuszko Foundation for helping us to organize research and teaching at the Pacific Institute and for supporting Polish-American cooperation.

We want to acknowledge the pioneers behind our different approach to communication with people in different states of consciousness: to Gary Reiss, Stan Tomandl, Ann Jacob, Tom Richards, Jan Webster, and Pierre Morin. We always stand on the shoulders of our mentors, elders, colleagues, and friends, who continue to guide us in our search for meaning and to open us to a wider range of human experiences.



Introduction

Deeper into the soul—how do we do that anymore in today’s busy, fast-paced world? We may enter into the richness of this question by asking: What is the meaning of our lives? Why are we here? For what do we live, do we struggle, do we mature? These are big questions seldom asked today. Yet these questions, and how each one of us tries to come to terms with them in our own lives, lie at the core of this book on entering deeper into our soul, on understanding more fully this phenomenon of forgetfulness.

To address the question of how we go deeper into the soul is to enter different terrain than we are used to walking in our everyday lives. Space and time begin to take on a new quality.

Case in point: one day we were waiting in our senior care home for a visitor and decided to sit next to one of our elderly residents. After acknowledging one another with small nods, we sat in silence on the small couch. Ten minutes later, the elderly man rose and said, “Thank you for sitting with me,” then slowly walked away, pushing his walker ahead of him. Thank you for sitting with me. How simple—and how hard to do sometimes.

We would like to invite you to slow down for a moment and open your mind to the mystery of aging and forgetting.

Alzheimer’s disease and other forms of dementia are a source of fear for many of us. We are afraid that we could lose the minds of our parents, relatives, and partners while their bodies are still with us. Moreover, we are jolted by the same fears every time we can’t find our keys or remember the name of a friend. We seem to take it for granted that a meaningful life is possible only when one is blessed with excellent memory and cognitive abilities. From this point of view, life makes little sense for the millions of Americans and countless others around the world afflicted with forgetfulness.

In this book we highlight a basic attitudinal shift: Dementia is our teacher. Rather than simply a disease, dementia has purpose and meaning. Rather than being people simply in need of our care, people who forget can teach us about life and living. Rather than a burden, people with dementia offer us an opportunity to deepen ourselves, to go deeper into our souls.

This shift of attitude demands more than a slight adjustment in how we perceive the world; it requires a fundamental change in the way we look at ourselves and the world we inhabit. It requires foremost a curiosity, an openness to all that is. An attitude of *not-knowing* allows that which manifests itself in front of or within us to present itself in the way it *is*, not in the way we already know it.

This attitude demands a willingness to live in the question, to appreciate the mystery that envelops us. Our sense that we can control and direct our lives is only one possible truth. There’s another possible truth, perhaps even more powerful, that places our direction in the hands of some other force, whether it be called God, Nature, the Tao, Quantum Wave, or some other word. From this point of view, events and relationships occur with meaning—that is, we ascribe meaning to them. As such, what happens to us, events we often categorize as good or bad, are part of our life-path, our destiny. The basic assumption here is that life has meaning, that somehow all—people, planet, universe—makes sense and has purpose.

In contrast, our prevailing attitude is less teleologically based and more grounded in a universe that is random. In such a universe we do not strive for meaning, but rather to manage the suffering that occurs when meaning eludes us. That is, symptom removal or alleviation is the final goal. After the symptom is removed, we don’t need to understand it anymore. In a random universe we distinguish between good and bad, right and wrong, acceptable and unacceptable.

Those who believe in a meaningful universe suffer, too, but their suffering gives rise to a desire to understand the meaning of that suffering, to delve more deeply into the reason and purpose of the events that occur in our and other people’s lives.

The first step in opening ourselves to the meaning of such events is to destigmatize terms that have come from a disease model grounded in the concept of a random universe. In the context of dementia, we suggest beginning by replacing the clinical term *dementia* with the concept of *forgetfulness*. In this way we focus on the experience of becoming forgetful and begin to understand forgetfulness as having a larger meaning and wisdom. The label *dementia* stigmatizes and dismisses the person with

symptoms of forgetting. Although dementia has diverse and clinically challenging manifestations, we will emphasize forgetting as a central theme of this book, and call this phenomenon simply forgetfulness.

A person who enters forgetfulness loses what you and I have no difficulty remembering: our name, address, age, profession, and the like. Remembering such facts is certainly convenient, and a keen memory is often rewarded with appreciation, accolades, even money. Forgetting, in contrast, garners few positive responses and gets little respect. Yet it is a stage of life that so many humans go through. We have asked, “Is there a way to move beyond aversion, toward a collaborative experience of learning with the person who has become forgetful?” Our answer has become the content of this book and is partly informed by observing human interactions in an elderly care home. We often see strong reactions of family members and caregivers when someone with forgetfulness can’t remember his or her or our names. Names are emotionally linked with identity. They differentiate us from others. Forgetting personal names is often a shock to those in contact with forgetful people. Clearly, the threat of losing our identity terrifies us.

