

SECOND EDITION

HEALTH LITERACY FROM A TO Z

Practical Ways to Communicate Your Health Message

Helen Osborne, MEd, OTR/L
President, Health Literacy Consulting
Natick, MA



JONES & BARTLETT
LEARNING

World Headquarters

Jones & Bartlett Learning
5 Wall Street
Burlington, MA 01803
978-443-5000
info@jblearning.com
www.jblearning.com

Jones & Bartlett Learning books and products are available through most bookstores and online booksellers. To contact Jones & Bartlett Learning directly, call 800-832-0034, fax 978-443-8000, or visit our website, www.jblearning.com.

Substantial discounts on bulk quantities of Jones & Bartlett Learning publications are available to corporations, professional associations, and other qualified organizations. For details and specific discount information, contact the special sales department at Jones & Bartlett Learning via the above contact information or send an email to specialsales@jblearning.com.

Copyright © 2013 by Jones & Bartlett Learning, LLC, an Ascend Learning Company

All rights reserved. No part of the material protected by this copyright may be reproduced or utilized in any form, electronic or mechanical, including photocopying, recording, or by any information storage and retrieval system, without written permission from the copyright owner.

The stories in this book are based on personal and professional experiences of the author and are intended for educational purposes. In some instances, actual names and details have been altered to ensure the privacy of individuals.

Production Credits

Publisher: David D. Cella
Managing Editor: Maro Gartside
Editorial Assistant: Teresa Reilly
Senior Production Editor: Renée Sekerak
Production Assistant: Sean Coombs
Marketing Manager: Grace Richards
Manufacturing and Inventory Control Supervisor: Amy Bacus
Composition: Cenveo Publisher Services
Cover Design: Kristin E. Parker
Cover Image: © lenetstan/Shutterstock, Inc.
Printing and Binding: Malloy, Inc.
Cover Printing: Malloy, Inc.

About the Author photo: Courtesy of Jane Hammond-Clarke

Library of Congress Cataloging-in-Publication Data

Osborne, Helen, 1948-
Health literacy from A to Z : practical ways to communicate your health message/Helen Osborne. —2nd ed.
p. ; cm.
Includes bibliographical references and index.
ISBN 978-1-4496-0053-2 (pbk.)
I. Title.
[DNLM: 1. Health Literacy. 2. Communication. WA 590]
LC-classification not assigned
613'.071—dc23 2011031271

6048

Printed in the United States of America

15 14 13 12 11 10 9 8 7 6 5 4 3 2 1

This book is dedicated to health literacy advocates everywhere. Together, we truly make it easier for others to understand and act on health information.

Contents

	Foreword	xi
	How to Use This Book	xv
	Acknowledgments	xix
	About the Author	xxi
	Reviewers	xxiii
Chapter 1	About Health Literacy	1
	What Is the Definition of Health Literacy?	1
	Why, How, and When Did Health Literacy Begin?	3
	Why Is Health Literacy Important Now?	3
	Advocating for Health Literacy	4
	Citations	5
	Sources to Learn More	6
Chapter 2	Assessing Health Literacy	9
	Starting Points	9
	Strategies, Ideas, and Suggestions	11
	Citations	13
	Sources to Learn More	14
Chapter 3	Assessing Readability with Grade Level Formulas	15
	Starting Points	15
	Strategies, Ideas, and Suggestions	16
	Citations	20
	Sources to Learn More	20
Chapter 4	Business Side of Health Literacy	23
	Starting Points	23
	Strategies, Ideas, and Suggestions	24
	Citations	26
	Sources to Learn More	27
Chapter 5	Communicating When Patients Feel Scared, Sick, and Overwhelmed	29
	Starting Points	29
	Strategies, Ideas, and Suggestions	29

