

HEADLESS JOE WONDER: ORDINARY LIVES GRIPPED BY

MEMORY'S EXTRAORDINARY POWER

By

Jennifer Cooper

Submitted to the

Faculty of the College of Arts and Sciences

of American University

in Partial Fulfillment of

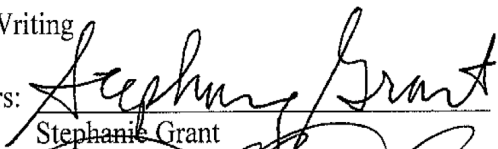
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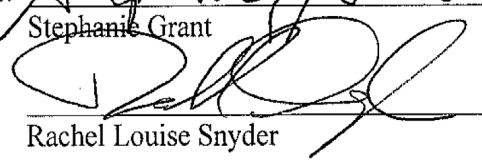
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Creative Writing

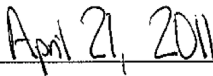
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Dean of the College of Arts and Sciences



Date

2011
American University
Washington, D.C. 20016

To Grandma Lil

HEADLESS JOE WONDER: ORDINARY LIVES GRIPPED BY
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ABSTRACT

Headless Joe Wonder: Ordinary Lives Gripped by Memory's Extraordinary Power is an original work of nonfiction about people whose lives have been affected by autobiographical memory in a profound way. The chapters in this book vary greatly in time, theme, and geography, but the subjects featured in this book all grapple with the tension between needing to remember and needing to forget. This book uses the struggles of individual people to explore what happens when the balance between remembering and forgetting is upset. It is the both the personal story of a granddaughter seeking to understand her grandma's dementia and the experience of a reporter investigating the power of autobiographical memory to construct, warp, or destroy one's identity.

PREFACE

Of all the earth's species, only humans have autobiographical memories, those memories that are personal recollections of our past, which we use to construct an identity – a unique self, an “I.” Only humans can reflect on our experiences, share them with others and make meaning out of what has happened.

“We are, after all, our memories,” writes Dr. James McGaugh, a pioneer in the neurobiology of memory. “It is our memory that enables us to value everything else we possess. Lacking memory, we would have no ability to be concerned about our hearts, hair, lungs, libido, loved ones, enemies, achievements, failures, incomes or income taxes. Our memory provides us with an autobiographical record and enables us to understand and react appropriately to changing experiences. Memory is the ‘glue’ of our personal existence.”¹

This dependence on memory can be troubling when we consider that our memories are regularly changed, conflated, damaged and distorted. Our brains do not work like video recorders. When we remember our first days of kindergarten or the family trips to the beach, our minds aren't inserting a DVD of the event. Instead, we're constructing our remembrance from fragmented memories stored throughout different regions in the brain. The more I study memory, the more I am proportionally distrusting

1. James McGaugh, *Memory & Emotion: The Making of Lasting Memories* (New York: Columbia University Press, 2003). 2.

of and awed by its power. The way our memories can be so disturbingly accurate at some times and so completely wrong at others is both fascinating and frightening.

On January 1, 2011, Kathleen Casey-Kirschling, the nation's first baby boomer, turned 65, setting off what experts have termed the "age wave." In a report titled "Generation Alzheimer's," the Alzheimer's Association predicts that 10 million baby boomers will develop Alzheimer's disease, a brain disorder that creates problems with behavior, cognition and memory – a brain disorder for which there is no cure. The impending age wave will affect more than those who are diagnosed. My grandmother was diagnosed with dementia in the late 1980s, and over the next 20 years, I watched the disease claim bits of her in devastating ways. Of course, mine is not the first family to watch a loved one's memories dry up like a riverbed, the clay bottom hardening into layers of dust blown away in the breeze. But if memory is a river, then its power is not just in drought but deluge, too. Sufferers of post-traumatic stress syndrome live with the rush of uncontrollable, intrusive memories that haunt their days and nights – a bad dream from which they can't wake up. If we remembered everything, we would be overwhelmed and lose our ability to function. Forgetting is our protection from the flood.

Dr. Daniel Schacter calls this tension memory's "fragile power."² Remember too much and you might stop functioning; forget too much and you might stop being you. Sitting in his Harvard office, Schacter tells me that this juxtaposition of fragility and

2. Daniel, Schacter, *Searching for Memory: The brain, the mind, and the past* (United States: Basic Books, 1996). 7.

power is the defining feature of our memories. No one can deny the power of memory in our lives, but we must also recognize that memory can be wrong in devastating ways. Most of us live somewhere between these two extremes. But this book is not about most of us. It is about those men and women who have found themselves somehow captive to memory's fragility or memory's power.

This book is about my grandmother and the 5.3 million Americans now living with dementia or Alzheimer's. It is about two memory scientists whose work with erasing memories in rats led to unexpected consequences when people began writing them, begging to have their own memories erased. It is about a group of bodywork therapists who believe that our memories are stored in the body as well as the mind. It is about a family torn apart by a daughter's claims of child abuse after she 'recovered' the traumatic memories during therapy. And it is about the men and women devoting their careers and lives to honoring the self that exists after memory is gone.

This instinctive need to understand memory has tugged at scientists, philosophers, artists, saints, and sinners for thousands of years. Today, researchers can see inside the brain with increasingly complex imaging techniques, and we now know that our memory isn't a singular system located in one specific place in the brain. In fact, our memory is made up of a variety of processes and systems that work together. Technology like functional magnetic resonance imaging (fMRI) allows scientists to monitor the slightest changes in blood flow in response to neural activity, and researchers are able to study

memory at the molecular level. But our understanding of memory is far from complete.

There is much that remains a mystery, and so the search continues.

ACKNOWLEDGEMENTS

This project would not have been possible without the guiding hand of my Lord and Savior, Jesus Christ. It is because of Him that I write. And it because of His inimitable creation that I've been inspired to investigate and explore the function of memory in our everyday lives.

I am grateful, too, for others who have contributed to this project in various ways. Dave Waddell continues to champion my writing and ideas with words of encouragement and support. My workshop peers have provided invaluable feedback, and many peers have read and reread and reread multiple drafts. The entire MFA faculty contributed to this work, whether it was a conference with Richard McCann or a hallway chat with David Keplinger. Stephanie Grant was an incredibly astute reader, often keying on the heart of a chapter. I want to especially thank Rachel Louise Snyder who has helped shape this project from its earliest stages. She has served as a sounding board, a cheerleader, an editor and a friend, always knowing when to fill which role. It is likely this project would never have been finished without her input.

Finally, I thank my family, who have answered questions, mailed documents, and racked their own memories for material. I hope you see yourselves and the legacy of Grandma Lil's love reflected in these pages.

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CHAPTER ONE

ROOTS AND BRANCHES

It is impossible for me to remember. It happened before I was born. Before my grandmother was a grandmother. Before walkers and dentures and pill regimens. Before dementia shrank the tissue of her brain and ravaged her memories.

She is tucking her three youngest daughters into the bed they share. She rubs their backs, as she does each night, while reciting her goodnight routine. “Pleasant dreams. I love you. God bless you. Good night.” Even after she turns out the light, closes the door and pads down the stairs, the scent of her Evening in Paris perfume lingers in the room – a comfort to the three girls as they drift asleep.

She returns to the dining room of their two-story house in Southern Minnesota where her husband Vernal is reading the newspaper at his desk and her own work is spread out in piles on the oak dining table. She sits down at the typewriter stand in the corner, next to the picture windows overlooking her garden where she will harvest rhubarb and tomatoes in the spring. But now, it is dark, and the steady snow, falling since noon, has coated everything a cotton-ball white.

Vernal walks up behind her, leans down to kiss her powdered cheek as he asks, “You coming to bed?”

“Just as soon as I finish this letter to cousin Della in Sweden. I want the kids to post it on their way home from school.”

“Don’t be too late,” he says as he leaves the room.

The only response he receives is the sound of her slender fingers pressing down the typewriter keys in a steady rhythm.

Nearly 50 years later, I sit on a couch during Thanksgiving break and thumb through the finished product of her efforts – 28 pages of genealogy records compiled in a clear folder with a green plastic binding. I should be working on other things: I have a stack of freshman composition essays to grade, a load of dirty dishes in the sink, an inbox of e-mails waiting for responses, but I keep returning to this family tree, mailed to me by mother at my request. On the front, my grandmother has sketched an actual tree, naming our ancestors on each branch. The pages inside are yellowed and fibrous, not like the smooth bleached paper we use today. The period mark of the typewriter is disproportionately large, leaving black dots throughout the pages that are crammed with information. It is so like my grandmother to make use of every inch of space. Growing up, she was known for sending postcards that contained detailed stories, written in her signature tiny scrawl and personal abbreviation system in which she substituted underlined single letters for words whenever possible—‘c u’ for ‘see you.’ She could say more in four inches than most could say on a whole sheet of paper. If she ran out of room, she simply rotated the postcard and continued her story in the margins so that the text wrapped around the entire perimeter.

At thirty, I’m sitting down for the first time to read the product of my grandmother’s hard work. I remember seeing these family histories growing up – in a closet, on a bookshelf, spread out on the kitchen table because Grandma was visiting and would update the pages in pen. Now I wish I would’ve read them sooner; the information is fascinating. I can trace my lineage back to my great-great-great-great grandfather

Anders Anderson who was born in Sweden around 1790. “Tiring efforts have been made to achieve accuracy, but limitations in communication and time have made it necessary to leave some approximate dates ‘as is’, with apologies,” my grandmother typed in her note near the front of the book. I also learn that my great grandmother, Ellen, studied zoology in college, played the guitar and wrote poetry. Elsewhere, I discover that she was also a teacher and that her mother also taught and wrote poetry. My own grandmother was a correspondent for the local paper and my mother is a teacher, meaning I come from a long line of teachers and writers.

On page 11, I find the family tree of my immediate family. In 1961, when the genealogy was completed, no grandchildren had been born yet. In fact, none of my grandmother’s children had even married. My own mother, the youngest, was only 7. My grandmother later filled in marriage data and the names and dates of all 12 of her grandchildren. Grandma also filled in other information in the margins: the years her children had all graduated from high school, their college majors, their spouse’s professions. Next to my mom’s typed entry – June Marie Madsen (June 21, 1952, Hawarden IA) -- my grandma scrawled the dates of my mom’s college graduation and sketched out her employment history from 1976-1980. Under my mom’s typed entry, my grandmother wrote in my father’s information: Geffrey Louis Cooper (1-30-53, Aurora Illinois), and underneath that she added in parentheses: Marine and Criminal Justice Student, St. Cloud State – Grad. ’79. Below that, she listed me and my sisters:

Jennifer Marie (10-19-80, Ft. Belvoir, Va.)

Jessica Lynn (4-19-83, San Onofre, Ca.)

Jacalyn Anne (5-26-85, San Onofre, Ca.)

No doubt she added all this information from memory; she was writing it down for our benefit. There are other pages, though, where most of the information is missing. My grandma had left blank spaces, separated by commas and enclosed by parentheses for the eventual subsequent generations. Her life's work is left unfinished. And I wonder why I never asked her about our heritage when I had the chance, before it was too late.

It's hard to say with any certainty when Grandma Lil's memory started to go. Perhaps her neurons had been dying off for years, so slowly that she didn't notice the effect. Or maybe we can mark the date on a calendar: October 22, 1988, the day an ambulance rushed her to the hospital. My Aunt Mary had returned home early from a weekend trip and telephoned to find her mother lying on the floor.

"Why are you on the floor?" Mary asked.

My grandmother didn't remember. She couldn't remember what time she'd fallen. She didn't know what time it was now.

It was after that stroke when a doctor first raised the likelihood of dementia. At the time, the diagnosis was surprising because grandmother, even at age 73, was known for her memory and mental health. Her body was aging, but overall she was in good shape. Apart from the stroke, another doctor told her she was "disgustingly healthy" for her age. It was easy to dismiss the doctor's prediction because Grandma Lil just didn't fit the stereotype of a dementia patient. She was still living alone in the five-bedroom, three-story house that she and Grandpa had bought as their retirement home. Still balancing her checkbook to the penny. Still driving herself to church socials. Still correcting her grandchildren's grammar whenever we said something like, "Can me and my sister have

a pop?” I wonder, though, if Grandma lived in the shadow of that diagnosis. If every time she forgot something at the grocery store or took an extra moment to remember a name, if she asked herself: Is this how it starts?

If my grandmother lived in fear of dementia’s onset, my sisters and I never knew it. To escape the harsh Minnesota winters, she came and stayed with my family in California. During the days, she often went to work with my mom, who taught kindergarten, or she stayed at home creating lists of around-the-house projects – folding laundry, sorting through the growing pile of mismatched socks, organizing junk drawers, boxing up old toys for the thrift store. She was tireless in her efforts, and that had my mom worried that our grandmother was overextending herself.

One night, when I was in third grade, my parents planned to go out and Grandma Lil was left to babysit. My mother called us into her room while she finished getting dressed.

“Grandma hasn’t taken a break in days,” she told us, insinuating that our grandmother’s hard work was a result of our own laziness when it came to chores. “Tonight, try to get her to relax. Maybe watch a movie with her.” My sisters and I didn’t respond.

“I’ll even pay you,” my mother added, desperate to enlist us in her plan. “Two dollars for whoever can get Grandma to watch television.”

I had already spent my money in my head by the time my parents walked out the door, but I underestimated my grandmother’s work ethic.

First, Grandma Lil had her mind set on cleaning underneath our beds. When I suggested instead that we watch T.V., she reminded me that she didn’t much care for

television. (Two summers later, while visiting Grandma Lil at her house in Minnesota, I would discover that she did, in fact, care for some television. After the local noon news on CBS, Grandma Lil would leave the kitchen television set on and watch *The Bold and the Beautiful*. I'm sure she justified it to herself by reasoning that this particular soap opera was only half-hour unlike all the others that were a full 60 minutes. In my whole life, *The Bold and the Beautiful* is the only "bad" habit I ever knew my grandmother to have.)

Looking back, I see that my strategy for getting Grandma Lil to abandon her chore agenda was doomed from the start. I should've asked her to sit down and tell my sisters and me stories about growing up on the South Dakota farm. It would not have been too late to ask her for details about how she and Grandpa fell in love when he was working on her father's farm. She would've remembered the night-- how he asked her to a carnival for their first date and how she always suspected he really wanted to go with her sister instead. Many years later, my aunts showed me a small, wallet-sized picture from my grandparents' first date. In the photo, Lillian's brown hair is pinned back in curls that frame her strong jaw line and angular nose. Vernal, always much taller than her, leans down close to her face, their cheeks pressed closely together, all thoughts of a younger sister apparently forgotten. I like to imagine that the tender warmth of her fleece-soft cheek lingered on Grandpa's skin long after they said their goodbyes that night.

When I enrolled at a college in Northern California, Grandma Lil told me about a distant relative on my grandfather's side who taught there. I ended up having him as a sociology professor during the spring semester of my sophomore year. I waited until I turned in my final exam to ask him to step out into the hallway so I could reveal our

shared ancestry. Prof. Alan Jensen was skeptical at first and insisted I must be confusing him with someone else. He was near the end of his academic career, and this was for sure the first time a student asked to speak to him privately so she could say, “Surprise! We’re related.” I convinced him by carefully explaining the connection: my Grandpa Vernal’s mother Christine was a cousin to his grandmother Margaret. Grandma Lil was tickled to hear the story of our meeting because it was a validation of her life’s efforts to track down distant relatives. My mom asked me several times to stop by his office and take a picture to send to her. I never did, though, and it’s too late now.

She stopped coming to California in 2000 because traveling was too taxing on her health, so I saw her only when my family and I visited Minnesota for family reunions or funerals. There were noticeable physical changes in her health – she used a walker, struggled to lift herself out of a car, took medication for high blood pressure – but she still seemed “all there.” My relatives who lived near her recognized some of the early signs – forgetting to eat, forgetting to turn off the stove, forgetting to hang up the phone. My aunt Carol would bring my grandmother to her lakeside house every other weekend. Grandma Lil liked sitting on the sun porch watching the birds fly over the water. But the visits became more and more stressful for my aunt. My grandmother began to require more intense care – even through the night, so Carole began sleeping with her in the guest room. One night, a panicked Grandma Lil shook Carole awake.

“There are supposed to be three girls,” she said. “Where’s the other girl?”

“Mom, it’s Carol. It’s just you and me in the bed. Nobody else is supposed to be here.”

“No, there’s supposed to be another girl.”

“What other girl?”

“There are three girls. One of them is missing.”

Carol never figured out who the missing girl was. Maybe Grandma woke up thinking she was back in that house in Lakefield, Minnesota where her three daughters once shared a bed. Or maybe she had traveled back farther, back to South Dakota where she and her two sisters had once slept in the same bed. Carol didn't press her for answers; instead she rubbed her mother's back and whispered gentle words of love until Grandma Lil fell asleep again.

My grandmother was the missing girl. She was disappearing in plain sight.

I had never considered the power of memory in our lives until I watched my grandmother's memory fail her as dementia eroded first her brain, then her body, and finally her identity. The present moment lasts a fraction of a second. Everything else is memory. My grandma's losing battle to remember inspired this book, and throughout my research, I saw reflections of her story in others' lives. After all, our autobiographical memories are part of what makes us human. I've come to agree with the narrator in Saul Bellow's *The Bellarosa Connection*: “Memory is life.” Who we are depends on who we remember to be, which is why dementia is such a devastating disease. There's nothing that can be done to slow dementia's progression. The disease doesn't slow down. It doesn't turn around.

For those who only saw our grandmother once a year, the dementia seemed to wipe out pieces of her in huge chunks. In July, she was Grandma. In January, she wasn't. We could no longer hold conversations with her. She never called my sisters or me by name.

I'm not even sure she knew who we were. It happened fast – so fast that by the time I cared to ask about the stories stored in her brain, it was too late.

In early November of 2008, I sat on my aunt's couch and my 93-year-old grandma sat next to me, her head resting on my shoulder as I told her stories from my childhood, stories about who she used to be.

“One year you taught our Dalmatian, Champ, to walk on his hind legs,” I said.
“You used to call it ‘dog dancing.’”

“I did,” she said. But I couldn't tell if it was a statement or a question.
I visited Minnesota again the following summer. My Aunt Mary, my grandmother's oldest daughter, invited the family for a casserole supper. At the dinner table, my mom sat with her arm around grandma's chair and carefully spooned small bites of tater-tot hotdish into her mother's mouth. It was too hard for my grandmother to manage cutting her own food with a fork and a knife. At the nursing home where she lived, the staff ground her meat into a slop that reminded me of baby food. That night, when somebody asked my grandma how many children she had, she answered confidently: “Six.”

