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# CHAPTER 5: YOUR TREATMENT TEAM

Pull quote: *In Medieval times doctors used leeches to drain the blood from their patients. Nowadays they prefer to have separate billing departments (greeting card I received)*

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With cancer comes a Treatment Team. Many times they will never sit in the same room together, but they are a team nonetheless. Your improved health is their unifying goal. And believe it or not, you're the head of this team.

## YOU

Most of this book is about how you can direct your cancer treatment as well as survive it. It's crucial that you change your perspective from *I'm the patient* to *I'm the patient and I'm responsible for my treatment.*

This does not mean that you are in charge of anything medical. If you really want to direct the oncology department at your regional hospital, go back to school and get a medical degree. Please keep in mind that you don't know diddly squat about the treatment you're receiving. And if you do know diddly squat, tread lightly.

Before having cancer, most of us went to the doctor when we had a problem, the doctor tested and diagnosed the problem, the doctor prescribed the treatment, and we were in charge of picking up the prescription or going to a therapy treatment or starting to exercise or whatever.

Now things are different. It's possible to go through cancer treatment in a similar way, but you won't get the best outcome possible. Let's look at two patients and compare.

### SUSAN I. KYEW

Susie Kyew has breast cancer. She's terrified and confused. At her first appointment with the oncologist she stares and nods a lot. Fortunately her oncologist has a great nurse who makes another appointment at which she walks Susie through everything that will happen. The nurse gives Susie a notebook filled with information specific to her diagnosis. And together they start making more appointments: a surgeon, the cancer center's billing department, and a social worker because Susie is still staring and nodding a lot.

For the next several months Susie dutifully attends every appointment and completes every task that she is assigned. Before leaving each office she stops and is assigned her next

appointment, sometimes to additional health providers. The number of people, locations, treatments, and tasks multiply until...

...she is done. Her oncologist says that her treatment is over and her next appointment will be in six weeks. Susie walks out into the sunshine and tries to feel relief. Instead, she sits in her car and weeps because she doesn't know what to do next.

Am I being hard on Susie? Well, I was a Susie Kyew for my first cancer. The nurses and phlebotomists and receptionists had become favorite companions. Suddenly I wouldn't see them every few days. I felt cast away. And anxious about my prognosis. To be honest, I was as big an emotional wreck as I had been at the beginning of the process.

Now let's look at the way I worked my second cancer.

### Thomas D. Mann

Tom D. Mann has prostate cancer. He's terrified and confused. At his first appointment with the oncologist he takes his wife, and she takes notes as he asks a lot of questions. His oncologist has a great nurse who makes another appointment at which Tom learns everything that will happen and is given a notebook filled with information specific to his diagnosis. Tom has more questions on a written list. When he's satisfied that he has the answers, he makes more appointments: a surgeon, the cancer center's billing department, and a social worker because Tom wants to know what support services are available for him and his family.

For the next several months Tom takes a written list of questions to every appointment. His wife goes with him to the major appointments. Together they talk over all of Tom's options. Sometimes they talk with their oncologist by phone. They understand that they're sometimes choosing between several unpleasant choices. Tom has a good sense of his treatment's probably outcome.

Finally his oncologist says that his treatment is over and that his next appointment will be in six weeks. Tom knew this day was coming, and he takes his wife to a celebratory dinner at their favorite restaurant. He feels exhausted but hopeful.

### Choices

There is no single "right" way to have cancer. But there *is* a way that will give you the best outcome, both physically and mentally.

## Your Oncologist

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"Onco" is an ancient Paleolithic term meaning "Healer with really, really big hopes." Your oncologist has completed four years of college, four years of medical school, and usually seven years of education beyond med school. She has successfully passed innumerable examinations and holds credentials from a number of agencies that require additional education each year. She consults with other oncologists and eagerly reads a bunch of monthly medical journals that would put to sleep any of us regular folks.

