

# Healthcare **Communication** Review

On Building Health Partnerships: Food-for-Thought, Practical Tips, Resources

Volume 8, Number 2

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## HEALTH LITERACY Understanding Health Information

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## The Health Literacy Problem

**Health Literacy:** *The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.*

US Department of Health and Human Service, in *Healthy People 2010*.

Today's healthcare, and the information about it, is complicated. Yet almost 1 out of 2 American adults (90 million) cannot understand and apply complicated health information.<sup>1</sup> This often hinders their recovery and puts them in harms way.<sup>2</sup> And because they tend to use costlier hospital services more, an additional \$58 billion dollars a year of otherwise avoidable costs of care are borne by individual patients, our healthcare system and most Americans.<sup>3</sup>

Why? Because the health insurance industry usually responds to higher healthcare costs by raising the price of premiums, reducing coverage and increasing co-pays. It also affects us as taxpayers because financially strained healthcare institutions cannot stay afloat and continue to provide care to their communities without government support via our tax dollars. In other words, everybody loses.□

<sup>1</sup> See *Health Literacy: A Prescription to End Confusion* at <http://books.nap.edu/catalog/10883.html>.

At bottom of Screen, click on PDF Summary, under Download Free.<sup>2</sup> See Note 1

<sup>2</sup> Visit [www.jointcommission.org](http://www.jointcommission.org). Search for 'Improving Health Literacy.'

<sup>3</sup> Visit [www.askme3.org](http://www.askme3.org)

## Health Literacy Skills

*"Nothing – not age, income, employment status, educational level and racial or ethnic group – affects health status more than literacy skills."*

Partnership for Clear Health Communication (PCHC) at [www.askme3.org](http://www.askme3.org)

Having a good job, a good income, and being able to read does not necessarily prevent low health literacy. In large part, this is because health literacy calls for other skills besides reading. It calls for people to be able to evaluate the quality and credibility of the information as well as the risks and benefits of treatment options (critical thinking skills). It calls for them to calculate dosages and understand tables (basic arithmetic skills). And, it calls upon them to ask questions, explain their views and concerns, and discuss treatment options (communication skills).<sup>1</sup>

Even when patients have these skills, however, they may not use them. Under the best of circumstances this is not an easy task. It is all the more difficult when patients are ailing and have little energy for anything other than getting through the day. Nevertheless, it is important enough that if patients cannot do these things themselves, they ask for help from family, friends or other advocates.□

<sup>1</sup> See Health Literacy article at <http://nmln.gov/outreach/consumer/hlthlit.html> and See *Health Literacy: A Prescription to End Confusion* at <http://books.nap.edu/catalog/10883.html>. At bottom of Screen, click on PDF Summary, under Download Free.

**Healthcare  
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Project, Inc.**

**A Not-For-Profit  
501 (c) (3) Organization**

PO Box 661  
Stone Ridge, NY 12484  
Phone/fax 845-687-2328  
[info@healthcp.org](mailto:info@healthcp.org)  
[www.healthcp.org/](http://www.healthcp.org/)

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Written/Edited by  
Judith A. Greenfield, PhD, RN  
[judith@healthcp.org](mailto:judith@healthcp.org)

## *From the Editor*

The subject of health literacy is usually not among our top concerns when it comes to the matter of healthcare in our country. Those spots are generally reserved for concerns such as : *How can I get health insurance?* or *Why isn't my insurance company paying (or paying so little) for the care I need?* and *Will I have to sell my house in order to pay my medical bills?* or *Will I have to file for bankruptcy because of my medical bills?* Indeed, while the quality of healthcare in America cannot be denied, access to it, and paying for it, is difficult for all too many Americans.

Why, then, has health literacy become a hot topic within the field of healthcare? The answer is simple, really. First, too many people with limited health literacy (90 million by some estimates) are not getting the care they need and face greater risk of medical errors when they do. Second, this, in turn, results in higher healthcare costs which ultimately affects us all.

