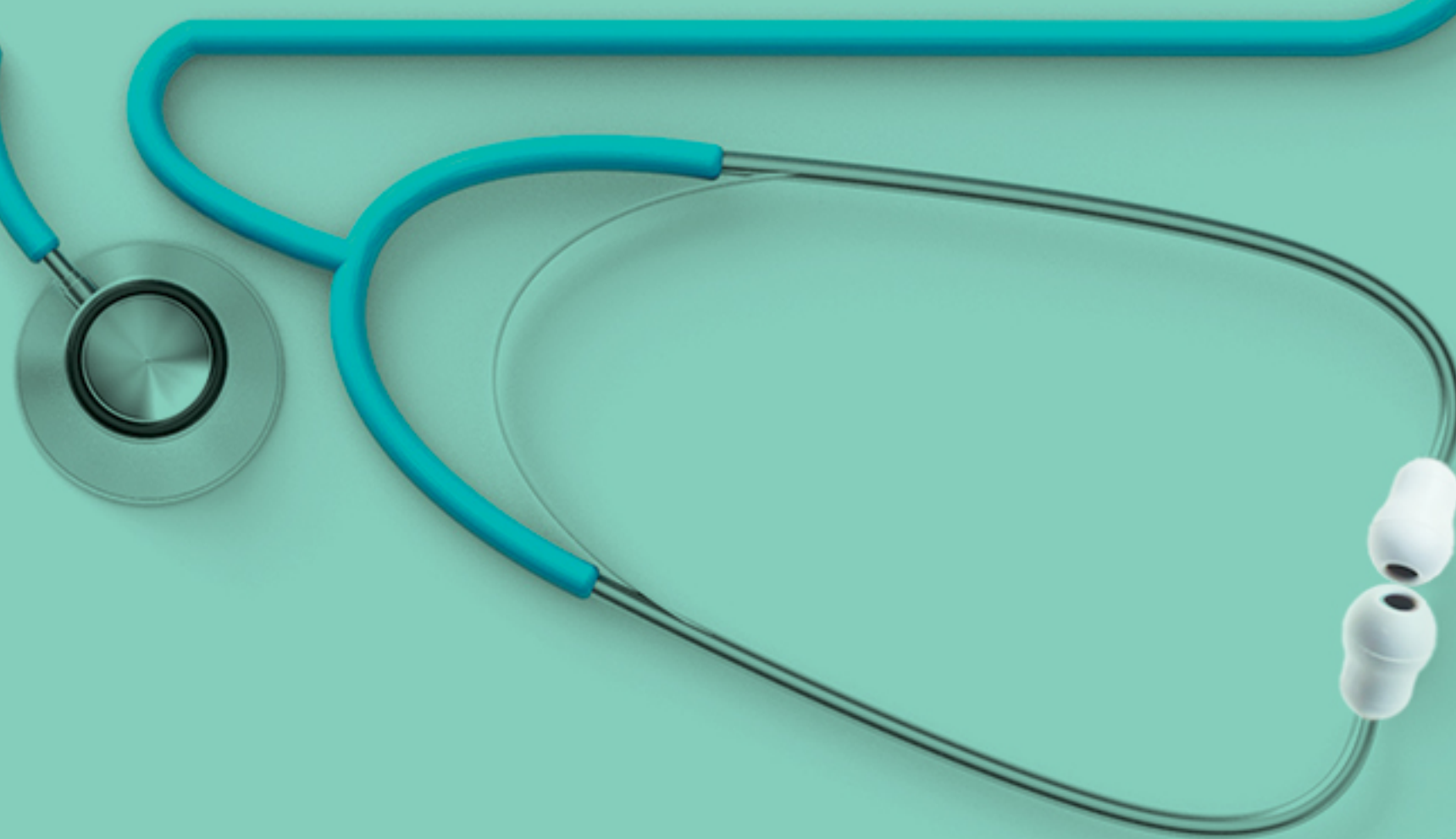


3rd Edition

# Health Literacy

from A to Z



Practical Ways to Communicate  
Your Health Message

Helen Osborne

3rd Edition

# Health Literacy from A to Z

Practical Ways to Communicate Your Health Message

Helen Osborne, MEd, OTR/L  
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Health Literacy from A to Z: Practical Ways to Communicate Your Health Message  
Third Edition  
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*This book is dedicated to Jack Bruggeman.  
He was the publisher and editor of my first two books and  
several versions of my third, the book you are reading now.*

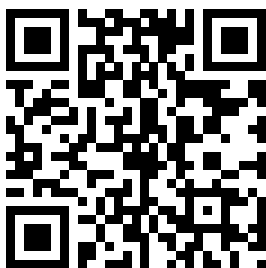
*Sadly, Jack passed away too soon. This edition is the only  
one that I wrote without him. At Jack's funeral, his widow,  
Paula, introduced me to their family and friends by saying,  
"This is Helen, one of Jack's authors."*

*I'm mighty proud of that. Thanks, Jack!*





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# Foreword

Our concepts of the role of literacy in our lives were deepened in 1993 with the publication of the National Adult Literacy Survey (NALS), which defined literacy as “an individual’s ability to read, write, and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one’s goals, and develop one’s knowledge and potential.” These concepts stimulated 30 years of continuing exploration and expansion of our understanding of literacy, communication, and their relationship to the health of individual patients and the public.

By 1995, researchers showed us the effects of “functional health literacy,” concentrating on identifying those at risk of poor health outcomes through tests of their ability to read (for example, designing and applying the TOFHLA—Test of Functional Health Literacy) to identify patients at risk, and to challenge all clinicians to not only be aware of the problems, but to come up with solutions.

In 1997, I was working as Director of Aging and Community Health at the American Medical Association (AMA). A small group of researchers was looking at this new concept of “health literacy.” I was invited to attend their meeting as a representative of the AMA.

When I reported back on the exciting new work I had just heard, the AMA Council of Scientific Affairs requested a full report, inviting the researchers I had just met to become the Ad Hoc Committee on Health Literacy of the AMA Council of Scientific Affairs. The charge was to prepare a comprehensive review of what was known about this new concept, the extent of the problems

uncovered so far, the research up to this point, the goals for research in the future, and the potential for advocacy to the broader community, including health care education and health care delivery national policies.

The report, with the Council's resolutions, was adopted by the AMA House of Delegates in 1998. It led to more than a decade of intensive work to implement its goals. This report included five recommendations that were adopted as AMA policy:

- Recognizing that limited patient literacy is a barrier to effective medical diagnosis and treatment.
- Working with relevant medical and non-medical organizations to make the health care community aware that approximately one-fourth of the adult population has limited literacy and difficulty understanding both oral and written health care information.
- Encouraging the development of undergraduate, graduate, and continuing medical education programs that train physicians to communicate with patients who have limited literacy skills.
- Encouraging the U.S. Department of Education to include questions regarding health status, health behaviors, and difficulties communicating with health care professionals in the National Adult Literacy Survey of 2002.
- Encouraging the allocation of federal and private funds for research on health literacy.

My role was to serve as an organizer, convener and advocate—working with physicians, researchers, policy makers, educators, community organizations, new readers (adults who had recently learned to read), and so many others to promote greater awareness and urgency in addressing the issue.

With financial support from the AMA Foundation, we developed a full curriculum, including a video to hear patients' voices directly, and offered a "train the trainer" program to medical societies and organizations who would provide a multidisciplinary panel of health professionals to come and learn the curriculum and agree to offer at least two training programs to their communities. Within a decade, we had trained 38 teams, who had reached over 30,000 physicians (who had completed the training and obtained CME credits for it) as well as similar numbers of other health care professionals.

One of our goals was to get health literacy into the public health goals for Healthy People 2010. It could only be a provisional goal because of the

lack of national data. Working with the U.S. Department of Education, it was possible to add questions to the soon-to-be-activated National Assessment of Adult Literacy survey of 2002. With that firm data in hand, improving health literacy became a permanent public health goal for Healthy People 2010, 2020, and now 2030.

As we learn more, the definition of health literacy expands. In Healthy People 2030, the overall goal is to “eliminate health disparities, achieve health equity and attain health literacy.” We have grown from talking about “limited literacy and poor health outcomes,” to recognizing that miscommunication is one of the foundations of health disparities and inequities.

The earliest recommendations were for simplifying the language used (“plain language”) in both written and spoken information provided to patients. That has proved to be difficult to do and a continuing challenge.

As we have studied the growing field of health literacy over the years, we have added concepts and skills to try to improve communication between all patients and their clinicians. This includes recognizing the importance of ensuring mutual understanding through a process of “closing the loop” or “teach-back.” While this appears to be a simple concept, it takes a great deal of intentional practice (with as many as 50 patients) before the clinician can state a patient’s issues in simple, easily understandable language and the patient can “teach back” the concepts completely, correctly, and know how to successfully apply them in their daily lives.

Helen Osborne has been a leader in this field, not only for establishing the worldwide Health Literacy Month, but also in helping us learn to listen to each other through her podcasts, which explore new concepts and discoveries through conversations with researchers and clinicians around our ever-expanding understanding of health literacy.

In this book, Helen examines and analyzes the increasing complexity of the field in ways that make its substance universally accessible. She has a wonderful way of stating each of the multiple issues simply and clearly. Helen offers the best approaches to the problem identified up to this point, and then embodies concepts in a human story that our hearts and minds can relate to.

Presenting what we have learned so far, Helen Osborne opens the door for us to understand the present and begin our own efforts to open future doors to mutual understanding and better care for all.

Joanne G. Schwartzberg, MD

Scholar-in-Residence

Accreditation Council for Graduate Medical Education



# An Introduction to This Book

The book you are reading now is the 3rd edition of *Health Literacy from A to Z*. For all editions, my goal is to highlight practical, how-to strategies we all can use to communicate health messages in ways that patients and the public understand.

I wrote the first edition of this book in 2005. There have been many, many changes in health literacy since then. These include an expanded understanding of what health literacy is, where it happens, and who it affects.

In the beginning, the primary focus of health literacy was patient–provider communication in medical settings. Health literacy has expanded to now include global public health concerns. Today, health literacy is increasingly seen as an essential element of equitable access to treatment and care.

The methods we use to communicate about health have changed, too. In the early days, we mostly distributed printed patient education materials. Today, there is a vast array of ways to communicate about health, including websites, patient portals, telehealth, and many forms of social media.

Yet some aspects of health literacy remain the same. That is why this book is a mix of time-honored tips you may recognize from previous editions and abundant new material, including timely stories and recent research.

## A-Z topics

The alphabetical structure of this book is admittedly artificial. I needed a way to organize the many varied topics. Organizing them from A to Z seemed the simplest structure for doing so. As you can see, there is at least one topic for each letter, though I did cheat a bit for X.

This range of topics is not intended as definitive or everything we will ever need to know. Rather, I prioritized topics that clinicians, practitioners, instructors, and others say they want to know about now, or will need soon.

Each chapter stands alone. You, of course, are welcome to read all of them in order, from A to Z. But there's no compelling reason for doing so. I recommend starting with those chapters that most interest you. Then later, when you have time, read more.



## How-to Strategies, Ideas, and Suggestions

The overall goal of health literacy is to communicate about health in ways that patients and the public can understand and use. In all editions of this book, I focus on the how-to's of doing so.

I refer to this collection of how-to's as "Strategies, Ideas, and Suggestions." Whenever possible, it includes evidence-based methods. But research has not always caught up with today's communication challenges. That's why strategies in this book include both general principles and specific recommendations from those doing, studying, and experiencing health literacy. They say that these strategies really do help.



## Stories from Practice

Health literacy is essentially about people: those on the giving end of health communication and those receiving it. Each needs to understand the other.

The stories in this book are real-life experiences. I include them here to highlight important principles and offer encouragement to try using them.

Many of these stories come from my podcast series, Health Literacy Out Loud (HLOL), which I started in 2008. These podcasts are conversations with researchers, clinicians, and others about many aspects of health communication, patient education, and health literacy. You can find a complete archive of HLOL podcasts, and transcripts for most of them, at [healthliteracyoutloud.com](http://healthliteracyoutloud.com).

Other stories and strategies come from my monthly "In Other Words. . ." column in On Call magazine. This magazine was published by a division of The Boston Globe, from 1999 to 2009. You can find an archive of these columns within my website, at [healthliteracy.com/articles/](http://healthliteracy.com/articles/).

All quotes in this book accurately reflect the cited conversations, but sometimes wording has been lightly edited for length and clarity. I identify people by their professional credentials and job title at the time we spoke or recorded that podcast.



## Citations and



## Sources to Learn More

This book includes extensive lists of resources, divided into two sections: Cited Sources and Sources to Learn More. In Cited Sources, I identify sources of information for that chapter. In Sources to Learn More, I offer additional ways to learn about each topic.

As much as possible, I include materials that are open access and available without a fee. Occasionally, the only option for an important resource is behind a paywall. Most links go to a web page where you can access the content directly or download a PDF. Sometimes, the only available link is to a direct download of that document.

All references and websites are correct at the time this book was published. But publications and links sometimes change. I plan to keep resources up to date on my website. You can access this list by scanning the QR code at the front of this book.

## My work in health literacy

In 1995, I read a research study about a topic that was totally new to me, “health literacy.” At the time, I was working as an occupational therapist on an inpatient psychiatric unit at a small hospital in one of the most diverse parts of Boston, MA. In addition to working directly with patients, I oversaw many of our hospital’s patient education programs.

Reading this study, I needed no convincing that health literacy mattered. I could see that health literacy was a concern for patients I treated each day. What I didn’t yet know was how to help. There were then few how-to resources. I soon left my clinical practice to help fill that gap and focus full-time on health literacy.

In 1998 I started my own business, Health Literacy Consulting. My intent was, and still is, to communicate health messages more clearly and teach others how to do the same. I do this by writing, teaching, and podcasting about many aspects of health literacy. I also work as a plain language writer and advisor on a wide variety of print and web-based materials.

I continually work to raise awareness about the importance of understandable health communication. In 1999, I founded Health Literacy Month, a grassroots campaign that is celebrated worldwide each October.



All these efforts converge, as I hope is evident in this book. I invite you to explore my podcasts, websites, and newsletter, and consider them to be complementary ways of learning about health literacy.

Thank you for all you do to improve health understanding.

Helen Osborne, M.Ed., OTR/L

# Chapter 1

## About Health Literacy

Health literacy is about communicating health information clearly and understanding it correctly. Health literacy is relevant at all points along the continuum of care, from wellness and health promotion, to disease prevention and detection, diagnosis and decision making, and treatment and self-care.

Health information is communicated in many ways. This includes one-to-one conversations and written materials. Health communication also takes other forms, including websites, text messages, podcasts, pictures, videos, phone calls, classes, and social media. Regardless of how communication happens, the consistent goal is health understanding.

### What is health literacy?

The definition of health literacy has evolved over the years. The newest iteration, one I whole-heartedly support, comes from the United States public health initiative Healthy People 2030<sup>1</sup>. This definition has two parts:

**Personal health literacy** is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

**Organizational health literacy** is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others<sup>2</sup>.

This definition builds on earlier ones. For years, the most widely used definition in the United States was that health literacy is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”<sup>2</sup>.

Others have framed health literacy in terms of the literacy demands in the environment of care<sup>3</sup>. Another definition focused on populations, not individuals, looking to public health decisions that benefit the community<sup>4</sup>. Yet another definition questioned whether health literacy is a clinical risk or personal asset<sup>5</sup>. That same year, participants in the Calgary Institute on Health Literacy Curricula proposed a definition of health literacy that included both givers and seekers of information, along with a set of core principles for curricula development and evaluation<sup>6</sup>.



### **Health Literacy: Communicating In Ways Others Can Understand**

Illustration by Mark Tatro, Rotate Graphics

My working definition of health literacy has been the same from the start. It is admittedly quite general, focusing on outcomes rather than specific health care settings or populations. To me, health literacy is a shared responsibility between patients (or anyone on the receiving end of health communication) and providers (or anyone on the giving end of health communication). Each must communicate in ways the other can understand.

## Why is health literacy important now?

Health literacy is now at the forefront of many health initiatives. But why? In my opinion, there are several reasons why health literacy matters today:

**Patients need to understand health information quickly** because they have little face-to-face time with their providers. This includes brief office appointments and short hospitalizations.

**Patients, along with their family members and other caregivers, are expected to correctly accomplish a wide array of health-related tasks.** These tasks may be complex and unfamiliar, such as using new technology or taking medication on time-sensitive schedules.

**Patients must be active learners.** This includes reading information given to them by providers as well as assessing the credibility and relevance of health information from family and friends, popular media, and the internet.

**Patients are increasingly seen as active consumers** rather than passive recipients of treatment and care. Patients today are often asked to make key health decisions and expected to advocate on their own behalf.

Somewhat cynically, I believe that one of the few ways left to reduce health care costs is by having patients and families take care of themselves. This requires knowing what to do, how to do it, and why it is important. In other words, this high level of self-care takes a heaping dose of health literacy.

## National Action Plan to Improve Health Literacy

There is a growing movement toward comprehensive health literacy solutions. In 2010, the United States launched the National Action Plan to Improve Health Literacy<sup>7</sup>. It includes seven goals and numerous suggested strategies to improve health literacy. In the years since its launch, many health care organizations, community services, educational programs, and others have worked toward these goals. The goals are to:

- Develop and disseminate health and safety information that is accurate, accessible, and actionable.
- Promote changes in the health care system that improve health information, communication, informed decision making, and access to health services.

- Incorporate accurate, standards-based, and developmentally appropriate health and science information and curricula in child care and education through the university level.
- Support and expand local efforts to provide adult education, English language instruction, and culturally and linguistically appropriate health information services in the community.
- Build partnerships, develop guidance, and change policies.
- Increase basic research and the development, implementation, and evaluation of practices and interventions to improve health literacy.
- Increase the dissemination and use of evidence-based health literacy practices and interventions.

As stated in the plan's summary, "[b]y focusing on health literacy issues and working together, we can improve the accessibility, quality, and safety of health care; reduce costs; and improve the health and quality of life of millions of people in the United States."

## Brief recap of health literacy history

Curious to know how, when, why, and who helped health literacy get started, I posted a query on the online Health Literacy Discussion list<sup>8</sup>. Here is a brief recap of what people shared about the history of health literacy.

**1974.** The first mention of the term "health literacy" was in a monograph by Scott K. Simonds entitled "Health Education as Social Policy<sup>9</sup>." In this monograph, health literacy was framed within the context of social policy.

**1980s.** Len and Ceci Doak (whom many consider to be the founders of health literacy as we know it today) studied the reading skills of hospitalized patients. The Doaks, along with Jane Root, wrote the landmark book *Teaching Patients with Low Literacy Skills*<sup>10</sup>, first published in 1985.

**Early 1990s.** Inspired by the work of Harold Freeman (then president of the American Cancer Society), Wendy Mettger, and others at the National Cancer Institute and the AMC Cancer Research Center created the National Work Group on Cancer and Literacy. This group brought together experts from diverse fields. Many of them continue to be health literacy leaders today.

**Mid 1990s.** Others got involved in health literacy issues and initiatives. They included not only physicians and other clinicians but also literacy practitioners, teachers, researchers, health communicators, patient educators, medical librarians, disability professionals, and social justice and environmental activists. The lay public, including new readers (adults learning to read) also became active in health literacy.

**Late 1990s.** The Council on Scientific Affairs of the American Medical Association (AMA) published an important paper on health literacy, including five recommendations adopted as AMA policies<sup>11</sup>. Joanne Schwartzberg was a key advocate for health literacy at the AMA. Health literacy also gained worldwide attention and action. Leaders included Irving Rootman and Linda Shohet of Canada, Donald Nutbeam of Australia, and Ilona Kickbush of Germany. Health Literacy Month<sup>12</sup>, a worldwide awareness-raising event, was started by me (Helen Osborne) in 1999.

**Early 2000s.** Interest in health literacy quickly grew thanks in part to the 2004 publication of the Institute of Medicine's report *Health Literacy: A Prescription to End Confusion*<sup>13</sup>. The AMA Foundation also championed health literacy, creating an educational toolkit with the powerful video "Health literacy and patient safety: help patients understand<sup>14</sup>." Around this time, the pharmaceutical company Pfizer got involved, providing grants for research, tools, and training<sup>15</sup>.

**Around 2010.** Howard Koh (then assistant secretary of the United States Department of Health and Human Services) said health literacy reached a "tipping point"<sup>16</sup>. He credited milestones including the Plain Writing Act<sup>17</sup>, the National Action Plan to Improve Health Literacy, and enactment of the Affordable Care Act<sup>18</sup> (ACA, also known as Obamacare).

**Today.** There are thousands of health literacy research articles, hundreds of health literacy programs, numerous health literacy coalitions, and too-many-to-count health literacy initiatives across the United States and around the world. Major milestones in the past decade include the formation of the International Health Literacy Association<sup>19</sup>, publication of the scholarly journal *HLRP: Health Literacy Research and Practice*<sup>20</sup>, and creation of a Health Literacy Specialist Certificate program<sup>21</sup>. I am excited to see what we, alone and together, will continue to accomplish when it comes to health literacy.



## Story from Practice: A big thank you to Len and Ceci Doak

Leonard (Len) and Cecelia (Ceci) Doak are widely acknowledged for leading the way when it comes to health literacy. Their award-winning book *Teaching Patients with Low Literacy Skills* was, and still is, an essential how-to guide for communicating clearly with patients.

In 2009, I asked the Doaks how they got started<sup>22</sup>. They said that their interest in health literacy began with their marriage in 1973. At that time, Len was a literacy tutor and Ceci a health educator. As Ceci explained, “When I met Len and he told me he volunteered as a tutor with people who couldn’t read and write, I said, ‘My heavens! How do people with low literacy skills understand medical advice? What happens when they go to the doctor?’ Len replied, ‘Often, they don’t understand.’”

And so began the Doaks’ health literacy journey. Their goal then, as it is for us now, is to help health professionals “work around” literacy issues so that patients leave appointments knowing what to do and how to do it.



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## Chapter 2

# Assessment Tools for Health Literacy

### Starting Points

Is it important to assess how well your patients can read, understand, and act on health information? If so, what assessment tool would you use to measure these skills? Would you use this to assess individuals or the overall level of your patient population or community? If it is important to make these assessments, you had the correct tool, and knew which patients to test, then how would doing so make a difference in your communication?

Clinicians, health educators, and others responsible for day-to-day health communication may grapple with questions like these. Here is a brief look at reasons to, and not to, routinely assess health literacy skills in clinical practice.

**Reasons to routinely assess health literacy skills.** Knowing the level of each patient's health literacy might guide the choice of teaching methods and materials. Here is an example:

Jane reads at a fourth-grade level. She is asked to fill out a health history form before seeing her new primary care provider. Jane has learned from experience that it is easiest to simply check “no” for all questions on the form about illnesses and allergies. This way, there are fewer follow-up questions. But it turns out that Jane's strategy has costly consequences when her provider unknowingly prescribes a medication to which she is allergic.

Those who advocate for routinely assessing health literacy might argue that if Jane's provider knew that she could barely read, then they could offer alternatives such as a simply written health history that includes graphics, or someone to assist Jane in completing the form.

**Reasons not to routinely assess health literacy skills.** Other professionals dispute the value of routine health literacy screening, arguing that formal assessments can do more harm than good. They feel that patients may perceive formal assessments as literacy tests which, in turn, can promote feelings of anxiety and shame.

Rather than assessing individual patients, many providers recommend using health literacy universal precautions. You can find a lot of information, including numerous evidence-based communication strategies for adult and pediatric practices, in the *Health Literacy Universal Precautions Toolkit* from the Agency for Healthcare Research and Quality<sup>1</sup>.



### Story from Practice: A New Reader's view of health literacy assessments

Archie Willard referred to himself as a New Reader—someone who learned to read as an adult. Among his many accomplishments and projects, Willard led a conference for New Readers called “Health and Literacy Working Together” in 2004<sup>2</sup>.

One of the topics discussed at this conference was literacy testing in health care settings. Most of the New Readers voiced strong concerns, saying that “a doctor's office is no place for a reading test.” They also offered this advice to clinicians: “Treat us as you would like to be treated. We are human beings that need to be understood. Make sure that we understand. It's about human respect. Yes, we lack a skill. But we're not less than.”



### Strategies, Ideas, and Suggestions

There is a growing array of tools to assess health literacy. Some focus primarily on reading or word recognition while others include skills commonly used in health care, such as numeracy. Most tools need to be administered by professionals or trained staff. Tools are also being developed for specific populations, diagnoses, and languages.

Here are some well-regarded health literacy assessment tools:

**NVS (Newest Vital Sign)**<sup>3</sup>. Patients are asked to answer six questions about a sample ice cream label. For example, “If you eat the entire container, how many calories will you eat?” The NVS takes about three minutes to administer and is available in English and Spanish. The researchers who created the NVS reported that it is “a reliable and accurate measure of literacy with high sensitivity for detecting persons with limited literacy”.

**REALM (Rapid Estimate of Adult Literacy in Medicine)**<sup>4</sup>. This tool looks at reading and recognition of health words. Patients are asked to pronounce 66 words that range in difficulty from “fat” to “impetigo.” The REALM is easy to administer and provides grade-level scores for people who read below a ninth-grade level.

**SAHL–S&E (Short Assessment of Health Literacy—Spanish and English)**<sup>5</sup>. This tool combines a word recognition test (adapted from the REALM) with a comprehension test using multi-choice questions. It can be given in Spanish or English. The researchers behind this tool reported that it “could be used to screen for low health literacy among Spanish and English speakers.”

**SILS (Single Item Literacy Screener)**<sup>6</sup>. This tool is very brief, with just one question: “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?” The creators of the SILS concluded that it “performs moderately well at ruling out limited reading ability in adults and allows providers to target additional assessment of health literacy skills to those most in need.”

**TOFHLA (Test of Functional Health Literacy in Adults)**<sup>7</sup> and **S-TOFHLA**<sup>8</sup> (shortened version). Each of these assessment tools includes a series of health-related reading tasks that measure numeracy and reading comprehension. These well-regarded assessment tools have been used in research studies for many years.





## Story from Practice: Health literacy screening tools in practice

Barry Weiss, MD is a professor and practicing physician. He has been involved in health literacy and patient-physician communication for much of his career. Among his numerous accomplishments, Weiss developed the NVS (Newest Vital Sign) health literacy screening tool. We spoke about this and other tools in 2014<sup>9</sup>.

Weiss said that the NVS and other health literacy screening tools are somewhat interchangeable and measure similar, but not identical, concepts. In his opinion, however, none of these is good enough for someone to say, “I now absolutely know for sure that this person has low literacy.”

Weiss later added, “I’ve been telling people that there are really only two reasons to perform health literacy assessments on patients. One is for research. The other is if you don’t really believe that limited health literacy is prevalent in your practice.”

He continued, “If that’s what you think, perform a health literacy assessment on the next 100 patients who walk in the door and see what you find. It will show you how prevalent it is, and perhaps change the way you communicate with patients.”

To Weiss, “there is no good (or really, any) evidence that if clinicians routinely test individual patients that they then are able to tailor communication to the literacy level of that patient. Rather, it creates anxiety for the clinician and it can make patients feel uncomfortable.” His overall recommendation is to communicate clearly with everyone.



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## Chapter 3

# Assessment Tools for Readability

### Starting Points

Many health writers say that their materials are easy to read and suitable for readers of average skills, or below. When I ask how they determine this, they often talk about assessing readability with grade-level formulas. Commonly, these calculate readability based on the average number of words in sentences and the average number of syllables in words.

While important, these factors alone are insufficient to determine reading ease. There are other important factors to also consider including how information is organized within the document along with its tone, layout, use of illustrations, and relevance to readers.



### Story from Practice: Many factors affect reading ease

Barbra Kingsley, PhD is an expert in information design and plain language. She is co-founder and managing partner of the Kingsley-Kleimann Group and chair of the Center for Plain Language. We spoke in 2020<sup>1</sup>.

Kingsley equated readability formulas to mathematical formulas, and explained that they measure different aspects of sentences and look at factors like syllables. “We’ve all seen these on our word processors. It will say something like: This is an 8th grade reading level, or a 5th grade reading level.”

But Kingsley said that this is just a gross measurement and does not take everything into account. “For example, you can have certain words that are longer, such as ‘grandmother’ and ‘hamburger.’ Those have several syllables but they’re very familiar to everyone.”

There can also be potential problems with very short words like “risk” that can carry a lot of meaning but may not always be clear to readers. “A readability formula can’t make that distinction of words you necessarily would know and be familiar with versus others that are long, esoteric, or complex.”

Kingsley and I agree that it is helpful to consider the many factors that affect reading ease rather than relying solely on grade-level formulas.



## Strategies, Ideas, and Suggestions

Reading grade level formulas are beneficial in that they are objective, easy to use, and the scores almost always get people’s attention. I often use such formulas at the beginning and end of plain language projects to confirm that I made significant improvements.

Two very well-regarded tools to assess readability are the SMOG (Simplified Measurement of Gobbledygook) and the Fry readability formula. While both give grade-level scores, they calculate them in different ways. You can find detailed instructions for these and other readability tools on numerous websites and writing guides.

**The SMOG<sup>2</sup>** counts all words with three or more syllables (including those that are hyphenated) in three 10-sentence passages. Use the total number to find the reading grade level on a SMOG chart.

Audrey Riffenburgh, PhD is an expert on assessing readability. She explains that the SMOG tends to score text 2-3 grade levels higher than other formulas (like the Flesch-Kincaid, found in Microsoft Word), because the SMOG requires 100% comprehension, which is the goal for most documents. She considers the SMOG to be a “gold standard” to assess readability.

**The Fry<sup>3</sup>** formula looks at the number of syllables and sentences in three 100-word passages. To use the Fry, select a 100-word passage, then count all syllables and the number of sentences in those 100 words, rounding to the nearest tenth of a sentence. Do this three times, and then average both the syllable counts and the sentence counts. Use these numbers to find the reading grade level on a Fry graph.

**Assess readability by hand.** You can do the SMOG and Fry by hand (using paper and pencil) or with an online calculator. Honestly, I like assessing readability by hand. I find the SMOG and Fry easy and quick to use. I can also decide for myself whether a group of words is a complete sentence, a sentence fragment, or simply a title. I especially like seeing problem areas. Once I see potential problems, I can decide what to do. For instance, I might replace the multisyllabic word “numerous” with the simpler “many.” But keep a necessary term like “syllable.”

**Assess readability by computer.** Many word processing programs include readability formulas within their spelling/grammar check tools. Admittedly, these are fast and easy to use. But there are several limitations, including how these formulas count words and sentences. For instance, formulas may be programmed to count all dots as periods that end sentences (which is not always the case). See below about how to prepare documents for computer-based readability assessments.

My preference when assessing readability by computer is to use software or a website designed for that purpose. You likely can find a wide array of readability software and online assessment tools, tests, and calculators. One that I use is Online-Utility<sup>4</sup>.

**Prepare documents for readability assessments.** Whether assessing readability by hand or computer, you can get more accurate results if you take time to first prepare the text. Start by removing headings, titles, subtitles, and sentence fragments within bullet points. But do keep all complete sentences within bulleted lists.

It is important to also remove dots that might be part of a numbered list, abbreviation, or number such as “Dr.” or “100.2.” That is because most computer-based assessments are programmed to recognize sentences as groups of words ending with a period, question mark, or exclamation point. If you keep in extra dots, the computer could incorrectly determine that these are short sentences and assess the text as easier than it really is.

**Follow, do not fiddle with, readability rules.** An area of dispute about readability formulas is whether it is okay to amend the rules and count repetitive, yet necessary, multisyllabic words (like “diabetes” or “hospital”) only once instead of each time they appear in the text. While I appreciate that fiddling with these formulas may lower the reading grade level, in my opinion this method can cause as many problems as it solves. For example, once you change this rule then you must create a new one about which multisyllabic words to count. My

method is to follow all the formula's rules but mention in a summary why these scores are so high.

**Be cautious not to over-interpret the results.** Reading grade level scores are accurate only by plus or minus one-and-a-half grade levels. This means that when a score drops from, for example, 7.3 to 6.8, the document is not necessarily easier to read. Riffenburgh advises looking for a larger shift in reading level of one to two grade levels, sometimes more.

