

**FAST FACTS AND CONCEPTS #153  
HEALTH LITERACY IN PALLIATIVE MEDICINE**

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**Background** Patient/family education is a cornerstone of palliative care. The ability to comprehend information from medication labels, appointment slips, and advance directive documents is often taken for granted. A report from the Institute of Medicine suggests that *health literacy* – the ability to read, understand and act on basic health information – is limited in nearly half of American adults, or about 90 million people. Health literacy problems span all socioeconomic domains; while most people with limited literacy in the US are white and native born, prevalence is highest among underserved minorities, those with limited education, and the elderly. This *Fast Fact* reviews assessment and management strategies for poor health literacy.

**Clues to poor health literacy** Guilt and shame are common in those with poor literacy skills. In response, many may develop strategies to mask their deficiencies. The first step in helping patients is to have a high index of suspicion. Suspect literacy problems when patients:

- Do not look at written materials (or if handed materials up-side down do not turn them right-side up).
- Offer excuses when asked to read written materials (e.g. left their reading glasses at home).
- Identify medications by color/shape rather than name (or by opening the bottle rather than reading the label).
- Take medications incorrectly (and cannot describe how medications should be taken).
- Have difficulty keeping appointments or filling out forms incorrectly or incompletely.

**Screening methods** People with limited health literacy skills learn to compensate – you cannot tell by looking at them. Research suggests that even though patients with limited literacy skills are masters in disguising their deficit, they are often honest to health care professionals if the professional directly addresses the issue: *Is there anything that would make it hard for you to learn today? Do you have any trouble seeing, or hearing, or reading?* You can ask patients to read from a prescription label or educational brochure. You can say, *Some patients have difficulty with text, maybe because it's too small or because it's too complicated, or because they just have trouble reading. This is important to your health, so I want to make sure you understand. Would you please look at the first few words and tell me what they say?* If there are doubts about comprehension, one can follow with, *Explain to me what this means to you?*

**Management strategies**

- **Written materials:** When possible, use materials with large print and simple language. The National Work group on Cancer and Literacy recommends written materials to be at or below the 5<sup>th</sup> grade level. Pictograms can improve comprehension and memory of instructions.
- **Verbal communication:** Many patients with poor written literacy also have poor oral literacy. All patients – but especially those with limited literacy – can struggle with medical jargon, basic numeracy, and unfamiliar concepts. Plan to spend extra time; slow down your rate of speech, use simple, common words and short sentences. When possible, limit information to a maximum of three key items; consider tape/digital recordings of conversations for later reference.
- **Medication regimens:** Simplify regimens; minimize the number of medications, the number of pills, and the frequency of administration. Fill several pill boxes for patients.

**Assure comprehension** Use the **Teach-back technique**: explain instructions to a patient and have them *teach them back to you*, repeating until they demonstrate satisfactory understanding. Use open-ended phrasing such as, *Please explain to me how you're going to take this medication*, rather than, *Do you understand how to take this medication?* **Elicit questions:** patients with limited literacy tend to ask few questions; invite questions using an open-ended format, *What questions do you have?* **Enlist allies:** ask office staff, caregivers and pharmacists to educate, assist, and support when necessary. In end-of-life situations, literacy of key caregivers may need to be assessed. **Follow-up:** plan on more frequent visits and telephone follow-up calls. **Refer:** for patients with a prognosis of at least several months, working with an adult literacy program can improve skills and heighten self-esteem. The nonprofit ProLiteracy ([www.proliteracy.org](http://www.proliteracy.org)) has over 1,200 affiliates in the US and is represented in every state.

Finally, work to create a shame-free environment; educate your staff about compassionate care for patients with limited literacy. The AMA foundation offers a variety of health literacy resources including a kit (Health Literacy: Help Your Patients Understand) and a newsletter (Health Literacy Update), both available at <http://www.ama-assn.org/ama/no-index/physician-resources/8115.shtml>.

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