



Health Literacy 101

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- What is Health Literacy, and what is the scope of the issue?
- What is the impact of low Health Literacy?
- What are the signs of low Health Literacy and why is it important?
- What can we do to improve our Health Literacy?
- Test your Health Literacy

What is Health Literacy and what is the scope of the issue?

Health Literacy includes the ability to understand instructions on prescription drug bottles, appointment slips, medical education brochures, doctor's directions and consent forms; and the ability to negotiate complex health care systems. Health literacy is not simply the ability to read, it requires a complex group of reading, listening, analytical, and decision-making skills, and the ability to apply these skills to health situations.

Health literacy varies in different situations and settings, and is not necessarily related to years of education or general reading ability. A person who functions adequately at home or work may have marginal or inadequate literacy in healthcare environment. With the health care system becoming more complex, and an emphasis on improving the quality of healthcare and to reduce cost, individuals need to take an even more active role in healthcare-related decisions. To accomplish this, people need strong health information skills.

The health of 90 million people in the U.S. may be at risk because of the difficulty some patients experience in understanding and acting upon health information. Literacy skills are a stronger predictor of an individual's health status than age, income, employment status, educational level, or racial/ethnic group.

One out of five American adults read at the 5th grade level or below, and the average American reads at the 8th to 9th grade level. Yet most health care materials are written above the 10th grade level. Limited health literacy increases the disparity in healthcare access among exceptionally vulnerable populations (such as racial/ethnic minority and the elderly). According to the Center for Health Care Strategies, a disproportionate number of minorities and immigrants are estimated to have literacy problems. 50% of Hispanics, 40% of Blacks, 33% of Asians, and more than 66% of U.S. adults, age 60 and over, have either inadequate or marginal literacy skills.

What is the impact of low Health Literacy?

- Low health literacy is an enormous cost burden on the American healthcare system – annual healthcare costs for individuals with low literacy skills are *4 times higher* than those with higher literacy skills.
- Problems with patient compliance and medical errors may be based on poor understanding of healthcare information. Only about 50% of all patients take medications as directed.
- Patients with low health literacy and chronic diseases, such as diabetes, asthma, or hypertension, have less knowledge of their disease and its treatment and fewer correct self-management skills than literate patients.
- Patients with low literacy skills were observed to have a 50% increased risk of hospitalization, compared with patients who had adequate literacy skills.
- Research suggests that people with low literacy:
 - Make more medication or treatment errors
 - Are less able to comply with treatments
 - Lack the skills needed to successfully negotiate the healthcare system
 - Are at a higher risk for hospitalization than people with adequate literacy skills

Signs of Low Health Literacy

People with low health literacy skills have developed a number of clever and successful coping strategies that allow them to conceal their problem. Some bring along a friend or family

member who can assist with reading. Patients may also watch the behavior of others in the same situation and copy their actions. Some ask for help from the medical staff, while others may ask for assistance from other patients.

Many people with low health literacy skills have figured out coping skills that allow them to maneuver in the healthcare system with the least amount of personal shame and/or embarrassment. These patients may appear, on the surface, to be in control of their healthcare and treatment regimens. But, they are often lacking the critical information they need to effectively manage their condition.

Although it may be difficult to identify if someone has low health literacy skills, there are clues that they may need additional help. These include:

- Registration and other forms filled out incompletely or incorrectly.
- Written materials handed to a relative or other person accompanying the patient.
- "I will read this at home."
- "I can't read this now; I forgot my glasses."
- Aloofness or withdrawal during physician/provider explanations.
- Frequently misses appointments, including appointments for specialty consultations or additional laboratory tests.
- Frequent errors in medications or self-care instructions, and consequently considered "noncompliant."

How can we improve our Health Literacy?

One of the most important things you can do is to take personal responsibility for your own health. Communicating with your doctor or other healthcare professionals, such as the nurse, pharmacist, or therapist, is up to you. Not understanding should not be an option. These helpful tips may get you on your way and leave you feeling more empowered about your own health.

