

Health Literacy Panel

(Central States Communication Association conference, April 8, 2005)

1. What do you see as competencies that health care providers need to possess in order to promote health literacy?

Ability to establish rapport and trust so patients will be honest about inability to understand (not so rushed! so people can ask questions)

Recap/review and ask patient to repeat back instructions to check for understanding / offer diagnosis and instructions in written and perhaps recorded form, or picture pages.

Ability to assess reading and number literacy/hearing/vision/memory/cultural barriers to comprehension—don't be biased by clothing, age, ethnicity, educational level. Illiteracy, and misunderstandings about health concepts, can occur anywhere.

Ability to develop and manage a treatment plan for chronic disease, negotiated with the patient (see question 6).

Recognize barriers to treatment adherence:

Go get a mammogram/bone scan/colonoscopy/flu shot (What? Where? How? Why?)

How many patients don't follow through on doctor's recommendations because they do not know why or how to do that? How many doctor's offices supply lists of appropriate places to get tests or therapy, and how to determine if one's insurance will pay before incurring the bills? More literate, savvy health care consumers figure out this stuff for themselves, but less sophisticated consumers won't. People who have emigrated from a different country/culture/health care system will hardly know where to start, even if they are highly educated.

Money—Doctor may need to teach patients that if they call around, different pharmacies will have wildly different prices from month to month—using the health care “system” may require a degree of economic “literacy” for success. Seniors learn to shop around for their heart medications from each other more often than from their doctors, and certainly their pharmacists aren't motivated to tell them. Very poor patients may qualify for poorly advertised programs the drug companies run to provide free or subsidized drugs, but they have to be savvy enough to find the appropriate program and fill out the applications.

Polypharmacy—if you want people to follow a drug regimen, make it one that people can follow (not even a PhD in pharmacology could reliably follow a regimen of fourteen different drugs, some to be taken with meals and some on an empty stomach, some to be taken on a strict time schedule and some once a day, some which must not be taken together with other drugs or foods, etc.)

Lifestyle changes—if you tell a patient to cut his sodium intake, for example, you may need to do some patient teaching about sodium, or at least refer the patient to a consumer health library (free) or a nutritionist (more focused and patient-specific information, for a fee). Many people do not know how to read food labels (my consumer health library has a video on reading food labels) and do not realize that removing table salt from the table will not help if they are eating convenience/prepared/junk foods, all of which tend to be loaded with sodium. This change requires more than will power, it requires a degree of health information literacy. For that matter, how can a special diet fit into his cultural expectations for food, or with the available choices in his local market? How do you motivate people to exercise if their neighborhood is not safe to walk in, and they can't afford to join a gym? These questions go beyond health literacy, but it all ties together.

Know referral options—If the health provider does not have the time or means to follow up on all the patient’s health information needs, he or she should refer the patient to other options:

Consumer health libraries, preferably staffed by a medical librarians/consumer health specialist—these allow health care consumers to study written and audiovisual materials at their own pace. (My library has books, videos/DVDs, online resources, anatomical charts and models, disability dolls and infant manikins, and more, in several languages and in a variety of reading and age-appropriate levels.) Free

<http://www.nlm.nih.gov/medlineplus/libraries.html>

<http://caphis.mlanet.org/resources/listdbase.html>

Community education classes—often hospitals or health or community organizations will offer classes for the community in first aid, healthy eating, low impact exercise, stress reduction, and even mini-medical schools for more advanced learners. Cheap.

Example: Healthy Kids University

<http://www.childrens-mercy.org/ParentsChildren/hku.asp?tab=PC>

HMOs/Ask A Nurse/etc.—some health insurance providers have online health resources and “Health Coaches,” particularly for subscribers with chronic conditions. Ask-a-Nurse telephone lines may be able to answer some types of questions and clear up misunderstandings about health conditions and treatments. Free.