For these reasons, this issue of the *Review* looks at the problems associated with limited health literacy and looks at some of the things that can be done about it – from communication tips to resources for finding easy-to-read and understand health information. As always, we hope you find the articles in these pages useful and extend our best wishes for all to...

Be well. *Judith Greenfield*

\* \* \* \* \*

## The Health Literacy Divide: Two Examples

*A two-year-old is diagnosed with an inner ear infection and prescribed an antibiotic. Her mother understands that her daughter should take the prescribed medication twice a day. After carefully studying the label on the bottle and deciding that it doesn't tell how to take the medicine, she fills a teaspoon and pours the antibiotic into her daughter's painful ear.*

Parker et al, cited in *Health Literacy: A Prescription to End Confusion*<sup>1</sup>

How many times have you, as a patient, found yourself confused about what you have, what you should do next, or what particular health instructions mean? If that has ever happened to you, you are not alone.

Being health literate is as important for making “simple” health decisions – such as how to follow instructions – as it is for making complex, life-and-death decisions. Not being able to do so can set patients up for what is often called, in medical terms, ‘adverse’ events – unwanted, unexpected, and even dangerous conditions.

It is also important to understand spoken as well as written information. Take the example of a physician who, when interviewing a hospitalized patient, asked her what she had been told was her problem. After she correctly answered that she had a fractured pelvis, he told her that he agreed with that diagnosis – her pelvic bone was “broken.” With a look of surprise, she said, “my pelvic bone is broken!?” It was only then that she realized what was actually wrong.<sup>2</sup>

In healthcare, just as in life, it is so easy to end a conversation thinking we have come away with the same understanding as the person with whom we were talking. That is not always the case, however – even when there is no literacy problem! This makes it especially important for both healthcare professionals and patients to give and ask for clear healthcare instructions and explanations.□

<sup>1</sup> Visit <http://books.nap.edu/catalog/10883.html>. Click on PDF Summary, under Download Free

<sup>2</sup> Visit [www.hospitalmedicine.org](http://www.hospitalmedicine.org), enter search term ‘health literacy,’ click on ‘Caring for the Hospitalized Patient.’

## What Patients Can Do: Communication Is Key

### Communication is Key

Ask the American Medical Association, the Agency for Healthcare Research and Quality, and the Joint Commission (which accredits hospitals and other health facilities) and they'll tell you that communication is key to improved patient safety.<sup>1</sup> It goes without saying that the healthcare community has great responsibility for this. That's why a push is being made within it to improve the ways healthcare professionals communicate with their patients. They are being urged to provide their patients with easy-to-read written information and instructions; they are being urged to use plain language and pay close attention to their use of words when speaking with patients; and they are being told to make sure patients correctly understand what was said.

But patients can play a role here as well. Indeed, we suggest that patients share some of the responsibility for doing so. After all, if we, as patients, are insisting that we're responsible enough to make our own healthcare decisions, doesn't it follow that we should shoulder some of the responsibility for making sure we understand enough to make those decisions?

### What Patients Can Do

On its website, [www.askeme3.org](http://www.askeme3.org), the Partnership for Clear Health Communication at the National Patient Safety Foundation suggests patients ask their doctors and other healthcare professionals the following three (3) questions: *What is my main problem? What do I need to do? And, Why is it important for me to do this?*

In addition to these three questions, we suggest asking the following questions as well. *What can I expect if I do this? How might it affect my daily life?* When their questions have been answered, patients can make sure they correctly understand what they have been told. If they realize that they haven't understood what the doctor said, then they should put aside any shame they may be feeling and ask for a simpler explanation. *"This is confusing to me. Can you please explain this using plain language?"*

If they are given written material and are not sure they will understand it when they read it at home, they can say: *"OK. I'll try reading this at home but I would like to know who I can call if there is something I don't understand."* Or, *"This looks like it may be hard for me to understand. Do you have, or can you tell me where to find, something that is easier to read?"*

Even if patients think they understand what they have been told, they can make sure by saying: *"I think I understand what you said, but let me make sure of that by telling you what I heard."* Then, using their own words, they can repeat what was said and what meaning it has for them. These are simple steps that can go a long way toward helping patients get the most out of their healthcare.□

<sup>1</sup> See [www.ama-assn.org/ama/pub/category/17114.html](http://www.ama-assn.org/ama/pub/category/17114.html), [www.ahrq.gov/consumer/5tipseng/5tips.htm](http://www.ahrq.gov/consumer/5tipseng/5tips.htm), and [www.jointcommission.org](http://www.jointcommission.org). Search for 'Improving Health Literacy.'