Results may also vary depending on which formula you use and how it calculates reading level. Riffenburgh's advice is to use the same formula to assess the reading level of documents both before and after you make them easier to read<sup>5</sup>.

**Explore additional ways to assess reading ease.** Instead of, or in addition to, using reading grade level formulas, health literacy experts advocate using other tools to assess reading ease, relevance, appeal, appropriateness, and other factors. Here are some excellent tools:

**CDC's Clear Communication Index<sup>6</sup>.** This research-based tool is designed to help when writing and assessing public communication materials.

**PEMAT (Patient Education and Assessment Tool)<sup>7</sup>.** Developed by the Agency for Healthcare Research and Quality, the PEMAT is a systematic method to evaluate and compare the understandability and actionability of print and audiovisual patient education materials.

**SAM (Suitability Assessment of Materials).** This well-regarded checklist from 1996 was published in *Teaching Patients with Low Literacy Skills* by Doak, Doak, and Root<sup>8</sup>. It is used to objectively and subjectively assess a document's strengths, weaknesses, and areas to revise. SAM looks at factors of content, literacy demand (including readability), graphics, layout and typography, learning stimulation and motivation, and cultural appropriateness.

**Test materials with readers.** Most health literacy experts agree that after determining that a document is at the appropriate reading level, you should ask for feedback from readers who represent the intended audience. From the first idea to the final draft, those representing your audience are the true experts about a document's relevance, appeal, usability, and readability. In my opinion, that's the best assessment of all.



## Story from Practice: Benefits and limitations of readability formulas

Audrey Riffenburgh, PhD is President of Health Literacy Connections. We are long-time health literacy colleagues and have seen this body of inquiry, knowledge, and practice grow and change over the years. One topic we have discussed has to do with the benefits and limitations of readability formulas.

“I believe in the proper use of readability formulas as one valuable tool in our arsenal when working to make documents readable and usable,” said Riffenburgh. “I teach that it is imperative to also look at all the other features of documents so as to get a complete picture.”

Riffenburgh added that she’s been feeling quite troubled lately at the frequent negative portrayals of readability formulas. “They are a valuable tool when used as intended,” she said. “I see them as a tool—perhaps as a hammer—which is not the only tool you need to build a shed but certainly is essential. A person building a shed has to know there also are other tools and learn to use each one as it was intended.”

“Readability formulas are the tool we use to assess the relative difficulty of the text. They must always be used in conjunction with assessing all the other features that contribute to a document being easy to read and use,” Riffenburgh wisely advised.



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## Chapter 4

# Business Side of Health Literacy

### Starting Points

Those of us on the front lines of health communication need little convincing that health literacy matters. Almost every day we learn of medical errors, hospital readmissions, compromised health status, or other costly outcomes caused, at least in part, by miscommunication and misunderstanding.

There have been numerous recent studies looking at the economic side of such misunderstandings<sup>1-7</sup>. Some have looked at overall costs of limited health literacy. Others have focused more narrowly on a specific diagnosis, medication, or type of care. Whatever the focus, these studies have agreed that there is a problem.

But few studies have looked at the economic benefits of health literacy. In my opinion, we need more research on this topic so as to make a compelling and convincing business case about why health literacy matters. With cost and benefit data, health literacy advocates could frame health literacy issues in ways that resonate with administrators, funders, policy makers, government officials, and others authorized to allocate resources.

Beyond making the case for health literacy, advocates also need to aim for sustainability when designing programs. From a business standpoint, sustainability means that organizations have the resources to continue in the long term and pay for needed staff, marketing, and programs or services.



## Story from Practice: Think big about health literacy

Mary Ann Abrams, MD, MPH, Cynthia (Cyndi) Hall, MHA, CPHQ, and Shelby Chapman, MA are helping to make health literacy a sustainable part of the culture at their respective health care organizations. We spoke in 2016<sup>8</sup>.

I asked what “thinking big about health literacy” means to each of them. Here are excerpts of their replies:

**Hall:** “I want to go beyond just the education of our employees and teammates and really get across the entire culture of our organization. We have a very large organization. That means getting support at the board level, at the physician level, with our teammates, and with all of our leadership. In order to make things work, you really need to have a cross-functional group, not only in disciplines but also in levels of the organization. Thinking big to me means being really inclusive and inviting the entire organization to work on health literacy together.”

**Chapman:** “For me, thinking big is about how we change the entire system to meet the needs of our patients and families. Thinking big means changing the organization at all levels. How do we think about meeting people’s needs, meeting them where they’re at, and increasing the ease of the system on the consumer end?”

**Abrams:** “Look down the road. Think about how to embed and hardwire changes you’ve made so they become part of the culture and standard operating procedures—the way people routinely think.”

They also spoke about what it takes to achieve these big ideas:

**Hall:** “Make sure everybody is ready to go. Implement things slowly and use scientific techniques to implement them, like small tests of change. While thinking big, you have to start small and then grow effectively and thoughtfully.”

**Chapman:** “You need to have buy-in. Include folks doing the work at the front lines from the very beginning in order to be successful with any kind of changes you’re trying to make.”

**Abrams:** “Don’t be afraid to get started. Don’t let the perfect be the enemy of the good. Try things that might be a little bit new, different, or uncomfortable. Help people work out the bugs, get comfortable, and start ramping up. They then become health literacy champions who share these successes with their colleagues.”



## Strategies, Ideas, and Suggestions

David Walsh consulted with Health Literacy Missouri to develop its initial long-term vision and sustainable business plan. He now helps zoos, aquariums, and other non-profit initiatives do the same. In 2010, Walsh and I discussed strategies for making a business case about health literacy<sup>9</sup>. Here are some of his recommendations:

**Think in terms of business and finances.** Walsh said that health care today is a multibillion-dollar operation with hospitals, health care centers, insurance companies, physicians, and many others all thinking about finances. “Think of the financial side. It’s really the money that allows hospitals and health care organizations to provide the highest level of care, to have the funds to do cutting-edge research, and have the resources to be their best.”

**Build a team.** Recruit allies and champions to voice support within, and outside, your organization. These include respected leaders at all levels of an organization, association, or community. Consider adding others who bring a wide range of knowledge and experience. These can include lawyers who help anticipate roadblocks and financial advisers to “crunch” numbers.

**Use business language.** Just as health care practitioners expect patients and families to be fluent in medical language, business people want others to understand and use their acronyms, jargon, and industry-specific terms. That includes common business terms like ROI (return on investment) and P&L (profit and loss). It also means understanding the distinction between not-for-profit and for-profit business structures.

**Create a business plan.** Regardless of the size and scope of your health literacy initiative, Walsh strongly recommends starting with a business plan. Key components should include defining your purpose and goals, identifying the primary audience or market, identifying needed resources, finding funding sources, and defining measures of success. Walsh advises revisiting this plan at least once a year. “Whether or not you feel you’re doing great or doing bad, you should always go back and say, ‘Okay, here’s what we said we were going to do. Now let’s see how we did.’”



## Story from Practice: Make a case for health literacy to senior leaders

Barbara Balik, RN, EdD worked as a nurse practitioner before moving into leadership roles, including as CEO of a large health care system. In 2016, we discussed ways to make a business case about health literacy to senior leaders<sup>10</sup>.

Balik needed no convincing as to why health literacy matters. “Health literacy is really the essential foundation for partnerships with patients’ families and community members. If we don’t have a mutual understanding, we’re not going to make the progress that we need in health care,” she said.

To build sustainable programs, Balik recommended partnerships at three levels. The first would be with those who have the closest relationship with patients and families such as clinicians who interact with them on a daily basis. The second level includes departments and clinics. Balik also recommended looking for ways to weave health literacy throughout the department’s written materials, posted signs, and terminology. The third level is about policy, reaching out not only to the board of directors but also community members.

Balik highlighted ways to make a compelling case for health literacy with senior leaders. Her recommendations included: link health literacy to the organization’s strategic plan, use both statistics and stories to make data “come alive,” build alliances with champions and partners, and be clear about your “ask”—what you need, when you need it, and in what sequence.

I asked Balik if doing all this would work. While acknowledging that there’s no guarantee, from her experience these strategies help. I also asked for her advice about dealing with naysayers or other negative folks. “Just smile, nod, and move on,” she said. “Recognize when you’re pushing a rock up a hill that’s just not going to go anywhere.” Spend your time and energy on those who are enthusiastic and positive, Balik wisely advised.



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## Chapter 5

# Community Connections

### Starting Points

“It takes a village to raise a child,” says an African proverb, though its exact source is uncertain<sup>1</sup>. To me, the essence of this statement is that it takes a community-wide effort to help children grow and thrive. So, too, it is with health.

Whether people live in large cities or small towns, they often have access to a wide range of community resources. These can include public agencies such as libraries and police and fire departments, along with elected officials. Also, community services like senior centers, literacy programs, and places of worship. Businesses, too, such as barbershops, hair salons, laundromats, and locally owned stores, as well as large enterprises including hotels.

When resources like these team up with health services, individual patients and the general public can both benefit. Below are examples of health and community pairings. The hope is that these inspire you to make connections in communities where you work and live.



### Strategies, Ideas, and Suggestions: Stories from many perspectives

**Librarians** are experts in finding and organizing information. Some have special training as consumer health librarians. Whether working at hospital-based or public libraries, librarians help connect patients and the public (or as librarians refer to them, patrons) to needed and timely health resources.

Amy Six-Means is a consumer health librarian. In a 2017 article<sup>2</sup>, she shared many examples of effective partnerships between libraries and health



services. One that she cited was GetHELP Health Literacy in Mount Vernon, Washington<sup>3</sup>. In this project, librarians, public health workers, and staff at the local senior center together designed a workshop for seniors with information about how to find and use reliable health resources.

**Elected officials** include local and national leaders and representatives. They often make decisions affecting health policy and funding. Michael Jackman not only has years of experience working in the office of a United States Congress member but also is a long-time advocate for health literacy. He is very familiar with how politics and health care can intersect. We spoke in 2017<sup>4</sup>. Jackman encourages health professionals, patients, and the public to contact their elected officials about important health issues. “You have to be intentional. Let elected officials know how improving health literacy can be beneficial for the constituents they represent.”

**Barbers, hair stylists, and other local business owners** often have trusted relationships with long-time customers. Sometimes they build on this trust to raise awareness about important health issues. A systematic review of studies of barbers talking with customers about specific health topics concluded that “barbershop customers are a captive audience receptive to health interventions delivered by trained barbers who are respected and trusted members of the community<sup>5</sup>.”

**Hotels**, too, can help, though perhaps in indirect ways. Andrés Valencia has many years of experience in international hospitality, including work at top-end hotels. He later brought this business savvy and experience to hospitals. We spoke in 2015<sup>6</sup>.

“One of the things that we do very well in hospitality is make sure that guests receive a warm welcome, have a pleasant stay, and get a warm goodbye,” Valencia said. He shared examples of doing the same in health settings:

**Warm welcome.** When patients check in for appointments, the receptionist might ask if there is a specific concern that the patient wants to discuss with their clinician that day. If so, add a note to the medical record alerting the clinician to this.

**Pleasant stay.** Admittedly, many medical tests and procedures are uncomfortable or unpleasant. Yet there can be ways to make them seem less so. An example is offering a warm blanket to patients who are having a procedure done in a chilly exam room.

**Warm goodbye.** This can include managing a patient's expectations about discharge from the hospital. To help, tell patients the time they likely will be discharged and what to expect will happen between now and then.

**Dentists.** Leila Jahangiri, BDS, DMD, MMSc is a prosthodontist and dental professor. In 2014, we spoke about some challenges in talking with patients about dental concerns<sup>7</sup>. One challenge is that patients cannot always see what's happening inside their mouths. To help, Jahangiri might use X-rays or other dental images to point out problem areas. Another challenge is communicating during procedures when the patient cannot speak. Knowing this, Jahangiri prepares patients ahead of time by telling them what to expect during and after procedures. An example is saying something like, "I think the procedure is going to take about an hour. You may be numb for two hours afterward. I don't expect that you'll be in any discomfort during the procedure."

**Veterinarians.** Alice Villalobos, DVM, FNAP worked as a veterinary oncologist until her retirement in 2021. In 2011, we spoke about the important bond between animals and humans and how this matters in health care<sup>8</sup>. "With a lot of elderly people, their kids are gone, they may have lost a spouse. But a sense of purpose can remain if they have a pet." Villalobos added, "This relationship should never be trivialized. People need to get up and feed and walk the animal. Their life routine is often centered on the animal."



### Story from Practice: Laundromats, literacy, and health understanding

Health information is notoriously hard to understand. It can be even more difficult for someone who is not a strong reader. One way to help is by promoting literacy from early childhood on. Brian Wallace is president and chief executive officer of the Coin Laundry Association and director of its charity arm, the LaundryCares Foundation<sup>9</sup>, which has a laundromat initiative called Family Read, Play & Learn spaces. Its mission is to help improve family literacy by installing mini-libraries in local laundromats.

We spoke about this initiative in 2020<sup>10</sup>. "Laundry is an essential chore that is done every week. We tend to find a lot of families. Our customers tend to be lower income folks from under-resourced neighborhoods." Wallace said that some of these communities have low levels of literacy.

Wallace shared reasons why installing a “literacy corner” or mini-library in the laundromat can be helpful. One reason has to do with proximity. He says that families who come to laundromats often are the ones whose kids could use the most help. A second reason has to do with long “dwell times” when people are at the laundromat. As Wallace described, “you’re there for two hours as a captive audience. You can watch the socks tumble or look at your phone. Why not read to your kids, engage in literacy activities, or learn about other resources available in the neighborhood?” A third reason is the recurring nature of this visit. “We’re all creatures of habit,” said Wallace. “If I take my kids and my clothes in every Thursday afternoon at 4:00, you better believe I’ll be there next Thursday, the Thursday after that, and the Thursday after that.”

Family Read, Play & Learn spaces in laundromats have been a great success. “I’ve observed kids walking in the front door with a sour expression, like, ‘oh boy, here we go with the laundromat again’ to lighting up and making a beeline for those tables and chairs, that bookshelf and little couch where we have hand puppets, magnet tiles, magnet letters and, of course, books. It’s a natural connection” said Wallace.

As we in health literacy know, stronger reading skills can help a lot when it comes to health understanding. I’m very appreciative that laundromats are aiding in this effort.



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## Chapter 6

# Confirm Understanding: Teach-back & Feedback

### Starting Points

Just because we say something, just because we write it, just because we know this information is important does not necessarily mean that the person we are communicating with will be able to read, relate to, and follow this information.

It is vital that we as health communicators confirm that our messages are truly understood. Two important ways to do this are with teach-back (for the spoken word) and feedback (for print and web information).

**Teach-back.** Sometimes referred to as “the interactive communication loop” or “return demonstration,” teach-back is a back-and-forth verbal exchange used to assess whether both sides of a conversation (the person communicating the message and the person receiving it) correctly understand each other.

**Feedback.** There are many ways to get feedback. These include interviewing one person at a time, meeting with several people in focus groups, or observing others as they use your materials. Feedback is helpful throughout the writing process, from the initial idea and planning through to publication and revision.



### Strategies, Ideas, and Suggestions: Teach-back<sup>1-4</sup>

**Prioritize topics.** Patients and providers likely discuss many topics. This often includes context such as what a symptom is and why, or why not, it is worrisome. Topics might also be about follow-up, such as when and where

to schedule the next appointment. It's likely that much of the patient-provider conversation is on "how-to" information such as directions for taking medicine, using a medical device, or recognizing side effects. While all topics can be helpful, use teach-back only for a few important ones.

**Set a tone of partnership.** Teach-back is a way to confirm that you, as the communicator, are clear. It is not to test how smart or savvy the other person is. Start by setting a tone of partnership such as "I want to make sure that I explained this clearly." Then ask open-ended questions in a conversational manner. For instance, "When you go home today, what will you tell your [spouse, adult child, or caregiver] about [key points we just discussed]?" Or focus on important actions, like saying "we talked about the importance of eating high fiber foods. What will you look for the next time you buy cereal?"

**Follow up to their response.** Say a bit more after the other person replies. If it's evident that they correctly understood, acknowledge that and perhaps add a bit more, such as, "It's great that you know about [topic]. I look forward to hearing how that helps." But if the patient does not seem to correctly or completely understand, reword the message to be more clear. Then use teach-back again to assess the patient's level of understanding. If despite your best efforts the patient still does not understand, adapt your teaching accordingly. This might be by showing a video on that topic or recommending they invite someone to come with them to the next appointment.

**Allow sufficient time.** Admittedly, teach-back takes some time. But perhaps not as long as you fear, especially once teach-back becomes a routine part of your clinical care. Consider, too, the extra time it might later take if patients do not understand and cannot correctly follow instructions.



### Story from Practice: Using teach-back

Dean Schillinger, MD is a primary care physician, professor, researcher, author, and long-time advocate for health literacy. In 2015, we spoke about using teach-back to confirm verbal understanding<sup>2</sup>.

Schillinger explained that teach-back is more than simply saying something and having the other person repeat back those words. It's about having a shared meaning of a diagnosis, treatment plan, or a whole range of issues that come up in the health care context. Schillinger shared this story from his practice:

A guy that I took care of had really severe hypertension. We had a nice relationship but every time he came back his blood pressure was through the roof. He was on about 9 or 10 blood pressure medications, which is not entirely unusual. But it was odd to me that we weren't making any headway. Usually you expect some improvement in blood pressure.

I had done the teach-back but now was going to do 'super teach-back' by asking him to bring in all his medicine bottles to show exactly what he takes. The patient brought in a shoebox full of pill bottles. There were medications I hadn't prescribed in over a decade. I asked if he was still taking these. The patient replied, 'Doc, I never told you, but I just don't like swallowing pills.'

My assumption had been that he had been taking these pills for a decade. But for a whole host of reasons, the patient wasn't comfortable telling me that he wasn't swallowing them. The long and short of this is that he's now taking 2 liquid medications and his blood pressure is perfect.

As Schillinger well knows, "there can be an exponential number of reasons why miscommunication happens. There's only one way to know. That is to not assume and explicitly have the person show you, or tell you."



## Strategies, Ideas, and Suggestions: Feedback<sup>5,6</sup>

**Invite people to share their opinions.** When you ask others for feedback on written materials, make it clear that it is about testing your writing and not their reading or comprehension skills. A good way to begin is by saying "will you help me?" Let them know how you plan to use their feedback and perhaps offer to share updated versions.

**Use feedback throughout the writing process.** A great place to start getting feedback is at the beginning of projects. Your intended readers can be really helpful about topics to include. As you write, continue asking for feedback to clarify your message. At the end of the project, ask for feedback again so you know what to do differently next time.

**Know your intended audience.** This includes their learning abilities and information needs. For instance, when writing about a certain medical procedure you could use feedback to learn which topics to address. Beyond explaining what to do, readers may be interested in how much this procedure costs, whether to expect pain, or how long it takes to recover. Then write about that.



**Build feedback into your project plan.** Admittedly, it takes time to get reader feedback. There may also be some costs, such as for focus groups, user testing, or financial incentives. My recommendation is to consider the expense of not doing so. As the subject matter expert and/or medical writer, you are so familiar with the content that you cannot objectively assess whether your words and concepts make sense to others. Matter of fact, I use feedback a lot—even when writing this edition of my book. Yes, feedback is worth the effort.

### **Here are some ways to get feedback:**

**Interview one person at a time.** This not only allows for flexibility in scheduling but also helps when asking opinions from people who may fear embarrassment (perhaps due to their reading skills) or are uncomfortable speaking in front of others.

**Focus groups.** This might be a group of 6 to 8 people who represent the audience in terms of age, literacy, language, culture, and familiarity with the subject matter. Focus groups are often co-led by a trained facilitator who asks questions and a recorder who takes notes. You might want to test your material with more than one focus group. Doing so, you can compare responses. For example, you could test a booklet about clinical services with one group of people who were hospitalized on an emergency basis and another group who had planned admissions.

**Usability (or user) testing.** This is usually a controlled setting in which you observe people actually using your materials. Watch as they complete specific tasks, such as finding specific information on your website. As the tester, you can see which tasks are easy or hard for people to do. Seeing this helps you figure out what needs changing.



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## Chapter 7

# Continuum of Care

### Starting Points

Health care can happen in many settings, at different times, and with almost infinite pairings of patients, caregivers, and providers. In other words, health care today can happen at all stages of what is commonly referred to as the “continuum of care.”

For simplicity’s sake, I divide this continuum into four stages, each with distinct tasks and communication challenges. These can occur in any order or even overlap. I refer to these stages as wellness, access, illness, and self-care.



Consider the  
Continuum  
of Care

Illustration by Mark Tatro, Rotate Graphics



## Strategies, Ideas, and Suggestions

**Wellness.** Wellness includes personal choices that support good health. These choices are often about food and activity. Wellness is also about making decisions such as whether to get screening tests like a routine mammogram or prostate exam. These tests are a way to detect (screen for) disease at an early stage before symptoms show up. They are not the same as diagnostic tests, which are used when someone has a specific cause for concern.

When it comes to wellness, here are two (of many) issues to consider and strategies to try:

**Explain both benefits and risks of routine screening tests.** Screening tests look for early signs of a disease, before any noticeable symptoms. They are used for large segments of the population who are at increased risk, such as people of a certain age, ethnicity, or sex. While it is true that screening tests offer great benefits, there also can be harms such as the risk for overdiagnosis<sup>1</sup> and overtreatment<sup>2</sup>. When talking about these types of tests, make sure to explain clearly not only how they can help but also potential harms.

**Teach how today's decisions might matter later on.** It certainly can be tempting to eat a gooey dessert rather than a piece of fruit. Or to binge on movies rather than go for a walk. In the short term, the easier or more tempting option might not cause harm. But the cumulative effect of such choices could affect long-term health.

You can help by teaching how today's decisions can have long-term consequences. An example is the public service announcements on television from the CDC (Centers for Disease Control and Prevention) about smoking and tobacco use<sup>3</sup>. One of these announcements features a smoker who, after years of smoking, developed cancer that ultimately disfigured her face. This woman's story now, paired with photos of her from years ago, convey an important warning about the lifetime consequences of today's decisions.



## Story from Practice: Promote healthy food choices

Anne Thorndike, MD, MPH is a researcher and physician whose work focuses on preventing cardiometabolic disease. Thorndike worked with a team to learn ways of promoting healthy food choices in real-life settings. One of these studies took place in her hospital's cafeteria<sup>4</sup>. We spoke in 2020<sup>5</sup>.

Thorndike explained that the research team used green, yellow, and red “traffic light” labels to guide employees, patients, and visitors toward healthier food choices. “Green meant that it was the healthiest choice, yellow less healthy, and the messaging for red was that there’s a better choice in yellow or green.”

One takeaway that Thorndike and team learned was that these traffic light labels work. “People do respond to it and we’ve shown this in several studies. They actually change the way that people purchase food,” she said.

**Access.** Patients, perhaps along with family or caregivers, not only need to determine the urgency of a medical problem but also figure out where to go for needed care and how to pay for it. While issues of access may be easier in countries with national health care systems, this can be a significant challenge for patients everywhere.

Here are two examples of ways to help:

**Offer up-to-date information about where to go for care.** Many of us have choices about where to go for care. These can include the primary care provider’s office, a hospital’s emergency department (ED), and nearby urgent care clinics. But how can someone who already is not feeling well make the right choice from all these options? One way to help is by having a “hotline” number to call for triage advice.

A 2013 study<sup>6</sup> examined the relationship between health literacy, access to primary care, and reasons for ED use among adults presenting for emergency care. The authors wrote that “results suggest that ED patients with limited health literacy may require clear communication on why primary care is beneficial to them and support in navigating the health care system to access timely primary care services.”

**Inform patients at increased risk about what to do should problems occur.** I can think of several instances when I was treated for seemingly simple medical problems. But at home hours later, I noticed some concerning symptoms. I was very appreciative of the handout my providers had given me earlier that day that not only listed possible problems but also instructions about what to do should they occur.



## Story from Practice: Navigators help explain health insurance options

Health insurance can be very hard to understand, especially in countries without national health care systems. In the United States, there is a wide array of health insurance plans. To learn more about ways to help the public make sense of these choices, I spoke with Donald Rubin, PhD, who is an emeritus professor of Speech Communication, Language & Literacy Education, and Linguistics at the University of Georgia. We talked in 2014<sup>7</sup>.

Rubin knows that communicating about insurance can be a challenge. He and others worked with local organizations to inform the public about expanded health insurance options offered at the start of the United States' Affordable Care Act (ACA, or Obamacare). "Health insurance is such a complex health issue that we need to bring to bear all the tools and resources that we've developed as health literacy professionals in order to help Americans understand this thing called health insurance and how they can begin to use it," Rubin explained.

Rubin and his team worked closely with community health navigators who are trained to explain health insurance options and encourage people to enroll. "Although there are some excellent print materials out there, many of which do conform to health literacy best practices, and there are excellent materials on the web, a huge number of people need to sit down and have somebody walk them through the process," said Rubin.

**Illness.** There is a lot to communicate when someone is sick. For starters, the provider needs to clearly explain a person's diagnosis (what is wrong) and prognosis (what to expect) and discuss options for treatment and care. Today, communication about these topics might include many people and happen virtually, not just in person.

Here are a few strategies to help:

**Explain diagnosis.** Many conditions are hard to see, especially when they involve internal organs. One way to explain is with pre-drawn anatomic illustrations, adding specifics about that person's medical problem. Other ways to explain a diagnosis are with videos, lifelike plastic models, and of course written information.

**Explain prognosis.** This includes risks and probabilities about what may lie ahead. The hope is that patients and their families will use information about their prognosis to make informed choices about treatment and care.

Stanford School of Medicine's Palliative Care website includes a page called "Tools to Improve the Communicated Prognosis<sup>8</sup>." It highlights four distinct elements of this process: preparation, content, patient's response, and the close. The website defines clear tasks in communicating each element, along with model scripts and a video example of their approach in use.

**Self-care.** The reality is that most health care happens when patients are on their own, without immediate guidance from health professionals. There are many tasks that patients must do, including: making, keeping, and preparing for appointments; taking medications correctly; and following all instructions for self-care. While the hope is that patients can, and will, do all these tasks correctly all the time, that is not always so.

Here are some strategies to clarify what patients need to do, why, and how:

**Explain what patients need to do.** This often includes step-by-step instructions, photos or simple illustrations, hands-on practice, and even models such as of common foods in recommended sized portions.

**Make it as easy as possible for patients to schedule, keep, and prepare for appointments.** Online patient portals seem to be growing in use. The portal I use includes options for same-day symptom screening, paying bills, communicating with doctors, accessing test results, and managing medical appointments. But some people do not have online access or prefer not to use patient portals. Make sure to also offer other options such as phone reminders and written appointment cards.



### Story from practice: Help patients take medication correctly

Taking medication is central to most health care. But it can be hard for patients and caregivers to always do so correctly. Benard Dreyer, MD and Shonna Yin, MD, MSc are pediatricians, researchers, and health literacy advocates. In a 2014 interview<sup>9</sup>, they discussed a common error parents make when measuring liquid medication for their children.

Yin said that many studies show that about half of all parents make errors when dosing liquid medications. She explained that part of the problem comes from different units used when medication instructions are given. Instructions may be given in teaspoons, tablespoons, dropperfuls, and milliliters. As Yin acknowledged, "It isn't a surprise that people can get confused."



Dreyer talked about the risk for significant consequences when parents measure medication incorrectly. These risks include overdoses and underdoses. “Both can be a problem because giving too little medicine, especially with antibiotics, could prolong disease. Obviously, giving too much of a medicine could cause serious side effects,” he said.

To make it easier and safer when giving liquid medication, Yin and Dreyer recommend that providers give instructions in milliliters only, and try not to use spoon-based terms. They both believe that milliliters could be easily accepted by parents across the country, and recent research shows that parents make fewer errors with milliliter-only dosing instructions. Numerous groups have now come out to support the use of milliliter-only, including the FDA and the American Academy of Pediatrics.



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## Chapter 8

# Decisions About Treatment, End-of-Life Choices, or Whether to Participate in Clinical Trials

### Starting Points

Patients, perhaps along with their family members or caregivers, are often asked to make important decisions about many aspects of treatment and care. For instance, it could be to choose between two surgery options, or to decide whether to begin treatment now or monitor symptoms and later make a choice about what, if anything, else to do.

Many times, patients are asked to make clear their wishes for care as they near the end of life. If the patient is too ill or injured to speak for themselves, then hopefully they have named a “health care proxy” (often a family member or close friend) to make decisions and speak with the health care team on their behalf.

Patients or members of the public might also be asked to participate in clinical research trials. These trials help scientists learn about a wide array of patient experiences, as well as ways to prevent health problems or detect diseases. Trials can also help scientists determine the safety and effectiveness of certain medications or medical interventions.



## Strategies, Ideas, and Suggestions: Decisions about treatment

**Engage in shared decision-making.** This is a process in which the doctor or other health care provider presents the patient with treatment options (including medical interventions, active surveillance, or comfort care), outcomes (what is likely to happen), probabilities (chances that these outcomes will occur), and uncertainties (what is unknown or not yet determined). The patient, in turn, shares their values and concerns about potential benefits and risks. Together, they plan a course of action.

**Find out how much patients want to be involved in decision-making.** While many patients want to be actively involved in decision-making, others may look more to doctors, family members, or trusted advisers for guidance. Assess each patient's willingness to participate in this process. As needed and if possible, refer patients to a trained "decision support specialist" such as a nurse or social worker.

**Acknowledge the importance of feelings and values.** Decisions that patients make may be influenced as much by their feelings and values as by data. For example, some patients are uncomfortable with uncertainty and opt for the treatment that has the most assured outcomes. Help patients sort through information and clarify their feelings throughout the decision-making process.

**Help patients make sense of research data.** Part of decision-making is helping patients understand data from clinical trials and research studies. Help them understand how to interpret these results. This includes whether subjects in the study are similar to them in terms of age, sex, race, and diagnosis. It also means discussing ambiguous findings and unanswered research questions.

**Use decision aids and other teaching tools to present information in understandable ways.** As defined by the Ottawa Hospital Research Institute, "patient decision aids are tools that help people become involved in decision making by making explicit the decision that needs to be made, providing information about the options and outcomes, and by clarifying personal values. They are designed to complement, rather than replace, counseling from a health practitioner<sup>1</sup>." Decision aids can include personal assessments, videos, booklets, and other informative or individualized resources.



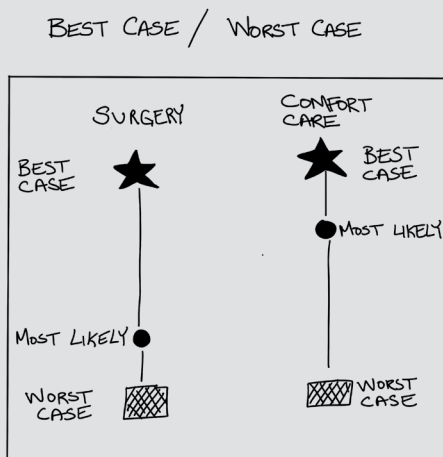
## Story from Practice: Making treatment options clear

There can often be several treatment options for a medical condition. What might be a good choice for one person is not necessarily the same for others. Gretchen Schwarze, MD, MPP is a vascular surgeon and health sciences researcher. She often treats frail, older patients who, along with their families, need to make decisions about whether to have high-risk surgery. In 2017, Schwarze and I talked about how difficult this communication can be<sup>2</sup>.

Schwarze shared the story of a vascular surgeon who was treating a frail older woman for a large aneurysm. "Surgery was going to be a really big deal for this patient," she said. "The surgeon sat down with the patient and her family and said, 'If we do surgery, you have a 50% chance of death. You have a 60% chance of kidney failure and a 90% chance of being on a ventilator after surgery.'"

"The family tried their best to make a reasonable treatment decision based on their understanding of these statistics. They did the math and figured their relative had a 10% chance of being exactly like she was before surgery." Schwarze then added, "But that was never possible nor what the surgeon wanted to convey."

To help in complex situations like these, Schwarze and her colleagues designed a decision-making strategy called "Best Case/Worst Case"<sup>3</sup>. This strategy uses a pen-and-paper diagram along with verbal and written explanations. The physician draws two vertical lines, each representing a treatment option. At the top of each line the physician draws a star representing "best case." At the bottom, a square indicating "worst case." The physician then places a circle high, low, or in the middle of each vertical line, indicating the most likely outcome. Here is an example.