Other health care professionals—some patients will pay if referred to dietitians, exercise physiologists, pain centers, speech pathologists, etc., but may need a referral from a physician, or may need to be told by one health professional that another may offer the help needed (for example, many people don’t realize that some speech pathologists and some occupational therapists work with people who have swallowing disorders).

2. What does the internet need in order to improve in terms of health literacy?

More health materials written at lower reading levels, with more visuals and/or sound, in more languages. Most medical sites require higher literacy levels than most consumers have, so low literacy people opt out, or never find their way in, even when highly motivated to find information.

Materials from credible, authoritative sources must be promoted and attractive enough to compete with the deluge of bad health information on the net. Example of very sophisticated phony medical site: <http://www.rythospital.com/> Note also this movie ad, which does NOT have a .com domain name: <http://www.godsendinstitute.org/>

There are many attempts to authenticate web health information: One indication of a responsible medical site is the HON logo. The Health on the Net Foundation allows a web site to display its logo if the site adheres to the HON Code of Conduct (www.hon.ch/HONcode/Conduct.html). Participation is voluntary, and many excellent sites do not register with this Foundation (www.aap.org, for example), but the HON logo is reassuring if you are presented with a complex web site. But does the presence of the logo really indicate compliance with the HON Code, or was the logo just cut and pasted into the web site? Click on the logo to verify compliance. The URAC logo (www.urac.org) works the same way. Click on it to verify a web site’s compliance with HI-Ethics (Health Internet Ethics, <http://www.hi-ethics.org/urac.asp>). An example of a web site that tries to address quackery and junk medicine on the Internet is Quackwatch at <http://www.quackwatch.org/>

Consumer health librarians offer instruction, individually or in classes, on how to use the web for health information. Learn more at CAPHIS <http://caphis.mlanet.org/consumer/index.html>

or at MLANET <http://www.mlanet.org/> and <http://www.mlanet.org/resources/healthlit/>

MedlinePlus Health Topic: Evaluating Health Information

<http://www.nlm.nih.gov/medlineplus/evaluatinghealthinformation.html>

Examples of health literacy materials on the internet provided by our tax dollars:

MedlinePlus <http://medlineplus.gov/> in English and Spanish, quality-filtered

Health Topics: <http://www.nlm.nih.gov/medlineplus/healthtopics.html>

Easy to Read materials

Low Vision materials

Interactive Tutorials—narrated slide shows with printed text summary in English and Spanish

NIHSeniorHealth.gov (customizable display, for large print, high contrast, and speech)

Home Genetics Reference <http://ghr.nlm.nih.gov/ghr/> (tries for under 8th grade reading level, a challenge in this subject area)

Cancer.gov <http://cancer.gov/> (many online support booklets, also PDQ summaries written both for lay persons and professionals)

Centers for Disease Control and the National Institutes of Health also have their own pages, with some additional lay language materials

<http://www.cdc.gov/> and <http://health.nih.gov/>

LaRue Medical Literacy Exercises (teaches how to read prescription labels in four languages) English, Arabic, Hmong, Somali

<http://www.mcedservices.com/medex/medex.htm>

Visiting the Doctor (online lessons for ESL students) <http://literacynet.org/vtd/>

24 Languages Project (Eccles Library, University of Utah) written and audio files (read by native speakers) on variety of health topics <http://medstat.med.utah.edu/24languages/>

Healthy Roads Media (written, visual/slides, audio files in English and several other languages) <http://www.healthyroadsmedia.org/>

Many health care organizations have put their patient education materials online

Example: Children's Mercy Hospitals & Clinics <http://www.childrens-mercy.org/>

Care Cards <http://www.childrens-mercy.org/CareCard/>

Storybook Tours (Mercy Bear's Big Adventures)

<http://www.childrens-mercy.org/mercybear/index.htm>

Picture book tours, maps, etc. <http://www.childrens-mercy.org/ParentsChildren/>

Healthy Kids Columns <http://www.childrens-mercy.org/HKC/>

Other examples: congenital heart defects

Cincinnati Children's Hospital—Heart Encyclopedia (flash movies, printable diagrams) <http://www.cincinnatichildrens.org/health/heart-encyclopedia/default.htm>