While an oncologist's knowledge is impressive, she isn't God. I don't find it comforting, but universities name their buildings "Medical Arts Complex," not "Medical Perfect Science Complex." And of course all doctors call their businesses a "practice." Yikes.

Take a deep breath. Grab a pen and paper. And start making a list of questions. Notice that the difference between Susie and Tom above (the difference between my first and second cancers) is asking questions.

### Sub-Specialties

The world of cancer is a world of specialists and specialists-within-a-specialty. A "plain vanilla" oncologist is called a medical oncologist. But wait – medical oncologists often sub-specialize in a part of the body like the lungs, or in a type of patient like children (pediatrics).

You may see a surgical oncologist who performs surgery only on cancer patients. This doctor may sub-specialize in gynecologic (women's reproductive organs) or urologic (bladder and kidney) or thoracic (chest cavity) cancers.

Radiation oncologists use radiation to treat cancers. You knew that. These doctors are rarely your primary cancer doctor; they work closely with other oncology specialists. Some sub-specialize in a type of therapy like brachytherapy (putting radioactive material into a tumor). Some treat only patients with specific cancers, like breast or prostate cancer.

### Knockers and Bargers

In addition to asking questions, it helps to know what type of oncologist you have. All doctors can be divided into two distinct personalities: Knockers and Bargers.

Knockers politely tap on the examination room door before coming in, and Bargers just rush in.

When you know what to expect from each physician you see, you can tailor your behavior to meet his expectations. This optimizes your treatment outcome and minimizes your number of co-pays to mental health professionals.

Type identification can be accomplished at the first office visit. Strictly speaking, a Knocker will tap authoritatively and wait for your muffled reply before entering the room. Occasionally you

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will find one who knocks but does not wait for a reply, or one who pounds on the door like an agent from Homeland Security. These doctors are really Bargers in disguise.

We have established that you will ask questions at each visit with your oncologist, radiologist, surgeon, etc. The format of these questions should vary with physician type. Knockers respond well to open-ended questions and requests for information: "Doctor Knocker, what do you think about these new studies on Tamoxifen side effects in ring-tailed lemurs?" Bargers give their best responses to Yes/No and follow-up questions: "Doctor Barger, if I take Tamoxifen will I become a ring-tailed lemur? Why or why not?"

Both types of doctors will return after-hours calls, but I've found that Knockers usually call back sooner than Bargers. Practice with a loved one before talking with your doctor on the phone. "Doctor Knocker, I'm tossing my cookies big time and I feel really yucky," or "Doctor Barger, I'm experiencing projectile vomiting at a rate of 25 milliliters per episode, four episodes per hour, plus concomitant fatigue. Do you want a sample for analysis?"

## Second-Opinion Doctor

Pull quote: *No trumpets sound when the important decisions of life are made.* –Agnes deMille

After your first appointment with your oncologist, get a second opinion. There are two reasons: first, you want to confirm that your proposed treatment is going to work; and second, you want to confirm that the first oncologist you saw will continue to be your doctor.

The rebuttals to your objections over getting a second opinion:

1. No, you will not hurt your doctor's feelings and make her hate you.
2. Yes, almost every insurance covers a second opinion. Many don't even charge co-pays for it.
3. No, unfortunately it's not ethical for your first doctor to give you the name of someone to see for a second opinion. You'll have to find her yourself.
4. Yes, it's hard to get excited about finding yet another doctor while you're still wrapping your head around the word *cancer*. Do it anyway.

Getting a second opinion does not mean that you don't trust the first doctor you saw. It means that you are confirming your trust in that first doctor. It means that you're being very thorough and very smart. Sometimes it means that your insurance won't pay for treatment until you get a second opinion.

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Why would you want a second opinion? And why would insurance want you to rack up yet another doctor's bill? Because you might, just might, find another treatment option. (Insurance hopes it will be a cheaper option.) Because when the second doctor confirms the first doctor's diagnosis, the insurance company is more likely to pay without questioning every little thing. Because you could like the second opinion doctor and practice better than the first. Because you will feel much more confidence in the doctor you eventually select.