Best Case/Worst Case is a way for patients and their families to clearly see their choices between two options. “It is about telling one story about what it might look like if everything went well and another about what it might look like if things didn’t go well,” said Schwarze.



## Strategies, Ideas, and Suggestions: Decisions about end-of-life choices

Aretha Delight Davis, MD, JD and Angelo Volandes, MD, MPH together create, run, and otherwise make possible ACP Decisions<sup>4</sup>, which is an ever-growing collection of video support tools designed to help patients and families make informed decisions about advance care planning and end-of-life care. Of note, I work as a plain language writer with Delight Davis and Volandes on many of ACP’s patient education materials. In 2017, we spoke about issues related to decisions at the end of life<sup>5</sup>.

**Advance care planning is a process.** Volandes explained that ideally this process includes a series of conversations in which a patient talks about their values and treatment preferences with family members, caregivers, and the health care team. These conversations could include what brings the patient joy and happiness and what they would want if they become too ill to do those things any more.

**Advance care planning is about shared understanding.** The goal is that everyone involved in decisions about a patient’s care have a shared understanding of the patient’s values and goals while also considering their medical status. Advance care planning is a way to honor and be concordant with the patient’s values and wishes, said Delight Davis.

**Advance care planning can be difficult for everyone to discuss.** Volandes acknowledged that this process can be hard for physicians who might not have had training about end-of-life conversations. And, of course, it can be hard for patients and their families. As Delight Davis explained, “Patients and families are not familiar with modern death. People may be blissfully unaware of what the dying process is like and not know the medical interventions that accompany this process may be nothing like what is on television or in the movies.”

**Advance care planning is about life.** “We’re all going to die. It’s part of living. So let us be the authors of our life’s final chapters,” said Delight Davis. “Don’t make this into a downer conversation. It’s about life. It’s about living as well as you can for as long as you can.”



## Story from Practice: PREPARE For Your Care

Rebecca Sudore, MD is a geriatrician, palliative medicine physician, professor, and health services researcher and program director. Sudore co-developed an interactive, easy-to-read advance care planning tool with patients, caregivers, and community members to help people prepare for medical decision making. This tool is called PREPARE for Your Care<sup>6</sup>. We talked about it in 2019<sup>7</sup>.

Sudore explained that advance care planning goes beyond specific “yes or no” choices, such as if a patient would want to be on a ventilator for breathing problems. She said that the advance care planning process includes finding out what is important to someone, helping them discuss their wishes with loved ones and clinicians, and preparing a family member or friend to be their advocate.

PREPARE for Your Care has many resources for patients, families, and community services. These include:

**Advance directives written at a fifth-grade reading level.** These directives not only are easy to read but also have large size lettering and pictures that help describe the text. There also is space on the form for people to note why they made certain choices. These directives are available for free in both English and Spanish, with versions for all states in the United States.

**Videos from patients and families about the advance care planning process.** These not only include people of different races, ethnicities, and genders, but also those making different choices about treatment and care. “We try to balance information so that people don’t feel pressured or swayed. We present stories as a way to help people figure out what’s important to them,” said Sudore.

**Explanatory movies and a toolkit for non-clinicians.** These can be helpful to people working in libraries, churches, or senior centers and have never done advance planning before, explained Sudore.

There have been several large-scale randomized trials looking at the effectiveness of PREPARE for Your Care. In these studies, PREPARE helped 98% of people engage in some form of advance care planning<sup>8,9</sup>. “This definitely seems to work and empower patients,” said Sudore.





## Strategies, Ideas, and Suggestions: Decisions about whether to participate in clinical trials

Sometimes patients or the public are invited to participate in clinical trials. To help everyone involved, Sylvia Baedorf Kassis, MPH and her team created a website called Health Literacy in Clinical Research<sup>10</sup>. In 2020, we spoke about ways to communicate with the public about clinical research trials<sup>11</sup>.

Baedorf Kassis said that researchers should include populations that reflect the people most likely to benefit from the results. She said that there are a lot of different stakeholders in the clinical research environment. They include patients or healthy volunteers deciding whether to be research subjects. There also are those responsible for communicating with patients or the public either directly (in person or by phone) or indirectly (such as with written materials).

In addition, there can be life sciences companies, institutional review boards, investigators, and clinical study teams. Baedorf Kassis said that using health literacy best practices helps everyone involved better understand the research goals and expectations.

Communicating directly with potential participants often starts with explaining the concept of research studies. Once someone informally agrees to participate, they then need to formally consent. This process begins by discussing risks, benefits, and other specifics followed by asking the participant to sign the informed consent document. Baedorf Kassis recommended re-contacting the participants at the end of the study. “Let them know what the study found so they have a sense of ownership and are thanked for their contributions to this research.”



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## Chapter 9

# Document Design

### Starting Points

Printed and online materials not only need to be written clearly and simply, they also should be designed in ways that readers find inviting and appealing. Document design refers to the art of doing that by combining words and images to encourage readers to start, and keep, reading.



### Story from Practice: Emotional responses to text and graphics

Karen Schriver, PhD is an expert on information design and author of the important resource *Dynamics in Document Design: Creating Texts for Readers*<sup>1</sup>.

In a 2009 interview, Schriver highlighted the importance of document design<sup>2</sup>. “Readers can feel respected and valued when two things happen,” she said. “One, when they understand the text; when they actually ‘get’ whatever is being said via words and graphics. The second is when they feel as though the text itself responds to them emotionally.”

“When people look at a text that is confusing, they don’t feel respected because they feel as though they’re not being talked to, just being talked at,” said Schriver. She gave an example of a pamphlet with difficult words, complicated sentences, and paragraphs that went on and on and on.

As Schriver explained, “Good information design considers the reader’s likely emotional response to text and graphics. We know from years of research that reading isn’t just an intellectual cognitive activity. It’s an emotional activity as well.”



## Strategies, Ideas, and Suggestions

**Choose an appropriate font type.** Which font should you use? Many people ask whether it should be a “serif font” with decorative strokes like Times New Roman, or a “sans serif” or “block” font like Arial. I asked Karen Schriver about this. She answered, “If you’re designing on paper, it’s usually a good idea to present your body text using a serif font. When designing for the web, generally speaking it’s a good idea to go with sans-serif fonts because they are cleaner and much easier to see with light projecting behind them.”

**Use an appropriate font size.** Make it a habit to use at least a 12-point font size. This is large enough for most readers to see. When writing for older adults or those with vision problems, you might want to “bump up” to at least a 14-point font size. The standard for large print is 16- to 18-point font.

**Have headings and subheads.** Headings identify key sections, while subheads mark topics within. Both make it easier for readers to find the information that they want and need. For instance, in this chapter there is the heading “Document Design.” Then there are several subheads: “Strategies, Ideas, and Suggestions,” “Story from Practice,” “Cited Sources,” and “Sources to Learn More.” As you can see throughout this book, some elements are differentiated from the rest of the text by indentation, shading, icons, and bold lettering.

**Combine upper- and lower-case letters.** Perhaps you’ve heard to not use all capital letters because this looks like shouting. Honestly, I haven’t a clue whether or not that is true. But there is at least one compelling reason to combine upper- and lower-case letters: lower-case letters offer important visual clues with their varying ascending and descending heights. Let’s say I’m writing about my trip to Africa. Without looking closely, can you recognize these words?

**ELEPHANTS AND GIRAFFES.** It might be hard to figure out these words by shape alone as the outside shape of the same-sized letters is just a simple rectangle.

**Elephants and giraffes.** When the letters “p” and “g” descend (go down), and “l,” “h,” “t,” and “f” ascend (go up), there are visual cues as to the meaning of these words. Add the fact that you already know the context for these words (that I’m writing about my trip to Africa), and you’re even more likely to figure out these words by their shape.

**Justify the left margin.** Line up (justify) the body of your text on the left so that readers can start reading at the same place on each line.

**Maintain “adequate” white space.** But what is adequate? My sassy answer is that you know it when you see it. A more analytic response is that adequate white space means about a 50/50 mix between printed and unprinted areas on each page.

**Use short lists.** As you can see from the design of this book, I’m a fan of lists. But I do urge some restraint. Do not overwhelm readers with too many lists, or too many items within each list. Instead, try to limit lists to no more than 8 items. If you need more items than that, divide the list into subgroups.

For instance, instead of listing 15 types of fruit in one long list, divide it into shorter lists, perhaps like this:

<b>Citrus fruit:</b>	<b>Melons:</b>	<b>Tropical fruit:</b>
Grapefruit	Cantaloupe	Banana
Lemon	Casaba	Mango
Lime	Honeydew	Papaya
Orange	Muskmelon	Pineapple
Tangerine	Watermelon	Pomegranate



### Story from Practice: Information design

Josiah Fisk is founder and president of More Carrot, a firm that combines plain language with information design to create simplified, user-centric documents<sup>3</sup>. We spoke about principles of information design in 2013<sup>4</sup>.

Fisk explained the difference between information design and graphic design. While both use many of the same tools, they do so for different purposes. He explained that graphic design is more about drawing attention, such as by using type, color, or illustrations to convey a document’s feeling. Information design can use many of the same elements, but its purpose is to improve function. “We don’t want people to say, ‘What a nicely-designed form or document.’ We want them to say, ‘It was easier than I thought to fill out that form,’” said Fisk.

Fisk gave examples of ways design can improve the function of health care documents. “It is pretty amazing the number of times when you aren’t sure whether you are supposed to write above the line or below the line,” he said. Fisk recommends using design to make it clear what line to write on or which boxes to

check. Another recommendation is to provide visual cues about how much information is needed, even for mailing addresses. “If there is as much room for the zip code as the whole rest of the address, then a user is not sure what information the form is asking for.”



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## Chapter 10

# Ethics of Simplicity

### Starting Points

In many ways, plain language writers act as translators of scientific and medical information—communicating complicated, rapidly-changing, numbers-based, and often-ambiguous health information in a manner that is sufficiently clear and simple for most readers to understand.

This task is more difficult than simply replacing multisyllabic terms with one- and two-syllable words. As I know from many years of experience as a plain language writer, there are often dilemmas to resolve and issues to consider. I’ve long referred to these as the “ethics of simplicity.”



### Story from Practice: Ethical dilemmas and challenges

Andrea Gwosdow, PhD is president of Gwosdow Associates Science Consultants. She is also a medical-writing colleague. Together, we led an “Ethics of Simplicity” workshop for the American Medical Writers Association.

To prepare for this workshop, Gwosdow and I polled medical writers about their ethical dilemmas and challenges when writing health materials for consumers. They said that their concerns include:

- Am I including too much information and overloading readers?
- Am I including too little information and omitting important facts and statistics?
- Is the tone appealing and respectful? Or does it sound condescending?

- Are the statistics simple enough for readers to understand, yet complete enough for them to make reasoned choices?
- Are my sources credible and unbiased?
- What is the best way to explain complicated medical concepts when even scientists and physicians disagree?

Gwosdow and I admit that we don't have answers to these and many other ethical questions. But we do believe that it is important for all medical writers to weigh the implications of such choices throughout the writing process.



## Strategies, Ideas, and Suggestions<sup>1,2</sup>

**Be clear about why you are writing this document.** A good way to identify project goals is by asking yourself what readers should know, do, and feel after reading this document. Use these goals to determine what is essential “need-to-know” information that must be included and what is “nice-to-know” background information that can be deleted.

When writing about diabetes, for example, need-to-know information may be about nutrition and exercise, while nice-to-know information can be in-depth details about the digestive process. Of course, a brief explanation about this physiology can help readers understand why exercise and proper nutrition are important.

**Create a writing team.** This team can help weigh choices and determine what information to include or omit. At a minimum, your writing team should include: subject-matter expert(s) such as scientists or clinicians to identify key points and verify accuracy; a plain language writer who not only knows how to write clearly but also is an unceasing advocate for the readers; and one or more readers who represent the intended audience. Opinions from experts and readers are equally important. Your job as a writer is to present information in ways that satisfy both needs.

**Use plain language.** Using plain language means putting information into context with examples, stories, or metaphors, and then using good design to make the document look inviting and be easy to read. Plain language also means using words people know or defining ones they must learn. Here are examples of dilemmas when it comes to words and numbers:

**Sometimes even seemingly “simple” words can cause problems.** For example, the word “suggest” can easily be misinterpreted. Even though scientists know that the phrase “study data suggest” refers to preliminary

data, lay readers may conclude that the term indicates more certainty. You can help by putting words like “may,” “might,” and “could” into context and clarifying terms that might be misunderstood.

**Numbers, especially very large ones, can pose concerns** because they are hard for most people to comprehend. When talking about statistics, for example, it’s generally easier for people to understand “about 1 out of every 3 people” rather than “3,289 out of 10,000 people.” Carefully designed graphics such as tables or pie charts can also help make statistics clear. One way to make tables easier is by having just two or three columns of the most pertinent information. When appropriate, round numbers out to no more than one decimal place such as “26.2” instead of “26.215.”

**Research your references.** Where information comes from is as important as how it is presented. Use the best data available to help readers make informed choices. This often means doing your own literature search, starting with articles in peer-reviewed journals. Consider supplementing those with information from “grey literature” (non-peer-reviewed materials) like magazines, newsletters, and conference proceedings. But in these times of rampant misinformation and disinformation, it is important to verify that the information is accurate, relevant, and up-to-date.

**Alert readers to possible uncertainty and ambiguity.** Another potential concern is the fact that medical information is constantly changing. Even experts may disagree about what is correct. For instance, should people eat a lot of high-fat proteins or more low-fat grains? Ambiguity needs to be both acknowledged and addressed so that your readers are not misled. One way is to preface information by stating that scientists continue to study and learn, letting readers know that what seems correct today may change tomorrow.



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## Chapter 11

# Forms and Other Reading-To-Do Documents

### Starting Points

Health care is filled with forms and other “reading-to-do” documents. I use this term in reference to written materials that require readers to perform text-based tasks such as filling in numbers, rating satisfaction, checking boxes, and signing consent. To accomplish these tasks, readers not only need to comprehend the text but also locate, recall, and enter information from other parts of the same document, from outside materials, or from memory. This is difficult for many people to do.

The National Assessment of Adult Literacy (NAAL)<sup>1</sup> assessed English language literacy skills of American adults. The most recent was in 2003. In years since, the Program for the International Assessment of Adult Competencies (PIAAC)<sup>2</sup> has measured adults’ proficiency in literacy, numeracy, and problem-solving. It has been used in over 30 countries and economies.

While similar, NAAL and PIAAC assessed different skills. Although it is older, I find some of the NAAL information still relevant for thinking about forms and reading-to-do. It identified three types of literacy:

**Prose literacy.** Knowledge and skills needed for searching, comprehending, and using continuous text. Examples include newspapers and brochures.

**Quantitative literacy.** Knowledge and skills needed for making calculations and using numbers embedded in print. An example is figuring out interest payments on a loan plan.

**Document literacy.** Knowledge and skills needed to search, comprehend, and use noncontinuous text in various formats. Examples include maps, tables, and drug labels.

NAAL results showed that many adults had difficulty with document literacy. Based on newer PIAAC data and personal accounts, there is no reason to assume that this finding has significantly changed.



### Story from Practice: PIN can be troublesome, too

One reason that documents are sometimes so difficult is that they assume readers understand acronyms and jargon. But this assumption can be incorrect. I was volunteering as a literacy tutor, working with an Egyptian woman new to English. Since we met at the library and because she had young children, I suggested that for one of our lessons she complete the application to get a library card.

We spent the entire session working on this form, which, until that point, I thought was clearly written and easy to complete. I was caught by surprise at how baffled this woman seemed when asked to write her PIN. Unfamiliar with this acronym for “personal identification number,” she wondered why she needed a safety pin to get a library card.

We both learned from this experience. I gained a greater appreciation of how even seemingly simple terms like PIN can be misunderstood. She learned how to complete the form and get a library card. Best of all, her children then had access to a vast collection of library books.



### Strategies, Ideas, and Suggestions<sup>3,4</sup>

**Know your audience.** Know generally, not specifically, about the people who will be using your form. This means demographics including age range, literacy levels, and languages spoken. It also means learning whether the audience is likely to have physical or cognitive limitations that might impair their ability to see, comprehend, and remember. Be aware, as well, of your readers’ fund of knowledge and make sure they are familiar with the types of information needed to complete this form.

**Limit your objectives.** When writing forms and other reading-to-do documents, ask people only for the information that you need now or will need soon. For example, don't ask people for their children's ages just because you might later need this data. Instead, ask only when you really need to know.

**Write in a friendly tone.** Let readers know at the beginning of your document why you need certain information. For example, start with "We take pride in patient care at XYZ Medical Center. Please fill out this short survey and let us know how we are doing."

**As appropriate, use a conversational tone.** This includes referring to readers as "you" and the organization as "we." Convey a friendly tone but don't get bogged down with too many pleasantries. Sometimes an abundance of "please" and "thank you" statements can obscure the form's intent.

**Use consistent wording.** Make sure that the document's labels, questions, and instructions ("given information") match its items and answers ("requested information"). Do not, for example, say "Age Group" in one place and "How old are you?" in another. Instead, you might keep the first heading and then ask, "What is your age?"

**Make clear what readers need to do.** Reading-to-do documents ask readers to take some sort of action. Here are some ways to make these tasks easier:

**Show, not just tell, how to take the needed actions.** For example, show an answer that is correctly circled rather than underlined, or a date written as mm/dd/yyyy.

**Be specific in your instructions,** such as stating whether to "check one box" or "check all that apply."

**Ask for information in a consistent way.** For example, ask people only for yes/no responses and not also to complete fill-in-the-blank statements and rate items on a 1-5 scale.

**Use accessible design.** Make sure that your documents are easy for readers to see and complete. This means having a 12-point font or larger, sufficiently large spaces for people to write answers, and generous white space so that the print doesn't look crowded. Please don't squeeze everything onto one page when two are really needed.

**Provide a comfortable environment.** This includes allowing sufficient time for people to read and adequate lighting for them to see. Encourage



staff to offer assistance to those who ask for, or seem to want, help. This can be done in a respectful way, such as saying, “Many people find these forms hard to fill out. Would you like me to help?”

**Test your document.** Make sure your documents are not only readable but also usable. Here are some ways:

**Assume the role of the reader** and ask yourself, “Is this difficult reading?” and “How complex are the tasks that readers are asked to do?”

**Try the form yourself** and make sure that you can complete it within the given time, in the appropriate space, and with the needed information.

**Test the form with intended readers.** Notice where they have difficulty and ask for their suggestions about how to improve. Consider their feedback when writing your next draft.



### Story from Practice: Patient-oriented discharge summaries

Shoshana Hahn-Goldberg, PhD is project lead at the University Health Network’s OpenLab in Canada, where she works with a multidisciplinary team to create solutions to issues in the health care system. She manages the Patient-Oriented Discharge Summaries (PODS) project<sup>5</sup> that is used at many Canadian hospitals. We spoke about this in 2020<sup>6</sup>.

Hahn-Goldberg and others in her lab met with patients, health care providers, and patient education professionals to discuss the patient experience. One problem they identified was the transition when a patient is discharged from the hospital to go home. As she explained, “People are overwhelmed. They’re sick. They’ve gotten so much information. A lot of it hasn’t been written down, yet they’re expected to remember it. When they get home they’re still not fully well. But they and their family are expected to take over their care.”

To help make discharge information more useful, OpenLab began with the philosophy of extreme user design. “It’s where you work with the people most likely to be affected by the problem or the solution that you’re going to create,” Hahn-Goldberg said.

For this discharge form, the team identified five key content areas: Medications I need to take; How I might expect to feel and what to do; Appointments I need to go to; Changes to my routine; and Where to go for more information.

Hahn-Goldberg said that they built on health literacy and document design best practices. This not only included using plain language but also having check-boxes for actions (such as scheduling follow-up appointments) and pictures or symbols to help those with language barriers or difficulty reading. They also allowed space for patients to write questions or add information from their health care providers.

Hahn-Goldberg encourages others to adapt this form for their own use.



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## Chapter 12

# General Public: Traditional Media

### Starting Points

Unlike the “old days” when most people learned about health from their doctors, today the general public is nearly bombarded with health and medical stories on television, radio, and in newspapers or other traditional media. In addition, people are no doubt flooded with health messages from many forms of social media.

While this groundswell of information can bring beneficial “teaching moments” for patients and their providers, it also creates some challenges. For instance, patients may panic after reading a newspaper article about someone who has the same diagnosis as their own. Or have unrealistic expectations about a certain treatment and insist they need a particular drug after watching direct-to-consumer (DTC) advertising on television.



### Strategies, Ideas, and Suggestions

Lisa M. Jones, MD, FACOG, knows a lot about the interplay of medicine and media. She is a gynecologist who also interned with the medical division of a major television broadcaster. In 2007, we spoke about ways that health professionals can help patients make sense of information from the media<sup>1</sup>. Jones offered these suggestions:

**Pay attention to the news.** Jones recommended that providers stay up to date with health reports by periodically checking news throughout the day. She explained that media stories are often aired the same day that studies are published. This happens because medical journals might send articles to news outlets in advance of the publication date but “embargo” this information by requesting it not be shared for a defined amount of time. In practice, this means that patients may see media stories on medical or health findings before providers have had time to review the research.

**Pay attention to the ads.** Direct-to-consumer (DTC) advertising about medication is another example of how the popular media can affect clinical practice. Help your patients appreciate the influence of ads. An example is an image of a cute teddy bear or sleeping baby on a label of children’s medication to subtly encourage parents to buy.

**Pay attention to the shows.** In addition to news stories and advertising, television shows can impact patients’ perceptions. Many of these create unrealistic expectations about access to care. Examples include shows in which the same doctor gives a diagnosis, does all scans and tests, and also performs surgery. Or shows that imply that there is always a quick and direct line from symptoms to diagnosis.

**Pay attention to spikes in phone calls.** In most medical offices, front-desk staff and nurses are the first to speak with patients. Jones asks that everyone working in her office be aware of spikes in the number of calls about certain topics or specific health stories. In anticipation of such situations, Jones recommended a standard office response to not only reassure patients but also make a follow-up plan. This might be something like, “Yes, the study came out yesterday and we know it is in the news. Dr. Jones is confident that [something the doctor thinks patients should know]. Let us make an appointment for you to speak with her after she reviews the article.”



## Story from Practice: Children and the media

Dina Borzekowski, EdD is an international expert on children, media, and health. Her research explores how children and adolescents use media, as well as media's effect on their health and wellbeing. We spoke about this work in 2016<sup>2</sup>.

Borzekowski said that media has a presence for most children worldwide. Their media use not only includes watching television but also accessing technology on their parent's phones. Media is also in the environment, such as advertisements on billboards and logos on kids' shirts and backpacks.

She then added, "Clearly, I don't think all media use is bad." Borzekowski shared how she and others use the media to encourage healthy eating practices and physical activity. This included her work on international projects with Sesame Workshop, the producers of "Sesame Street."

Borzekowski said that in certain countries, "Sesame Street" takes on topics in addition to literacy and numeracy. She shared an example from a project in India, Bangladesh, and Nigeria. They created a Muppet named Raya who conveys information about health and hygiene. "Raya is a very strong advocate for wearing her sandals whenever she's outside of her house. She always makes sure to wash her hands after using the latrine."

These days, Borzekowski is working with Ubongo, a media production company based out of Dar es Salaam, Tanzania. She advises how to reach children in sub-Saharan Africa with educational media, delivered by print, radio, video, and text messaging.

She has also put forth a new concept regarding media in the lives of children and adolescents called "constancy." Youth around the world are never without their technology, said Borzekowski.



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## Chapter 13

# General Public: Public Health Concerns

### Starting Points

In some ways, communicating to the general public about health is easier than ever. There are multiple channels and numerous formats to convey information about all aspects of wellness, illness, safety, and risk.

But communication today can also be much harder. The public has what seems like infinite options for accessing health information including television, radio, newspapers, websites, social media, and word-of-mouth. It certainly can feel overwhelming and be confusing.

There are many aspects to consider when communicating about general health concerns. The COVID-19 pandemic highlighted several of these. Admittedly, some of the stories below focus specifically on the pandemic. These lessons learned, however, can apply to many situations when communicating with the public about health.



### Strategies, Ideas, and Suggestions

**Consider differing priorities.** Glen Nowak, PhD is a professor, program director, author, and consultant on topics that include infectious diseases, immunizations, public health programs, and public health research. In 2020, we spoke about the challenges of communicating complex public health messages<sup>1</sup>.



Nowak addressed why communicating about a public health emergency such as COVID-19 can be so difficult. One factor is that segments of the population may have different priorities. He shared these examples:

**In public health,** the top priority is to prevent the spread or transmission of a health condition.

**In government,** the priority may be more about the economic impact.

**The public** may be looking at information in consideration of their own priorities. They might ask, “Is it worth changing my life or not doing the things that I want to do?” This often has to do with a person’s tolerance for risk. Nowak explained that those who are risk-averse may interpret health recommendations one way and those who are risk-tolerant may take it another way.

To help, Nowak advised, “Look at the world through the eyes of your audience or the individuals that you’re trying to communicate with. What are their priorities, beliefs, concerns, and questions?” Then tailor your information to address those.

**Improve vaccine literacy.** Scott Ratzan, MD, MPA, MA has three decades of pioneering accomplishments in health literacy, health communication, and strategic diplomacy. Ratzan is now taking on the challenge to improve vaccine literacy. We spoke about this in 2019<sup>2</sup>.

Ratzan acknowledged that inconsistent terminology is one of several problems when communicating about vaccines. He shared an example of five different terms with similar meanings: “vaccines,” “vaccinations,” “immunization,” “shots,” and “jabs.”

He said that another problem is that some words and terms can mean something specific to scientists and clinicians but perhaps not be understood by the public in the same way. Ratzan gave the example of the public health term “herd immunity,” which means that a large portion of the community has become immune to a disease. But, Ratzan said, someone in the public who is unfamiliar with this term might assume it means “being heard,” as in “I’m listening to you.”

Ratzan recommended defining important words that the public needs to know and being equally clear about what people should do, whether as individuals, parents, siblings, or health professionals.

**Communicate about uncertainty.** Paul Han, MD, MA, MPH is an internal medicine and palliative care physician. He also is a scientist whose research focuses on understanding and improving the communication of uncertainty in health care. We spoke about this in 2021<sup>3</sup>.

Han defined uncertainty as “a conscious awareness of our ignorance.” Or more simply stated, “when we know that we don’t know something.” Uncertainty can feel uncomfortable, Han acknowledged. “There’s a very deep human fear of the unknown. Any time we’re reminded of what we don’t know, that’s a very aversive state. It makes us feel at risk, vulnerable, and insecure. It prevents us from making decisions and, in that sense, we may feel paralyzed.”

Han also described an upside to uncertainty. “It can help us face life with the appropriate amount of caution and prevent us from being overconfident or excessively certain.” And as Han knows from caring for patients in palliative medicine, uncertainty can sometimes be a source of hope and possibility.

Han offered these tips:

**Acknowledge what’s uncertain.** One way is to say, “We don’t know everything right now, but here’s the best of what we do know.” Han said that even a simple admission that we don’t know is important.

**Admit that uncertainty is normal and an expected state of affairs.** This might be phrased as “We’re still waiting for evidence but our best evidence to date shows that \_\_\_\_\_. We will update this as more studies come in or we obtain more or better evidence.”

**Set appropriate expectations.** This includes what we know, what we do not know, and when we will know more. When it comes to new health information, Han says that it helps to explain that uncertainty is not a flaw but rather the way this system is supposed to work.

**Explain truths, confront misinformation.** While there often are a range of opinions and beliefs about many public health topics, COVID-19 communication seems extra difficult. People have passionate feelings and deeply-held beliefs that often conflict, not only with each other but also with science and traditional medical advice. For example, these might be about the origin of the virus, who is at most risk, and ways to deal with symptoms.

The challenge for public health is to explain truths and confront misinformation in ways that the public can understand and will accept. Scientists, clinicians, journalists, government officials, and many others are working hard to figure out effective ways to do so.



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## Chapter 14

# Health Equity in the Context of Health Literacy

### Starting Points

As defined by the Robert Wood Johnson Foundation, “Health equity means that everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care<sup>1</sup>.”

Health literacy is about communicating health information in ways that your intended audience can understand, relate to, and use to make decisions or take needed action. To do so in an equitable way, consider not only the information itself but also the lived experiences and realities of those receiving this information.



### Story from Practice: Intersection of health literacy and health equity

Janet Ohene-Frempong, MS and I share a long-time commitment to health literacy. We are the same age and have comparable professional backgrounds. Yet we have differences. A notable one is that Ohene-Frempong is a Black woman and I am white. Our lived experiences shape our views about health and equity in deep and profound ways. Ohene-Frempong and I spoke about this in 2020<sup>2</sup>.

Ohene-Frempong framed health literacy as “communicating health messages in ways that give everyone—individuals, families, and communities—the same

chance to stay alive and live as well as possible. It's about equitable access to care and equitable treatment once you get in."

She said that doing so means considering a person's level of basic literacy and science literacy along with their situational realities such as housing, transportation, income, and access to food. Ohene-Frempong said that it's also important to take into account factors such as race, religion, and views about sexuality. "Be open to otherness and other people's humanity."

Ohene-Frempong strongly recommended not judging the other person's ability to control certain situations or behaviors. She offered this advice: "If you have a sense of where someone is living, what somebody is having to do, how many jobs they have to take on in order to make a living, how many kids they have to manage and all of those kinds of things, it sort of brings you down off of your high horse and onto the ground with regular people who are doing their best to stay alive and live as well as possible."



## Strategies, Ideas, and Suggestions from diverse perspectives

One of my many joys is speaking with people who candidly discuss important aspects of their lives and share ways to communicate about health in informative, actionable, and relatable ways.

Below are excerpts from 3 episodes of my podcast series, Health Literacy Out Loud. Admittedly, these do not cover the vast range of human experience. Rather, they are intended as a small sampling of what to consider when it comes to health literacy and health equity.

**LGBTQIA+.** Jaime Collins and I spoke in 2021<sup>3</sup>. Collins said that it was through a lifelong journey of self-discovery that she learned and unlearned the societal dictates that, for years, kept her imprisoned in a gender that wasn't hers. At 52 years old, Collins came out as transgender.

Collins explained the acronym LGBTQIA+: LGBT stands for lesbian, gay, bisexual, and transgender; Q is sometimes added for queer or questioning; I stands for intersex; and A for asexual. Collins said that a plus sign (+) is often added to indicate other possibilities for sexual orientation or gender identity. This sign can also refer to allies who help tell the story of those who are LGBTQIA.

Collins talked about bias, stigma, and discrimination that LGBTQIA people often experience. She said this often begins with the problematic concept of "gender binary." Collins explained that this postulates that there are only two

genders—man and woman—and that these are biologically determined at or before birth. Gender is also about how a person is supposed to act because of their sex<sup>4</sup>.

Collins offered ways to work toward equity in health care:

**Create a welcoming environment.** This can include visual indicators such as a sticker, sign, or banner with a rainbow flag. “My community will instantly recognize that this indicates a safe place.”

**Establish trust.** When meeting for the first time with a patient of ambiguous gender, one way to set the stage for respectful communication is by perhaps saying, “My pronouns are she/her. What are your pronouns?” Collins said that doing so normalizes this offering of your own pronouns while asking about the patient’s.

**Review your organization’s forms,** including for intake and registration. They may have just two options for sex, male and female. Collins said that this can make it feel like “we’re erased from the population if we have to check just one or the other.”

**Have space to write alternative names.** “If I change my gender, I’m likely to change my name,” said Collins. “If I was originally named Bob and now I’m Sandra, when the nurse calls me in and asks for Bob I have to stand up dressed as a woman. That’s problematic. That is sort of outing somebody in a very public environment.”

**Justice-involved individuals.** David Young is a professor and community health specialist whose work involves improving the health and well-being of vulnerable, at-risk, marginalized, and hard-to-reach populations. This includes those who are incarcerated. Young and I spoke in 2018<sup>5</sup>.