“No, mom, you have five kids” my aunt explained. Then she used the fingers on her left hand to count off and name the children from oldest to youngest.

My grandma stared for a moment at those five fingers, like she was trying to think of something, anything, to corroborate my aunt's claim. She raised her hand to her lips as she concentrated. Still, nothing came.

“Oh, I thought I had six.”

In her desk drawer in her room on the memory-care ward of Riverdale Nursing Home, we found a small pink Post-it note. Down the left margin, she had scrawled the

names of her twelve grandchildren, in order from oldest to youngest. Even into her 80s, my grandmother never required notes to recall the names of second cousins twice removed, but now she needed a cheat sheet for the names of her own grandchildren. She was trying not to forget us. This is what dementia does. It eats away at your memories until they fit on a Post-it note. She also kept old birthday cards in her desk. In a 91st birthday card from my mom, underneath where my mom signed her name, Grandma Lil penciled in “fourth daughter.”

If my grandmother had devoted her life to music, it’s possible that dementia might have left her muscle memory untouched. It’s possible that she might still be able to sit at piano and play melodies from her youth. Had she been a seamstress, her fingers might still remember the way to thread a needle through fabric. But she was neither of those things. She was a historian. So when the dementia came, it took the thing that used to give her the most joy – the memories of her family, the faces, names, places, dates of our ancestry. Maybe that’s why she worked so hard all those years to preserve our family information. Maybe she knew even then, on those nights when she stayed up after everyone else had gone to bed, that her mind could go. Maybe by putting her passion and memory on the page, she was trying to leave something of herself that would last.

CHAPTER TWO

THE MEMORY MOLECULE

Dr. Andre Fenton was walking to the Number Two train one Saturday evening, the stifling heat of a New York City summer day finally beginning to ebb with the setting sun. He'd been working in his laboratory at SUNY Downstate and now had to rush to meet up with his wife and college roommate for dinner in Clinton Hill. To save time, he checked his e-mail on his Blackberry as he walked the few short blocks to the subway stop. One particular message caught his attention: "*I have read with much interest and enthusiasm on the internet regarding the recent research and discovery being made regarding erasing memory,*" the e-mail began. "*This is no joke. My story is very sad. I was fine all of my life, a happy and productive contributor to society. But a recent terrible event in the last three years changed my life. I hope there are clinical trials to be done. I would be the first in line. Please inform me if I have any hope or help. I need to save my life.*"

This wasn't the first e-mail request Fenton received from someone asking to have his or her memories erased, but the desperation in this particular request shook Fenton: *I need to save my life*. When Fenton joined Dr. Todd Sacktor to study a single molecule and its role in long-term memory storage, they didn't set out to make a memory-erasing drug or cure people of traumatic memories. They were simply trying to identify whether

a single type of molecule – out of thousands – was responsible for storing information when you weren't thinking about it. It was science, not therapy. Yet their discovery – called one of the top 10 scientific breakthroughs of 2006 – illustrates the newest frontiers of memory research and the profound control of memory in our lives.

It's not inaccurate to say that Todd Sacktor has been interested in memory all his life – or at least since he was nine years old. At that age, Sacktor launched his first – albeit unsuccessful – experiment with memory. His test subject was his three-year-old brother. His goal: to implant a memory in his young brother's brain. Sacktor recognized that he didn't have any memories from being a baby or even a three-year-old, so he wanted to see if he could produce a memory in his very young brother. Many memory scientists believe that we start forming autobiographical memories around age three, but Sacktor didn't know this then. So he went ahead asking his brother every day to remember their conversation about the experiment. The memory to be implanted was the memory of the memory experiment – a meta experiment if there ever was one. The experiment stalled after two days when Sacktor himself forgot to continue to ask his brother to remember. Today, his brother has no recollection of the experience.

"I was always interested in grandiose kind of discovery," he said, sitting in his office on the 7th floor of SUNY Downstate. The sounds of East Flatbush, Brooklyn – car horns, ambulance sirens, the screech of city bus brakes – drift up from the streets through the open windows, but Dr. Sacktor is unfazed. Perhaps because he has a captive audience to listen to the story of his life's research studying one of the most complex human processes at the molecular level. I'm scribbling notes furiously, nodding my head, and

trying to keep up with his crash course in molecular neurology. He is a patient teacher, stopping often to offer up a simple analogy when the conversation becomes laced with terms like long-term potentiation and protein kinases, as if he could actually see inside my own brain and observe the synapses bursting like fireworks, trying to absorb it all.

Sacktor's lifelong research of a single protein molecule turned out to be a product of luck and coincidence. His first fortuitous break came in 1982 when he met Dr. Jimmy Schwartz, the man who would become Sacktor's teacher, mentor and friend until Schwartz's death in 2006.

Schwartz and Eric Kandel, a Nobel Prize-winning scientist, had pioneered studies of memories at the molecular level using *Aplysia*, a type of sea slug. Schwartz's hypothesis for long-term memories held that certain enzymes called protein kinases could be converted to a form that would keep them perpetually active. Many kinases, triggered by other molecules, remain active for just a few seconds before they turn off again. Schwartz hypothesized that proteins that were perpetually active, that is that never "turned off," would make sense as mechanism for storing memory. Schwartz and his lab at Columbia were studying a protein kinase called protein kinase A (PKA) – 'A' because it was the first one ever discovered. Schwartz and Kandel had already proved that PKA was important for short-term memory, and Schwartz believed it would also play a role in long-term memory.

The second important piece of Sacktor's luck came in a crowded car on a family trip to see the wild horses of Assateague Island, Maryland. Sacktor remembers sitting bored in the backseat, feeling that as a medical student, he was a little old for family road trips, when his dad, a biochemist, suggested that Sacktor look at a recent article about a

newly discovered protein kinase. After reading the article, Sacktor felt that this new kinase, protein kinase C, made more sense than PKA as the mechanism for storing long-term memories. First of all, there was a lot of PKC in the brain, far more in the brain than anywhere else in the body. Second, PKC could be activated by calcium or other neurotransmitters like adrenaline or serotonin, which scientists had already shown to be important to the process of maintaining long-term memories. And finally, with enough calcium, PKC could be converted to PKM, which suggested to Sacktor that this molecule was the right mechanism for converting short-term memories to long-term memories.

A few weeks before he began his internship in Schwartz's lab at Columbia University, Sacktor asked Schwartz for permission to research protein kinase C (PKC) even though everybody else in the lab would continue to research PKA. Schwartz agreed, and Sacktor set off on his research journey, devoting his career to a molecule nobody else was paying much attention to.

Over the next five years, Sacktor was able to prove that PKC was indeed involved in the short-term memory of *Aplysia*. When it was time for Sacktor to start his own lab in 1990, he decided to switch from studying memory in the sea slug to studying a phenomenon that happens in the mammalian brain: long-term potentiation. *Aplysia* had been the classic model for studying learning and memory for more than a decade because of its relatively simple neural network and large neurons – some even visible to the naked eye.³ But Sacktor felt that interest in the marine snail was beginning to wane among researchers. Long-term potentiation, a process of increased, long-lasting synaptic

3. Eric Kandel, *The Search for Memory: The Emergence of a New Science of Mind*. (New York: W. W. Norton Company, 2006). 147.

strength, was the new frontier in memory research, and it would give Sacktor the chance to study mammals' brains. Sacktor already knew that PKA and PKC were mechanisms for memory storage in *Aplysia* and he reasoned that there could be several molecules involved, but there would be no way to tell which molecules were important for human memory by simply studying a sea creature. Sure, mammals had more complicated brains and a more complex genome, but Sacktor knew that a discovery about memory in a rat's brain was almost certain to correspond to a human's brain as well.

Human brains, of course, are different from rat brains, rabbit brains, and even chimpanzee brains in key ways. At birth, a newborn chimpanzee's brain weighs in at 60 percent of its mature weight; a human brain weighs about 25 percent of an adult brain⁴. Up until about age six, our brains grow around 30 synapses every second under every square centimeter of our brain's surface. In fact, researchers call the human brain "uniquely plastic"⁵ for the way that it continues to mature and morph throughout our lives. Many of those changes depend on our environments and our experiences, especially during the formative years of childhood and adolescence. In fact, our brain changes every time we make a memory. When you use your brain, you change your brain. Who you are today is not who you were yesterday, and it's not who you will be tomorrow.

Our brains contain around 100 billion nerve cells called neurons. These neurons come in different shapes and sizes, but all have the same basic parts: cell body, axon and dendrites. A motor neuron looks something like a leafless tree in wintertime. The cell

4. Hans J. Markowitsch and Harald Welzer, *The Development of Autobiographical Memory* (New York: Psychology Press, 2005). 9.

5. Hans J. Markowitsch and Harald Welzer, *The Development of Autobiographical Memory*. 9.

body would be the part where the trunk meets the branches. The dendrites shoot out of the nucleus, just like branches. The axon of neuron is the trunk and it carries electrical signals down the cell. The places where these neurons meet are called synapses, and our brain has more than a 100 trillion of them. Scientists call this network of brain cells and synapses a neuron forest.⁶ Messages get relayed through this forest when one neuron sends an electric signal down its axon to the synapse it shares with other cells. This electrical stimulation triggers a chemical reaction at the synapse and causes genes in the neuron's DNA to be read in a particular way so that selected genes produce RNA, which in turn makes proteins. Many of our most complicated human functions – including memory – rely on proteins to work properly.

The popular terminology at the time described this protein influx as a “cascade of proteins,” which was responsible for strengthening the synaptic connections between neurons. This is known as synaptic plasticity – the ability of synapses to grow or shrink based on the degree to which they are active. In this way, synaptic connections are a bit like friendships. You're likely to strengthen a friendship with someone with whom you frequently communicate. Contrast that to the stranger you meet on the train. Although you share an initial connection and may genuinely enjoy one another's company, if you never talk to them again after your stop, you will eventually lose your connection. Scientists believe that our memories are stored at these synapses, so stronger synaptic connections were thought to produce stronger memories, while weaker synaptic connections produced fading memories that would eventually be forgotten. This

6. Alzheimer's Association. “Brain Tour.” <http://www.alz.org/brain/05.asp> (accessed May 19, 2010).

phenomenon of enhancing the communications between neurons is known as long-term potentiation (LTP), but for decades scientists did not know for sure what facilitated the process of LTP. Sacktor's hypothesis was that LTP was maintained by the presence of protein kinase C. Now, he just needed to prove it.

Sacktor was able to locate two forms of PKC in *Aplysia* and eight forms in rats. In order to find out which protein form was important for memory, Sacktor had to study all eight. Ten years after he began his exploration of PKC, Sacktor identified a form of the C kinase – PKMzeta – that always remained in an active state. He designed experiments that allowed him to create and strengthen the synapses in a slice of brain tissue. He stimulated the tissue with electrical impulses, ground up the brain tissue, and then looked for which proteins had changed. If he looked shortly after the electrical activation, Sacktor observed several protein changes, but when he looked hours later, after the synapses had been continually strengthened, PKMzeta was the only one that had changed. In 2001, Sacktor was able to prove that PKMzeta was “necessary and sufficient” for memory storage – “necessary,” because if you inhibited the zeta molecule, the brain would not undergo long-term potentiation, and “sufficient” because the zeta molecule was enough to produce stronger synapses. But now that Sacktor had proved this in a slice of brain tissue, he needed to find a way to link his findings to mammalian behavior. And for that, he knew he needed help.

Sacktor was an expert on the biochemistry of the PKC molecule, but behavioral studies were out of his realm. He remembers vividly sitting on panels at the National Institute of Health and listening to behavioral scientists rip apart other scientists' work based on flawed behavioral analysis. “They would just dismiss other people's work in

ways that didn't make any sense to me at all. I mean, it just seemed like a bizarre and dangerous world. I basically needed a guide." Sacktor found his guide to behavioral studies surprisingly close by: two floors below his 7th-floor lab.

Dr. Andre Fenton is younger, smaller and quieter than Sacktor, but he shares the same interest in memory. On the day I meet him, he is wearing a royal blue vest over a brown button-down shirt. His glasses are thick black plastic frames, and I can't help but think that he looks a little too fashionable to be a scientist. I guess I was expecting a lab coat. Instead, he walks into the lab talking on his Bluetooth and carrying his miniature poodle, Rocco, who barks and growls when visitors stop by to chat about the lecture he gave last night in Manhattan. Mostly, though, Rocco's content to play underneath Fenton's desk with a collection of chew toys, his ID tags jingling away.

Sacktor and Fenton met when Fenton was a graduate student at SUNY Downstate and Sacktor served as a consultant on Fenton's thesis. Sacktor remembered Fenton as a smart guy open to new ideas, unlike many of the behavioral scientists he knew from the NIH panels. Now that Fenton was a professor in the Department of Physiology and Pharmacology, Sacktor turned to him for advice. He told Fenton about his PKMzeta hypothesis and said he was looking to link his molecular theory to mammal behavior. Sacktor suggested several behavioral experiments – Water maze? Radial arm maze? Fear conditioning? – but Fenton said the results of those tests would be too difficult to interrupt. After all, they were going to be working with rats. They couldn't ask a rat what it remembered. They needed an experiment that would allow them to objectively observe the animals learning and remembering a behavior. Out of ideas, Sacktor asked Fenton what test he would recommend.

The task Fenton suggested is the one he invented – active place avoidance. A rat is placed on a moving carousel and, in one section of the rink, the rat is given an electric shock and eventually learns to avoid that specific part of the arena. With this test, Fenton and Sacktor knew the rats could learn the task quickly – within five minutes. Fenton’s test is also the only behavior task in which the hippocampus is always involved, regardless of the time that elapses after initially learning the task.

Neurologists and psychologists have long focused on the role of the hippocampus in memory storage, ever since the landmark case study of an amnesic patient known to science and the world as H.M. His full name – Henry Gustave Molaison – remained private until his death in 2008. H.M. was born in 1926 and developed a debilitating case of epilepsy that doctors often attributed to a bicycle injury when he was nine. As a teenager, he was teased relentlessly because of his frequent seizures; he eventually dropped out of high school. He later got a job repairing typewriters, but his epilepsy – he was having as many as 10 blackouts and one major seizure a week – kept him from holding the position. At 27, he was living with his parents, his life on hold.⁷ He took high doses of anti-epileptic medication, but it had no effect on his condition. Out of options, H.M. agreed to an experimental procedure. In 1953, he allowed a surgeon to drill two 1 1/2-inch holes above his eyes, raise his brain with two metal spatulas, and then insert a silver straw to suction out the inner surface of his two temporal lobes, including the majority of his hippocampus, a small, S-shaped collection of neurons. All in all, the

7. NOVA. Science Now. Public Broadcasting System. “The Man Who Couldn’t Remember. <http://www.pbs.org/wgbh/nova/body/corkin-hm-memory.html> (accessed May 19, 2010).

surgeon removed a fist-sized chunk from the center of H.M.'s brain⁸. The surgery was somewhat successful in that his epilepsy improved marginally, but it had a devastating, unforeseen effect on his memory. From the time of his operation in 1953 until his death 55 years later, H.M. could not create any new long-term memories. He couldn't remember names, faces, what he ate for breakfast, what he did last night or even what he said minutes earlier.

Psychologist Brenda Milner worked with H.M. for more than 40 years, and each time he saw her it was for the first time. He could remember general events from his childhood – roller skating, target practice, banjo lessons – but he couldn't recall specific episodes about particular times and places, like what he did on his 12th birthday or on his first day of high school. In the 1990s, his family released audio recordings of Milner and H.M. On these tapes, Milner asks H.M. simple questions about recent experiences.

“Do you know what you did yesterday?” she asks.

“No, I don't.” There's an undertone of surprise in his response, but his voice is calm, without any sense of alarm.

“How about this morning?”

“I don't even remember that.”

“Could you tell me what you had for lunch today?”

“I don't know, to tell you the truth.”⁹

Milner supervised several important memory studies involving H.M. She found, for example, that H.M.'s IQ was not affected. He also retained memories of motor skills

8. Phillip J. Hilts, *Memory's Ghost: The Nature of Memory at the Strange Tale of Mr. M.* (New York: Simon & Schuster, 1995). 96-97

9. National Public Radio. “H.M.'s Brain and the History of Memory.” <http://www.npr.org/templates/story/story.php?storyId=7584970> (accessed May 24 2010).

and tasks like language and counting. Milner also found that H.M. could learn – and remember – new skills. Milner taught him to trace a star by watching his hand in a mirror rather than looking at the paper. He did the task 10 times for three days. With each trial, the numbers of errors he made decreased. His brain was remembering how to complete the outline, but when Milner asked him on Day 3 if he had ever done this test before, he had no memory of his earlier trials. Milner's test proved that different parts of the brain play a role in different parts of memory storage. The hippocampus is vital in converting short-term memories to long-term memories, but it doesn't hold all other perceptual and cognitive abilities. Alzheimer's Disease and dementia attack the hippocampus first. This explains how my grandma could forget how many children she had and yet still remember how to write her name. The disease didn't raid her brain all at once. Starting with the hippocampus, the dementia worked methodically, irreversibly as it moved on. To the temporal lobe. To the brain stem. To the amygdala. All the while eating away at her independence and identity in undetectable then troubling then devastating ways.

Sacktor and Fenton also keyed in on the hippocampus to test the role of PKMzeta. The challenge now was that they were working with live animals instead of brain slices in Petri dishes. Injecting an inhibitor drug into the brain of a rat required some complicated pre-testing.

“The brain isn't used to having a dollop of anything put inside it,” Fenton said. “In the brain of an awake, behaving animal that you don't want to disturb, you have to figure out how to introduce something to a particular place in the brain, and you have to figure out how much. You also have to figure out when you put it in a particular place, where it would go.”

Working with graduate students and post-docs, Fenton and Sacktor oversaw several early experiments in order to figure out that one microliter (about the size of a pinhead) of a drug called zeta inhibitor protein (ZIP) would undo long-term potentiation (LTP) two hours after it had been injected. Knowing the proper dose and time frame, Fenton and Sacktor proceeded with their original experiment.

SUNY Downstate doesn't look like a location of cutting-edge research, a place where molecules are being discovered and the mysteries of memory are being unraveled. Situated in East Flatbush, Brooklyn, the campus is really just a collection of poorly marked buildings set amid a hodgepodge assortment of pharmacies, churches and donut shops. Before my arrival, I'd been instructed to check-in at the guard stand where they would page the public relations director to escort me to Fenton's lab. The guard stand turned out to be a folding table in the hallway. The pager system was a rotary telephone.