Go to a different practice or hospital than the one your first opinion doctor is in. Call someone you know who has had cancer (you know a lot, don't you?) and ask for a referral. Or make an appointment at a cancer center that advertises in your area. Either way, tell the scheduler that you want a second opinion appointment. You'll get in sooner because they know you're deciding on treatment.

<checklist for second opinions; put all checklists at end of book?>

Don't just lean across the aisle at church and whisper to your friend the proctologist, "They think I have ovarian cancer. Should I have surgery?" Your second opinion has to be by an oncologist. You can't count any comments made by your veterinarian golfing buddy. Make an appointment, go into the office, and have a proper evaluation.

## Sidebar or Pullout: When and how to change doctors

Imagine that you've gotten a bad piece of meat from your grocery store. For the second time in a month. Will you give them a third chance? Or a fourth?

Health care is a lot like food: they are both expensive, and there is lots of competition for your business. Most importantly, although you may be comfortable with your grocery or doctor, there is nothing holy about the relationship. You can change either one without making a scene. You'll be spending a lot more time and money at the hospital or clinic than you'll ever spend in your grocery story, so expect a higher level of service than you get from your meat counter manager.

Health care is a business. Your medical team will give you services and you will pay them. If the services don't meet your needs, talk with the doctor. Try not to worry about hurting someone's feelings; this is your health, and it's more important than any possible misunderstanding.

Many hospitals and large clinics have patient ombudsmen or patient representatives to help with billing and service questions. But the most important relationship is between you and your doctor. If that's not working out, you always have the option of switching physicians or practices.

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Here's how you change doctors: Call the new doctor's office and tell the scheduler that you'd like to switch to their doctor from Dr. What. The scheduler will make the appointment and call Dr. What's office to get your records. You never have to step into Dr. What's office again. Unless you move in the same social circles, you'll probably never even see Dr. What again. Simple.

But. Do not change doctors on a whim. Don't do it while you're mad. In fact, don't make any cancer-related decision while you're hungry, angry, lonely, or tired. (That's the HALT warning.) It's an important decision and one that should be treated as such.

## Your Best Friend: a Nurse

Pull quote: *Courage is knowing what not to fear*. -- Socrates

The nursing profession has more letters indicating certification and career level than any other profession in the world. If you want you nurses to like you, ask about his letters.

And I can't emphasize this enough: you do want your nurse to like you. Anything uncomfortable that happens while you're conscious will be done by a nurse. Doctors knock you out first. Most everything that is written in your chart will be recorded by a nurse. And sometimes nurses are sources of great crafting supplies like rolls of gauze and cotton balls.

In truth, most nurses will like you before they meet you. It's part of the required personality. Another part of the standard nurse personality is the ability to look good in short-sleeve tops with little froggies all over them. And white shoes.

It's only in the final years of nursing school that students learn the awful truth: some of what they will do to help patients will hurt, too. By this time nurses are in serious debt with student loans, so they have to finish the degree. So be patient with your nurses; they don't actually enjoy drawing blood from your hand and taking rectal swabs.

When you call your doctor's office with a question or concern, it will almost always be your nurse who calls back. Most likely you will get the issue resolved then and there. But if a prescription is called for, the nurse will confer with the doctor before calling your pharmacist. Never underestimate the expertise of a nurse by insisting to talk with a doctor. Some nurses have education that rivals that of doctors'. And all nurses spend hundreds of hours talking with and listening to patients. Nurses know the answers to just about anything you'll need to know about your cancer treatment. And anything else, for that matter.

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They also wear white shoes year-round. In ages past this was to demonstrate that nurses were virginal and had clean feet. Neither is really important to your care today. The reason nurses like white shoes is not their color, it's their comfort. Look closely at those things. They're sensible, unfashionable, actually quite ugly shoes. If they were brown or black they'd be confiscated by the Fashion Police. But because they're white, you don't notice the style. Smart nurses.