But what is this phenomenon called identity? Is it who we say we are, or who others say we are? And we know how rich and complex we are as persons. When asked to identify ourselves, we often say: I am a man/woman, this young or old, live here or there, have this job, like this or that food, am with this or that person. Yet, we also know that it describes only a small part of us. When we are in an intimate relationship, we speak less of these demographic facts and focus on what is not so obvious: our dreams, desires, ambitions, vulnerabilities, and hopes.

Of course, these also form a part of who we are, the most important part, many would say. Thus, we see at least two aspects of how we define our identity. The first involves our consensus, factual reality. The other is more personal and involves our subjective, inner life.

This is not the place to enter into the rich topic of exploring the nature of human identity. Rather, we simply want to point out how malleable this concept of identity is and how it may only partially be related to our ability to remember. We suggest here that certain parts of our identity might even benefit from forgetting. Forgetting may allow for other, deeper parts of our

identity to come to the foreground, parts our remembering keeps forgetting. The stories behind identity, behind remembering and forgetting, are not fixed but fluid; they depend much on our vantage point, our priorities, and our lives.

The medical definition of forgetfulness does not allow for any other possibility than the one it itself proposes: the person with forgetfulness is “less than normal,” and hence nothing can be gained or learned from *demented* people. In contrast, if we try to understand forgetfulness from a different point of view, we will observe that as people forget and enter *Dreamland*, they can allow us to remember and capture that which is essential: to appreciate them for who they are and for what they show us from their place of forgetfulness. That is, if we do not make their world a disease, make their condition wrong, they can give us a chance to search for a deeper understanding of who we are, for our essential humanity. People with forgetfulness symptoms can allow us to be with what frightens many of us, namely staying open to the unknown, staying open to the flow and the unpredictable process of life.

This is not to diminish the pain and hardship both caregivers and those afflicted with forgetfulness can suffer. In fact, this proposed alternative view is meant to lessen the suffering and fear often associated with forgetfulness symptoms. It is also meant to broaden and deepen our understanding of human nature.

Forgetfulness can be understood as an invitation to remember something we may have forgotten in our hurried lives. Those suffering from forgetfulness—through their very forgetting—can remind us of the rich and complex essence of our humanity, an essence at least as much about being as about doing, as much about wonder as about knowing, as much about forgetting as about remembering.

Accounts of caregivers and spouses of people with forgetfulness tell us that their loved ones change as a result of this condition. They also tell us that their loved ones are still *there*, that a real person still lives inside. Perhaps people with forgetfulness symptoms are not present in the way that our consensus reality expects them to be, but they are there nonetheless. The story of an Australian psychiatrist further illustrates this point. One day he visited his parents—diagnosed as *demented*—at their house, where he spent some

time exchanging basic pleasantries with them. As he was driving away, he sensed an urge to tell his parents about his relationship with a woman he had just met and the difficulties he was having with the relationship. He turned his car around, drove back, and reentered their house. Both parents were surprised by their son's quick return.

He told his parents about his new girlfriend, that it had been difficult to communicate with her and that he was confused about what to do next. The parents listened attentively to their son's story. After he'd finished, the father addressed his son in a reflective tone, saying that it would be best to tell his girlfriend his concerns and to have her do the same. This way they would gain clarity and openness and an understanding about each other's needs. The mother nodded in approval, adding that it would be wise to exchange these concerns as openly as possible, early in the relationship, so there would be no false expectations.

The psychiatrist, suddenly aware that he was talking to *demented people*, listened with astonishment to his parents' astute and wise suggestions. After he left his parents that night, he remained puzzled by their clarity, and wondered to what degree his attitude toward them influenced their behavior toward him. Was it his momentary openness to their world, his trust in their ability to *know* on a different level, which allowed them to connect to their son? Or was it just a chance encounter where, as the medicos would have it, the veil of the "disease" had lifted for a moment?

Another story comes from a nurse employed at an intensive care unit of a large European hospital:

During the usual morning rounds, a group of doctors, nurses, and students stood around the bed of a young boy in a coma. The doctor looked at the boy's chart and announced: "Well, nothing will come out of this one!" A moment later, the nurse saw a tear fall from the boy's eye. Others saw it too and they all stood in shocked silence. Later, the doctor said: "From now on nobody talks about the patients as if they were not present, no matter how unconscious they seem. We may discuss our opinions elsewhere. Perhaps that tear was just an automatic reflex, but the truth is—we don't know. Let's take it as a lesson in humility: what happens between body and soul is a complete mystery."