Fenton's fifth-floor lab doesn't do much to alter my initial impressions: The walls are painted a pale sky blue and a maze of royal blue desks form narrow pathways through the crowded room. The equipment scattered throughout the lab looks outdated and fake – like relics from a 1980s science fiction movie. The newest-looking piece of equipment is an espresso machine sitting on top of a black mini fridge. A large bookshelf holds see-through plastic bins, each about the size of a shoebox. Each one houses a rat so that the whole collection strikes me as an apartment complex for rodents.

There are several smaller rooms that branch off from the main lab, and it was in one of these back rooms that Sacktor and Fenton tested their hypothesis that PKMzeta helped our brains store memories. They placed a rat in the moving arena, and after being shocked several times, it learned to avoid that area. Once Fenton and Sacktor were

confident the rat had learned the skill, they removed the rat and waited a day, which is enough time for the rat to commit the task to long-term memory. Then, they injected ZIP into the rat's hippocampus, waited two hours for it to take effect, and then placed the rat back in the arena and said, "show us what you know." As it turned out, the rat knew nothing. It scurried around the platform, wandering right into the shock zone, all memory of yesterday's experience gone.

They ran the test again, this time with a control rat that had been injected with a saline solution instead of ZIP. The control rat remembered the shock and avoided the area. For both Fenton and Sacktor, the conclusion was obvious: Blocking the function of PKMzeta erased the memory in mammalian brains. This powerful effect also showed zeta to be the molecule that sustains the process of LTP.

What happened next depends on whom you ask. Fenton remembers he and Sacktor hunched over a computer screen, anxiously watching the experiment, which was being filmed in another room to make sure human presence wouldn't affect the rat's behavior. After the successful results of the first trial, Fenton remembers high-fiving, shaking hands and celebrating by drinking champagne out of margarita glasses Sacktor had brought down from his own lab.

"That's not how I remember it," Sacktor said. In fact, he doesn't remember much of the experience. "I remember the champagne, but that could be a reconstructed memory from lots of stuff." It's Sacktor's tradition to celebrate a successful experiment with a champagne toast, but only after the experiment can be repeated successfully three times. "You've got to enjoy it," he said. "But again, if you do it after the first experiment, you feel like an idiot for having champagne over the Titanic."

Of course it's ironic that these two men who have devoted their entire careers to studying memory have a surprisingly weak recollection when it comes to a pivotal moment in their professional lives. Then again, that's the nature of memory. We remember what's most important to us – a highly subjective process since each person defines 'important' for himself.¹⁰ For Fenton and Sacktor, though, the experience of that specific moment wasn't important. They cared about the science – repeatable, reliable, empirical science.

Through their controlled experiments, they had isolated a single molecule, from a pool of thousands, that facilitated memory storage. As trained scientists, they were already thinking of other possible reasons for their results by the time they finished their glass of champagne. Maybe they hadn't erased the memory and instead just damaged the brain? Or maybe the rat had a headache from the ZIP and just didn't feel like working to avoid the shock? So they made sure they hadn't damaged the brain by testing if the rats could make new memories. Could they relearn to avoid the shock? They could. They couldn't remember the information for very long, but that was enough to prove to Fenton and Sacktor that the rats could, in fact, make new short-term memories. They also ran another cycle of experiments. This time instead of waiting just one day, they waited a whole week – enough time to allow any possible side effects of ZIP, like a headache, to wear off. The results were the same. The rats wandered around the arena as if they'd never been in it before, proving to Fenton that "if [PKMzeta] is the memory storage mechanism and you stop it and the memories are gone, then they're gone forever."

10. Schacter, *Searching for Memory: The brain, the Mind and the Past*, 46.

ZIP, a drug Sacktor invented, doesn't remove PKMzeta from the brain; it just keeps the zeta molecules from working by disrupting the organization of memory. PKMzeta molecules group together at synapses, but when scientists add ZIP to the cells, the zeta molecules diffuse and drift away. ZIP is like a gust of wind that shakes the seeds of a dandelion from its stem and then sends the tiny fluffs floating away in the breeze. Once the ZIP decays and is no longer active, the zeta molecules are still in the brain, but they aren't in the right places and don't know how to get back to their original synapse, and that's why the memory is lost.

Fenton and Sacktor published their results in 2006 in a paper titled "Storage of Spatial Information by the Maintenance Mechanism of LTP." The scientific community, while initially skeptical that a singular molecule could play such a key role in a complex system, embraced their findings. The results were too convincing to ignore. Other labs went on to replicate their experiment and study the effect of ZIP with other behavioral tasks. But scientists weren't the only ones paying attention to the results.

Even before the mainstream press began to report on Sacktor's and Fenton's findings, the two began receiving dozens of letters and e-mails from people asking to be a part of clinical trials using ZIP to erase their memories. Many of the people who wrote to Sacktor and Fenton were rape survivors, plagued by recurring, intrusive memories.

Epidemiological studies report that more than half of women and 60 percent of men will experience at least one traumatic event in their lives¹¹. I think science low-balled the numbers. Life scars us all – in little and big ways. These traumatic experiences

11. Daniel Schacter, *The Seven Sins of Memory: How the Mind Forgets and Remembers* (Boston: Houghton Mifflin, 2001). 174.

often leave us with dramatic, detailed images of the moment. The problem with traumatic memories is that they often capture the very details of an event that people most wish – or need – to forget.

There is a longstanding and well-documented connection between memory and emotion. Even without a detailed understanding of the brain, people in the Middle Ages recognized that emotion affected memory. Since writing wasn't yet used to keep track of historical records, medieval officials would select a young child, around seven years old, and have him carefully observe some event of importance – a land exchange, family truce, or an important wedding. Immediately afterward, the child was thrown into a river. They believed the shock of the cold river would help preserve the memory of the preceding events¹². It's an extreme and drastic mnemonic device, but our feudal ancestors were onto something.

A scientist I interview tells me the moon is made of purple cheese. Then he says, "You're so stupid. It's not worth my time spending time with you." The scientist is Dr. James McGaugh, the founding director of the Center of Neurobiology of Learning and Memory at University California, Irvine and he's using this insult as a way to demonstrate the connection between memory and emotion. He's spent his career proving what people in the Middle Ages suspected: Our brains are designed to remember moments of emotion – fear, triumph, defeat, joy, shame—regardless of whether we want to remember or not.

Sitting in his spacious corner office on a perfect Southern California summer afternoon, here's how Dr. McGaugh explained it to me: When we have a learning

12. McGaugh, *Memory and Emotion: The Making of Lasting Memories*. ix.

experience, different brain regions kick in to store that memory. So when he tells me the moon is made of purple cheese, my brain goes to work to store that new information, without any conscious effort of my part. When he follows up that information by calling me stupid, my brain's response activates an additional process. McGaugh explains: "Now what happens next, if you believe me, is your adrenal gland goes *whoosh* and you're going to start to release adrenaline – massively – and you're going to turn red and you're going to turn warm." He's right. Even though Dr. McGaugh warned me about his upcoming hypothetical insult, I feel my neck start to flush and I try to will my facial muscles not to move. Without my commanding it or knowing it, my adrenal gland releases stress hormones, which in turn activate the amygdala, a small almond-shaped structure deep in the temporal region. The amygdala then signals to other brain sites like the hippocampus, alerting those brain regions to the potential significance of the experience. Emotions, then, are a cue for the brain to make a stronger memory. This process of modulating memory strength happens every day, even with seemingly small events. "If someone insults you, you're going to remember it," McGaugh says. "There's nothing you can do about it. You're just going to remember it."

Perhaps this is best illustrated in a phenomenon scientists call flashbulb memories. Every generation has a defining moment – an event so life-changing that the memory of their own personal experiences sticks with them for their lifetime. For my grandparents it was Pearl Harbor, for my parents, Kennedy's assassination, and for my generation, it's September 11. We're powerless to erase our memories of what we were doing when we learned of the attacks. We'll always remember where we were when we

watched men and women jumping out of their 107th-floor windows. Those images stay with us – for months, for years, forever.

In the last years of my Grandma's life, one of my cousins confessed she avoided visiting Grandma in her nursing home. My cousin saw Grandma at family gatherings at relatives' houses, but she no longer rode the elevator to the second floor of the nursing home, to the memory care unit. She said she didn't want that picture of Grandma in her head, didn't want to remember her that way – tired, disoriented, shrunken and sunk into a mauve recliner that seemed to swallow her bony frame. So my cousin just refused to go—refused to allow that memory to take shape and encroach on all the others she had of Grandma as a younger, quicker and more complete version of herself.

But not all unwanted memories can be avoided. In fact, many unwanted memories are *unavoidable*. For the people writing to Fenton and Sactor, the traumas of their lives created powerful memories they were desperate to erase. As news of their experiment began to percolate through the scientific community, dozens of people sent e-mail and letters. *Please help. I need to save my life.*

The scientists would write back, explaining that their work wasn't intended to be used clinically and that in order for ZIP to be clinically useful, it would take at least another decade of work by a much bigger lab staff. Fenton tried to highlight the dangers: “Given what we know today, I don't think we can erase a specific memory. We can erase all your memories and that would be erasing you,” he said. “That's the most scary thing you can tell me, but that didn't seem to frighten these people. They said, ‘I don't care. I'd be happy to start over.’”

Fenton remembers an exchange he had with a woman calling from Greece to volunteer for clinical trials. He created a worst-case scenario for the woman: “Imagine this: We might be able to erase your memories, but you have bad feelings also connected to those memories and those feelings are what’s debilitating, so imagine the horrible possibility that we erase the memories but those feelings are still there. You would now simply feel debilitated and distraught and horrible, and you’d have no way to know why. That would be an even worse nightmare and you would be completely unrecognizable to yourself and anyone else. Do you understand how bad that would be?” The woman agreed that, yes, that would be horrible. Before they hung up, the woman had just one more thing to say: “So if you’re doing any clinical trials, I’d be happy to volunteer. I’d come to New York anytime.”

“This made me nervous,” Fenton said. “You have to remember that I’m a scientist. I work on what memory is and that’s all. I’m not trained to talk to anyone about their medical or mental health problems.”

There are endless implications when you open the door to selective memory editing. Our brains change in response to our experiences, so even bad or traumatic experiences can serve a purpose; they may teach us something and shape our responses in the future. Because of memory, all future experiences are mediated by previous events. “What you learn might cause you to change how you behave in the future,” Fenton said. “It might cause somebody to be a more rational individual, a more tempered individual, a more compassionate individual, a more aggressive individual and these are our human

characteristics.” In other words, our memory and our humanity are intimately, intrinsically linked, connected like a playground see-saw so that any change on one side of the fulcrum causes a reaction on the other

At this point, science has no way of pinpointing specific memories to erase. It’s not possible to lay out your life’s experiences like a menu and pick which ones to delete. And any sort of treatment based on PKMzeta and ZIP runs the risk of erasing more than what’s intended. “It’s possible in humans that whole swabs, whole groups of memory are linked in a way that could be erased that would be horrific,” Sacktor said. “We just don’t know how much of the network of memories would be erased.”

As an example, Sacktor uses the scenario of a person suffering from post-traumatic stress after a bombing by continually reliving the blast in flashbacks. Trying to erase that memory could result in erasing the letters b-o-m-b. And once you erase those letters, maybe you end up erasing all the letters because they’re linked. “A is next to B, right? You sing the song in your head. Maybe you’re going to erase all of that,” Sacktor said.” And then maybe you’re going to erase every word that you can spell. You just don’t know.” The possibilities don’t end there: “The bomb happened in a certain city. Well, you may have a map in your mind in which you link that city to a state and that state gets linked to the United States and the United States gets linked to the rest of the world. You don’t really know how much you’re going to erase.”

Today, Fenton no longer responds to e-mail requests for clinical trials. He found his efforts of caution and logic a poor match for the desperation of those writing the letters and making the phone calls. Sacktor, too, rarely responds to the requests that arrive in his inbox. That’s not to say the two have grown jaded and unsympathetic. Far from it.

When Fenton was interviewed for a segment on the public radio show “This American Life,” he choked up partway through reading the e-mail he received on his walk to the subway. “This is sad to me,” he said, blinking back tears. And while Sacktor is fully aware of the potential dangers in erasing memories, he also knows that people haunted by memory may turn to suicide as the only way to shut off the replay. It may be a ways off, but Sacktor hopes that there will be a treatment someday based on his work with PKMzeta and ZIP.

Scientists are currently studying ways that zeta and ZIP might be helpful in treating three specific diseases: drug addiction, schizophrenia and Alzheimer’s. Already, scientists have noted a relationship to the distribution of PKMzeta molecules in the beta-amyloid tangles of Alzheimer’s patients. In the future, a treatment based on PKMzeta may be able to cure the amnesic part of dementia. But these possibilities are not promises, just a mix of hypotheses and hope.

For Fenton, any discussion of tampering with the memory circles back to H.M. “There was one H.M. created,” he said. “Today, if a patient with severe epilepsy is determined to require a resection of both temporal lobes, no one would do it.” Memory is that important.

And while there is only one H.M., there are millions of men and women losing their memories to dementia. There are 5.3 million people living with dementia in the United States alone. That number is expected to rise to more than 7 million by the year 2030. Unlike my cousin, I have many memories of my grandma in her nursing home—her sitting alone in the dining room, the last to finish her meal; her struggling to remember the names of her grandchildren who came to visit; her shuffling past her room

because she forgot which one was hers—memories that make it impossible for me to see those Alzheimer's projections as just another statistic. I see grandmas, grandpas, moms, dads, husbands, and wives disappearing, their lives collapsing into a prolonged goodbye. All those brains shrinking, all those neurons wilting and dying, all those zeta molecules drifting, drifting, drifting.

CHAPTER THREE

WHAT THE BODY REMEMBERS

I recently framed a picture of my mother and grandmother, taken two summers ago in the beige hallway of her nursing home. Grandma Lil is looking straight at the camera, her hair a halo of fluffy white curls and her ivory skin dotted with light tan age spots. Underneath her eyes, the skin is loose and wrinkled. She is smiling so widely that her already thin lips almost disappear. My own mother sits with her left arm draped over Grandma Lil's hunched shoulders, and her head bent to kiss grandmother's cheek. The picture captured my mother's own white roots, where her hair has grown out past the dye. In white cursive on black matting, the frame reads: "We are what our mothers made us." I can so clearly see the lineage of what my grandmother passed down to my mother, what my mother then passed on to me. Pointy chin. Poor eyesight. Peach fuzz on our cheeks. A recipe for monkey bread. We're all teachers, my grandmother, my mother and me. All Christians. All multitaskers. All rememberers.

My grandmother could recall minute details and dates about our family history – the year her parents settled as farmers in South Dakota, the names of first cousins once removed, the name of every town she ever lived in. At church, she made it her personal duty to introduce herself to new faces. The following week she would always greet them by name. Even after she moved into a nursing home, before the dementia had advanced very far, trivia was one of my grandmother's favorite activities.

My own mother earned the nickname “Memory Queen” in college for her ability to remember names and lyrics to old hymns. She kept her title until I was born. In my family, I am now the one who remembers. I’ve become the keeper of our family traditions because I’m the one who remembers them with accurate detail – what we ate for Christmas dinner, what we wore to Easter sunrise services, which year my mom dressed us as butterflies for Halloween. Often, when I ask her about events from 10 years ago, last month, yesterday, my mother has trouble remembering the details. When this happens, when she has no memory of something that is still vivid to me, she bites her tongue between her lips and shakes her head, like she’s trying to knock the memory loose.

For all science has discovered about memory, there is still much that remains a mystery. And there are other ways to understand memory beyond molecules, neurotransmitters and synapses. My mother has her own answer to what scientists cannot quite pinpoint. According to her, a woman’s memory is stored partially in her womb. She doesn’t lose her memory when she becomes a mother; she simply passes it on to her children.

My mom’s womb theory serves as a good excuse for her forgetfulness, but it isn’t grounded in any sort of scientific research. After all, my mom studied drama in college, and as a kindergarten teacher, her science experience is limited to dissecting owl pellets – neurology isn’t really her thing. In fact, she would be surprised as anyone to learn about a talk-touch therapy based on the idea that our memories and emotions are stored in the body as well as the mind.

The idea behind the theory is that our bodies are like the black box recorders of airplanes – that is, they record every experience and emotion of our lives. That doesn't mean the body is operating independently of the mind; more like, as one scientist put it, "the body is the unconscious mind!"¹³ The Rubenfeld Synergy Method is a type of therapy built around the idea that memories and emotions can become lodged throughout the cellular systems of our body. Traumatic memories locked in the body can cause pain, sickness, disease and a range of emotion, synergists believe. They're convinced these memories – repressed, distorted or misinterpreted by the mind – can be accessed in their wholeness through the unconscious body with the help of trained practitioners who offer a listening ear and a listening touch. Illana Rubenfeld pioneered this method in the 1960s after she felt disappointed by traditional psychoanalysis that excluded physical touch and by body therapies that ignored the emotional roots of her pain. She began studying therapeutic methods and created her own synergy of bodywork and more traditional talk therapies.

The result is a method that views the body, mind, and spirit as three totally integrated systems. Synergists believe that the body has its own story to tell, that we process our life's experiences through the trillions of cells throughout our bodies, and that the memories of those experiences can be unlocked through a listening touch. Let's say you've been having pain in your back and that your shoulders feel tight all of the time. You could opt for massage or chiropractic therapies that would focus on kneading the muscles, realigning the body, fixing the pain. Or you could go to a synergist who might

13. Candace Pert, *Molecules of Emotion: Why You Feel the Way You Feel* (United States: Simon & Schuster, 1999). 141.

place her hand on your shoulder and ask you to listen to the sensations in your body. The goal of the session wouldn't be just to get rid of the muscular tension, it would be to understand why the muscle was tight in the first place. A synergist's touch can be as simple as moving a client's arm through the air or cradling a client's heel in his or her hand. And sometimes that's enough. "Just out of a shoulder or hip, you might have a whole story start tumbling out," one synergist told me.

Rubinfeld synergists believe the body's story is different from the story the cognitive mind tells because the mind has the ability to lie, to rationalize, to justify, to repress, to do what one synergist calls "smoke and mirrors." But the body – the body never lies.