## Low Health Literacy: An Ounce of Prevention...

Our educational systems can play a key role in resolving our low health literacy problem. As such, beginning with the 1995 publication of *National Health Education Standards: Achieving Health Literacy*, that goal has been at the heart of health education standards for grades K – 12.<sup>1</sup> Embedded within these standards are the goals of helping students build critical-thinking and problem-solving skills, as well as becoming self-directed learners and effective communicators.

A key recommendation for achieving these goals is the creation of Coordinated School Health Programs (CSHPs) – an approach that, in grade-appropriate ways, introduces health topics and increasingly builds the necessary skills for becoming health literate. Other components of CSHPs include collaborations with teachers from other disciplines within their schools (a science teacher, for instance, can cover the effects of cigarette smoke on the environment and human body) and with parents and local community businesses and institutions. This approach, in fact, encourages parents and the community to help with the development and implementation of standards for their local/regional/statewide education systems.<sup>2</sup>

Many state education departments have since developed their health education standards in ways that draw heavily on both the national standards and the recommendations for implementing them. But while a state's health education standards are mandated, the methods for implementing them are often merely encouraged. Unfortunately, for reasons that generally include limited resources, many districts have not followed through on school, parent, and community partnerships. With these recommendations in place, however, parents have an opportunity to play a significant role. They can learn what standards have been adopted and implemented by their states and explore ways in which they can help their children's school districts to achieve their goals. An ounce of prevention, after all, really can be worth a pound of cure.□

<sup>1</sup> See summary of 2007 National Health Education Standards at [www.aahperd.org/aahe/pdf\\_files/standards.pdf](http://www.aahperd.org/aahe/pdf_files/standards.pdf)

<sup>2</sup> See [www.cdc.gov/HealthyYouth/CSHP/](http://www.cdc.gov/HealthyYouth/CSHP/)

## Low Health Literacy and Language Barriers

What can the more than 20 million, foreign-born Americans do when they need healthcare but have limited English proficiency (LEP)? That is, when they cannot read, speak, or understand English very well. How can they clearly tell doctors and other healthcare clinicians what they are experiencing? How can those same clinicians clearly explain what is wrong and what should be done about it? The answer is, unfortunately, with great difficulty. As a result, access to healthcare by LEP patients has long been hindered – putting them at greater risk of harm.

So it was that efforts to address this problem led to the issuing of Executive Order # 13166, in August of 2000, by then President Clinton. This order, entitled, *Improving Access to Services for Persons With Limited English Proficiency*, calls for hospitals, clinics and physicians who receive federal monies to provide patients with free professional interpreters and written health information that is easily understood AND in the native language of each patient.

### Federal Guidelines

Federal guidelines for meeting these requirements allow for differences based on the number of LEP patients seeking healthcare in particular institutions or private practices. The more Spanish-speaking or Chinese-speaking patients using their services, for instance, the greater the requirements they have for meeting those cultural and language needs. Since the issuing of Executive Order # 13166, many hospitals, clinics and physicians have begun using professional interpreters for their LEP patients. Because of cost and other concerns, however, many others have not. Instead, their tendency has been to use patients' family and friends as interpreters.

### Why Not Family and Friends?

Federal regulations call for the use of professional interpreters for good reasons – they help maintain the patient's privacy and confidentiality and they can more accurately interpret what is being said. Why? From a technical standpoint, one's spouse, child, other relative or friend may not be fluent enough in both languages. On top of this they may be unfamiliar with medical terminology and have difficulty translating these words. And they may be unskilled in interpreting. From a cultural or psychological standpoint, either they or the patient may feel embarrassed, or otherwise uncomfortable with the topics covered. As such, either party may withhold or ignore information, leading to a

continuation of gaps in communication – gaps that may be crucial.