	Citations	33
	Sources to Learn More	33
Chapter 6	Confirming Understanding: Feedback from Interviews, Focus Groups, and Usability Testing	35
	Starting Points	35
	Strategies, Ideas, and Suggestions	36
	Citations	38
	Sources to Learn More	38
Chapter 7	Confirming Understanding: Teach-Back Technique	41
	Starting Points	41
	Strategies, Ideas, and Suggestions	41
	Citations	44
	Sources to Learn More	44
Chapter 8	Decision Aids and Shared Decision-Making	45
	Starting Points	45
	Strategies, Ideas, and Suggestions	45
	Citations	48
	Sources to Learn More	48
Chapter 9	Document Design	51
	Starting Points	51
	Strategies, Ideas, and Suggestions	51
	Citations	54
	Sources to Learn More	54
Chapter 10	Environment of Care: Entrances, Questions, Signs, and Feng Shui	57
	Starting Points	57
	Strategies, Ideas, and Suggestions	57
	Citations	61
	Sources to Learn More	62
Chapter 11	Ethics of Simplicity	63
	Starting Points	63
	Strategies, Ideas, and Suggestions	63
	Citation	66
	Sources to Learn More	66
Chapter 12	Forms and Other “Reading-to-Do” Documents	67
	Starting Points	67
	Strategies, Ideas, and Suggestions	68
	Citations	70
	Sources to Learn More	71

Chapter 13	General Public: Talking with Patients About What They Learn from the Media	73
	Starting Points	73
	Strategies, Ideas, and Suggestions	73
	Citations	76
	Sources to Learn More	76
Chapter 14	Humor and Healing	77
	Starting Points	77
	Strategies, Ideas, and Suggestions	77
	Citations	79
	Sources to Learn More	79
Chapter 15	Interpreters and Translations	81
	Starting Points	81
	Strategies, Ideas, and Suggestions	81
	Citations	85
	Sources to Learn More	86
Chapter 16	Jargon, Acronyms, and Other Troublesome Words	87
	Starting Points	87
	Strategies, Ideas, and Suggestions	89
	Citations	90
	Sources to Learn More	91
Chapter 17	Know Your Audience: Children and Youth	93
	Starting Points	93
	Strategies, Ideas, and Suggestions	93
	Citations	96
	Sources to Learn More	96
Chapter 18	Know Your Audience: Culture and Language	97
	Starting Points	97
	Strategies, Ideas, and Suggestions	98
	Citations	102
	Sources to Learn More	102
Chapter 19	Know Your Audience: Emotions and Cognition	105
	Starting Points	105
	Strategies, Ideas, and Suggestions	105
	Citations	109
	Sources to Learn More	110
Chapter 20	Know Your Audience: Hearing Loss	111
	Starting Points	111
	Strategies, Ideas, and Suggestions	112
	Citations	114
	Sources to Learn More	114

Chapter 21	Know Your Audience: Literacy	115
	Starting Points	115
	Strategies, Ideas, and Suggestions	117
	Citations	119
	Sources to Learn More	119
Chapter 22	Know Your Audience: Older Adults	121
	Starting Points	121
	Strategies, Ideas, and Suggestions	122
	Citations	124
	Sources to Learn More	125
Chapter 23	Know Your Audience: Vision Problems	127
	Starting Points	127
	Strategies, Ideas, and Suggestions	127
	Citations	131
	Sources to Learn More	131
Chapter 24	Listening and Speaking	133
	Starting Points	133
	Strategies, Ideas, and Suggestions	133
	Citations	137
	Sources to Learn More	137
Chapter 25	Metaphors, Similes, and Analogies	139
	Starting Points	139
	Strategies, Ideas, and Suggestions	139
	Citations	141
	Sources to Learn More	141
Chapter 26	Numeracy	143
	Starting Points	143
	Strategies, Ideas, and Suggestions	144
	Citations	148
	Sources to Learn More	148
Chapter 27	Organizational Efforts: Health Literacy at the Community, State, and National Levels	151
	Starting Points	151
	Strategies, Ideas, and Suggestions	152
	Citations	155
	Sources to Learn More	155
Chapter 28	Plain Language	157
	Starting Points	157
	Strategies, Ideas, and Suggestions	159

