

MAKING
CHOICE
AN
OPTION

BY MAGGIE MAHAR

Dr. Richard Barth, director of surgical oncology at DHMC, confers here with breast cancer patient Claudine Spencer about her treatment options. But before that, she made use of DHMC's Center for Shared Decision Making.



ALL: JON GILBERT FOX

Are patients who sign informed-consent paperwork really informed about the treatment they're about to undergo? Of course not. The fine print on such forms is for lawyers, not sick people. But *should* patients understand the risks and tradeoffs of different treatment options they face? Of course. Dartmouth has been leading the way, not just asking for informed consent, but giving patients informed choice.

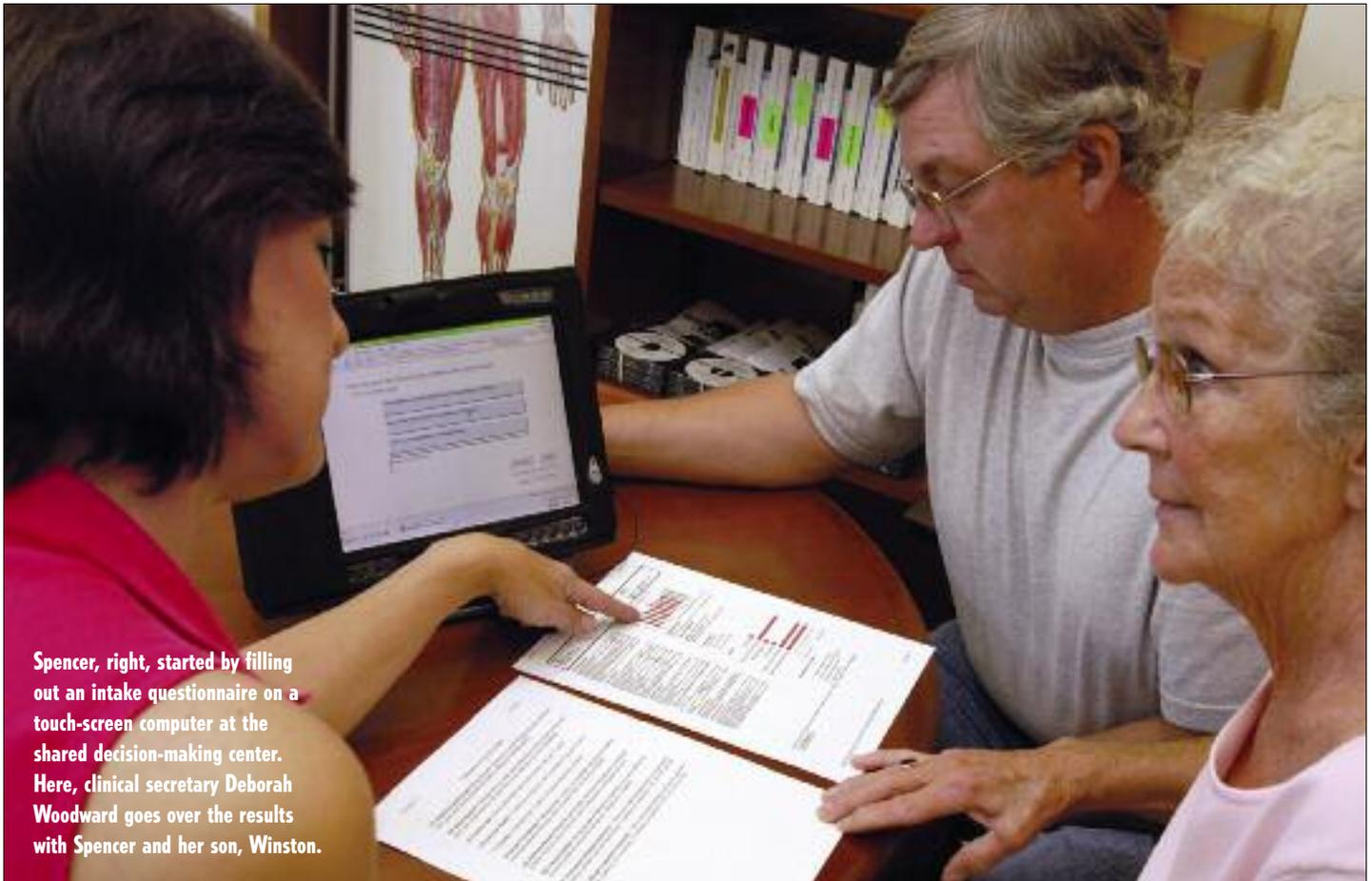
When Joe Rubin returned home from a visit to his urologist five years ago, he had bad news for his wife. “The doctor says that I have early-stage prostate cancer. They can treat it—I’ll be okay,” he assured her. “But I’m going to have to have this radiation treatment. The doctor thinks that in a case like mine, it’s the best option. He said, ‘If you were my father, this is what I would advise you to do.’”

“What are your other options?” asked his wife.

