My Notebook

A Notebook Guide for Newly Diagnosed Cancer Patients and the People Who Love Them

By Barbara B. Jaffe

For men and women who have just learned they have cancer, to help them in those first few weeks and months as they make the necessary decisions about their treatment.

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Dedication

This guidebook is dedicated to family, close friends and colleagues of the author who have either been diagnosed with cancer or are loved ones who have shared their cancer journey. Because of them, it reflects a very personal insight into how to cope when you learn you have cancer, and how to deal with fighting the disease while still getting on with your lives. Most were told at some point that they should get a three-ring binder to keep all the information they are juggling in one place to help with the overwhelming and often impersonal medical maze faced by a newly diagnosed patient. They were told it would lessen the frustrations of dealing with the day-to-day information overload and annoyances of medical care delivery and the endless insurance claim paper chases.

Well, most said that it was a great idea, but that they were dealing with too much just then to take time to create their notebook. So, I have created your notebook for you and your family. Use it toward, and in, good health.

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So they told you, you have cancer . . . Now what?

Three important things to keep in mind before you begin:

1. Being told you have cancer is not an automatic death sentence. The number of long-term survivors is growing every year.

2. For most people, there is no clear reason why they have cancer. Although we all want and need to know why, make your focus now on beating the disease, not on figuring out why you have it. Leave that until later.

3. You will improve your chances to beat this disease and return to a healthy, normal life by learning about your disease and treatment options, and becoming an active participant in choosing the best treatments to fight your disease. And, you will improve the quality of your life and that of your loved ones by using this Notebook to help organize, right from the start, all the paperwork associated with doctor's visits, lab tests and results, treatment regimens, health status, and insurance claims and appeals.

About The Author

Hi. My name is Barbara Jaffe. I am a counselor and advocate for newly diagnosed adult cancer patients and the people who love them. I worked for over 30 years analyzing cancer research data and developing information materials and databases used by cancer researchers, cancer doctors, and cancer patients. I was one of a six-member team of National Cancer Institute (NCI) employees and consultants charged with developing a database called "PDQ." Today, it is a well-respected "authority" website for information on all types of cancer diseases and their treatments. My responsibility was to collect and analyze the incoming results of all clinical trial studies funded by the NCI. I loved my job, because it was a wonderful way to stay current on all the newest and most promising cancer treatments for many different specific cancer diseases.

Acquaintances, knowing my work background, often called to tell me about a family member or friend, (or about themselves) when they had just been given the devastating news that they had cancer. Would I help them find out what they should do next? I met with families, went with them to doctor's appointments, simplified what they were hearing, and helped them choose and embark on treatment. It made me aware of how appallingly little practical information these families were getting from their doctors -- information they were desperate to get, in the first weeks and months after they received the news, and at a time when they were at their least capable of gathering and assimilating what they needed to know.

Over the years, more and more friends, or friends of friends, called me for help. Through only word-of-mouth, the demand for my volunteer advocacy services became overwhelming with a full-time work schedule and raising three kids. I began writing down notes and suggestions for people to share with their families and friends. First known only as "Barbara's Book," it was distributed about two decades ago through a pilot program to new cancer patients of Georgetown University's Vince Lombardi Cancer Center. It was also critiqued by the hospital's oncologists and by oncology nurses, nurse navigators, and clinical psychologists. Barbara's Book was used by an ever-expanding circle of newly diagnosed patients and their families. Over 150 patients and their primary caregivers from cancer hospitals in the Washington, D.C. area responded to my request for feedback, and those patients have given me suggestions for revisions which I incorporated into the first edition of My Notebook. I have continued to add users' recommendations. This is the second edition of My Notebook.

Since retirement, I have also conducted workshops and seminars for health professionals and newly diagnosed cancer patients and their support persons. I remain wholly committed to working with cancer care professionals and newly diagnosed cancer patients and their loved ones to ensure that those families living with cancer know about and have access to the combined non-clinical and clinical support services to help them as they face their personal cancer journey.

About My Notebook

Most newly diagnosed cancer patients were told at some point in the chaotic weeks after diagnosis that they should get a three-ring notebook binder to keep all the information they are juggling in one place, to help with the overwhelming and often impersonal medical maze faced by a newly diagnosed cancer patient. Well, most of the people I spoke to said that it was a great idea, but they were dealing with too much just then to take time to create their notebook. So, here it is, and each of you can personalize and customize it for your own use. Take what you need and leave the rest.

It offers only enough basics about cancer and treatment options to allow you to actively participate in determining what treatments are best for you. It has been shown that being fully engaged in the process of choosing the best treatment options improves your chances to beat this disease and return to a healthy normal life. This notebook helps you do this.

And it does more than that: It can minimize the stress of dealing with the day-to-day information overload and can lessen the frustrations of medical care delivery and endless insurance claim paper chases. In short, it helps allow you to focus on getting well.

My Notebook has four sections

Getting Control – This section has four steps to follow, in answer to a new patient's most demanding question: What do I do now? It includes detailed lists of questions to ask the diagnosing doctor, the surgeon, and the oncologist.

Getting the Facts – This is a quick cram course in cancer diseases and treatments. It is not specific to each cancer disease, but offers enough of an explanation for the patient to use so that he or she and a family member or loved one can better understand what the doctors are telling them.

Getting Treatment – This section has simplified information on standard vs. clinical trial treatments, aggressive vs. conservative treatments, and alternative or complementary treatments vs. conventional treatment. It serves to inform the discussion with the doctors, so that the patient can more fully participate in choosing the best treatment or treatments.

Getting Organized – This final section is a tool to organize and keep handy important information – physician and lab and treatment facility contacts, test results, insurance information, etc. – to make the medical paper chase less daunting and allow the patient and their family to deal with the most important goal of survivorship.

It differs from most other resources on the internet, in that it also supports the needs of the new patient's family and loved ones. This is important, because "when someone gets cancer, everyone who loves them does, too."

How to Use My Notebook

📌 Where you see this little thumbtack expect to see tips or references the author has added.

📌 Use this blank side of each page of the notebook to make notes and reminders to yourself.

Knowing what a difficult and crazy-making time this is for you and your loved ones, I have condensed the Getting Control section into only 28 pages. Nonetheless, it is a lot of important information to take in.

If you have access to the internet, visit “newcancerpatient.org” and watch the six short videos found there. It will make reading the Getting Control section less overwhelming. Then read Getting Control and browse through the last section, Getting Organized.

These first few weeks will be the most difficult. But having you and your loved ones read and reread Getting Control will help you begin to implement its very specifically detailed suggestions.

Take as much time as you need to review the videos and get through Getting Control . . . and discuss it with friends and family, and if they offer to help you with it, say YES.

Next, when and as you feel up to it, once you gain more control of things, read through the Getting the Facts section and Getting Treatment section. These two sections give you basic facts to help inform your talks with your physicians. And that is important. The information is non-cancer type-specific, but it will give you enough information to be able to ask the right questions of the right specialists.

Also, follow the website "newcancerpatient.org" for announcements of updates and other support services offered by blogs that will help you and your family cope with all the non-medical issues that people deal with while living with cancer.

One last thing. . .

While all newly diagnosed patients need information, each of you has unique needs. Some patients want only the barest essentials of information, while others want detail — the more the better. ***My Notebook's*** first three sections offers very basic information, but certainly enough to help you to know **what questions to ask** of the right people during these first few weeks after you've been told you have cancer. But for those of you who want more detailed information, now or later, during the time you are making your treatment decisions with your doctors, there are pointers to other resources with more detailed information.

My Notebook
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- Information on Changing Insurance Plans

TAB F:

Receipts for Expenses
(for itemized deductions on your tax returns)

Section 1

Getting Control

Getting Control
A checklist of things to do right after you've been diagnosed.

You've recently been told you have cancer. You are, no doubt, swamped by a range of emotions. Other patients have said they've nearly shut down with shock, fear, anger, and denial, as well as uncertainties and concerns about their future, family, job, and finances. They've said they wanted to – and knew they must – take charge of things and make crucial choices, but that it was a time when they felt at their least capable to do so.

And they had questions:

☐ Who should treat me?
☐ Where will I be treated?
☐ What are the best treatments for me?
☐ What do I have to do, and how do I put my life on hold while I do it all?

They've said that their doctor helped them with some of this but still, it was hard to focus on what questions to ask and to understand all you are being told after the doctor said, "You have cancer." And mostly, they've said they just felt so out of control. This first section of *My Notebook* will help.

There are 28 pages to this section, plus reference to forms and organizational aids found in the last section. It is a LOT to take in. But don't let it throw you. Take it as slow as you need to, so that you can make yourself strong and able to be a cancer survivor.

This tip is for a close family member/friend: In the first 2-3 weeks after being told they have cancer, most newly diagnosed patients really shut down – it is a struggle to get out of bed and put one foot in front of the other. It takes some time to accept this new reality and begin to take control. And you are probably also in shock, and asking yourself what you can do to support them and feeling helpless in knowing how best to help them. It is likely YOU will be the first to read *My Notebook*. It is my hope that in reading and rereading this section and in viewing the companion videos on www.newcancerpatient.org, you can help your loved one to gain cotrol and strength now, at the beginning of this "journey."

The Getting Control Checklist

Other patients have been where you are now. They have said they felt like they were doing a high wire act with nothing beneath them. Now is the time to construct the safety net you will need to navigate your road from diagnosis to your goal of survivorship. It is really important.

To make things a little less overwhelming, here is a checklist of things you should do, to get control in this out-of-control time.

☑ Find out all the particulars of your diagnosis and pathology reports.

☑ Ask about the advisability, and availability, of getting a "physician panel" or specialists' second opinion.

☑ Find out where you stand on medical coverage.

☑ Choose the doctors who will plan out and execute your treatment program (your "medical team" of specialists).

NOT on the checklist is the issue of how and when to tell your family, friends and your employer about your diagnosis. For each of you, these questions of timing are uniquely personal. But during this out-of-control time, while completing the four tasks on the checklist, you should certainly rely on the loving support of these people. Once they are told, immediately enlist their help.

In any case, don't face these tasks alone. If you are alone, tell the doctor who diagnosed you that you need immediate referrals to support resources.

Find out the Particulars of Your Diagnosis and Pathology Reports.

You need to know all the details of your diagnosis, so that you can participate fully in the decisions regarding what treatment options are best for you, where you will receive treatment, and who will be treating you. Most newly diagnosed patients say they don't even know what questions to ask!!!

This is how you begin: (1) Make an appointment to go back to the doctor who diagnosed your cancer, or the doctor he or she recommended for you to see next. (2) Before you go in for the appointment, prepare for the meeting by writing down questions in this notebook (see the list of questions on the following pages, and add other questions you have.) (3) If you can, take someone you love and trust with you, and ask him or her to listen and take notes with you. (4) Use your smartphone, if you have one, to record your visit with the doctor, so you can listen to it later for clarification, and maybe share it with your family and concerned friends, so they know first-hand what was discussed.

When you go to your appointment, write down all the doctor's answers to the questions you have brought with you. Review what you have written down with the doctor to make sure you got it right. Later, there is a place in your notebook to keep your notes in Tab A of the *Getting Organized* section.

You don't necessarily need to understand everything he or she tells you. Just write as much as you can so you will have it for future reference.

Amplified from materials prepared by the National Coalition for Cancer Survivorship (NCCS) www.canceradvocacy.org

Questions for the Doctor Who Diagnosed You.

1. Exactly what kind of cancer do I have? What is its full name? What does the name mean? Is it in just one place in my body, or more than one?

