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The Shapes of Memory Loss

*Stories, Poems, and Essays from the University of Michigan Medical School and
Health System*

Nan Barbas

Laura Rice-Oeschger

Cassie Starback

Contributions by Patients, Family Members, and Health Professionals

Disclaimer: Writings in this anthology may include authors' experiences receiving health care or medical treatments. We acknowledge that each author may have had personal and individualized medical experiences and received a variety of recommendations for managing their illness. The contributions to this anthology do not reflect the organizers' or editors' perspectives or recommendations. The content of the writing contained in this anthology is not necessarily representative of state of the art medical knowledge for dementia care.

Cover Design by Kim Cinko

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Aviva Robinson's paintings have been shown in numerous galleries and exhibitions throughout Michigan. She has won awards for her art and her philanthropy to the arts. The Detroit Institute of Art, Arts Foundation of Michigan, and Concerned Citizens of the Arts of Michigan are only a few of the organizations for which she has served as board member or committee member. She continues to be a productive painter well into her journey with memory loss.

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SHAPES OF MEMORY LOSS
University of Michigan

CONTENTS

Preface
Foreword
Acknowledgments

Perspectives of those who live with memory loss

Good Fortune
Ken Saulter

Between Us
Ken Saulter

My Mask
Ken Saulter

How I Learned to Speak English: An Elementary School Memory
Josephine Moreno

Wandering Together
Pam and Phil Hoffer

Sweetheart
Pam Hoffer

Elderberry Club
Kathi Tobey, Elaine Reed, members of the Elderberry Club

Evermore
Kathi Tobey, Elaine Reed, members of the Elderberry Club

Wisdom Keeper
Kathi Tobey, Elaine Reed, members of the Wisdom Keepers Group

Tick, Tock
Gretchen Smith

Stall
Leslie Rzeznik

Brain Kisses Bone So Hard It Forgets What It Is
Leslie Rzeznik

Approaching Joy
Leslie Rzeznik

When Your Worst Fear Becomes Reality
Myriam Torres

If You're Dealing with Memory Loss
Myriam Torres

Family and friends reflect

Memory of a Poem
Julie Young

Alzheimer's Stole My Grandma
Alberta Sabin

My Husband is Leaving
Anita Buckmaster

Little Bunches of Joy
Barbara Tucker

The Fawn Enters the Wood Where Things Have No Names
Lauren Scott

Our Petoskey Stepping Stones
Shari Thompson

My Mother was Here Yesterday, Today; Now Gone Away Forever
Sharon Greene

They Didn't Teach Me This in College
Joanne Lord

Memories of My Mother
Gail Fromes

Hector and Elizabeth
Donna Zajonc

My Brother
Alvesta Smith

Father
Christine A. Yared

The Play
Christine A. Yared

A Sister's Perspective
Frieda H. Morgenstern

Stewart A
Pam McCombs

Homemade Phantoms
Carol Burton

Where Has My Love Gone
Deborah Mecks

Good News/Bad News
Katharine Stribe

Medical students creatively interpret

Talking to June
Shilpa Gulati

Pieces
Jonathan Awori

Unconventional Art
Amanda Wong

Evergreen
Gregory Jaffe

Karen
Thomas Filardo

The Ones Left
Brittani Jackson

This is You
Emily Smergel

Everywhere's A Mountain
Sarah Williams

A Word about the U-M Supporting Programs

Online Resources

Support Future Programs

The Editors

PREFACE

I recently finished reading Per Petterson's beautiful novel, "Out Stealing Horses," set in Norway, narrated as a reflection by sixty-seven year-old Trond. He reflects on events from the summer when he was fifteen years old that reverberate through the rest of his life. Trond postulates:

"If I just concentrate I can walk into memory's store and find the right shelf with the right film and disappear into it and still feel in my body that ride through the forest with my father."

Petterson's passage beautifully describes the connection that exists between memory and sensation, memory and emotion. I believe that the strength of this type of connection is one explanation for those moments of lucidity that my patients with memory loss or dementia often experience.

We stay connected to our emotional lives and our sensations though, for some, it may be difficult to communicate that connectivity to others. One of the authors of an essay included in this collection becomes reflective when she is told by a woman facing dementia that she intends to write about her illness as "the last thing I write about." The author states this "is interesting since dementia is a disease of memory and personality. In saving your illness for last, your spirit is portrayed...teasing dementia, saying that you will still be able to write your story."

This anthology is a collection of writing that demonstrates the contributors' ability to "walk into memory's store" and to "tease dementia."