TX Heart Institute – heart as a house <http://www.childrenheartinstitute.org/>

Many patient education files are unique, in that only one hospital has written and published a lay language explanation of a condition or procedure; ask your consumer health librarian to help you identify such files. For example, St. Louis Children's Hospital has a very useful file on rhizotomy for CP, available in four languages, at <http://www.stlouischildrens.org/default.aspx?tabid=89&acn=view&aid=1470>

Internet is a conduit for health information to health care practitioners' offices.

Electronic databases of lay language and foreign language information can be purchased or subscribed to and delivered to the point of care (physicians' offices, examination rooms). This includes

such services as Clinical Reference Systems (<http://www.patienteducation.com/>), AAP compendiums (http://www.aap.org/bst/showprod.cfm?&DID=15&CATID=138&ObjectGroup_ID=735) and those video-loop kiosks installed in many clinic waiting rooms.

Free access to information on how to write low literacy health materials is also available on the Internet, for example:

MedlinePlus: How to write easy to read health materials

<http://www.nlm.nih.gov/medlineplus/etr.html>

Clear and Simple (National Cancer Institute) <http://cancer.gov/aboutnci/oc/clear-and-simple>

See an **Author's Guide** at <http://uuhsc.utah.edu/pated/> (readability tests, word substitution lists, etc.)

Commercial services accessible online include:

U-Write (lots of advice, also refers to off-the-shelf suppliers) <http://www.u-write.com/>

Plain Language Service <http://www.pls.cpha.ca/> (offers translations)

3. In what ways are providers and other health care professionals who need to communicate lifesaving messages to the public failing?

Health care professionals don't write down diagnoses; patients often don't know what they have, can't pronounce it, can't spell it

We've all heard of children's misunderstandings of their diagnoses ("sick-as-hell" for sickle cell, "65 roses" for cystic fibrosis, and diabetes does not mean you are going to die from this diagnosis). When communicating with children it is important to consider their developmental age; if you tell a three year-old not to worry about the operation because "we'll knock you out first" she will stop worrying about the operation and start worrying about that big hammer you are going to hit her with. (At children's hospitals, children choose their favorite flavor of "sleepy air" to make them sleepy but NOT to "put them to sleep," as a child may have lost a beloved pet that way.) But adults with high school graduations who are life-long English speakers can still be bewildered by medical terminology.

Examples: SUV (patient meant SVT, or supraventricular tachycardia), Venus hum (patient's mother wrote it this way but was not referring to a cunnilingus technique but to venous hum, a cardiovascular sign), and imperfininis (imperforate anus). Many anatomical structures look and sound alike but are very different (peritoneum and perineum) and the same is true of drugs (nifedipine and meperidine).

BTW: Deciphering MedSpeak brochure (English, also available in Spanish) at

<http://www.mlanet.org/resources/medspeak/index.html>

http://www.mlanet.org/resources/medspeak/index_spanish.html

Health care professionals don't review instructions and check for understanding, or provide written or recorded versions

They could refer patients to consumer health libraries more (Information prescriptions) so patients could have help getting "health literate." They should NOT simply tell people to "look it up on the Internet" and expect patients to get good information; reference to a specific, reliable site such as MedlinePlus is preferable. <http://www.ihealthbeat.org/index.cfm?Action=dspItem&itemID=109069> FYI—our hospital is drafting no smoking "prescriptions" for preemies, which explain very simply and clearly that no one should smoke around a premature baby. The intention is to have the doctor or discharge nurse write in the baby's name and sign it, as a specific prescription for the baby, to impress on smoking parents that they must protect the baby's underdeveloped lungs and immune system from passive smoking,

and to give non-smoking parents authority in talking to their own parents about this. Many young parents find it very difficult to tell their own parents how to behave, especially if they are dependent on their parents for some help with babysitting.