2. What stage or grade is my cancer? What does it mean in terms of my chances of recovery?

3. What tests have I had so far?

4. What do the results of these tests mean to me? What do the numbers mean? What is "normal"?

5. What factors went into determining this diagnosis?

6. What other tests or procedures do you need to finalize your diagnosis? (*FYI: Stage of the disease is sometimes expressed as I, II, III, or IV; or there may be a formula-like report that looks like Tn Nn Mn; or both. These are indicators usually of any evidence of the cancer being in more than one site and describes how advanced the disease is. The grade is generally used to describe most leukemias There may be the need for more tests, called definitive diagnosis tests, to further describe the characteristics of your cancer, as these characteristics may be factors in choosing the best option for treatment.*)

7. After you explain the results of my biopsy and any other exploratory surgery, may I have a copy of the reports for my own files? ***

8. Should my biopsy slides be examined again, by someone else? Why or why not?

9. What were the results of CT scans or MRIs?

10. Can I please have a copy of the results of all these tests to take with me when I leave? ***

11. Are there more tests I need? What are they? What will we learn from these tests or procedures? Will I need to repeat these tests if I get a second opinion? Where will I go for further tests? When will I get those results, and how will I receive them? ***

You will want to have a copy for yourself of every pathology report and test results that have been done to definitively diagnose all the characteristics of your health status and your cancer, so you will be able to share them with other doctors you will consult. Keep the ***'d pathology and test information in Tab A of *Getting Organized*.

12. Is there anything else we can do, to make certain that the diagnosis is complete?

13. What do you recommend for me to do next? Which cancer clinics do you recommend I contact? Which type of cancer specialists will I need to see now? Will you recommend doctors for me to see? Why do you recommend him/her?

14. Is surgery a likely option at this point? What kinds of surgery can I consider? Which kind do you recommend, or what questions do you think I should be asking of the surgeon? Will you recommend a surgeon? Why do you recommend him/her?

*** Punch holes in these reports and place them in Tab A of the Getting Organized section

15. Are other members of my family (such as children or siblings) at greater risk of getting this cancer because I have it?

16. (add your questions) ______________________________

17. ____

18.____

19.____

☑ Ask about the Advisability and Availability of Getting a "Physician Panel" Second Opinion.

Why You Need a Second Opinion

You may really love your doctor, and have complete trust in his/her ability to diagnose and treat your cancer. You may be reluctant to talk to your doctor about getting a second opinion because you might be implying that he/she isn't capable of helping you. But you need to get over that. There can certainly be different opinions about the best treatment plan for you. So, you will no doubt want to get a second opinion not only to make sure the diagnosis is completely and definitively correct, but to ensure that you have as much information as you can get from other doctors, regarding their opinions on the best type of treatment you should receive.

Ask about a "Physician Panel" Second Opinion

Specifically, ask your doctor if it is possible for you to get a special type of second opinion, done collectively at many major cancer hospitals, conducted by a panel of several cancer specialists. This is a perfect example of the old adage that many heads are better than one. Cancer treatment doctors are generally really current on their special treatment modality and its effectiveness. But no one individual specialist can be expected to know what new treatments are being used in other specialties.

Currently, standard cancer treatments fall generally into categories of medicine: surgery, drug therapies, and radiation therapy. Newer treatments include immunotherapy, gene therapy, and bone marrow transplants. Your best treatment may be one or more of these types of treatment – alone, consecutively, or simultaneously administered. You want to learn about all your options, first. And then, you and your doctor together can choose the best one, or best combination of treatments.

The best way to do this is to get doctors from all the medical specialties to look at your case together, from all their specialties' angles, so you get a panel of all the appropriate "ists" that might treat your kind of cancer (medical oncologist, hematologist, radiologist, surgical oncologist, immunologist, endocrinologist, pathologist, etc.) in the same room to review and discuss your case. This is called a "second opinion panel" or sometimes a "tumor board" or multi-modality panel.

You may want to ask the panel if there are any clinical trials available to you. If there are clinical trials offered for your specific cancer, look at the explanation of clinical trials in the *Getting Treatment* section.

Why should I consider getting this?

Your doctor may not know about the newest treatments for your particular cancer, outside of his or her own specialty. You need the collective opinion of a team of specialists, because each specialist knows the most about his/her own treatments. No matter how competent and current the doctor is in his or her own specialty, he or she can't always keep current with all the new treatments being developed in other promising cancer treatment specialties.

Where do you go to get this done?

Such panels are readily available at major hospital centers such as Johns Hopkins Cancer Center, Mayo Clinic, Memorial Sloan Kettering, Dana Farber, to name some of the more famous ones, but if you are not able to travel to one of these, ask your doctor if such second opinion panels are available to you locally.

Major hospitals have “tumor boards” where specialists from all the different treatment specialties get together to review patients’ cases. Many cancer research centers offer second opinion services that operate like tumor boards – some are even offered free of charge.

When there is a charge, these second opinions are often covered by insurance policies.

Find Out Where You Stand on Medical Coverage.

Every cancer patient I have talked to has said that, regardless of how hard it is dealing with their treatment regimens and the daunting tasks of getting on with the rest of their lives while in treatment, the ongoing misery of dealing with insurance claims and all the paperwork involved in getting their health care services paid, even with good medical insurance coverage, just stinks. And it goes on long after treatments are over!!

Even if you can't escape this part of fighting your cancer, you can get control of the paperwork right from the start, and it will make the whole process less overwhelming over time. Use the checklist in this Getting Control section, and the simple methods laid out for you in the Getting Organized section to stay on top of this nasty chore.

Here are the steps you can take now:

1. Surprisingly, many cancer survivors don't take full advantage of their insurance, either because they don't know about a benefit or are confused or put off by the paperwork. Start by getting a copy of your insurance policy(ies) and find out exactly what your coverage includes (and excludes). Check your plan's deductible and out-of-pocket maximum for presciption drugs. Specifically, you may need or consider needing coverage for exploratory and reconstructive surgeries, experimental (verses standard) treatments, medically prescribed dental care (regular dental services may be a requirement for some cancer treatments), complementary and alternative therapies (such

This tip is for a close family member/friend: Somebody besides the patient should be assigned this task!! If there is no one that comes to mind, seek out what resources are available at the hospital or social services. In these first few weeks, your loved one is likely to be completely overwhelmed and incapable of facing this daunting part of the cancer journey. Some cancer centers offer oncology financial navigators. They are there to help, right from the start. Right after diagnosis is the best time to take control. Go to the website, www.myhealthcarefinances.com for guidance on lowering your medical costs and managing health insurance issues.

Some of the side effects of your treatment may include mouth sores and other oral maladies. If you can, prepare for treatment by taking care of any dental issues you may have before starting treatment.

There are for-profit companies who provide services to optimize and manage your health insurance coverage and claims process. You may want to explore hiring one of these companies.

In Tab E of the Getting Organized section, insurance-related information logs and forms and clear pocket sleeves to put each claim's paperwork separate from other claims will help you manage information such as what you are covered for, co-pay information and claims tracking.

as acupuncture, therapeutic massage), physical therapy, and post-operative home health care and rehabilitation. Also check out your dental insurance. This way, you can get all the benefits your policy provides. Record this information on the form in Tab E.

2. For each of the doctors and other health care professionals that you add to your medical team, and for each hospital/treatment center/lab facility where you receive treatment or have your health status monitored – get the name of the person on staff who files the insurance claims, and talk to each of them about the paperwork he or she submits to your insurer. In the case of physicians, this is particularly important because, often, the way the doctor describes a treatment can help or hurt your chances of insurance coverage. You may improve your chances of getting claims approved with the help of the physician's insurance forms staff person. In the case of facilities, it will help you track your claims in the months to come if you know a name and contact information for checking the status of your claims. A log for this information is in Tab E.

3. Ask your primary care doctor or oncologist which type of specialists you will likely be referred to over the course of diagnosis and treatment (for example, surgeons, oncologists, radiologists, hematologists, plastic/reconstructive surgeons, occupational and physical therapists, etc.). Then, if your insurance requires you to see doctors who are participants in their insurance plan, ask the doctor for a list of those types of specialists who are local and are participants in your plan.

4. Keep careful records of all your covered expenses and claims, and file claims for all covered costs. You can keep all this organized in the Insurance Claims Tab E of your notebook. I suggest filing them in see-through pocket folders, one each for each claim. As more paperwork comes to you for a partic-

ular claim, put it with the others related to that claim number. If you don't understand or simply can't continue to deal with the claim forms, this is the time to say "YES" when the people who love you ask what they can do to help. A trusted friend or family member could, from the start, take on this job. If they can't assist, ask a case or social worker for help finding resources. Private companies and some community organizations also offer insurance claims filing and tracking services, and many patients have said it was worth the money.

5. If you are handling your own claims paperwork, and if your claim is turned down, file again. Ask your doctor to explain to the insurance company why the services meet the requirements for coverage under your policy. If you are turned down again, find out if the company has an appeals process. If so, request an appeal.

6. As a last suggestion, find ways to supplement your insurance. For instance, if you itemize deductions when you file your income tax, take all the Federal income tax deductions for health care costs that you are allowed. Examples include not only copays and non-covered doctors' bills and hospital and lab costs, but gas mileage for trips to and from medical appointments, out-of-pocket costs for prescription drugs and equipment, and meals during lengthy medical visits. Keep the receipts in the tab marked Receipts for Expenses (Tab F) in your notebook. If you are a family caregiver of a cancer patient, AARP.org has a list of tax exemptions specific to your expenses as a caregiver.

7. In a later section of the notebook is a brief discussion of "clinical trials." It may or not be presented as a possible treatment for your cancer. If you are told you might consider participating in a clinical trial, work with your doctors to get maximum coverage of clinical trials' costs. Many clinical trials do offer some part of your cancer treatment and lab work, free

of charge. Insurers may or may not cover certain costs when a new treatment is under study. Ask your doctor about the experience of other patients in the trial. Have their insurers paid for their care? Have there been any consistent problems? Many companies handle new treatments on a case-by-case basis, rather than having a blanket policy. You always can ask about their coverage of specific therapies. However, some patients say that their questions may have hurt their chances for coverage by raising a red flag.

A word about seeking financial assistance:
Do it soon!! It makes sense to apply for financial assistance as soon as it is necessary; don't wait until your bills have piled up and treatment is over. There is a new buzz-word around cancer institutions and cancer advocacy programs called "financial toxicity." Many who are facing the loss of a good salary and mounting medical bills don't realize that they may be eligible for financial aid, so they don't even ask. But you should, and there is no harm in asking. Most people qualify for something. Financial toxicity, left untouched, does more harm to people than asking for assistance."

❗

TIP: If your insurance is an employer-provided benefit and you have choices to make in its coverage, or if you are choosing a new plan either because of changing jobs or retiring, review the additional material in Tab E of the Getting Organized section, called "Changing Insurance Plans."

If you have no insurance, there is also a discussion and additional material in Tab E.

In addition, there are websites that talk about changes in the law as a result of the Patient Protection and Affordable Care Act. The American Cancer Society (www.cancer.org) and the National Coalition for Cancer Survivorship (www.canceradvocacy.org) , among others, offer detailed information.

☑ *Choose the doctor(s) who will plan out and execute Your Treatment Plan*

An important message: You don't need to rush to judgment on finding your primary oncology specialist. This is the go-to person who specializes in your particular type of cancer disease. The best use of the time right after you've been told you have cancer is to find a doctor you think can be your "partner" in fighting your disease. You have the time to be choosey. **In all but very rare cases, a few weeks spent finding the right primary oncologic doctor will be a wise investment of your time, and won't jeopardize your health or your chances for survivorship.**

The National Cancer Institute (NCI) defines the state of cancer survivorship as being from the time of diagnosis, and throughout the continuum of the patient's life. So, right now, as you begin to use this notebook, define yourself as a survivor.

Your primary care doctor and/or a member of his/her practice should offer, or direct you to, resources that help you clarify and resolve not only the best medical treatment options and the locations where you can receive treatment, but ALL issues related to the survivorship journey: quality of life issues (physical, occupational, family, social, functional, financial and emotional) while you are being diagnosed and treated, and even after your treatment is completed.

This, again, is a great opportunity to say YES!! to loved ones and friends who ask what they can do, because choosing your doctor is best done with a lot of "networking:" asking everybody you know to ask everybody they know about doctors who treat cancer patients, and writing down every doctor's name, and what you were told about them. You (and/or your family members/ friends) can draw up a list, recording the information on the log sheet found in Tab A, collecting names of potential doctors and brief information for follow-up inquiries.

On the facing page is a copy of a breast cancer patient's list of specialists and information about these prospective doctors.