	Citations	163
	Sources to Learn More	164
Chapter 29	Question-Asking	167
	Starting Points	167
	Strategies, Ideas, and Suggestions	169
	Citations	171
	Sources to Learn More	172
Chapter 30	Regulatory and Legal Language	173
	Starting Points	173
	Strategies, Ideas, and Suggestions	174
	Citations	176
	Sources to Learn More	176
Chapter 31	Stories	179
	Starting Points	179
	Strategies, Ideas, and Suggestions	180
	Citations	182
	Sources to Learn More	182
Chapter 32	Teaching and Learning	183
	Starting Points	183
	Strategies, Ideas, and Suggestions	184
	Citations	186
	Sources to Learn More	187
Chapter 33	Technology: Audio Podcasts	189
	Starting Points	189
	Strategies, Ideas, and Suggestions	190
	Citations	192
	Sources to Learn More	192
Chapter 34	Technology: Blogs and Other Social Media	193
	Starting Points	193
	Strategies, Ideas, and Suggestions	194
	Citations	196
	Sources to Learn More	196
Chapter 35	Technology: Email and Text Messaging	199
	Starting Points	199
	Strategies, Ideas, and Suggestions	199
	Citations	202
	Sources to Learn More	203
Chapter 36	Technology: Interactive Multimedia	205
	Starting Points	205

	Strategies, Ideas, and Suggestions	205
	Citations	207
	Sources to Learn More	208
Chapter 37	Universal Design in Communication	209
	Starting Points	209
	Strategies, Ideas, and Suggestions	209
	Citations	212
	Sources to Learn More	212
Chapter 38	Visuals	215
	Starting Points	215
	Strategies, Ideas, and Suggestions	216
	Citations	219
	Sources to Learn More	219
Chapter 39	Writing for the Web	221
	Starting Points	221
	Strategies, Ideas, and Suggestions	222
	Citations	224
	Sources to Learn More	225
Chapter 40	X-tras	227
	Starting Points	227
	Strategies, Ideas, and Suggestions	227
	Citations	230
	Sources to Learn More	230
Chapter 41	You: Empathy and Humanity	231
	Starting Points	231
	Strategies, Ideas, and Suggestions	231
	Citations	233
	Sources to Learn More	234
Chapter 42	Zest and Pizzazz	235
	Starting Points	235
	Strategies, Ideas, and Suggestions	236
	Citations	238
	Sources to Learn More	238
	Checklist: Using This Book in Practice	239
	Checklist: Using This Book to Teach	241
	Checklist: Using This Book with Patients	243
	Index	245

Foreword

For the past 45 years, I've been able to work in health care as a clerk, manager, administrator, executive, teacher, and student. Exceptional circumstances at three Massachusetts healthcare organizations—the Children's Hospital in Boston, the Dana-Farber Cancer Institute (DFCI) in Boston, and the Institute for Healthcare Improvement (IHI) in Cambridge—allowed me to gain early experience and be part of the leading edge of patient- and family-centered care (PFCC). Along the way I discovered the power and privilege of PFCC as care that is anchored in four concepts: dignity and respect, information sharing, participation, and collaboration at every level of care. In pursuit of achieving PFCC for those patients and families whom I served, I met and ultimately partnered with Helen Osborne.

We first met about 15 years ago when Helen was presenting on health literacy at DFCI. Dana-Farber was examining gaps in its practice and discovering the enormous power of the patient and family in care. We needed to learn how to move beyond aspiration to action and engagement; Helen was a teacher and guide. In the years since, Helen and I have worked together on other projects and initiatives, including simplifying IHI materials for the public and expanding personal and public engagement as part of the important Massachusetts health reform journey.

Much has changed in PFCC in recent years. Today, whether you look at the strategic plan for the U.S. Department of Health and Human Services or a strategic plan for a small rural healthcare organization, you will see an exceptional push and priority placed on PFCC and on personal and public engagement in health and health care. Surveys demonstrate that over 90 percent of healthcare organizations have been optimizing the patient experience as one of their top five strategic priorities, and 35 percent have set it as their top priority. Essential to achieving this goal, and the goals of PFCC, is meeting patients where they are, at their current knowledge base. A cornerstone of achieving this is ensuring effective communication and health literacy.

During a recent tour of a children's hospital, I asked a literacy expert what delighted her in her work. She told me the story of a boy hospitalized with a

very serious cancer. He was receiving many medications, and his healthcare team was preparing to transition him to home. His mother was bilingual but unable to read or write in either language. Staff asked how she could possibly take care of her son if she couldn't read the bottle labels. It was obvious to the staff that she was a very caring mother. One staff member, working with the mother and a pharmacist, came up with a color-coded system for all the medications, which enabled the mother to administer them perfectly in the home. The mother and the staff member were thrilled.