1. Write a list of questions and concerns before your doctor's visit.

Many people get into the office and forget what they wanted to ask their doctor. The best way to avoid this problem is to write out a list of questions and concerns before you go. Don't be afraid to pull it out in front of the doctor or the nurse.

2. Write down instructions and information your doctor gives you before you leave the office.

If you have a new diagnosis, write it down and get the correct spelling. Also ask what further tests or treatments you may need and write those down too. You can look them up later when you have time to absorb the information.

3. **Repeat the instructions back or practice what your doctor showed you in front of him.**
Repetition will help both of you know if you understand the instructions for taking medications or using new equipment.
4. **Ask for written materials about your diagnosis, medication or condition.**
Most doctors' offices have written information on common diagnoses. If he doesn't have it readily available, chances are he can print it up fairly quickly. That way you are sure to get information that he believes is accurate and reliable.
5. **If the doctor has explained something to you but you don't understand, ask him to clarify.**
It is easy for medical professionals to forget how to explain things to patients. To them, it is easier to explain it in medical terminology, which to most people, may as well be a foreign language.
6. **If your doctor's explanation just isn't making sense to you, try asking his nurse.**
Just hearing a different person explain it in a slightly different way may help it make sense. She should be giving you the same information, but it may be easier to understand. But be sure you are actually talking to a nurse and not the receptionist or other office personnel.
7. **If you have questions after you get home, call your doctor back.**
You should be able to get an answer from either the doctor or the nurse within 24 hours. They are there to be sure you are comfortable, no question is too small.
8. **If your doctor is in a hurry, but you don't feel comfortable with what he has told you, tell him you do not understand.**
He should either sit down or talk with you or schedule a time (within the next day or two) that he can sit down with you. If he is not willing to do this, find a new doctor. Any doctor who is not willing to take the time to make sure his patients are comfortable does not deserve your money.
9. **At the very least always try to get these three basic questions answered:**
 1. What is my main problem?
 2. What do I need to do?
 3. Why is it important to do this?

Testing your Health Literacy

Many people, even highly literate people, have trouble understanding words used in healthcare. In some instances, a word may be totally unfamiliar. In other cases, a word may be familiar, but the person may not understand it in a healthcare context.

For example, upon hearing "keep your glucose in a normal range," people know what normal means about a person, and they may have a range in their kitchen, but they may miss the intended concept in terms of healthcare. Even people who understand the concept may need

more information than the phrase provides. They need to be told what glucose measurements are considered normal.

Words with a Latin or Greek prefix present special problems. The health science field is full of such words. Here is a small sampling: pre-op, post-op, prenatal, premature, unsweetened, decontaminate, antibacterial. For example, the risk factor for poor readers with diabetes is that they may recognize one part of the word, such as the sweetened in unsweetened, and then skip the un. This kind of guessing can lead to the opposite behavior.

- Medical words
- Concept words
- Category words
- Value judgment words

Sources:

National Patient Safety Foundation www.npsf.org

National Network of Libraries of Medicine <http://nnlm.gov/outreach/consumer>

Pfizer <http://www.pfizerhealthliteracy.com>

MATCHING ACTIVITY

You can test your own understanding of some common terms used in the medical world. Try and match the problem word what the medical professional is really trying to convey.

Test and answer key provided on the following pages

Medical Word Examples: Words frequently use by doctors and in health care

Problem Word	What they are really trying to tell you
Ailment	Dizziness
Benign	Something done to treat our problem; operation
Condition	Sickness, illness, problem with your health
Dysfunction	Will not cause harm; is not cancer
Inhibitor	By mouth
Intermittent	Wound; sore; infected patch of skin
Lesion	Off and on
Oral	Drug that stops something that is bad for you
Procedure	Problem
Vertigo	How you feel, health problem