Not all professionals are clear and forthright, especially when topic is sensitive or uncomfortable. Don't beat around the bush!
(Example: chronic biliary cirrhosis patient who learned her diagnosis from a billing form, and learned that it was terminal from the library)

Chronic illness not well-managed by many physicians; system set up for acute interventions (the seven-minute office visit).

Badly written forms abound! (One hospital CEO tells the story of trying, and failing, to decipher his own mother's billing forms resulting from a stay at another hospital. He had to ask his own hospital's billing department head to help him read and understand them. Patients may receive multiple statements resulting from what they perceived as a single procedure: for example, a patient who receives an X-ray ordered by his family physician may receive a statement from the Radiology Lab, and a separate statement from a physicians' group because a radiologist the patient never met submitted a bill for reading the X-ray.) HIPAA and consent forms are often written at a 12th grade reading level, complete with "legalese," which begs the question: how informed can the consent be?

Health care providers could take histories of new patients in person, rather than asking the patient to fill in a long form. (One clinic presented patients with a four page, closely written form asking extensive questions about personal and family health history, dates of past treatments, diagnostic procedures, hospitalizations, and medications, all to be filled out in a crowded, noisy waiting area.)

Pharmacy counseling is seldom private or comfortable, therefore seldom used.

Social support issues are not always addressed. In some hospitals, physicians refer patients to social workers or other professionals to sort out problems like how to register with the utility and fire departments if the patient will be technology dependent or disabled at home, or how to transport the patient. Many senior caregivers of parents and spouses have to sort this out on their own, however.

Except in children's hospitals or cancer centers, **people are given little to no help in organizing their health information** (meds, diagnoses, insurance info, appointment schedules, therapy and medical equipment providers, care notes and symptom diaries). Nurse practitioners, consumer health librarians, medical social workers, and even legal aid attorneys sometimes help by default, but most adults with complex medical conditions have to figure it out on their own. (Example: woman who cares for elderly father with Alzheimer's, gout, hypertension, etc. realized that she could not answer many questions at clinic visits, and needed to put together a notebook she could take with her to appointments—librarian helped her.)

Personal health history notebooks Seattle Children's online Care Notebook
<http://www.cshcn.org/resources/carentbk.cfm>
Arkansas Vital Records guide
http://www.medicalhomear.org/pdfs/vital_records_guide.pdf

Medication Reconciliation—a target of the 100K Lives campaign of the Institute for Healthcare Improvement—health providers could do a lot more to reconcile drug regimens as patients move from doctor to doctor, insurance plan to insurance plan, clinic to hospital to clinic, so the patient gets a workable plan with clear and consistent instructions.

Health care providers often provide little opportunity for follow-up questions. Once the

doctor leaves the examination room, the patient has probably lost the opportunity to think of and ask questions. Patients who call the office later with questions will be referred by the office staff to the doctor's nurse, or the nurse's voicemail, but will not talk to the physician directly. Messages can be muddled when filtered through so many layers, and patients who developed a rapport with the doctor may feel less confident in communicating with/through others.

Health care providers make recommendations but don't always help patients navigate the system to follow those recommendations. For example, if told to "get a mammogram" I know that the FDA approves mammography centers, and has a database searchable by zip code on its web site at <http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfMQSA/mqsa.cfm>. I would then go down the resulting list, calling to see which one accepts my insurance plan, and has a location and schedule compatible with my work schedule. How many people do not follow through on recommendations because they do not know how to navigate the "system" of health care in this country?

Health care providers fail to communicate information even with a system in place.

Have you ever had lab tests or a pap smear, and the only feedback you ever get is a postcard in the mail which says:

Your results were ___normal ___inconclusive ___abnormal

Please make an appointment with your doctor ___ immediately ___in 3 months ___in one year ?