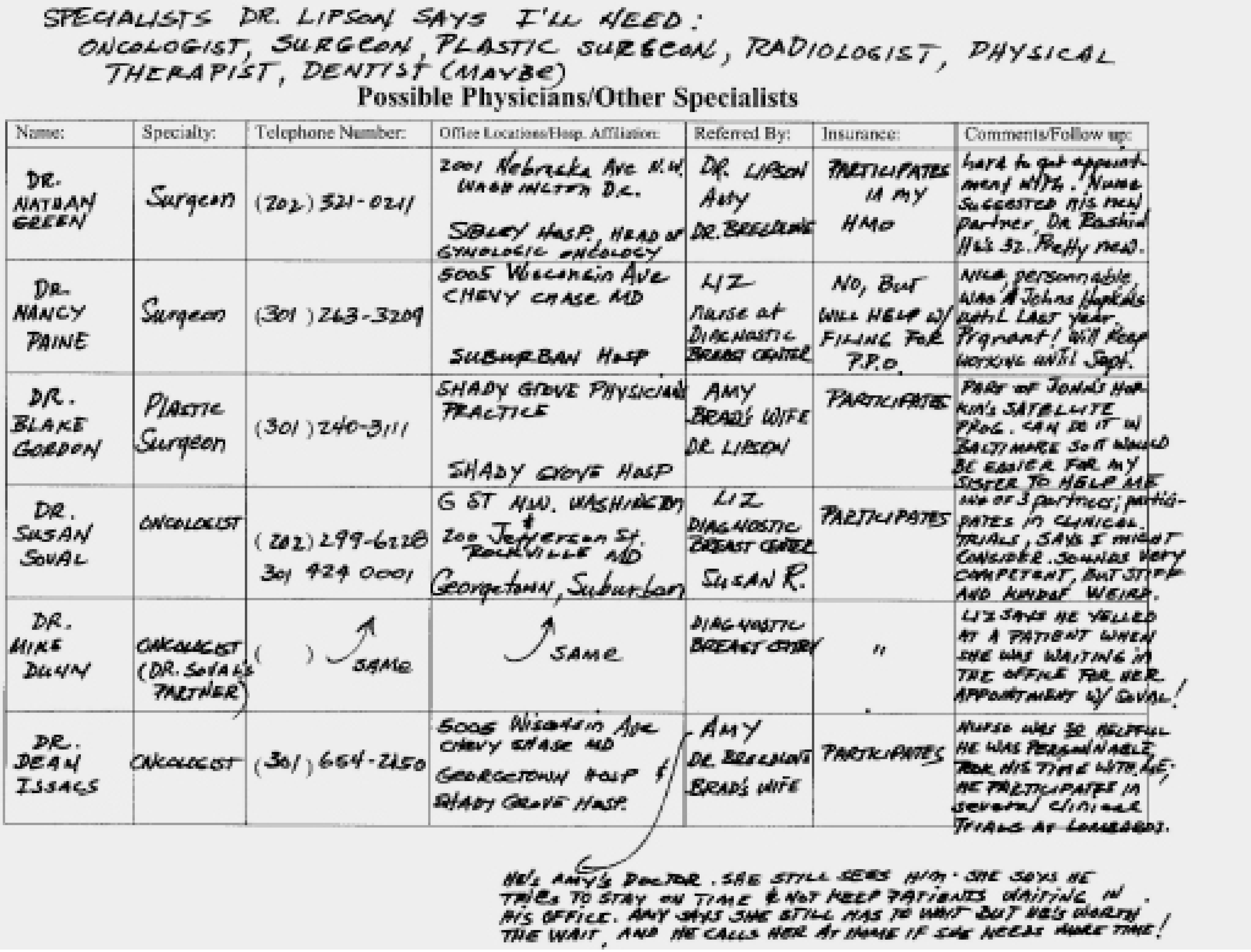
To help you choose among all the local specialists you might consider as your primary oncology doctor, you can:

- Ask the doctor(s) who diagnosed you and their staff for recommendations of well-qualified doctors in the most appropriate specialty for your cancer.

- When you are in the hospital or go to labs for more tests, ask staff for suggestions, especially Oncology Nurse Practitioners and Nurse Navigators. They are trained to answer and resolve each and every concern that you have or, failing that, to help identify resources that you can rely on for help.

- Network acquaintances who have been cancer patients, especially those who have a similar cancer disease as your own, for their recommendations for a competent, committed doctor.

- Find out as much as possible by telephone. Check for basic credentials. He or she should be board-certified in the oncology specialty, and be a cancer specialist affiliated with a local hospital, preferably a "comprehensive cancer center" if there is one in your area.



SPECIALISTS DR. LIPSON SAYS I'LL NEED:
ONCOLOGIST, SURGEON, PLASTIC SURGEON, RADIOLOGIST, PHYSICAL THERAPIST, DENTIST (MAYBE)

Possible Physicians/Other Specialists

Name:	Specialty:	Telephone Number:	Office Location/Hosp. Affiliation:	Referred By:	Insurance:	Comments/Follow up:
DR. NATHAN GREEN	Surgeon	(202) 321-0211	2001 NEBRASKA AVE N.W. WASHINGTON D.C. SIBLEY HOSP. HEAD OF GYNOLOGIC ONCOLOGY	DR. LIPSON AMY DR. BREGMAN	PARTICIPATES IN MY HMO	hard to get appointment w/ him. Nurse suggested his new partner, Dr Bashid. He's 32. Pretty new.
DR. NANCY PAINE	Surgeon	(301) 263-3209	5005 WISCONSIN AVE CHEVY CHASE MD SUBURBAN HOSP	LIZ NURSE AT DIAGNOSTIC BREAST CENTER	NO, BUT WILL HELP W/ FILING FOR P.P.O.	Nice, personable. Was at Johns Hopkins until last year. Pregnant! Will keep working until Sept.
DR. BLAKE GORDON	Plastic Surgeon	(301) 240-3111	SHADY GROVE PHYSICIANS PRACTICE SHADY GROVE HOSP	AMY BRAD'S WIFE DR. LIPSON	PARTICIPATES	PART OF JOHNS HOPKIN'S SATELLITE PROG. CAN DO IT IN BALTIMORE SO IT WOULD BE EASIER FOR MY SISTER TO HELP ME
DR. SUSAN SOVAL	ONCOLOGIST	(202) 299-6228 301 424 0001	G ST NW. WASHINGTON & 200 Jefferson St. ROCKVILLE MD Georgetown, Suburban	LIZ DIAGNOSTIC BREAST CENTER SUSAN R.	PARTICIPATES	ONE OF 3 partners; participates in clinical trials, says I might consider. Sounds very competent, but stiff and almost weird.
DR. MIKE DUNN	ONCOLOGIST (DR. SOVAL'S PARTNER)	( ) SAME	SAME	DIAGNOSTIC BREAST CENTER	"	LIZ SAYS HE YELLED AT A PATIENT WHEN SHE WAS WAITING IN THE OFFICE FOR HER APPOINTMENT W/ SOVAL!
DR. DEAN ISSACS	ONCOLOGIST	(301) 654-2250	5005 WISCONSIN AVE CHEVY CHASE MD GEORGETOWN HOSP & SHADY GROVE HOSP.	AMY DR. BREGMAN BRAD'S WIFE	PARTICIPATES	NURSE WAS SO HELPFUL. HE WAS PERSONABLE. TOOK HIS TIME WITH ME; HE PARTICIPATES IN SEVERAL CLINICAL TRIALS AT LOMBARDI.

HE'S AMY'S DOCTOR. SHE STILL SEES HIM. SHE SAYS HE TRIES TO STAY ON TIME & NOT KEEP PATIENTS WAITING IN HIS OFFICE. AMY SAYS SHE STILL HAS TO WAIT BUT HE'S WORTH THE WAIT, AND HE CALLS HER AT HOME IF SHE NEEDS MORE TIME!

- Pick the "best" ones and make appointments to interview them (as many of them as it takes) to find one you trust and are comfortable with. Assess their potential to be the partner in your cancer treatment. Because that's what he or she is going to be.

- Going in for the office visits to interview doctors is, for most people, a very anxious experience. You'll probably be nervous. Distract yourself while you're waiting by observing the doctor's staff. If you choose this doctor, his or her staff is going to play a big part in your treatment and day-to-day support. Are they helpful and supportive of the patients? Is there a nurse or two who take calls from patients while the doctor is busy? Do they seem to have positive and caring attitudes? Do they seem to be offering advice and explanations to the patients about their concerns?

OK, then. Have you settled on the person who will be your primary care oncologist? The next thing is to set up clear lines of communication with him or her and his office staff. Again –

1. Write down your questions in advance (see the following sample questions)

2. Bring the notebook and your recorder/smart phone

3. Take a family member or a friend to take notes on what the doctor says, because four ears are better than two, and

4. Make absolutely sure if you don't understand something to tell your doctor then and there!!!!

Questions to ask the cancer specialists:

These are a broad spectrum of questions, many of which will not apply to you individually. So, make your list of questions for the oncologist by choosing which ones apply, and add any other questions that are important to you. The purpose is to maximize what you learn at your doctor's appointment, not to be overwhelmed with irrelevant information.

1. What treatments do you offer patients with my kind of cancer? How many have you treated in the last year?

2. Are your treatment options all standard treatments for my kind of cancer, or do you also treat some of your patients with new clinical trial treatments? (You are asking for help in identifying the newest promising treatment approaches.)

3. What treatment(s) do you recommend for me? Is it a series of treatments? How often between treatments? How long will they last? What do I do to prepare for the treatments?

4. What do you expect the results of this treatment to be? What results have other patients like me had from this treatment?

5. What are the possible risks and side effects from this treatment? Am I likely to be able to return to work in between treatments? Exercise? Travel restrictions?

6. How is this going to affect me, day to day? Will I be able to continue working? Will I need assistance at home after my treatments?

7. How will I/you know if the side effects are “normal” or if I am having a bad response to the medications/ treatment?

8. (If you are of an age to possibly have children), will this treatment make me infertile? If so, what can I do to try to preserve my eggs or sperm?

9. Are there other options (other mainstream treatments or “CAM” (Complementary and Alternative Medicine) treatments of my cancer that you know about? Tell me about them, and about the results patients like me have had from these treatments.

10. Are there any clinical trials for this type of cancer? Would I be able to participate in such a trial? If I choose to have this treatment if it is considered a “standard treatment,” would I then be ineligible for any clinical trials treatments that might give me a better outcome than the standard one, if this one fails?

11. When will you know if my treatment is/is not working? What will you recommend if this treatment doesn’t seem to be working or if the treatment is making me really sick?

12. What can I do to stay as healthy as possible now and during treatment, and after this treatment is completed?

13. Would you discuss with me the possibility for using alternative medicine options (for example, supplements, acupuncture, aromatherapy, hypnosis, massage, music therapy) for my pain or treatment side effects? Are there nutritional supplements I may be currently taking that I should not take while I am being treated?

14. Who is available for emergencies and urgent medical questions when you are not? Who covers for you? Do they have access to my records in your absence or unavailability?

15. If I need to ask you questions between visits, how do I reach you (Phone? Email?)? What time during the day is best? When do you normally return calls?

16. Is there someone on your staff besides yourself that I can rely on to answer non-emergency questions and refer me to support services? What is his or her name and contact information? When is (s)he available?

17. Is a nurse or someone else in your office available to talk with me about how much this treatment costs and if it is covered by my health plan? How are the insurance matters handled in your office? Are your costs generally within range of insurance coverage? What is the name of the person in your office who files my claims? Can I contact her/him to see what my part will be in the procedure for filing the claims?

18. (add other questions here)______________________________

19. ____
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20. ____
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Questions to ask the surgeons you are interviewing:

1. What kinds of surgery can I consider? Which operation do you recommend for me? Why?

2. At which hospital(s) do you have surgical privileges? Do I have a choice of where I have the surgery?

3. How many (or what percentage of your practice) have you done of this surgery in the last year?

4. For how long has this surgical procedure been practiced? What have been the results for past patients, relative to other surgical choices? What are the possible complications associated with this particular surgery?

5. What sense of urgency should I feel regarding getting this surgery done immediately? Do I have time to put some order to my household and job before I get the surgery, without affecting the outcome or decrease my chances of survival?