Rosie Jackson was the first one to tell me about Rubinfeld Synergy. My first real friend in graduate school, ours is one of those opposites-attract-type friendships. She's married to a musician, prefers to write her poetry without punctuation or capitalization, and will be the first to tell you she's tested just about every type of therapy out there from traditional psychotherapy to more alternative methods like Reiki Energy. She began seeing Sarah Baker, a Brooklyn-based synergist, about four years ago. At first she found the sessions laughable, the way she would have to talk to her body parts as if they could talk back. Even for the free-spirited poet, this seemed like a stretch. She stuck with it though, and eventually she began to hear her body tell her stories. After four or five sessions, Rosie had a breakthrough as she lay on the massage table. As Baker gently rotated her shoulder, a memory from Rosie's childhood came rushing back to consciousness: She is around eight years old at the tennis courts in the wealthy

neighborhood up the hill from her own house in South Carolina. It is a hot and humid day in the south and Rosie is tired and thirsty after a full hour of playing tennis. All the other children are drinking Gatorade and water to cool down, but her mother forgot to bring any for Rosie so she stands there, the sun's summer rays bouncing off the courts and rushing up to her sweat-soaked face, and watches all the other children gulp down their grape Gatorades and bottled water.

Some twenty years later as she's remembering this in a climate-controlled apartment, Rosie begins to cry.

"It was absolutely heart-breaking when I remembered it," she said. "In my way it represents my mother's negligence. It was like 'are you kidding?' It was like South Carolina, dead summer heat, 100 degrees and this is a sport." Another time, as Baker moved her hands over Rosie's belly, she felt a pain and remembered a clip from an old home video: She is 9 years old and her newly remarried mother has moved Rosie and her siblings in with their new stepdad. In the video, Rosie shuffles her feet down the dirty tan carpet of the hallway, clutching her stomach, whining that her "tummy hurts."

"It was another crying breakthrough," Rosie said. This breakthrough came from her realization that she used her stomachaches as a way to compete with her stepdad for her mother's attention. "It was my vehicle for getting noticed, for getting tended to," she said.

Now, Rosie describes her synergy sessions as being flooded by memories from a childhood that she had willfully blocked out. The remembrances were often accompanied

by tears – not a gentle, calm trickle of tears, but more like a rush of wet sobs. “I remember at some times it would be pouring so bad that Sarah would stop and I would roll on to my side and get comfortable,” she said.

This flood of memories troubled Rosie’s former psychotherapist, who she still kept in touch with. Her therapist feared that synergy would unlock too many memories, too quickly – and that without any control over how or when the memories and emotions resurfaced, the process could be overwhelming and ultimately dangerous. Other psychologists question the very foundation of synergy practices. Many professionals are skeptical of body therapies, believing that using hypnosis, imagery, and suggestion could result in false or mistaken memories. They view these alternative treatments as fads that are likely to invent and perpetuate rather than heal trauma.

Of course, not every session of Rosie’s ended in uncontrollable wailing. “There were definitely points where I left her building with a pep in my step, loving that I had got some of the grieving out for the first time.”

If synergist Noel Wight had heard Rosie discuss her sessions, Wight would describe that relief as the result of energy movement. Those memories and emotions that had been locked like prisoners in her shoulder, in her stomach were released with her remembrance.

Wight, a synergist and faculty trainer for the Rubenfeld Synergy Method, said there’s value in remembering unpleasant experiences because it can allow the body to take care of unfinished business. Wight and her husband operate a synergy practice in Pennsylvania and have 54 years of combined experience between them. She said there are two common experiences clients often have with memory. The first is that they

develop a new understanding of a memory by listening to how that event is remembered by the body. For example, Wight once had a female client whose back was extremely tight, so tight she had trouble breathing when she lay on the synergist's massage table. "It felt like steel cables up her back," Wight said.

Wight asked the woman to roll onto her side to help her catch her breath, and as she gently touched the woman's back, Wight asked her to describe the sensations she was feeling. The woman told Wight that it felt tender, like someone had delivered a strong blow to her back, leaving behind a wide black and blue bruise. "She was having a hard time taking a deep breath so I said, 'What's the blow that took your breath away?'" The woman answered: "My sister's death."

"It wasn't like she didn't remember her sister's death, but she didn't realize that it was still hurting her so deeply and that the grief was not done and it was still held so tightly in her body." The woman's sister had died 13 years earlier, but the energy of that emotion had never been fully expressed, Wight explained, so it lodged itself as tension in her back.

The second type of memory experience is when clients bring to consciousness a memory that lived in the unconscious body. Consider another one of Wight's clients, a 48-year-old-man who felt pain in his arm when Wight touched it. As he started to describe the pain, he remembered being a young boy and having his dad yank him out of the car by that arm. "Sometimes in their body they will have sensations that then remind them, and it brings to consciousness what was unconscious in their body," Wight said.

Most mainstream scientists, those of the peer-review model, would describe this event in different terms. The memory of being yanked from the car wasn't repressed or

buried by the mind, it was simply forgotten until the right cue (the synergist's touch) produced the memory trace. I hadn't yet talked to Wight when I made my own synergy appointment with Sarah Baker, Rosie's old bodymind therapist, so what I knew about synergy at the time produced a mix of equal parts fascination and fear. On one hand, I thought it could be wonderful to remember something with my body that my mind had unremembered. On the other hand, I worried I risked upsetting my mostly balanced sense of self. I've never had any sort of professional therapy or counseling. I've been able to solve most of my life's problems with some combination of long conversations with good friends, chocolate chip cookie dough, and Sarah MacLachlan's "Fumbling Through Ecstasy" CD. So what if, I wondered, I actually come out of this session realizing that my life is more screwed up than I ever knew? What if my "normal" life gets thrown into a tailspin from which I never recover?

Baker's apartment is on the third floor of dark brown walk-up in Park Slope Brooklyn, just a few blocks from Prospect Park. I notice that many of the apartment doors aren't numbered, and I worry briefly that I won't know which door is hers. When I get to the third floor, I see a door behind the staircase displaying a wreath of dried leaves, and that fits my stereotype of her earthy, healing approach. Before I can knock, though, she opens the door, smiling. Baker welcomes me into her living room, where sunlight is streaming in through two large windows. End tables underneath the windows hold books stacked neatly from largest to smallest so they form a tiny pyramid. I notice right away Illana Rubinfeld's book, *Listening Touch*, displayed on the table. Two burnished metal Buddhas serve as bookends on the mantle above the fireplace. A bold purple massage

table is pushed to one corner, the one element that doesn't seem to fit with the sage and beige décor of the room. Plus, seeing it is a reminder of what I'm about to do – open up to a complete stranger in hopes of hearing my body tell a story. Baker directs me to make myself comfortable in a chair near the windows. We make small talk and I relay news about Rosie, telling Sarah that Rosie is now married and in the process of buying a house. It occurs to me that Rosie might have wanted to share the details herself, but I'm nervous and unsure of what else to talk about. Baker sits across from me, dressed in a blousy gray shirt and Capri-length black leggings. Her thick brown hair bursts from the scalp in tight spirals that run down her back.

Whenever the conversation lags, I rush to fill the silence with inane small talk. Baker is congenial and agrees that, yes, today is a lovely spring day. And, yes, this is a neighborhood with a lot of charm. When I've run out of topics, I smile and nod my head. Baker smiles back. I smile bigger, racking my brain for something else to say. I can't tell if Baker's quiet smile means she's waiting for me to talk or if she's simply just content with the silence. Finally, she passes me a clipboard of forms for first-time clients and asks me to read one of them out loud:

Underlying the practice of Rubenfeld Synergy Method is the belief that each person is an inseparable combination of body, mind, emotion and spirit. Any dimension of the person allows access to the whole, in different ways at different times. In RSM the body is the essential starting point for the Exploration of Self, for it reacts, responds and remembers in its structure and in its muscles the story of our lives.

*In Synergy sessions, touch and gentle movement will be used in combination with verbal expressions. The sessions are conducted with the client fully clothed on a Synergy table. Synergy sessions are done with **absolute respect for you and with full permission from you**. If you have any questions, please feel free to ask.*

*The Synergist is present as a caring facilitator who evokes the awareness of the innate healing of wisdom of the person and guides the client through the process of heightened awareness and change. The **responsibility** for change, however, rests with the client. Through new awareness, conscious choices can be made which establish alternative patterns to old habits of thought, movement or feelings.*

I sign my name and pass the forms back to Baker, wondering if she's able to detect the extent my nervousness.

She asks me: "On a first session like this, I like to ask my clients if they could give themselves a gift through this session, what would that gift be? What would that gift look like?"

I tell her I want to come away from the session with a genuine understanding of Rubenfeld Synergy. I know this is not the answer she is looking for, but I'm hoping it will pass. Baker sees right through it.

She laughs and leans forward, careful not to break eye contact. "OK, I'll ask you again," she says. "Apart from the understanding, which you want for your project, what do *you* want? What would be a gift for Jen?"

I take a breath and resign myself to honesty. A gift? A gift would be a break. A chance to not have to think about anything else. In my world there are no breaks. I'm putting myself through grad school by working as a live-in nanny. Work is home; home is work. Even when I'm not technically on duty, I'm only a single flight of stairs away from the chaos. And because of grad school demands, I treat my bedroom more like a library than a sanctuary. A break would be nice.

"A break, yes," she says. "OK, and how will you know when you've received that gift? What will it feel like to have a break?"

I have no idea how to answer this. Baker senses my struggle to come up with the words. "Sometimes it helps to close your eyes, and just place your hand on your chest and go inward," she says and demonstrates by arcing her arm in a semi-circle before resting it on her chest.

I mimic her motions, close my eyes, and rest my right hand over my chest so I can feel it rising with my breaths. With my eyes closed, I notice the pleasant smell of spicy citrus throughout the apartment. I tell her I'm picturing a clean slate, like I'll be able to choose what I want to think about, choose what I want to do rather than rushing from one obligation to the next.

"A clean slate. Choosing what to think about," she repeats.

She tells me explicitly that part of her technique is to repeat my words. "I could use my own words," she explains, "but oftentimes your words have specific meanings, so I want to use the words that you use." At first, it's a little unnerving to constantly hear my words repeated back to me. Her tone is gentle and yet emphatic, her voice rising and falling as she enunciates each word, like a mother repeating back her child's first words.

If I didn't know better, it would be tempting to think she was mocking me. Besides, I already feel a little foolish for not picking a better gift. This is going to be a recurring feeling, this wondering what to say and then questioning the wisdom of my word choice. I know this session is supposed to be about listening to my body, but I can't turn down my mind.

As we move to the table portion of the session, Baker starts by asking me to close my eyes and imagine myself lying on a sandy beach. She tells me to take a Polaroid picture of my body and to notice how it feels. I tell her my shoulders feel tight and my breath seems shallow. I keep telling myself to relax and to take slow breaths, but it doesn't work and I feel myself instead taking rapid shallow breaths. There are school children screaming on the street below and their voices and laughter drift through the window.

"We're just going to let those kids playing be there in background," Sarah says, acknowledging the noise, but not distracted by it. I don't know if the kids left or if I just tuned them out, but after a few minutes, I never heard them again. Before she touches me, though, she always asks. "I'm going to put my hand under your head. Is this OK?" I can feel her hand near the base of my skull as she presses lightly against my head with her fingers. She had explained to me before our session that this part of our body, near the occipital lobe of our brain, is especially responsive. "The occipital ridge is like a gold mine for touch and sensation," she had said. "Touch heightens feelings. It also heightens awareness."

I tell her that when she touches the back of my head, I feel a tingling sensation in my knees. As she moves her hands away from my head and through my hair, I tell her

that reminds me of the way my two sisters and I love to play with each other's hair. Even now, as we're all in our 20s, when we get together as a family, we beg each other to brush our hair. Often, we'll sit in a straight line on the living room floor and brush and braid and run our fingers through one another's hair. Sharing this memory, though, feels a bit disappointing since that's what I always think of when anyone touches my hair. I'm still hoping that I'll remember something new, something my mind had forgotten but that my body remembers.

Baker moves to my feet. Again before she touches anything, she asks my permission. This time she slides her hand under my left heel so that it is gently resting in her palm – or at least, that's what it feels like. I can't actually see what she's doing since my eyes are closed.

Throughout the session, her manner is always professional, but her personality occasionally cracks through the therapist façade. When she's cupping my heel, she asks me for adjectives to describe what I'm feeling. Again, there's this pressure to pick the right adjectives. Throughout our session, whenever she's asked me for descriptions, I've always said, "it feels light." I'm determined to do better this time: "I think of the word pamper. It reminds me of how I used to get pedicures with my mom and friends, before I was on a student budget."

"Hmmm. OK, so there's this feeling of pampering," she says repeating my words back in her careful tone. "Pamper," she says it again, this time her tone is playful. "I like that word. I like to know the history of words, but when you said pamper, the first thing that I thought of was Pamper's diapers. So somewhere there must be something in the meaning of that word so that they would name their product Pampers." Her tangential

ruminating seems to break the spell of the session as she suddenly seems more like a quirky girl than a bodymind therapist.

She bends my leg so that my foot is resting flat on the massage table. Again, her touch makes my knees tingle and I mention this to her. “Let’s pretend that you could talk to this tingling sensation in your knees,” she says. “What might you say?”

“Why are you tingling?” I’m not trying to be a difficult patient, but it’s the first thing that comes to my mind.

Baker asks me to listen to my knees to hear how they would answer my question. If only they could actually speak so I wouldn’t be worried about misinterpreting the message. I tell Baker that my knees are tingling because they want me to know they’re there, they just want to be noticed.

“I’m here! Notice me!” Baker repeats, giving my knees a squeaky child’s voice.

From my feet, she moves up to my left arm. She holds my elbow and my wrist as she brings my arm off the table and moves it through the air. It’s a relaxing, weightless feeling and I think this might be what flying feels like. I don’t tell her that it feels like flying because I’m trying to conserve what I deem to be “good” insights, and I decide to save this observation for when she moves to the right arm. The problem, though, is that my right arm does not feel like flying.

As soon as she lifts my right arm, everything feels tense. Part of the practice is to let Baker control my body movements. I’m supposed to simply let my body rest in her touch instead of trying to move it or manipulate it to do a certain thing. My arm is bent in a right angle and as she lifts it up, moving my hand toward the ceiling, I want to yank my arm out of her hand and move it myself. I’m actually having to concentrate on not

moving my muscles on my own. When she asks me to describe the sensations, I tell her that my arm feels resistant to her movement.

“Yes, I could feel that right away,” she tells me. “Let’s try that movement again.”

But it feels the same. My right arm does not like being moved by someone else. When Baker asks questions to investigate, I reveal that I am right-handed, that my right hand is my writing arm, my doing arm.

“And so if you could say something to appreciate your right arm, what might that be?”

“Well my instinct is not to appreciate it,” I say. “I want to tell it to do what it’s supposed to do, to be like the left arm.”

Baker laughs a little, and I’m relieved that she’s not going to launch into a lecture about why I shouldn’t compare my body parts. Instead, she again asks me to talk to my right arm and to thank it for something. This whole talking-out-loud-to-my-body thing (in front of another person, no less) still feels a bit awkward to me, but I go with it.

“Well, I guess my right arm is capable. I mean, I’ve always been able to support myself with my work.”

Baker continues to move my right arm, which still feels only slightly less tight, like a stubborn child who continues to pout after the tantrum is over. She doesn’t press me to continue my conversation with my right arm -- maybe because it’s only my first session or maybe because we’ve already gone over the usual 50-minute time limit. Or maybe she’s heard all she needs to pinpoint my emotional issues.

To close out the session, she asks me to return to that mental Polaroid picture I took of my body earlier. I notice that my breathing is much more relaxed, and I envision

my body as fully sunken into the imaginary sand. Whereas before I felt like my body's weight was being held up by my heels and shoulders, it now feels like every muscle is resting on the massage table. In my mind, I see the indentation of my body in the soft sand picture of my mind. And even though I'm miles from a beach, something about this image is oddly satisfying and relaxing.

When I open my eyes and sit up on the table, it feels as if I'm reentering the world, like waking up from a deep sleep and being surprised by the bright daylight. I can feel the blood rushing back to different parts of my body and my head feels heavy again on top of my neck. Sarah had told me earlier that clients during a synergy session are in somewhat of an altered state. It's not hypnosis, but it's definitely a different type of consciousness. It feels like I just woke up from a vivid dream. She tells me to move slowly at first and take a few moments to sit on the edge of the table, my legs dangling off the side. Next, she instructs me to walk the length of the room, pivot and repeat. She has me do this several times, asking me to listen to my body.

It feels like I'm realizing for the first time that my feet are capable of supporting my whole body. Other than that, I'm at a loss for words. Sarah helps me out, telling me she's sensing that I'm more grounded. Sure, grounded, that sounds good, I think. As I leave her apartment, I'm trying to convince myself that I do, in fact, feel different. But with each step on the three-block walk to the subway, that heightened awareness of my body ebbs away until I feel nothing extraordinary.

I called Baker the next day to get her take on my session. She was first introduced to synergy in 1997 as a client. She's been practicing as a synergist for seven years and is

halfway through a four-year training to become a certified Rubenfeld Synergy mentor. In her practice, she's worked with about 50 clients, and I was eager to hear how she perceived my experience. When I told her about my frustration with finding the right words, she assured me that can be a typical first-session occurrence. "In this work, I'd almost liken it to people having to learn a new language," she said.

If it feels like learning a new language, that's because it is, according to Wight. She said the body has a different vocabulary than the mind. For example, take a client who visits a synergist to cope with a bout of depression. In asking that person to describe their depression, the mind will answer with words like stress, anxiety, sadness, confusion. But if you ask the body the same question through touch, the body will answer in terms of weight, density, and volume. "It's a very different language than the mind's language," Wight said, and it's clues like these that let synergists know who's speaking – the unconscious, truthful body or the conscious, censoring mind. Some bodywork therapies believe that certain emotions are stored in certain areas – so that a feeling in the stomach always means one thing, while a feeling in the feet always means something different. But synergists believe that every person is different and there is no universal translation for sensations. For example, a tingling sensation could mean two very different things for different clients.

Baker also told me my resistant right arm and hesitancy to give up control is something that happens often in sessions and if we were to continue meeting she would look for opportunities for me to experience not being in control, which she said would blend well with my wanting a gift of a break. "There were a couple of moments that really had my attention," she told me. "Some of them are almost clichés, like you being

the older sister, and some of them I can relate to, like being a young woman in 2010, a time when we're supposed to be fiercely independent and self sufficient."