If your results were inconclusive, were you able to get anyone to tell you what that meant? Were the results contradictory, barely outside the range of normal, or were there no results because the sample was lost or contaminated and no one wants to tell you? Providers may hesitate to provide specific information, because it would take more time and trouble to explain the significance of results (think of cholesterol tests, HDL to LDL ratio and total count)

Health care providers may provide excellent, evidence-based care and even have some disdain for patients who adopt ineffective and unsafe alternative medical practices, but should recognize that even the most unscrupulous alternative medical practitioners are often better communicators than rushed doctors and nurses. Health care providers need to find a way to take the time to connect and care, which most would prefer anyway, if the present system would allow it.

4. In what ways are providers and other health care professionals succeeding at communicating life saving/enhancing messages?

Doctors are a little more conscious of giving health messages to patients like: don't smoke! Exercise! A personal message from the doctor or nurse practitioner: "YOU should quit smoking" has much more impact than an article in the paper or even a video in the waiting room.

Some health care professionals "prescribe" information therapy, handing out brochures, referring to consumer health libraries or specific sources of additional information (web sites like MedlinePlus, organizations like the Epilepsy Foundation of America, National Cancer Institute help line 1-800-4-CANCER, etc.) "You can look it up on the Internet" is not an information prescription, it is a brush-off.

Many hospitals offer community education classes (Healthy Kids University, for example:

<http://www.childrens-mercy.org/parentschildren/hku.asp?tab=PC>

and patient education materials (see question 2 for online examples).

Some hospitals and nursing homes use software to create simple communication boards. A stroke victim with loss of speech and mobility may be able to ask for the toilet or a hairbrush by pointing to a large picture (requiring less dexterity than a small picture) on a communication board. A patient who speaks a non-English language may find a communication board with words labeled in English and her own language helpful in understanding and being understood. One example of software for making communication boards is Picture This 1.0 from Silver Lining Multimedia (www.silverliningmm.com) which prints color pictures of food, activities, household items, etc. with labels in English, French, German, Spanish, or Italian. Many other communication aids are used to aid health care providers with the most basic communication (food choices, close the blinds, etc.) For examples, see www.communicationaids.com

More patient information is offered in translation.

More patient information is offered in lower reading levels.

More patient information is offered in alternate media (videos, picture pages, etc.).

More patient information is offered through medical interpreters (Family members do not make good interpreters, especially when the topic is sensitive or the family member has a vested interest in the medical decision-making which the patient is entitled to make. It also may violate patient privacy to offer no alternative to communication other than through a family member.)

Improvements have been made in these areas; twenty years ago health providers had less awareness of the issue and fewer resources to address the issue. Concern with addressing health literacy has come a long way, and **consumer and patient health information has never been so available, in so many languages, at so many reading levels, as it is now.**

There are many more consumer health libraries for the public now, and MLA has a Consumer Health Specialization Program

<http://www.mlanet.org/education/chc/index.html>

Communicating Health Information Literacy (MLA)

http://www.mlanet.org/pdf/healthlit/hil_comm_plan.pdf

These libraries are full of books, videos, and other materials ideal for improving health communication, and can be used by consumer themselves or by health professionals. The librarian can provide additional resources and recommendations. It should be noted that consumer health libraries do not only carry materials concerned with medicine, but also materials to support patients and caregivers with practical, psychosocial, and legal/financial issues surrounding illness and disability. How to feed a child with a tracheostomy, and to encourage his speech development, for example (book). Financial management during crisis (video). Estate planning for the child who will never be able to support himself (book). How to cook for a spouse on a soft mechanical diet (cookbook). How to brush one's teeth and do other activities of daily living one-handed (book). How to breastfeed a premie (video). How to challenge an insurance company's denial of claim—the list goes on. Anyone concerned with health literacy or patient education should acquaint themselves with these resources.