Young uses the term “justice-involved individuals.” He said that this term was recently coined by the United States government to describe people who are housed in secure facilities like a jail or a prison. This term also refers to those under community supervision, including pre-trial waiting, probation, parole, pre-release, or wearing an ankle bracelet with location tracking.

Young’s work often focuses on health literacy and health insurance literacy programs to help a person’s re-entry to the community. He said that this is important to address, as many in the justice-involved population have diabetes, heart disease, hypertension, mental illness, substance use disorder, or other chronic health conditions.



To help, Young created curricula for classes about health literacy and health insurance literacy. The goal is to improve a person's self-care and skills. Young hopes that these classes will become widely adopted. He suggested these ways to help:

**Work with jails and prisons to have someone serve as the equivalent of a hospital discharge planner.** Young said that this planner can help “returning citizens” (those going back to the community) learn about local health centers and ways to get needed medication.

**Contact your local detention center and ask about available health education programs.** “Talk to the correctional health nurse or whoever is doing correctional health and ask, ‘Is there a health literacy program here? Would there be interest in having one for inmates who want to learn about health literacy?’” Young knows from experience how important these programs are and how much they can help.

**People experiencing homelessness.** Samantha Wood was a case manager at a multi-resource day shelter for people who are experiencing homelessness when she spoke in 2019<sup>6</sup>.

Wood described what it can be like to be homeless. “Being homeless is not a fun experience by any means. It’s highly stressful and traumatic. You are constantly worrying about survival, where to eat, where to sleep, how to get clothing on your back, and safety.” She added, “It’s very tough, not just physically but also mentally. It’s not a life that a lot of people can handle.”

There can be many reasons why someone is homeless. Wood explained that it often has to do with a lack of human relationships. She said that a person might not have a backup plan if they lose their job or have a major health crisis. “I’d say that the number one reason for homelessness is just lack of having a social network, lack of having human relationships that you can fall back on in dire need.”

Being homeless not only can be a very emotional time in a person’s life but also weigh on them physically. “There’s a statistic that if you’re homeless and you’re in your 50s, you have the same or similar health issues as an 80-year-old. It can age you drastically, faster than the general population,” Wood said. She offered some recommendations:

**Understand why someone might not follow medical advice.** Wood shared an example of someone who has a diagnosis of diabetes and eats at a soup kitchen. She said that soup kitchens often have very limited budgets. Spaghetti is sometimes that day’s only food option. “It’s not like a

person who is homeless can run out and get a salad or something with less sugar or carbs. This is your meal for the day.”

**Consider alternatives for care.** Some cities and towns have mobile clinics staffed with a social worker, psychologist, doctor, nurse, and nutritionist. They might meet people now living in abandoned malls, campsites, homeless shelters, or other places. “People are often more receptive when they’re able to meet with doctors or a mental health professional who is coming to them versus having to go to a place that’s very scary,” said Wood.

**Have a friendly demeanor.** There’s a lot of stigma attached to being homeless, acknowledged Wood. She said that having a “friendly face” and establishing a human connection goes a long way. “I’ve learned in my work that nothing else matters if someone doesn’t trust you or feel you have their self-interest at heart. They will not follow through with anything if they don’t feel like you truly, genuinely care.”



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## Chapter 15

# Humor and Healing

### Starting Points

Health care is admittedly serious business. While there are many conversations about life-and-death issues that cannot and should not be taken lightly, there also are occasions when a dose of humor can help build rapport, facilitate learning, and improve understanding. Indeed, humor is a powerful tool that providers can use to enhance communication and demonstrate compassion and humanity.

Izzy Gesell knows a lot about the healing power of humor and play. He sees the value of humor in all his work, whether as a special education teacher, a stand-up comic, or an organizational consultant. We spoke in 2010<sup>1</sup>. “Humor is not always about being funny. It’s about seeing the world from the same perspective as someone else,” Gesell explained. He said that people tend to feel more connected and less alone when laughing with others. “Even if you are not naturally funny, there is room to have joy and fun in our lives.”



### Strategies, Ideas, and Suggestions<sup>1,2</sup>

**Gauge the other person’s sense of humor.** Humor includes jokes, riddles, word play, visual gags, and silly objects or cartoons. Consider the other person’s learning style, age, culture, and gender when choosing which, if any, type of humor to use. One way to gauge humor is by noting how the person reacts to funny pictures in the room or silly pins you are wearing. Try also to notice the other person’s style, such as whether they enjoy visual cartoons or prefer word play such as puns and quips. All of these things can serve as signposts about where you can go with this person in terms of humor.

**Show humor.** If you're not comfortable telling jokes or being silly, you can show humor in quieter ways. For example, in your waiting room you might place amusing photos on the wall or display magazines with great cartoons. If your dress code permits, you might show your sense of humor by what you wear, such as colorful scarves or bow ties, silly pins, and doodads on your stethoscope. In print, too, you can include a dose of humor with clever illustrations or ridiculous examples.

**Bridge from humor to teaching.** When teaching new concepts or treatment techniques, you might want to use humor in your introduction or as a way of keeping people interested and engaged. For example, you might heighten teenagers' interest in proper nutrition by first showing them a special "food chart for teens." When the teens see refined sugar, fat, caffeine, and salt listed as the four major food groups, they can laugh at how ridiculous this diet is and be more receptive to learning about healthy foods.

**If in doubt, don't say it.** Humor should be used in small doses and not detract from treatment and care. Certainly there are times when humor is not appropriate, such as when people hear bad news, are angry, or are struggling emotionally. People may need to cry before they can laugh.

**Recover when humor backfires.** Despite good planning and sensitivity, sometimes humor backfires and is not appropriate or appreciated. If your attempts at being funny fall flat, quickly apologize and let the other person know that you are not trying to be hurtful. In turn, when someone tells you a joke that you find offensive, don't overreact. You might say something like "that's a creative way of looking at things" and then quickly change the subject.



### Story from Practice:

#### Humor connects in personal and positive ways

Karyn Lynn Buxman, RN, MS, is recognized for her expertise in applied and therapeutic humor. She not only was a nurse and is a humorist, but also published the *Journal of Nursing Jocularity*.

Buxman and I spoke about humor in health care and she shared many stories. One that particularly resonated with me was about when she worked as a home health care nurse, caring for a woman with terminal cancer. Buxman visited this family each week. Obviously, the patient and her family appreciated these visits, as they wanted to give Buxman a present.

When asked what she would like as a gift, Buxman said she would enjoy hearing a funny story. So the next week, the woman and her husband told Buxman something amusing that their young granddaughter just said. The following week they shared another anecdote. And even as the woman's health declined, every week this family found something lighthearted to share.

To me, the lesson of this story is that humor is a wonderful tool to connect people in personal and positive ways, even during stressful and sad times.



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## Chapter 16

# Interpreters and Translators

### Starting Points

Patients need to be knowledgeable about health problems affecting their lives. It often is a challenge for providers to communicate this information clearly. This can be even more difficult when patients and providers lack a common language. Language gaps like these are increasingly common. In 2015–2019, 21.6% of the U.S. population who were 5 years and older spoke a language other than English at home<sup>1</sup>.

Interpreters and translators help bridge language gaps. Interpreters convert the spoken word from one language into another, such as from English to Hindi or from spoken English to American Sign Language (ASL), which is used by many people in the Deaf community. Translators do essentially the same, but with the written word. This can include translating medical instructions, patient's rights, informed consent documents, bills and other financial information, and signs or maps to help newcomers find their way in unfamiliar places.



### Strategies, Ideas, and Suggestions: Working with interpreters<sup>2-5</sup>

**Professional medical interpreters** are the best source of help. They not only are trained in medical vocabulary but are also instructed in how to maintain neutrality, adhere to confidentiality, and not impose personal views. When onsite-trained medical interpreters are not available, organizations might engage over-the-phone interpretation services like Language Line Solutions<sup>6</sup>.

There may be times when providers seek language help from bilingual volunteers, perhaps staff members or the patient's family. But this can lead to problems, such as if an untrained interpreter inadvertently misinterprets a term, interjects their opinion, or chooses not to interpret something they find awkward or culturally unacceptable.

Another concern is about violation of privacy and confidentiality. Children, especially, should not interpret for their parents or other family members, as doing so can place them in the midst of conversations they shouldn't be a part of.

**Help patients feel welcome.** When you do not share a common language, you can create a feeling of welcome by signing "hello" in ASL to someone who is Deaf or greeting a patient in their native language. Even if your efforts are somewhat amiss, it is evident that you cared enough to try.

**Allow sufficient time.** Conversations may take two to three times longer when using interpreters. Ideally, allow sufficient time in your schedule to meet briefly with an interpreter before and after speaking with the patient.

**Look at, and speak directly to, the patient and not the interpreter.** You not only show respect this way but also can notice a patient's nonverbal cues. When working with an ASL interpreter, the interpreter should sit a little behind and to the side of the health provider. This way, the patient can see both the provider and interpreter in the same visual field. The provider, in turn, can listen to the interpreter while looking directly at the patient.

**Provide tools with translated basic phrases.** There inevitably will be times when you need to communicate with non-English-speaking patients and a qualified interpreter is not available. In these instances, cards or electronic apps with translated phrases and simple visuals might be helpful. They might ask basic questions like, "Are you hungry?" or "Are you in pain?" and offer a choice of answers including "Yes," "No," and "I don't know." To use these tools, however, patients must be able to read in their native language and the phrases must be accurately translated.

**Communicate your message in alternative ways.** This could be by making simple drawings such as about how many pills to take at certain times. Or using an anatomic model to show which part of the body is causing the patient's pain. When possible, also offer audio, video, and written health information in that person's language.

**Appreciate differences in body language.** Beyond words, some gestures are not universally understood. While feelings of anger and happiness may look

alike around the world, even “yes” and “no” are sometimes communicated in different ways. In the United States for example, it is assumed that a nod means “yes,” while in other languages, a nod may simply mean “I hear what you said.”

**Notice signs of difficulty.** Regardless of language differences, it is the health provider’s responsibility to make sure that medical information is communicated accurately. If you sense that there is a problem, such as lengthy conversations between the interpreter and patient and only one-word answers to you, withdraw from the situation and speak privately with the interpreter to make sure the message is communicated correctly.

**Verify understanding.** Just as when communicating in English, ask patients to tell you, via interpreters, how they understand information and instructions. Ask open-ended questions like “How would you take this medicine?” rather than yes-no ones such as “Do you understand what to do?”



### Story from Practice: Serving as an interpreter and cultural broker

Wilma Alvarado-Little, MA, MSW focuses on health equity from a linguistic and cultural perspective. Her experience includes work in public policy, research, health literacy, and prevention of health disparities. She also is a certified health care interpreter. We spoke in 2018<sup>7</sup>.

Alvarado-Little acknowledged that there are many challenges when communicating about health. “Health care is complicated even in English,” she said. “When we add the cultural and linguistic component, it becomes even more interesting.”

She shared an example of interpreting for a patient about to have a test for gastrointestinal concerns. The health care provider told the patient that she needed to drink a special liquid for a contrast. Alvarado-Little interpreted this in the patient’s language. The patient then asked, “If I drink this, is it going to address my stomach problem?” The provider answered, “Yes, it’s going to help.”

“Based on my code of ethics, I interpret everything that hits my ears,” said Alvarado-Little. “However, the patient was thinking that this special liquid was going to help with her loose bowel movements. But that wasn’t what the contrast was for. It was to prepare for an imaging test rather than be a treatment.”

Noticing that the health care provider was not addressing what the patient really wanted to know, Alvarado-Little then served as a cultural broker by saying to the provider, “Please explain a little bit more about the purpose of the contrast.” Doing so helped clarify the communication.



## Strategies, Ideas, and Suggestions: Working with translators

**Develop and test materials with intended readers.** Translated materials, like all forms of communication, must be presented in ways readers can understand and relate to. One of the best ways to accomplish this is by working collaboratively with those who represent the intended audience. This includes working together to develop ideas, decide about words and illustrations, and test drafts all along the way.

**Adapt for linguistic and cultural differences.** Rather than insist on a literal (word-for-word) translation, work with a professional translator or community team to make needed adaptations for linguistic and cultural differences. Confirm that the translated document is accurate by asking others to check whether this version is correct. Also make sure that the typist is familiar with the language being used. Even well-translated documents can lose their meaning when important accent marks are omitted or misplaced.

**Inform patients about translations.** I've seen many health care documents with statements like, "Please let us know if you need this booklet in [a specific] language." Ironically, sometimes these statements are only in English. Make sure to also translate those statements into the language of your readers.

**Decide whether to put two languages in one document.** Sometimes there are requests to put two languages in the same document. This may mean having one language at the top of a page and the other language on the bottom, or one language upside-down from the other. While these layouts may work well for readers, they can present design challenges. For example, English is a tighter language than most. This means that it takes up less space than a language like Spanish or German, in which text tends to be about 30 percent longer than in English<sup>8</sup>. As a result, text may look crowded with two languages on the same page.

**Use meaningful examples and illustrations.** Translated documents usually include more than just words. Make sure that the examples and illustrations you use are consistent with the culture, age, and interests of your readers. For example, when translating a nutrition brochure you might choose whether to mention tacos, egg rolls, crepes, or blintzes.



## Story from Practice: Translating text from one language to another

Lise Anne Boissonneault lives in Northern Ontario, Canada. She is fluent in both French and English, and has worked for many years as a language instructor and health care translator. In 2015, we spoke about the process of translation<sup>9</sup>.

Boissonneault explained that there are different ways of translating. One is literal word-for-word translation. She said this works when there are no context issues. An example is translating the phrase “What time is it?”

But other translations need to take into account both context and culture. An example is the common adage “Birds of a feather flock together.” For this, a literal translation would not work well.

Boissonneault recommended first having a conversation with the translator about context and audience. If you want the information in plain language, then it should already be written that way. “If a client gives us something that is highly technical, we have to assume that the client wants it rendered in technical terms. It’s important that the work be done behind the scenes before it gets to the translator,” said Boissonneault.

After translation, it’s important to verify that intended readers can understand and use the information. One way of doing so is with back-translation. This means having another translator put the information back into English and then asking the original author to confirm that this is the message they intended to convey.



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## Chapter 17

# Jargon, Acronyms, and Other Troublesome Words

### Starting Points

Health professionals spend many years learning a specialized medical language. It is usually quite effective to use this language for shorthand when communicating with colleagues. But to patients and other outsiders, such specialized language can be confusing or unclear.

Here are examples of some troublesome types of words:

**Jargon.** Medical jargon refers to technical terms and phrases or words used in special, idiosyncratic ways. While these terms are familiar and helpful to health professionals, patients and families may not understand jargon in the same way. For example, in health care the term “unremarkable” generally means “you’re fine,” while the term “positive” (as in “your blood test came back positive for [disease]”) may mean you’re not. Laypeople might not understand these words in the way you intended.

**Abbreviations, acronyms, and initialisms.** These refer to shortened ways of referring to longer, more complicated terms. They can be very efficient when talking with peers or entering data in medical charts. Abbreviations are usually shortened versions of longer words, such as “prep” for “preparation” and “meds” meaning “medications.” Acronyms and initialisms usually take the first letters from each word in a phrase to create something new. Sometimes they sound familiar like “CAT” for “computed/computerized axial tomography.” Other

times, they create a new “word” (which really isn’t a word) like “ADL,” which stands for “activities of daily living.”

**Homonyms.** These are words that sound alike and may or may not be spelled the same way, but have very different meanings. Health care uses a lot of homonyms like “stool,” “gait,” and “dressing.” Be aware that patients can easily misinterpret homonyms. As with all new words, make sure to clarify exactly what you mean.

**Idioms.** These are phrases that mean something quite different from their actual words. Generally, idioms have special meaning to people from a certain region or culture. This meaning, however, may be unfamiliar to outsiders. Because most health materials are written for a general (not local) reading audience, try to avoid using idioms like “feeling blue,” “heads up,” and “watch your sugar.”

**“Simple” words that aren’t so simple.** Sometimes even common words like “may,” “might,” and “suggest” are difficult to understand. This often happens when describing risk. While the phrase “this treatment might help” can mean to a scientist that there is no conclusive evidence, it can be interpreted as “this treatment will help” to a patient desperate for hope.



### Story from Practice: Abbreviations in the ED or ER<sup>1</sup>

Imagine what it is like to be suddenly injured or ill. You or your family member calls 911. **EMTs** arrive and take you to the nearest **ER** or **ED**. You or your family member is given a lot of paperwork, including **HIPAA** notification. The doctors and nurses say you need an **IV**, **MRI**, and **CT** scan. And all this before you are admitted to the **ICU**.

Now replay this scenario and imagine being someone who never needed emergency care before. Maybe you also are new to this country and speak only limited English. You now not only are dealing with pain and uncertainty but also must fully comprehend a new language of health care abbreviations (shortened words and phrases) and acronyms (new terms, usually made from the first letters in a series of words).



## Strategies, Ideas, and Suggestions

**Make sure the meanings of acronyms are clear.** Choose only those acronyms and abbreviations that benefit the other person, not just you. For instance, there may be no need to introduce an acronym if you use the term only once. For instance, does your audience really need to know that the acronym for “National Institutes of Health” is “NIH”? Maybe yes, maybe no. My recommendation is that you make choices about acronyms based on what matters to the audience.

If an acronym is really needed, help by explaining its meaning. Put either the acronym or full term in parentheses alongside the other, such as “BP (blood pressure).” While some editors may disagree, for the sake of clarity and understanding I recommend deciding in each instance whether to put the full form of the word or its acronym first. I tend to write the most commonly-used term first, and then either the acronym or full wording. Readers might sometimes benefit from a clear explanation rather than the acronym spelled out. For instance, “IV (a needle that goes into your arm).”

Acronyms can have different meanings depending on where and how they are used. For example, “AAA” can stand for the American Automobile Association, the Area Agency on Aging, or an aortic abdominal aneurysm. Provide context to help readers determine which acronym you mean.

**Be aware of pronunciation.** Acronyms and initialisms are pronounced differently. For example, “HIPAA” (Health Insurance Portability and Accountability Act) is an acronym and pronounced as a single word. But “CHF” (congestive heart failure) is an initialism and pronounced as three distinct letters.

**Write out full directions rather than abbreviations.** This is particularly important for dosing instructions. While clinicians know the meaning of terms such as QD or SID (once a day), QOD or EOD (every other day), BID (twice a day), and TID (three times a day), patients may not. Clearly explain what to do, giving instructions like “Take this pill two times a day—one pill at breakfast and one pill at dinner time.” It can help even more to specify the time, such as “8:00 in the morning and 6:00 at night.”



## Story from Practice: Medical jargon in everyday practice

Dean Schillinger, MD is a primary care physician, researcher, and long-time health literacy advocate. In 2013, he and I talked about medical jargon<sup>2</sup>.

Schillinger explained that jargon is “technical terminology or a characteristic idiom of a special activity or group that is used with the tacit assumption of common understanding.” Doctors, nurses, and other health professionals learn this jargon as part of their professional training. But patients may not know or understand these terms in the same way.

Rather than using jargon, Schillinger recommended explaining information in ways people can understand. He shared this example. Instead of saying “draw your blood,” you can say, “We’re going to take some blood out of your arm.” Schillinger said that you don’t lose anything by saying it that way.

Schillinger also recommended using the teach-back method to confirm understanding. “If you are unsure as to whether you have used jargon, or you used jargon and made a tacit assumption that the patient understood, you can use the teach-back method. Have them teach back what they understood about what you just said.”

Those of us who advocate for clear and simple language may sometimes get push-back from colleagues who question whether this is “dumbing down.” I asked Schillinger his opinion. “Most people, even highly sophisticated patients, like clear explanations,” he said. Schillinger added that in his many years of clinical practice, he had never heard a patient complain that a doctor was speaking too clearly.



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## Chapter 18

# Know Your Audience: Children and Youth

### Starting Points

Health literacy is a factor for children, parents or other caregivers, and pediatric health care providers. Each has an important role to play in helping children be healthy. As succinctly stated in a 2009 article in the journal *Pediatrics*, “What is most complex and distinct about pediatric health literacy is that it must be considered in terms of parents’ or caregivers’ health literacy as well as the children’s own health literacy (which is evolving as children grow, learn, and develop)<sup>1</sup>.”



### Strategies, Ideas, and Suggestions

Kate Cronan, MD is a pediatric emergency medicine physician, health literacy champion, and seasoned editor for KidsHealth.org<sup>2</sup>. In 2013, she shared these tips about communicating with children<sup>3</sup>:

**Know you are talking to two audiences.** Children usually come to appointments with a parent, caregiver, or other adult. This means that there essentially are two audiences for communication. When the child is old enough to understand and not in an acute medical crisis, Cronan starts by talking directly with the child. The nearby adult hears this conversation, too. Cronan finds that helpful as the parent or caregiver gets to listen twice, when she talks to the child and then the adult.



**Position yourself at the child's level.** Cronan offered examples: "If there's room, I'll sit on the stretcher right next to the child or bring up a stool or a chair next to the stretcher or bed. I'll sit close to focus on the child but also try to keep my back away from the parent because I don't want them behind me. Sometimes I'll turn my head back and forth to make sure I'm making eye contact with both."

**Engage the child before discussing medical concerns.** Just like when caring for adults, it's important to first establish a relationship. Cronan said she might start by asking the child something friendly like, "Your hair is done so nicely. Who did your hair?" If they're older, then perhaps, "What grade are you in? What's your favorite thing to do after school?" Cronan said that starting with informal conversation like this can help engage the child, decrease their fear, and set the stage to discuss medical matters.

**Choose words with meaning to children.** Children often have special words to talk about bodily functions and medical concerns. For example, words about pain. To help, Cronan might ask the child or parent what words they use. They might say something like, "It's a boo-boo," or "I have an ouchie." During the physical exam, Cronan might then ask the child, "Is this where your boo-boo is?" or "Is this where the ouchie hurts?"

**Choose words with meaning to parents, too.** Discharge instructions are of course written for adults responsible for the child's care. Even though the adult has higher-level vocabulary, Cronan likes to include words that also have meaning to the child. For example, she might write on the discharge instructions, "Come back to the emergency department if your child is urinating (peeing) less." She might do similarly about bowel movements, using that term and adding "poop" in parentheses.

**Teach terms that children need to learn.** Sometimes children are diagnosed with conditions that have unfamiliar words like "appendicitis." Cronan said that despite this word's difficulty, children need to learn what it means as it will be used throughout their medical care. "I would point on the body to where the appendix is. I'll also grab a simple picture of what the inside of the abdomen looks like and show the appendix. That helps both parent and child," she said.



## Story from Practice: Helping teens transition to adult care

There comes a time when children transition from going to a pediatrician with their parents to being independent for their own adult health care. To learn more, in 2015 I spoke with Corey Ellen Nouri, MSS, MLSP, then a transition social work coordinator at Nemours Children's Hospital, Delaware<sup>4</sup>.

Nouri said that there should be no surprises in this transition. The child, parent, and provider should be “working together on the same page, making sure that everybody is working toward a shared goal of having that young adult be as independent and responsible for themselves as possible.”

To help an older child learn how to refill their own prescription medication, Nouri might equate it to actions they already know how to do. “If this young adult knows how to go online to buy something or download a video, they have the right skills to refill a prescription. It’s just a different website or app on their phone.”

This transition includes working with parents, too. As Nouri explained, “One of the biggest things that we do in transition discussions is talk with parents about breaking that mold of taking care of, and doing for, their child. The transition discussion is often about the parent letting go of the control as much as it is helping that young adult rise to the occasion.”



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## Chapter 19

# Know Your Audience: Culture and Language

### Starting Points

Accessing, using, and understanding the United States health care system is difficult for almost everyone. For people who speak limited English or come from other cultures, these tasks might seem impossible. For example, people may not know how to access appropriate health care services. Or not understand new and complicated medical terminology. These and many other tasks can be difficult and confusing. As the United States population grows increasingly diverse, situations like these are becoming more common.

In terms of language, it can take people many years to become fluent. With limited English, people may have sufficient social language to talk about the food or weather. But until they are truly fluent, they might have difficulty discussing “how” and “why” concepts common in health conversations.

Culture, too, impacts how people understand and make sense of health information. Whether born and brought up in the United States or elsewhere in the world, people bring their own experiences, values, customs, and logic to each situation. For example, those from regions where health resources are scarce may not understand why screening tests such as mammograms, Pap smears, and blood pressure checks are routinely recommended.

Despite cultural and linguistic differences, health providers must communicate in ways that all of their patients can understand. This is more than just good patient care. It is also the law. Under Title IV of the U.S. Civil Rights Act of 1964<sup>1</sup>, health professionals are responsible for bridging communication gaps with patients who speak other languages and come from other countries.



### Story from Practice: Health care from a Native American perspective

Linda Burhansstipanov, MSPH, DrPH is of the Cherokee Nation of Oklahoma. We spoke in 2010 about health care from a Native American perspective<sup>2</sup>.

We began by discussing terminology. Burhansstipanov said that, as with other sensitive issues, acceptable wording depends on who you are talking to. She said that some tribes prefer the term Native American, while others prefer American Indian, First Nation, or indigenous people.

Burhansstipanov's research and teaching focus on cancer screening, early detection, and treatment. Beyond the usual challenges teaching these topics, she said that communication is often even harder because, until recently, cancer was not openly addressed in the Native community. She explained that some people felt that using the word "cancer" spreads the "cancer spirit." For a while, instead of using the word "cancer," people referred to it as "the disease for which there is no cure."

Burhansstipanov also talked about framing cancer messages within a cultural context. She used the example of mammograms. Rather than focusing on personal health benefits of mammograms, she recommended framing these in terms of the family. Burhansstipanov offered examples such as, "Have a mammogram to show your family how a well woman behaves," or "Have a mammogram to be alive to tell your stories to the next generation."



### Strategies, Ideas, and Suggestions<sup>2-7</sup>

**Create a welcoming atmosphere.** Welcome patients by displaying multicultural artifacts, globes, and worldwide maps. Translated signs are important as well. Greet patients in their native languages and ask how to pronounce their names correctly. Even if your pronunciation is less than perfect, you at least conveyed a willingness to communicate despite linguistic differences.

## **Work with interpreters and translators.**

**Interpreters** work with the spoken word, communicating what one person says in words that another person understands. When talking about important health information, work with trained medical interpreters rather than bilingual family, friends, or volunteers. Trained interpreters are educated in medical vocabulary, ethics, and confidentiality and can also serve as “cultural brokers” to present information in keeping with the other person’s beliefs and practices.

**Translators** work with the written word, taking information from one language to another. Beyond words, translated materials should be culturally appropriate and include graphics and examples that readers can accept and relate to.

**Ask who makes decisions.** In some cultures, patients are not the ones to make health decisions. Find out whether the patient, a family member, or a designated decision-maker assumes this responsibility. Then include that person in discussions about diagnosis and treatment decisions.

**Speak at a slower pace.** When talking with people who speak limited English, focus on essential need-to-know skills and behaviors rather than nice-to-know background information. Speak at a slower pace, pausing for two or three seconds after asking questions or giving new information. But do not speak louder just because people have limited English—doing so can come across as angry and does nothing to improve communication.

**When possible, use common words.** Examples include using the word “cancer” rather than “oncology,” or “kidney doctor” and not “nephrologist.” Avoid medical jargon and acronyms like “BP” when you can just as simply say “blood pressure.” Be aware that some concepts, treatments, and tests may not be able to be translated into a single word. This includes terms for some treatments and tests, such as “genetic testing” and “psychiatric counseling.” It may take many translated words to clearly explain their meaning.

**Pay attention to nonverbal language.** Whether you communicate through an interpreter or talk directly with patients, pay as much attention to nonverbal communication as you do to words. Notice the volume and speed at which people speak. Pay attention to their silences, as well. Look also at their posture, gestures, and eye contact. Be cautious, however, about making assumptions. In some cultures it is considered rude to look another person in the eye. Likewise,

a nod does not always indicate agreement. Sometimes a nod simply means “I hear what you are saying.”

**Invite questions.** Many patients find it hard to ask questions. It can be even more difficult when people have learned that questioning those in authority is a sign of disrespect. You can help by inviting, encouraging, and even modeling good questions. Burhansstipanov recommended making a statement like “It’s okay for you to ask me a question.”

**Find additional ways to communicate your health message.** This can include pictographs (simple line drawings that show ideas or actions), demonstrations, stories, and metaphors. Consider “hands-on” practice as well. For example, instead of just telling patients how to take a new liquid medication, use an actual dosing device to demonstrate what to do and then ask patients to re-demonstrate how they would do it.

**Confirm understanding.** When communicating with patients who speak other languages and come from other countries, do not assume that a nod and a smile necessarily mean that your message is understood. To confirm understanding, ask an open-ended question such as, “How will you \_\_\_?” rather than a yes/no question like, “Do you know how to \_\_\_?” When it appears that the other person does not understand, find other ways to communicate the same message.



### Story from Practice: Implicit bias

Winston Wong, MD, MS, FAAFP, is a physician whose work includes developing community and organizational partnerships to eliminate health disparities. In 2016, we spoke about many factors affecting health communication, including implicit bias<sup>8</sup>.

Wong explained that bias is a reflexive process within our brains that connects people to certain stereotypes almost beyond the level of consciousness. He cited research showing how people react to certain images based upon facial types, skin color, and more. He described these reactions as implicit bias or unconscious bias.

We can have implicit bias yet not know it. As Wong explained, “When clinicians are asked, ‘Does bias play a role in terms of how you make decisions?’ studies pretty much suggest that virtually 90% of clinicians say, ‘I treat my patients all the same and bias does not play a role.’”

Wong added, “On a conscious level, I don’t think it really factors into people’s decision making. At a subconscious level when we process information very quickly, I think it does.” He said that clinicians may unconsciously take into account how the patient enunciates, their vocabulary, and the patient’s rhythm and tempo when speaking. “Those associations start to form a path in terms of how we understand the best way to treat that patient within our frame of understanding.”

To help, Wong recommended asking ourselves, “Are we assuming that this person can’t understand or doesn’t have the same intellectual capacity as me because they use a different parlance of communication?” A more helpful approach, he said, is consciously asking ourselves, “What am I assuming about this patient?”



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## Chapter 20

# Know Your Audience: Emotions, Cognition, and Behavioral Health

### Starting Points

Beyond focusing on certain illnesses or specific body parts, there is a lot to take into account when communicating about health. We need to not only address the other person's physiology but also their emotions, ability to think clearly and remember, and perhaps issues related to substance use.

For many years, I worked as an occupational therapist on both inpatient and outpatient psychiatric units. It was during this time that I first learned about health literacy. I immediately knew that health literacy was essential to consider in all aspects of patient care. Decades later, I remain convinced that we need to consider the full range of human experiences when communicating about health. Below are a sampling of stories and strategies when it comes to emotions, cognition, and behavioral health.



### Strategies, Ideas, and Suggestions: Emotions<sup>1</sup>

Health care is filled with emotions like anxiety, anger, and worry. When we, or those we love and care for, are ill or injured these emotions can override even the best of communications. Seemingly routine medical events may raise our level of anxiety. A new diagnosis or urgent need for decisions and actions can make communication that was already difficult even harder. Here are some suggestions about ways to help:

**Find a private place to talk.** If a patient or family member is upset, try to take them aside and speak privately about their concerns. If a separate space is not possible, you might close curtains or reposition chairs to offer a sense of privacy.

**Avoid using judgment phrases.** It can minimize a patient's experience to say that a procedure has been delayed for "only" a day, or that the patient is "just" having gallbladder surgery. This surgery may be routine to you but likely not so for that patient.

**Help people comprehend and remember.** Appreciate that when people are anxious, they may only comprehend part of what you are saying. Be prepared to repeat information. Offer a pad and pencil so they can write notes and jot down any questions.

**Consider your nonverbal language.** Smile and approach patients and families in a calm manner. Help patients relax by speaking audibly, but softly. You might also mirror their actions such as by matching the other person's vocal tone, gestures, or posture. Attitude can also make a huge difference. As said by one nurse who earns high praise from patients and families, "It isn't anything magical I do. I'm just nice to patients."

**Listen, and let the patient talk.** Don't argue, even when you know you are right. Listen to what patients or family members have to say—they might calm down simply by being able to share their concerns. Do not insist on meaningful conversation when patients and families are not willing or ready to participate.