6. Will anyone be assisting you with the surgery? What will they do? Tell me about your choice of anesthesiologist and pathologist(s).

7. What types of cancer specialists should I have identified before I have my surgery to continue my treatment when your

surgery is completed?

8. What access do you have to pathologists and oncologists during the surgery?

9. When will we have the results from the pathology report? How many pathologists will see it? Who will tell me the results of the pathology report? Will I automatically get a copy of the results for my own records? Will the members of my medical team automatically get copies?

10. How much surrounding tissue will you remove for best results in terms of survival? In terms of cosmetic or need for reconstructive surgery?

11. Should I go donate blood in case you need it during my surgery? Where do I go and how soon before the surgery is scheduled?

12. How long will I be in surgery? When will I see you again? When will family/friends know something?

13. How will I feel after the operation? If I have pain how will you help me? Will there be drains, catheters, staples, anything like that?

14. Where will the scars be? What will they look like? Any need for a plastic/reconstructive surgeon? If I decide to have plastic surgery how long before I have it done?

15. How long will I be in the hospital? What help will I need when I first go home? What things should I look for that would make me need to call you about?

16. How long before I can resume normal activities? Drive a car? Go back to work? How long before I can travel?

17. If I have other questions between now and the surgery, are you available to answer them without another office visit? If I have the surgery, how do you prefer that I reach you after the operation? In an emergency? From home? Who covers for you? Do they have access to my records in your absence or unavailability?

18. How are the insurance matters handled in your office? Are your costs generally within range of insurance coverage? What is the name of the person in your office who files my claims? Can I contact her/him to see what my part will be in the procedure for filing the claims?

19. ____
____
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20. ____
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Additional steps in getting control

And now, as they say, your cancer journey begins. A daunting schedule of treatments, visits to old and new specialists, and procedures and lab studies to monitor your progress ALL need to be interwoven with the work and family obligations and commitments of your life while you fight this disease. PLEASE NOTE: Be your own self-advocate. The doctors, nurses, lab technicians, and clinical technicians – and all the staff who work in their offices and clinics – may not treat you as though you are their most very important patient because they are busy and (let's face it) may not be having their very best day, on the day you have your appointment. BUT, each of their jobs depend on you, the patient. Expect the most of each and every one of them, each and every appointment.

Once you have made copies of the New Patient Information form that you filled out, ready to take to a new doctor, there is a tab in the Getting Organized section to store these copies until you need them. Similarly, make several copies of the distribution authorization form and keep it in Tab C, ready to take to every lab test, so all your doctors will be able to see its results.

Please take a moment before you begin your journey to flip back to Tab C in the Getting Organized section of your notebook. Here you will find two forms and two logs you will want to have at your disposal from now on until you have completed your treatments.

The New Patient Information Form:

Starting now, and throughout the months or years while you fight to beat your disease and remain disease-free, you are going to be seeing A LOT of doctors. And on the initial visit to each one you are going to be asked to fill out a New Patient Form by the receptionist as soon as you arrive. It will get very tedious and you may want to just scream in frustration at, yet again, another repetitive thing you must do while you are planning and getting treatment at the same time you are juggling everything that is going on at home and at the office.

So look for the three-page New Patient Form in the forms tab of the Getting Organized section of the notebook. Make a copy of the four pages. then fill in your current information on the clean copy. Get several copies of this completed form and keep them in the forms Tab C. Take a copy of that information each time you see a new doctor. These are all (and sometimes more) of the typical questions asked on a doctor's new patient intake form. Hand your copy to the receptionist when (s)he asks you to fill out his/her office's form. If s(he) insists you need to fill out their doctor's form, be firm. You don't need to do it.

Test Reports and Results Distribution Authorization Request Form:

By now, you will have chosen/identified the members of your medical treatment "team." You can take a great step towards self-advocacy by using this form to fill out the following information:

- names, addresses, telephone and fax numbers of all the doctors
- your name, address, and fax (if you have one) or telephone number

Type on the top of the page: **"I, (name), authorize you to send copies of results/reports to the following patient and recipients:"**

Whenever you go in for a procedure or test, give a signed copy (authorizing them to share your information with those specified on your list) to the medical personnel administering the treatment procedure or test. You do this because not every health care provider you will see over the entire time of your treatment and aftercare is a great record keeper. Communication between the medical team members is often inconsistent or non-existent. If you are in an area where patient records are part of a systematic access across all doctors participating in a multi-modality care program this might not be necessary. But sometimes even these systems fail.

To ensure that your records are complete, you can do this: Each copy of reports or results you receive should be kept in your notebook in the “Pathology, Lab, and Treatment Reports” tab of the Getting Organized section of the notebook. Take the notebook with you when you have a consultation with any/each of your specialists or a visit with a new specialist for a consultation. In this way, you optimize the chances that all your medical team specialists have access to your most recent treatment status and lab work.

This will also come in handy if and when you add a new physician to your medical team. When you have your first appointment with this person, be sure to allow him/her to see this information, to offer a clear and current picture of your health history and status.

ⓘ

TIP: The people that make up your medical treatment team may change during your treatment and aftercare. When that happens, be sure to change your “send copies of results/reports to:” form, accordingly.

Chronological Logs for Drugs and Procedures:

Additionally, as you begin seeing the various members of your medical treatment team, including your primary care doctor, remember that they each need to be kept abreast of what the others are doing. Particularly, it is because not every health care provider you see over the entire time of your treatment and aftercare is a great record keeper. Communication among the medical team members is often inconsistent or non-existent. If you are in an area where patient records are part of a systematic access across all doctors participating in a multi-modality care program this might not be necessary. But sometimes even

these systems fail. It's important for him or her to know what drugs you are currently taking, when prescribed by another of your doctors, and when and if taking the prescribed drug has been terminated. It also helps each doctor to know if you have had trouble continuing to take a certain drug because of side effects and what another of your doctors has done about it.
So, help yourself and them out by keeping a "drug history and chronology" log (your notebook has a template for one in Tab C) of the drugs you are taking – prescribed drugs, of course – but over-the-counter drugs and nutritional supplements you are taking on a routine basis should also be added to the list. Keep the log in your notebook and show it to the doctors when you go to your appointments with them.

Similarly, keep a log in your notebook for all procedures you have during your treatment, even if it is a precedure to treat some other health issue besides your cancer. There is a log template in Tab C for recording a chronology of your procedures.

A final word on this:

Choosing your doctor is part medical matching (someone up to date and in the right specialty for your cancer) and part emotional matching. This doctor should be someone with whom you feel free to share all your important personal issues: your *goals* for treatment (Cure? Comfort? Seeing my child married? Becoming a grandparent? Being able to work while in treatment?); your *fears* (How bad are the side effects going to be? Losing my hair? Sex life?); and your *needs* (How can I or my support person reach you with urgent questions between visits? Is there someone on your staff who can answer non-urgent questions as they arise? Can you tell me of local support services that might help us once I begin treatment?)

It's not a good match if, in your gut, you feel this person is not right for you. You have a right simply to just not like a doctor, even if you respect his or her credentials. You are a consumer, as well as a cancer patient, and you have the right to shop around.

SECTION 2 TAB

Section 2

Getting The Facts

Getting the Facts: What You Need to Know to Participate Fully In Your Treatment Decision-making

The information presented in this and the third section of My Notebook will help you and your doctors speak to one another using understandable "cancerspeak" language. Its goal is to make it easier for you to participate more fully in making the decisions that are best for you. The information is broken up into several brief segments that can be viewed or reviewed separately. You may want to review parts of it throughout your diagnosis, treatment, and aftercare, because it has pointers to more detailed information resources. For now, just read as much as you feel you need to.

Getting the Facts and the following section, Getting Treatment, provide the following information:

- A Quick Cram Course in Cancer Diseases & Treatment
- Using Your Diagnosis and Pathology Results to Research Your Treatment Options
- Understanding What Clinical Trials Are (There Are Several Types) and How They Work
- Finding out about What Clinical Trials Are Available for Your Type and Stage of Cancer

A Quick Cram Course in Cancer Diseases and Definitive Diagnoses:

It is only human that, at times when things are at their most overwhelming and uncertain in our lives, it is harder to intake and process new information. The information presented here is very basic and general. But it is enough information to help you to ask the right questions.

(!)

TIP: Here's the thing: You are getting a huge overload of information right now. You'll increase your success at handling all the new information and details about your cancer treatment by using your three-ring binder, with items such as a planning calendar for appointments and reminders and a place to record your diagnostic and pathology results, names of doctors and referrals, treatment centers' patient liaison contact names, treatment options, insurance information, local support groups, etc.

Your notebook is, just now, a generic three-ring binder that has space for you to add, record, and organize all the information you will need to juggle in the coming months and years. It offers insight into what you should start collecting, right from the start, so you don't have to play paperchase catch-up down the road – the road toward your survivorship.

The Basics on Cancer Definitive Diagnosis

Your diagnosis and pathology results can be "lumped" into three important types of descriptive information:

1. The site of the disease

2. The type of the cancer cells

3. The nature of the cancer cells

These three things make up your "definitive diagnosis" and will be keys to the decision of what treatment or treatments you and your doctors are best for you. You have been diagnosed with one of about 100 diseases that are lumped together and called "cancer." Treatments are very different for each of these different diseases. Even for the same cancer disease, treatment options are quite different, depending on the results of your diagnostic tests. Definitive diagnosis of your cancer examines if it is an early-stage disease, or if it is a later or advanced stage of the disease. It also includes an identification of the cancer cell type (or cytology) of your cancer tumor or tissue. From that, your doctor can determine the comparative aggressiveness of your specific type of cancer. More and more, even for later and advanced stage cancers, new treatments are helping patients survive their disease.

To review the questions so you can ask your doctor for this information, reread the *Getting Control* section. To review the answers, refer to what you wrote down and stored in Tab A.

Your objective is to learn about all the different treatments that are currently available for your type and stage (or phase) of cancer. Your treatment options are defined by the type of cancer you have (which is determined by the organ or site where the cancer started, and the type and appearance of the cancer cells), and the stage of how far the disease has progressed. So, your first step in researching your treatment options is to find out everything your doctor knows that fully describes your diagnosis, including what your pathology reports found out about your disease type and stage.

Cancer diseases are diagnosed and described, based on the initial biopsy results and on the pathology reports, which contain what was found from laboratory examination of the tumor and the cancer cells taken from your biopsy.

Diagnosing cancer diseases almost always starts with a biopsy, in which the doctor draws a fine needle aspiration from a suspected tumor site (especially useful for diagnosing hard-to-reach tumors suspected in organs like the pancreas or liver). Surgical biopsy procedures can be a relatively minor surgery, where a surgeon removes a sample, or several samples, of tissue from a site thought to be cancerous (an incisional biopsy), or more major surgery, like removing part of, or whole, organs (an excisional biopsy). Suspected blood-born cancers are often definitively diagnosed by bone marrow biopsies.   Pathologists often examine the tissues while the surgeon waits, and if the tissue is cancerous, the surgeon removes more tissue from nearby sites, to see if they are also involved, or sometimes removes the surrounding tissue or an organ entirely.

The biopsy's pathology report tells your doctor where the cancer started (called the primary tumor site), the kind of cancer cell it is (often described by terms with -oma at the end, like carcinoma, adenocarcinoma, or sarcoma), the appearance or type (cytology) of the cells, and whether these cells have spread to other areas.

Another step in definitively diagnosing cancer is generally to perform certain blood tests and CT or PET scans, bone scans, and

MRIs to determine the size of the cancer, and to detect if the cancer is anywhere else in the body. This will show if the cancer has spread to other organs or sites in the body, described as metastasis.

Even if you don't understand everything the doctor tells you about your diagnosis and the results of your tests (you don't have to, anyway) you want to have, written down to take home with you, all the information about your diagnosis, including the surgeon's and pathologist's results and reports. You don't need the films of your scans, but you want to have every written report the radiologist or pathologist or hematologist has submitted.   If and when your results are examined by a second opinion specialists' panel or a tumor board, they will see everything. When you go to see other specialty doctors, they will need to see these reports, and it is easier if you have your own copies to give to them.