Other important health literacy initiatives to know about:

AskMe3 <http://www.askme3.org/>

AMA Health Literacy Kit <http://www.ama-assn.org/ama/pub/category/9913.html> and

AMA Online Video <http://www.ama-assn.org/ama/pub/category/8035.html>

See also: <http://www.ama-assn.org/ama/pub/category/print/11231.html>

Building a Health Literacy Curriculum

<http://www.healthsystem.virginia.edu/internet/som-hlc/home.cfm>

Health Literacy: A Prescription to End Confusion <http://www.iom.edu/report.asp?id=19723>

5. How can we prepare the public to be good health consumers?

Teach health literacy concepts from birth (why questions, the third of the AskMe3)

Cover your mouth when you cough/wash your hands/use a tissue:

Why? Germs!

Take the full course of your antibiotic; don't stop once you are feeling better:

Why? Drug resistance

Medicine is not only used in response to symptoms; some you take to stay well

Why? Asthma/epilepsy/diabetes/hypertension drugs prevent symptoms and maintain health

Any treatment powerful enough to have beneficial effects is likely to be powerful enough to cause harmful effects (herbs may be natural but are not necessarily safe, OTC meds can be toxic, it is possible to overdose on vitamins, etc.)

FYI: In a poster session last year I proposed a model web site called Why My Child which would explain causes of birth defects on a basic, intermediate, and advanced level, using fetal alcohol syndrome as an example.

Teach preparedness and organization for health appointments:

Bring your meds in a bag, or know their names and doses (include OTC, etc.)

Know which doctor/clinic you are there to see (many patients arrive at a large medical complex without this information clearly in mind)

Bring a list of questions (and don't leave until you've asked them)

Keep a symptom/behavior diary (especially good for symptoms awaiting a diagnosis; the symptoms do not always obligingly display themselves while the doctor or therapist is watching)

Maintain a personal health history notebook (see <http://www.cshcn.org/resources/carentbk.cfm> for an example)

Be specific about symptoms ("sometimes I don't feel so good after I eat" is less helpful diagnostically than "I get a terrible constricted sensation in my throat and chest after I eat in some restaurants, especially Chinese.")

Be honest with your health care provider (what worries you, what alternative remedies you use, whether and how much you use alcohol/tobacco/street drugs, what your treatment goals are, whether money or home life is a barrier to obtaining care, etc.)

Insist on getting and reviewing clear instructions (have a treatment plan, whether only to get another checkup in one year, or whether to make lifestyle changes or follow a treatment regimen).

Support consumer health libraries and librarians! In my library I offer books, videos/DVDs, brochures, contact information for support groups and agencies, anatomical charts and models, teaching dolls and manikins, searches of professional medical literature, resources in foreign languages and resources appropriate for various ages. Consumer health librarians often teach consumers about health resources and how to tell a good resource from a bad one (health information literacy).

Are you aware of these resources?

Making Informed Medical Decisions: Where to Look and How to Use What You Find by Nancy Oster, Lucy Thomas & Darol Joseff (O'Reilly, 2000, www.patientcenters.com)

What to Do When Your Child Gets Sick (one of the easy to read series from the Institute for Healthcare Advancement, www.iha4health.org, available in English, Spanish, and Vietnamese).

6. What can health communication scholars do to improve health literacy? In other words, what areas of research need to be further examined and then translated into usable information?

If a doctor recommends a screening test or other health system intervention to a patient, how does the patient proceed? For example, if told to “get a mammogram,” do they ask friends where to go? Do they ask the doctor’s nurse or office clerk? Do they look up FDA-certified mammography centers on the web? How many do not follow through on instructions simply because they do not know the pathway from one service (doctor) to the other (mammogram)? One could just as easily study any screening test, or even flu shots or recommended over-the-counter remedies.

If researchers can prove that recapping the treatment plan (take two aspirin and call me in the morning) just before the patient leaves, and asking the patient to repeat back the instructions improves treatment adherence, reduces follow-up visits, reduces hospitalizations, and other measurable effects (evidence-based medicine) it would be easier to get physicians to make this a consistent part of their behavior.