Concept Words- Words use to describe and idea or notion

Problem Word	What they are really trying to tell you
Active role	Good health; feeling good
Avoid	Choice
Collaborate	What you eat or drink; what goes into your body
Factor	Other thing
Gauge	Stay away from; do not use (or eat)
Intake	Take part in
Landmark	Work together
Option	Measure; get a better idea of; test (dependent on context)
Referral	Very important, important event; turning point
Wellness	Ask to see another doctor; get a second opinion

Category Word Examples: Words that describe a group or sub-set that may be unfamiliar

Problem word	What they are really trying to tell you
Activity	Bad
Adverse (reaction)	Non-cancerous
Cognitive	Product sold without a brand name, like ibuprofen (Advil is a trade name)
Hazardous	Learning; thinking
High-intensity exercise	Chicken, turkey
Generic	Not safe; dangerous
Noncancerous	Help with your needs—for money, friendship, or care
Poultry	Use an example, such as running
Prosthesis	Something you do; something you do often, like driving a car
Support	Replacement for a body part, such as a man-made arm

Value Judgment Words: Words that may need an example or visual to convey their meaning or clarity.

Problem word	What they are really trying to tell you
Adequate	With care; slowly <i>Example: making sure to hold onto the handrail</i>
Adjust	Gets worse (or better)
Cautiously	Fine-tune, change
Excessive	Too much <i>Example (bleeding: if blood soaks through the bandage)</i>
Increase gradually	Not too much <i>Example (exercise) so you don't get out of breath</i>
Moderately	For a limited time; for about (an hour a day...) <i>Example for less than a week</i>
Progressive	Enough to make a difference <i>Example: (smoking/heart disease) 2 times the chance of having heart disease</i>
Routinely	Enough <i>Example (adequate water); 6-8 glasses a day</i>
Significantly	Add to <i>Example (exercise); add 5 min. a week</i>
Temporary	Often <i>Example: every week; every other day</i>

Key to Medical Words

Problem Word	What they are really trying to tell you
Ailment	Sickness, illness, problem with your health
Benign	Will not cause harm; is not cancer
Condition	How you feel; health problem
Dysfunction	Problem
Inhibitor	Drug that stops something that is bad for you
Intermittent	Off and on
Lesion	Wound; sore; infected patch of skin
Oral	By mouth
Procedure	Something done to treat our problem; operation
Vertigo	Dizziness

Key to Concept Words

Problem Word	What they are really trying to tell you
Active role	Take part in
Avoid	Stay away from; do not use (or eat)
Collaborate	Work together
Factor	Other thing
Gauge	Measure; get a better idea of; test (dependent on context)
Intake	What you eat or drink; what goes into your body
Landmark	Very important, important event; turning point
Option	Choice
Referral	Ask you to see another doctor; get a second opinion
Wellness	Good health; feeling good

Key for Category Words

Problem word	What they are really trying to tell you
Activity	Something you do; something you do often, like driving a car
Adverse (reaction)	Bad
Cognitive	Learning; thinking
Hazardous	Not safe; dangerous
High-intensity exercise	Use an example, such as running
Generic	Product sold without a brand name, like ibuprofen (Advil is a trade name)
Noncancerous	Non-cancerous
Poultry	Chicken, turkey
Prosthesis	Replacement for a body part, such as a man-made arm
Support	Help with your needs—for money, friendship, or care

Key to Value Judgment Words:

Problem word	What they are really trying to tell you
Adequate	Enough <i>Example (adequate water); 6-8 glasses a day</i>
Adjust	Fine-tune, change
Cautiously	With care; slowly <i>Example: making sure to hold onto the handrail</i>
Excessive	Too much <i>Example (bleeding: if blood soaks through the bandage)</i>
Increase gradually	Add to <i>Example (exercise); add 5 min. a week</i>
Moderately	Not too much <i>Example (exercise) so you don't get out of breath</i>
Progressive	Gets worse (or better)
Routinely	Often <i>Example: every week; every other day</i>
Significantly	Enough to make a difference <i>Example: (smoking/heart disease) 2 times the chance of having heart disease</i>
Temporary	For a limited time; for about (an hour a day...) <i>Example for less than a week</i>