Healthcare delivery revolves around a seemingly endless process of communicating health information clearly and ensuring it is understood correctly. It is hard for those of us (patients, family members, clinicians, colleagues, and leaders) doing the communicating. We are all in very different places. It is also hard for those of us doing the listening. We're coming from many different cultures and literacy levels, and we are scared, busy, confused, and a lot more. Patients and family members have told me for 40 years that I ask them all what they think but then don't stop talking long enough to listen. Telling healthcare professionals just to work harder and to do it better won't get us to where we need to be. Making it up as we go along won't get us what we want.

In recent years I've had some relevant profound learning as a leader. Our systems are too complex to expect ordinary people to perform perfectly 100 percent of the time. We, as leaders, must put in place systems (structures, processes, tools, and techniques) to support safe and effective practice. These systems include communications and specifically all that health literacy has to offer. Helen's efforts make up an exceptional gift in this space.

Reading Helen's whole book (all 42 chapters) honestly wasn't my original plan prior to writing the foreword, but in the end I did. As I started skimming, I realized that I was learning a lot and went back to the beginning. I also realized that this book would help me not only in my interactions in care, but also in leadership, in teaching, in my community, and in my home. It wasn't a "read" but a reference, and a just-in-time resource from which I could seek counsel—for example, just before meeting with someone who is scared, deaf, or emotional. The chapter on document design is helpful for anyone who writes, and the ever-present "Stories from Practice" ground the content in real-life experience. The almost encyclopedic "Sources to Learn More" feature in every chapter is a wonderful alternative to the Google search with a million hits. Content from the chapter on storytelling will no doubt find its way into my Harvard School of Public Health course on leading change.

As a healthcare professional I am proud to be writing this foreword. I know through experience (the name we give to our mistakes) that we will achieve exceptional and reliable results in health and health care when we engage and build the system around the patients, their families, and the public we are privileged to serve. Full engagement will require dramatic improvements in communication, listening, and understanding, and it will build on a strong foundation of systems, processes, tools, and techniques. Few things are more important in the remarkably diverse world we live in than health literacy. Helen's book is an exceptional read, tool, reference, encyclopedia, and just-in-time guide for staff at the front line, healthcare executives, and policy analysts.

This foreword began by noting the four concepts that make up patient- and family-centered care. I would like to end it on the first one, dignity and respect. Above and beyond everything else, *Health Literacy from A to Z: Practical Ways to Communicate Your Health Message, Second Edition* is anchored in the core value of respect. To me, nothing could be more important or worthwhile. I thank Helen and all involved for their effort and recommend this book to all.

Jim Conway
Adjunct Faculty, Harvard School of Public Health
Senior Fellow, Institute for Healthcare Improvement

How to Use This Book

The Second Edition of Health Literacy from A to Z: Practical Ways to Communicate Your Health Message, is written for someone who cares a lot about communicating health messages clearly and simply. It is also written for someone to whom health literacy is just one of many projects competing for time and attention. In other words, this book is written for you.

Regardless of your profession or practice setting, you probably are wearing one or more health literacy “hats.” I categorize these as: (1) Producers—who are responsible for day-to-day health communication be it in print, in person, or on the Web; (2) Polishers—who manage, edit, or otherwise influence someone else’s written, oral, or other communication; and (3) Policy makers—who establish policies, set standards, and work to ensure that these are met. Regardless of which health literacy hat or hats you wear, this book is designed to help.

What is health literacy? Health literacy is about communicating health information in ways that others can understand. It has three central components: communication skills of the person expressing a message; learning needs of each person receiving the message; complexity of the message itself. Each can vary for infinite reasons. That’s why it is so hard to communicate health messages simply. Nonetheless, it is vital that we do.

How does this book help? This book is intended as an easy-to-use guide to be used as a starting place for your health communications. It is written in a way to inform and inspire you, not overwhelm you.

There are 42 stand-alone chapters. You can read as much or as little as you need to know now. Later, you can always read more. The chapters are arranged alphabetically from A to Z, and each includes:

- **Starting Points.** Introductory information providing context for the strategies that follow.
- **Strategies, Ideas, and Suggestions.** Lots and lots of practical, how-to ways of communicating health messages clearly and simply.
- **Stories from Practice.** Real-life experiences from a wide range of perspectives. These help make key points “come alive.”

