

DISPATCHES FROM THE LAND OF ALZHEIMER'S

Daniel Gibbs is a retired neurologist in Portland, Oregon, with early-stage Alzheimer's disease. Having spent 25 years caring for patients, many with dementia themselves, he is now an active advocate for the early recognition and management of Alzheimer's. He has written previously about his experiences as seen from two points of view, doctor and patient, in A Tattoo on my Brain: A Neurologist's Personal Battle against Alzheimer's Disease (Cambridge University Press, 2021 and 2023 [revised edition]).



"Dr. Daniel Gibbs taught me neurology when I was in training, and he continues to teach me thirty years later. In A Tattoo on my Brain and in his speaking and advocacy, he turned the bad luck of his Alzheimer's disease into gifts for the rest of us: rare insights, thoughtful analysis, and an inspiring example of how to live and thrive in the face of great challenges. Dispatches from the Land of Alzheimer's is his latest gift, weaving together personal experiences, reasoned commentary on "pop science", analysis of cutting-edge research, good advice on a brain-healthy lifestyle, and through it all the reminder to "live in the moment".

Joseph Quinn, MD, FAAN Ericksen Endowed Professor for Neurodegeneration Research, Parkinson's Center Director, Department of Neurology, Oregon Health and Science University

"Daniel Gibbs is a warrior. And that's a blessing to him and to the world!

We are members of a club that neither of us wanted to join. I met Daniel over the phone a few years ago; we both had been diagnosed with Alzheimer's. I encouraged Daniel to write about this serpentine journey, as I have done. Over time, Daniel has inspired me to make lemonade without the lemons – the bittersweet of life. Those on this trek are best to write and talk about it, to tell their own stories, as Daniel has done as a neurologist who has been on both sides of this aisle; first as a doctor, now as a patient. As scripture notes in Luke 4:23, "Physician, heal thyself." The only conundrum is Daniel cannot – the plight of millions diagnosed with Alzheimer's and other dementias, as the experts race for a cure. Dispatches from the Land of Alzheimer's delivers in all ways as a soulful, edifying roadmap into this prowling demon of a disease."

Greg O'Brien, author, On Pluto: Inside the Mind of Alzheimer's



"What is it like to be a person living with Alzheimer's disease? In his collection of essays, Dispatches from the Land of Alzheimer's, Dan Gibbs provides a detailed, clear, vivid and candid account. Detailed and clear because he's a retired neurologist with a keen understanding of science. Vivid and candid because he's a person living with the disease. These poignant essays recount his experiences with loss of smell, changes in empathy, face blindness, making sense of the biomarkers of the disease as they misfold in his own brain, and day-to-day challenges like carrying on a conversation and working. Dan Gibbs has a notable talent to feel both sides of an experience – the losses and the gains. This book ought to be required reading for anyone who wants to live well with Alzheimer's disease."

Jason Karlawish, author of The Problem of Alzheimer's: How Science, Culture, and Politics Turned a Rare Disease into a Crisis and What We Can Do About It

"Dr. Gibbs' book is an honest, upbeat, moving and informative story of his journey through an Alzheimer's diagnosis and its aftermath. His indomitable spirit permeates every page."

> Professor Adriane Fugh-Berman, Director, PharmedOut, Georgetown University Medical Center.



Dispatches from the Land of Alzheimer's

DANIEL GIBBS
Emeritus of Oregon Health and Science University







Shaftesbury Road, Cambridge CB2 8EA, United Kingdom

One Liberty Plaza, 20th Floor, New York, NY 10006, USA

477 Williamstown Road, Port Melbourne, VIC 3207, Australia

314–321, 3rd Floor, Plot 3, Splendor Forum, Jasola District Centre, New Delhi-110025, India

103 Penang Road, #05-06/07, Visioncrest Commercial, Singapore 238467

Cambridge University Press is part of Cambridge University Press & Assessment, a department of the University of Cambridge.

We share the University's mission to contribute to society through the pursuit of education, learning and research at the highest international levels of excellence.

www.cambridge.org

Information on this title: www.cambridge.org/9781009430050

DOI: 10.1017/9781009430067

© Daniel Gibbs 2024

This publication is in copyright. Subject to statutory exception and to the provisions of relevant collective licensing agreements, no reproduction of any part may take place without the written permission of Cambridge University Press & Assessment.