### Types of Nurses

Because nurses are so important to your care, the nursing profession has gotten specialized.

A nurse practitioner (NP) can do almost everything that a doctor can do. They can diagnose and prescribe. They can order tests. Because of billing practices, NPs usually schedule more time for each office visit than do doctors. Most NPs will ask you to call them by their first name.

Registered nurses (RNs) are what we usually think about when we say "nurse." They have extensive education and can perform almost every medical task in a doctor's office. RNs can become administrators and often head chemotherapy suites and radiation programs, under a doctor's guidance. Call a nurse by his or her first name.

Physician assistants (PAs) are similar to nurse practitioners in that they can diagnose, prescribe, and order tests. The educational path of a PA is more like that of a doctor than of a nurse. Some states allow NPs to set up their own practices but PAs always work under the supervision of a doctor. They will usually ask you to call them by their first name.

### Thanks!

In a moment of unexpected energy, bake brownies for your nursing staff. Or leave them a card on your way out of the office. You could even write a nice letter, with a copy going to the doctor and hospital administrator. This is an especially good idea, because these letters usually end up in the nurse's personnel file, where they can make a difference at the next work review.

The most important thing you can do for your nurse is also what you mean the most: say Thank You.

## Administrators

In most medical settings doctors are treated like Patrick Stewart at a Star Trek convention. That is to say, with reverence and a smidgen of fear. Physicians call each other by their surnames: "Doctor Schmellen, have you seen Doctor Anodor? We're meeting on the links this afternoon." It's like being in elementary school all over again, where the most powerful people have titles and you have only a first name.

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But where does the actual power lie? It's with administrators and support staff. They make your appointments, order little specimen cups, interface with medical research sponsors, clean surgical suites, coordinate volunteers, hire and train staff, bill your insurance, call your insurance to argue on your behalf, call your insurance again.... you get the idea.

Some night you'll find yourself awake and worrying. At that moment try to think of all the jobs required to keep your cancer center or hospital running. When you get to listing everyone it's... it's.... well, someone had to write the copy for that pamphlet called "Your Pancreas: Friend or Foe?" and then someone made the brochure look pretty and someone else got it printed. Another person paid the printer and yet another person distributed the final brochures to offices. Eventually someone put a few copies in a waiting room.

Yes, all of these people get paid for doing their jobs. But they could work elsewhere, and they choose to work in the field of health care. As patients we are the ultimate reason that each of these people work where they do. I think patients should recognize that administrators and support staff are on our medical teams.

## Pharmacist

"Ask your doctor or pharmacist." It's the second most-frequently uttered phrase on television, behind "...but wait, there's more."

Your pharmacist used to be the whiz-kid in your high school chemistry class. You remember: the one who knew that Krypton is a real thing and that it's number 36 on the periodic table. Put your old resentments aside, because your pharmacist is important. Besides you, your pharmacist is the only person who has an up-to-the-minute list of every prescription you're taking. (Oh – and keep a written list of these plus all of that over-the-counter stuff, and carry it around with you *all the time*.)

I've been warned that one should avoid pharmacies when one's infection resistance is down. The carts, counters, and products are often handled by other sick people and one could pick up the latest flu from Kyrgyzstan. However, I know that one will loose one's few remaining marbles if one doesn't go someplace besides home and the doctor's office.

Pharmacies are great for short trips because you can browse the greeting cards, magazines, dish detergent, roller-ball pens, mascara, and Easter candy while waiting for your anti-nausea prescription to be filled. If your resistance is down you should buy some masks and wear them. The pharmacy sells masks.

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## OTHER PROVIDERS

You'll see other healthcare providers who are on your team. Nutritionists, research nurses, nurse educators, and genetic counselors are professionals you'll likely see only once. You'll see these people many times: home care workers, physical or occupational therapists, mental health specialists, and support group leaders.

