

THE HARDEST PASSAGE

THE HARDEST PASSAGE
A Psychoanalyst Accompanies
Her Patient's Journey
into Dementia

Maxine Anderson



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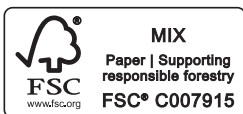
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To Sally and David, whose courage to face and to live this hardest passage has been fortifying to me and, hopefully, others; all of whom may realize that facing the pain of loss fosters openness to new experience and perhaps deepens our humanity.

Contents

About the author	ix
Opening thoughts	xi
<i>CHAPTER 1</i>	
Introductions and re-engagement	1
<i>CHAPTER 2</i>	
Emerging themes as noted in detailed notes from selected meetings over a three-year period	13
<i>CHAPTER 3</i>	
Reflections, learnings, and some conclusions from my experience on this passage	65
Selected readings on dementia	73
Epilogue	91
References	93

About the author

Maxine Anderson, MD, trained in psychoanalysis in both the US and London, England. She is a training and supervising analyst for several psychoanalytic institutes in North America and is a Fellow of the International Psychoanalytical Association. She has published widely on psychoanalytic topics especially relevant to contemporary Kleinian and Bionian thought. In addition, she has published two previous books: *The Wisdom of Lived Experience: Views from Psychoanalysis, Neuroscience Philosophy and Metaphysics* (Karnac, 2016) and *From Tribal Division to Welcoming Inclusion: Psychoanalytic Perspectives* (Routledge, 2019). She lives and practices in Seattle, Washington.

Opening thoughts

Until recently many of us in Western society have seemed to be afraid of dementia. And we need not look too far to realize why. Much of our lives is given over to growth and development, including enhancing our senses of who we are, who we love, and what we care for. We strive to succeed in our efforts to build families and to leave legacies.

But in our latter years, many of us observe among our friends and loved ones, and maybe ourselves, a reversion from that longtime effort to flourish. There may be both pain and fear in that reversion: loss of memory, and other capacities comprising one's self-control and management in one's world is, of course, painful to consider, but perhaps a deeper fear is the helplessness one feels in terms of recession of the selves we have known and developed over the years. And, if we are too afraid of these losses and fears, we may turn away from recognition of them in others as well as in ourselves. Such a turning away, however, may be very costly as it might well rob the declining self of the vitalizing resources available via attentive accompaniment.

I propose that this turning away, borne out of helplessness and fear, may significantly contribute to the course, perhaps, even, the emergence, of dementia. This book aims to explore and test this proposition.

For clarity, *dementia* is an umbrella term referring to symptoms of cognitive decline such as receding memory, judgment, and abstract thought, which can have several sources and, in many cases, may be reversible. Alzheimer's disease, the most common form of dementia, and that which is chronicled in this book, is being widely studied, but as yet has no known cure. The literature on dementia, perhaps especially Alzheimer's, has expanded since the 1990s, offering diverse perspectives, some of which are listed and reviewed in Chapter 3 and in the References.

This book traces the journey of an Alzheimer's sufferer accompanied by her caregiving husband. My invitation to join this sojourn came as a request to resume therapy with Sally, after a break of about four decades from several years of previous work. The couple encouraged this book, saying there is not enough understood about the disease. I have thus kept a log of our almost 300 meetings over a three-year period. Part of my current work with Sally and her husband has been to clarify the turbulent emotions and fears relevant to the disease; but it has also been to track the confusions, blind spots, the terrors and uncertainties in all three of us.

Approaching this journey, then, as an expedition into uncharted territory, I have endeavored to map our course through a constantly shifting emotional landscape, with best efforts to stay vigilant amid uncertainty. One valuable lesson learned is that maintaining presence in the midst of loss and disappointment can offer new insights into the realities and possibilities of this stage of life. Perhaps, not surprisingly, the individual in decline, when attentively supported, may be able to maintain a significant connection with him or herself for much of the course of the illness.

Thus, our experience suggests, if we can turn toward rather than turn away from truly being in this elder time of life, we may help ourselves and others to look and feel beyond the accompanying fears of this hardest passage toward new depths of experience, offering wisdom and hope, even new aspects of our humanity.

Throughout this book, the names of the patient, her husband, and the eventually added caregiver have been changed to protect their privacy.