A brief word about an important type of cancer research that you might want to find out more about now:

Another great contributor to promising new and better cancer treatment, besides clinical trials, is studying the behavior of human cancer cells or tissue, and human genetic materials, where cancer patients' tissues (generally, the "leftovers" from your biopsies, blood work, and surgical procedures) are used in research laboratories. These studies may find out why you got cancer, what can cure it and make it not come back, and what makes some people or some families more at risk than others for getting cancer. If you are interested in learning more about the possibility of contributing your cells, tissues, or genetic material to research projects, check with your pathologist, surgeon, or oncologist. If they are unfamiliar with such programs, ask if they are willing to find out about them.

SECTION THREE TAB

Section 3

Getting Treatment

Getting Treatment: The Basics of Cancer Care

First, here is some basic "Medspeak" lingo about cancer treatments:

There are two general types of therapies for cancer patients: cancer therapies aimed at killing off your cancer cells or reducing your tumor(s) or stopping the progress of your disease (simply called cancer treatments); and treatments aimed at lessening your cancer treatment's harmful side effects (called supportive treatments).

Your treatment may be a combination of a primary treatment and one or more adjuvant treatments, or secondary treatments which are given before (neo-adjuvant), at the same time as, or following your main treatment and are aimed at improving the results of the primary treatment.

Conventional cancer treatment specialties include surgery (provided by surgical oncologists), chemotherapy, hormonal therapy and immunotherapy (provided by medical oncologists and hematologists/oncologists), and radiation therapy (provided by radiation oncologists and therapists). Ask your doctor which one, or which combination of therapeutic treatment specialties may be applicable in treating your type of cancer.

A brief description of these therapies will be enough to inform your discussions with your specialists.

<<Surgery>> If yours is a solid tumor, the primary (first or only) treatment will be to surgically remove it. There are several surgical techniques in use including, where possible, minimally invasive procedures.

<<Chemotherapy>> To kill rapidly multiplying cells, drugs are administered either intravenously or orally. Chemotherapy may be used alone or in combination with other therapies. A "regimen" of chemotherapy refers to the cycles of drug delivery, typically a treatment followed by a rest period, for X number of cycles.

Find excellent lay-language information about chemotherapy drugs including how they work, their potential side effects, and self-care tips while on these therapies at Chemocare.org.

<<Targeted Therapy>> Targeted therapy agents block or modify the DNA or proteins inside cancer cells themselves to alter basic cell functions, such as cell division and cell death. These agents can be effective to stop cancer cells from growing or spreading. Many are given orally in combination with conventional drug therapies.

<<Hormone Therapy>> Hormones that occur naturally drive the growth of some cancers. Hormone therapy (either surgical or chemotherapeutic) blocks the stimulating effect of those cancers that use your body's hormones to drive cancer's growth and spread.

<<Immunotherapy>> Immunotherapy, sometimes called individual or personal therapy, uses you own body's immune system to "search and destroy" cancer cells. It has been found to work for some individuals but not for others, even those with the same cancer type. But when it works, it is a great option in that it destroys only the "bad" cells, and it has fewer side effects than chemotherapy.

<<Radiation Therapy>> Radiation Therapy uses high energy X-rays or proton beams to destroy cancer cells. Treatments are given either externally (the most common type of radiation therapy, using radiation machines) or internally with radioactive implants delivered either by swallowing or injection. You may hear of proton therapy, using proton beams, or cyber knife radiation therapy, both of which are cutting edge, external radiation treatments that cause less damage to surrounding healthy tissue. Brachytherapy is a type of internal radiation, where radioactive seeds are placed near a tumor site.

<<Stem Cell Transplantation>> Stem Cell Transplantation (using your own harvested stem cells) and Bone Marrow Transplantation (using bone marrow of a compatible donor) are used after a patient has received high doses of chemotherapy and/or radiation. Stem cells are then transplanted in the patient to re-establish their immune system and jump-start their production of blood cells.

Whichever treatments or combination of treatments you and your medical team decide are good options, expect some potential side effects, ranging from merely annoying, to tolerable, to intolerable. It is up to you to carefully consider your ability to tolerate the side effects. This is individual, subjective, and very personal. Discuss your fears with your doctor. Take as much of your doctor's time as you need to learn as much as you can.

For purposes of participating with your doctor in making choices among treatments or a combination of treatment options, there are some basic decision parameters you need to be aware of. They are:

- Aggressive vs. Conservative Treatment
- Standard Treatments vs. Clinical Trials
- Conventional vs. Alternative (or Complementary) Therapies

Aggressive vs. Conservative Treatment

When you and your doctor begin reviewing the various options available to you to treat your type of cancer, your objective will be to choose a course of treatment that is "aggressive" enough to stop the progression of the disease, but "conservative" enough that you are spared radical surgery or very high-dose chemotherapy or radiation treatments, unless there is clear evidence based on patients who have had these treatments that they result in an outcome that is better than the conservative treatment.

Your doctor can't tell you with certainty which treatment or treatments will have the best outcome for you, but he or she should review your treatment options with you and tell you their comparative pro's and con's — how difficult it will be for you to get through the course of treatment, and statistics about the response that other patients with your type and stage of disease at diagnosis had when they were given this treatment course.

Discuss with your doctor your views about conservative vs. aggressive treatment. You need to be as open as you can with your doctor in describing your feelings about what you are willing to undergo to treat your cancer, and which treatment options you believe are too risky or will cause you too much distress, with too little chance of helping you.

In the end, the decision is based on you and your doctor weighing treatment risk vs. benefit. If you and your doctor have reviewed all the treatment options, and believe that the more aggressive treatment option has been shown to have a clearly better outcome, and if you are willing to go through this treatment course after the doctor describes what you can expect, and if you believe you have a better chance for a good outcome — that's the treatment you and your doctor will choose.

Standard Treatments vs. Clinical Trials

"Standard" treatments are adopted and approved by medical oversight groups such as the National Cancer Institute and the Food and Drug Administration because they have shown success at cures or at stopping the spread of certain types of cancer. Your oncologist has probably already told you about them. As a patient, if your doctor tells you that there is a standard treatment for your type and stage of cancer that offers an excellent, close to 100% "chance" (based on long term survival percentages) of curing your cancer and allowing you to return to a full and active life, with tolerable side effects during treatment and/or few harmful after-treatment effects, that is the treatment choice you will probably make.

But if you have not been told that there is a standard treatment available that worked extremely well in other patients who shared the same characteristics as yourself (for example, age, gender, race) – then you will want to learn about, and check into the possibility of, all other treatment options. You will want to ask the question, "Is a clinical trial right for me?" Here is where you and your "home team" of supporters should be your own medical advocate – and **do the research**. Ugh. I know I have been asking you to learn about this and learn about that. You must be wondering if I have any idea of just how over-loaded you are right now. But, this is super important.

Understand that it is possible that your doctor just doesn't know about any, or all, of the experimental trials for your type of cancer. And if your oncologist is not participating in clinical trials, he or she may have a bias against recommending that you even look at the possibility of participating in one.

So, begin by asking at all the cancer centers/hospitals near you geographically, "Do any of your doctors participate or are principal investigators in clinical trials for my type of cancer?" If the answer is no, and if you are willing to travel for treatment, you can also look up all clinical trials for your specific disease that oncology doctors are conducting throughout the country which are sponsored by the National Institutes of Health, by going to www.clinicaltrials.gov. To get current information on drug company-sponsored trials, go to the Internet site, www.CenterWatch.com.

Even if you find that you are not a candidate for a new trial that is just starting, circle back and check these databases for interim results of ongoing trials or study results of completed clinical trials, where your type of cancer is being studied. It may help you, as you examine all your treatment options and hopes for better treatments later.

Here are some of the common reasons why you might want to consider becoming a participant in a clinical trial. If you:

- Have a cancer for which there is currently no standard treatment that has been shown to be routinely effective in reducing or curing your cancer
- Have a cancer for which the standard treatment has been effective in some patients, but not shown to be effective for many others
- Are diagnosed with a later stage of disease, or were treated for your cancer, but it recurred later

- Have a cancer for which the standard treatment has been effective, but for which the research doctors are looking for new ways to reduce the side effects or to find new approaches that work better than standard treatment
- Want to consider a treatment that will take less time, cost less, or need less radical surgery or high doses, but still have the same or better outcome.

It is important for you to know that for some clinical trials, you may not be able to receive these new research treatments if you have already been given an older, standard treatment, so it may be very important to find out what clinical trials may be available before you and your doctor decide on an initial course of treatment.

What are Clinical Trials, exactly?

Clinical trials are basically studies funded by the government, by other cancer foundations, and by pharmaceutical and medical devices companies who are developing new cancer-fighting treatments and techniques. Two different types of trials you may want to inquire about are: ***treatment trials*** to evaluate a new type of treatment or combined treatments to see if it is better than standard treatments and ***quality-of-life trials*** to study ways to minimize disease-related and treatment-related adverse effects. The advances in cancer treatment that are saving more and more lives and allowing cancer survivors to return to healthy, normal lives are achieved through clinical trials.

The results of these clinical trial studies, called "treatment outcomes" may include better methods for eliminating your cancer tumor or cancer cells, shrinking the tumor's size, stopping the cancer cells from multiplying, keeping your cancer from spreading, and/or keeping it from coming back. Or, the outcomes may focus on easing your post-treatment nausea, avoiding side effects such as hair loss, bolstering your system's defense against infection or other secondary illnesses, or managing your pain. These second set of treatment outcomes may be of benefit to you, even if you have already begun a standard course of treatment.

Two important misconceptions to clear up immediately: (1) The patients who are being treated in clinical trials studies are not human "guinea pigs." The laboratory animal testing of these treatments has been exhaustive before the treatment research has progressed into clinical trial studies. (2) If you participate in a drug treatment study, you will not be given a "sugar pill," or placebo, instead of a cancer treatment drug. You will either be given the new treatment(s) that are the subject of the study, or you will receive the standard treatment(s).

For your specific disease, there may be no current clinical trials; there may be one or two; there may be many. There may be trials going on for your disease, but they could be in another part of the country (so you would have to decide if you would be willing to consider going there for treatment), or they could only include patients of a certain age or sex or some other "eligibility" requirement that would exclude you from participating in the trial.

If you are going to consider a clinical trial, and there is a trial that is studying your type or site or stage of cancer disease, you will need to meet the trial's "*eligibility criteria*." These are strict entrance rules for participating. You may not "qualify" for a study, even if the researchers are studying your cancer disease. The reason might be because you are not within the age range they are studying, or because you are a male and they are only studying females, or because you are of child-bearing age, or because you have had or are having medications or treatments that would interfere with, or be confused by, the results they are trying to achieve in this individual study. These eligibility requirements are developed at the time the research study is designed, for two purposes: first, to protect the volunteer patients from any undue risk, and second, to make the results of the research more reliable.

The bottom line on eligibility requirements is this: If you don't qualify, don't take it to mean that you aren't treatable. You may be eligible for another clinical trial studying your type of cancer, either now or a later time.

What Should I Know If I Am Eligible for a Clinical Trial?

All clinical trials are conducted in a rigidly consistent way, so that each patient is treated exactly the same as all the other patients in the study. This way they can reduce, as much as possible, any variables that would confuse the anticipated outcomes. You will receive the exact same treatment, according to the exact same schedule, and your check-ups and follow up appointments will record the exact same types of information. Regardless of where you are treated – in a small hospital or a big cancer treatment center – the clinical trials doctors whose patients are accepted into the study are responsible for a strict adherence to protocols and reporting standards. These doctors in small communities and rural settings make it possible to treat patients in their own hometowns, offering these newer treatments to a larger study population. If you participate in a clinical trial, you will either be given a standard treatment (because you will be in the control group), or you will be in the study group and given the new treatment. In most cases you – and not even the doctor – will know which group you are in.

The trial team is required to clearly explain all and any potential risks and inconveniences to you, even minor ones. When applicable, you will also be told about alternative, recognized medical therapies available. In addition, investigators must make you aware of any information that becomes available during the trial that may be relevant to you. You will be asked to sign a consent form clearly explaining that your participation in the trial is voluntary. And you will be given the name and contact information for the trial's main investigator and a person from the Ethics Committee.