Case managers, sometimes called care managers, help you coordinate your care across doctors. They're usually registered nurses. Sometimes they work for your insurance company, although they can also be employed by your cancer center.

In university hospitals, medical students often accompany doctors. The students spend several weeks working in a specialty and then rotate to another specialty before deciding on what to focus their education. If your doctor has a med student with her, she will ask if you would like to have the student in the room during your appointment. Answer honestly. You may be comfortable at one visit and not at another. Both the doctor and student have many important things to think about, and your preference on that day isn't one of them.

You'll see technicians of all types during your treatment. They have at least an associate's degree (usually 2 years of college) and some have years of training beyond that. Technicians are certified by states and/or national agencies for the specialty they perform. Some specialties are drawing blood (phlebotomists), taking X-rays, and running MRI scans. In a busy medical practice a technician may show you to your exam room and take your vital signs.

Many doctors are so specialized that you will see them only once, if at all. A pathologist diagnosed or confirmed your cancer by studying your body's cells under a microscope. As important as this doctor is, you won't see her or him. Anesthesiologists work with surgeons to keep you pain-free during surgery. They also manage your pain medications after surgery while you're in the hospital. It's becoming common to meet your anesthesiologist just before surgery, but you probably won't see her or him any other time.

Physiatrists are trained to help you manage pain and fatigue. Patient navigators, sometimes called nurse navigators, help you "navigate" the health care process by explaining treatments, making appointments, and helping with insurance forms. Social workers can specialize in talk therapy, financial issues, home care services, and referrals to community services.

You get the idea: there's a world of people who work in health care, and many care exclusively for cancer patients. At one time I thought I'd keep track of everyone I saw so that I could write thank-you notes. Seriously. I was reared to be a Southern Lady. Anyway, I lost track very quickly and gave up on that plan.

It's easy to feel overwhelmed by the number of people who want to do something to our bodies. When someone you don't recognize comes into your examination or hospital room, it's entirely respectable to ask their name and what they do. In a perfect world they'd tell you before you asked, but...

### TALKING WITH YOUR TEAM MEMBERS

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*I recall being wheeled into a surgical suite for my hysterectomy. It's always cold in those rooms, and they smell like disinfectant that's too expensive to use at home. Over my body hung the usual bright light with a dozen bug-eye bulbs and a handle so that it can be positioned just so.*

*The nurse asked me to wiggle from my wheely-bed onto the surgery table. Those tables are always so thin. With mechanical, clanking sounds she pulled stirrups out of the table's end. "Now, honey, I'm going to help you remember not to move your legs," she said while she strapped my thighs onto the widely-spaced stirrups.*

*I panicked, someone said something, and the next thing I knew I was in post-op. Mercy is sometimes an anesthesiologist's trade.*

THE LINGO

A lot of the time, medical people speak like regular people. But not always. It's important to know what is really happening, so you need to know the lingo.

In general, your medical team will go out of the way to avoid saying anything indelicate. They will ask you about your "nasal secretions" when they could just say "Got any boogers today?" All of the cutsie words you taught your children about bladder function will get replaced by the term "voiding." I'm sure there are seminars in medical school on how to keep a straight face when discussing erections, vaginal secretions, nipple tenderness, ejaculations, and masturbation. Not since sixth grade have you had such discussions!

In the medical world no one ever "throws up" or "tosses their cookies." They have vomiting or retching episodes. Factoid: vomiting produces material that someone has to clean up, and retching is all the work with no tangible rewards. Just look at what you can learn as a patient.

Often it's the small words that you should make note of: possibly, mild, occasionally, might. When you doctor says, "Your chemotherapy *may* cause hair loss," you can count on it. When your pharmacist says, "*some* stomach discomfort," carry a bucket around after you take that pill. In general, expect the worst and be occasionally surprised.