“I can’t quite remember—there’s surgery, but he said I didn’t need that,” said Rubin, whose name has been changed to protect his privacy. “And there are a couple of kinds of radiation, but he likes the new kind where they implant radioactive seeds in your prostate. He seems to know what he’s talking about—I trust him.”

“I’d just like to know a little more about the options,” his wife replied. Janice Rubin knew that Dartmouth-Hitchcock Medical Center had created a shared decision-making center that helps patients

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Spencer, right, started by filling out an intake questionnaire on a touch-screen computer at the shared decision-making center. Here, clinical secretary Deborah Woodward goes over the results with Spencer and her son, Winston.

“[It] gave me a warm feeling, like somebody out there really cares.”

—Feedback about shared decision-making at DHMC

understand the risks and benefits of various treatments, so that evening she went online and found the center’s website (see dartmed.dartmouth.edu/fall2007/choice_we.php for a link to the site), which, in turn, led her to other websites, including one for the Ottawa Health Research Institute.

When she was done browsing, she gave her husband a full report. “I’m glad he doesn’t think you need surgery,” she told him. “Even among men under 65, one out of a thousand die during or right after the operation, and five out of a hundred have a serious problem afterward—like a heart attack, a stroke, or blood clots in their lungs. Plus, five years after the surgery, more than a quarter are incontinent and more than three-quarters can’t get an erection.”

“Yeah, I remember the doctor talking about that,” Joe replied. “But I’m not going to have surgery—just the radiation, and it’s the new kind where they implant little seeds.”

“But there’s a catch,” said Janice. “Because that’s a new treatment, the doctors don’t know a lot about its side effects. What they do know is that with the older type of radiation—which is still in use—two out of a hundred men have a serious complication like a stroke, and many also have problems with incontinence and impotence. Five years after treat-

ment, four percent are still wearing pads and nearly two-thirds can’t have erections.

“Some doctors think the risk of any of these problems is lower with the seed radiation,” she added. “But they don’t have enough evidence to be sure. On the other hand, the good news is that the radiation is pretty effective—especially if you’re a low-risk patient.”

“The doctor did say I’m very low-risk,” Joe responded. “The PSA test they gave me—the blood test that can indicate prostate cancer—showed that my PSA level is pretty low. But they also did a biopsy, and showed that I do have cancer. Still, the doctor said that this is a kind of cancer that progresses very slowly. In fact, he said it’s likely I’ll die of something else before I get to a point where the cancer causes me any problems.”

“So why do the radiation?” his wife asked. “Why not just keep an eye on things and see if they get worse? That’s the third option they talk about in the medical research. It’s called ‘watchful waiting.’ You just go for regular exams and let the doctor keep track of any changes. Why don’t you ask the doctor what he thinks about watchful waiting?”

Two weeks later, Rubin went back to his urologist, explained what his wife had said, and asked, “Would watchful waiting be a good idea for me?”

His doctor smiled broadly. “I think watchful waiting would be an *excellent* idea.”

When Rubin got home and told his wife, she shook her head. “Whatever happened to ‘If you were my father . . . ?’”

“I don’t know,” said Rubin. “Maybe I just didn’t listen well enough the first time.”

Choice, not just consent

Joe Rubin’s story illustrates why “informed consent” is such a slippery idea. While doctors try to give patients the information they need to decide how to treat diseases like early-stage prostate cancer, it is extraordinarily difficult for most patients to absorb all the facts about their disease, understand all the treatment options, weigh their differing risks and benefits, and determine what is right for them. For some conditions, such as a broken hip, there’s no decision to be made—there’s a single, agreed-upon course of treatment. But for an increasing number of conditions—ranging from back pain to breast cancer—there are several acceptable options. Some doctors favor one, some another.

Little wonder, then, that most patients ask their doctors: “What would *you* do?” In many ways, this reliance on the doctor’s expertise makes sense: the physician knows more about the disease and has seen many patients try the various options.

Nevertheless, when asking “What would *you* do?” the patient is asking for the doctor’s personal preference. Would a doctor with prostate cancer like Joe Rubin’s choose radiation and risk impotence—or opt for watchful waiting and take a chance that the cancer won’t progress? If he decides on watchful waiting, would he be able to put the cancer out of his mind—or would he feel a sword hanging over his head?

But the answers to these questions aren’t universal. They depend on an individual’s temperament, priorities, values, and personal situation. That’s why DHMC opened its Center for Shared Decision Making in 1999—to help patients sort out what’s important to *them* when deciding whether to choose radiation or surgery, whether to undergo PSA screening, whether to try a second chemotherapy regimen for ovarian cancer.

Traditionally, patients who choose an elective procedure provide “informed consent” by signing a document detailing all the things that might go wrong during the treatment. What’s different about Dartmouth’s Center for Shared Decision Making is that it goes beyond just offering more information—it provides patients with an array of tools and materials to help them truly understand their treatment options so they can make a real choice.