The problem with this, Baker continued, is that we live in bodies that want to be tended to. Through conversation, my cognitive mind revealed that I wanted a break; through touch, my arm said it wanted to be in control and my knees said they wanted to be noticed. Based on the talking/touch combination, Baker came to this initial conclusion: I have issues with being in control, so much so that it's not easy for me to receive help or support from others. And that keeps me from feeling a sense of total relief. She also suspected there were some relational issues tied up in all of that as well. "I don't know exactly why, but that's just my hunch."

Her assessment came as a relief. At 29, I'm well aware of my control issues; I am, after all, the oldest of three girls, the daughter of a military father with a penchant for perfectionism. I was relieved not to be surprised or ambushed by her assessment. Control issues? That's nothing new. It also meant I wouldn't be needing to dip into student loans to pay for therapy sessions. Hearing her analyze our session felt like I had shown her a part of my soul and she had seen in it what I've always known was there.

If we were to continue our sessions, Sarah said she'd try to get me to open up more about what it's meant for me to be "seen" in my life. She also said repetition would play a key role. She would continue to work with moving that right arm until it learned to accept her movement. Through repetition, I would be teaching my right arm to receive that help.

The first step in change, though, is simply awareness, Wight said. Only once a person becomes aware of their unconscious habits can they choose to change. "Without

awareness, you don't have a choice," Wight said. Synergists rely on three tools to help the body respond in nonhabitual ways: simile, metaphor, and imagery. By describing and comparing sensations, clients can use imagery to re-imagine events or to finish out an unfinished event. "We allow a rescripting," Wight said. "They get to have a more accurate picture of themselves."

Much has changed in our understanding of the mind and body since Illana Rubenfeld first developed therapeutic synergy, yet the practice continues today. There are currently more than 200 certified synergists practicing in the United States. Ideas about the bodymind that seemed radical forty years ago have become more accepted beliefs, partly because scientists are now able to study bodies and minds at a molecular level that was unheard of in the 1960s.

Dr. Candace Pert was one of the earliest scientists to speak out against what she calls a "neurocentric" conception of memory and emotion. The brain is not the only place where memories and emotions are stored, she argued. Instead, opiate receptors, which operate like sensory antennae throughout our bodies, relay information to the brain. It's not just a matter of neurons and synapses, according to Pert. In 1999, she published a book called "The Molecules of Emotion: Why You Feel the way You Feel" which documented her work with opiate receptors and amino acid chains called peptides. Her studies found that there are opiate receptors in the stomach that relay information to the limbic system of the brain. The limbic system is responsible for regulating our feelings. Her findings, she said, validated the axiom about "feeling sick to my stomach" over an emotionally charged incident – a break up, a mistake at work, a family fight. When someone describes a hunch as a gut feeling, that's exactly what it is. The opiate receptors

in his stomach are responding to stimuli and relaying that information to the brain. In the process, the gut is affected physically.

Pert's work resonates with synergists because it echoes their ideas about bodymind integration. "We're not just a bunch of bones and muscles," Wight said. "We live through our senses." Which is why it's so important to be aware of those senses.

"If we accept the idea that peptides and other information substances are the biochemicals of emotion, their distribution on the body's nerves has all kinds of significance," Pert writes in her book. "Repressed traumas caused by overwhelming emotion can be stored in a body part, thereafter affecting our ability to feel that part or even move it." Of course, Illana Rubinfeld and her followers believed this long before Pert demonstrated the connection in her Johns Hopkins lab.

In fact, Wight said she continually becomes more convinced that most physical pain has emotional roots. "I think they're all so interwoven and one impacts the other all the time, so there's nothing that's ever solely physical and nothing that's solely not physical."

When we consider the molecules of emotion and the connection of mind and body, it becomes understandable why so many of our strongest or earliest memories are tied to emotional events. Harvard psychologist and philosopher William James wrote in 1890 that "an experience may be so exciting emotionally as almost to leave a scar on the cerebral tissue." Or within the tissue, within the very cells themselves.

Scientific studies in recent decades have proved that there is a direct correlation between the accuracy of a memory and the emotion of an experience, whether it was

positive or negative¹⁴. This is why we are more likely to retain vivid memories of our weddings, the death of a relative, nasty break ups, that last dance from senior prom.

One of my earliest memories is from kindergarten, when I was five years old. My dad has the day off work, so he walks me to school with my younger sister Jessica. When the morning bell rings, I don't want to leave my dad and sister. Inside the classroom, I'm pushing back tears as I listen to Mrs. Smith deliver the morning greeting. When it's my turn to put my stuff away, I walk to the back of the classroom, where each student has a cubbie box for holding our backpacks. The cubbies line a wall right underneath a row of large picture windows overlooking the playground. I see my dad, dressed in a baby blue Adidas sweat suit, pushing Jessica on the swings. I just stand there watching them until they leave the playground hand-in-hand to head for home. Remembering this even now I have a physical reaction. There's this sinking in my stomach, this deep longing.

The fact that I still have a physical reaction to this memory nearly 25 years later probably means something significant – like that Sarah Baker was right when she heard my knees asking to be noticed. That really it's not my knees who want to be seen – it's me. That unconsciously my whole life I've been the girl on the other side of the glass.

For better or worse, these memories have made me who I am today. “As much as there's physical DNA, there's an emotional DNA that gets passed along in the same way,” Wight said. “All these influences shape us, and they're in our body, unconsciously most of the time.” According to Wight, my emotional DNA is just as important in making me “me” as the 46 chromosomes in every cell.

14. Schacter, *Searching for Memory: The Brain, the Mind, and the Past*. 209.

When I last saw my grandma, she couldn't walk without using her walker or someone's arm for support. When we all gathered at my aunt's house, we folded up the walker and opted to escort her to wherever she needed to go, which was usually one of two places: the bathroom or her favorite chair next to the picture windows in the back of the living room. She liked to sit there and gaze outside for signs of life. Hummingbirds, pheasants, an occasional deer. On one visit, I remember sitting with her in those chairs, wanting to talk to her about her past but not knowing what to say. I didn't want to ask questions that would upset her when she couldn't answer. So we mostly sat in silence. I'm not even sure if she knew who I was. Now, I think of that moment and wonder if her body was holding onto stories it wanted to share. What were the memories locked in her small frame? There's no evidence to suggest that bodywork might help dementia patients remember or make sense of their memories once the mind begins to go, but I can't help but wonder what we would have heard if we had put our hands on grandma's hunched back and listened. If we had held her hands in ours and just asked grandma to remember – anything, anything at all.

Of course, if my mom's theory is right at all, then maybe Grandma had given out her memory long before the dementia set in. Maybe she had passed it along to her five children, doled it out in pieces with each birth.

How else am I to explain these memories that are not mine? I see my parents as freshmen in high school, sitting in a classroom on the second floor of Aitkin High School: June with dark brown hair, parted straight down the middle; Geff flashing that goofy grin with ears too big for his scrawny build. They're both dating others, but during Family Planning class, when the teacher turns off the lights to show a film, they scoot

their desks closer together in the back row. They reach across the aisle and hold hands in the dark classroom, as the beam from the projector lens illuminates dust specks drifting through the air.

I see my Grandma Lillian as a young woman driving home to the family farm. Her brown curly hair is pinned back, and her slender fingers are wrapped around the black steering wheel. She's talking and laughing with her sister Helen when a pheasant flies into the road. My grandmother doesn't swerve. Even though she brakes, she hits the bird, sending a flurry of feathers into the nearby ditch. Grandma Lillian pulls over and rushes out to where the pheasant lies wounded. He tries to fly away, but his wings are broken and he must try to escape with his legs. My grandmother catches him in a patch of cattails growing alongside the road and wrings his oily green neck the same way she kills the chickens on the farm. That night, the family eats pheasant for dinner.

Science has myriad explanations for my claim on these memories, but I'm beginning to prefer my mother's theory. Yes, these are my memories now. I stole them right from my mother's womb. Or perhaps I didn't steal them as much as they were given to me. Maybe my mother's cells whispered them to my cells. A gift. A lullaby of memory.

CHAPTER FOUR

REMEMBER WHEN?

The evacuation order came just after Eileen Landry had arrived back in Santa Barbara after a trip to visit her cousin in Germany. Her husband James had stayed in Los Angeles for the night, leaving her alone to pack up whatever she could fit in her car. The dark brown smoke of the wildfire blocked out the sun as she rushed in and out of the house, her arms filled with framed photos, boxes of medical records, pieces of her mother's china collection. By the time she reached the freeway, the fire was threatening to overtake the six-lane road. In just four hours, the 1990 Painted Cave Fire rushed through the hills of California's central coast, destroying 440 homes.

The next morning, Eileen returned home to find only the chimney standing. Days later, Eileen, James and their three adult children – Kathleen, Garrett, and Sherry – returned to where their house once stood. They sifted through the cooled ashes looking for anything salvageable. James found his mother-in-law's wedding ring, but most of their lives' keepsakes and mementos were destroyed: The box of slides from James's family, school pictures, their children's artwork. Even the family cat. Standing there, in the charred ruins, James and Eileen thought they were experiencing the worst kind of loss – total and irreparable. How could they have known then that a still worse loss was

still coming? That a year later, their youngest daughter would claim to recover memories of childhood sexual abuse? That she would name James as her abuser and accuse Eileen of knowing about the incest. Rummaging through the ashes, their fingernails blackened with the dust, James and Eileen had yet to experience the unimaginable loss of a child – a devastating, lingering loss that never heals.

“It’s really easier to have lost your house than it is to have lost a child,” Eileen says, crying. “This is definitely much harder to deal with than having to rebuild your whole house and your whole life.”

The late 1980s and early 90s saw a dramatic rise in the number of reported child abuse cases. These reports weren’t coming from children, though. They were coming from adults, mainly women, who claimed to suddenly remember instances of extraordinary abuse – incest, rape, satanic cults, ritual abuse. Because many women did not report their allegations to law enforcement agencies, there is no way to track the official figures; however, one author, using survey responses from several different organizations, estimated there were 2.5 million recovered memory cases by 1995.¹⁵

Most often the reports came from women who recovered such memories during the course of therapy. Therapists from a wide range of disciplines assured their patients that these abuse memories had been repressed as a way for their child-self to cope with the trauma they had experienced. As more women came forward and the accusations became more fantastical, skeptics in the scientific and therapeutic community began to question the validity of these recovered memories. Suddenly, children, parents, scientists,

15. Mark Pendergrast, *Victims of Memory: Incest Accusations and Shattered Lives* (Vermont: Upper Access, Inc., 2005). 491.

scholars, lawyers and therapists were locked in a bitter battle over whether traumatic experiences could even be repressed and recovered later. This period became characterized as “The Memory Wars.”¹⁶

Twenty years later, the Memory Wars have mostly subsided, with scientific evidence, personal experience and updated therapeutic practices coming down on the side of the skeptics. Overwhelming research supports the conclusion that our memories are both fragile and fallible, and therefore susceptible to all sorts of distortion. The lessons of Memory Wars highlight the complications and consequences of staking our identities on memories that can be not just mistaken, but downright wrong. And while the scientific, therapeutic and legal communities have largely resolved the debate, there are thousands of families still caught up in the wildfire of recovered memories, families still living in the aftermath of those accusations. People like James and Eileen who continue to sort through the rubble of burned relationships, wondering if the damage can ever be repaired.

Construction on Highway 101 backs up traffic for 10 miles south of Santa Barbara. I call Eileen from my cell phone to tell her I’ll be late and to eat lunch without me, but when I finally knock on their door 30 minutes later, she and James have waited to begin lunch. Eileen greets me at the door with a wide smile and warm handshake, as if she’s been waiting for a long-lost friend to arrive and not a stranger, coming to interview her and her husband about one of the most painful experience of their entire lives. James rises from the computer in the living room and walks to say hello. I don’t want to, but I

16. Paul R. McHugh, *Try to Remember: Psychiatry’s Clash Over Meaning, Memory and Mind* (New York: Dana Press, 2008). 49.

can't help sizing him up and deciding that he doesn't *look* like a child molester. In fact, he looks like the type of elderly man you'd wave to on your way to work when he walks outside to pick up the newspaper. He's tall and slender, with soft brown age spots on his scalp where his white hair has receded. I get the sense that he's sizing me up, too – perhaps wondering if I'm wondering if he's a child molester. Eileen shows me to a guest bathroom where I can wash my hands before lunch. When I return to the kitchen, she's laid out a spread of ham sandwiches and orange slices on a small table underneath a kitchen window.

For the next five hours, we sit and talk at this table, only realizing how much time has passed when it becomes necessary to switch on the lights after the sun dips below the Pacific Ocean horizon. During our conversation, Eileen occasionally gets up to grab picture frames from the living room, copies of letters from her file cabinet, and scrapbooks with cards and pictures and graduation announcements from their three children.

She pulls down a family picture from a bookshelf to show me. It's a family photograph taken at a relative's wedding in Portland sometime in the late 1970s. In it, Eileen and James pose at the church's altar with their three children.

"Everything was hunky dory then," she says. "We were a normal happy family and all three of them were really good students."

"And they were very close," James adds.

The oldest, Kathleen, was the most rebellious; their only son, Garrett, was the rambunctious one; and the youngest, Sherry, had a creative spirit.

“When she was three years old, she put words together in an interesting way and she just had a mind that was really creative,” Eileen says.

Other photos show the three siblings posing by a fireplace in outfits Eileen sewed herself. There are photos of the children on Christmas morning, stretched out on the floor in their pajamas, surrounded by piles of wrapping paper. Eileen is trying to prove a point with these photos: “We were involved with our kids,” she says. “We always ate meals together, we went to church together, we were involved with school.”

Which is partly why the accusations of incest came as such a shock.

In the year after the 1990 fire, James and Eileen found themselves consumed with the process of rebuilding – from finding a temporary place to live and haggling with insurance adjusters to making decisions about the types of light fixtures they wanted in their new house. It was a busy time for their children as well. Kathleen, now married with two children, was working fulltime as a teacher. Garrett was also newly married living in the Bay Area. Sherry had recently graduated from college and decided to move to San Francisco to live with a married man – a decision that upset both James and Eileen. That already put a strain on their relationship, and the trauma and stress of the fire only exacerbated the tension. James and Eileen sensed something was bothering Sherry, but whenever they asked, she brushed off their questions.

On January 27, 1992, Eileen walked to the mailbox of their temporary home and found an envelope from Sherry addressed to James. Along the bottom, she had made an asterisk with the note: “To be opened by Dad only.”

“When he opened it, he just started shaking like he was having an attack of some sort, Eileen remembers.

“I don’t remember that part of it,” says James. But Eileen says that moment is etched in her mind: “Your whole body was just shaking and you were just kind of like a zombie.”

The typed one-page letter began *Dad – You have been wondering and asking me what has been bothering me in the recent past to make me so angry. I have an answer for you now.*

In the course of therapy, I have recovered memories of being sexually abused as a child. I remember that it was you who did these terrible things to me, Dad. I remember many specific incidents. I am angry and hurt. This has had a terrible effect of me and I am furious with you.”

The letter goes on to ask James to pay for her therapy bills, which totaled \$1,895 for 1991. It also stipulated that the only contact she would have with her dad is through the mail and only if he first wrote to tell her he’d started psychological treatment. She also said she would only have contact with her mother through the mail – no phone calls. She closes the letter by saying, *Incest is a terrible and grotesque thing to do to your daughter. I will do what I can to make sure you never do this to any other girls.*

-Sherry.

“I don’t think I was angry; it just blindsided me,” James says, but when he continues, the emotion spills out. “What more could you accuse your father of? What’s the worst thing you could accuse somebody of?”

Stunned, Eileen and James called their pastor who immediately rushed over. They didn’t know who else to call and they didn’t know who else to talk to. At that time, accusations of abuse were presumed true unless there was empirical evidence to counter

them. When Kathleen called to ask about the situation, James followed the advice given to him by a lawyer friend: “I’ve been advised not to talk about it until I’ve talked to a lawyer who could help us,” he told her. To James’s horror, Kathleen took his statement as an admission of guilt and believed Sherry’s accusations.

Now the family was split, with Kathleen and Sherry seeking therapy and believing their dad was a child molester. In the following years and months, James and Eileen communicated with their daughters mostly through letters. When they did visit Sherry in San Francisco, the visits were tense, short and her accusations were never discussed. “It was like visiting an ice cube,” James remembers. “Like the polar express.” Whenever James and Eileen tried to bring up the accusations, Sherry shut down the conversation.

Their son Garrett never believed the allegations and tried pleading his father’s case in a letter to Kathleen: “Think for a moment about how you both feel about your own kids and how you’d go to the ends of the earth to give them the best life possible? Do you honestly think mom and dad felt any differently while raising us? I’m sure neither one of you could fathom hurting your own child by sexually abusing them, and I’m equally sure mom and dad are no different.”

Kathleen wrote her own letters, in one telling her mother, “Mom, what a choice you have to make: believe your daughter or believe your husband. Your peace in life as you knew it is gone.” But Eileen said she never believed the accusations, “I had scenarios going through my head of how this could possibly ever happen and nothing ever fit together.”

Eileen and James learned that Sherry was seeing a therapist from the hospital where she was working. They also learned that she had read *The Courage to Heal: A Guide for Women Survivors of Child Sexual Abuse*—a book often dubbed the Incest Survivor’s Bible. In fact, Sherry told one of her aunts she had read the 500-page book five times and completed the accompanying workbook. *The Courage to Heal*, written by Ellen Bass and Laura Davis, was published in 1988 and became one of the most controversial texts of the recovered memory movement. In the book, the authors claim that remembering the abuse is not requisite for believing you were abused: “Often the knowledge that you were abused starts with a tiny feeling, an intuition. It’s important to trust that inner voice and work from there. Assume your feelings are valid. So far, no one we’ve talked to thought she might have been abused, and then after discovered that she hadn’t. The progressions always go the other way, from suspicion to confirmation. If you think you were abused and your life shows the symptoms, then you were.” Bass and Davis open their book with a chapter called “Taking Stock” where they offer a series of question checklists that are supposed to indicate whether or not you were abused. A sample:

Do you have a hard time nurturing and taking care of yourself?

Do you find it hard to trust your intuition?

Do you have a sense of your own interests, talents, or goals?

Do you use work or achievements to compensate for inadequate feelings in other parts of your life?

Do you have trouble expressing your feelings?

Do you feel confused much of the time?

Do you find it hard to set clear boundaries with your children? To balance their needs with your own?