Clinical studies are conducted in four phases. If you are told it is a **Phase I** study, this means there will be a relatively small number of volunteers (maybe as few as 20) and the study will be used to determine the best dosage, or the best delivery method (oral, IV, etc.), or how often it should be given. These studies monitor the safety and the side effects of the new drug, dosage, or method, or schedule. If the study you are offered is a **Phase II** study, this means that there will be a larger number of volunteers (say, 100+). These studies are continuing to carefully monitor the safety and side effects of the best dosage, delivery method, and schedule for a treatment studied in a Phase I trial. If you are told it is a **Phase III** trial, you will be part of a study that includes many patient volunteers (say 1,000+). These are the studies that determine if the new treatment or combination of treatments is safer and/or has less harmful after effects or side effects than the standard treatment(s) for the same cancer. At the end of the **Phase III** trials, the treatment may be approved for use on all patients. **Phase IV** studies continue to monitor the treatment for its long-term safety and efficacy. Often **Phase IV** studies test the new treatment in specific populations such as male vs. female, patients between the ages of 20-40 vs. 40-55 vs. 50-70, etc. (Just so you know: There are trials specifically for minority racial or ethnic populations. Because fewer numbers of these minority groups are volunteering for trials, **Phase IV** trial doctors are actively trying to enlist minority patients for these treatments.)

Are there risks to participating in clinical trials? The answer is that the risks are *really* just the same as for all other cancer treatments. Almost every type of cancer treatment has known side effects and may also have potential long-term harmful adverse effects. So, it is important to talk with your medical team about the relative risks you may face with every treatment option you are considering, and then weigh the possible risks and benefits of the treatment options. Ask yourself what you want out of the treatment. Then discuss your personal expectations regarding opting for the clinical trial with your oncologist and with the doctor who will be treating you in the clinical trial, and ask the doctors if they believe it is a worthwhile alternative. Consult your insurance coverage to determine if your benefits include clinical trials. The bottom line is this: Clinical trials present many potential benefits that may outweigh the potential risks, when compared with other treatment options. Become as informed as you can about the option of participating in a research study that may help you, and may help other cancer patients as well. You can review an excellent overview of a clinical trial "journey" and timeline on www.abbvieclinicaltrials.com for corporate-sponsored clinical trials, and www.clinicaltrials.gov for government-sponsored clinical trials. These explain in detail what you may expect as a clinical trials participant.

Lastly, here are the important questions you will want to ask of the doctors conducting the clinical trial:

1. Who are the doctors and nurses who will oversee my medical care during the clinical trial, and when do they begin overseeing my care and when will I go back to my own oncologist after the trial is over?
2. How long will the clinical trial run?
3. Under what circumstances might the trial be shortened or cancelled?
4. Who decides which treatment I will receive?
5. How do the expected side effects differ between the two groups?
6. Who will pay for my participation? If my insurance doesn't

pay, does the cancer center where I am going to be treated have any assistance programs for this clinical trial?
7. Will I need to be in the hospital for these treatments? How long? How do I prepare for the day of treatment?
8. What can I expect in the next few days after treatment?
9. If this is a Phase III or IV study, what adverse reactions were experienced by other patients in the earlier studies of this treatment?
10. If I feel I must withdraw from the study, what happens then?
11. If the trial is successful, will I still be able to get treatment after the trial ends?

Conventional vs. Alternative Therapies

In your research to learn about all your treatment options, you will no doubt be wading through a lot of conflicting information about conventional vs. alternative therapies. Here is a condensed version of this very complicated topic: Conventional treatment (biomedical therapies practiced by all the doctors you've probably seen over your lifetime who work within the mainstream medical community) will, no doubt, be the treatment or treatments your oncologist will advise you to take. But it is important that you understand the role of alternative medicine therapies (all the other treatments and practices not generally recognized by the medical community as standard or conventional medical approaches) in today's cancer treatment. And make sure that you know the differences between the various treatments that fall under the umbrella term, alternative medicine, as you consider their potential to help you survive your cancer.

Alternative medicine, in the not-so-distant past, was dismissed vigorously by the medical community because it was defined specifically as a treatment used in place of (alternatives to) conventional treatments. These alternative treatments (often in the form of drugs that were derided as “snake oil” treatments) had no research-based evidence that backed up their safety or effectiveness, and no governmental regulation overseeing their production. Some had no therapeutic benefits at all, and some were life threatening. Some were later exposed as criminally exploitive of cancer patients, who trustingly believed they might be helped by them. Beware of websites that hawk such treatments. Here’s the bottom line for you, the patient: only if, down the road, the course of treatments you have received have failed to help, and only if your doctors have told you they can do no more to help you, should you ever take the risk of an unregulated, unevaluated “alternative” treatment offered on the many diffuse cancer websites.

On the other hand, there are other alternative therapies often used in addition to conventional treatments that you should know about and possibly consider. For the purposes of discussing this large body of therapies and treatments, this discussion will be broken up into four categories:

1. Natural Treatments, for those who determine that pharmaceutical drugs, radiation treatments and some surgeries are not an option for them at all, or at least not the only option;
2. Nutritional Supplements, used by some patients as anticancer and anti-toxicity agents;
3. Complementary Therapies, which are non-medical approaches and wellness practices used in conjunction with conventional treatments;
4. Integrative Therapies, which combines evidence-based complementary therapies with conventional treatments.

These are all versions of alternative therapies that should be given consideration, as you research all your treatment options. So, let’s discuss each of these in more detail. If you want more detailed information on this, check out the website for the Office of Cancer Complementary and Alternative Medicine, www.cancer.gov/occam.

Natural Cancer Treatments

Some natural treatments are chosen by patients to totally replace standard/conventional surgery, chemotherapy, and radiation therapies. When a patient believes he or she has compelling reasons why standard treatments will likely be harmful, he or she will almost always be met with a huge amount of pushback from their oncologists. However, if you are one of these people, there are a few holistic or natural cancer clinics scattered throughout the U.S., Canada, and Central and South America that are treating cancer patients. There are also a few cancer centers here in the U.S. offering to incorporate, as much as possible, whole-body approaches using the latest promising natural and nutritional regimens into your treatment plan. If you are considering using cancer centers who offer holistic treatments, please visit their physical location, and do a thorough background check of their treatments and treatment facilities. Ask about evidence-based outcome studies the center has conducted. Use this information to make a fully informed decision.

Nutritional Supplements

Many cancer patients who have chosen to undergo conventional treatments still want to explore what is being said about the efficacy of taking supplements to increase their chances of surviving their cancer or to relieve treatment side effects. More and more, the safety and efficacy of supplements are being studied, with the aim of being accepted into mainstream medicine. Research those studies and their results. Look for evidence-based studies on dietary supplements, rather than advertisements and anecdotal stories of one or more individuals' personal experiences. Don't be misled by all the accounts of how well this or that supplement works. Here is why: The use of nutritional supplements that may be said to help cancer patients poses a host of problems in terms of assuring yourself that they are safe to take and that they are beneficial. Ask yourself: Were the natural substances grown in a pollutant-free environment? How, if supplements are a mixture of herbs that are unstandardized and unregulated, can you decide which ones to use? How can the natural compound or "active ingredient" be studied when there is no standard in the way it was developed? How can you judge the safety and efficacy of a supplement regimen, based only on anecdotal hearsay?

Finally, some supplements have been shown to be harmful when taken by themselves or with other substances or if used in large doses, when dosage information is not well described by the producers of many supplements. On the other hand, some supplements have been shown to be effective and safe. Taking them may aid your body to better cope with the side effects of chemotherapy and radiation, when taken in a prescribed dosage regimen while in treatment. If you decide to take nutritional supplements, be sure to tell your oncologist what supplements you are taking. Some studies show, for instance, that high doses of vitamins may affect how chemotherapy and radiation work. Some herbs may cause certain anticancer drugs to be less effective (examples: St. John's Wort or Ginseng).

Complementary Therapies

Healthful diet and exercise, and "whole-body" therapies, when practiced while you are being treated with conventional cancer treatments, have been shown in clinical trial studies to be beneficial in two major ways: first, it promotes a status of wellbeing that is good for any individual, regardless of their disease status, before, during and after treatment; and second, it strengthens and bolsters your ability to tolerate, and therefore benefit from, even very aggressive cancer treatments. Complementary therapies are embraced much more readily these days by most oncology specialists. For good reason, and about time, I'd say. These treatments and practices are non-invasive, non-medical approaches. They are effective and safe adjuncts to mainstream care.

As a recently diagnosed cancer patient, you undoubtedly have had to reassess your lifestyle choices and priorities. You were probably doing a constant juggling act to keep up with your professional and family commitments before you were diagnosed. Many of us have paid far less attention to nutritional needs and healthy exercise schedules. In other words, like most of us, you took your health for granted.

If your lifestyle is one that has built-in components to maximize your physical and emotional wellness, and conscious efforts to maintain balance in mind, body and spirit – well, good for you because you are good to go forward on your cancer journey.
If not, now is the time to reprioritize!!!! Why? Because cancer survivorship begins right now. First with "pre-habilitation," i.e., targeted exercises designed to optimize a treatment's outcome, done before treatment begins. For example, pre-operative lung cancer patients should do breathing exercises; prostate patients may do pelvic floor exercises, and neck and buccal cancer patients may do swallowing exercises. Additionally, there are numerous studies that prove that healthy eating habits and moderate exercise are associated with reduced recurrence of some types of cancer, including colorectal, prostate, and ovarian cancers. Following a healthy diet helps people recover from surgery and provides protection from the nutritional detriments of chemotherapy and radiation. And moderate exercise has been shown to combat the overwhelming fatigue that most cancer patients in treatment experience, as well as sleeplessness.
On that subject, sleep is an important component in maximizing your body's immune system, which in turn fights the cancer cells' spread.

Most cancer centers, hospitals and clinics either have, or can direct you to, nutritional and wellness counselors. In most instances, their services are free to cancer patients. Get guidance from these professionals. Use them to develop a plan that is tailored to your individual needs as a cancer patient. Regard it as an important part of your cancer care.

In addition to nutrition and exercise, there is another component of your self-care. It is stress management and attention to your mental and emotional wellbeing. Stress, anxiety, and depression are increasingly shown to be as detrimental to your body's ability to fight cancer as your physical wellbeing. The term "mind-body connection" is no longer a new age bunch of stuff that you may have dismissed until now. You are now coping 24/7 with fears and uncertainties. Being a cancer patient has become a full-time job, even as you are juggling time commitments to your family and employer. If you have a friend or spouse who is your primary support person, have them participate in wellness practices with you. They are living with cancer every day as you are, with many of the same stressors, and they need to stay strong to help you stay strong.

BC (before cancer) life goals and priorities are in a reset mode. AD (after diagnosis) realities are day-by-day and unpredictable. "Keeping it together" has taken on a whole new meaning. You need coping skills, not necessarily to reduce the stressors you are currently under (wouldn't that be nice?) but to help you better live with stress. Stress doesn't cause cancer, but studies have shown that it does feed the mechanisms that make cancer spread. Even if the other stuff going on for you as a cancer patient is overwhelmingly, all-consuming of your time and energy, take a breath, and make the time to develop those needed coping skills. Find what works for you and ask your main support person(s) to do the same. It could be "support groups." It could be yoga or tai chi. It could be learning proven stress management techniques and utilizing stress management tools. It could be journaling or music and art therapy. Whatever works, know that it will increase your chance of surviving your cancer.

Here is the bottom line on complementary therapies: most are not directly aimed at curing your cancer, but many mainstream cancer practitioners are very willing to endorse them. Ask your doctor, or investigate online sources, about complementary and alternative medicine (CAM) therapies, such as acupuncture, massage, herbals, nutritional supplements and macrobiotics, relaxation therapies, biofeedback, and creative therapies. Their use for you, the cancer patient, is to relieve some of the side effects of conventional cancer treatments, ease pain, and reduce the physical trauma and psychological stresses of cancer. They may also strengthen your body and your mind and lessen your level of stress while you are in treatment. The stressors of living with cancer can overwhelm a patient's ability to beat this disease, so these therapies are well worth exploring.