**Be aware of your own feelings.** Health professionals are not immune to anxiety or anger. When you find yourself in an upsetting situation or having a bad day, talk with your colleagues or supervisor. Let them help you find ways to empathetically and effectively communicate today.



## Story from Practice: When there is a wide range of worry

Emilie Johnson, MD, MPH is a pediatric urologist and health services researcher. She addresses medical and surgical needs involving a child's urinary and genital systems. Johnson and I spoke in 2019 about communicating when parents are worried about their child's condition<sup>2</sup>.

Johnson shared the example of communicating with expectant parents about a condition called “hydronephrosis” (swelling on the kidneys), found on their baby's prenatal ultrasound. “Some parents are incredibly worried about the condition that their child has. Some are much less worried or maybe not worried at all,” said Johnson. She adds that some parents are not sure how worried they should be.

I asked if parents should worry about this condition. “Most of the time the answer is no. But once in a while, the answer is yes. Sometimes I notice that the level of the family's worry is very different from the level of worry I have after looking at the ultrasound pictures of their baby's kidneys,” said Johnson.

To improve communication, at the beginning of appointments Johnson asks parents to tell their story. She said that starting this way gives her a sense of what the parents are most worried about. She then can put to rest any unfounded fears and focus on information most relevant today.



## Strategies, Ideas, and Suggestions: Cognition<sup>3</sup>

Cognition affects learning, memory, perception, and problem solving. There are a wide range of cognitive disorders. Some are lifelong, as with intellectual and developmental differences. Other cognitive disorders happen later in life, perhaps due to dementia or brain injury. Acute and chronic mental illnesses can also affect concentration, memory, and communication. Here are some ways to communicate clearly when cognition may be a concern:

**Connect new pieces of information to old.** It is much easier to remember unfamiliar or new information when linked to something familiar. You can do this by introducing new information within a known context. One way is with a metaphor or analogy. For instance, you might explain the concept of “rare” as like finding a 4-leaf clover.

**Chunk information.** People tend to hold onto only a few new pieces of information at a time. You can help them better remember by “chunking” health information into shorter segments. For instance, when explaining about high-fiber foods you might chunk this into categories of breakfast, lunch, dinner, and snacks. This can be easier to remember than one long list with all of the items.

**Write down important information.** Most people can remember spoken information better when they have a written (visual) reminder of the conversation. Ideally, patients would take notes during even routine medical appointments. Doing so, they would have a way to remember all their new data including weight, height, blood pressure, new diagnoses, and follow-up instructions. Providers can assist by giving the patient a printed after-visit summary of topics discussed.

**Encourage the use of memory aids.** One way to help people remember key messages is by using an acronym, which is a short word or phrase made up of the first letter of each word in a series. For instance, to help people recognize the warning signs of a stroke, you might use the acronym “FAST.” In this acronym, F stands for Face drooping, A for Arm weakness, S for Speech difficulty, and T for Time to call 911<sup>4</sup>.

**Use teach-back to confirm understanding.** Teach-back is a technique in which you ask the other person to explain back in their own words what you just said. Teach-back is an opportunity to confirm understanding or clarify topics they may have missed or found confusing.



### Story from Practice: Dementia

Katrien Goethals is a partner at the Institute for the Advancement of Health and Wellbeing. We spoke in 2019<sup>5</sup>.

Goethals explained that the term “dementia” refers to a decline in mental functioning and cognitive impairment. It can be used in reference to a range of disorders including Alzheimer’s disease, frontotemporal dementia, and vascular dementia. While there is not yet any treatment or cure for dementia, Goethals offered these suggestions about ways to help:

**Raise awareness.** Goethals hopes that dementia will move from a “hush illness” to something that people can comfortably discuss. She recommended making it easy for caregivers and people to learn more by putting information about dementia in clinic waiting rooms.

**Decrease stigma.** Goethals acknowledged that there is a lot of stigma surrounding dementia. She would like to see public awareness campaigns about dementia similar to what was done to reduce stigma about HIV, certain cancers, obesity, and heart disease.

**Reach out to others.** “Very often, families feel alone in this,” said Goethals. When you sense that someone is struggling with their own memory loss or caring for someone who is, Goethals recommended reaching out “from your heart” and asking how they are doing. “Very often, that person will share what is going on.”



## Strategies, Ideas, and Suggestions: Behavioral health

According to the United States federal agency SAMHSA (Substance Abuse and Mental Health Services Administration), behavioral health is about promoting mental health, resilience, and wellbeing, along with treating mental and substance use disorders and supporting those experiencing or in recovery from these conditions<sup>6</sup>.

There are so many issues to consider when it comes to behavioral health that it's hard to identify just a few. To get more insight about one aspect of behavioral health, I interviewed Alex Hogan, who produced the documentary film “Runnin”<sup>7</sup>. In 2018, we spoke about the origins of the opioid crisis and ways that we as communicators can help<sup>8</sup>.

Hogan said that the real beginnings of the opioid crisis can be traced back to the late 1990s, particularly with the introduction of the pharmaceutical drug Oxycontin. “That drug was marketed very aggressively. There was a lot of misleading information. They said it would be less addictive, but that turned out to be not the case. It was incredibly addictive.”

Hogan spoke of some communication challenges related to this crisis. “One of the big problems that got the epidemic kicked off was an impression people had that ‘if it’s prescribed by a doctor then it can’t be that bad.’” He added, “If you’re more versed in health literacy then you would know that’s not necessarily the case. There are all sorts of substances prescribed by doctors that are unsafe if not prescribed for you.”

He shared some recommendations. One is to avoid stigmatized language. “You don’t want to say someone is ‘clean,’ as in, ‘He’s been clean for six months.’ The flipside of clean is dirty and that’s stigmatized language.” Hogan recommends saying instead that a person is “in recovery.” Another recommendation is to use the term “substance use disorder” rather than saying that a person is “abusing drugs” which has a negative connotation.





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## Chapter 21

# Know Your Audience: Hearing Loss

### Starting Points

Hearing loss ranges from hard of hearing (mild hearing loss) to being deaf (total hearing loss). People who are deaf from birth often identify themselves as Deaf (with an uppercase “D”) to indicate that they are part of a specific cultural and linguistic community. Approximately 15% of adult Americans aged 18 and over report some trouble hearing<sup>1</sup>. This percentage significantly increases as people age.

People who have hearing loss need to communicate in ways other than talking and listening. Many Deaf people use sign language. There are a lot of different sign languages, including American Sign Language (ASL). ASL is more than simply using hand gestures to substitute for spoken English. It is a complex language with its own grammar and syntax that makes use of facial expressions, body movements, and hand signs.

Other strategies that people with hearing loss may use include reading lips, communicating in writing, or using assistive listening devices such as hearing aids and telephone amplification systems. Communicating these ways is not just common courtesy. The 1990 United States Americans with Disabilities Act (ADA) requires that public facilities, including hospitals and health centers, communicate in ways that people with hearing loss can understand<sup>2</sup>.



## Strategies, Ideas, and Suggestions<sup>3-5</sup>

**Determine the preferred method for communicating.** Ask patients with hearing loss how they prefer to communicate. This may be to face them directly so they can see your lips, to provide written information, or to use an ASL interpreter. Also find out whether patients use assistive listening devices or other types of electronic equipment.

**Consider the environment.** Meet in a quiet space that is free of distracting noises such as air conditioners or overhead pages. Look for a space that has adequate lighting so that the other person can clearly see you speaking. As appropriate, tap the person lightly on their shoulder to get their attention and orient them to where the sound is coming from.

**Articulate clearly.** Speak distinctly, not necessarily loudly. Shouting is unpleasant and not helpful, as it distorts mouth movements and makes lip reading more difficult. Shouting may also interfere with a hearing aid's ability to pick up usable sounds. Instead, use a slower rate of speech, but don't exaggerate pronunciation to the point that you distort individual words.

**Facilitate lip reading.** People lip-read when they look at someone's mouth and speech-read when they also look at that person's gestures, expressions, and pantomime actions. Messages are sometimes misinterpreted because pairs of words look alike as with "bed" and "men," or "pain" and "main." People who rely on visual cues may have particular difficulty understanding someone who has a mustache or speaks with an accent. To improve understanding, do not cover your mouth, chew gum, or talk at the same time as someone else.

**Be aware that written notes don't always work.** It is widely assumed that all people with hearing loss benefit from written information. But this is not necessarily so, particularly for those who have been Deaf since birth and, despite normal intelligence, may read at only a fourth- to fifth-grade level. One reason for this lower reading level is that those who have never heard speech cannot "sound out" words, a technique that hearing people commonly use to figure out unfamiliar words. Rather than assume that written notes will help, ask the other person about best ways to communicate.

**Use photos, illustrations, and other visual images** to provide everyone, including those who have trouble hearing, with standard information. Options include drawing diagrams or adding relevant words on anatomic illustrations. These days, there are many online sources of visual tools and libraries. Check to see if the images you want are free to use or require a fee or copyright permission.

**Use electronic devices and equipment.** Enhanced technology is opening up a lot of communication options for people with hearing loss. A while ago, TTY (telephone typewriter, a device that allows people with hearing or speech loss to communicate by telephone) was commonly used. Today's options include email, text messaging, and video phones. No doubt there will be even more electronic devices and apps in the years ahead.

**Use ASL interpreters.** When communicating with people who use ASL, ask to work with certified or qualified interpreters whose competency is verified according to professional and regulatory standards. Despite good intentions, untrained family members or friends who volunteer to interpret may not be skilled at communicating medical information and might also bring confidentiality and privacy concerns.

With a trained interpreter, start by making sure the patient is comfortable with the interpreter and familiar with the specific sign language being used. (ASL is not the only sign language.) Throughout the session, speak directly to the patient and not the interpreter. Position yourself so that the interpreter sits a little behind you and to the side. This way, the patient can see you and the interpreter in the same visual field. You, in turn, can listen to the interpreter while looking directly at the patient.

**Confirm understanding.** As with all types of health communication, take time to confirm understanding. Whether communicating directly or through an interpreter, ask patients to share their understanding of topics just discussed. If a concept is unclear, rephrase rather than simply repeat it. Confirm understanding throughout your time together, not just when the appointment is almost over.



### Story from Practice: Hearing loss and health understanding

Michael McKee, MD, MPH is a family medicine physician, professor, and health literacy researcher. He also has a profound hearing loss. In 2015, we spoke about the spectrum of hearing loss and how this can affect health understanding<sup>4</sup>.

McKee said that the experience of hearing loss is not necessarily the same for everyone. For instance, a person with mild hearing loss may need to make minor adjustments such as avoiding noisy environments. Someone with more profound hearing loss might look for accommodations such as technology, sign language interpreters, and visual aids.

It's important to assess each person's preferred mode of communication rather than make assumptions, said McKee. Some people are "oral speaking" in audio language while others prefer sign language. It is important for clinicians to know this. When patients make an appointment, the scheduler should ask about the preferred mode of communication and note that in their medical chart, McKee recommended.

Another factor to consider is that those with hearing loss may lack health knowledge that is often taken for granted. McKee referred to this as "incidental learning" that those with hearing loss may miss. He compared this to casual "water cooler" conversations at work. "The same thing can happen at family get-togethers," said McKee. "Somebody may talk about another family member having a health problem, high cholesterol, or heart disease. This is crucial health information that may be missed or misinterpreted."



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## Chapter 22

# Know Your Audience: Literacy

### Starting Points

The 2003 National Assessment for Adult Literacy (NAAL) is the most recent and comprehensive measure of adult literacy in the United States<sup>1</sup>.

NAAL defined literacy as using “printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential.” Within this broad definition, there are three types of literacy:

**Prose literacy.** Needed to understand and use text found in materials like newspapers, magazines, and books.

**Document literacy.** Required for items such as applications, schedules, forms, maps, graphs, and tables.

**Quantitative literacy.** Necessary for arithmetic operations such as those needed to compute interest payments for a loan.

The Program for the International Assessment of Adult Competencies (PIAAC)<sup>2</sup> is a more recent look at literacy worldwide. The PIAAC survey is conducted at least once a decade in more than 30 countries worldwide. It measures “cognitive and workplace skills . . . from reading simple passages to complex problem-solving” in adults aged 16-65. The most recent PIAAC data for the United States was collected in 2017.

NAAL and PIAAC are admittedly not the same. Their differences are not only about populations studied but also the specific skills that they measure. To

me, the relevance of these studies to health literacy is that we as communicators still have a lot of work to do when it comes to writing health information in ways that most of our audience can understand and use.



### Story from Practice: Why some people struggle to read

Michele Erikson is the executive director of Wisconsin Literacy, Inc. In 2015, she explained to me how and why some people struggle to read<sup>3</sup>.

One reason can be learning disabilities such as dyslexia, said Erikson. Another reason can be that parents may not start building literacy skills when children are young. “When a child isn’t spoken to or engaged in oral literacy from the very early years, those circuits and connections aren’t made as frequently as with kids whose parents might be talking to them, singing, reading, and engaging them.”

As adults, people may not want to let others know that they struggle to read. “If you’re an adult and don’t have that skill yet, it’s not something you’re really anxious to share,” said Erikson.



### Strategies, Ideas, and Suggestions<sup>3-6</sup>

**Use consistent terms and common words.** Make it easier for readers to understand by using consistent wording. This includes using the same form of a word, such as “surgery” and not also “surgeries” or “surgical.” Refer to items and procedures with the same wording each time, such as “stitch” or “suture.” If possible, use common one- and two-syllable words. But when more complicated words are truly needed, like “chemotherapy” or “bronchodilator,” use them and give easy-to-understand explanations.

**Select written materials that are sufficiently easy to read.** When writing for those who read at a basic literacy level, it is often recommended that materials be written at a fifth- to eighth-grade reading level. When writing for those with below basic literacy skills, materials should be written at a third- to fifth-grade reading level. But writing at these levels is often very hard to do.

**Make it easier to read difficult documents.** Sometimes, you only have hard-to-read documents. If so, find ways to make them easier for readers. You can do this visually by highlighting or circling key points. You might also encourage readers to look again at these materials when they are relaxed, have sufficient time, or are with others who can help explain unfamiliar words.

**Offer non-written options.** These include other forms of teaching tools such as pictographs, objects, and videos. You might also consider using assistive technology such as screen readers that read online text aloud. A good resource to learn more about this technology and find useful tools and techniques is the Web Accessibility Initiative<sup>7</sup>.



### Story from Practice: Struggling to read health materials<sup>4</sup>

Basic literacy is essential for reading, understanding, and using written health information. I learned a lot about what it is like to be an adult who struggles to read from a dear colleague, Archie Willard. I often refer to him as my “Health Literacy Hero.”

Archie Willard was an articulate, ardent advocate of health literacy. He organized health literacy conferences, participated in health literacy panels from the American Medical Association and the Joint Commission, and was a featured speaker at health literacy conferences nationwide. Willard did not learn to read until he was 54 years old.

In 2008, I asked Willard what it was like for him and other “adult learners” (adults learning to read) in health situations. “When a person does not have strong reading skills, you go into a doctor’s office, a clinic or a hospital, there’s always paperwork automatically handed to you.”

I asked if he was referring to health history forms, booklets, or other printed information. Willard said that it was all of the above. “You take a step back in your mind. You have fear of, ‘How am I going to spell this word? Am I going to be able to write?’”



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## Chapter 23

# Know Your Audience: Older Adults

### Starting Points

Adults aged 65 years and older are a significant and ever-increasing percentage of the United States population. Collectively, older adults are a remarkably diverse group. People in their mid-60s are apt to have far different needs and abilities than those who are two, three, or more decades older. Individually, older adults of course can differ even more.

Despite this diversity, a commonality as people age is that they are increasingly likely to be diagnosed with acute illnesses and chronic conditions. Consequently, older adults and their caretakers (if any) need to learn a lot about health and wellness, treatment and care, and what to do in a medical emergency.

But learning this information can be a challenge. There are many reasons that can be so. For instance, health information is inherently complex and filled with many new words, concepts, instructions, and devices. Older adults may have diseases or take medications that affect their ability to see, hear, and remember. Emotional issues, too, can make learning difficult. It indeed can be hard for anyone to concentrate when coping with stressors like selling a home or losing a spouse.



## Story from Practice: Brain changes as people age

Mark Hochhauser, PhD was, until his retirement, a psychologist, readability consultant, and long-time health literacy champion. His work often focused on issues about brain changes as people age. We spoke in 2017<sup>1</sup>.

“When you look at human abilities across the lifespan, you find that some abilities like cognition, attention, and working memory tend to decline with aging,” he said. “The older people get, the harder it will be for them to remember pieces of information, to think about it, integrate it, and make decisions.”

Hochhauser shared three examples:

**Selective attention.** This refers to a person’s ability to filter out noise or distracting information and focus on what’s most important. Problems with selective attention can cause a “communication disconnect” in health care, as when clinicians quickly introduce several topics but patients can only focus on one or two.

**Working memory.** This refers to how much information a person’s memory can hold and how much they can work on while their memory holds it. This often is just three to five pieces of information. “If you’re driving and ask for directions and someone starts explaining how to get to where you want to go, after about two pieces of information you get lost,” said Hochhauser. The same can happen in health care when patients try to remember multistep self-care instructions.

**Processing speed.** This is the amount of time it takes to retrieve a memory and then process that information. This can lead to problems in health care, especially in brief appointments. “It is easy for health care providers to give the patient more information than their working memory can hold. It may be given to them in a way that they really can’t process it quickly enough,” said Hochhauser.



## Strategies, Ideas, and Suggestions<sup>2-5</sup>

**Offer a positive and supportive approach.** Create “shame-free” learning environments in which older adults can comfortably acknowledge when they do not understand. Let patients who seem confused know they are not the only ones having trouble and that many people find it hard to learn new health information. When possible, offer assistance.

**Speak in ways people can hear.** Speak slowly, clearly, and concisely, and introduce just one concept at a time. Use everyday language with words that older adults know and are comfortable with. Pay attention as well to nonverbal

communication, both yours and the patient's. Throughout your conversation, pause periodically to allow the patient to ask questions.

**Use a variety of formats to teach about health.** This includes printed materials that are written in plain language with examples and illustrations readers can understand and will relate to. Supplement spoken and written information with pictographs and illustrations, videos, or demonstrations using real objects or simulated models. You can also help older adults learn by sharing stories—yours or theirs—to help them connect with health information in a more personal way.

**Help patients participate.** Encourage older patients to bring lists of concerns and questions to their appointments. When you meet, discuss their confidence in managing illness. Periodically ask for questions, but be sensitive to the fact that many older adults were brought up to not question medical professionals and may be uncomfortable or unwilling to do so.

**Help patients remember.** Call patients ahead of time to remind them of appointments and perhaps afterward to reinforce instructions and discuss any unanswered questions. Other ways to help can include suggesting they keep notebooks with personal health information and using pill boxes or other aids to correctly take medication. You might also encourage patients to invite a trusted friend or family member to go with them to appointments. This way, older adults not only learn in the company of people they find supportive but also have a “second pair of eyes and ears” to reinforce and clarify information later on.

**Verify understanding.** Regardless of age, make sure that patients understand the information you are communicating. You can do this with the teach-back technique, asking relevant and specific open-ended questions. For example, after introducing a medication that could cause light-headedness, you might say, “Some people get dizzy after taking this medicine. If that happens, what will you do?”





## Story from Practice: Elderspeak

Anna I. Corwin, PhD is a linguistic and medical anthropologist whose work focuses on how cultural practices and communication shape older individuals' experiences of their lives, their bodies, and aging. She spent a year living in a convent with American Catholic nuns researching issues about care at the end of life.

In 2018, Corwin and I spoke about one aspect of this research, “elderspeak<sup>6</sup>.” She explained that this term has been used for several decades. “The easiest way to think about elderspeak is baby talk. In America, the way we often talk to children includes simplified speech, slower speech rate, exaggerated intonation, elevated pitch and volume, and really simple vocabulary. It also usually involves collective pronouns, such as ‘we’ rather than ‘you’ or ‘I.’” For example, “Shall we put on our sweater now?”

Corwin shared that sometimes people use elderspeak due to stigma, a sense that older adults are not to be addressed the same way as others. But using elderspeak with older adults can have negative implications. “Research has found that not only is the experience problematic, of feeling disrespected or patronized, but also can trigger negative self-assessment.”

Corwin added, “If older adults are only exposed to elderspeak, it can be associated with cognitive decline, social isolation, and also some negative behaviors such as being resistant to care.”



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## Chapter 24

# Know Your Audience: Vision Problems

### Starting Points

In a 2018 National Health Interview Survey, more than 32 million adults in the United States reported experiencing vision loss<sup>1</sup>. This included people who had trouble seeing even when wearing glasses or contact lenses, as well as those who reported that they were blind and could not see at all.

Health facilities are required to accommodate the needs of people with vision problems. The 1990 Americans with Disabilities Act mandates that public facilities (like hospitals and health centers) provide reasonable accommodations for people who are blind or visually impaired<sup>2</sup>. These facilities must provide information in large print, audiotape, or braille formats, or have someone available to read information aloud.



### Strategies, Ideas, and Suggestions<sup>3,4</sup>

**Ask if the person wants assistance.** The amount of assistance a person with vision loss desires depends on the situation and their comfort. Ask if that person wants help and, if so, how to best be of assistance. They may want descriptive or directional information, such as where objects are located within a room or an explanation of any unusual sounds. The person may also ask to take your elbow and walk alongside you.

**Introduce yourself and others.** Identify yourself by name when you enter a room where there is a person who is blind or has significant vision loss. When a person comes into the room, introduce yourself and everyone else who is present. When someone leaves the room, communicate this too.

**Use everyday words.** Give clear, specific information and use common words, not medical jargon. Don't be afraid to use verbs such as "see" and "look." These words are part of everyday speech.

**Provide descriptive directions.** Give specific and descriptive directions from the other person's perspective. Include notable landmarks such as "Turn right just after you pass the entrance to the cafeteria." Avoid generalized statements like, "It's over there."

**Have clear signage.** Use both braille and large print to identify offices, room numbers, departments, building directories, elevator call buttons, and elevator door jams (panels by the door that indicate the floor number). Make sure printed signs have sufficient contrast between foreground and background and that the sign contrasts with the wall color.

**Use design to help people with limited vision see written materials.**

**Use a simple font** and avoid italics or other stylized or decorative lettering.

**Use at least a 12-point type** for all readers. For those with limited vision, increase the size to 16 to 18 points, which is the standard for large print.

**Have a high color contrast** in between foreground and background. This might be black lettering on white, yellow, or other light-colored paper.

**Use matte rather than glossy paper** to reduce glare.

**Have margins that are at least an inch wide.** Increase line spacing to at least one and a half spaces.

**When writing by hand, use a thick felt-tip marker and large-sized letters.** Use print or block lettering rather than script. Use upper- and lower-case letters as all capitals can be difficult to quickly decipher.

**Talk with patients about nonvisual sensory cues.** For example, when teaching a person how to recognize signs of a wound infection, in addition to redness include warning symptoms of oozing, swelling, tenderness, smell, and sensation of heat. Help patients learn nonvisual ways to accomplish tasks. For instance, if a person is having difficulty seeing the numbers on a thermometer even with a magnifier, let them know about talking thermometers.

**Distinguish between different medications.** Pill bottles are often identical in shape and size. One way people with vision problems can distinguish between two medications is by putting one rubber band (or piece of tape) on the first bottle and two rubber bands (or pieces of tape) on the second. Another way is by asking pharmacists to put the medications in differently shaped containers. In addition, people with vision problems might keep one medication in the bedroom and another in the kitchen to keep track of which is which. There is also an ever-growing array of technology options designed to help. These include audible medication reminders, such as smartphone apps and stand-alone devices<sup>5</sup>, and 3D-printed medication labels<sup>6</sup>.



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## Chapter 25

# Learning and Teaching

### Starting Points

All health care encounters are opportunities for providers to teach, exchange knowledge, and engage in mutual learning with patients. This includes teaching patients about their diagnoses and treatment options. It also includes learning about patients' symptoms, priorities, and choices.

Health learning and teaching can happen informally, as when chatting with patients just before procedures and tests, or more formally in structured educational situations. Here are some examples:

**One-to-one teaching.** This traditionally has referred to the dyad of one health care professional and one patient. But today, there may be more people involved such as several health care team members, the patient's family or a caregiver, and perhaps also an interpreter.

**Health education classes.** These are usually led by a health professional and structured with a formal curriculum and clear-cut goals. Classes may focus on specific topics such as diseases and medical procedures or more general themes like health and safety.

**Support and self-help groups.** Usually led by a patient or consumer, these types of groups tend to be fairly informal with built-in flexibility to accommodate participants' specific needs and interests.

Teaching about health is challenging for many reasons. Instructions may be complicated and explained in unfamiliar words or with lots of numbers. Patients may have limited literacy or language skills, cognitive changes, or other



learning barriers. When people are overwhelmed with new diagnoses or are scared, sick, or in pain, they likely are not at their learning best.



### Story from Practice: Before building knowledge and skills, find out what people know

Susan Reid lives in New Zealand. Reid is a skilled health educator whose work builds on years of experience teaching literacy. Her accomplishments are many and include health literacy research and initiatives for patients, families, and the workforce. We spoke in 2014<sup>1</sup>.

Reid said that an important first step when building health knowledge and skills is finding out what the other person knows, feels, or believes about that topic. “In health, we often assume that people know nothing and so we tell them a whole heap of stuff. Or we assume they know everything and then don’t tell them enough.”

Reid said that asking people what they already know helps build skills and knowledge in three important ways. “First, if you find out what people know then you can link to that knowledge in ways that make sense to the patient. Second, it helps you as a health professional decide if you can give this person more information or if they are at such a basic level of knowledge that you can’t provide all the information you had in mind.” She added, “The third thing it does is show the patient that you’re trying to personalize it for them. It’s not a square peg that you’re trying to ram into a round hole.”

Reid’s overall advice was to “believe that people are able and interested to learn. Sometimes as health officials we get a bit jaded and think that people aren’t interested. But people do want to learn about their health and their medicines.”



### Strategies, Ideas, and Suggestions<sup>2-5</sup>

**Appreciate that people learn in many ways.** Some people are auditory learners and learn best when listening to lectures or hearing spoken instructions. Others are visual learners who understand better when looking at pictures or reading books. Still others are kinesthetic learners who absorb information when touching objects or doing activities. Often, people have more than one style and learn best through a combination of these ways.

**It often helps to use a variety of teaching strategies.** For instance, when teaching someone newly diagnosed with asthma, you might talk about the

condition, show a model of a lung, have them practice using an inhaler, and provide written handouts that they can read later.

**Teach when patients are ready to learn.** The timing of your teaching can be nearly as important as its content. Patients may be unable to learn when they are distracted or uncomfortable. Take your cues from patients about how much information to present in each session. For example, scheduling a follow-up meeting to continue your teaching later.

**Encourage people to be active learners.** People learn best when actively involved in the learning process, and not just passive recipients of information. Ask people what they want to learn and set the agenda together. Allow opportunities for interaction with ample time for learners to ask questions and raise concerns. And, of course, provide lists of print and non-print resources for people who want to learn more.

**Explain instructions in plain language.** This includes defining unfamiliar but essential words and giving examples to help people understand. For instance, instead of just instructing patients to “lift no more than five pounds,” let them know that five pounds weighs the same as a bag of flour. As well, clarify instructions like “take pills twice daily.” While you might intend this as “take one pill in the morning and one at night,” patients might assume they can take two pills at the same time.

**Watch for cues that you are going either too fast or too slow.** A good way is by observing whether people look “glazed over” or their body language indicates boredom. You can also ask if you are teaching at a good pace. It is admittedly easier to notice these clues when teaching one person at a time. But even when teaching a group, you can check pacing by periodically stopping to allow people to ask questions or practice actions just taught. Encourage participants to let you know if you are speaking too softly or printed information is too small to see or hard to read.

**Confirm understanding.** The goal of all learning and teaching is knowledge. Make sure that people truly understand and can make use of information you are presenting. Stop periodically and make sure that learners are keeping up with you. You can do this by asking them to teach back, in their own words, what they understood, or to show how they will do an action you just taught. As knowledge is a two-way process, confirm that you understand what patients are teaching you, too.



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## Chapter 26

# Listening and Speaking

### Starting Points

Just because listening and speaking happen a lot doesn't mean that this form of communication is always easy or effective. For instance, speaking can be hard when providers are rushed, explain the same concepts over and over again, or assume that patients understand everything being said.

For patients, listening can be hard because of complicated concepts like risks and benefits, abstract ideas such as wellness, and multisyllabic terms that might sound like a foreign language. They also might be distracted by pain or concerns about paying for care. Despite these many challenges, providers have a responsibility to communicate health information in ways that patients and their families or caregivers can understand.



### Strategies, Ideas, and Suggestions<sup>1,2</sup>

**Try to talk in a place that is private, quiet, and well-lit.** The space you meet in is almost as important as topics you discuss. If a separate room is not available, then at least pull curtains or move chairs to create a sense of privacy.

**Develop rapport.** Set a positive tone by beginning conversations with a smile and perhaps a handshake. Introduce yourself by the name you wish to be called and, in turn, ask patients how they prefer to be addressed. Meet patients at eye level, sitting down if they are seated or in bed. Often, you can build rapport by first chatting about nonmedical matters such as the weather or traffic. Make

sure the person you are talking with is not so distracted or uncomfortable that meaningful conversation is impossible.

**Give patients your undivided attention.** You can do this by encouraging patients to fully state their thoughts by saying “that’s interesting,” or “please tell me more.” Make sure not to interrupt and, instead, make a note to yourself of issues to revisit when the patient stops talking.

**Choose your words carefully.** Health care has its own vocabulary. For example, medical jargon like “dressing” has nothing to do with clothing or salads. Terms like “formulary” and initialisms or acronyms (new “words” made up from longer phrases) such as “ADL” and “HIPAA” may be unknown to others. Patients can get understandably confused when you interchange words like “hypertension” and “high blood pressure.”

When you truly need a word that patients don’t already know, explain it and give an example. For instance, say “ADLs—activities of daily living, like getting dressed or eating.” Often, you can take cues from patients about which words to use. For example, if they say “sugar” rather than “diabetes,” you should feel comfortable doing the same so long as you make clear that the disease is more commonly called diabetes.

**Pay attention to tone of voice, pacing (the speed at which you speak), and sighs.** Nonverbal utterances like these can be as expressive as words. Talking quickly and loudly may convey impatience, while a more relaxed and quiet tone can indicate caring and concern. When health care providers make eye contact and smile, patients likely get a sense of caring and compassion. But when providers look away or scowl, patients may instead feel that providers are unfriendly or even hostile.

**Confirm understanding.** Use the teach-back technique to make sure that you and your patients truly understand each other. Start by putting responsibility on yourself (where it rightfully belongs) by saying something along the lines of, “Let me see if I’ve made myself clear.” Then ask relevant and specific open-ended questions like, “Some parents wonder when to call our office. If your child’s fever goes over 102 degrees, what will you do?” Or, “What will you tell your family about this medical procedure?” And after talking about the dosage for a liquid medication, you might say, “Show me which device you will use to measure this medicine.”

Likewise, make sure you understand correctly. Periodically stop and repeat back what patients say. For instance, “I heard you say that you have a lot of shoulder pain. Does that keep you from carrying grocery bags into the house?”

This way you not only confirm that you “get it” but also demonstrate that you are listening and paying attention.



### Story from Practice: The power of pausing

Donald Rubin, PhD, is a professor and researcher whose work focuses on assessment, training, and analysis of oral communication. This includes the concept of “listenability.” In 2010, we spoke about interactive health literacy and oral communication<sup>3</sup>.

Rubin said that silent pauses can be powerful tools when eliciting information. He said that just as nature abhors a vacuum, conversations abhor silence. “We all have a natural inclination to want to fill that space when we’re face to face with somebody.” He said that a pause over two seconds is pretty noticeable. A pause of 10 seconds can be uncomfortable.

“If a physician or any kind of health care provider is interested in eliciting information from a patient or consumer, imposing those kinds of silent pauses is very powerful. It’s probably even more powerful than asking direct questions. A lot of times, patients are not very well prepared to answer questions. They may answer them in very vague ways. When they’re confronted with silence, they will open up and do whatever they need to fill that silence,” said Rubin.