As the discussion about U.S. health-care reform

heats up, Dartmouth’s shared decision-making center—the first in the nation—is stirring interest as a potential model for hospitals nationwide. In August, Senator Hillary Clinton spoke at DHMC as part of a series of appearances by the major presidential candidates. In her talk, she singled out Dartmouth’s shared decision-making program for praise, noting that it gets high marks from patients. And in a press release detailing her proposals for reform, Senator Clinton said she’d like to see the federal government invest \$25 million to encourage the development of similar programs elsewhere.

No right answer

Shared decision-making means that both the clinician and the patient must face up to the ambiguities of medicine. When it comes to “elective” surgery there often is no “right” answer. Is radiation, surgery, or watchful waiting better for a given stage of prostate cancer? Can back pain be managed with medication or improved with exercise, or is spine surgery indicated? Is hip or knee pain so

Dartmouth’s John Wennberg agrees. “What the patient needs to realize is that deciding to have elective surgery is a wager,” he explains, “and different patients will be comfortable with different risks.”

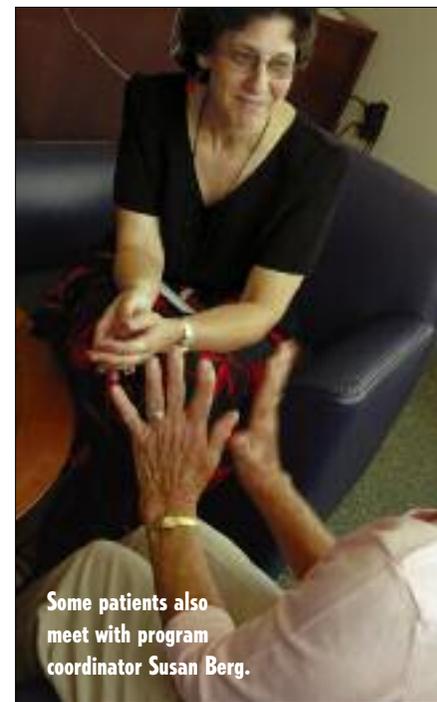
intractable that a joint replacement is called for? What about bypass surgery versus drug therapy to treat ischemic heart disease? The benefits of each option must be weighed against its risks—and then the options weighed against each other. What is right for one patient won’t be right for another.

It is crucial for patients to realize that virtually any medical intervention carries the possibility of complications and side effects. “When it comes to risk, I know that many of my patients are thinking, ‘I trust my doctor. He is so good that nothing bad will happen to me,’ says Dartmouth’s Dr. James Weinstein, an orthopaedic surgeon and the director of the Center for Shared Decision Making.

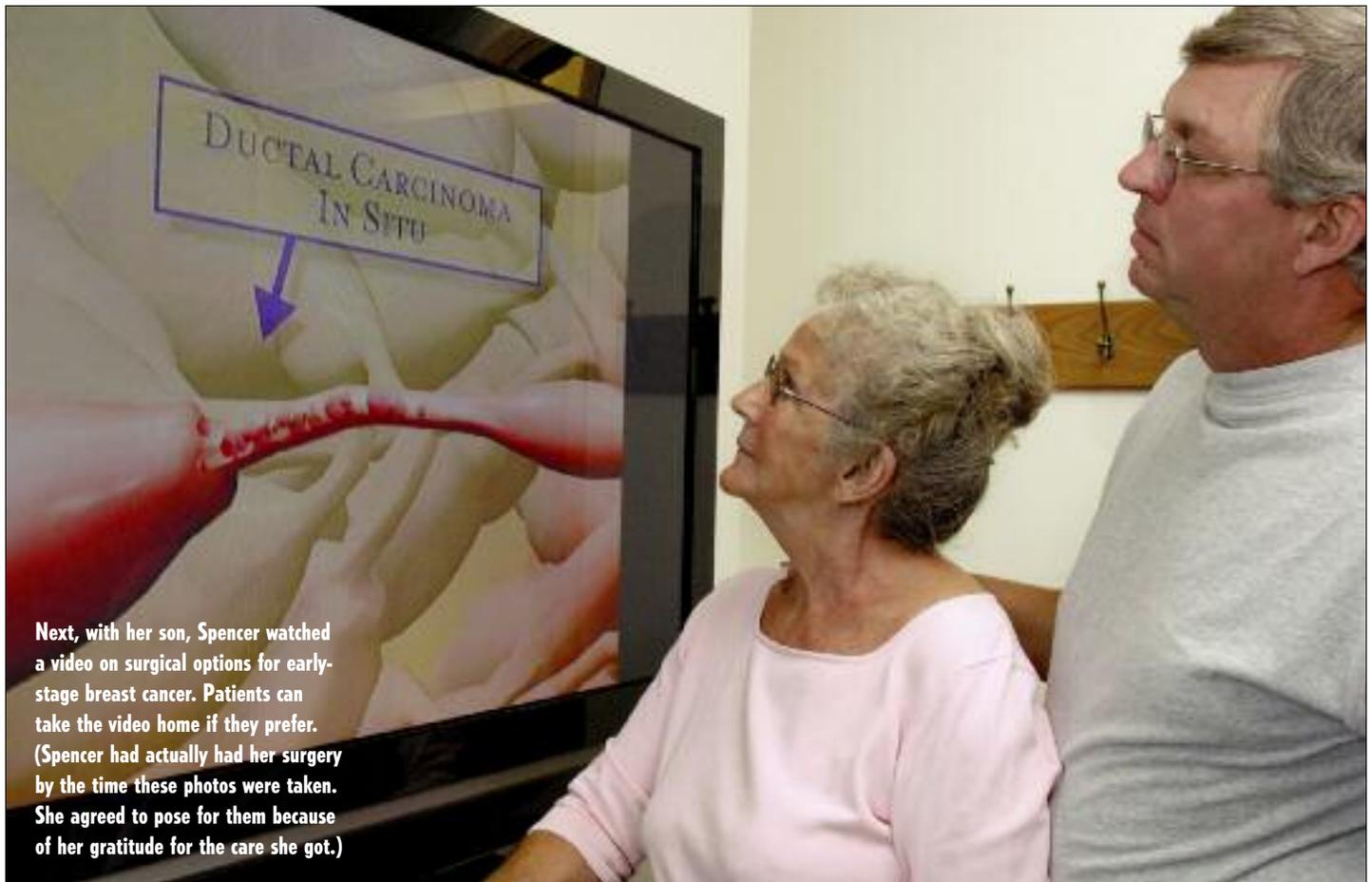
“I want to say, ‘Wait. Stop. This is important. You could die. You could get an infection.’ We’re not trying to scare people, but . . .”