- **Citations.** References used within each chapter. These include many of my articles, podcasts, and interviews with health literacy leaders, champions, and researchers.
- **Sources to Learn More.** Extensive listing of books, articles, Web sites, podcasts, and additional resources to continue learning about each topic.

Admittedly, it was challenging for me to find the just-right words and examples—especially when writing for an audience from diverse backgrounds, interests, and levels of experience. As needed, please substitute your words and examples for mine. For instance:

- When I use the term “providers,” you might instead think of doctors, nurses, technicians, therapists, pharmacists, health educators, practice managers, public health specialists, writers, graphic designers, librarians, agency directors, or teachers.
- Instead of “patients,” it might be more meaningful for you to think of families, caregivers, the general public, patrons, members, Web site visitors, or students.
- When an example takes place in the clinic, feel free to think of a similar situation happening in your community center, classroom, library, or other practice setting.

For better or worse, the field of health literacy has been around long enough to develop its own jargon. Here are some terms I often use that you might not already know:

- “Intended audience.” I use this as an overall term to refer to those we are trying to reach with health messages. Your audience may be one person, or many. Your audience can be local, from across the country, or from around the world.
- “Teach-back” and “feedback.” These are methods to confirm understanding. Teach-back is generally used when communicating verbally. Feedback is the process of testing materials with those representing your intended audience.
- Health literacy “ally,” “champion,” or “advocate.” These refer to you—someone who is convinced that health literacy matters, knows that health communication can and should be improved, and is determined to make a long-lasting difference.

What’s new in the Second Edition? When I agreed to write this *Second Edition*, I heard from other authors that doing so is often harder than writing a book the first time. Now I know that’s true. But I also discovered that the

process of updating, reorganizing, and rewriting is exceptionally exciting and energizing. Here are some highlights of what's new in the *Second Edition* of *Health Literacy from A to Z: Practical Ways to Communicate Your Health Message*.

New health literacy topics include: Business Side of Health Literacy; Communicating When Patients Feel Scared, Sick, and Overwhelmed; General Public: Talking with Patients About What They Learn from the Media; Organizational Efforts: Health Literacy at the Community, State and National Levels; Regulatory and Legal Language; and Writing for the Web.

Also new in the *Second Edition*:

- Expanded focus on knowing your audience. Seven chapters offer in-depth information about: (1) children and youth, (2) culture and language, (3) emotions and cognition, (4) hearing loss, (5) literacy, (6) older adults, and (7) vision problems.
- Timely information about technology: (1) audio podcasts, (2) blogs and social media, (3) email and text messages, and (4) interactive multimedia.
- “Stories from Practice,” one or more stories in each chapter that highlight real-life solutions to everyday problems.
- Checklists. Intended to remind and encourage you to put health literacy strategies into action. These three checklists are tools you can use in practice, when teaching, and with patients.

How to keep learning about health literacy? The field of health literacy continues to evolve and grow. It seems like almost every day there are new policies, guidelines, research, resources, tools, and technologies. This book, of course, cannot stay up to date with them all. Here are some resources to help you keep learning about health literacy:

- Go to my Health Literacy Consulting Web site at www.healthliteracy.com. There you can sign up for the monthly e-newsletter “What’s New in Health Literacy Consulting.”
- Listen to my *Health Literacy Out Loud* podcasts at www.healthliteracyoutloud.com. You can subscribe for free to hear them all.
- Visit the Jones & Bartlett Learning Web page at <http://go.jblearning.com/HealthLiteracy>. There you can learn more and order additional copies of this book.

Thank you for joining me on this journey called health literacy.

Acknowledgments

Health literacy is bigger than any one person, profession, program, or point of view. Whatever our job or setting, we share an awareness about problems associated with miscommunication and misunderstanding. We also share a sense of advocacy and responsibility to communicate in ways that others can understand.