**Ensure clarity during telephone conversations.** A lot of health communication these days takes place by telephone. This includes one-to-one conversations, conference calls, “hotlines” and other crisis services, telephone triage centers, and recorded voice messages that you leave for others or they leave for you. In a 2000 interview, Suzanne O’Connor, RN, MS shared these helpful strategies when talking by phone<sup>4</sup>:

**Have help in your voice.** Set a pleasant tone in order to help the person at the other end of the conversation absorb information. Be as positive as possible, saying “I will” and “I can,” rather than “I won’t” and “I can’t.” When you must say “no,” state why and offer alternatives.

**When the caller is cheerful or friendly, respond in a similar fashion.** If the other person is sad or disappointed, be empathetic and acknowledge these feelings. When the caller is angry or agitated, stay calm and try to defuse the situation.



**Take responsibility for the direction of the conversation.** Redirect talkative callers. For example, you can say, “I hear your concern about \_\_\_\_\_. I’d like to help and wonder if you are calling to make an appointment.”

**Choose your words carefully.** Since the phone is auditory only, make sure your words are easy for others to understand. This often means using common one- and two-syllable words, like saying “doctor” instead of “physician.” It also means defining new or complicated terms, such as “durable medical equipment.”

**Record messages clearly.** When you leave a voice message, speak slowly and clearly. Give your name and phone number at the beginning and again at the end. This way, the other person hears twice how to reach you. It is also helpful to say the best times for returning your call. Another tip is to stand up when recording voice messages. I’ve learned from experience that you’re likely to sound more energetic this way.



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## Chapter 27

# Metaphors, Similes, and Analogies

### Starting Points

Metaphors, similes, and analogies are figures of speech used to help people understand unfamiliar words and concepts. They do so by comparing new information to that which people already know. While there are important distinctions among the three forms of speech, for the sake of simplicity, I'll use the overall term “metaphor.”



### Strategies, Ideas, and Suggestions<sup>1</sup>

**Determine when to use a metaphor.** Some health care concepts are straightforward and a simple explanation is sufficient. Save metaphors for times when you are teaching something that is unfamiliar or hard to understand. For example, you might use a metaphor to explain a new diagnosis like congestive heart failure but not for a well-understood condition like the common cold.

**Use words, terms, and examples that people know.** To be effective, the person you are speaking with needs to know what your analogy (example) means. For instance, saying “getting a vaccination is like installing antivirus software” may have meaning to someone familiar with computers. But if the person prefers camping to computing, you might instead say, “getting a vaccine is like putting on bug spray before going into the woods.”

**Explain the metaphor.** Metaphors by themselves are seldom sufficient. After you use one, follow up with a fuller explanation. If you say “An aneurysm is like a bulge in a garden hose,” explain how these concepts are alike by perhaps saying, “The bigger the bulge, the thinner the wall and more likely it will burst.” Acknowledge the limitations of your metaphor, as well. In this instance you might say that aneurysms happen only in certain parts of the body, while garden hoses can get bulges almost anywhere.

**Move beyond the metaphor.** After you confirm that the other person understands the metaphor, transition to the correct medical terminology. In the example above about an aneurysm, this means teaching relevant terms like “aortic aneurysm” and “cerebral aneurysm.”

**Confirm understanding.** Metaphors aren’t always obvious, nor are they necessarily understood in the way you intend. Sometimes they add to confusion. A physician was explaining to a patient that her heart is “like a pump.” He assumed that since the patient lived in a rural area, she would certainly understand this metaphor. While the patient smiled and nodded politely, it wasn’t until several visits later that she told the doctor she had no idea how pumps work. Knowing this, the physician explained her cardiac condition in another way. As with all forms of health communication, make sure that patients truly understand.



### Story from Practice: Examples of metaphors and analogies

In 2010, David Casarett, of the Center for Health Equity Research and Promotion at the United States Veterans Administration, and several collaborators, studied the use of metaphors and analogies in difficult medical conversations<sup>2</sup>. They found that this type of figurative language is a common communication technique.

Their study identified potential benefits and harms of this approach. For instance, metaphors and analogies can offer a simple and relatively easy way to enhance communication. But figurative speech might minimize or obscure certain information, such as prognosis or illness trajectory.

Here are examples of some of the metaphors and analogies in this paper:

- The rash will look just like a sunburn.
- Participating in an experimental trial is like being a pioneer, of sorts.

- Your bone marrow is an elephant. It has a long memory. It remembers everything it has even seen before.
- [Your treatment regimen] isn't a sprint. It's more like a long run. A marathon. You have to pace yourself.



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## Chapter 28

# Numeracy: Numbers and Data

### Starting Points

To understand most health information, people need a working knowledge of numbers. This is for tasks such as making sense of risk data, selecting healthy foods by reading nutrition labels, estimating costs and figuring budgets, and rating satisfaction or pain on scales from 1 to 10. Number-based tasks like these are considered part of “health numeracy.”

Health numeracy, as defined by Amanda Golbeck and her colleagues at the University of Kansas School of Medicine, is “the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistics, and probabilistic health information needed to make effective health decisions<sup>1</sup>.” This definition has been cited many times over the years.

Golbeck and her colleagues categorized health numeracy skills as:

**Basic.** This includes skills needed to identify numbers and make sense of quantitative data. These are used in tasks such as counting pills or knowing the time and date of appointments.

**Computational.** This includes skills to count, quantify, compute, and manipulate numbers. An example is totaling the number of grams of carbohydrates eaten in one day.



**Analytical.** These skills are needed to understand inference, estimation, proportion, percentage, and other high-level concepts. Examples include determining whether cholesterol numbers are within normal range, understanding basic graphs, and comparing insurance benefits.

**Statistical.** These skills are needed to critically analyze quantitative information to comprehend concepts such as risk and randomization or “blind” studies.

Nearly all health numeracy studies to date have concluded that the vast majority of the lay public struggles to understand and use numbers. In 2003 (the last year this survey was completed), the National Assessment of Adult Literacy<sup>2</sup> looked at quantitative literacy as a subset of literacy skills. The survey’s findings showed that:

- 22% of the adults in the United States had below basic quantitative skills
- 33% of the same population had basic quantitative skills
- 33% had intermediate quantitative skills
- 13% had proficient quantitative skills

More recently, the Program for the International Assessment of Adult Competencies (PIAAC)<sup>3</sup> has conducted surveys on similar topics. The PIAAC is a “large-scale international study of key cognitive and workplace skills,” of people between the ages of 16 and 65. These skills include the ability to use basic mathematical and computational methods. In surveys of 32 countries in 2012–2015, “U.S. adults scored higher in literacy than the PIAAC international average across participating countries; however, they scored lower in both numeracy and digital problem solving<sup>4</sup>.”



### Story from Practice: Know why you are using numbers

What message are you trying to convey? Are numbers essential to making this point? Despite any difficulty people may have understanding numbers, there are times when data should be used, says David Nelson, MD, MPH, an epidemiologist, health communication scientist, and author of numerous articles and books including *Making Data Talk: Communicating Public Health Data to the Public, Policy Makers, and the Press*<sup>5</sup>. We spoke in 2012<sup>6</sup>.

“Science is based on numbers,” said Nelson. “They are a way in which we distinguish ourselves by saying that this is actually based on some sort of research that we know. It’s not just an opinion or my belief about things.”

Nonetheless, Nelson advised considering whether to use data in some situations. He shared an example about communicating to the public what to do in a hurricane or other natural disaster. “I don’t think it’s necessary to quote some studies that say it’s a good idea to go to the basement and get away from a window.” If the primary purpose is to explain how to prevent injury, Nelson advised, “I would just tell them to take shelter without having to cite the scientific evidence and the numbers to prove it.”



## Strategies, Ideas, and Suggestions<sup>7-9</sup>

**Make concepts easier to understand.** Here are some ways:

**Appreciate that while clinicians and scientists may talk in terms of populations** (such as “2,753 out of 10,000 people are likely to \_\_\_\_\_”) many people are much more interested in “Will this happen to me?”

**Make clear what the risk is.** For instance, explain whether this risk is for getting diagnosed with a certain condition, or dying of it.

**When possible, state risk as absolute** (a new drug reduces a person’s risk from 2 out of 10 to 1 out of 10), not relative (the new drug reduces a person’s risk by 50 percent).

**As indicated, present results in positive terms** (95 percent of patients improve) rather than negative (5 percent of patients do not improve or get worse).

**Provide context.** For instance, if your patient’s cholesterol test came back with a level of 220 mg/dL, help them determine if this number is good or bad. One way is by giving additional information such as high and low parameters or what their cholesterol level was last year.

**Help people measure correctly.** Here are some ways:

**Mark how high to fill a drinking cup.** Or use a divided plate to show proper proportions of vegetables, fruits, protein, and grains. An example of doing this with graphics is MyPlate from the United States Department of Agriculture<sup>10</sup>.

**Compare quantity to known amounts**, such as “4 ounces of meat is about the size of a deck of playing cards.” Or “You can lift up to 5 pounds, the same weight as a bag of flour.”

**Use familiar measurements** such as ounces instead of grams, or cups instead of liters.

**Demonstrate fractions.** Fractions can be confusing. Some people may think that a bigger number in either part of the fraction means more. But a bigger denominator (bottom number) can actually mean a smaller piece of the whole. You might show what certain fractions mean such as comparing drinking glasses filled  $\frac{1}{3}$  and  $\frac{1}{2}$  full of water.

**Make calculations easier.** It’s preferable to give complete information and not require the other person do any calculations. But sometimes people do need to do so, such as adding the number of grams of fat or dividing a recipe in half. If meeting in person, sit next to them and do this together. In writing, line up numbers to show how to handle decimals, such as:

$$\begin{array}{r} 101 \\ 100.2 \\ +102 \\ \hline 303.2 \end{array}$$

**Consider how others might understand your words and symbols.**

**Clarify important concepts using both numbers and words.** For example, informed consent forms often include terms like “common,” “uncommon,” and “rare.” Make clear what these terms mean, such as by adding “A common risk affects at least 4 out of 10 people.”

**Avoid vague words** that are open to interpretation, such as “adequate,” “moderate,” and “some.”

**Be sensitive to words with multiple meanings.** This includes the word “and,” which could mean “to add” or “also.”

**Know that not everyone understands mathematical symbols.** These include: <, >, and +/–.

**Be willing to bend the rules.** Really, it’s often okay to write “5” rather than “five.”

**Confirm understanding.** Make sure patients truly understand numbers and data. You might, for example, ask patients to tell you how they will explain number-based information to a friend or family member. Make sure that you truly understand, too. Just because you are a health professional does not make you immune from number trouble.



### Story from Practice: Making an informed choice based on numbers

Maybe you're like me and of that age when body parts don't always work the way we want. Several years ago I was diagnosed with something serious, but treatable. Bitu Tabesh, MD was one of my many medical specialists.

Like patients and providers often do, Dr. Tabesh and I talked a lot about medication. She said that there are two very different classes of drugs for women with my health history. She explained them both and asked me to make an informed choice. To help me better understand the implications of each, Dr. Tabesh talked about numeric data including absolute risk, relative risk, numbers needed to treat, and five-year outcomes.

What I hadn't told her before was that I don't "do" numbers, at least not very well. Luckily, she noticed the blank look on my face and then gestured what these numbers mean: "Here's how much this new drug could help"—holding one hand high. "Here's the risk if you take it"—gesturing low with her other hand.

I'm a visual person. Thanks to her gestures, I "got" what Dr. Tabesh was talking about and made an informed medication choice. What's so special about this story? Nothing. And that's why it's important. Imagine what health care would be like if all providers explained numbers as clearly as Dr. Tabesh did with me.



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## Chapter 29

# Organizations: Health Literacy Across Programs, Companies, Communities, and Countries

### Starting Points

Health literacy initiatives often begin with just one person who is a health literacy advocate. Perhaps that is you. An advocate needs no convincing as to why health literacy matters. This person's "job," often as a volunteer, is to raise awareness about health literacy and encourage others to take action.

One person is often the way that health literacy initiatives begin. It usually takes a team to make a sustainable, long-term difference. Many teams start internally with employees and leaders of the organization. A good mix includes subject-matter experts (like clinicians, educators, and administrators), producers of health materials (such as medical writers and web designers), and people representing the intended audience including patients, families, and community members.

As teams experience success, they may branch out from their own initiative or program to the wider community. The goal could be to create a broader, more unified approach for health literacy. When the time seems right, this larger group might then reach out to like-minded others to form regional, statewide, multistate, and even national partnerships and coalitions.



As I know from many years of leading October's Health Literacy Month<sup>1</sup>, there is no need for health literacy efforts to stop at geographic borders. Indeed, since 1999 Health Literacy Month has been celebrated worldwide.



### Story from Practice: International Health Literacy Association

Kristine Sørensen is from Denmark. She's the first president of the International Health Literacy Association (IHLA), chair of Health Literacy Europe, and advisor on health literacy to the World Health Organization. In 2019, we spoke about how health literacy is growing worldwide<sup>2</sup>.

Sørensen shared the origin of her interest. Soon after learning about health literacy, Sørensen wanted to introduce this concept to European colleagues who did not yet know about it. She shared with them why health literacy is important not only in medical settings but also for the marketplace, political arena, work, and other aspects of everyday life.

Sørensen also met with, and learned from, health literacy advocates and scholars worldwide, including those in Asia, Australia, the United States, and Canada. She then established local and national health literacy networks with participants from many sectors and disciplines, all working towards the same goal.

She wanted a mix of participants who included not only “frontrunners and other health literacy champions who grasp this concept and run away with it,” but also those more resistant. It's important to address the needs of both, said Sørensen. “We as health literacy champions have an obligation to keep questioning whether this is the right way to do it and focus not only on the mind but also the heart.”



### Strategies, Ideas, and Suggestions<sup>3</sup>

I find it helpful to begin most projects by “dreaming big.” For example, when thinking of what to do for Health Literacy Month, you might first envision what it would be like if health professionals, patients, and the public always understood one another. Consider ways that your program or organization can help make it happen. Then break this into realistic “bite-sized” steps that you and others can do to accomplish this big goal.

Invite people who can help. This often includes those doing the day-to-day work of health communication along with patients, family members, and community representatives who share a similar vision. It helps to also include “influential others” such as elected officials, local business owners, and senior executives, who add visibility and can serve as health literacy champions.



## Story from Practice: How one person can make a big difference

Laurie Myers is the director of Global Health Literacy and Equity for Merck, leading the company's health literacy efforts worldwide. Myers has worked closely with others on numerous health literacy efforts. These include projects to improve communication about medication labeling, clinical trials, and patient education. In 2018, we spoke about these efforts<sup>4</sup>.

While Myers is just one person, she has overseen successful health literacy projects around the world. She shared tips about how one person can make a big difference:

**Make sure that health literacy aligns with your company's mission and purpose.** This is an essential first step.

**Meet with people representing your audience.** They not only include those doing the day-to-day work of health communication but also senior leaders who could serve as sponsors and champions. Listen to their needs and present a compelling case about how health literacy can help make what they do even better.

**Look for someone willing and able to lead this effort.** Myers serves as their coach by providing support, information, and encouragement.

**Believe that it's possible.** Dream big and be resilient, said Myers. If you don't, it will never happen. "As impossible as it seems, you can change a culture, whether it's with a 10-person company or a much larger one."



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## Chapter 30

# Patient and Family Perspective

### Starting Points

Providers and patients each need to communicate in ways the other can understand. Providers need to present information about diagnoses, treatment options, and self-care instructions. Patients need to describe their symptoms, ask questions, and express opinions about treatment and care. Both need to listen closely, respond thoughtfully, and remember clearly what the other just said.

This type of back-and-forth communication is often hard to do. It can be even more difficult when patients feel sick, scared, and overwhelmed. Here are strategies about how providers can help patients—and how patients can help themselves—when communicating about health.



### Strategies, Ideas, and Suggestions for providers<sup>1,2</sup>

**Appreciate why communication can be hard for patients.** Many patients find it difficult to participate in health conversations. They may fear that providers won't like them if they ask too many questions. They may be ashamed of not understanding certain medical terms or concepts. And as I and many others know, when faced with health challenges, it's exceedingly difficult to think quickly and communicate clearly if feeling vulnerable and exposed. In other words, it's very hard to communicate when naked.

**Honor the patient's experience.** Patients are, or after a new diagnosis will soon be, experts on what it's like to live with their disease or condition. Find out how much information patients want to know and how willing they are to actively be involved in decisions and care.

**Help patients ask questions.** One way to help could be to create a question-asking worksheet with headings of key topics like diagnosis, treatment, and self-care instructions. Leave sufficient space on this worksheet for patients to also write your answers.

**Acknowledge articles and printouts that patients bring to you.** Patients may come to appointments already somewhat informed about their illness or medication. They may have gotten information from the newspaper, television, the internet, or direct-to-consumer advertising. Let them know that you are open to discussing this. Also make clear that information like this is sometimes incorrect, biased, or sensationalized.

**Confirm that you and your patients understand each other.** Pause periodically and ask patients to tell you, in their own words, what they understand about topics just discussed. Make clear that you are doing this to check whether you explained information clearly. This is not a test of the patient's ability to learn.

**Help people learn more.** Make it easy for patients to learn as much as they want to know. Prepare lists of credible resources including books, articles, websites, blogs, hotlines, and associations.



### Story from Practice: My perspective as a patient

Talking about health and other medical matters had always been easy for me. As an occupational therapist and health-literacy consultant, I felt confident and in charge of conversations no matter which professional "hat" I was wearing. But after a routine mammogram turned out to be not so routine, I felt more than hatless. I felt naked. Now I had to communicate not as a provider or consultant, but as a patient.

The diagnosis was DCIS (ductal carcinoma in situ, a very early stage of breast cancer). Ironically, this was a condition I knew a good deal about. The year before, I had helped write the National Cancer Institute booklet *Surgery Options for Women with Early Stage Breast Cancer*. But now, as a patient, I was easily overwhelmed when talking with doctors about my diagnosis and treatment. I was often so flooded with emotion that I had trouble thinking and remembering.

Eventually, conversations got easier and I learned what I needed to know and do in regard to this diagnosis. I learned something else, too. It's that health literacy truly matters—to all of us who are, or ever will be, on either side of health conversations.



## Strategies, Ideas, and Suggestions for patients<sup>1,2</sup>

**Take note of your symptoms.** Keep track of when your symptoms started, how often they occur, and how long each episode lasts. Describe your symptoms in ways that help the provider understand. For instance, you could describe the intensity of pain using a combination of numbers and words. Even if your provider doesn't ask, you can rate the pain on a scale of 1 (no pain) to 10 (worst pain ever). You can supplement this with descriptive words about the pain, such as “achy,” “burning,” “stabbing,” “stiff,” “tingly,” or “annoying.”

**Invite family members or friends to act as advocates.** It can be extra hard to advocate for yourself when feeling vulnerable, scared, overwhelmed, or ill. If you anticipate that conversations might be difficult, consider inviting a family member or friend to come with you to this appointment. They might help by taking notes, voicing concerns, and later talking with you about what was said.

If this person cannot be present at important meetings, try to arrange other ways for that person to be involved, such as saying to your provider, “I'd like you to talk with my son. When is a good time for him to call?” A statement like that not only creates a follow-up plan but also gives permission for your provider to speak with this person.

**Overcome communication barriers.** If you have hearing aids or eyeglasses, use them during appointments. Tell your provider if they are speaking too softly, if written materials are hard to see, or if you do not fully understand certain words and concepts.

**Learn only as much as you want to know.** What surprised me the most when dealing with a serious diagnosis was that, for at least a while, I did not want a lot of “outside” information beyond what each provider told me. I've come to appreciate that there is no right or wrong amount of learning. While I was satisfied with limited amounts of outside information, others find it helpful to research as much as they can. My advice is to learn only as much as you want to know now. Later, you can find out more.

**Create your own medical record.** Just as health providers keep records about our diagnoses, treatments, and test results, patients can benefit by doing the



same. Especially in this era of medical specialization, it helps to keep track of what each provider tells you. There are many ways to do this, as with computer “thumb drives” or paper files. I use a three-ring binder with separate sections for medical reports, doctors, questions to ask, medications, and even a copy of my health care proxy. I also include a zippered pouch that serves as a catch-all for patient identification cards, upcoming appointments, and a pen for taking notes.

## Stories from personal experiences

Patients, often along with their families, are the true experts on what it is like to live with an injury, illness, or medical condition. I learn so much from hearing their stories about what this experience is like, how they manage, and what they want health care providers to know. Here are snippets from a few of these conversations from my podcast, *Health Literacy Out Loud*:

**Sudden injury**<sup>3</sup>. Bridget Gaglio, PhD, MPH was a senior program officer at PCORI (Patient-Centered Outcomes Research Institute) in Washington, D.C. Walking to work one morning, Gaglio also became a patient: the driver of a turning car didn’t see her in the crosswalk.

Gaglio was badly injured. It took several months and a lot of medical appointments for her to recover. Despite strong literacy skills and savvy about the health care system, it was hard being a patient. “In addition to the pain and misery, it was overwhelming to feel very vulnerable,” Gaglio said.

Until this injury, Gaglio had never been a high utilizer of the health care system. She said that there was a lot for her to figure out. This not only included keeping track of multiple appointments and test results, but also remembering medical instructions that were told to her when she was not feeling well. An important way that Gaglio learned to manage all this information was by creating her own medical binder.

**Chronic illness**<sup>4</sup>. Rosalind Joffe is founder and president of ciCoach, which gives people who live with chronic health conditions the tools they need to thrive at work. Joffe knows these issues well, as she has lived with a chronic illness for many years.

In our conversation, Joffe highlighted the importance of patient–provider engagement, which she describes as the joint sharing of information. “The health care provider has medical expertise that you don’t have. You have expertise about your needs, wants, and values,” said Joffe.

To learn more about each patient’s experience, providers should ask lots of questions, Joffe recommended. These should go beyond “Did you take your medicine?” Providers should also ask about the patient’s daily experiences, such

as “What’s it like for you to take four hours off from work to come to my office?” For patients, Joffe recommended taking responsibility by preparing and getting organized for appointments.

**Lifelong condition**<sup>5</sup>. Becky Curran was born with achondroplastic dwarfism (or, as she says, being a “little person.”) It’s a relatively rare genetic condition affecting about 1 in 15,000 to 40,000 people<sup>6</sup>.

As Curran said, it can be a problem when health care providers are not experienced treating patients with a rare condition like hers. She shared an example of getting weighed during a routine medical appointment. The doctor hadn’t met her before. Based on her age, rather than her height (Curran is 4-foot-1), this doctor said she was underweight. But when Curran later talked with another doctor who had experience treating people like her, she was told to lose weight, not gain more. She said it can be frustrating to get conflicting information like this.

Curran shared some recommendations for health professionals. “Be open to learning rather than assume that you know all the answers,” she said. “It’s better to say ‘I don’t know’ than just make something up. That can make the patient more upset and uncomfortable and begins to break the level of trust that they may have initially had.”

Another piece of advice is to use the right terminology. While Curran is comfortable with the term “little people,” someone else might not be. “If you’re hesitating in any way, call someone by their name and then work on the terminology with them. We’re a person before anything else,” she said.

**Family perspective**<sup>7</sup>. Sharon Cray has a degree in accountancy and worked in business for several years. But when two of her three children were diagnosed with cystic fibrosis, she entered the world of health care as a parent, caregiver, and very active volunteer.

In 2019, Cray and I spoke about the importance of including the “family voice” in treatment and care. She described this as a shared model in which the provider listens to a family or patient to come up with the best medical plan.

Cray spoke of the value of providers learning about the patient’s or family’s experience. “If you’ve never been in the situation where you have a sick child in a hospital room, you’re sleep deprived and stressed, I don’t think you can possibly understand what this is like.”

For providers who are uncertain about how to find patients and families to engage with this way, Cray said “They’re there. They’re right in front of you. If you need someone on your committee for that voice, start with the Family Advisory Council at your hospital or institution.”

For family members who may be reluctant to get involved, Cray advised, “I got better at this as we went along. You’re not going to be super great at the very beginning. You have to learn how to speak with medical professionals and that takes experience. She added, “If you have a professional that you don’t think is listening to you or even cares what you have to say or what your thoughts are, then you have to find another provider.”



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## Chapter 31

# Plain Language

### Starting Points

Plain language helps everyone, not just readers who have limited literacy or limited English skills. According to the Plain Language Association International (PLAIN)<sup>1</sup>, “A communication is in plain language if its wording, structure, and design are so clear that the intended audience can easily find what they need, understand what they find, and use that information.”

Writing in plain language is both a science and an art. The “science” part has to do with following established guidelines and using proven strategies. The “art” has to do with putting information together in ways that not only are understandable but also inviting, appealing, useful, and relevant.

Writing in plain language probably isn’t the hardest job you’ve ever done. But don’t be surprised—it may not be the easiest, either. I’ve learned from many years of experience that it can be hard to be simple.



### Story from Practice: Before and after examples

Here is a “before” version of flu vaccine information written when two flu shots were needed, not just one. I wrote the “after” as an example of what it might look like in plain language. Which version do you think readers would find easier to read, understand, and act on?

**“Before” example of original text<sup>2</sup>:****What You Should Know and Do This Flu Season If You Are 65 Years and Older.**

The best way to prevent the flu is with a flu vaccine. People 65 years and older are recommended for annual seasonal flu vaccination. People 65 and older who have not yet gotten a seasonal flu vaccine should still seek vaccination, although supplies of seasonal flu vaccine are limited because of early availability of, and high interest in, seasonal flu vaccine this year.

People 65 years and older are now encouraged to seek vaccination against the 2009 H1N1 virus. Supplies of the vaccines to protect against the 2009 H1N1 virus have increased dramatically and most places have opened up vaccination to anyone who wants it. This vaccine is the best way to protect against the 2009 H1N1 pandemic virus. Those who have been patiently waiting to receive the 2009 H1N1 vaccine, including people 65 years and older, are now encouraged to get vaccinated.

**“After” example in plain language:**

**Know what to do about the flu.** The best way you can help prevent the flu is by getting two flu shots. One is a shot to prevent the seasonal (winter) flu. The other is a shot to prevent a new flu called H1N1. The U.S. Centers for Disease Control (CDC) recommends that people who are at least 65 years old get both shots. You may have heard a while ago that there was not enough flu vaccine. That has changed and there now is enough vaccine for everyone who wants flu shots. There is no need to wait. Get your flu shots today.

**Strategies, Ideas, and Suggestions<sup>3-5</sup>**

**Build a team.** It takes a team to write a readable document. To me, this team should include: a plain language writer who is skilled in plain language and an unceasing advocate for readers; one or more content experts who determine what information must stay, or can go; and readers who represent your intended audience in terms of literacy level, language, age, culture, and interest in and familiarity with the subject matter.

**Identify project goals.** Whether working on your own project or writing documents for someone else, identify goals from the start. I do this by asking what readers should know, do, and feel as a result of reading this document. I jot down the answers, refer to them while writing, and review these goals when the project is nearly complete.

## Organize content in ways that make sense to your readers.

**Identify one primary message and support it with a limited number of (usually three to five) key points.** Obviously, when you write in plain language you cannot include everything because documents would be too long. Instead, prioritize “need-to-know” skills and behaviors that readers must learn rather than “nice-to-know” background information that is not essential.

**Organize key points in ways that make sense to readers (not just writers).** Generally, this means starting with the concept of “what’s in it for me,” which is about why people should read this information. When writing about a new surgical procedure, for example, begin with how patients can benefit from this procedure rather than how many awards your medical facility has won from doing it. At the end, summarize key points and include non-print resources (phone numbers, videos, organizations) as well as written and online materials.

## Use understandable words.

**Use common one- or two-syllable words.** It can be hard to choose the “just right” words, especially when writing medical information with lots of technical, multisyllabic terms. If possible, use common one- and two-syllable words that people know and already understand. An example is “high blood pressure” instead of “hypertension.”

**Define unfamiliar, yet necessary, words and terms.** Certainly there are times when you need a more technical term. If so, define it, show the correct pronunciation, and include a simply worded example or explanation. For instance, “Bronchitis, bron-ki-tis, a disease that makes you cough.”

**Be consistent,** using the exact same wording each time. Choose one term and use it consistently. For example, if you choose “bandage,” use it throughout the booklet rather than alternating with “gauze,” “compress,” and “dressing.”

**Be cautious when using contractions like “don’t” and “you’ll.”** Though contractions like these sound friendly and conversational, people with limited reading skills or those learning English may not understand them. Instead, write out the full words, as in “do not” and “you will.”



**Be sensitive to concepts, category, and value judgment words<sup>6</sup>.** Though familiar, these types of words can be difficult, as readers may not have a framework to understand their meaning. Concept words describe general or abstract ideas like “wellness” and “health status.” Category words include overall groupings such as “poultry,” rather than specifying chicken or turkey. Value judgment words refer to amounts or thresholds that readers must determine, such as “rarely” and “moderate.”

### **Write succinct sentences.**

**Have just one main idea** and no more than about 15 words in each sentence. This lessens the chance of writing complex sentences with lots of commas and clauses. You might break up large amounts of text with dotted (bullet) points, bold font, or extra white space.

**Vary sentence length and style.** It is possible to be clear and simple but not boring. Mix up your sentence length and style just a bit. For instance, instead of always writing choppy sentences like “Take 4 pills before breakfast. Eat breakfast. Go for a 30-minute walk,” you could write, “Start your day in a healthy way. Take 4 pills before you eat breakfast. Then go for a 30-minute walk after you finish eating.”

**Identify who is doing the action.** Use an active sentence structure to make clear who does what. An example is “Pat is baking an apple pie.” The passive and harder-to-read version is “An apple pie is being baked by Pat.”

**Be sensitive to conditional if/then sentences.** Health care is filled with lots of “iffy” conditional information, with sentences starting with “if” and having “then” in the middle. But these can be hard to understand, as readers must comprehend the “if” clause, the “then” clause, and relationship between the two.

### **Use an engaging tone.**

**Write in a friendly and conversational tone,** though not overly chatty or cute. Your tone should match the content. Sad or difficult subjects should not be treated lightly.

**Write as though you were talking, using personal pronouns like “you” and “your.”** One way to achieve this is by reading aloud as you write.

**Present information in as positive a manner as possible.** For example, start with what people can do rather than what they cannot. But also be honest. Do not refer to a medicine as a “pleasantly flavored drink” when it really tastes like chalk.

**Be clear and specific, not asking readers to guess or assume what to do.** For example, write “take two 10-minute walks each day” rather than “exercise moderately.”

### **Consider format and layout.**

**Write in a font size that is large enough to see.** Generally, this is 12-point type; 14- or 16-point type is preferable when writing for older readers or those who have limited vision. Avoid stylized or italic letters and instead use more traditional fonts such as Times New Roman or Arial.

**Use a combination of upper and lower case letters,** rather than all capitals. This way, readers get visual cues about the letters they see.

**Justify (line up) words on the left,** not centered or on the right. Centered text often results in uneven spacing that makes reading difficult. Also, readers know where to focus first when all lines begin at the same place on the left.

**Allow adequate white space.** Generally this is about a 50/50 split between print and non-print areas. Have margins that are at least an inch wide. This not only is easy on the eyes but also allows room for people to add notes, comments, questions, and doodles.

**Have a visual contrast between letters and background.** This usually is black type on non-glossy white or light colored paper. When making copies, make sure they are clear and easy to read. Sometimes, copies of copies are unreadable.

**Use headers to identify main topics.** Often, the most informative ones are written as questions such as “What Is Diabetes?”

### **Use graphics wisely.**

**Select graphics that are informative,** not just decorative. But some decorative designs are so appealing that they motivate people to read. If so, choose designs that do not distract from the message.

**Use recognizable images** rather than abstract symbols that might be misunderstood. For example, a red circle with a slash across it is commonly understood by people in the United States to mean “don’t,” but it may not be as familiar to those from other parts of the world.

**Show and tell readers the correct way to perform tasks** by having pictures with simply-written captions beneath. This can be very effective, such as when showing each step in a sequence of instructions.

**Select pictures that are culturally relevant and appropriate** to your audience. An example could be photographs of healthy, active seniors in a brochure for older adults.

**Draw internal body parts in context of the entire body.** This not only conveys size and proportion, but also avoids “disembodied body parts,” which people may find confusing or upsetting.