Dartmouth’s Dr. John Wennberg, cofounder of the Foundation for Informed Medical Decision Making, agrees. “What the patient needs to realize is that deciding to have elective surgery is a wager,” Wennberg explains, “and different patients will be comfortable with different risks.”

Of course some decisions are slam dunks. If a woman is diagnosed with early-stage breast cancer, virtually everyone agrees: she needs surgery. But doctors honestly don’t know what’s the best treat-



Some patients also meet with program coordinator Susan Berg.



Next, with her son, Spencer watched a video on surgical options for early-stage breast cancer. Patients can take the video home if they prefer. (Spencer had actually had her surgery by the time these photos were taken. She agreed to pose for them because of her gratitude for the care she got.)

“I had changed my mind by the end of the video.”

—Feedback about shared decision-making at DHMC

ment for early-stage prostate cancer because long-term studies comparing how similar men fare when they choose different options just haven’t been done—in large part because the disease progresses so slowly. But the medical evidence on stage 1 or stage 2 breast cancer is in. Normally, surgery is the only option.

But the breast-cancer patient does have to decide if she wants to have a mastectomy—removal of the entire breast—or a lumpectomy—removal of just the tumor and a margin of surrounding tissue. The patient has a choice because research has shown that her chance of surviving breast cancer is about the same, whether she chooses the aggressive mastectomy or the breast-sparing lumpectomy.

But when it comes to risks and benefits, there are tradeoffs. Following a lumpectomy, she will almost certainly need radiation therapy; after a mastectomy, she is much less likely to need radiation. But if she chooses lumpectomy, there is a greater chance the cancer will recur locally, requiring further treatment (but not affecting survival).

“Here you can divide women into two groups,” says Wennberg, “those who are most concerned about preserving the breast and those most concerned about preventing local recurrence of the disease. The second group is likely to prefer the more

aggressive mastectomy—these are patients who just want to get it over with.”

For women who choose mastectomy, there’s yet another decision to be made—whether to wear a breast prosthesis after the operation or to have breast reconstruction surgery. Those who choose the latter option then need to decide whether to have the reconstruction done at the same time as the mastectomy or later. And there are, of course, different risks and benefits associated with each of those choices.

In the past, women traditionally followed their doctors’ preferences. Some physicians recommended lumpectomy; others felt strongly that mastectomy was the safest course—even though there was no solid medical evidence to back up their belief. Over time, the predilections of physicians in each community created a medical culture that favored one treatment over another.

In the early 1990s, Dartmouth researchers investigating geographic variations in patient care discovered that the rate of mastectomies fluctuated widely from one part of the country to another, and even one part of a state to another. For example, Medicare records for patients near Elyria, Ohio, revealed that 48% of breast-cancer patients had lumpectomies. But 30 miles away, in Cleveland,

only 23% wound up with the less invasive procedure. Meanwhile, a mere 1% of women in Rapid City, S.D., had lumpectomies. To argue that patients' preferences drove those decisions, one would have to believe that women in Elyria placed a far higher value on preserving their breasts than women in Rapid City—an inherently unlikely proposition.

More likely, women in each region were following their doctors' druthers. And indeed, when an investigative reporter went to Rapid City, she discovered that the physician who performed nearly all of the breast surgery in the area was a strong advocate of mastectomy—and did not offer his patients any other option.