First published 2024

Printed in the United Kingdom by TJ Books Limited, Padstow Cornwall

A catalogue record for this publication is available from the British Library.

Library of Congress Cataloging-in-Publication Data

Names: Gibbs, Daniel, author.

Title: Dispatches from the land of Alzheimer's / Daniel Gibbs.

Description: Cambridge, United Kingdom; New York, NY, USA: Cambridge University Press, 2023. | Includes bibliographical references and index.

Identifiers: LCCN 2023031195 (print) | LCCN 2023031196 (ebook) | ISBN 9781009430050 (paperback) | ISBN 9781009430067 (epub)

Subjects: MESH: Alzheimer Disease | Neurologists | Oregon | Personal Narrative | Collected Work

Classification: LCC RC523 (print) | LCC RC523 (ebook) | NLM WT 7 |

DDC 616.8/311-dc23/eng/20230828

LC record available at https://lccn.loc.gov/2023031195

LC ebook record available at https://lccn.loc.gov/2023031196

ISBN 978-1-009-43005-0 Paperback

Cambridge University Press & Assessment has no responsibility for the persistence or accuracy of URLs for external or third-party internet websites referred to in this publication and does not guarantee that any content on such websites is, or will remain, accurate or appropriate.

[Medical disclaimer:]

Every effort has been made in preparing this book to provide accurate and up-to-date information that is in accord with accepted standards and practice at the time of publication. Although case histories are drawn from actual cases, every effort has been made to disguise the identities of the individuals involved. Nevertheless, the authors, editors, and publishers can make no warranties that the information contained herein is totally free from error, not least because clinical standards are constantly changing through research and regulation. The authors, editors, and publishers therefore disclaim all liability for direct or consequential damages resulting from the use of material contained in this book. Readers are strongly advised to pay careful attention to information provided by the manufacturer of any drugs or equipment that they plan to use.



> Dedicated to the memory of my parents, Zack Edward Gibbs and Elizabeth Martin Gibbs





LOST IN THOUGHT

What was that plan I made in the shower? It slipped down the drain just out of my grasp, Long gone by the time I toweled dry.

What was that story on the radio today? I know it was good and I'm trying to remember. Maybe I'll recall if I drive by the place where I heard it.

What are the names of the neighbors next-door?
They've lived there for years, but I just can't remember.
Their names might return in a flash, in a minute,
A few hours.

A few days

I stand around lost in thought But too often the thought is lost.

Damn, what was I thinking?

November 23, 2013



CONTENTS

Acknowledgments		page xii
PROLOGUE		
1	PHYSICIAN HEAL THYSELF	5
2	EVALUATING NEW ADVANCES IN ALZHEIMER'S RESEARCH: SEPARATING HYPE FROM FACT	9
3	ALZHEIMER'S DEMENTIA OR ALZHEIMER'S DISEASE: WHAT'S THE DIFFERENCE AND WHY SHOULD WE CARE?	S 12
4	THE FIRST PATIENT WITH ALZHEIMER'S DISEASE	18
5	KIDNAPPED IN KINSHASA	21
6	SMELL, DISGUST, AND ALZHEIMER'S	26
7	APOLIPOPROTEIN-4 (APOE-4): BAD FOR THE BRAIN AND BAD FOR THE HEART	30
8	LOST IN THE FOG OF ALZHEIMER'S	34
9	MY FATHER'S "STUFF"	38
10	FACE BLINDNESS DURING A PANDEMIC	43
11	BIOMARKERS FOR ALZHEIMER'S DISEASE	49
12	OLFACTORY IMPAIRMENT IN COVID-19 AND ALZHEIMER'S	52
13	ALZHEIMER'S DISEASE AND WORK	56
14	CROSSWORD CONTROVERSIES	60