We have invited writers to share their experiences with memory loss, to tease dementia. Members of the University of Michigan community submitted poetry, short fiction, journal entries, and narrative essays. Amongst the authors of the pieces included in this collection are patients at the University of Michigan who are experiencing memory loss or cognitive changes due to illnesses such as Alzheimer's disease, strokes, head injuries or other conditions. Some wrote independently of memories of their lives or of their thoughts and feelings about living with changes in their memory or thinking abilities and the effect of those changes on their lives. Some received assistance in expressing these ideas in writing. Other authors included family members and friends who have watched, lived with, cared for, struggled with, or shared laughter about the changes that their husbands, wives, sisters, parents or friends have endured. Professionals who care for patients with cognitive impairment also contributed their reflective thoughts, and a group of doctors-to-be contributed pieces written in the context of interviews conducted with individuals with memory loss.

The inspiration for this project came from our experiences sharing in the journeys of our patients at the Cognitive Disorder Program in the Department of Neurology, and with individuals and groups affected by memory loss who participate in programs at the Michigan Alzheimer's Disease Center and the U-M Silver Club Memory Loss Programs. On a daily basis, we strive to help our patients and their families live the most comfortable and fulfilling lives they can, even as changes confront them. We have drawn on the processes of writing, storytelling, and creative communication. It is in this spirit that this collective, collaborative project, including patients and their extended communities, was undertaken.

We hope readers of this collection enjoy the original, creative, and inspired pieces they will encounter here. We think you will gain a deeper understanding of what it means to live with cognitive changes and memory loss.

Lastly, kudos to the authors. We are awed by their courage to examine the emotions that come with the experience of memory loss due to illness, the immense creativity they demonstrate in recording their emotions in written words, and their extraordinary generosity in sharing their words with others.

Nan Barbas
March, 2013

FOREWORD

“Papa, is that...is that your dad?”

Papa cried. We knew it was so. He had painted an abstract image of his father, richly portrayed in vibrant blue-green watercolors. But he had done it in late-stage Alzheimer’s disease, after he had lost his words. Yes, his words. But not his father’s memory. Not his own emotional self. Papa was still in there. And he came out in spirit colors for all of us to see and know afresh.

As a neurologist who treats cognitive disorders, I shouldn’t have been surprised at his persistent (even new-found) abilities. Research has provided many accounts of incredible expressive potential unleashed in the throes of dementia, traumatic brain injury, stroke, epilepsy, and other neurologic conditions. But I didn’t really see it for what it was. My dad was getting his story out. He needed to let us know who he was. He wanted us to feel his elemental fire, still burning in the soul space deep within.

Papa taught me that the soul of a person with Alzheimer’s disease still sings and paints and dances and writes and portrays itself to all who truly perceive. There remains a story to “tell,” though the affliction of cognitive impairment may alter the voice, making it unrecognizable to even the speaker at times. But I am convinced there is no greater privilege in this world than to help another person find and express his/her true voice, and no greater crime than to silence it.

We all have richly-woven life stories. Like a memory quilt, these stories are meant to be shared and felt. They can bring comfort, along with a blood stain or two. But they must not be left in the cedar chest. Such treasure is too fine for rot and moth. We need the warmth of home found in their weave. And all quilt makers need their work to be loved and valued.

It took very little time during my visit to the Michigan Alzheimer’s Disease Center and Cognitive Disorders Clinics in 2012 to realize how special the place, and its directors, staff, patients, and care givers are. There is such an atmosphere of affirmation and validation there; a focus on living life as richly as possible in every moment we are given. And the Center is determined to provide all the tools and support needed to make life quality as good as it can be. I actually felt a sense of personal wellness just being there and interacting with those fine people.

And here, showcased on these pages, true to form, they have taken things soaring to another level altogether. Contained herein are memories, emotions, quilts and paintings, songs and stories, lilting dance and weary plodding, blacks and whites, darks and lights, the rain and sun of life in this world. All expressed through the realities of affliction, unfiltered, unframed, and untethered.

And on each page, in each emotive line, the light of personhood illuminates the dark of human affliction, revealing a multi-faceted diamond of the self. The treasure of each life, to be seen, touched, known.

And when we all reach in to cherish the find, we join hands with the rest of humanity. And that is the only way we win.

So open the chest, wrap up in some quilts, and behold the hidden treasures of life and memory contained herein. As you do, remember the lives, remember the stories, pass them down to the young ones. In doing so we honor our elders, validate ourselves, and inspire our children.

Daniel C. Potts, M.D.

Founder and President, Cognitive Dynamics Foundation
www.cognitivedynamics.org

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Some of the creative contributions to this collection were the result of interviews completed during an elective narrative medicine class by second-year University of Michigan medical students with members of the U-M Geriatrics Center's Silver Club Programs. We want to acknowledge both students and Club members for the invaluable experience they provided for each other. We thank each artist and interviewee for providing permission for us to publish these works. Names and some personal details have been altered by the authors to maintain privacy and allow for creative interpretation.

Members of the Silver Club and Elderberry Club Programs provided the artwork included in this collection. Students of the U-M School of Art and Design, working with Professor Anne Mondro, provided artistic support.

We thank each and every author and artist for contributing to this community effort. And we thank you, the reader, for your interest.