The book itself is laid out in chapters. Chapter 1 offers historical background including the nature of my previous work with Sally and

how we came together again for the present work. Chapter 2 offers recurrent themes and selected notes from my diary of our work which illustrate the progression of Sally's illness and our various responses and tentative understandings. Remaining open to learning and thus tentative throughout this passage was essential as this was new emotional territory for us all. Chapter 3 offers reflections about my experience during this sojourn, considerable attention being given to the function of Care. It also offers other learnings and concluding thoughts, verifying initial considerations with subsequent observations and clinical work. The "Selected readings on dementia" section offers notes on readings that I found especially useful as guideposts for my own learning. Included, as well, is a review of an especially helpful book on dementia which I sent to Sally and David. The References list offers the wide range of readings I found of interest regarding dementia and its care.

CHAPTER 1

Introductions and re-engagement

“in ... dementia, ... there (likely) remains the undiminished possibility of reintegration by art, by communion, by touching the human spirit ...”

*“The Lost Mariner” in *The Man who Mistook his Wife for a Hat* (1985), Oliver Sacks*

I first met Sally as a patient nearly forty-five years ago. Our re-contact began with a phone call and a message left on my voicemail during August 2020. I immediately recognized her name, and her voice in the message about having had therapy with me a long time ago. But I was startled by what came next: she was having early memory loss and was I available to see her again? I felt both deeply moved and a bit daunted. I was deeply moved to hear from someone who had been one of my very first psychoanalytic patients, whom I had not seen nor heard from since the ending of our previous work. Awed as well, that she would call after all this time, but daunted, too, as at the time of that phone call, I felt I had little therapeutic knowledge about early memory loss in the older individual.

We agreed to meet via a video link, as was common during the COVID-19 pandemic, and as we did I felt once again that recognition of her face and her voice. Not uncommonly for therapists who work intensively with individuals, such reminders opened a trove of memories from our previous work. But during those first moments I felt that I noticed something new as well. With her husband by her side, Sally seemed to recognize me in those first visual moments, but then seemed to lose that recognition and start searching the screen for a familiar face.

At first, I wondered whether Sally was either unable to recognize me after all this time or that she was feeling that I had disappeared after a brief connection. Later, thinking back, I pondered whether this momentary event might also have been a living expression of the problem she was facing: fading memory leading to valued parts of herself and others becoming lost from view after a flickering presence. Her husband, David, asked her whether she could see Maxine there on the screen, but it was not until I asked Sally whether she knew who I was that she really seemed to see me. She responded, “Oh, yes, you are Maxine Anderson.” We both smiled and nodded as our possibly fragile connection seemed to become sturdier. I wondered whether Sally needed to hear my voice as well as to see my image in order to bolster her sense of my presence. I was reminded of the power of vocal recognition, which I had experienced upon hearing her message on my answering machine.

Sally’s immediate question had been whether I was still working and whether I would have time to see her. While faced with a full schedule during the pandemic, I felt impelled personally and professionally to see her again. Therefore, I added two full fifty-minute sessions a week, trying to find a regular rhythm for her as soon as possible. While it feels important to establish a connection with each person I work with, given Sally’s fragile memory it felt especially important to establish a reliable link with her. And this reliability over time has seemed to be important, as the continuity of our meetings, bolstered by the sense of our knowing each other over decades, has seemed to offer some trust and stability in the face of her current increasing dread of “losing parts of ... [her] mind.”

Memories of enduring relationships generally offer comfort and stability as we age. But there may be other memories, such as for Sally the pain of viewing her own mother's "disappearance" into dementia, which has triggered dread as Sally feels sure that this is also her own impending fate. Intense fear, presenting as absolute truth, may further the sense of inevitability for any of our minds, but maybe especially for the mind impeded by fading cognition.

A word about what aids mourning and its resistances may be helpful here. Whenever we face significant loss, we often feel it initially as a dull heavy feeling, only later to be more describable as somatic and psychic pain. This dark cloud of unarticulated fear may highlight the value of Sally's trust: feeling my or another's quiet presence helps to clarify her emotions because even as she experiences unbearable pain, the cloud appears to lift to some degree. One reason for this seems to be that she does not feel so isolated and alone: patient accompaniment amidst trust seems to make almost anything more bearable. This may be a very important realization regarding this illness.

And these elements may also be part of what fosters mourning as a creative response to loss. An alternative to suffering the pain of loss is to feel frozen in terror of the abject disappearance of self as one's capacities wane.