### What Can LEP Patients Do?

Clearly patients with limited English proficiency will have great limits on the steps they can take to improve communication between themselves and the healthcare professionals whose care they seek. With the help of English-speaking family, friends and advocates, however, there are a few things they can do.

The first is to think ahead and, before any scheduled or emergency visit, they might try to find out what local hospitals, clinics or private practices provide professional interpreters and translated health information in their language. If they are able to find at least one that does so,

*With help, there are a few things that patients with limited English proficiency can do to help improve the quality of their healthcare.*

they will have a better idea of where to go when they have a health problem that needs professional attention. They might even make a well-visit appointment to get the feel of the clinic or private practice. This can help in two ways. It can provide clinicians with helpful base-line information and it allows them to start the all-important process of developing a clinician-patient relationship.

Second, with the assistance of their English-speaking helpers, they might translate the questions found on page 3 of this issue as well as on [www.askme3.org](http://www.askme3.org). It's just as important for them, as for any patient, to have those questions asked and answered. Third, they might have the name

of the language they speak written on a piece of paper in both English and their language. In other words, they might carry with them at all times a piece of paper that says: 'I speak (the name of the language, i.e. Vietnamese)'. Note that the whole "I speak..." sentence can be written in both English and Vietnamese. This will help clinicians get an appropriate interpreter.

Yet another 'thinking ahead' step they can take, with the help of someone who speaks English, is to prepare a list of words that can help them tell clinicians why they are there. Each item on the list should be written in their own language (so they know what it means and can point to it) and in English (so the clinician will understand it). For example, items might include the symptoms of pain, itch, and burn as well as body parts such as head, ear, ankle and so on. The use of something similar to this – by emergency service personnel – is gaining ground as a good first step in helping LEP patients. With all these, and perhaps other steps, LEP patients may find they can help improve the quality of their care.□

## What Patients Can Do: Revisiting The 3 Tasks of Information Seeking

Given that health literacy is defined as being able to find, process, and understand health information, now may be a good time to take another look at the ‘Three Tasks of Information Seeking’, which first appeared in the July 2001 issue of this publication. What follows, then, is an updated look at those three tasks: finding accurate information, figuring out what the information means, and finding out whether that information is relevant to your situation.

### Task # 1: Find Accurate Information

We are told that this is the “Information Age” and, indeed, information is much more available today than it has been in the past. With the emphasis on patient-centered care and informed consent, today’s doctors are expected to tell us what’s happening to us, what our treatment options are, and to answer any questions we might have. Other good sources of information – articles from medical journals and disease-specific national societies (such as the American Cancer Society) – can also be found on the web.

The problem is that many unreliable sources can be found there as well. So what can we do when we come across a website of an organization with which we are unfamiliar. It may be offering reliable information. Then again, it may not. How can we tell the difference between the two?

Fortunately, the Medical Library Association offers guidelines for telling if a website is likely to have accurate information. By visiting, [www.mlanet.org](http://www.mlanet.org) and clicking on ‘For Health Consumers,’ we can find those guidelines along with a list of the top ten most useful sources that includes the sites listed below. Note that those sites marked with an \* also offer information in Spanish.

- **The American Academy of Family Physicians\***  
[www.familydoctor.org](http://www.familydoctor.org)
- **HealthFinder\***  
[www.healthfinder.gov](http://www.healthfinder.gov)
- **Kidshealth\***  
[www.kidshealth.org](http://www.kidshealth.org)
- **Mayo Clinic**  
[www.mayoclinic.com](http://www.mayoclinic.com)
- **Medline Plus\***  
[www.medlineplus.gov](http://www.medlineplus.gov)

### Task # 2: Find Out What the Information Means

A lot of health information may use medical words that are hard for patients to understand. Medical dictionaries and encyclopedias can help readers understand those words and articles. Webster, Taber and Mosby publish some of the medical encyclopedias and dictionaries that bookstores carry, or can be ordered if there are none in stock. Medical dictionaries may also be found at [www.medlineplus.gov](http://www.medlineplus.gov) and [www.healthfinder.gov](http://www.healthfinder.gov). Of course, physicians may be helpful here as well.