Today that one-right-way mindset is changing. Caregivers are much quicker to admit to the uncertainties inherent in medicine—and to the importance of the patient's own preferences in making medical decisions. Or, as Dr. Annette O'Connor, research chair of the Ottawa Health Decision Centre and a visiting professor at DMS, puts it: "Every patient should get what they need—and no less, and what they want—and no more."

Progress, despite obstacles

Nevertheless, some doctors still resist the idea of relinquishing their authority. And it's not just older physicians who object, says Dr. Robert McNutt, a professor at Chicago's Rush University and chair of medical informatics and patient safety research at Rush University Medical Center.

When McNutt tackles the subject in his classes, he told the Associated Press in 2005, "the students get up and scream at me: 'If this is true, why am I going to medical school?'"

Some physicians grouse that they are not reimbursed for the time they spend talking to patients about making decisions. "Doctors ask: 'Why should I do this—and who is going to pay for it?'" Dartmouth's Weinstein reports. Moreover, "a lot of physicians believe that they are already doing everything that we do at the [shared decision-making] center. They say they tell patients all about risks and benefits.

"And I say, 'You can't possibly be—this isn't a five- or ten-minute discussion.'"

Too often, physicians "seek informed consent simply by presenting a scenario along the lines of 'here's what we have to do and why,'" observes Dr. Jerome Hoffman of the University of California at Los Angeles. He was the lead author of an article on informed decision-making published in the journal *PLoS Medicine* last year. "This may or may not be accompanied by a brief mention of the possible risks of the proposed strategy," he says, "and in rare cas-

es even by a very brief mention of potential alternatives—although this last element would typically be followed by a description of why such alternatives are not really reasonable."

By contrast, Weinstein explains, true shared decision-making is a process by which the doctor shares any relevant information that he or she has about treatment options and their risks and benefits, while the patient shares any relevant personal information that might make one treatment or side effect more or less tolerable than others. "Then the physician helps the patient sort out what's best for him or her," Weinstein says.

The goal, he concludes, is to move medicine beyond informed consent—which means agreeing to what the doctor proposes—to informed choice—an active choice based on the patient's own hopes and fears.

Despite resistance to the concept, shared decision-making is reaching a tipping point, its advocates say. Dartmouth-Hitchcock is no longer alone in having such a center. In Massachusetts, Mass



The video includes insights from other patients—some who chose lumpectomy and some who chose mastectomy.

"A lot of physicians believe that they are already [telling] patients all about risks and benefits," surgeon Jim Weinstein reports. "And I say, 'You can't possibly be—this isn't a five- or ten-minute discussion.'"

General Hospital, more than 20 cancer centers, and 10 community-based primary-care practices are using "decision aids" (many developed at Dartmouth) to help patients and physicians make collaborative decisions. Doctors at the University of California at San Francisco and at Pennsylvania's Allegheny General Hospital are incorporating decision aids into routine breast-cancer care, while the University of North Carolina is using them to help patients make decisions about colorectal cancer screening.

Most impressively, this spring, Washington became the first state to pass a law endorsing shared decision-making as part of informed consent. Under the new law, a caregiver who uses certified patient decision aids enjoys a higher standard of immunity from malpractice suits claiming a failure to inform patients about the options open to them.

The decision-making process

Dr. Hilary Llewellyn-Thomas, research director for the Dartmouth Center for Shared Decision Making, outlines the stages of a process that she calls decision support. "We don't so much share in the decision-making as share information," she explains, and then "coach" the patient through the process of actually making that decision.



In addition to gathering all sorts of information at the shared decision-making center, Spencer also met with Laurel Ludy, continuing care manager at DHMC's Comprehensive Breast Program.

“[It] helped me to feel more comfortable with my decision.”

—Feedback about shared decision-making at DHMC

Typically, at the outset, the patient is going to feel what Llewellyn-Thomas describes as “intense decisional conflict”—an extremely uncomfortable state of uncertainty and unease. “Our goal is to reduce that conflict. It’s one thing to be worried and concerned—another to be panicked.”

Dr. Dale Collins, a Dartmouth reconstructive surgeon who works with breast cancer patients, agrees. “Often, the first reaction is ‘Oh, my God, I have cancer—just take it off.’ But usually you can get them down off the chandelier,” she says.

One way to do this is to bring some order to the process. Llewellyn-Thomas describes how a caregiver takes a patient through the four steps of making a decision:

First, you’ll work together through information about the risks and benefits of various treatment options, and the caregiver will make sure you understand it.

Second, you’ll sort out your own values and priorities.

Third, you’ll filter out undue influences from family or friends and evaluate whether you’re getting adequate support.

And fourth, you’ll put together a reasonable plan of action.

At Dartmouth, patients often begin to assimilate

information about their options by taking home a 45-minute video or DVD that outlines the risks and benefits of various treatments and includes testimonials from patients describing how they used this information to reach a decision.