Research how differences between patient and health provider alter perceptions on both sides. Does the male doctor tell the patient’s husband or father more about the patient’s case than the patient herself? When the patient says “yes, doctor” does he mean: “I understand” (comprehension), or “I’m listening but not entirely following” (attention without comprehension), or “I hear you but don’t agree” (avoiding confrontation/negotiation of treatment plan), or “I show respect” (authority figures deserve a bow) and **how does the doctor tell the difference**. Research shows that patients will seek help filling out forms from people who look like them (passing janitors, for instance); could research show benefits from hiring diversity, especially training diverse clerks to help with forms? What makes health provider staff look more accessible/approachable to people with health literacy deficits?

Example of different meanings: Patient asks phlebotomist “how many jugs are you going to take this time?” As a long ago lab tech, I remember this question well. Sometimes it actually meant the patient was concerned that he would become anemic from all the daily testing. Sometimes it meant the patient was joking to cover nervousness about needles. Sometimes it expressed anxiety that so many tests were being taken and the doctors still couldn’t say what was wrong or if the patient would ever be well again. Sometimes it expressed frustration that the patient was stuck in a passive role, with daily blood draws. It never literally meant that they saw “jugs of blood” when we walked in with a lab tray full of tubes.

Example of differing perspectives: how long does a colonoscopy take? Doctor: 20 minutes (actual procedure time). Patient: 1 ½ days (prep to results).

Research how much failure to comprehend and act on written or oral instructions is due to un-assessed hearing, vision, or memory problems. Develop a short and simple way to assess these barriers to comprehension. [There are some assessment tools of varying validity and complexity already in existence, your medical librarian should be able to help you identify them.] Research efficacy/cost effectiveness of redundant instructions offered in different media (For example, written AND recorded treatment plan, video to keep and review on procedures like blood glucose monitoring. If recordable chips can be put in greeting cards and picture frames, why not have a medic alert-type pendant with a recordable chip for a patient with low vision or memory problems, to be reviewed and possibly re-recorded at each office visit?)

Research how new media can be employed to teach health literacy concepts to the coming generation (computer games to teach nutrition concepts, risk assessment, etc.).

Research how adolescents make health decisions and how to improve their health literacy, given their developmental age. Teens make independent health decisions every day (do I eat the fries instead of the fruit, do I go on an extreme diet, do I smoke/take Ecstasy/etc., do I play “chicken” with the family auto, do I have sex with that guy or girl, do I get a tattoo, do I skip the sunscreen again, do I stay with the boyfriend who hits me?). How can one frame health information to be most effective with this group (and its various cultural subgroups)?

Find out how many elders with chronic conditions know their treatment plan?

How to recognize worsening symptoms

When to adjust one's meds or diet or exposure to "triggers"

When to call the doctor

When to go directly to the ER

When / how to refill meds, equipment, oxygen, etc.

How to handle emergencies (power outage, run out of meds while traveling, etc.)

Research medication reconciliation issues. Example: a cognitively impaired patient aged 30 lives on his own and works as a parking lot attendant. He must take two medications for serious chronic health conditions. One pill must be taken once a day, and the other must be taken 3X a day, with meals. To reverse the instructions can lead to poisoning and death. To help the patient keep the instructions straight, the doctor draws a picture of a bed on a sticky label and adheres it to one pill bottle, and draws three pictures of food on another sticky label for the other pill bottle. This is successful, until the young man refills his meds. There is **no system in place** to transfer this information to the refills, he forgets which pill must be taken only once a day, and is found unresponsive by his employer after overdosing on one drug and under-dosing the other. An ambulance brings him to the ER, he spends several days in the hospital, the doctors send him home with carefully labeled meds, and worry that the same thing will happen again but feel powerless to prevent it. **Once a successful health communication is devised for an individual patient, how does one devise a workable system to preserve and replicate that success?**

These notes, complete with shameless plugs for consumer health libraries and librarians, compiled by
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