Bass and Davis offer 75 different questions to assess one's incest-survivor status. Writing in *The New York Times*, Carol Tavis, like so many other critics, raised doubts about the catch-all checklist: "The trouble is that the same list could be used to identify oneself as someone who loves too much, someone who suffers from self-defeating personality disorder, or a mere human being in the late 20th century. The list is general enough to include everybody at least sometimes. Nobody doesn't fit it."¹⁷

When it comes to memories, the authors encourage readers not be discouraged or dissuaded from belief if they can't remember any specific details. Instead, Bass and Davis write, "You may think you don't have memories, but often as you begin to talk about what you do remember, there emerges a constellation of feelings, reactions, and recollections that add up to substantial information. To say 'I was abused,' you don't need the kind of recall that would stand up in a court of law." In other words, you don't need proof – or memories even – before you accuse your father, your uncle, your brother of molesting you. All you need is a hunch. If you believe it, it will be true.

Because of this "belief first, proof second" approach, Bass and Davis have been frequent targets of memory researchers. Dr. Elizabeth Loftus is often characterized as the

17. Carol Tavis, "Beware the Incest Survivor Machine" *The New York Times Book Review*. January 3, 1993.

chief crusader against the validity of recovered memories. Dr. Loftus conducted hundreds of studies, showing how easily suggestive questioning, imagination prompts and visualization can produce distorted or false memories.

In the most famous of her studies – the lost-in-the-mall experiment – Loftus was able to coax a quarter of her subjects to “remember” childhood events that never happened. With each participant, Loftus collected stories from that person’s childhood from family members and then shared four short stories with the subject. One of those stories, describing an experience of being lost in the mall, never happened. When the subjects were asked to recall the stories, none of the participants initially remembered being lost in the mall. But after several weeks had lapsed and they were asked again, 25% of the subjects described memories of being lost in a mall. Some of the subjects even added and embellished the details of the original narrative. Loftus also found that when study participants were asked to imagine that the event had happened, they later reported with increased confidence that the event was real.

This study has been replicated in labs across the country, sometimes planting memories of even more outlandish childhood stories: Remember when you were hospitalized overnight for an ear infection? Remember the time the sprinkler system was activated at the grocery store and you had to evacuate? Remember the time you spilled the punch bowl on the bride’s parents at a wedding reception? When presented with the wedding story during the initial interview, one participant rightly had no memories of spilling the punch, but when she was asked again in a subsequent interview, she said: "It

was an outdoor wedding, and I think we were running around and knocked something over like the punch bowl or something and made a big mess and of course got yelled at for it. "18

Here's how false memories can happen: When someone tells you that you were lost in the mall as child, your brain stores that information as a memory trace. Your brain differentiates between the information as a suggestion and an actual fact. But over time, the distinction between suggestion and fact can deteriorate as the suggestion of being lost becomes linked with other actual memories of being lost or being in a shopping mall. Time and stress are two factors that contribute to the collapsing of suggestion and fact. With enough time, your memories of shopping in malls become conflated with the suggestion that you were once lost. If you were asked months later if you had ever been lost in the mall, your brain would activate the images of being in a mall and images of being lost. You may now "remember" a specific incidence of being lost in mall. The 'memory' may feel real, complete with vivid images and particular details, but it is actually a composite of different experiences and events. Your brain has, to put it simply, 'forgotten' that the lost-in-the-mall scenario was originally a suggestion.

Loftus' studies highlight two key characteristics of our memories: their high susceptibility to suggestion and their propensity for error. We all make memory errors throughout the day, but most are inconsequential. Does it really matter if I "remember" my mother giving me a recipe for monkey bread when really it was my aunt who gave it

18. Elizabeth Loftus, "Creating False Memories," *Scientific American* 227 no. 3 (September 1997): 70-75.

to me? There are other instances, though, where entire lives depend on the accuracy of our memories.

In his book, *The Seven Sins of Memory*, Dr. Daniel Schacter tells the story of psychologist Daniel Thomson who was arrested for assaulting and raping a woman in her home based on the woman's detailed description of his face. The woman even picked him out of a lineup. The problem, however, was that there was no way Thomson could have committed the rape. At the time of the crime, he was being interviewed on live television. The woman had been watching the interview when she was attacked and mistakenly recalled the memory of Thomson's face as the face of her attacker.

Since 1989, 266 prisoners have been exonerated through DNA testing. The leading cause of these convictions was mistaken eyewitness identification. In fact, 75 percent of these overturned convictions were a result of eyewitnesses whose memories were wrong.¹⁹ This capacity for error is a result of the constructive nature of our memories, Dr. Schacter said.

"We're not taking a picture, a snapshot of the world," Dr. Schacter said. "It's a much more active process where we're kind of linking together moments of experiences, and when we remember them we're reactivating some of those links. It's much more of an active construction. Things like our current mood, our current knowledge, our current beliefs, all that can influence exactly how we reconstruct something." A therapist is part of that retrieval environment, and what the therapist believes can influence what the patient believes about his or her past. When women like Sherry sought counseling in the

19. Innocence Project. "Fact Sheet." Innocenceproject.com. (accessed February 1, 2011).

1990s one of the biggest indicators of whether or not they would eventually recover memories was whether or not their therapists themselves believed in recovered memories.

Dr. Schacter and his colleagues at Harvard conducted one of the earliest experiments with subjects who claimed to have recovered memories in therapy. They used standard laboratory test where subjects commonly create false memories by word association. The experimenter reads a lists of related words – thread, pin, eye, sewing, sharp, point, prick, thimble, haystack, thorn, hurt, injection, syringe, cloth, kintting – and then later gives a memory test asking subjects to decide which words had been read aloud earlier. The choices might include: sewing, door, needle, sleep. Schacter and his colleagues found that people frequently “remember” hearing the word needle, even though it was never on the list²⁰. Furthermore, experimenters found that those people who claimed to have recovered memories showed a higher susceptibility to creating these types of false memories in a lab setting.

So far, scientists have yet to identify a biological basis for why certain people are more prone to false memories. Researchers have, though, been able to repeat their results using subjects who claimed to be abducted by UFOs – a category of people who scientists could be sure had false memories.

But it wasn’t just individuals who were prone to buying into false memories. For years, the therapeutic community embraced Sigmund Freud’s idea of repression. Even though there’s never been any scientific evidence to confirm that human brains will bury traumatic experiences to protect our psyches, the romantic notion has persisted – and still persists – in popular psychology, literature and media. This belief in repression coupled

20. Schacter, *The Seven Sins of Memory: How the Mind Forgets and Remembers* 98-99.

with a flawed conception of memory as a tape recorder contributed to the storm of abuse claims in the '80s and '90s.

The hysteria began in the mid-80s and mainly focused on day care centers. In the most famous case, employees at the McMartin Pre-School in Manhattan Beach, California, were accused of sodomizing children, engaging in satanic ritual abuse and constructing elaborate underground tunnels to transport, hide and abuse the children. When detectives and officials questioned the children at the preschool, the children denied witnessing any abuse, but under suggestive and aggressive questioning, they eventually “remembered” seeing witches fly, riding in hot air balloons, and being flushed down toilets to secret hiding rooms where they were abused. The claims seem fantastical and unbelievable now, but at the time, the country was engulfed by a panic over sexual abuse. In the late '80s and early '90s, adult women began seeking therapy for depression or anxiety or stress and became convinced their problems were manifestations of horrific abuse they'd experienced – and then forgotten – as children. Well-intentioned therapists became convinced of the brain's ability to repress and later recover traumatic memories; even respected institutions like the National Institute of Mental Health backed the idea. Weekly magazines in newsstands covered the phenomenon with celebrity survivor stories: “I Am an Incest Survivor,” the headlines read. Victims told their stories to Geraldo, to Donahue, to Oprah, to anyone who would listen. Book stores stocked self-help titles like *Unlocking the Secrets of Your Childhood Memories*, *Repressed Memories: A Journey to Recovery from Sexual Abuse*, *Secret Survivors*, *Silently Seduced: When Parents Make their Children Partners – Understanding Covert Incest* and tell-all survivor memoirs like *Michelle Remembers* and *Dancing with Daddy*.

Looking back on that time, there have been many explanations offered for how the recovered memory movement became such a cultural phenomenon. Some, like Johns Hopkins Psychiatrist-in-chief Paul McHugh, blame pernicious therapy: “With the procedures promoted by psychiatric “experts,” a craze reminiscent of the Salem witch hunts had emerged from the psychiatric clinics.”²¹ Some, like cultural critic Carol Tavis, point a finger at feminism: Incest claims were waved about as proof of a “system that endows men with the sense of entitlement to own and abuse women and children.”²² Still others blame America’s obsession with victimhood status, with salacious sex stories, with hypocritical moral outrage. But one thing is clear: None of this ever could have happened if more people understood how our memories actually work. The frenzy was based on dramatic survivor stories not on empirical evidence about the nature of memory, which led to a full-blown sex panic. And it was only going to get worse before it got better.

This is the climate James and Eileen found themselves caught up in 1992. Suddenly, they were reading books on memory, scanning newspapers for articles about repression, and, because they worried Sherry would go public with her accusations, familiarizing themselves with their legal rights. It was a lonely time for them -- they were estranged from both their daughters and couldn’t turn to anyone else. They simply didn’t know which friends to trust with their experience.

“Any time a guy is accused of incest, you don’t want to talk about that to your friends,” James said. “This is something you’ve got to be very careful about, because particularly back then [the accusations] were automatically true.”

21. Paul R. McHugh, *Try to Remember: Psychiatry’s Clash Over Meaning, Memory and Mind*. (New York: Dana Press, 2008). 2.

22. Tavis, “Beware the Incest Survivor Machine.”

They had no way of knowing then that there were thousands of other families struggling with the same challenges, thousands of mothers and fathers desperate to reunite with their accusing daughters. That is, until they discovered the False Memory Syndrome Foundation.

University professors Peter and Pamela Freyd founded the False Memory Syndrome Foundation in 1991 after their own daughter claimed to recover memories of childhood abuse in therapy. Stunned by the accusations, Peter and Pam began researching memory and recognized a need for an organization where parents could share information and feel supported in their quest to repair their reputations and their relationships.

On the day I visit the foundation's headquarters in Philadelphia, Pam ushers me into her second-floor office where the bookshelves are crammed with books and thick plastic binders – labeled and sorted by year. Stacks of papers and folders cover both her desk and the small conference table near the door. She is dressed casually in maroon velour pants and a matching ribbed shirt. The hard work of the last 20 years hasn't done much to slow her down, and she moves around her office with frenetic bursts of energy. Throughout our conversation, she alternates between her roles as executive director and mother. When she's speaking as executive director, her tone is confident and her words are carefully chosen, selected only after she's paused to think through her response. Other times, though, she speaks from the pain of personal experience. Toward the end of my visit, Pam shows me her collection of quartz rocks that sit haphazardly along her bookshelves.

“These remind me of a story about my grandmother,” I tell her. “When she was a child, she took a wheelbarrow to the quarry every day and filled it with stones that her father used to build a wall. The wall is still there to this day.”

At first, Pam smiles at my story. Then, the reality of her own situation overtakes her.

“That’s what’s so tragic about this,” Pam says, referencing the wasteland of fractured families. Now, she’s speaking as a mother whose daughter won’t talk to her, as a grandmother forbidden to see her grandchildren. “There are all the stories that aren’t getting passed down to the next generation.”

There’s only one other staff person in the office on the day of my visit, and the foundation has rented out some of its space to other nonprofit organizations. The only phone calls come from Pam’s contractor, who’s working on remodeling their apartment just a few blocks away.

It wasn’t always such a quiet office. Pam remembers the stream of phone calls and the huge bins of letters delivered by the post office in the early 1990s. The foundation’s staff quickly grew to thirteen people to handle the volume of phone calls and mail. “The phones used to be off the hook,” she said. “We had one person who did nothing but take phone messages.” Whenever the media reported on the conflict of recovered memories, the foundation would receive 1,000-2,000 calls in the next 24 hours from parents and family members desperate for answers and support. By 1995, more than 15,000 families had contacted the organization, and the foundation had more than 7,500 members.

Eileen and James heard about the FMS Foundation in the fall of 1992. “We began getting information that we weren’t alone in this whole thing,” Eileen said. “That was a huge relief to us.”

Finally, Eileen and James found a support group of people who understood their situation uniquely and intimately. Eileen agreed to serve as a contact person for the Santa Barbara region and helped organize local meeting and conferences. For many years, the Santa Barbara chapter met in the back room of a local restaurant – a place where they could discuss their stories in private, away from the hype of the media and the suspicious glances of eavesdroppers.

In the ten years they met regularly, more than 100 people cycled in and out of the Santa Barbara chapter. They came from all different backgrounds, but there were remarkable similarities among their stories. In FMSF circles, there’s no need to explain how they learned of the accusation through the mail; they just all refer to it as The Letter. Eileen and James learned that therapists often helped their patients draft these letters to the men they were accusing of abuse. It was also common to request the accused to pay for the therapy and to stipulate strict terms for any future communication – *Don’t call me. Wait for me to call. I do not want to talk to you about this* – and to claim to remember specific instances of abuse without explicitly describing any of the details. To this day, Sherry has never told James or Eileen about the specifics of the abuse she “remembers” – nothing about when this abuse took place, where it took place, or exactly what the abuse was.

In 1995, the False Memory Syndrome Foundation published the findings of a survey of 40 women who had retracted their claims of abuse. The results highlight even

more commonalities: All the survey respondents were white women, half of whom had graduated from college. The average age at the time the accusations were made was 32. Eighty percent of the women accused their father of incest. Three-quarters of the respondents reported reading *Courage to Heal* and nearly as many said their therapists used guided imagery to help them recover their memories.

The FMSF also published statistics about the families of accusers: Most were white, well-educated, middle- to upper-class families. James and Eileen attended several conferences organized by the foundation, and even organized a local conference that attracted roughly 250 people.

“It’s really interesting to see when these families come into a big meeting room and everybody’s had the same issue, and you look around and these are just ordinary folks,” James said. “This does not fit the population of child molesters. It doesn’t look like that at all. In fact, it looks like a senior citizens’ assembly.”

The monthly meetings of the Santa Barbara chapter became a place where the members could swap information on the latest memory research and recommend book titles. “We would get together and be able to feel totally free to say anything in the group with each other,” Eileen said. “And I’ll tell you, some of the men have gotten so angry. I mean, just red-hot angry.” And then, after years of meeting, the group was able to do something many thought they’d never be able to do – they laughed. In the comfort of their friends, bonded together by their shared pain, they could joke about false memories and bad therapists and their “crazy daughters.” To an outsider, the smiles might have looked like they’d moved on. They hadn’t. It was just part of their grieving and healing process.

At one meeting, Eileen and James encouraged the members to bring a copy of *The Courage to Heal*. Most members already had copies (or several) that they had purchased and read in an effort to understand their daughters. In fact, Eileen often bought used copies when she saw them at thrift stores or garage sales – anything to prevent other young girls from reading it. For this meeting, Eileen and James brought large paper bags and the group happily ripped up copies of the book, shredding the “toxic” text into bags that James and Eileen then brought home and burned. The members found other ways to be proactive. They seeded their local libraries with books that argued against recovered memories. Eileen and a few other women handed out False Memory Syndrome Foundation pamphlets at a conference teaching the basic principles of recovered memory therapy. Whenever James went to a bookstore, he moved *The Courage to Heal* to the electronics division. In these little ways the parents felt like they were fighting back; the small victories helped sustain their hope.

After years of strained and sporadic contact with their oldest daughter, Kathleen wrote a letter to James in 1995: “I’m not sure at all you did anything to Sherry but try to be a good father,” she wrote. “I just wanted to tell you I don’t think it was you.” Months later, when Kathleen came to visit her parents, she and Eileen went for a walk. Eileen asked her, “What was it that made you not believe anymore?” Kathleen wouldn’t give any details, just said that something that Sherry had said made her change mind. Eileen still doesn’t know what caused Kathleen’s change of heart, and Kathleen doesn’t want to talk about the accusations, the therapy, or the years she kept her two sons from their grandparents.

While Eileen and James began repairing their relationship with Kathleen, they continued to also reach out to Sherry. As always, Sherry refused to talk about the abuse allegations. For many years, Eileen sent Sherry postcards and letters throughout the year. She used to send gifts at Christmas, but they were often returned to her. Slowly, Sherry began to cut them both out of her life. The last time Eileen tried to send a book, the postal service returned it – undeliverable because the resident had moved and left no forwarding address. Neither James nor Eileen has had any contact with their youngest daughter for the last four years. They think she's living in Colorado, but they've had no luck tracking her down through the Internet or realty searches.

In 2010, James and Eileen hosted a family Christmas at their home. It was the first time that Kathleen's children and Garrett's children had seen each other in almost 10 years, even though they live in the same state. In the aftermath of the family split, Garrett and Kathleen have never truly repaired their sibling relationship. "They're not friends, but they're brother and sister," James said. Which is why Eileen was so pleased to host both Kathleen's family and Garrett's family at the same time.

"It's challenging. There are emotional levels involved," James explained. "You know those simple things you do as a family? Those go away."

Around the holiday dinner table, the family laughed as Garrett confessed to the boyish antics he got away with as a kid – things like shooting arrows at the neighbor's house. They talked about their jobs, the grandchildren's school projects. They all complimented Eileen's cooking. But there was one subject nobody talked about.

"Sherry's name never came up," James said.

"Never came up, no," Eileen said, shaking her head.

“Not once?” I asked.

“Not once. Not even one-on-one,” Eileen said.

“It’s as though she’s gone, just disappeared and never was,” James added. “But I’m sure it’s on their mind.”

Sherry remains on James and Eileen’s mind. Her face still smiles out from behind framed photographs in the living room. In a white hallway near the bedrooms, James has taped hundreds of family photos to the wall. The edges of the photos curl up where the tape has lost its stickiness. The photo wall got started more than 15 years ago, when Sherry was coming with her husband to stay for one night. James taped the photos to the wall directly in front of the door to the guest room, hoping she would see the pictures of her family – a family that loved her – and would reconsider the truth of accusations. Sherry never once commented on the photos, but James didn’t take them down. In fact, he’s continued to add photos over the years – a memorial to the living, to the gone but not forgotten.

On account of my visit, Eileen invites some members of the local FMSF chapter over for afternoon tea. Their parents’ group stopped meeting regularly about four years ago. Some of their members moved away. Some passed away. Some reunited with their children. And some just wanted to stop living in the pain of the past.

Many of James and Eileen’s friends outside the FMSF group have stopped asking about Sherry. Eileen doesn’t blame them – after so many years of asking about Sherry without any change in the situation, those friends probably feel uncomfortable even asking. But in the comfort of their support group friends, James and Eileen can discuss the most intimate and painful details.

