

The Take-Charge Patient

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By Carol Marie Cropper

he willingness to question a physician has always been a key survival skill for patients. But with new drugs and medical procedures flooding onto the market at an unprecedented pace, patients are confronting more choices about treatment than ever before. Many are now insisting on something more than a few minutes of dialogue. They want to weigh therapeutic options with their physicians and share in the decision-making—to be partners in, not simply recipients of, their medical care.

In the U.S., many people are already primed to do their own medical homework. After years of wrestling with managed care, they've become skeptical health-care consumers. They're also more aware of their role as buyers, thanks to constant marketing assaults by drug companies, hospitals, and health plans—and new employee-benefits initiatives that threaten to shift more costs to employees.

Awareness, however, is not enough. Patients must really take charge of their own care, and the Internet provides the tools to do so. In a matter of hours, anyone can research a wide range of medical matters, from symptoms and pathology right up through clinical trial enrollment. And even doctors acknowledge that research can pay off. "A more informed patient makes a better patient and has a better outcome," says Dr. J. Edward Hill, chairman of the American Medical Assn.'s board of trustees. Such patients tend to take better care of themselves and more quickly understand what their doctor tells them, he says. "Knowledgeable patients keep us on our toes."

Dr. Albert G. Mulley Jr., chief of general medicine at Massachusetts General Hospital, notes another reason patients should take an active role. "More than doctors or patients generally appreciate," he explains, "many medical decisions have more to do with personal preferences than they do with medical probabilities." Surgery to treat a man for benign prostatic hyperplasia—an enlarged prostate—will probably relieve his need to make late-night trips to the bathroom, but might leave him incontinent or with a sexual

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dysfunction. Only the patient can decide if the problem is annoying enough to make him want to take that risk, says Mulley. Similarly, clinical trials show that women with early-stage breast cancer are just as apt to survive with a lumpectomy and radiation therapy as with a mastectomy. One woman might fear six weeks of radiation treatments and a possible recurrence in the same breast. Another might want to save her breast at all costs.

Heart patients confront equally perplexing trade-offs. A patient facing double-bypass surgery might have to weigh the prospect of relief from angina pain against the possibility of cognitive loss and an increased risk of dying soon after surgery. Whether they opt for the knife or rely on beta-blockers and aspirin may depend on how bearable the pain is—something only the patient can know.

In many cases, doctors don't agree on what's best. That much is clear from the *Dartmouth Atlas of Health Care*, a Dartmouth Medical School project that tracks how doctors treat patients in different parts of the country. Examining 10 years of Medicare data, the researchers concluded that the type of treatment patients receive often depends on their location. Folks in Bend, Ore., for example, are four times more likely to have surgery for lower back pain than those in Honolulu, says Megan McAndrew Cooper, editor of the *Atlas*. The rate for spinal fusion—a procedure in which the vertebrae are fused to relieve chronic back pain—is almost 10 times higher in Provo, Utah, than in Worcester, Mass. The latter example is especially troubling because there may be far less drastic alternatives: Surgeons can go in and clean away bone spurs and ruptured disk fragments to ease the pressure on pinched nerves. “We joke that which way you turn off the causeway determines what kind of treatment you get,” says Cooper.

The problem isn't simply that some regions are more backward than others. Consumers' Checkbook, an organization that evaluates doctors and hospitals, cites a study that highlights the uneven distribution of medical knowledge. Four years after the National Institutes of Health concluded that a type of bacteria called *Helicobacter pylori* causes the majority of peptic ulcers—not stress and stomach acid, as many doctors previously believed—large numbers of


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practices

Michigan physicians still were not prescribing antibiotics to treat the cause of the ailment.

In some cases, the treatment depends less on geography, and more on the type of doctor consulted. Clinical trials suggest that a man with early-stage prostate cancer lives just as long whether he has his prostate removed or not, says Dr. John E. Wennberg, a Dartmouth researcher. But when a man under 75 years of age consults a urologist who performs such surgeries, a likely recommendation is radical prostatectomy. A radiation oncologist might favor (no surprise) radiation therapy. Even when doctors agree on an answer, it can change from one day to the next—witness the about-faces on hormone replacement therapy and on knee surgery to treat arthritis.

Patients who do their own homework often turn up information their doctors may have overlooked, according to Steven Schneider, a family doctor and chief medical officer of Healthwise Inc., which provides medical information on the Internet. Schneider describes his own comeuppance at the hands of a patient with atrial fibrillation, a quivering of a heart chamber. Schneider had prescribed Coumadin, a blood thinner that requires monthly monitoring. Then the patient produced a study showing that aspirin was a reasonable alternative for low-risk patients. Schneider switched the man to the cheaper, less dangerous drug, and “he did just great.”

Chalk one up for the patient. ■

Doing Your Homework

In the growing ocean of medical information, some sources are better than others. Here are a few you can trust:

NLM.NIH.GOV The National Library of Medicine's Web site features MEDLINE and MEDLINEplus. Entries range from technical articles to general health info.

NATIONALHEALTHCOUNCIL.ORG Disease info, and links to member societies and foundations, such as the American Cancer Society and the American Heart Assn.

MAYOCLINIC.ORG/HEALTHINFO/ Medical information from the famed Rochester (Minn.) clinic.

ONCOLINK.COM A user-friendly info site, from the University of Pennsylvania Cancer Center.

GUIDELINE.GOV Sophisticated information on treatment guidelines from the National Guideline Clearinghouse, a project of the U.S. Agency for Health-care Research & Quality.

HEALTHWISE HANDBOOK, A SELF-CARE GUIDE FOR YOU Home reference, with advice for treating common medical problems.

MAYO CLINIC FAMILY HEALTH BOOK Comprehensive medical reference from the Mayo Clinic.

FOUNDATION FOR INFORMED MEDICAL DECISION MAKING Videotapes examining patient options for prostate and breast cancer, lower-back pain, and other common ailments.

Data: BusinessWeek