Х		CONTENTS
15	CAN LONELINESS INCREASE RISK FOR DEMENTIA?	63
16	EXCESSIVE LAXATIVE USE AND DEMENTIA	67
17	DOG DEMENTIA (CANINE COGNITIVE DYSFUNCTION)	70
18	THE POSSIBLE ROLE OF BRAIN INFLAMMATION IN ALZHEIMER'S DISEASE MAY BE MORE SIGNIFICANT IN APOE-4 CARRIERS	74
19	SURPRISINGLY GOOD NEWS ABOUT THE ACETYLCHOLINESTERASE INHIBITORS (DONEPEZIL, RIVASTIGMINE, AND GALANTAMINE)	E 77
20	MORE ABOUT THE IMPORTANCE OF EXERCISE	82
21	ROLLING ON THE RIVER	85
22	THE MIND DIET REVISITED	91
23	MY PHOTOGRAPHS, THEN AND NOW	96
24	DOES CATARACT SURGERY REALLY DECREASE THE RISK OF DEMENTIA?	101
25	HEARING LOSS, APHASIA, AND DEMENTIA	103
26	TO SLEEP, PERCHANCE TO DREAM	106
27	THE AMYLOID HYPOTHESIS IS NOT DEABUT IT MAY BE GASPING FOR BREATH	AD, 110
28	COULD LECANEMAB OFFER A RAY OF HOPE?	115



Contents		хi
29	A FATAL CASE OF MULTIPLE BRAIN HEMORRHAGES ASSOCIATED WITH LECANEMAB	119
30	CEREBRAL AMYLOID ANGIOPATHY (CAA): SHOULD IT BE A CONTRAINDICATION FOR DRUGS LIKE LECANEMAB?	123
31	HITTING THE SWEET SPOT IN THE SPECTRUM OF ALZHEIMER'S DISEASE FOR FUTURE TRIALS OF ANTI- AMYLOID MEDICATIONS	127
32	DISAPPOINTING RESULTS OF TWO HUMAN TRIALS OF MONOCLONAL ANTIBODIES IN PARKINSON'S DISEASE	130
33	REPURPOSING OLD DRUGS FOR ALZHEIMER'S TREATMENT	134
34	WRITING WHILE IMPAIRED	138
35	SPREADING THE WORD	141
36	SAYING GOODBYE TO LIZZIE G	145
37	AMYLOID AND TAU PET SCANS OF MY BRAIN	149
38	RUNNING ON A FIELD OF DREAMS	155
39	LIVING IN THE MOMENT WITH ALZHEIMER'S	158
Index		161

Color plates can be found between pages 84 and 85

Unless otherwise noted, all photographs were either taken by the author or are from his personal collection.



ACKNOWLEDGMENTS

Thank you to Anna Whiting and her team at Cambridge University Press for believing in this book from the start and marshaling it through the editing and production process at what seemed at times to be warp speed. Thanks to Dr. Gil Rabinovici at the University of California, San Francisco, for allowing me to use the PET scans of my brain. Dr. Joseph Quinn at Oregon Health and Science University has been a friend and colleague for many years, and more recently, he has been my neurologist and guide as I enter the dementia phase of Alzheimer's disease. Thanks for being there, Joe.

Cambridge University Press and I are grateful to the publications that have kindly allowed for us to adapt articles originally published within their pages: *Alzheimer's Today* (the official publication of The Alzheimer's Foundation of America), Ageing Research Reviews, and Scientific American.

A special thank you to my wife of 50 years, Lois Seed. With the sharp eyes of a retired librarian, Lois was the first, second, and third reader of this book. She encouraged me to add more personal anecdotes, and she called me to task when my writing became potentially inaccessible to lay readers. Thank you for everything Lois.

The Alzheimer's Foundation of America is a nonprofit organization whose mission is to provide support, services, and education to individuals, families, and caregivers affected by Alzheimer's disease and related dementias nationwide and to fund research for better treatment and a cure. Its services include a National Toll-Free Helpline (866-232-8484) staffed by licensed social workers, the National Memory Screening Program, educational conferences and materials, and the "AFA Partners in Care" dementia care training for healthcare professionals. For more information about AFA, call 866-232-8484 or visit www.alzfdn.org. AFA holds the Charity Navigator's top four-star rating for its commitment to fiscal efficiency, transparency, and accountability.