**Confirm comprehension.** The best way to determine whether readers can understand is by asking for feedback. Ask those representing the intended readers to review drafts of your written material. Find out what they think about the document’s organization, words, tone, layout, and graphics. Ask how they would use the information that they just read. Allow sufficient time not only to make needed edits but also to again ask for feedback so as to make sure you did not introduce new problems.



### Story from Practice:

#### Plain language means smartening up, not dumbing down

Karen Schriver, PhD is president of KSA Communication Design & Research, a consultancy focused on making information clear, compelling, and usable. Her book, *Dynamics in Document Design: Creating Text for Readers*, has been called a landmark in its field. We spoke in 2018<sup>7</sup>.

Schriver talked about the evolution of plain language over more than 75 years. “We’ve moved in enormous ways to include ideas about word choice, sentence style, structure of our sentences, and so on. We’re also looking at whole texts, paragraphs, quantitative displays, visuals, tables, charts, and everything that goes into the mix of good communication today.”

Schriver and I, along with many others, know that there are many benefits to writing in plain language. But we also know there are sometimes skeptics who question whether writing this way is “dumbing down.” Schriver addressed this by saying, “That pushback is coming from a place where people think that plain

language is only about substituting easy words for hard words. It makes people think that if you just make the hard words go away that results in a text that is less sophisticated and may be unprofessional or not smart-sounding. They may think that you're taking away the intellectual integrity of their text."

Schrivier shared an example of a project she worked on with clients who initially were plain language skeptics. Shriver explained, "I wasn't taking complex language and making it simpler. I was taking complex ideas and making them apparent in the structure of the text."

Once they could see how Schriver shifted the document's focus from the point of view of the organization to that of the reader, the skeptics overcame their reluctance. "We forgot to tell readers what to do," they acknowledged.



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## Chapter 32

# Question-Asking

### Starting Points

“Do you have any questions?” the provider asks. The patient shakes his head, indicating “no.” While the provider might assume that this response means she did a good job communicating, the patient may think this is a polite way of not saying how confused he really is.

It is hard for many people, no matter how savvy or well educated, to think of questions to ask when sitting in a medical exam room wearing only a skimpy hospital gown. Question-asking can be influenced by emotions and culture. It might be that patients do not ask questions because they feel scared and overwhelmed, or fear asking a “stupid” question. This reluctance may also be cultural or generational, as when people believe (like my mother did) that it is rude to question those in authority.

Despite these challenges, health literacy and patient safety experts agree that question-asking brings many benefits. Those include helping people learn new content, confirming they understand key concepts, and framing information within a more personal context.

“Questions Are the Answer” is an initiative to encourage question-asking from the United States federal Agency for Healthcare Research and Quality (AHRQ)<sup>1</sup>. Its website includes “10 Questions You Should Know,” with sample questions including “What is this test for?” “Are there any side effects?” and “How many times have you done this procedure?” There also is a Question-Builder app, designed to “help patients and caregivers prepare for appointments and maximize visit time.”



## Strategies, Ideas, and Suggestions

**Elicit questions with open-ended phrasing.** Ask questions in ways that encourage a range of responses, such as “What are your questions?” This open-ended phrasing lets patients know that questions are expected, as opposed to close-ended (yes/no) phrasing like, “Do you have any questions?”

**Offer reassurance.** Help patients feel more at ease by letting them know they can ask any question they want. When patients sheepishly admit they have some “stupid questions,” reassure them that there are no “bad” (rather than “stupid”) questions. Indeed, you’ve most likely heard all these questions before.

**Encourage patients to write questions ahead of time.** Make it easy by providing pens and paper in waiting areas and exam rooms. As needed, add a clipboard or other hard writing surface. You could also let patients know about helpful resources to prepare for appointments, including questions they might want to ask. An example is “The Patient’s Toolkit for Diagnosis” from the Society to Improve Diagnosis in Medicine<sup>2</sup>.

**Consider the expense of not eliciting questions.** Do you fear that answering a patient’s question will take too long? If so, consider the potential expense when patients later call to clarify information or cannot follow directions for a medical problem that might have been avoided if only they correctly knew what to do.



### Story from Practice: Prepare commonly asked questions

Lisa Bernstein, then of the What to Expect Foundation, worked with providers at prenatal clinics who often saw women with limited education, literacy, or language skills. We spoke in 2006<sup>3</sup>.

Bernstein said that these women were often reluctant to ask questions. One helpful strategy that she recommended is for providers to prepare commonly asked questions. Then when a woman says she has no questions, the provider can readily say, “A lot of women in their [x] month of pregnancy ask about [topic]. Is that a question you want me to answer?”

Bernstein found that doing this not only starts a dialogue about the topic but also models good question-asking behavior.



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## Chapter 33

# Regulatory and Legal Language

### Starting Points

Regulatory and medical-legal documents, such as research informed consent documents, HIPAA (Health Insurance Portability and Accountability Act) materials, and institutional administrative or procedural forms, are notoriously difficult to read and understand. Many are written at college reading levels or beyond and filled with “legalese” and medical jargon, a combination understood mostly by lawyers, administrators, and bureaucrats.



### Story from Practice: Research consent forms

Kristofer Griffith is the associate director of Human Subjects Protection at the University of Texas MD Anderson Cancer Center. Among his many responsibilities, Griffith works with an editorial team to manage regulatory aspects of human-subjects research as submitted through their Office of Protocol Research. That includes writing research consent forms. Griffith and I spoke about this in 2012<sup>1</sup>.

Griffith acknowledged that these forms can be difficult to write, and to read. He says that research consent forms are different for every study or research project. They often include very long drug names and are about complicated procedures. “It’s a challenge to bring down the readability level so patients can understand exactly what they’ll be going through when they join a research study.”

With experience writing thousands of research consent forms, Griffith and his team have found ways to make elements of them easier. One way is with formatting. “Let’s say you have 100 different side effects that may occur with a drug. You could put those in a paragraph or bullet them,” said Griffith. “In our department, we bullet them not only in three columns so that they’re nice and straight, we also organize them alphabetically by body systems so that the cardiacs are together and the hepatic toxicities are together.”

Beyond the form itself, Griffith and his team write a one- to two-page study description. “We highlight the purpose of the study in one or two sentences. We state the aim, whether it is to shrink the cancer or check quality of life. Then we briefly describe the possible tests that can happen. We talk about the most important side effects.”

Griffith acknowledged that this companion piece does not meet any legal requirements. Rather, it can serve as a reminder for patients. “They can take this home and put it on their fridge. They also have the full consent form, but this will give them a quick reference guide. It’s something that’s understandable for patients.”



## Strategies, Ideas, and Suggestions<sup>2,3</sup>

**Organize information from easier to more complex.** While the content of medical-legal documents may be mandated by in-house policies or outside agencies, the order in which information is presented is generally not. To improve readability:

**Consider starting as newspapers do** with basic information about who, what, when, where, why, and how.

**Include an introductory statement** about why this information is relevant to readers. Some refer to this as WIIFM, “What’s In It For Me.”

**Present easier information first**, followed by the more difficult. You can do this for the entire document as well as each section.

**Provide a “layered notice.”** This is a brief (1- or 2-page) summary of key points written in plain language. You can attach this summary to the more complex legal document.

**Apply the principles of plain language.** As possible:

**Write in a conversational style** using terms like “you” (the patient) and “we” (the organization or provider).

**Explain new concepts by putting them into context and giving examples.** That includes important terms such as “risk” and “benefits.” I frequently describe risk as “problems that sometimes happen” and benefits as “ways that this [medication, treatment, or procedure] can help.”

**Design documents so that readers can easily find needed information.** One way is with headers clearly indicating each section.

**Use common words that people already know.** Examples include “choice” instead of “alternative,” and “tell us” rather than “notify.”

**Show words with close variations in parentheses.** An example is “‘Co-patient’ (sometimes called ‘co-insurance’ or ‘co-pay’).”

**Encourage readers to take action.** Provide spaces below key content with directions such as “Write any questions about what you just read.” You might also ask readers to circle words they do not know or might not fully understand. Follow up by explaining these words in greater detail.

**Remember that patients may be reading an informed consent document for the first and only time.** The purpose of informed consent is twofold: (1) to inform the patient about a medical procedure so they can make an informed decision, and (2) to obtain legal consent for the provider to perform it. When providers do the same procedure thousands of times, it can be easy to forget that patients might be reading this document for the first and only time.

**Create an environment in which people can ask for help.** Make sure that the environment in which people are asked to read and sign legal forms feels private and is secure. For example, if you ask patients to write phone numbers on a form, have a way to shred discarded copies. Be sensitive to people’s physical and emotional states, as well. For sure, it is difficult for patients to concentrate on complex information when they are sick, anxious, or pre-medicated for a procedure. One way to help is by giving patients consent forms for elective medical procedures ahead of time. Another is by offering to read documents aloud.



## Story from Practice: A lawyer's perspective of health literacy

Christopher Trudeau, JD is a lawyer, law professor, and long-time health literacy advocate. In 2016, we spoke about a growing awareness of health literacy among lawyers<sup>4</sup>.

Trudeau's background is in plain language. He said it's a natural fit for him to write employment contracts, business agreements, and other legal documents in ways non-lawyers can understand. But Trudeau is well aware that encouraging other lawyers to do likewise might be a "harder sell."

He said that one factor for reluctance is that lawyers often build upon what they've done in the past, including choice of words. An example is the long-ago term, "inter alia" which he says could just as clearly be stated as "among other things." Another factor is the necessity to include terms that have specific legal meanings.

Trudeau spoke about the origin of his interest in health literacy. "Every single person uses the health system. That's what really motivates me." He advocates that lawyers and health care professionals find ways to work together. The shared goal is to protect health care organizations legally while also taking the patient's perspective into account. Trudeau shared examples of ways health professionals might encourage lawyers to get on board when it comes to health literacy:

**Include lawyers on the team that develops documents.** Trudeau said that doing so gives lawyers some ownership in the creation of documents rather than just oversight or review.

**Look for ways to compromise.** "If the lawyer's sticking point is about specific regulatory language that must be included, that's fine," said Trudeau. But look for other ways to help readers, such as with designs that make the document easier for patients to see and use.



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## Chapter 34

# Stories

### Starting Points

Stories are powerful health communication tools. Combining emotions and facts, stories help people connect with health information in a very personal way. Audiences of all ages and cultures relate to stories because they help people bridge differences and find qualities they have in common. Stories are not only engaging and entertaining, but also easy for most everyone to understand, even those who have trouble reading or paying attention.

Distinct from other types of communication, stories have a beginning, middle, and end, though not always in that order. They also have characters (real or imagined) who convey feelings and communicate ideas. While stories should always contain essential truths (the points you are trying to convey), the details do not all need to be factual (such as changing a character's name or setting where the story took place).

You can tell a story to one person or to many, to professionals or the lay public, to children or adults, in formal as well as more relaxed settings. For most people, albeit not everyone, a well-told story is almost always welcome.

Here's my story about understanding the power of stories: I met Senator Edward M. "Ted" Kennedy many years ago at an event about health care reform. We spoke briefly and I asked about his commitment to health care. Senator Kennedy responded by telling me stories about his family's health care, including his mother's home health care, his son's leg amputation, and his own experience with a broken back. Beyond hearing why health care issues mattered so much to him, I also learned that even a United States senator knows the value of personal stories.





## Story from Practice: *My Life, My Story* from the VA Healthcare System

The United States Veterans Administration (VA) Healthcare System launched an initiative called *My Life, My Story* to help patients tell and share their personal stories<sup>1,2</sup>. Susan Nathan, MD is a geriatrician and hospice and palliative medicine physician. She also is site director for the *My Life, My Story* Project at the VA hospital in Boston, Massachusetts. Thor Ringler is a poet, therapist, and national program manager for *My Life, My Story*. He works as a writer and editor at the VA hospital in Madison, Wisconsin. The three of us spoke about this initiative in 2020<sup>3</sup>.

Ringler explained that *My Life, My Story* was started by a psychiatry resident and two of his mentors who wanted to get to know their patients, even before meeting them. “They had this thought, ‘Wouldn’t it be great if there was a story, a short narrative, about the person and what matters to them in the medical record that providers could read?’ That’s where the project really got its genesis,” said Ringler.

Nathan is a full-time clinician. While caring for a patient in the hospice unit, she read his story, written by a social work intern just a few months prior. “It gave me so much information,” said Nathan. “It was almost like I could see him again compared to where he was now, so declined and alone.” She said that to her this experience was transformational.

Ringler, Nathan, and others now help make this program happen throughout the VA system. The process starts by asking veterans if they want to share their story. They are welcome to do so, or not.

For those who choose to participate, a writer, trainee, or volunteer might begin by asking, “What do you want your care team to know about you as a person?” Interviews take about 45 minutes, after which the interviewer writes up a story of about 1,000 words. It’s told in the veteran’s voice, in the first person, and reflects the contents of the interview. The writer then returns that story to the veteran who can make any changes they want. The story goes into the medical record only after the veteran approves it.

By many accounts, *My Life, My Story* has been a great success. Ringler shared this comment from a veteran, “Going through this process of writing my life story has helped relieve some of the pain, physical and emotional. But more importantly, just when I thought I hadn’t made an impact on anyone’s life, after sharing my story with family and friends, I realized that I did.”



## Strategies, Ideas, and Suggestions<sup>4-6</sup>

**Tell stories.** When telling stories in health care settings, make sure the stories are relevant and true, do not violate anyone's privacy, and are not told simply to be entertaining. Sometimes, you will need to make clear why you are telling the story, perhaps by saying, "Let me tell you about someone with a health history like yours who \_\_\_\_." Other times, the reason for the story is evident. Stories don't have to be lengthy or stand alone. As you can see, I sprinkled mini-stories (anecdotes) throughout this book to make key points "come alive."

**Encourage patients to share stories.** By listening to stories, providers can learn a lot about patients' strengths, concerns, and points of view. You can encourage patients to tell you stories by saying "Tell me about a time that \_\_\_\_." Or "Give me an example of the problems you have when \_\_\_\_."

**Help patients focus on the point of a story.** Telling stories needn't take a long time. If you feel that patients are talking in too roundabout a way, help them focus by saying something like, "You started talking about your heart and now you're telling me about your feet. Please tell me more about how these problems connect." Being directive like this is preferable to asking patients to be "brief," which may cause them to filter out details that may or may not be important.

**Listen for what's missing in a story.** When listening to stories, especially ones told by patients, consider the story in its entirety. If the story does not make sense, find out what is missing or is wrong. Encourage patients to listen to their own stories, as well. It's likely that the version they tell you differs in some way from what they share with family and friends. Make sure you understand patients' stories correctly, perhaps by saying, "Let me tell you what I heard," or "Correct me if I have any of the details wrong." And, of course, thank patients for sharing their stories.

**Decide whether to share stories from your own experience.** Whether you use stories in clinical practice or educational settings, there are risks and benefits in talking about your own experience. When sharing your own story, you run the risk of diverting attention from points you want to make or the person you are treating. But used carefully and told well, stories can be an effective way to help patients and health care providers better understand what the other has to say.



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## Chapter 35

# Technology: E-health

### Starting Points

There are many recent advances in communicating about health and providing care in ways other than in person. These include telemedicine, email, patient portals, and open notes. I refer to these collectively as e-health. Below are some stories, examples, and how-to suggestions.

### Telemedicine

The terms “telemedicine” and “telehealth” refer to similar, but not exactly the same, ways of communicating clinical information remotely. These are often done by phone or with video conferencing. Topics can vary, whether about general health issues or more focused clinical encounters. For the sake of simplicity, I refer to both as “telemedicine.”

Telemedicine greatly expanded in 2020 due to the COVID-19 pandemic that prompted an urgent need to reduce in-person contact. This change was abrupt. Clinicians were learning how best to do telemedicine while they were doing it.

Cliff Coleman, MD, MPH is a family medicine physician and health literacy researcher and champion. When we spoke in 2021, he had just written a paper about the benefits and downsides of telemedicine, along with ways to make the most of this new form of health communication<sup>1</sup>.

Beyond its value during the pandemic, Coleman sees many benefits of telemedicine. “It’s been known for decades that many primary care practice visits don’t actually require seeing someone face-to-face.” He shared the example of diabetes self-management. “What we really need is a half-hour discussion about

why a person's blood sugars are not being well controlled. That doesn't necessarily require physically touching the person."

But there also can be drawbacks to telemedicine visits. Coleman said that it's a lot easier to express empathy and non-judgmental attitudes when meeting in person such as by leaning forward, having good eye contact, and having a non-judgmental look on your face. But these non-verbal strategies are, of course, not possible when communicating only by phone. Coleman says it is as yet unknown how these apply to two-way video communication.

Building on health literacy best practices, Coleman finds these strategies helpful in telemedicine:

**Have a clear agenda.** Coleman said that it is important to know upfront what's important to patients. He recommended finding out what patients want to discuss and then helping them prioritize these topics. "I spend as much time as it takes doing that," he said. "Otherwise I've found that visits will run way past their allotted time and we may not get to the thing that the patients are most concerned about. That's bad for patient satisfaction. It's bad for the provider's satisfaction, as well."

**Conclude your conversation in a meaningful way.** After addressing everything on the patient's agenda, Coleman will summarize key points. He also offers patients an opportunity for clarification and questions.

**Use teach-back to confirm understanding.** Coleman always wants to check whether patients understood the topics just discussed. On a telemedicine call, he might begin with, "Since I'm not there with you, I want to make sure I've done a good job explaining. Can you tell me what the plan is in your own words?" Coleman said that teach-back is an important strategy regardless of your mode of communication.

## Email<sup>2,3</sup>

Email seems to be growing in use as a way for patients to communicate directly with clinicians. There are many advantages. People may respond at their convenience, messages can be printed and saved, and hyperlinks can be added so people need only click for more information.

But email also brings concerns about privacy and security. For instance, people who share computers can sometimes access messages intended for others, and employers might be allowed to read personal messages their employees send from work, even when using a personal account<sup>4</sup>.

Here are some suggestions to use in practice:

**Make clear that email is not to be used for medical emergencies.**

Patients need to fully understand that this form of communication is not for emergencies. There is no guarantee that providers will see messages quickly enough, nor is there assurance that patients will read responses in time to take needed action. Talk with patients ahead of time about what to do for more immediate health concerns.

**Use plain language.** Make sure that your email messages are easy to read. This means using plain language principles such as common 1- and 2-syllable words, short sentences of up to 15 words, and short paragraphs with only 2 or 3 sentences. These principles are even more important when replying to a patient's email that has a lot of spelling, punctuation, and vocabulary errors. Those might be indications that the writer has problems with literacy, language, or technology.

**Replying to messages.** Let patients know when to expect replies from you—such as within 24 hours, or 1 to 2 days. It helps to have an automatic response that notifies patients that you received their message and has a phone number they can call for assistance.

**Consider the most appropriate way to respond.** Just because patients send you email messages doesn't mean you need to reply the same way. For example, you likely will not want to use email when conveying bad news or discussing complex treatment options. Instead, you might email to arrange a follow-up call or in-person appointment to talk more about these issues.

## Patient Portals

Patient portals are secure websites where patients can easily access their personal health information whenever they want. This includes information about recent visits, medications, and lab results. While this easy and rapid access can be helpful, it can also be problematic, as when patients see their lab test results without a clinician to interpret those results.

Brian J. Zikmund-Fisher, PhD is a professor and researcher who designs and evaluates novel communications to make health data more intuitively meaningful. This includes visual ways of helping patients make sense of lab test results accessed through a patient portal. We spoke in 2018<sup>5</sup>.



“Most patients have no experience interpreting results and don’t know how worried they should be,” said Zikmund-Fisher. His research has identified a variety of ways to use visuals that help make results easier for patients to understand and act on.

In particular, he noted that simply providing the standard (normal) range is not enough; patients need more context. For example, effective test result communications should also do the following:

**Break down the space outside the standard range** in terms of degrees of risk, such as borderline or high risk.

**Provide a clear threshold** of when patients need to act.

**Show target ranges** when a patient’s real-world results fall outside the standard range. As an example, for someone diagnosed with Type 2 diabetes, there can be a range of results for A1c (a measure of blood glucose) that fall outside the standard range but nonetheless are what they should aim for.

As Zikmund-Fisher has learned, “Evidence is pretty clear that using visual displays can make a difference in helping patients understand what their test result is and not to worry too much.”

## Open Notes

In April 2021, the United States implemented the 21st Century Cures Act<sup>6</sup>. This states that patients must be given free access to most of their personal electronic health information, including eight types of clinical notes, using a secure website or smartphone app. This can take the form of “open notes,” a way for patients to access clinical notes in their own medical records.

Susan Woods, MD, MPH is a general internist and consumer health informatics expert. Her work focuses on technology to engage patients and their families in health and health care, including with open notes.

Woods and I spoke in 2016<sup>7</sup>. She acknowledged initially being a skeptic about open notes. She now is a big proponent. She said that this shift came from understanding the perspectives of both patients and providers.

Woods looked at many surveys and studies about the patient’s thoughts about open notes. “An overwhelming proportion of people say, ‘Yes, absolutely, I’d love to have access to my information.’”

We discussed how some doctors initially responded to open notes. Woods said that some were concerned that certain information might worry patients.

Her reaction to this was, “Shouldn’t you be telling them? Shouldn’t you be communicating that?”

Woods acknowledged that patients may have trouble understanding some medical terms in open notes. Her advice to medical colleagues was, “Keep at the front of your mind that the patient or family member is also going to be reviewing this. Write to them, as opposed to about them.”



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## Chapter 36

# Technology: Online Teaching and Video Games

### Starting Points

Technology allows us to do amazing things, including teaching remotely and playing online games. Technology also allows for multimedia, by presenting information using elements of text, animation, video, music, and the spoken word. Given the rapid development of new technology, it is likely that there will be numerous options to use technology in health education. This chapter is a place to start.

### Online Teaching

Teaching, whether for patients or staff, is increasingly taking place remotely, as with virtual conferences and online webinars. There certainly are advantages to teaching this way. Participants can be from outside the local geographic area. They might be able to attend at times that are personally convenient, whether that means participating in real time or later watching a recording of the session.

Admittedly, there also are disadvantages. People without access to adequate technology or comfort using it might not be able to participate. Instructors have limited ways to “read” the audience’s level of interest and engagement when teaching from afar. That makes it difficult to adjust the content or pacing based on participants’ non-verbal responses.



## Strategies, Ideas, and Suggestions: Online teaching

Mark Hagerty is an instructional designer and learning specialist. We spoke in 2020 about creating webinars and other training programs for times when, as he described, “there is a layer of technology between you and your audience or students<sup>1</sup>.”

Hagerty shared recommendations for designing online teaching programs.

**Design programs with a team.** In addition to designing programs with content experts, include another person to serve as its producer, Hagerty recommended. The producer not only can help design the program but also watch as it happens and respond to technical questions from participants.

**Consider timing, pacing, and flow.** Obviously, teaching online is not the same as teaching in person. Hagerty recommended that online programs be no longer than two hours, and preferably less than one. He recommended creating an outline that takes into account pacing, flow, and when to insert stories, slides, and opportunities for interaction.

**Decide about slides.** Do you really need all those word-based slides? I doubt that I’m the only one who thinks not. While most participants appreciate visuals, it is your choice as to what kind and how many. When teaching about health literacy, my preference is to use visual slides, rather than word-based ones. I work with a graphic artist who creates these for me. Based on audience feedback, these slides not only are fun to look at but also make key points more clear.

**Allow for interaction.** Participants like to participate, not just be passive recipients of facts and instructions. Many online teaching platforms have the capacity for chats, quizzes, polls, and other forms of interaction. There also may be options for participants to break into small groups for practice and discussion.

## Online Games

Nick Bowman, PhD teaches, researches, and writes about the uses and effects of video games and other interactive media. In 2020, we spoke about online games in regard to health<sup>2</sup>.

Bowman explained that there are many types of online games. They include active character-driven ones as well as activities like playing bridge or other card games. What these diverse types of games have in common is that each has rules and a defined goal or outcome.

Bowman acknowledged that online games have both advantages and drawbacks. Advantages include:

**Stress management.** Bowman researched how video games can help people who are experiencing stress or other “noxious mood states” that damage their ability to be mentally healthy, perform, or be comfortable. “Video games are remarkably absorbing,” said Bowman. “You’ve got to process information, think about your opponents, do strategy, and basically take a bunch of mental notes.” He added, “It’s hard to do that and be stressed at the same time.”

**Increased attention.** Bowman found that playing games requires visual attention and mental rotation. “You’re looking at a screen that’s two-dimensional and often the things you’re thinking about are three-dimensional,” he said. “Whether you realize it or not, you’re practicing those muscles. You may not sweat doing so but find that your attention increases.”

**Socialization.** While online games are often played by one person alone at a computer, games can promote socialization, Bowman said. Some of the early video games required two or more players. Bowman said that this was because the games needed components from multiple computers. Later, people started playing online games in social spaces like bars and arcades. Now, thanks to built-in interactive features such as chats, players can interact with each other remotely. As Bowman found, “People often spend as much time talking to each other about life as they do playing the video game.”

There also can be drawbacks to online games. These include spending more time than originally planned on this activity. I know from playing a lot of online bridge how time seems to whiz by and, despite my best intentions, many hours pass before I stop. Bowman said that this is referred to as a “flow state,” when people are engaged in an intrinsically motivating activity. Another important concern is the potential for harassment when people who would not ordinarily interact play online games together.

Online games are increasingly being used as tools to teach about health. MedlinePlus can be a good place to start searching for online health games<sup>3</sup>. This list includes a wide array of interactive games on topics that include child nutrition, drug use and addiction, and vision impairment.





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## Chapter 37

# Technology: Social Media and Podcasts

### Starting Points: Social media

Digital content includes blogs, tweets, podcasts, and many forms of social media. Some technology experts believe that sharing content this way is as significant a milestone in communication as the invention of the printing press, radio, and television. But, of course, it also brings risks such as the very real concerns of privacy and credibility.

Digital content today is being used in all aspects of our lives, including health communication. Pamela Katz Ressler, MS, RN, HNB-BC is a nurse and expert on building resilience, including with social media. In a 2017 interview, Ressler shared examples of using social media as an adjunct to patient education and a forum for peer support<sup>1</sup>:

**Patient blogs.** Ressler thinks of patient blogs as expressions of their experience of illness. She said that blogs offer tremendous potential for helping patients feel less alone and more in control of an illness or caregiving situation.

**Peer-to-peer online health communities.** These offer a forum for patients to share experiences with others who have the same, or similar, illness. In many ways, peer-to-peer online communities are like traditional in-person support groups. Ressler was enthusiastic about the benefits of meeting online. “It’s not that different from what we used to do around the kitchen

table or across the back fence,” she said. Except that now “we’re doing this in global, digital communities.”

**Tweets.** Tweets are very short bursts of communication posted on the social network Twitter. They can be an effective and efficient way to quickly share up-to-date news and information about certain diseases or health conditions.

**Tweet chats.** These are when many Twitter users share information on a focused topic at the same time, using the same hashtag to connect tweets of the same topic. “The beauty is that there are many different voices happening. The downside is it can be a bit like drinking from the firehose,” said Ressler. For those who cannot participate in real time, tweet chats can be accessed later by searching for that hashtag.



### Story from Practice: Social media creates personal connections

Pam Ressler’s interest in social media began because of her role as a mom, not as a nurse. In 2001, her 14-year-old son Nick was hospitalized with advanced cancer. While blogs and social media hadn’t yet been invented, Nick liked staying in touch with his school friends by IM (instant messaging—like text messages today). “Nick wanted to be a kid without his cancer diagnosis in the forefront,” said Ressler in an informal conversation. She said that by IM-ing with his friends, Nick could maintain a sense of normalcy despite his incredibly difficult situation.

Sadly, Nick passed away. But his enthusiasm for connecting through technology lives on. Ressler, then and now, sees tremendous potential for using social media to allow people, no matter their diagnoses or limitations, to create incredible and personal connections in age-appropriate, no-hassle ways.



### Strategies, Ideas, and Suggestions: Social media

The use of online communication for health is rapidly changing. There admittedly is a lot yet to figure out when it comes to best practices. Here are two examples of ways to help.

**Have a digital strategy.** Leigh Curtin-Wilding, MSc is a marketing communication professional. She also directs and teaches at Boston University’s graduate program in Health Communication. In 2018, she and I spoke about the importance of having a digital strategy<sup>2</sup>. Curtin-Wilding said that this strategy can serve as a roadmap to better understand who your users are, how they

came to your information, what they're using it for, and how long they remain engaged with your digital content. She recommended creating content that is agile and adaptable for many digital platforms. That includes headlines, questions to users, and short bursts of information that can be adapted to tweets or other social messaging.

**Curate content to match information needs.** Andy Rosenberg founded Responsum Health, an online educational tool with curated content for people who have chronic or rare diseases<sup>3</sup>. In 2017, Rosenberg and I spoke about the importance of offering information in regard to where patients are along their journey of chronic disease<sup>4</sup>. He explained that phases of this journey include noticing symptoms, getting diagnosed, doing research, receiving treatment, and living with the disease. People may have very different information interests and needs in each of these phases.

## Starting Points: Podcasts

In many ways, podcasts are like radio shows, in that listeners can hear what interests them, including interviews on focused topics. But unlike radio, listeners use their own audio devices to access podcasts whenever and however they want.



### Strategies, Ideas, and Suggestions: Podcasts

I'm a long-time podcaster. In 2008, I created the podcast series Health Literacy Out Loud (HLOL)<sup>5</sup>, and continue as its producer and host. Since the start, I've been working with Adam Weiss as the audio editor. He also is a podcast and media consultant.

Here are some of our recommendations about starting a podcast series:

**Choose a podcast format.** The three most common are: 1) Highly produced radio shows. These often have several separate segments that are later mixed together. An example is *This American Life* with Ira Glass<sup>6</sup>. 2) Lecture format. This is just one person talking. But unless they are especially well done or the topic very compelling, people may find it tedious to listen to long lecture-type podcasts. 3) Interviews. To do these well, the interviewer needs to be an excellent questioner and listener, and committed to making guests shine more than the host. That is what I aspire to.

**Decide about time.** This includes the length of each podcast along with the frequency of new episodes. The upper limit for HLOL episodes is about 25 minutes, which often fits within the span of someone's commute

or workout. Try to post at least one new podcast each month. That way, listeners can anticipate when they can hear the next one.

**Acquire needed technology.** These days many podcasts are recorded by phone, rather than in-studio or face-to-face. If you can, use software that records in stereo, with each person's voice on a separate track. This is helpful when editing. For good quality audio, it is best to use a plug-in microphone rather than the one built into your phone or computer.

**Edit the podcast.** While there certainly is software to do this yourself, I prefer working with an experienced audio editor. After each HLOL recording, I send Weiss the audio file along with edit notes. These include specific requests, such as to lessen extraneous sounds or replace a mispronounced word with the correct one. Weiss also cleans up some repetitive yet unnecessary words, like “um” and “er.” But he does not delete or change any content unless I specifically ask. Weiss describes what he does as an audio editor as “I make you sound like you, only better.”



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## Chapter 38

# Universal Design

### Starting Points

Universal design describes a concept of designing products, environments, and communications that not only considers the specific needs of people with disabilities but also takes into account the more universal changes that everyone faces as they age.

Curb cuts on sidewalks are an example of universal design in the built environment. They help people in wheelchairs and are valued by parents with baby strollers and travelers with wheeled suitcases. Likewise, in health communication, universal design can be helpful to all. This includes easy-to-read brochures and easy-to-use websites that almost everyone can see, understand, and use.

Imagine being a new patient or visitor at your hospital or clinic. You are feeling sick or scared and perhaps having trouble finding where you need to go. It is not just written materials, websites, and oral communication that impact health understanding. The environment of care matters too.



### Strategies, Ideas, and Suggestions: Health communication

Valerie Fletcher is executive director of the Institute for Human Centered Design (IHCD) in Boston, MA. She and I talked about universal design as it applies to health communication in 2001<sup>1</sup> and in 2010<sup>2</sup>.

Fletcher said that universal design is a framework for the design of places, things, and information that focuses on the widest range of people operating in the widest range of situations without special or separate design. “If a design



works well for a person with a disability, it probably works better for everybody.”