Integrative Oncology

Some of the major cancer centers in the country are offering what they call "integrative oncology." Combining the helpful complementary therapies with mainstream oncology care to address patients' physical, psychological, and spiritual needs constitutes the practice of integrative oncology. If you are fortunate enough to find a cancer center close to you that offers these programs, choose that cancer center.

Here is what I think is the most important take-away from these programs: The physicians who work with each patient to provide nonclinical treatment modalities are out there now in increasing numbers each year. These physicians' aim is to reduce symptom "burden" (medspeak for all the symptoms and complaints you have due to your disease and treatments aimed at curing your disease) and improve your quality of life as a component of their clinical cancer treatments. And the doctors thus become partners with their patients to enable them to have an active role in their own care, which in turn improves the physician–patient relationship, the quality of cancer care, and the well-being of patients and their families. A "win-win" all around. You and your concerned loved ones have every right to find an oncologist who is willing to discuss and explore all aspects of integrative oncology treatments. If the doctor dismisses this notion outright, keep looking until you find another doctor.

This is your life. It is your family's lives. You deserve a medical team who see you and your family as more than a cancer disease.

Section 4

Getting Organized

This part of *My Notebook* is completely unique to you and your loved ones. We expect you will be using it for several years. We recommend that you purchase another notebook for keeping sections, or pages of other sections, that you are no longer currently using. In that way *My Notebook* can be easily carried with you to treatments and appointments.

Getting Organized……

A place to keep your cancer information and records

Here is where you personalize your notebook. We have set up tabs for you to keep the information easily at hand and organized.

Tab A:	Doctors' Information and Q&A
	Initial Pathology Reports and Test Results
	Networking Log to Find Members of Your Medical Team
	Information on Possible Physicians/Specialists
	List of Local, Non-medical Cancer Support Services
Tab B:	Monthly Calendar
	My Medical Team
	Medical Visit Log
Tab C:	New Patient Information Form
	Test Reports and Results Distribution Requests Form
	Chronology Log for All Prescriptions and Other Medication Log
	Chronology Log for All Procedures

Tab D: Test Reports and Results

Tab E: Insurance Information Log
Claims Tracking (Clear Sheet Protectors for each claim)
Information on Changing Insurance Plans

Tab F: Receipts for Expenses (for itemized deductions on your tax returns

Trust me you'll be glad you started, right from the beginning, collecting all this information in an organized way.

If you can, get family member(s) or friend(s) to help you with managing the different aspects of keeping your medical paper trail.

Keep the information in Tab C updated, and make sure to take copies of the forms, medication chronology log, and medical procedures log with you when you go on doctors visits.

Save your strength, energy, and mental focus for the important stuff, not all this crazy-making paperchase.

TAB A PAGE

Tab A

Initial Pathology Reports and Test Results

(See Getting Control pp 4-6)

(This is the place to store the reports from the procedures and results of your lab work-ups. Use a three-ring hole punch to punch holes in the lab reports and test results you have received)

Tab A - Networking Log to Find Potential Specialists

Date:	Doctor's Name	Telephone Number:	Specialty:	Referred by:	Comments/Next Step/Follow up:
		( )			
		( )			
		( )			
		( )			
		( )			
		( )			
		( )			
		( )			
		( )			
		( )			
		( )			
		( )			

Tab A - Networking Log to Find Potential Specialists

Date:	Doctor's Name	Telephone Number:	Specialty:	Referred by:	Comments/Next Step/Follow up:
		( )			
		( )			
		( )			
		( )			
		( )			
		( )			
		( )			
		( )			
		( )			
		( )			
		( )			
		( )			

Tab A Information on Possible Physicians & Other Specialists

Name:	Specialty:	Telephone No.:	Office Address: Hospital Affiliation	Re-ferred by:	Insurance:	Comments/Follow up

Tab A Information on Possible Physicians & Other Specialists

Name:	Specialty:	Telephone No.:	Office Address: Hospital Affiliation	Re-ferred by:	Insurance:	Comments/Follow up

Tab A

Non-medical Cancer Support Programs

Here is a task you can ask a family member or friend to do when he or she says, "What can I do to help?" Ask them to research the local programs that address non-clinical needs near you, and list them here. Include physical, nutritional, and psychosocial support needed by patients, their family members and loved ones/caregivers. Be sure to search specifically for cancer support groups, counseling, wellness programs, and survivorship education, including programs for your loved ones as well as yourself.

PROGRAMS	Days and Hours Open	WHERE THEY ARE	PHONE NO.

PROGRAMS	Days and Hours Open	WHERE THEY ARE	PHONE NO.

tab b page

Month:

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Month:

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Month:

Sunday	*Monday*	*Tuesday*	*Wednesday*	*Thursday*	*Friday*	*Saturday*

Month:

Sunday	*Monday*	*Tuesday*	*Wednesday*	*Thursday*	*Friday*	*Saturday*

Month:

Sunday	*Monday*	*Tuesday*	*Wednesday*	*Thursday*	*Friday*	*Saturday*

Month:

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

My Medical Team (Tab B)

Name and Specialty:	Address of Main Office	Phone and Email	Name/Number/email of Staff Person to ask questions of, if they can answer for the Doctor	Emergency and off hours' telephone numbers for Doctor	Insurance Claims Staff Person's Name/Number	Date of 1st Visit

My Medical Team (Tab B)

Name and Specialty:	Address of Main Office	Phone and Email	Name/Number/email of Staff Person to ask questions of, if they can answer for the Doctor	Emergency and off hours' telephone numbers for Doctor	Insurance Claims Staff Person's Name/Number	Date of 1st Visit

My Medical Team (Tab B)

Name and Specialty:	Address of Main Office	Phone and Email	Name/Number/email of Staff Person to ask questions of, if they can answer for the Doctor	Emergency and off hours' telephone numbers for Doctor	Insurance Claims Staff Person's Name/Number	Date of 1st Visit

Tab B

Medical Visit Log

Date:	Type of Visit, Test or Treatment	Name of Doctor, Lab or Hosp. Dept.:	Telephone Number of Billing Office:	Co-pay Amount You Paid:	Claim Number (fill in later):
			( )		
			( )		
			( )		
			( )		
			( )		
			( )		
			( )		
			( )		
			( )		

Tab B

Medical Visit Log

Date:	Type of Visit, Test or Treatment	Name of Doctor, Lab or Hosp. Dept.:	Telephone Number of Billing Office:	Co-pay Amount You Paid:	Claim Number (fill in later):
			( )		
			( )		
			( )		
			( )		
			( )		
			( )		
			( )		
			( )		
			( )		

Tab B

Medical Visit Log

Date:	Type of Visit, Test or Treatment	Name of Doctor, Lab or Hosp. Dept.:	Telephone Number of Billing Office:	Co-pay Amount You Paid:	Claim Number (fill in later):
			( )		
			( )		
			( )		
			( )		
			( )		
			( )		
			( )		
			( )		
			( )		

Tab B

Medical Visit Log

Date:	Type of Visit, Test or Treatment	Name of Doctor, Lab or Hosp. Dept.:	Telephone Number of Billing Office:	Co-pay Amount You Paid:	Claim Number (fill in later):
			( )		
			( )		
			( )		
			( )		
			( )		
			( )		
			( )		
			( )		
			( )		

TAB C PAGE

New Patient Information Form

(See *Getting Control*, page 25)

Tab C

First Visit Patient Information Form

Patient Name: ______________________________

Address: ______________________________
Street

Address: ______________________________
City State Zip

Telephone (Home): (   ) ______________ Email Address ______________

Telephone (Work): (   ) ______________

Date of Birth: ______________

Gender: ______________

Next of Kin: ______________ Relationship: ______________

Telephone (Home): (   ) ______________

Telephone (Work): (   ) ______________

Insurance Information:

Primary: ______________________________

____

Secondary: ______________________________

Name of Insured: ______________ Employer: ______________

Address of Employer: ______________________________

Address of Insurance: ______________________________

Group Policy Number: ______________________________

First Visit Patient Information Form

Name of Patient: ______________________________

Health Assessment	**Yes**	**No**
Abnormal bleeding/bruising	______	______
Anxiety	______	______
Breathing difficulties	______	______
Changes in appetite/weight	______	______
Chronic constipation	______	______
Chronic diarrhea	______	______
Depression/sadness	______	______
Dizziness	______	______
Drug or alcohol abuse	______	______
Fatigue	______	______
Fecal incontinence	______	______
Fertility Concerns	______	______
Fever/Sweats	______	______
Hearing Loss	______	______
Heartburn/indigestion	______	______
Hot flashes/night sweats	______	______
Jaundice	______	______
Memory/concentration issues	______	______
Numbness/weakness on one side	______	______
Pain (constant)	______	______
Pins and needles/numbness	______	______
Premature menopause	______	______
Rectal bleeding/hemorrhoids	______	______
Recurrent colds/coughs/infections	______	______
Sexual dysfunction:	______	______
Skin changes:	______	______
Sleep/wake disturbances	______	______
Slurred Speech	______	______
Swelling of arm or leg	______	______
Swollen lymph nodes	______	______
Teeth/mouth issues	______	______
Urinary incontinence	______	______
Vaginal discharge	______	______
Vaginal dryness	______	______
Vision problems	______	______

First Visit Patient Information Form

Name of Patient:

Allergies and Sensitivities:

Prior Surgeries/Dates:

List of Current Medications, including over-the-counter and supplements/herbal:

Medication:	**Dosage:**	**X's a day, time of day**

Test Reports and Results Distribution Requests Form

(See *Getting Control,* page 25)

Tab C

(Request for Copies of Results/Reports)

Send Copies of Results/Reports to the Following Patient and Physicians:

Patient:
Telephone(home): (   )
Telephone (work) (   )
Telephone(fax): (   )
Address:

Specialist:
Name:
Address:
Street
City State
Zip
Office Telephone: (   )
Office Fax: (   )

Specialist:
Name:
Address:
Street
City State
Zip
Office Telephone: (   )
Office Fax: (   )

Specialist:
Name:
Address:
Street
City State
Zip
Office Telephone: (   )
Office Fax: (   )

Specialist:
Name:
Address:
Street
City State
Zip
Office Telephone: (   )
Office Fax: (   )

Specialist:
Name:
Address:
Street
City State
Zip
Office Telephone: (   )
Office Fax: (   )

Patient Signature:

Date:

(Request for Copies of Results/Reports)

Send Copies of Results/Reports to the Following Patient and Physicians:

Patient:
Telephone(home): (   )
Telephone (work) (   )
Telephone(fax): (   )
Address:

Specialist:
Name:
Address:
Street
City State
Zip
Office Telephone: (   )
Office Fax: (   )

Specialist:
Name:
Address:
Street
City State
Zip
Office Telephone: (   )
Office Fax: (   )

Specialist:
Name:
Address:
Street
City State
Zip
Office Telephone: (   )
Office Fax: (   )

Specialist:
Name:
Address:
Street
City State
Zip
Office Telephone: (   )
Office Fax: (   )

Specialist:
Name:
Address:
Street
City State
Zip
Office Telephone: (   )
Office Fax: (   )

Patient Signature:

Date:

Tab C
Chronology Log of Prescription Drugs

Drug:	Dosage:	Prescribing Doctor:	Date began:	Date stopped:

Tab C
Chronology Log of Prescription Drugs

Drug:	Dosage:	Prescribing Doctor:	Date began:	Date stopped:

Tab C
Chronology Log of Prescription Drugs

Drug:	Dosage:	Prescribing Doctor:	Date began:	Date stopped:

Tab C
Chronology log for all procedures

Date	Procedure	Physician	Outcome notes

Tab C
Chronology log for all procedures

Date	Procedure	Physician	Outcome notes

TAB D PAGE

Test Reports and Results

(This is the place to store all the lab results and reports of your scans. Use a three-ring hole punch to punch holes in the reports.)

Tab D

TAB E PAGE

Tab E What My Insurance Covers

	Name of Insurer:	Customer Service Telephone Numbers	Insurer's Representatives Name:
Primary:		( )	
Secondary:		( )	
Other:		( )	
		( )	

What's Covered? % Covered?
What's the Deductible? Out of Pocket Premiums?