On the prostate cancer video, one man who chose surgery says: “If something is going to happen, I want it to happen. Fix it and get it over with.”

Another explains: “I don’t worry too much about uncertainty. All of life is uncertain. You don’t know what’s around the next corner. In the meantime, I want to enjoy what I have.” He opted for watchful waiting.

The breast cancer video features a woman who explains: “I was pretty clear that I didn’t want a mastectomy. I didn’t want to be a jerk about it, but I didn’t want to go that route.”

By contrast, another says: “I realized I didn’t need it to live because it doesn’t make me who I am.” She had a mastectomy.

“About 30 percent choose the mastectomy,” says Collins, who is director of the Comprehensive Breast Program at DHMC. “Preserving the breast is just not that important to them. Some say they didn’t like the breast to begin with.”

This may be especially true of women who watched their mothers die of breast cancer. “When

they are diagnosed, many say, 'It's a relief. I've been waiting for this all my life,'" Collins reports. "Because of the familial risk issues, they are more likely to want the more radical procedure."

The videos come with booklets that provide more information. For example, the breast-cancer booklet advises patients that the statistics regarding how often cancer recurs after a woman chooses lumpectomy are only "'averages.' Your doctor will give you numbers that are more specific to your situation." The booklet also explains that sometimes, medical reasons make mastectomy the better choice—such as if, for example, a woman has cancer in two or more separate areas of the breast; if she is pregnant and so cannot have radiation after surgery; or if she has had a lumpectomy that did not remove the entire tumor along with a margin of healthy tissue around it.

Finally, the booklet urges patients to take their time deciding: "Breast cancer is not a medical emergency. You can take several weeks to learn about your choices, talk with your doctors, think about your preferences, and make a good decision."

The great advantage of the decision aids, says Kate Clay, program director of the Center for Shared Decision Making, "is that patients can take them home to read them and view them—usually more than once. One thing we've learned," she adds, "is that people make decisions jointly, with other family members as well as with health-care providers. And they find it very useful to look at the videos with their families, so that they are all sharing the same information."

Most importantly, patients know that the information they're getting is based on the best medical evidence available at the time. Without these decision aids, many family discussions are riddled with the spotty anecdotal evidence that begins "When my neighbor's daughter had breast cancer, her doctor said . . ."

But videos and booklets only complement the dialogue between patient and doctor. Patients do not want to be left on their own with the research: "The video helps women address their conflicts, but there is still a lot of uncertainty," says Collins. Typically, after DHMC patients review the materials at home, they meet with their doctors. At that point, physicians ask questions to make sure that patients understand what they stand to gain or lose if they pick a particular option.

Understanding the odds

At this step, it often becomes apparent just how difficult it is for many patients to come to grips with statistics about probability and risk. For example, how does a patient assimilate the fact that in

one Swedish study, "15 out of 100 men who chose watchful waiting died of prostate cancer over the next 10 years—while, over the same span, 10 out of 100 men who had prostate surgery died of the cancer"?

One way to express the difference is to say that surgery cut the chance of dying from prostate cancer by one-third—from 15 men out of 100 to 10. That sounds like an enormous improvement. But another way to look at the same numbers is to say that among the 100 men who didn't choose surgery, only 5 more died, while 85 avoided the risks of death, complications, incontinence, and impotence. The patient needs to understand that both statements are true. The question, then, is this: What type of risk is he more willing to tolerate?

Doctors find different ways of "framing" what the odds mean. "You have to watch the patient's face," says Clay, "until you find a formulation that you can see makes sense to them."

Some doctors use visual aids like colored pie charts to make the figures easier to understand.

When women learn they have breast cancer, says reconstructive surgeon Dale Collins, "often, the first reaction is 'Oh, my God, I have cancer—just take it off.' But usually you can get them down off the chandelier."

Many patients can grasp ratios and percentages better when they're explained graphically rather than numerically. "In my early days, I used a cardboard wheel with two colored layers," Llewellyn-Thomas recalls. "I'd show people how it looked when it was 10 percent purple and they'd grab it from me: 'Yeah, yeah,' they would say. 'That's what 10 percent looks like.'"

Doctors in the shared decision-making program stress that patients should realize that they can make choices not only about treatments but also about certain screening tests. Even a test carries risks as well as benefits. In some cases, there is little question and the advantages clearly trump the hazards. Pap smears to detect cervical cancer, for example, have all but wiped out the disease in the U.S.—while the risks are negligible. The PSA test for prostate cancer, by contrast, offers uncertain diagnostic benefits—and the danger of life-changing side effects if the patient goes ahead with treatment for early-stage prostate cancer.

The trouble is that there's no hard evidence showing that a PSA test will significantly reduce a man's chance of dying of prostate cancer—or even extend his life. The issue is complicated by the fact that because prostate cancer usually takes so long to develop, men who discover that they



Ludy talked through the options with Spencer and answered her questions.