Today, they take turns updating one another on their situations and James and Eileen share that they still don't know where Sherry is living, although they think she is probably still living near Fort Collins, Colorado.

Sitting in the formal living room on floral couches and dusty pink arm chairs, the friends laugh as the conversation flitters from topic to topic-- recent holiday celebrations, new book releases, updates on mutual friends. Despite their closeness and comfort, the members of the group don't agree on everything. The parents who haven't reunited with their children, who are still living in the limbo of the accusation, want their daughters back, but they want answers too.

Others like Eugenia, a gentle but opinionated woman with wavy gray hair that falls just above her shoulders, said she doesn't feel need to demand explanations from her daughter who accused her husband after he had passed away. She said she was never bad at her daughter, only sorry for her. Sorry because years of therapy and medication had led to her believe something about herself that wasn't true. And in order to maintain her new identity, her daughter had to cut out her family, her friends, anything that reminded her of her life before she came to believe she was an incest survivor. Many of the young women who have eventually retracted their sexual abuse allegations have also shared the difficulty in recanting their stories. It can be an embarrassing and painful process to return home to the parents you once accused of abusing you. The struggle of those women who recanted highlights the consequences of building an identity on memories that were at best distorted and at worst wholly invented. Their struggle also explains why Dr. Schacter calls memory a fragile power: for all its control in our lives, we can't ever forget its limitations.

“It’s like becoming a republican after being a democrat; you have to change all your friends,” James quips. The women all laugh at his joke, but then the conversation turns serious again. “I agree with you in the sense that our children were victims, but there is a level of culpability.” James still wants answers from Sherry: *How could you believe that I would hurt you? How could you not trust me more than the therapist? How could you never give me the chance to defend myself? How could you just cut us out of your life?*

James doesn’t say anything as the women talk about their reconciliation. I get the sense he’s wondering if he’ll ever feel the same way as Eugenia, if he’ll ever be able to *not* discuss the horror and pain of these last 20 years with the daughter who caused it all. James told me earlier that he knows he can forgive Sherry, but can he forget, too?

“They keep saying don’t give up, but it’s been 18 or 19 years now for us,” Eileen says with resignation.

“Don’t give up,” Eugenia encourages her with a faint Midwestern accent, softened by years of California living.

“Don’t give up,” Eileen repeats. She’s saying the words, but it’s clear that it’s hard for her to believe them.

“Don’t give up.” Eugenia says again, emphasizing each word.

In fact, James and Eileen haven’t given up. They’re both waiting and hoping that Sherry will one day return to their lives, although neither of them can imagine how the mess will sort itself out.

“I don’t think it would be an easy time,” Eileen says. “She’d have to really, really understand what she’s put us through. And we’re willing to forgive her, at least I am, but she has to understand the pain also that has been on both sides. Hers and ours.”

“I don’t think there’s any reason to try to guess what it would be like,” James says. “You know, if the doorbell rang and she was there, I’d give her a hug.”

CHAPTER FIVE

LIFE AFTER MEMORY

The nursing staff was exasperated. Despite their insistence that he stay in bed, George continued to get up every night and wander the halls of the nursing home. For more than a year, George had made it his routine to shuffle down the high-gloss vinyl floors, past the windows overlooking the Hudson river, making loops through the H-shaped care facility. His caregivers tried logic: “George, it’s three in the morning. It’s time to sleep.” They made personal pleas: “It would make me so happy if you would go to bed, George. Do it for me, please.” Worse still, George couldn’t answer the staff’s most common question: “Why are you out of bed, George?”

In fact, George couldn’t remember or explain much of anything. He had dementia. Frustrated, the nursing home called in psychologist Dr. Judah Ronch to see if he could figure out what was “wrong” with George. In a conversation with George’s son, Dr. Ronch learned that George had worked as a prison guard before retiring.

When George was found wandering again the next night, Dr. Ronch didn’t ask him to return to his room. He didn’t ask him to explain his behavior. Instead, borrowing some jail jargon he’d picked up while working in a youth detention center earlier in his career, he approached George in the corridor and asked, “George, is everyone on the count?”

George instantly looked him in the eye, answered “Yes” and continued his rounds. He was no longer able to harness his memories and then communicate them to others, but something in George remembered the procedure of pacing the halls on duty. All of us rely on our procedural memories for thousands of tasks throughout the day. It is this form of memory that enables us to get dressed, butter a bagel and drive to work without explicitly having to think through the mechanics of our actions. Remember H.M.? The epileptic man who could no longer make memories after his surgery? When Dr. Milner taught him to draw a star on a piece of paper by looking in a mirror, she was relying on procedural memory. H.M. never had any explicit memory of having completed the task, but his accuracy and ease improved each time he drew the star. We don’t have to know we’re remembering in order for our procedural memory to work. For Alzheimer’s patients, procedural memory often outlasts other forms of memory.

For years Dr. Ronch had listened to caregivers complain that their patients were behaving strangely. Nursing staffs labeled the actions as inappropriate and unpredictable. But Dr. Ronch’s exchange with George crystallized his ideas about the purpose of these so-called random behaviors. Dr. Ronch learned to approach each case like a detective, looking for clues about what might be motivating such behavior. And since most of the patients he observed couldn’t talk about their behavior, he looked at what they did, rather than what they said. In most cases, Dr. Ronch found these patients simply to be acting out their life’s narrative in an unfamiliar environment. “They’re bringing an old memory to bear in an environment where that memory isn’t relevant,” he said.

After years of working with Alzheimer’s and dementia patients, Dr. Ronch has come to believe “a person is more than their memory.”

But how much more?

If we build our identities on our memories, what happens to that identity when we can no longer remember? Memory-impairment illnesses like Alzheimer's and dementia are different from other terminal diseases, like cancer. Cancers are caused by renegade cells that continuously multiply and then invade and destroy the surrounding tissue. With Alzheimer's, cells in the brain called neurons die off, interrupting the flow of electrical signals that form memories and thoughts. In advanced Alzheimer's, the cortex of the brain shrivels from such severe cell loss. The hippocampus, central for forming new memories, shrinks by as much as 40 percent in late-stage Alzheimer's²³

"You have to recognize that while they're diseases with a physical basis, they're really existential diseases," Dr. Ronch said. "It's a loss of self."

Sometimes, dementia patients are aware of this loss. Dr. Ronch remembers a woman who was constantly rummaging in other residents' rooms and belongings. He gently asked her why she was going through other people's things and her answer surprised him. "She laid the most profound quote on me that I've ever heard. She said 'I used to read and I'd remember what I'd read; now I read and I can't remember. That's not the real me. So I go around looking for myself, but I'm nowhere to be found.'"

Families, too, are left searching for the self of the loved one they used to know. "Grandma just stopped being grandma," one of my cousins told me, explaining why she rarely visited our grandmother, even though she lived only an hour's drive from the nursing home. It was easier to forget Grandma Lil since she had already forgotten us, my

23. Roberts, Eleanor. "A Shrinking Hippocampus & Alzheimer's." Lance Armstrong Foundation. <http://www.livestrong.com/article/146378-a-shrinking-hippocampus-alzheimers/> (accessed January 17, 2011).

cousin said. It was only later that I thought about the truth of my cousin's description. Dementia hadn't just taken my grandma's memory and independence and health. It robbed her of her. It robbed the rest of us of her, too.

My grandmother was hardly the most advanced dementia patient on her second-floor ward. Some were bedridden, some just sat in the hallways, staring blankly at us as we followed my grandmother, shuffling down the hallway with her walker. But each time my family and I left after visiting our grandmother, we wondered if we had just said our final goodbyes. We avoided eye contact with each other on the elevator ride to the first floor, concentrating instead on the dingy beige tile floor.

Women are more likely than men to develop dementia. Recent studies have also linked dementia to high cholesterol, diabetes, excessive belly fat, smoking, pesticide exposure – there's a new risk factor every week. So I can exercise regularly, drink tea one to four times a week, take daily Vitamin D supplements, chew gum for 20 minutes to stimulate activity in my hippocampus, but I can't change my genetics or the fact that my family has a history of dementia. And ultimately, despite the barrage of studies, a neutral panel of 15 scientists convened by the National Institutes of Health recently concluded that there is no definitive way to prevent dementia and Alzheimer's. Of the top ten causes of death, which include heart disease and cancer, Alzheimer's is the only disease with no way to prevent, cure or even slow its progression²⁴. There's no such thing as an Alzheimer's survivor.

So when I looked at my grandma slumped in that mauve recliner, I saw my mom.

24. "Generation Alzheimer's: The Defining Disease of the Baby Boomers." Alzheimer's Association. February 2011.

And then I saw me. Adult diapers, compression pantyhose, flesh-colored orthopedic shoes, floral-print house dresses, plastic jewelry, fuchsia Mary Kay lipsticks – these were the parts of aging I could accept. But the forgetting, the isolation, the confusion, the lonely stretches of time without even your memories to keep you company – that seemed a fate worse than dying.

The term “dementia” didn’t enter the English language until 1806, and even then it was considered a condition of insanity. The “demented” were often placed in state hospitals where they were tied down with physical restraints and given heavy doses of medication as a way to sedate their peculiar behaviors. The prevailing diagnosis of the time was senility, a condition of physical and mental infirmity because of old age. In 1906, Dr. Alois Alzheimer’s published research that related symptoms of senility to a pathological cause: clusters of insoluble protein fibers inside brain cells²⁵. It took nearly 70 years before Alzheimer’s groundbreaking discovery was accepted by the larger medical community. No longer was senility considered an inevitable outcome of old age; instead, there was a specific pathological reason for the memory loss, the inability to communicate and decreased mental functions. The elderly weren’t insane, they were sick. The protein clusters Dr. Alzheimer first identified are now known as neurofibrillary tangles and their presence, along with beta amyloid plaques between nerve cells, are the hallmarks of Alzheimer’s disease.

Society, however, continued to view dementia patients as insane, as incapable of existing in what one bioethics professor labeled the “hypercognitive world of the

25. Mark McKenzie, “Dementia and Human Eldercare: A History of Dementia Care in the Age of Alzheimer’s Disease.” *American Educational History Journal* 32, no. 2 (2004): 195-201.

intellectually intact.”²⁶ Even as nursing homes replaced state hospitals, the old models of care persisted. A 2004 survey of care practices found that caregivers continued to see people with dementia through the outdated senility paradigm, which treated men and women in their 70s, 80s, 90s as if they were going through a second childhood. The study’s author reported, “[Caregivers] spoke of the people in their care in the same way, using the exact same words as they spoke of caring for their own children. The phrase ‘my babies,’ was interchangeable used for both the caregivers’ own children and for the people with dementing illness they looked after.” The meaning of these findings seemed clear to me: Lose your memory, lose your life.

Today, in his role as the interim dean of the Erickson School for Management of Aging Services in Maryland, Dr. Ronch argues for what he calls a “culture change” in the way the memory-impaired are viewed and cared for. For an example of this culture change, he tells me to check out Silverado Senior Living in California.

On the day I visit a Silverado community in San Juan Capistrano, I’m eager to replace the image of nursing homes I’ve carried with me for years: the expressionless faces of the residents, the harsh yellow glow of fluorescent lighting, that same sour smell of cafeteria food and dried urine.

But I’m skeptical too: Silverado makes big claims about its success in treating Alzheimer’s patients. Much of the success Silverado claims stems from the freedom it allows its patients. It’s company policy to allow employees to bring their children to work with them, so the full range of ages walks Silverado’s halls. Pets also roam the

26. Stephen Post, *The Moral Challenge of Alzheimer’s Disease*. (Baltimore: The Johns Hopkins University Press, 1995).

carpeted halls. Company regulations call for at least one cat and dog for every twenty-five residents, one bird for every five and one tank of fish for every forty. Some communities keep miniature horses, pigs, even a kangaroo. Silverado residents also have unregulated access to food throughout the day, can wander outside to the garden and are encouraged, but not forced, to choose from more than 12 activities a day. A typical day's activities might include Nintendo Wii, hockey, English Tea, and Literature Club. According to statistics published by the company, more than 3,300 memory-impaired people who wouldn't walk when they came to Silverado have begun to walk again. More than 2,400 who were unable to eat on their own regained that ability.²⁷ Basically, Silverado sounds too good to be true.

Founded in 1996, Silverado Senior Living now operates 20 memory-care facilities, in Texas, Utah Arizona and California. Each one is designed especially for Alzheimer's and dementia patients. At meals, the staff seats the residents at tables according to ability so that the earliest-stage patients capable of conversation can socialize. Each facility operates a salon room, complete with beauty chairs, hair-washing bins and a magazine rack. Residents who resist grooming in their rooms will often agree to have their hair washed and brushed in the salon. Most of the rooms at San Juan Capistrano are double-occupancy, partly because there's a long waiting list and partly because Silverado staff has found that when residents wake up in the night disoriented and confused, the presence of a roommate is comforting.

27. Loren Shook and Steve Winner, *The Silverado Story: A Memory-Care Culture Where Love is Greater Than Fear* (Irvine: AJC Press, 2010). 69.

Carole Shaw, the administrator at Silverado San Juan Capistrano, walks me through the halls. Her strawberry blonde hair matches the reddish tone of her skin, and she speaks with the pride of a parent as she talks about her facility. A set of keys jingles in her hand as she points out Silverado's special touches: The floral-patterned sepia carpet is shampooed daily to keep away odors. The paisley wallpapered walls are free of scuff marks because staff takes extra care when maneuvering wheelchairs down the hall. The doorway to each bedroom is framed by a wooden curio cabinet built into the wall. Silverado calls these Memory Boxes, and families of residents are encouraged to bring in pictures and memento's of their loved one's life. She is eager to move the tour along, to show me the storage closet they converted to a store where residents use fake money to buy candy, sundries and other trinkets. I follow her down the hallway, but I want to linger at these glass displays. They're mesmerizing and tragic. I ask if the memory boxes ever make her sad, make her feel like a person's full life can be reduced to a few glass shelves in a wooden case. She sees the collections differently, she says. The arrangement of photos, diplomas, framed certificates and trinkets – porcelain angel, glass dolphin figurine, wooden cross – help staff get to know the residents and see them as people, not just patients. The boxes also serve another critical function: They help the residents find their way home.

The memory boxes, the custom overhead lighting that doesn't hum – these are cosmetic differences at Silverado. The real distinction of their care is their guiding philosophy about memory and the self.

“The memory can go, but the spirit never dies,” Carole said. “There’s no one who could ever tell me differently. Your spirit is there until your eyes shut and your heart stops.”

Carole believes Alzheimer’s robs people of the ability to express that spirit in the same ways they used to or in ways most of us would understand. But the human spirit remains. And with it, the desire to live and to be loved. Too often, long-term care becomes a place where people go to die. Carole said she wants residents to feel as if they come to Silverado to live. “If you lost a limb, it doesn’t mean you can’t ski. Why does it mean if you lost your memory you can’t live?” she said.

At Silverado, you won’t find residents sitting in wheelchairs, holding dolls or playing with blocks. You will find them helping out in the kitchen, gardening, petting Lucy the golden retriever or one of the other five dogs that wander throughout the building. On the day I visit, Maeve, an activities assistant, has gathered a group of five men for Veteran’s Club. There are 38 veterans living here, but no one is forced to participate in the activities or clubs. Staff does all they can to encourage participation, including dressing the part. For example, during Golf Club earlier in the day, Maeve passed around golf caps for all the men to wear.

When she switches the activity to Veteran’s Club, she stacks the golf caps in the corner and puts up patriotic posters around the walls of the small sitting area where the men are gathered. She also displays a poster board, showing current pictures of the resident veterans along with several shots of the men from their military days.

I pull up a chair to the small group while Maeve is talking to the men about Pearl Harbor, which she says is a topical subject since last month marked the 69th anniversary

of the attack. Maeve tries to engage them in remembering their experiences of Pearl Harbor, but one man, Doctor Taylor, keeps interrupting.

“I’d like my hat please,” he says. “I had a hat when I came here.”

Maeve, unfazed by the interruption, walks over to the stack of golf hats and hands him a khaki hat engraved with the logo of Rotary International. Dr. Taylor fingers the engraving above the bill while Maeve listens to Carl talk about his memory of rationing during World War II.

Again, Dr. Taylor interrupts, “This is a nice hat. But it’s not my hat.” Maeve assures Dr. Taylor that she’ll find his hat later. She knows he’s remembering one of the golf caps that he wore earlier during Golf Club. To distract him from his hat, she leans over Dr. Taylor, speaking loudly into his right ear. “Dr. Taylor, we’re talking about military service,” she says. “Can you tell us what you did in the military?”

“I was a captain in the medical corps.”

“In World War II, right?”

“I served overseas in the Pacific, the Philippines, Guam. I wound up several other places. I was in Korea, too.”

Maeve takes the board of resident pictures and moves to stand in front of Alan. Alan is wearing a black cowboy hat, black shirt and jeans. His face has a youthful spark to it, and you could never tell by looking at him that he suffered from memory loss. She points to his picture and asks him what he did in the military. When he doesn’t answer, she reminds him, “You served in the Cold War.”

Alan flashes a quick smile. “Nearly froze to death,” he jokes, a line he’s clearly rehearsed for years.

Next, Maeve moves to Lyle, and shows him the picture board. “Lyle, we’re talking about military service. Can you tell us what you did in the military?”

It’s like Lyle hasn’t heard the question because his eyes are searching the poster board for a familiar face – his face.

“Is that me?” he asks. “I don’t know whether that picture was taken when I was in the army or not.”

Maeve points to a photograph of Lyle, taken sometime recently at Silverado.

“Oh, there I am,” he says, relieved.

Maeve asks him again about his military service and Lyle says he was a mess cook during World War II.

Carl remembers that the group had been talking about Pearl Harbor and says, “The thing about young people today is that Pearl Harbor doesn’t mean anything to them.” He’s the only one in the group to remember the topic or to be at all interested in discussing military experience. He begins sharing a story about how his father used to return from his military duty stations with all sorts of souvenirs.

Again, Dr. Taylor interrupts, oblivious that Carl, sitting right next to him, was in the middle of a story.

“We won’t lose out on our luncheon hour will we?” he asks Maeve.

“No, it’s at 4:30.”

“Why did they pick that hour? For transportation?” He turns to me and says, “You can get something to eat if you ask for it.”

Maeve picks up on his hint and asks him if he wants a sandwich.

“What do you have?” he asks her.

