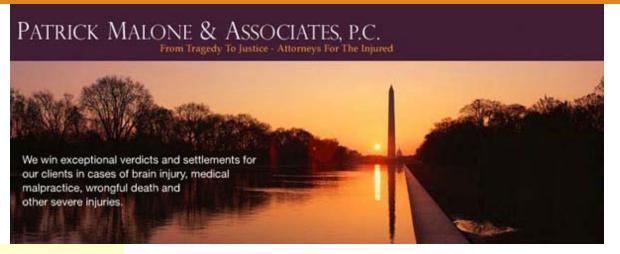
Getting the Best Medical Care: a Newsletter from Patrick Malone



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"Informed Refusal" of Health Care

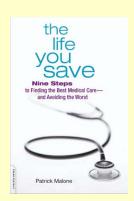
The Big Three Options for Colon Cancer Screening

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Saying No to Your Doctor: Sometimes Wrong but Always Right

Dear Patrick,

Saying no to your doctor's advice is sometimes "wrong" when you let fear and ignorance guide your decisions. You're always "right," though, in whatever you decide about your own body, because your health and how you sort out your choices is your own business, and no one, no matter how superior his/her knowledge, has a right to force any recommendations on you.

Still, nobody wants to feel like a fool, when they discover too late that they had their facts wrong. So how do you sort this out?

In this month's newsletter, we focus on screening options for one very common disease -- cancer of the colon and rectum -- to show you how you can get the facts and be always right: making an informed choice, including the option to just say no. Read on for more.

Refusing Health Care Is OK, as Long as You Have the Facts

I got the idea for this newsletter from reading a doctor-to-doctor advice column where the questioner, a Dr. "Michaels," was beside himself because his patient, Mr. "Elgie," had refused his advice to get a colonoscopy. The basic advice from his fellow doctor was: "Doctor, take two aspirin and lie down," and then work on an attitude readjustment.

When patients say no to the doctor's advice, this is called "informed refusal." It's the flip side of "informed consent." Although some doctors are stunned and shocked when patients reject their advice -- these are the ones for whom all conversations with patients are rituals ending in "consent," whether informed or not -- most modern doctors realize that their job is to provide the patient the key facts in an emotionally supportive way, and help the patient reach the decision that's right for that patient.

When it comes to cancer screening, one problem is that its benefits have been oversold to the public. The <u>"number needed to treat" (see our newsletter on this important</u> <u>medical concept</u>) is around 1,100 -- that is, 1,100 colonoscopies for every premature cancer death prevented. That statistic is good enough for a lot of us to line up for the



Read our <u>Patient Safety</u> <u>Blog</u>, which has news and practical advice from the frontlines of medicine for how to become a smarter, healthier patient.



test, but it also means that those who say no are not crazy either.

Here was the core of the advice in the medical Ann Landers column that got me thinking about this subject:

"The ethical model for preventive screening, as for most other encounters in medical practice, ought to be shared decision making. According to this model, Mr. Elgie and Dr. Michaels should be partners in deciding whether and how to screen for colon cancer. Different partnerships work differently; some are 50-50 and some are 80-20. Mr. Elgie should have a say in the extent to which he wishes to meet Dr. Michaels; will it be half way? Will he defer to Dr. Michaels' well-informed clinical recommendations? Or will Mr. Elgie demand veto rights over any and all decisions? Whatever level of participation Mr. Elgie chooses, he should emerge from the encounter feeling that he has been as involved as he wished to be in whatever decisions have been made. Dr. Michaels should also recall that there is nothing about "shared decision making" that makes it wrong for him to try to persuade Mr. Elgie that he might be making a mistake. This is especially true if Mr. Elgie's refusal seems to be based on a misunderstanding of his actual level of risk because he has had no relatives with colon cancer. The persuasion should be grounded, however, in genuine respect for Mr. Elgie and his right to make his own decision and not in fervor to "tick off" another colonoscopy referral on the scoreboard."

The author was Dr. Howard Brody, a professor of family practice and medical ethics at Michigan State University. <u>Read his full column here, and another doctor's take on the subject</u>.

Sorting Your Options for Colon Cancer Screening

The colon is the body's factory for stool, so the idea of probing into it is nasty, unpleasant and best avoided if unnecessary. So here is one fact you need to know: cancer of the colon and rectum kills more Americans than any kind of cancer except lung cancer -- about 50,000 every year. Only <u>one in four of those victims has a family history of colon cancer</u>, which means it can strike anyone.

And a key second fact: You can reduce your odds of dying early from colon cancer with a regular screening program. (However, as noted above, it's no magic bullet -- the number needed to treat is over one thousand.)

That means for most of us, the best informed choice is not over whether to screen or not, but which form of unpleasant testing to undergo and how often.

Most gastroenterologists -- the specialty that covers the digestive system from mouth to rear end -- will tell you that there's only one real choice they recommend. That is a full colonoscopy every 10 years, starting at age 50 and ending at age 75. (That's for average risk people with no family history or no colon disease.)

That means cleaning out the entire colon with a very unpleasant solution you drink until your bowel movements are completely clear looking. Then they sedate you and stick a flexible tube in your anus and run it the entire five foot length of the colon. As they pull it back out, the doctor uses a telescope at the end of the tube to inspect the entire colon.

HOWEVER, and here's where it gets interesting, colonoscopy may logically make more sense than other types of screening, but it's never been proven by statistics to save more lives than the other options.

The main alternatives to colonoscopy are:

- Testing the stool once a year for hidden blood. The test is called high sensitivity
 fecal occult blood testing. It requires you to put a dab of your stool on a piece of
 paper for three consecutive days and send that to your doctor's office. Most
 people leave the doctor's office with the test kit and never mail it in. If you don't
 do it every year, your odds of a sudden discovery of a more advanced cancer
 are greatly increased.
- Flexible sigmoidoscopy. This is a scoping of the lower part of the colon -- the six-inch length of the rectum which adjoins the anus, and the one foot of the next part of the colon that runs from the top of the rectum diagonally toward your left side. This is where most colon cancers are found, and the testing is easier than full colonoscopy. It's recommended once every five years, as opposed to every 10 years for colonoscopy. However, as one gastroenterologist told me, sigmoidoscopy is like doing a mammogram on only one breast.

Statistically, none of these three major options has been proven to save more lives than any other. But you can see the clear tradeoffs: less fuss but more often testing with the blood stool test, more fuss but less often with the scoping techniques.

The <u>National Cancer Institute</u> is an excellent source for unbiased advice on the different kinds of screening tests. If you really want to go in depth, check the <u>comparison from the National Guideline Clearinghouse</u>, which lines up the recommendations of the leading groups: the American Cancer Society, the U.S. Preventive Services Task Force, and the Kaiser Permanente Care Management Institute.

Past issues of this newsletter:

Here is a quick <u>index of past issues of our Better Health Care newsletter</u>, most recent first. You will see 23 previous issues, as we approach the end of our second year of monthly newsletters.

To your continued health!

Sincerely,

Trick Molane

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