The *Second Edition of Health Literacy from A to Z* is only possible thanks to the many people who so graciously shared stories, provided resources, reviewed drafts, offered suggestions, or otherwise helped me all along the way. From A to Z, my most sincere gratitude and appreciation goes to:

Lee Aase, Mary Ann Abrams, Andrea Apter, Elyse Barbell, Karen Baker, Jeff Belkora, Michele Berman, Lisa Bernstein, Kevin Brooks, Jack Bruggeman, Linda Burhansstipanov, Karyn Lynn Buxman, David D. Cella, Carolyn Clancy, John Comings, James (Jim) Conway, Sean Coombs, Sandra Cornett, Ken Crannell, Arthur Culbert, Terry Davis, Cecelia (Ceci) and Leonard (Len) Doak, Bill Dupes, Matthew Ferraguto, Catherine Finn, Valerie Fletcher, Kathleen Friedman, Maro Gartside, Izzy Gesell, Mary Alice Gillispie, Steven Grossman, Andrea Gwosdow, Jane Hammond, Healthwise, Jessica Hennessey, Mark Hochhauser, Charity Hope, George Isham, Lisa M. Jones, Randi Kant, Naomi Karten, Joseph Kimble, Perri Klass, Jennifer Knopf Munafo, Harold Law, Winston Lawrence, Joanne Locke, Winona Love, Michael Mackert, Jeanne McGee, Joan Guthrie Medlen, Phyllis Moir, Jo-Elle Mogerman, Erika Vinograd Osborne, Hilary Osborne, Suzanne O'Connor, Janice (Ginny) Redish, Teresa Reilly, Pamela Katz Ressler, Grace Richards, Audrey Riffenburgh, Stacy Robison, Linda Rohret, Donald Rubin, Rima Rudd, Terry Ruhl, Kathryn A. Sabadosa, Dean Schillinger, Karen Schriver, Domenic Screnci, Mache Seibel, Carolyn I. Speros, Cynthia Stuen, Bita Tabesh, Mark Tatro, Linda Varone, Constanza Villalba, David Walsh, Curt Wands-Bourdoiseau, Adam Weiss, Joe Weisse, Archie Willard, and Joseph Zoske.

Thank you!

About the Author



Helen Osborne, MEd, OTR/L

Recognized for her expertise in health literacy, Helen helps health professionals communicate in ways that patients and their families can understand. She does so through a range of consulting, training, and writing services.

Helen is president of Health Literacy Consulting, based in Natick, Massachusetts. She is also the founder of Health Literacy Month, a worldwide campaign to raise awareness about the importance of understandable health information. In addition, Helen produces and hosts the podcast series *Health Literacy Out Loud*.

Helen brings clinical experience, educational training, and patient perspective to all her work. She gives health literacy presentations across the United States and Canada as well as overseas. She also serves as a plain language writer/editor on numerous projects. Several of these have won plain language awards from the National Institutes of Health.

For many years, Helen was a columnist for the Boston Globe Media's *On Call* magazine, writing about patient education and healthcare communication. She is the author of several books, including the award-winning first edition of *Health Literacy from A to Z: Practical Ways to Communicate Your Health Message*—considered by many as the most important health literacy reference today. To learn more about Helen's work, please visit the Health Literacy Consulting Web site at www.healthliteracy.com. You can also listen to her *Health Literacy Out Loud* podcast interviews at www.healthliteracyoutloud.com.

Reviewers

Michael D. Aldridge, MSN, RN, CNS
Assistant Professor of Nursing
Concordia University Texas
Austin, Texas

Su-yan L. Barrow, RDH, MA, MPH
University of Melbourne
Melbourne, Victoria
Australia

Nancy Danou, RN, MSN, CPN
Associate Professor
Viterbo University
La Crosse, Wisconsin

Diane H. Gronefeld, MEd, RT(RM)
Associate Professor, Department of Allied Health
Northern Kentucky University
Highland Heights, Kentucky

Mark Jaffe, DPM, MHSA
Associate Professor
Nova Southeastern University
Fort Lauderdale, Florida

Allison Kabel, PhD
Assistant Professor, Health Sciences Program
School of Health Professions
University of Missouri
Columbia, Missouri

Cindy K. Manjounes, EdD
Department Chair, Healthcare Administration
Lindenwood University
Saint Charles, Missouri

Carol Shenise, MS, RN
Professor
Excelsior College
Albany, New York

Melissa Vosen, PhD
Academic Adviser and Lecturer
College of University Studies and Department of English
North Dakota State University
Fargo, North Dakota