“Ham and cheese or peanut butter and jelly.”

“What was the first choice?”

“Ham and cheese.” Her voice is calm and gentle, without any hint of exasperation at being interrupted or having to repeat herself.

“Ok, ham and cheese,” he answers.

As Maeve leaves the group to fetch the food, Dr. Taylor calls after her, “Well, I hope you’ll bring some for the whole group.” Maeve does, in fact, return with a tray of sandwiches and begins passing them around the group. As the men eat, Maeve begins to share a story written about the history of the song “Taps.” She shares about the song’s origin during the Civil War, but I can’t help but think of the present-day use of the song: The bugle call is played at military funerals and daily at sundown. Dr. Taylor doesn’t seem to be listening, concentrating instead on his white-bread sandwich.

“Whoa, this is quite a sandwich, Thank you friend,” he says. “You won’t need much after this.”

Before Maeve can finish her story on Taps, Dr. Taylor interrupts again, this time holding out the hat he had earlier sworn wasn’t his. “This hat was a gift to me. It’s a quality cap. This is good cotton. Thank you,” he says, nodding at Maeve.

Maeve plays the song “Taps” for the men, and Dr. Taylor gets up to go to the bathroom. While he’s gone, Maeve passes out American flags to the remaining men and instructs them to wave the flags and move around to the music. She plays the Star Spangled Banner and Carl happily waves his flag in beat with the music. Lyle rolls up his flag and holds it in his lap. When Dr. Taylor returns from the bathroom, he walks right past the group and begins marching down the hall, counting off “1 and 1 and 1 and 1.”

Activities are so important at Silverado that they offer 12 different activities a day, although the staff doesn't follow a strict calendar. Sometimes, residents just aren't in the mood to cook or play bingo. When that happens, the staff tries to be flexible and attempt something new. The goal is to keep residents engaged rather than check off activities from a list.

"What does an activity do for someone's life? It makes them feel useful, feel fun," Carole said. Carole was trying to promote those same feelings when she decided to form a restaurant club. Once a month, the staff takes several of the early-stage residents out to a restaurant where they can order what they want and then give the establishment a letter grade. Another time, Carole and some of her staff took Claire, a new resident, shopping at Kohl's.

"We all went into the dressing rooms, and I haven't let anyone see me in the dressing room since I was a teenager," Carole said. "We kept our doors open and we all tried things on and we would model." She smiles as she remembers the story. When they returned to Silverado, Claire told them she felt happy because loved getting to ride in the car.

"Even the little thing of riding in a car gets taken away from them and we wonder why they behave the way they do. They're probably mourning their environment," Carole said. "They don't get to do normal things. We're trying very hard to bring those things back to them."

At Silverado, these normal things include preparing food for cooking club, field trips, gardening – things that, for years, people assumed the memory-impaired could no longer do. Or should no longer do. After all, what if a man with Alzheimer's cuts himself

with a knife in the kitchen? What if a woman tips her wheelchair into a rosebush (which actually happened at Silverado San Juan Capistrano)? Accidents will happen, Carole said. But the company practices “care with risk,” meaning that they do the best they can to ensure their residents’ safety without cutting out the activities and passions that give them joy. In the event of an injury, Carole said most families are understanding, recognizing that their loved ones hurt themselves doing something they were enjoying.

But this level of care doesn’t come cheap. A double-occupancy room at Silverado San Juan Capistrano costs \$6,500 month. For many families with a loved one who suffers from Alzheimer’s, that price tag just isn’t feasible. The same socioeconomic factors that put African-Americans and Hispanics at greater risk for developing Alzheimer’s also prevent them from affording the kind of care Silverado provides. I can’t remember a single non-white face from my time at Silverado. But caring for a loved one at home isn’t always an option either. A 2010 report from the Alzheimer’s Association reported that one-third of family caregivers reported symptoms of depression. The stress of taking care of a mother or father with Alzheimer’s can be so overwhelming that 72 percent of caregivers reported experiencing a sense of relief when their loved one died²⁸. So when vanguard residential facilities aren’t affordable or accessible and the burden of at-home care isn’t feasible, many families, my own included, turn to nursing homes that operate under the senility model of dementia care, where residents stare at cartoons on a television, fold washcloths in a corner or carry around ragged baby dolls in their wheelchairs.

28. Alzheimer’s Association. “Alzheimer’s Disease Facts and Figures.” (2010). 28.

Too often, the memory-impaired get dismissed, as if they're incapable of learning new things or enjoying certain activities. That perception is changing, but slowly, in part due to care models like Silverado and other groups that showcase and honor the abilities of Alzheimer's and dementia patients.

TimeSlips Creative Storytelling Group is one such group that celebrates the freedom of imagination rather than the pressure to remember. Founded by Dr. Anne Basting in 1998 as a way for dementia patients to experience the still-strong power of their imaginations, the concept is simple: Show dementia patients a picture and let them create a story about the image. Caregivers then ask open-ended questions, echo their responses and use the group's ideas to make one story. The stories are often nonsensical and disjointed, but that's not the point of the activity. The goal is to create an environment where dementia patients can succeed. To do this, TimeSlips storytelling groups go through the same process each week, creating a ritual that can be learned by participants' subconscious procedural memory.

The disease may have taken their ability to tell stories from their own past, but it doesn't take their ability to make up stories. And often, bits of their past sneak into the stories. The key is that they are not being asked to remember, a task that is difficult and often discouraging for a dementia patient. With TimeSlips, there is no wrong answer, which frees up participants to experiment with sounds, gestures and language. The result is something like this story from a TimeSlips group at a nursing home in Prescott, Ariz. This particular story, titled, "Is This Where Babies Come From" was inspired by a black-and-white photo of a smiling baby sitting inside a large leather bag.

It's in the 1920's. There is a satchel. I was there. This baby came from Europe. No, it's from England. Look at its eyes and nose. When kids are little, they have that kind of nose. He looks like Churchill—his round face and smile. They live in a farmhouse. The floor is tongue and groove. The walls are lattice work. This is a boy. His name is "Cuddles." The baby is a girl—you can tell because her mouth is open and she's talking.

Someone is positioning the baby. His name is "Tim." Her name is "Winnie." She is in the satchel because her father is a doctor. Someone decided to put him in the suitcase, to take his picture, just to be different. The baby is a millionaire and has nothing better to do. So he got in the suitcase. He is sitting on his money.

He has no teeth, but he's smiling. He is 5 weeks old. He has teeth—his is a year or so. I think he is 6 months. He is darling, but I don't know his family. His nickname is "Ears." When I was in high school the captain of our basketball team was called that because of his ears. They won the championship.

Don't bring attention to his features. I could just kiss him. They will put this picture in the newspaper. This is clever. Lots of kids will want to get in Father's suitcase. Maybe they will send us the baby so we can spoil him. He looks like Dick. Yes, they have the same haircut. I appreciate all the attention. The End.

It's not exactly prize-winning literature, but does that matter? No, say professionals like Dr. Ronch. He says TimeSlips exemplifies the strengths-based approach that is needed in more nursing homes today. Alzheimer's is sometimes called "The Great Unlearning," but that description focuses on what patients can no longer do rather than what they can do. It highlights what's been lost rather than what remains -- waiting to be unlocked and expressed.

And occasionally, what gets expressed is indeed profound and poignant. When staff showed one group a picture of a man hiding his head in his coat, the participants named him Headless Joe Wonder. “He lives in a room of despair,” they said. “He takes it as it comes. You think you can’t do anything without a head, but Headless Joe Wonder can . . .”²⁹

A recent study by the University of Iowa also found that dementia patients also retain their capacity for emotion. The feelings associated with an experience linger even after the memory is forgotten. In this 2010 study, researchers studied amnesic patients with damage to their hippocampus. They showed the patients emotional film clips and observed how the happy film clips produced laughter while the sad clips brought on tears and sorrow. Ten minutes after the clip ended, researchers tested the patients to see what they remembered. People with functioning memories generally remember around 30 details from a single 20-minute clip. One participant in the study couldn’t remember a single detail from the scenes he’d watched 10 minutes ago. Next, researchers asked the patients questions to gauge their emotional states. In all the subjects, the emotions produced by the films outlasted their memories of the movies.

These findings have profound implications for understanding the emotional needs of the memory impaired. And they confirm what some caregivers, like Chaplain Jim Day, have known for years.

I hear Chaplain Jim Day before I ever see him. He is whistling a hymn as he walks up behind me. I’ve been waiting in the lobby of Country Meadows Retirement

29. Anne Davis Basting, “Exploring the Creative Potential of People with Alzheimer’s Disease and Related Dementia: Dare to Imagine.” *Mental Wellness in Aging: Strengths-Based Approaches*. Eds. Judah L. Ronch and Joseph A. Goldfield (Baltimore: Health Professionals Press, 2003). 360.

Community, which houses just over 100 residents in the middle of Lancaster, Pennsylvania and is a leader in a practice called Validation therapy, which is a specialized way of communicating with dementia patients. Dressed in a black pinstripe suit, he ushers me quickly past a dining area where a few residents sit at the tables decorated with flower vases and candles, through a television room with green fabric couches, down a corridor of bedrooms to an elevator that takes us to the bottom level of the facility – the locked unit for Alzheimer’s patients.

It is here, in a windowless office that looks like it might be a converted janitorial closet, that Pastor Day has spent the last 11 years, serving a community who some would say no longer have need for church services, hymns or prayers since they can’t remember them anyway. But Pastor Day’s time here has taught him that the memory-impaired just need to access their faith and relationships with others in different ways.

When he began leading services at Country Meadows, Pastor Day said he followed the model that would be most typical in Protestant church services today – a cognitive, minister-centered sermon where church-goers came, sat in pews, listened to a sermon, followed along in their hymnbooks, greeted other parishioners and then went home. He tried preaching like that for many years, but on a floor with about 40 residents, only five or six would show up to each service.

“They would say out loud in the service, ‘I don’t know what he’s talking about; he doesn’t make any sense to me.’” Pastor Day remembers. “And one would get up and leave and I would have five left, and I would be doing the best I could. I didn’t know any better.”

Pastor Day realized he would have to abandon his old model of church and instead design a service that wouldn't require participants to rely on their memory or cognitive abilities. A successful service doesn't mean a powerful sermon anymore; instead Pastor Day judges a service based on how many of the seniors are involved. It's an emotional-based service instead of a cognitive experience. He invites me to sit on a Sunday afternoon service to see what it looks like.

While he finishes preparing his notes, I find a seat in the back of the chapel room. Judging from the lone "Happy Birthday" helium balloon floating on the ceiling, this room serves multiple purposes throughout the week. Metal chairs with mauve cushions are lined up in rows like pews. A small wooden lectern waits for Pastor Day at the front of the room, to the left of a piano where a volunteer sits playing old hymns from memory.

One of the residents, Hank, passes out spiral-bound, large-print hymn books to the other residents as they shuffle in. Pastor Day told me that a service usually draws around 20 residents, but there are only three or four in the room now. Hank, who sits in the chair next to me while he's waiting for more residents to come, notices the small crowd as well.

"You think there's going to be more coming?" he asks me, motioning to the empty seats.

"I don't know," I say. "This is my first time."

"After that last one, I wouldn't be here."

"Oh, really. What happened at the last one?"

"Huh?"

"What happened at the last one?" I repeat, moving my mouth next to his ear.

“I didn’t hear you.”

“What happened at the last one?” I say again, trying to emphasize each word without being condescending.

“I don’t know.” He chuckles and shrugs, as if I’ve asked him a question to which he could not possibly know the answer.

By the time Pastor Day walks in the room, the crowd has grown to 12 residents. He begins the service by greeting them and asking them to pray for an elderly man who is battling an infection in the hospital. He makes sure to personalize the prayer request. The man becomes his “friend Bob,” a businessman man who owned a ladies clothing store. Bob was in the hospital for 23 days. “Can you imagine that?” he asks the group. Then he asks if they’ll join him in prayer. When he prays, he prays a few words at a time and then pauses so that the residents can repeat back his words. It’s similar to how someone might translate a prayer into another language, and it gives the seniors a chance to participate in the service.

His sermon is short and filled with anecdotes and personal stories about his own family. His tone may be casual, but he tells me afterward that he takes great care so that the residents know he’s not talking down to them. The message may be simple, but it’s not childish because the memory-impaired retain their emotional intelligence and can still recognize a condescending tone.

Pastor Day has witnessed three other acts that the memory-impaired are capable of – things that, even though he’s seen them before, still shock him. The first is that often a woman who can’t piece together a full sentence during the week will suddenly be able to sing a song from her childhood or adult life. “It’s like branded on their emotional life,

on their heart,” Day says. The second is the ability to recite a poem or say a prayer without interruption. Seniors with dementia are also capable of an act of kindness. Groups of school children often come to sing to the residents and after the performance they are encouraged to mingle with the seniors. Pastor Day remembers one particular moment at such an event: “A lady that cannot put two words together during the week sees a little boy coming up to her and she goes, ‘Hi, hello son, what school do you go to?’ And they’re having this conversation and you’re going How is this possible? How is that possible?”

In fact, Pastor Day has developed his own theory for how such capabilities and acts are possible: “I’ve come to a non-medical, nonprofessional viewpoint that there are moments, however brief, that the heart bypasses the mind and it just comes straight out.” And moments like these confirm to Pastor Day that a person retains a sense of self even after his or her memory has failed. They may be a changed person, but they are still a person, Day believes, and that is enough of a reason to continue loving them and seeking out opportunities to make them feel happy.

I am reminded of a woman I saw at Silverado several months earlier. I watched Eleanor sit in front of the fish tank in the television room, mesmerized by the darting colors. Silverado’s activity director weaved her way through the clusters of wheelchairs and walkers, stopping to say hello to each of the residents by name. When she came to Eleanor, she said hello and introduced herself to a young visitor sitting behind Eleanor.

“I’m Marlene. I’m her daughter,” the visitor said, nodding at her mother. Eleanor snapped her head around. “Whose daughter?” she asked. Marlene reached out, placed her

hand on her mother's arm. "Yours. I'm your daughter," she said. Eleanor's face lifted, she arched her eyebrows, pleasantly surprised by the news and said, "Oooh."

Even if Eleanor quickly forgot that Marlene was her daughter, the tender touch on her arm, Marlene's gentle tones as she spoke to her, the joy at learning she had a visitor – these feelings would stay with Eleanor. She would feel again and again the reverberations of that moment, even if the details slipped out of focus. She would remember being touched, being known.

EPILOGUE

Each cornfield looks like the next, and I'm wishing these rural Minnesota county roads had actual street names instead of numbers, something that would let me know I was headed in the right direction. It's not the first time I've been on these roads, traveling between my grandmother's house and my aunt's farm. But today is the first day I've made the trip alone, without someone else to navigate. There are long stretches where I don't recognize anything, but then: the stone Evangelical Free church, the cluster of two-story homes next to the lake, the sign for Isanti's city limits. Of course, I still don't really know where I'm going. I know that I want to go to my grandmother's old house, the one she lived in when my sisters and I were children. She hasn't lived there in nearly 15 years, but it is always the house I remember her in – before the one-bedroom apartment, before the assisted-living community, before the single-occupancy room in the nursing home. I've convinced myself that if I can find my way to Elim Baptist – the church my parents were married in, the church where we held grandmother's funeral service yesterday – then I could trace my way back to her old house. I used to walk that route the summer after fifth grade, when we visited my grandmother for a month and my parents enrolled my sisters and me in the summer church play. I don't remember street names, but I know the general direction – over the railroad tracks, past the hardware store, past the drug store.

I slow down as I approach the city limits, my eyes scanning the cross streets for Main Street. I drive past a set of tennis courts on the right and my stomach lurches. Without thinking, I slam on the breaks and yank the wheel hard to the right. This is it. This is my grandmother's street. The corner park gives it away – the merry-go-round, the slide, the monkey bars, the teeter-totter. We used to scramble over this equipment when my grandmother would shoo us out of the house in the afternoons with empty gallon ice cream tubs to collect frogs in the crick. I drive slowly until I come to her house, kitty corner from the park.

In my childhood, my grandparents' house was huge – a three-level home painted pale blue with white trim. Now, it was just a mid-sized home on the corner lot, painted a dove gray with burnt orange trim. It looked nothing like the house in my memory. I pulled my parent's Buick over to the curb and stared at the house, waiting to feel something. My impulse to come here had been so strong that I expected this occasion to mean something profound. But sitting there, I felt nothing. I didn't knock on the door or even get out of the car. This was not grandma's house. That house was gone. It existed only in my memory. Just like my grandmother.

She had passed away eight days ago. Early in the morning of October 24, 2009, around 3:30 a.m., nurse Marjourie Llorente went to my grandmother's room to administer her shot. Grandma had been lightly sleeping and she perked up when Marj came in the room. As Marj turned her on her side to give her the shot, she tried to explain what to my grandmother she was doing. But grandma wasn't listening. She kept pointing to the left corner of the room. She was trying to tell Marj something, but her speech was coming out rushed and slurred. Finally, Marj was able to make out her words:

“There’s an angel,” grandmother said.

“An angel?”

“Yes, an angel.”

When a nursing assistant came back to check on my grandmother a few hours later, Grandma Lil was out of her bed, slumped in a chair in the left corner of the room, too weak to support herself in a chair without armrests. Her breathing was labored – more gasps than breaths. She gasped a few more times. And then she stopped. She was gone.

Sometimes I wonder how things might have been different if I’d studied memory before my grandmother passed away. If I knew then that fifty percent of advanced dementia patients who contract pneumonia die, maybe my grandmother wouldn’t have died alone. If I knew to ask leading questions with hints of information, maybe talking with her wouldn’t have been so strained and one-sided. If I knew the importance of loving, physical touch for dementia patients, I would’ve held her hand while we sat in the common room of the nursing home and watched an early November snowfall dust the branches of a leafless tree.

It is a Saturday night in July and the family is gathered at my aunt’s house for dinner. I have no way of knowing that tomorrow will be the last day I ever see my grandmother alive. After dinner, before my aunt drives her back to the nursing home, I squat beside her chair, rest my hand on her bony arm.

“We’ll see you tomorrow morning,” I say

“Maybe,” she answers.

“We’re going to stop by the nursing home on our way out of town, so we’ll definitely see you tomorrow.”

“Maybe,” she says again, like she is trying to hide a secret.

“Well is there someplace else you’re going to be?”

“Maybe way high up in the sky.”

I lean in close, kiss her pale, peach-fuzz cheek and say, “If you go, I’ll see you there.”

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