### Task # 3: Find if the Information is Relevant to You

If you do get and understand medical information but do not share and discuss that information with your doctor, you may be doing yourself a disservice. If you agree that doctors should treat patients, not diseases, because diseases affect different patients differently, then logic would suggest that seemingly relevant information in an article, may not be relevant to you at all. **YOU NEED TO TALK WITH YOUR DOCTOR** to find out if it relates to you.□



## Public Libraries and Librarians

If you don't have access to the Internet from a home computer, don't worry. Many local public libraries now offer access to the Internet and their librarians are usually prepared to help newcomers learn how to search for information. Also, visitors to the library will have free access to online databases that will allow them to find and print out articles from medical and other health-related journals. They can, for instance, access the Health-Reference Center, which contains many full-text articles on medicine, health, nursing, nutrition, family health, and more.

In addition, libraries with Internet access usually allow individuals to search the catalogs of one or more local and regional library systems for particular books. When a search is conducted and the book is found, the information provided identifies the library where the book is found, provides its call number and indicates its availability. With this information in hand, the librarian can often get the book in question through the interlibrary loan system.

With a library membership card, those with access to the Internet from a home computer can usually access their library's online databases from home. Remember, there is no charge for membership in public libraries.□

## Online, Interactive Tutorials: How Patients Can “Get the Picture”

Written information about a condition, or treatments for that condition, can greatly help patients to understand their problem and ways to treat it – unless of course, they are one of the 90 million American adults with low health literacy. Wouldn't it be great, then, if there was some other way to get and learn this information? Wouldn't it be great if that way had written and spoken explanations that were easy to understand; if it was illustrated by pictures; and helps viewers make sure they correctly understand it by asking questions, telling them if their answers are right or wrong, and explaining why? Wouldn't it be even better if all this were free? Happily, there is such a program and it's called, X-plain.

Created by the Patient Education Institute, X-Plain is an online, interactive tutorial program that can be accessed for free by going to [www.medlineplus.gov](http://www.medlineplus.gov). Once there, click on 'Interactive Tutorials.' This will bring you to a list of tutorials that fall into the categories of 'Diseases and Conditions', 'Tests and Diagnostic Procedures', and 'Surgery and Treatment Procedures.' Clicking on a link under one of these categories brings up the tutorial. These tutorials are also found at [www.westchesterlibraries.org](http://www.westchesterlibraries.org). Scroll down and click on 'Easy to read health information online.'

### What to Expect When Accessing the Tutorials<sup>1</sup>

Once a link to a specific tutorial is clicked, viewers will have three choices: *Start Tutorial*, which starts a presentation that includes questions; *Start Self-Playing Tutorial*, which runs the tutorial without questions; or *Text Summary*, which displays a printer-friendly written version. Note that the first two options require the computer to have a Flash Player installed on it. If it doesn't, a link for a free download of Flash is provided. The last option, *Text Summary*, requires Adobe Acrobat, with a link for a free download provided for that as well.

When one of the first two tutorials is clicked, the program will begin and an announcer will read what is written on the screen. First-time viewers can click on the instructions button for easy-to-understand tips on how to proceed through the program. When the tutorials with questions are selected, viewers will be asked to answer yes/no or true/false questions at the end of sections. They'll then be told if the answer is correct or incorrect, with a brief explanation. This is a wonderful program that even great readers will appreciate!□

<sup>1</sup> This describes tutorials found at MedlinePlus.

## Finding Easy-to-Understand Health Information in English and Other Languages

What follows is a list of websites that provide easy to read and understand information that can help patients of all reading levels better understand how to find information, what the information means, how to medical prevent errors and more.