Watch out for tone of voice, too. When you hear that sing-song sound that is usually reserved for children in diapers, go on alert. You could hear, "Well, Mr. Earbud, let's just wheel you down the hall to a room where you can lie down." Translation: "Mr. Earbud, your blood pressure is off the charts and I'm going to get you into a horizontal position before your head explodes all over my nice new shoes."

Lots of information you'll be given is just unnecessary. You'll get good at knowing what NOT to know. Consider this from a radiation technician: "Mrs. Newshoes, I'm going to adjust the

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flibbergibber on this machine so it cohabbilates my pixits and gives us a correct rabimontominal reading. Just hold still while I sufferterminalate."

The only thing Mrs. Newshoes needs to know is "hold still."

### Specifically, What You Mean Is...

Your pharmacist might tell you to expect "a mild sedating effect" with your new prescription. This could mean nothing more than the relief from pain you would get with an aspirin. Or you could be holding something akin to opium. How can one know?

Ask what you will be able to do, but don't use heavy machinery as the standard. You're not supposed to operate heavy machinery after taking anything. Ask about something that will really give you an idea of your capacity: "Will I remember how to program my VCR?"

Another technique is called rephrasing. Say what you think you heard, but in regular people-speak. "So I hear you saying that my left breast's reconstruction will hang like my original breast did, but my right reconstruction will stay up high like it's in an invisible bra." "Yes" to that question will tell you exactly what you're dealing with.

### Predictable

Trained as scientists, medical professionals avoid making definitive statements about your prognosis. They just won't predict. Don't be distressed. They're trained to be vague about everything. Hang around the hospital cafeteria and you'll hear them:

"There are indications that I liked the lasagna last week, but more servings are required before I can give an opinion with relative certainty."

"My daughter's soccer team is favored in the Dinky League by a 20% margin over their nearest competitor. But that's just an estimate across many teams."

"Have you heard? Penelope in Accounting went into labor last night, and a resolution may be forthcoming as soon as this afternoon. Or it could be several days."

Some of this behavior is probably the result of abuse at the hands of litigation-happy patients and their lawyers. ("What do you mean, I have eight weeks to live? Last week you said ten. Malpractice!") But sometimes it's because we cancer patients have been getting so much better, so much faster than expected, that doctors are not really sure what our prognosis will be. Take comfort in the knowledge that some day your name could come up in a staff meeting and everyone will nod knowingly and quietly say, "It's amazing. Just incredible. So inspiring. Yeah, I really like him."

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*Dr. Martinez's nurse handed me a prescription for a painkiller. "Fill this on your way home and take one as soon as you can. It will take over when the anesthetic wears off. When the prescription is all gone, start taking Tylenol."*

*"I may just take Tylenol." I felt no pain after the surgery, and I didn't want to feel groggy.*

*"Oh, I wouldn't do that. You'll want to have this prescription filled. Don't wait until it starts hurting; keep ahead of the pain."*

*"But if I can take Tylenol later, won't it be enough now?"*

*"Well. . .no."*

*Ah. I see.*

SIDEBAR: THE CHART

Have you ever wondered how your doctor remembers the details of your treatment? He doesn't remember, really. Everything is written down in your chart – medical-speak for "fat file folder." Most charts are electronic now. Make sure the information in this record is correct, by listening carefully to what your doctor says. It's a good idea to keep a notebook yourself, with copies of test results and blood counts. Even if you don't know what any of it means, you'll feel more in control. That's good.

SIDEBAR: FLIPPY THINGS

Outside each treatment room is a set of plastic flag-like flippy things. In a large practice each doctor has a color. When the red flippy thing is pointing out into the hall, that's the room the red doctor needs to go into. Some colors mean "The lady in here is the one who needs her blood drawn," or "This guy is ready to go as soon as someone finishes his paperwork." Without these flippy things some guy named Tony would wait all night for his temperature to be taken.

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