Fletcher spoke of functional limitations that people often face as they live longer or survive serious illnesses and accidents. She prefers to think of these as a “diversity of abilities,” rather than disabilities or deficits. These are not necessarily obvious. Fletcher gave the example of a patient with a slight hearing loss who might miss key points of what their health care provider is saying. “It’s quite possible that neither the provider nor the patient is aware that this is happening,” she said.

Fletcher shared some strategies for universal design in health communication:

**Present important information in redundant ways.** This might be to offer equivalent information in a written format along with a video or illustration.

**Choose a font that is not overly stylized.** Some people prefer serif fonts, in which letters have little “feet” or “wings.” An example is Times New Roman. Others favor sans serif fonts (sometimes referred to as “block lettering”), like Arial, without those wings. As yet, there is little consensus among design experts as to which type of font is best.

**Use a type size between 12 and 16 points for regular text.** Fletcher said that type smaller than 12 points is hard for most people to see. Type larger than 16 points can result in more pages than most people want to read.

**Have sufficient contrast between background and lettering.** Often this is dark lettering on a white or light-colored background. But some people prefer “reverse contrast”, which is light print on a dark background. Fletcher recommended finding ways to accommodate both preferences in critical elements of your design. An example is using reverse contrast in the title and headings and standard lettering in the body of text.

**Write in plain language.** This means using words and terms that readers already know and explaining important new terms in ways they can understand.

**Think broadly about your website users.** This includes not only the needs of those with vision loss but also users who have cognitive or learning disabilities. Fletcher said that there are many ways to make it easier for users to find and use online information. She recommended learning more at the Web Accessibility Initiative<sup>3</sup>.

**Solicit opinions from those who represent your readers and website users.** Ask for their feedback as you design printed and online information. Consider their recommendations as you make needed changes. Then ask for their feedback again to confirm that your material is appealing, usable, and understandable.



### Story from Practice: What zoos can teach us about navigation<sup>4</sup>

Oddly enough, health literacy came to mind when I visited the elephant house at the Chicago Zoological Society's Brookfield Zoo. I had a question about the exhibit and then suddenly noticed the answer on a sign right in front of me. It was so well placed it made me wonder what we in health care might learn from zoos.

To find out, I contacted Jo-Elle E. H. Mogerman, PhD, then vice president of planning and community relations for the Chicago Zoological Society, and Andre Copeland, the Society's public programs manager. They explained the role of design, wording, and placement of signs in helping zoo visitors get where they want to go and learn while getting there.

Mogerman and Copeland also spoke of Maslow's hierarchy of needs, and how they keep in mind what is most important to a visitor at any particular point. For instance, when people enter the Brookfield Zoo they often first ask about the location of bathrooms and places to eat. In Mogerman's and Copeland's opinions, as well as my own, considering what is foremost to patients and families can be equally effective in health care facilities.



### Strategies, Ideas, and Suggestions: The environment of care<sup>2,5,6</sup>

Many people, from many perspectives, have added to our knowledge about the environment of care. The suggestions below are based on interviews and conversations with experts in health literacy, architecture, and universal design.

Health understanding depends not only on what we say or do but also the environment in which we meet with others. Look critically at the built environment where you work. Here are some aspects to consider:

**Outside entrance.** Hospitals and clinics are busy places, with people coming in and out all sorts of doors. Consider how your patients and visitors determine which one to use. Sometimes a sign such as "Ambulatory Entrance" adds to confusion, as patients might assume this entrance is for ambulances, not patients. Instead, use simpler and more familiar wording, such as "Patient Entrance."

**Navigation.** This means that newcomers can quickly and correctly figure out where to go. If it's not intuitive, then find ways to make navigation easier such as having a staffed "help desk" and not just written signs.

**Maps.** Make sure that the font size is sufficiently large for people to see. Confirm that departments have not moved since the map was last published. Use wording that matches what people know and are looking for, such as "Mammogram" instead of "Women's Health." And even when maps meet all these criteria, know that there will always be people who cannot, or prefer not to, use maps.

**Signage.** Be consistent in the words you use, such as always calling a place to eat the "coffee shop" or "cafeteria." Use this same wording in the doorway sign, on facility maps, and in verbal directions.

**Acoustics.** Is there a noisy air conditioner in rooms where you meet with patients? If so, ask maintenance to try to reduce the background hum. Or meet somewhere else, with fewer acoustic distractions.

**Lighting.** Rooms should be sufficiently lit, so that people can clearly see each other. Whether or not someone has an identified hearing loss, they might look at your face for extra clues about spoken words. Adequate lighting also helps people better see what they read.

**Tours and audits**<sup>7</sup>. One of the best ways to find out if your environment of care is easy to navigate is by accompanying a newcomer as they first make their way around your facility. While you cannot be sure that their experience will be the same as for someone else, these types of tours can raise awareness of potential problems.



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## Chapter 39

# Visuals

### Starting Points

Visuals include artwork like pictograms, icons, photographs, anatomic diagrams, comics, and other images that convey actions or ideas. Many people enjoy and learn from visuals. They include visual learners (those who learn best when seeing, reading, or being shown) as well as people with limited literacy or language skills who benefit from illustrations, not just words.

The airline industry is an example of doing this well, with picture-based emergency instructions provided at each seat. The same principles can be applied to health materials, whether as single-page fact sheets, fold-over brochures, or multi-page instructions.



### Story from Practice: Visuals help patients understand

Here is a story a colleague shared with me. Herb, a 66-year-old general contractor, had a major heart attack several years ago. His doctor performed an emergency coronary angiography to examine the blood vessels and chambers of his heart. After the procedure, Herb's doctor explained what happened and gave him a simple line drawing of the heart and arteries. She colored in where each of his arteries was blocked and wrote alongside how much it was occluded.

Seeing so clearly what was wrong, Herb readily agreed to participate in a cardiac rehabilitation program and change his diet and exercise habits. In fact, Herb did so well that he was asked to speak with other patients who were just diagnosed with cardiovascular disease.

To Herb's surprise and disappointment, not one of the more than 100 people he spoke with had ever been given a "heart picture" like his. They often commented how a drawing like the one Herb's doctor gave him could have helped them better understand their diagnosis and treatment plan.



## Strategies, Ideas, and Suggestions<sup>1-3</sup>

**Acquire the artwork you need.** There are many ways to acquire needed artwork. You might begin by looking online for free or low-cost visuals. I often start my search with Google Images<sup>4</sup>. When you find an image you like, make sure you can freely use it, or follow the instructions to obtain copyright permission.

Another way is to hire a graphic artist, photographer, or cartoonist to create visuals specifically for you. I do this and have often worked with Mark Tatro of Rotate Graphics<sup>5</sup>.

Of course, there is always the option of creating your own artwork or asking an artistic colleague or friend to help. Here is some advice when you are the artist:

**Include the most important elements.** My dermatologist drew an impromptu picture of a mole she recently removed from my toe. She included only enough detail to show how far the mole had spread. This picture, even more than her words, reassured me that the diagnosis wasn't as dire as I had feared.

**Ask patients if they'd like to keep your drawing.** While you may think that your drawings are nothing special, patients may find them very helpful. Ask patients if they want to keep your drawing—even if you drew it on paper from the exam table (as the doctor did when sketching my mole). Then add a few key words so patients can later accurately recall the meaning of this drawing.

**If you really lack artistic talent,** consider using an illustrated sheet as a base and adding words or numbers or highlighting areas to personalize the message.

**Show sensitivity and respect.** Choose visuals that are realistic and show people at their best. For instance, when writing about general health issues, include some people who are active and not just ill or infirm. As possible, represent the culture of your audience. This might be to include pictures of men wearing berets or turbans, not just baseball caps. Resources for inclusive photos include Black Illustrations<sup>6</sup> and The Gender Spectrum Collection<sup>7</sup>.

**Select visuals appropriate to the subject matter.** For example, you might use humorous, cartoon-like characters when writing about well-baby care, but more subdued illustrations in booklets about serious diagnoses.

Consider the color of paper, too. I still recall a fact sheet about colonoscopy that was printed on light brown paper. Not a good color choice, in my humble opinion.

**Show people in their entirety, not just body parts.** When communicating about just one part of the body, such as the spleen, it's tempting to show only this aspect of anatomy. It's preferable to include at least one picture of the whole body with the spleen clearly labeled. This helps readers see where the spleen is and how it fits within the body. It also avoids showing “disembodied body parts,” which some people, especially those traumatized by violence or war, may find upsetting.

**Combine pictures and text.** Visuals alone are seldom sufficient, especially when explaining complicated information. To improve understanding, include simply worded captions beneath each visual. Captions not only help readers know what they're seeing but also reinforce key ideas and actions.

**Appreciate that symbols are not always understood.** Symbols, just like other types of visuals, are subject to interpretation. For example, a picture of a pill bottle alongside a knife and fork may be intended to show that medication should be taken with a meal. But for those from countries where food is taken by hand from a common serving bowl, this symbol may not have the same meaning or relevance.

**Consider the needs of those with visual or cognitive disabilities.** Make visuals easy to see by having a lot of contrast. Generally this means black ink on white, ivory, buff, or other light-colored paper. Don't rely on colorful print or illustrations to convey your message. Some people cannot differentiate between two shades of the same color or may not be able to see colors at all. Also, avoid decorative backgrounds like watermarks that make it hard for people to know where to focus their attention.

**Confirm understanding.** As with all forms of communication, make sure that your readers can understand and use visual information. For print materials and websites, ask for feedback, including whether your illustrations, colors, and symbols are appealing and informative. If you sketch a drawing when meeting in person, you might begin in a lighthearted way such as, “Let's see how good an artist I am. What does this picture mean to you?”



## Stories from Practice

There is no one right choice for visuals. Consider the needs of your audience along with your creative interests, talents, and resources when deciding what visuals to use.

**Pictograms.** In 2020, I spoke with Mareika Phillips, a graphic designer at CommunicateHealth, about using pictograms in health communication<sup>8</sup>.

Phillips explained that a pictogram is a drawing or image representing an idea in a simple or literal way. They can be especially helpful for those who have cognitive disabilities, reading problems, or are feeling stressed. Phillips shared tips about using pictograms in health materials:

**Make sure the pictogram supports the content** you are trying to convey. Don't include visuals just for the sake of having a visual.

**Use a consistent visual style.** When including several pictograms in one document, Phillips recommends consistency. "Don't be using silhouettes for one, outlines for another, and then a fully colored pictogram."

**Avoid abstract symbolism.** This is especially important when communicating with a diverse audience. Your readers may not be familiar with certain symbols and not know what these mean.

**Show features of a character's face** rather than leave it blank with no eyes, mouth, or nose. Phillips says that facial features help everyone, including those with cognitive disabilities, understand that this visual represents a person.

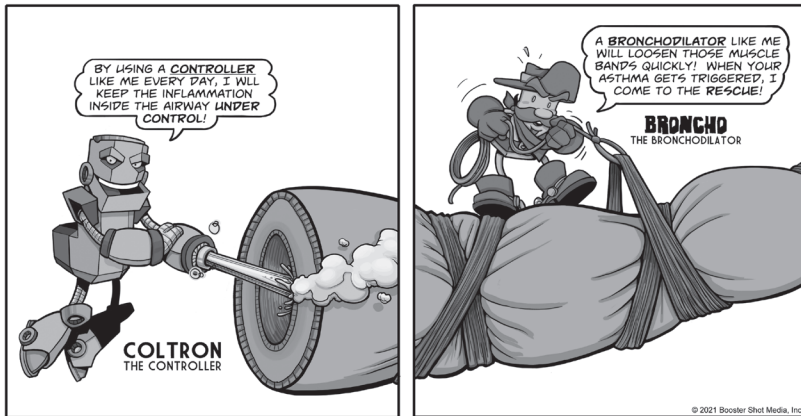
**Focus on what to do, rather than what not to do.** Phillips gives the example of the message "Wash your hands." She said that the pictogram should convey "When you come home, wash your hands," not "When you come home, don't forget to wash your hands."

**Visual metaphors.** Alex Thomas, MD, and Gary Ashwal, MA are co-founders of Booster Shot Media. They apply their combined experiences as a physician and a health communication specialist, respectively, to produce visual projects that teach people of all ages about complex health topics. In 2018, we spoke about a concept they refer to as "visual metaphors<sup>9</sup>."

Thomas and Ashwal explained that visual metaphors are a way to express potentially complex medical concepts while not appearing too didactic or boring. They can be helpful to both adults and children.

They shared an example from a comic book they created, called *Iggy and*

*the Inhalers*<sup>10</sup>. The goal was to teach kids not only about the pathophysiology of asthma but also about different types of inhalers. They created characters as metaphors of this message.



“**Coltron the Controller**” embodies the inhaled corticosteroid. Thomas explained that he is a “large, deep-voiced, slow-moving but powerful robot with a fire-extinguisher arm that shoots inside the airway to decrease inflammation, as if putting out a fire.”

“**Broncho the Bronchodilator**” embodies the quick-acting inhaler. He is “a fast-talking cowboy with a lasso that loosens the muscle bands outside of the airway that cause bronchoconstriction.”

Research using these cartoon characters has shown that they help readers understand the different mechanisms of these two medications<sup>11,12</sup>. “If you just understand the story and know the characters, you’ll more intuitively understand your medications without feeling that you’re memorizing facts from a sheet of paper,” said Thomas.

**Comics.** MK Czerwiec describes herself as a nurse who makes comics, building on a degree in medical humanities and background in nursing. Czerwiec co-runs the website [www.GraphicMedicine.org](http://www.GraphicMedicine.org)<sup>13</sup>, which looks at the intersection between comics and the discourse of medicine. We spoke in 2014<sup>14</sup>.

Czerwiec explained that comics are sequential art that convey a narrative. They often incorporate text, but don’t have to. “I’d like people to think about comics as analogous to films. It’s a medium and within that medium are many genres,” she said. Genres for comics include superheroes, of course. Comics also include animated films that children enjoy along with graphic novels for adults.”

Czerwiec encourages people to not only find relevant comics but also to try making their own. “Make a couple of boxes, add a few words, put a few images to accompany those words, and then make another box,” she said. “There’s something about the sequential nature of the boxes that helps draw out the narrative and tell a story.”



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## Chapter 40

# Writing for the Web

### Starting Points

Many people go to websites for health information. These “web users” (or more simply “users”) may go to websites to find information about whether they really need to get medical care. If so, they might search for a facility that offers it. Afterwards, users may look online for more information about their diagnosis and treatment. They might also seek out additional support such as online chats and patient forums.



### Story from Practice: Website for users with limited literacy skills

Stacy Robison, MPH, CHES is a certified health educator and co-founder of the consulting company CommunicateHealth. One project she worked on was MyHealthfinder, a website primarily for people with limited literacy or limited online experience<sup>1</sup>. We spoke about this in 2010<sup>2</sup>.

Robison acknowledged that some people question whether those with limited literacy look online for health information. Robison said that this can be a self-fulfilling prophecy. “If we don’t have any easy-to-understand or easy-to-use health information online, then folks with limited literacy skills aren’t going to start using the internet to search for health information.”

She said that adults with limited literacy skills may have little training or experience searching the web. They might struggle not only with reading the words but also navigating the website. Robison suggested some ways to help:

**Focus first on basic information.** People most want to know about strategies and actions, said Robison. After presenting that information, give users the option to drill down further into the content they want.

**Create stand-alone sections of text.** This lets users move around the page and still get a full piece of information. “We found that a lot of users with limited literacy skills had a hard time scanning the whole site. They would just skip around or skip over whole chunks of text.”

**Break up text into small groups, lists, or anything to avoid dense wording.** Robison said that they found that users would skip over a paragraph when there were more than three lines of text. “That’s not sentences; that’s actually lines of text.”

**Test your website with users to see where they are getting stuck.** Can they find information? Do they know how to click on the button? “If they don’t find what they’re looking for or are not able to do the task, then you go back to the drawing board and fix it,” said Robison. “It’s the job of the web writers and designers to make the website clear and easy to use.”



## Strategies, Ideas, and Suggestions<sup>2-4</sup>

Janice (Ginny) Redish, PhD is an expert in plain language and web writing. She also is the author of the book *Letting Go of the Words: Writing Web Content That Works*<sup>5</sup>. Redish said that people access information differently on the web than they do in print. She compared navigating websites to talking on the phone. Redish described going online as a dynamic and interactive conversation with users searching for a particular topic and then clicking links they think are relevant. This contrasts to printed information, where readers follow the flow of information as organized by the author.

Here are some strategies from Redish and others about what to do when writing for the web:

**Include standard conventions that most users expect.** These include:

**Navigation bar.** Like a table of contents, the navigation bar is a clickable list of key topics and pages. It usually is located on the left or along the top of each web page.

**“About Us” page.** This is where users can check the source and credibility of information. It should include names and credentials of key people who created, or sponsor, the website.

**“Contact Us” page.** This should include contact information for the sponsoring company and for larger websites, technical support.

**Headings.** Redish recommends using questions, statements, or verb phrases that connect people to information they are looking for. An example is the heading “What is strep throat?”

### **Consider layout and design.**

**Make hypertext (links) evident with bright or contrasting colors.** Blue is commonly used for hyperlinks, with purple for links that have been clicked. You might also include symbols or text that makes hyperlinks evident to those who are color blind or have limited vision.

**Use about half the number of words as you might in print.** When lengthy materials cannot or should not be shortened, format information so users can easily print pages rather than reading online.

**Make the site accessible.** Consider the needs of people with disabilities as well as of those with older computers or slow connections. Here are some ways:

**“Test drive” your website on a slower or older machine.** You might be able to do this by going online at a public computer (such as at a library or senior center) to see how well the website works.

**Use simple photographs, illustrations, diagrams, or other graphics.** More complex designs can take a long time to download or slow the process of going from page to page.

**Test with your intended audience.** Can users understand and make use of your information? Can they easily navigate from one section to another? The answers to these as well as many other questions can be learned through usability testing. This means watching people who represent your audience as they try out your website.

**Learn more about making websites accessible.** One excellent resource is the Web Accessibility Initiative<sup>6</sup>.





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## Chapter 41

# X-tras

### Starting Points

X-tras (or “extras” for spelling enthusiasts) make programs unique and yours. Always creative and often fun, extras include “far-out” ideas, “out-of-the-box” thinking, and “off-the-wall” communication strategies that can help people better understand health information.

Extras aren’t just entertaining. Indeed, they are rooted in the philosophy that people have more capacity to learn when they are relaxed and having fun. Extras often include a wide array of formats such as music, poetry, drama, and even puppets. They appeal to people’s varied learning styles of seeing, doing, listening, and interacting. Extras are effective with audiences of all ages and abilities, including health professionals, patients, students, and the general public.

Creativity drives many of these extras. Whether inspired and developed by just one person, a whole department, or the entire organization, creative extras can provide education and information to meet today’s health care challenges. Even one person can make a creative difference. What’s needed is passion for an idea, some imagination, willingness to take a risk, and commitment to follow through.



## Story from Practice: Poetry to make clear why health literacy matters

Elsbeth Murray is a Scottish poet whose background is in cultural anthropology, health promotion, public health policy, and patient involvement in cancer care. In 2013<sup>1</sup>, we spoke about a poem she wrote, “This is Bad Enough<sup>2</sup>.”

Murray wrote this poem when working with the Southeast Scotland Cancer Network. She said that this network gathered patient viewpoints about how services need to be changed or improved. Murray said that this group found that “people are more concerned about being treated with respect than they are about the length of the wait, the size of the machines, or how modern the building is.”

This poem was Murray’s way to condense viewpoints from a lot of people and present it in as straightforward a way as she could. “It matched what people were saying,” she said. “It’s been amazing to see how many people have recognized something in that—whether they’re in cancer care, other kinds of health care, or people who are dealing with information that’s not even in health care.”

I wholeheartedly agree. I often show a video of Murray reading this poem as part of health literacy presentations<sup>3</sup>. After hearing her, audiences everywhere immediately “get” why good health communication matters.



## Strategies, Ideas, and Suggestions

**Get creative.** Admittedly, some people are more naturally creative than others. But even those who believe they are not can learn to think in innovative ways. When I supervised occupational therapy students, they often faced clinical situations in which traditional interventions didn’t work, or didn’t work well.

To help the students come up with doable alternatives, I invited them to participate in two creativity exercises. One was “making the strange familiar,” brainstorming what an unusual gadget might be used for and could be called. The other was “making the familiar strange” by coming up with a ridiculous background story for an everyday object. The purpose of these exercises was to encourage students to take risks and consider old problems in new ways.

**Know your audience.** Whether your innovative idea is geared more for students, patients, health professionals, or the general public, learn about your intended audience. Know about their literacy, language, culture, and learning needs. Be sensitive, as well, to people’s capacity for humor, tolerance for uncertainty, and willingness to try something innovative, fun, and new.

**Make it easy for others to support your innovative project.** Innovative ideas are seldom in the budget. Almost always, it takes another dose of creativity to get needed staff, funding, and other resources. Let internal funders know how this project can help generate income (such as by enrolling more patients) or reduce expenses (like decreasing the rate of re-hospitalization). Another way to gather support is by partnering with like-minded groups or asking local foundations for grants to sponsor your project.

**Here are some examples of extras:**

**Contests.** In the early years of Health Literacy Month<sup>4</sup>, I was looking for a tagline that succinctly made its purpose clear. Given that this initiative had a budget of nearly zero dollars, I created a “tagline contest.” The prize was 100 Health Literacy Month postcards and unlimited bragging rights. I was amazed at the response, with more than 50 submissions from health professionals and even advertising agencies. Kenneth Lo, then working in Cross-Cultural Communications at the New York City Department of Health and Mental Hygiene, came up with the terrific winning tagline: “Finding the right words for better health.”

**Music and song.** Mache Seibel, MD is a doctor and an advocate of using music and song to teach positive health messages. Seibel writes, produces, and performs songs about health and wellness for people of all ages. He told me in 2008 that music can communicate important information in a format that people can retain and act on<sup>5</sup>. “If you can sing about, you can talk about. If you can talk about it, you can take action. And once something becomes actionable, you can change it.”

**Puppetry.** The St. Louis Christian Chinese Community Service Center in St. Louis, Missouri has used puppetry to teach its members about ways to talk with health care providers. Harold Law, then vice chair of the board of directors for the Center, once said to me that many within their Chinese community, especially elders, found it difficult to speak up to their doctors and ask questions.

Puppets have conveyed important messages for thousands of years in China. Law thought that they could be effective in teaching health concepts, too. Law and others created a puppet show with five characters (doctor, patient, family member, nurse, and interpreter) who role-played a scenario of effective health communication. Based on audience feedback, this puppetry worked very well.



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## Chapter 42

# You: Compassion, Empathy, and Humanity

### Starting Points

In addition to knowledge, skills, and experience, you bring “you” to each patient encounter. “You” includes compassion by recognizing and addressing the concerns of others. It also includes empathy and being sensitive to another person’s feelings, thoughts, and experiences. “You” also is about humanity and responding to patients in caring ways that you would want for yourself.

Compassion, empathy, and humanity go a long way to improve health communication. When patients feel valued and listened to, they likely will relax and be more receptive to learning new health information, even when that news is scary or sad. But when patients feel they are being treated in an impersonal or judgmental manner, they may well “tune out” and not fully process what providers are saying or asking them to do.



### **Story from Practice:** **A father’s story of unfortunate communication**

Here is my friend’s story about his family’s experience. Ken’s son Chuck had many moles. When Chuck was 12 years old, his doctor biopsied two of these moles in a rather unpleasant procedure. A few days later, on a stormy New Year’s Eve afternoon, the doctor called from a pay phone to tell Ken the test results. “I just received a report that your son has melanoma. We need to remove it right away.”

Not expecting the call that day, and startled by the bad news, Ken's first thought was of the unpleasant biopsy. When Ken asked, "What happens if you don't remove it?" he expected to hear about treatment alternatives. Ken was dumbfounded when the doctor said, "Then your son has only eight months to live."

More than 20 years later, Ken still vividly remembered this call. While thankful that Chuck's melanoma was successfully removed (by another doctor), Ken remained upset about what he felt was an insensitive, unempathetic manner in which this physician communicated bad news.



## Strategies, Ideas, and Suggestions<sup>1-4</sup>

**Demonstrate your empathy.** Empathy is conveyed as much by actions and timing as with words. Listen—truly listen—to what patients are saying. Use eye contact, body posture, and tone of voice to let patients know that they have your full attention. Observe their body language, too. If a patient seems to have trouble focusing, then, if possible, reschedule this conversation to a more appropriate time.

**Build rapport.** When initially meeting with patients or families, start by establishing rapport and building a trusting bond. Steven Grossman is an oncologist who is recognized for his expertise in gastrointestinal cancers. One way he develops rapport is by finding out how much information people already have. To do this, he asks open-ended questions such as "What is your understanding of what you have?" While one person might say, "I think I have cancer and you'll tell me the rest," another may talk about website printouts they brought to the appointment.

**Offer hope.** Almost universally, patients want hope. Even when dealing with progressive illnesses, patients and families appreciate it when their providers offer encouragement and support their goals. The standard of care for Grossman is to openly discuss diagnosis, prognosis, and treatment options with his patients. Within this standard, however, he uses clinical judgment to decide how to present the information. While one patient may want to know mostly about prognosis, another may be more eager to discuss treatment options. Regardless of the news, Grossman always finds something positive to say. For instance, he might focus on comfort and quality of life for a person without options for a cure.

**Consider whether to bring in others from the health care team.** There may be times when it is helpful for someone else from the health care team to talk with patients and their families. Reverend Christiaan Beukman and I worked

as colleagues on an inpatient psychiatric unit. He was a hospital chaplain. I was an occupational therapist. In 2020, we spoke about the role of chaplains in a hospital setting<sup>5</sup>.

“What the chaplain is really there to do is assist anybody, religious or not, in the process of making meaning out of an illness or event,” he said. “Imagine you’re a patient and all of a sudden there is a really bad diagnosis. Your doctor will help you interpret that. Maybe your surgeon will talk about surgery. As the patient, you may be questioning, ‘Am I going to die? Am I going to live? Even if I die, does that mean I live on? What does my diagnosis or illness mean to my family?’” As the need arises, consider who else on the health care team can help patients deal with difficult conversations like these.



### Story from Practice: Compassion and empathy

Beth Lown, MD, FAACH is a general internist, associate professor of medicine at Harvard Medical School, and chief medical officer of The Schwartz Center for Compassionate Healthcare, a nonprofit organization dedicated to supporting health care workers and leaders in bringing compassion to every health care experience and creating more compassionate health care systems. We spoke in 2014<sup>6</sup>.

Lown explained that compassion is about recognizing, validating, and then addressing the concerns, distress, and suffering of others. Empathy means coming to understand and, to some extent, share the thoughts and feelings of another person by imagining oneself in their shoes.

“I think of compassion as a process,” said Lown. “It emerges as a result of the interaction between two people. Sometimes it’s people plus family and sometimes it’s people plus a clinical team. The first thing you have to do is notice that someone is in distress.”

Lown acknowledged that it can sometimes be hard to focus on the needs of each patient. She has found it helpful to use what she calls the “doorknob strategy.” Lown said, “Before I went into an exam room or hospital room, I put my hand on the doorknob (either physically or metaphorically) and consciously set aside everything that I was thinking about. Then when I walk through the door I can fully receive the patient or the family on the other side of that threshold.”

The Schwartz Center for Compassionate Healthcare is a valuable resource to learn more about compassion and ways to help. The Schwartz Center “unites clinical care providers and staff from a range of disciplines to share experiences, learn from each other, and focus on the human dimension of medicine.”<sup>7</sup>



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## Chapter 43

# Zest and Pizzazz

### Starting Points

Zest and pizzazz include the commitment and passion that you bring to health literacy. These qualities are also about the energy that sustains and motivates you to continue. Admittedly, it's fairly easy to remain enthused when colleagues rave about your new health literacy workshop or when patients beam with understanding after you point out the source of their discomfort on an anatomic model.

But it can be much harder to maintain the momentum when you must explain, yet again, what health literacy is and why it matters. Or when you have colleagues who still don't "get it" and continue communicating in ways that are neither effective nor understandable. And it can indeed be exhausting to continually search for needed funding to sustain health literacy programs that you know are worthwhile.

Through good times and bad, it helps a lot to remember why you care so much about health literacy. Whether your motivation is personal, professional, or a bit of both, keep in mind that health literacy is everyone's responsibility. As a dear friend and colleague once said to me, "If you don't keep advocating for health literacy, who will?"



### Strategies, Ideas, and Suggestions:

**Find your passion.** Health literacy is seldom in anyone's job description. To have the energy to keep going, remember why health literacy matters. You may recall a personal experience as a patient or family member when health communication worked exceptionally well, or particularly badly. You may remember

a patient who stared blankly when you gave her a brochure and another who grinned with understanding when you drew him a picture. You might reflect on why you chose this profession and feel it is important. *Zest and pizzazz* start with understanding why you are so passionate about health literacy.

**Take risks.** Health literacy is still a somewhat new concept. Figuring out how you can make a difference may, at times, feel like going on a journey without a map. For some, it is exciting to forge a path that others can later follow. For others, it is uncomfortable venturing into the unknown. If you, like me, are willing to take some risks, then health literacy includes trying the untested. Sometimes what we do will work well, sometimes it won't. Regardless of the outcome, we almost certainly will learn something new. To me, that's the key to navigating this health literacy journey.

**Develop a support network.** It's hard to remain enthused when you feel like you are the only health literacy advocate. I know from experience that it helps to be part of a network that shares common goals. Whether in person or online, networks might include people from health care facilities, public health departments, literacy programs, libraries, social service agencies, and the general public. I learn a tremendous amount from the many health and literacy colleagues who participate in the online Health Literacy Discussion List<sup>1</sup>.

**Learn from those around you.** Health literacy is bigger than any one person, profession, or program. A lot of my knowledge comes from others who share similar, yet not identical, communication challenges.

For example, I learned about cross-cultural communication from my neighbor who taught middle and high school students who came from other countries and spoke many languages. I appreciate the power of creativity when artists convey complex ideas with just a few lines and squiggles. I value the simplicity of words when reading succinct, yet eloquent, essays. I treasure those times when someone apparently took a risk and tried something innovative and new.

And when patients and family members tell me how hard it is to understand health information, I again remember why I do this work. Look around. The world is filled with health literacy *zest* and *pizzazz*.



## Story from Practice: Why I do what I do

People often ask how I got involved in health literacy. It was December, 1995. I happened upon an article published in *JAMA* titled “Inadequate functional health literacy among patients at two public hospitals<sup>2</sup>.” It was a cross-sectional survey of patients at two urban public hospitals. The research objective was to “determine the ability of patients to complete successfully basic reading and numeracy tasks required to function adequately in the health care setting.”

At the time I was working as an occupational therapist in the psychiatric unit of a small community hospital in Boston, MA. The hospital is in a diverse part of the city, with patients from many lands, languages, and levels of educational attainment. Patients admitted to our psychiatric unit were also dealing with major mental illness.

Part of my job was leading psychoeducational groups such as one for stress management. I also oversaw our department’s (and later, the hospital’s) patient education program. In nearly all of these programs we taught skills, facilitated discussions, and used written materials.

Until reading this *JAMA* article, I had never questioned the value of our teaching methods and materials. It was startling and humbling to read the authors’ conclusion: “Many patients at our institutions cannot perform the basic reading tasks required to function in the health care environment. Inadequate health literacy may be an important barrier to patients’ understanding of their diagnoses and treatments, and to receiving high-quality care.”

This conclusion was like a “clunk on the head.” I immediately knew that health literacy mattered. I also knew that I wanted to help but was clueless as to how. At the time there was only a handful of research studies and the book *Teaching Patients with Low Literacy Skills* by Doak, Doak, and Root<sup>3</sup>. There wasn’t a lot of information about what I and others in everyday practice could do.

I decided to help address that gap. Soon thereafter I left my clinical practice to focus singularly on health literacy. In the 20+ years since, I’ve seen health literacy grow from a new notion to a large body of research, policy, and practice. Yet from what I hear from others and experience myself, there’s more work ahead in figuring out ways to clearly, simply, and effectively communicate health information.

That’s why I keep doing what I do.





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