### Regarding ESL Students

To help people new to seeking information from the Internet, we begin with a website aimed at helping English as a Second Language (ESL) students learn how to use the computer as well as to learn and practice health-related words. Visit [www.reepworld.org](http://www.reepworld.org). Click on 'Students,' then on 'Student ESL links.' There visitors will find a number of links, including exercises on using a computer 'mouse' and under the heading of 'ESL' a link to 'Learn English about health.'

### Regarding Safety Tips

To help reduce the risk of medical errors, an easy to read fact sheet, entitled '20 Tips to Help Prevent Medical Errors,' can be found at [www.ahrq.gov/consumer/20tips.pdf](http://www.ahrq.gov/consumer/20tips.pdf). This document tells patients what steps they can take regarding medications, hospital stays, surgery and more. Also, the FDA, at [www.fda.gov/womens/taketimetocare/mymeds.html](http://www.fda.gov/womens/taketimetocare/mymeds.html) offers 'My Medicines,' in fourteen languages (including English), that tells people how to use medicines wisely: what to look for in the label, how to avoid problems, what questions to ask, and how to keep records of medicines.

### Regarding Prescriptions

Visit [www.mlanet.org/resources/medspeak/medshort.html](http://www.mlanet.org/resources/medspeak/medshort.html) to find a list abbreviations used on prescription forms and their meanings.

### Regarding the Healthcare System

[www.familydoctor.org](http://www.familydoctor.org), one of the Medical Library Association's top ten most useful websites, offers easy-to-read information in English and Spanish on understanding insurance, managing health conditions, talking with doctors and much more. From the home page, click on 'Smart Patient's Guide.'

See **Find Easy to Understand Information** on Pg. 8

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We envision a healthcare system where patients who want to be active participants in their healthcare will be encouraged and supported by the healthcare professionals who provide that care.

**Our Mission**  
Our mission is to improve patients' understanding of, and participation in, their healthcare by fostering meaningful communication between patients, their caregivers and healthcare professionals.

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**Find Easy-to-Understand Information, continued from Pg. 6**

Watch *Following the Clues: a visit to the doctor and the library* at <http://www.unmc.edu/library/clues/>. This 11-minute video, viewable in English, Spanish or Sudanese, follows a young girl and her grandmother as they make and prepare for a doctor's appointment, see the doctor, then go to a library for health information. (Note: when RealPlayer is clicked, a box will come up asking for an email address. To bypass this and watch the video, click the 'X' and the top right of the box, then click 'Exit.')

**Regarding General Health Information**

Medline Plus at [www.medlineplus.gov](http://www.medlineplus.gov) offers information in 45 languages. Click on 'Multiple Languages,' then on the desired language to find available information. Similarly, to read or watch health-related videos in a number of languages, visit Healthy Roads Media at [www.healthyroadsmedia.org](http://www.healthyroadsmedia.org).

**Regarding Senior Citizens**

For health issues that affect senior citizens, visit [www.fda.gov/oc/seniors](http://www.fda.gov/oc/seniors). To order a free CD of easy-to-read health information on bones, Muscles, Joints and Skin, call toll free, 1-877-226-4267 or visit [www.niams.nih.gov](http://www.niams.nih.gov). Seniors who speak Arabic or Spanish, can also find information at [www.oakwood.org](http://www.oakwood.org). Place the cursor over Health Education and click 'Multilingual Health Info.'

**Regarding Disease/Condition Specific Information**

Patients should not forget the valuable information found at the American Cancer Society, [www.cancer.org](http://www.cancer.org); the American Heart Association, [www.hearhub.org](http://www.hearhub.org); at the National Institute of Diabetes and Digestive and Kidney Diseases, [www2.niddk.nih.gov/HealthEducation/HealthEzToRead.htm](http://www2.niddk.nih.gov/HealthEducation/HealthEzToRead.htm), and other national organizations.

Those who wish to look for more sources of easy-to-read health information, might try entering both 'health information' and 'easy to read' in a search engine such as [www.google.com](http://www.google.com). This will bring up many sites each of which, in turn, can lead to numerous others. Just remember to check the guidelines for figuring out if a particular site is likely to be accurate by going to [www.mlanet.org](http://www.mlanet.org). □