For a **WEB EXTRA** about shared decision-making, see dartmed.dartmouth.edu/fall07/html/choice_we.php.



Finally, after she was familiar with the terminology, knew the risks of each option, and had sorted out her own priorities, Spencer met with her surgeon, Rick Barth. Patients may have some questions at that point, but not as many.

“[It] helped me . . .
to understand and
calmed my anxiety.”

—Feedback about shared
decision-making at DHMC

have it will probably die *with* the cancer but not *because* of it. They may never even experience any symptoms.

The American Cancer Society (ACS) recently came out with a clear new position on PSA testing—saying that “because the current evidence about the value of testing for early prostate cancer detection is insufficient to recommend that average-risk men undergo regular screening,” PSA testing should be offered to men 50 and older, but not recommended. Instead, the ACS now favors “shared decision-making” and advises doctors to discuss with their patients the “potential benefits, limitations, and harms associated with testing” and then let the patient decide. In fact, the ACS’s prostate cancer advisory committee considers it “inappropriate” for doctors to either “recommend” or “discourage” PSA testing.

At this point, it’s worth mentioning that five years after his urologist diagnosed early-stage prostate cancer, Joe Rubin’s PSA levels remain below 4, indicating a very low risk of dying of prostate cancer. There is no sign that the cancer is growing or spreading. Nevertheless, he still goes for annual PSA checks.

“Once you’ve been told you have cancer, you feel you have to,” he says, “even though I’m not re-

ally worried. Frankly, I wish I’d never had the first test. Then I wouldn’t have to do this. On the other hand, Medicare pays for it and I still like my urologist—I really don’t mind seeing him.”

His wife is a little less generous. “This is why Medicare is going to go broke,” she says.

Individual values

Step two on the decision-making list is sorting out “your own preferences.” As the Dartmouth breast-cancer video observes, a patient must face up not only to the facts—about risks and benefits—but also to her own feelings. Studies show that physicians are not good at guessing patients’ preferences; they need to hear from the patient.

One way for patients to begin to communicate them is by filling out a form like the personal decision guide developed by the Ottawa Health Research Institute. It gives patients an opportunity to show the doctor what they already know about risks and benefits, what risks they think are “most likely to happen,” and what matters most to them (on a scale of one to five stars).

Once patients begin to spell out their concerns, the physician can help guide them through the often very difficult process of sorting out priorities. Life circumstances can play a major role.

A breast-cancer patient with young children may be worried about dying before her children are grown and so may lean toward the most aggressive choice—a mastectomy. But her husband may feel she gives their children too much attention already, to the detriment of their sex life. Would a mastectomy further affect their relationship?

A prostate cancer patient with an understanding employer may feel he can take time off to undergo external beam radiation—a brief treatment five or six days a week for six to eight weeks. Another patient may fear that if he missed that much work, he'd lose his job. Yet if he opts for watchful waiting, will it only add to the anxiety that makes it hard for him to stand up to his boss?

As patients begin to articulate their fears, “people start to think in a very circular way, so their thoughts are chasing each other. You can almost see it physically when they walk through the door,” says Kate Clay. “What I bring to the table is my expertise as a nurse and the ability to pick out what it is that seems to be really troubling them.”

Then, with help from a decision-making coach, patients begin to untangle their fears. “This is a very distressing period for patients,” explains Dartmouth’s Dale Collins. “In addition to giving them decision-making support, we screen them for depression, anxiety, and panic. About 50 percent of our patients hit a clinical threshold [for mental-health concerns], so that we intervene and refer them to specialists in these areas.”

Patients are also encouraged to talk about whether friends or relatives are bringing inappropriate pressure to bear as the patient goes through the decision-making process. “Often, the other person will think of the pressure as ‘encouragement,’” says Hilary Llewellyn-Thomas. The physician can help the patient separate that “support” from his or her own preferences.

The physician also determines whether the patient wants to make the ultimate treatment decision or would prefer that someone else make it. At some point, the patient and the doctor may realize that the patient truly does not want to make the choice. The patient has gotten far enough along in the process to understand what is at stake—and thus is an “informed” rather than a “naive” patient, as Llewellyn-Thomas puts it. In such cases, the patient’s choice, based on knowledge of the medical facts and of his or her own feelings, is *not* to make the final decision.

“The patient has gone through the decision-making preparation,” Llewellyn-Thomas explains. “But decision support only goes as far as the patient wants to go—without imposing on him or her. We don’t have the right to run roughshod over

patients. These are people experiencing decision conflict in real time, and we are helping them in real time.”

This is what is truly compassionate about Dartmouth’s shared decision-making program—that it does not demand, in the end, that the patient take sole responsibility for choosing a treatment. Strict advocates of patient autonomy insist that only the patient can know what he or she wants. If a patient asks for help deciding, the physician is supposed to say, “I don’t know, Joe. I’m not you.” But many others would argue that such ironclad insistence on patient autonomy constitutes “abandoning” the patient.