With the elderly, we are confronted with this mystery again and again. We so often experience deep moments of closeness with people who are supposedly not *here* anymore, who have problems with the simplest tasks of daily living. In this book we invite you to perceive contact with the forgetful elderly as an enriching journey for both sides. We draw from both modern science and spiritual traditions, all the better to understand this journey of forgetfulness and to make it more meaningful.

Being with forgetfulness indeed takes us deeper into the soul. Whether we experience forgetting in others or glimpse it in little moments within ourselves, forgetfulness offers us a gift, if only we are capable of seeing it as such. Perhaps loss is always a gateway to the real gains; perhaps we must forget in order to remember. In the words of Seng Ts'an who lived in China in the sixth century,

*The great way has no impediments;
It does not pick or choose.
When you abandon attachment and aversion
You see it plainly.
Make a thousandth of an inch distinction,
Heaven and Earth Swing Apart.*

For those who can truly lay aside their aversion or discomfort and learn to accept what is, the gifts of the soul await: equanimity, intimacy with the dream-world and its magical ways, slowing down to the speed of soul essence.

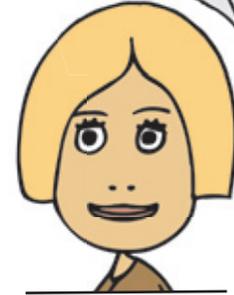
This book is meant as a practical guide for people who work and live with relatives or residents with symptoms of forgetfulness. It is also a guide for people who would like to shift their conceptual and emotional thinking, perhaps learning to make friends with their own forgetfulness. We offer tips and ideas for dealing with aggression or wandering, but we also explore new ways of understanding people for whom we care.

Completing this introduction, we would like to present four characters who will guide us through this book. They represent divergent types of knowledge, attitudes, and feelings, since contact with forgetfulness symptoms in the elderly evokes different emotions and thoughts in us. We see all these perspectives as important and valid.

Join our guides, as we search for meaning, comfort, clarity, and reason, on our journey deeper into the soul.



Master Susushi is a sage. It's difficult to pin down his tradition or religion, but we like listening to him. No matter how difficult or bizarre things are for our rational mind, he finds something important and meaningful there. He continually reminds us of the fundamental questions and mysteries of life.



Ms. Jenny is a young trainee. She is enthusiastic but apprehensive. She has a clash of feelings when confronted with aging, erratic behavior, speech problems, and dying. She has deep questions about herself and her life; sometimes she wants to be comforted; but mostly she just wants to do a good job.



Dr. David has a degree in psychology and social work. He likes rational information, clarity, and structure. During his training, he wanted to learn how to understand and influence human behavior. He paid special attention to information that could be directly applied in practice.



Dr. Karen is a passionate, competent physician and researcher. She loves talking about the brain and how it works. She will show us the amazing richness of the biological basis of our behavior. She will provide us with information about the medical understanding of dementia.

Sometimes these four people will talk to you directly; other times you will sense their perspective in the text.

Now we'll let them introduce themselves.

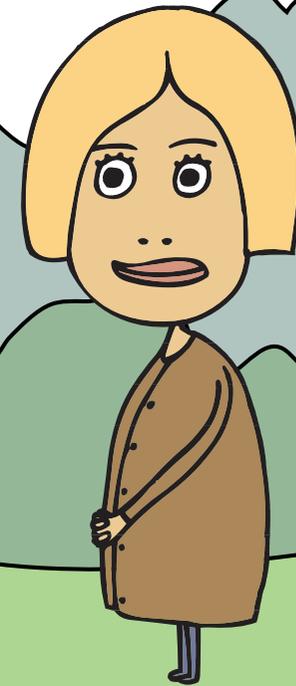
**Sage
Master Susushi**

I look at the world with peace in my heart, with curiosity and acceptance. I believe that everything that exists is important, meaningful, and needs our attention. I love being with all kinds of people—especially old people—and I see each behavior or symptom as an attempt to express our true nature. I find what people do fascinating, and I keep learning from them.



**Trainee
Ms. Jenny**

I am a new trainee in a residential care home. I would like to work with the elderly, but I see so many behaviors that are different from what I am used to. I do not understand what some of the residents want. I do not know how to react and what to do. I am a little anxious as I start work.



**Psychologist and Social Worker
Dr. David**

I am a social worker, and I just got my degree in social work and psychology. I have a lot of information that helps me deal with people and their difficult behaviors in everyday life. I like knowledge that is practical. I am interested in what works; what helps people adjust to groups and to society as a whole.



**Physician and Researcher
Dr. Karen**

I am a medical doctor and I specialize in Alzheimer's and other forms of dementia. I am in touch with the newest research, and I believe that once we understand the cause of these diseases, we will be able to find a cure for them. I am interested in the brain and the effect of changes in the brain on human behavior. I believe in the scientific view of the world. Science has the tools to resolve complex issues and can help us in many ways.