These difficult-to-bear emotions significantly contribute to both the sufferer's and caregivers' withdrawal and possible abandonment of emotional connection. The impaired individual may withdraw from true engagement with self and other when the dread of loss, helplessness, and isolation is feared to be too unbearable. As well, caregivers may protectively turn away in the face of similar emotions of loss and helplessness. I wonder whether these dis-engagements, meant, of course, to avoid pain, might actually contribute to the processes of cognitive and emotional decline. If this turns out to be the case, bringing to light more open discussion and understanding of this painful dilemma may offer some benefit to both patients and caregivers who so often feel that they struggle with very little support. All of these measures could be seen as aspects toward and away from mourning, an issue so important in our considerations about loss that it will occupy later sections of the book.

There are many questions that I hope to explore. One is the potential anchoring function that an analysis or other deep connection may serve over one's lifetime, as may be the case for Sally. And whether such trusted emotional accompaniment might really slow cognitive decline. But, more acutely, I am trying to remain open and to face the pain and terror that my patient experiences as she, to use her words, "loses her mind." In so doing, I might gain experience and insight into the bearable and unbearable emotions that such a situation stirs, but also the maneuvers attempting to defend against them. For example, at times when I am feeling in the throes of helplessness, I find the urge to falsely reassure Sally almost impossible to resist. Such reassurance, from my own experience, brings only temporary comfort. Such self-soothing on my part only abandons rather than accompanies Sally amidst the agonizing loneliness and loss she is having to endure.

In the chapters to come, we will delve further into the complexities of mourning, the impact of emotional engagement on cognitive well-being, and the delicate balance between facing the harsh realities of dementia and the instinctual urge to shield oneself and others from the pain it brings. Through this journey, both shared and deeply personal, an abiding hope is to contribute to a collective understanding that extends beyond the realm of dementia—a journey through the hardest passage that reveals not only the challenges but also the resilience of the human spirit.

Relevant background of Sally and David

Most prominent currently in Sally's mind is her marriage to David which has lasted nearly sixty years. Both mentioned that they met in their teens, and that they became exclusive partners shortly thereafter. Apparently, Sally's nuclear family has been remembered as offering little emotional nurture. My understanding has been that her mother's family were relatively recent immigrants to the United States. As such, they may have felt isolated in unfamiliar terrain and circumstances, leading to both her mother's and her grandmother's tendency toward discontent and withdrawal, rather than toward a robust engagement with life. The most prominent current memories are of her mother's decline and final "disappearance" into dementia in her early seventies,

a specter which frightens Sally as she, now in her mid-seventies, fears she is following the same path.

There is a warm memory of rescue by her father whom Sally recalls scooping her up after she, as a young child, was knocked down by a wave at the beach; this memory concludes with his wrapping her in a warm towel and tucking her safely into the back seat of the family car. And there are other memories of a paternal grandmother finding pleasure in cooking good food and tending to the children's needs in comforting ways. But the most prominent recollections of childhood are less pleasant, such as her family consisting of parents and siblings enmeshed in bickering and conflict, tensions which contributed significantly to Sally's leaving home as a teenager once she had met David.

Their partnership, begun when he was nineteen and she seventeen years of age, has continued in marriage, in building businesses, and, in more recent decades, traveling together to many parts of the world. From what I hear, they have forged a sturdy relationship upon which they both have relied for most of their lives. So, Sally's current illness brings change for both of them, and loss deeply felt by each.

The most prominent themes in our work together have clustered around Sally's feelings of loneliness and isolation, due in large part to waning cognition and memory. And yet, when she comments that she has always had trouble making friends, I wonder how much may be due to old issues as well as to the current ones. Another contributing factor, of course, may be the protective isolation recommended during the COVID-19 pandemic. Our work has been nearly entirely virtual, with very occasional meetings in person when they are in town. The image of a long braid of entwined strands of isolation and loneliness comes to mind.

As Sally struggles with isolation, she often wishes that her two sons would visit more. While she feels sensitively responded to by them, she worries whether her waning cognition might create distance sooner than any of them would wish. Another prominent wish is for more women friends who would share her interests. Sally wishes that she and her three-year younger sister could grow closer, and both have made sincere efforts in that regard during the past few years. In addition, there is a longtime friend to them both, a woman who seems to have been able to face some of the pain and uncertainties at hand and to