The final step in the decision-support process is to help the patient make a feasible plan to act on his or her decision. This means dealing with practical issues such as arranging child care or taking time off work. At this point, the typical patient is confident enough to confront logistical problems. Indeed, research shows that patients who have collaborated in decision-making feel far more secure



The decision made, Spencer and her son head home.

“Decision support only goes as far as the patient wants to go—without imposing on him or her. We don’t have the right to run roughshod over patients,” emphasizes decision-making researcher Hilary Llewellyn-Thomas.

than those who simply “consented” to whatever their doctor proposed. And they are also far less likely to experience regret after the fact.

Reducing overtreatment

Dartmouth’s Jim Weinstein, director of the shared decision-making center, says he first became interested in the concept when he participated in a research project at the University of Iowa more than a decade ago. An orthopaedic surgeon, Weinstein was surprised to see that some surgery rates fell by 30% when patients were given more information about their options.

“I didn’t feel like they [the patients] were getting the information they needed to make their decisions,” he says. “They were talking to me, but maybe that wasn’t good enough because I was a surgeon and surgeons do what surgeons do. Maybe they weren’t getting a fair shake.”

His colleague Jack Wennberg notes that what a doctor defines as “clinically appropriate” can be quite different from what a given patient wants. He points to a study that began by listing the symptoms and pathologies that make a patient an “appropriate” candidate for a knee replacement. Researchers then gave patients—all of whom who fit

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Making Choice an Option

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that bill—full information about the risks and benefits of surgery and the postop recovery time. After considering the tradeoffs, only 18% chose surgery. “Some said they had learned to live with the pain. Others said it wasn’t bad enough yet,” Wennberg says.

Study after study has revealed that surgeons are more enthusiastic about surgery than patients are. In clinical trials, Wennberg says, it’s typical for somewhere between 21% and 44% of patients to decide against a discretionary procedure after they have gone through the shared decision-making process.

This should come as no surprise. Good surgeons are proud of their craft and of their ability to help people. It is patients, however, who experience the pain, the risks, and the inconvenience of surgery; understandably, they may be more hesitant about an operation than the doctor proposing it.

Furthermore, in this country’s fee-for-service payment system, the economic incentives are aligned to reward doctors who do more procedures and provide more treat-

ments. But patients, studies show, often don’t want more. When it comes to chemotherapy, for example, too many oncologists encourage patients to undergo “another round,” says Dr. Peter Eisenberg, an oncologist in Marin County, California. “From where I sit, the problem is clearly one of perverse incentives which reward guys like me for giving folks lots of chemo—whether or not it will likely help them and whether or not they really understand the implications of their decision to have it.

“As a board member of the American Society of Clinical Oncologists, I have tried to get our professional organization to be more active in this area,” Eisenberg adds. “Unfortunately, they are a trade organization and have not yet been very active. So I’m speaking for ‘Pete,’ not for the board.”

In his own practice, Eisenberg says he does not urge patients to continue chemo unless he is quite sure it will help them. “Most oncologists don’t talk about the important stuff,” he says. “They just say, ‘In six to eight months, if this doesn’t work, we’ll try Plan B.’ . . . I ask my patients: ‘How do you want to spend the rest of your foreshort-

ened life? Do you want to spend it hanging out with me and my staff—or do you have something else that you want to do? I know I can make you sick. I’m not at all sure I can make you better.”

So if some patients endure treatments that are unnecessary or futile, could that be contributing to the nation’s bloated health-care budget? And could shared decision-making help rein in runaway costs? Advocates of the concept are quick to say that saving money is not their primary goal. The cost of overtreatment, they emphasize, is measured first in terms of human suffering.

Financial side-effects

Nevertheless, there is good reason to believe that decision support like that offered at Dartmouth could reduce the number of unwanted treatments, tests, and elective surgeries in the many gray areas of medicine where it’s not certain whether the advantages of a procedure outweigh its disadvantages for many patients. If so, the financial savings that could follow from widespread use of shared decision-making would be a very welcome byproduct.

In fact, DHMC is participating in a \$5-million demonstration project, funded by the Centers for Medicare and Medicaid Services, that’s designed to explore whether shared decision-making might save the federal government money by reducing the number of unwanted and unneeded procedures. Research has shown that 40% of Medicare inpatient spending on surgery is concentrated on just 10 conditions involving invasive procedures. If patients had a chance to make an informed choice, current evidence suggests that the number of surgeries for these 10 conditions might fall by at least 20%, resulting in annual savings to Medicare of roughly \$3.5 billion. Even a much more modest decline would result in substantial savings: \$860 million if surgery drops by only 5%, and \$1.7 billion if the decline is 10%.

Make no mistake: the ultimate goal of shared decision-making is not to save money but to move toward a more efficient, higher-quality health-care system that provides the right care to the right patient at the right time. In the many cases where there’s no single “best” treatment, an informed patient’s preferences should come into play when determining if he or she is indeed the right patient for that treatment at that time. ■