- *Specific coverage policies for cancer patients?* ______________________________
- *Second opinions?* ______________________________
- *Medically prescribed dental care?* ______________________________
- *Investigational or experimental studies?* ______________________________
- *Reconstructive/Plastic surgery?* ______________________________
- *Post-operative home care?* ______________________________
- *Physical Therapy/Rehabilitation?* ______________________________
- *Alternative/Complimentary therapies?* ______________________________
- *Psychiatric services?* ______________________________
- *Prescription drugs – is there a yearly "cap"?* ______________________________

Tab E - Billing/Insurance Contact List

(see Getting Control. p. 10)

Name of Doctor, Lab, or Hospital:	Name of Person Who Handles Making Insurance Claims:	Telephone Number:
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Tab E Insurance Claim Tracking

Claim Number: (Also name of insurer, if more than one)	Doctor, Lab or Hospital Name:	Total Amount of Bill:	Date of First Response from Insurance:	Amount Paid by Insurance:	Amount Paid by You:	Need to Resubmit? (Comments, Dates of Re-Submission)

Tab E

Insurance Claim Tracking

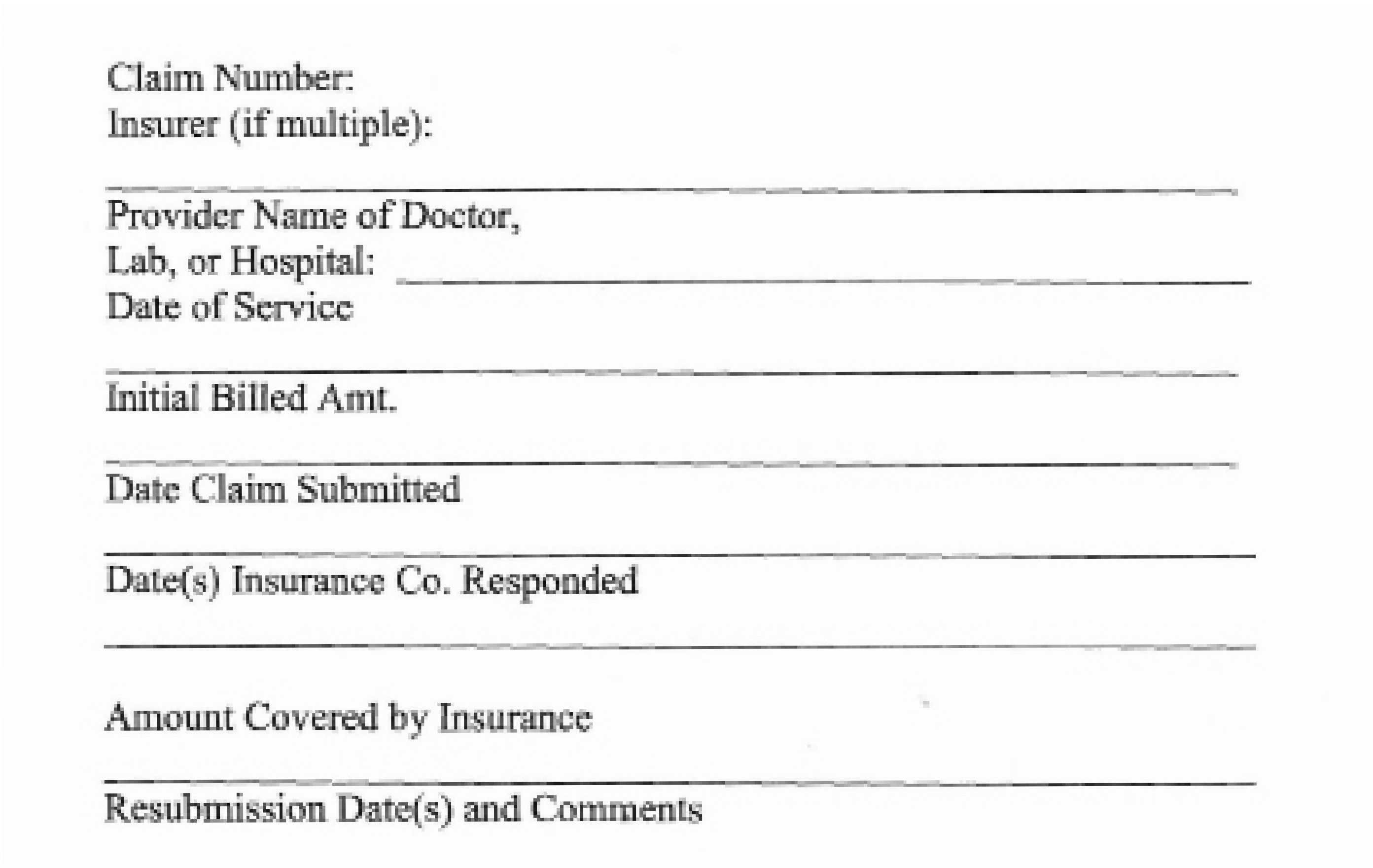
Claim Number: (Also name of insurer, if more than one)	Doctor, Lab or Hospital Name:	Total Amount of Bill:	Date of First Response from Insurance:	Amount Paid by Insurance:	Amount Paid by You:	Need to Resubmit? (Comments, Dates of Re-Submission)

Clear Protectors, one for each Claim

Tab E

Clear Plastic Sleeves to Store Claim Paperwork

There are five plastic sleeves labeled for you to use, one for each claim. When you need more, copy, cut and paste one of these on the front of each clear plastic protector. Use one plastic envelope for each claim number. As new correspondence on each claim is mailed to you, simply store it togeter with all the rest.



Claim Number:
Insurer (if multiple):
Provider Name of Doctor,
Lab, or Hospital:
Date of Service
Initial Billed Amt.
Date Claim Submitted
Date(s) Insurance Co. Responded
Amount Covered by Insurance
Resubmission Date(s) and Comments

Claim Number:
Insurer (if multiple):

Provider Name of Doctor,
Lab, or Hospital:
Date of Service

Initial Billed Amt.

Date Claim Submitted

Date(s) Insurance Co. Responded

Amount Covered by Insurance

Resubmission Date(s) and Comments

Claim Number:
Insurer (if multiple):

Provider Name of Doctor,
Lab, or Hospital:
Date of Service

Initial Billed Amt.

Date Claim Submitted

Date(s) Insurance Co. Responded

Amount Covered by Insurance

Resubmission Date(s) and Comments

Claim Number:
Insurer (if multiple):

Provider Name of Doctor,
Lab, or Hospital:
Date of Service

Initial Billed Amt.

Date Claim Submitted

Date(s) Insurance Co. Responded

Amount Covered by Insurance

Resubmission Date(s) and Comments

Claim Number:
Insurer (if multiple):

Provider Name of Doctor,
Lab, or Hospital:
Date of Service

Initial Billed Amt.

Date Claim Submitted

Date(s) Insurance Co. Responded

Amount Covered by Insurance

Resubmission Date(s) and Comments

Tab E
Changing Insurance Plans:

Keep insurance needs in mind when you are changing job status. Don't leave a job with insurance benefits until you have a new job with good coverage or you have made other plans for health insurance. This is also an important thing for your spouse to keep in mind if you are covered under his or her policy. Look at the differences in insurance coverage and other benefits offered by various employers. You may be better off taking a new job with a lower salary that has better insurance coverage.

Consider continuing to take part in your current company's group plan after you leave. If a new job does not work out, you could be left with no coverage.

Federal law (Public Law 99-272), the Consolidated Omnibus Budget Reconciliation Act (COBRA), requires many employers to allow employees who quit, are let go, or whose hours are reduced, to pay their own premiums for the company's group plan. This protection lasts 18 months for employees (up to 29 months if they lose their jobs due to disability and are eligible for Social Security disability benefits at the time they leave the job) and 36 months for their dependents. If an employee leaves a company and takes a new job, continuation coverage by the former company can be kept for up to 18 months if the new company’s coverage is limited or excludes a pre-existing condition, such as cancer. (COBRA applies to employers with 20 or more workers who already offer group health insurance.)

Contact your personnel department to enroll. In addition, you can contact your state insurance commissioner to learn if your state has continuation-of-benefits laws. They may help you receive additional insurance rights protection.

Take advantage of your right in some company group policies to convert to an individual policy when you leave the company or retire. Typically, a cancer survivor can obtain coverage for about a year under a converted policy. Premiums for individual policies, however, may be considerably higher and less comprehensive. You may want to check around with different companies for the best coverage at the lowest rates because each may have a different system for assessing premiums.

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TIP: Look for work in a large company, whose group insurance plans rarely exclude employees with a history of illness.

If you are choosing a new plan, your health insurance coverage should include the following:

Benefits: Inpatient hospital care, physician services, laboratory and X-ray services, prenatal care, inpatient psychiatric care, outpatient services, and nursing home care. Prescription drug coverage may be important if you will be taking a medicine for a long time. Dental care may also be an important benefit to have prior to, and following, chemotherapy.

Financial protection: The insurer should pay at least 80 percent of the covered services, except for inpatient psychiatric care, which may require that the policyholder pay more than 20 percent of expenses. In addition, the insurer should pay at least $250,000 for catastrophic illness coverage, with the patient paying no more than 30 percent of his or her income toward these expenses.

Confirm conversations with insurance representatives in writing. If you think the representative is wrong, ask to speak with his/her supervisor. Consider filing an insurance complaint if you feel you have been treated unfairly. Address these questions and complaints to the following agencies:

- If your insurer is a private company (e.g., Blue Cross, Prudential), it is regulated by your state department of Insurance.

- If your insurer is a licensed health care service plan (e.g., Kaiser and other HMOs), it is regulated by your state department of insurance.

- If your insurer is a federal qualified Health Maintennance Organization, it is regulated by the U.S. Health Care Financing Administration, Office of Prepaid Health Care Operations and Oversight.

- If your insurer is a private employer or union self-insurance or a self-financed plan, it is regulated by the U.S. Department of Labor, Pension, & Welfare Benefits Administration.

- If your insurer is Medicaid (sometimes called other names; e.g., in California it's known as MediCal), it is regulated by your state department of social services or medical

If You Have No Insurance:

If you have no insurance, or if your health insurance does not cover specific health services you require, you may want to seek financial assistance. Resources to help you identify sources for financial aide include:

1. Local Groups

- Local cancer support organizations, which may provide referrals to community sources for financial aid.
- Your local office on aging, if you are an older adult.
- The county board of assistance or welfare office.

2. United States Government

- The U. S. Government has a number of programs designed to help people with low incomes or disabilities pay their bills. For information, call local offices of:
- Aid to Families with Dependent Children (AFDC) and Food Stamps Programs. Look for the numbers under the Local Government, Social Services, section of your telephone book.

- Medicare/Medicaid Information. Call your local Social Security Administration office to receive an explanation of the medical costs covered by these federal health insurance programs. Note: For people under age 65, Medicare coverage does not begin until two years from the date they are declared disabled.
- Social Security Administration. Call 1-800-772-1213 for general information on Social Security benefits you may be eligible to receive.
- The Department of Veterans Affairs. Request information about medical benefits for veterans and their dependents.
- The Cancer Information Service of the NCI.
  Call 1-800-4-CANCER to request information about drug companies with assistance programs for cancer patients.

Tab E

What to do if you dispute what the insurance says it will pay

(See *Getting Control*, page 11)

Confirm all conversations with insurance representatives in writing. If you think the representative is wrong, ask to speak with his/her supervisor. Consider filing an insurance complaint if you feel you have been treated unfairly. Address these questions and complaints to the following agencies:

- If your insurer is a privage company (e.g. Blue Cross, Prudential) or a licensed healthcare service plan (e.g. Kaiser and other HMOs) it is regulated by your state's Department of Insurance.
- If your insurer is a federal qualified Health Maintenance Organization it is regulated by the U.S. Health Care Financing Administration, Office of Prepaid Health Care Operations and Oversight.
- If your insurer is a private employer or union self-insurance or a self-financed plan, it is regulated by the U.S. Department of Labor, Pension & Welfare benefits Administration.
- If your insurer is Medicaid (sometimes called other names, e.g., in California it's known as MediCal) it is regulated by your state's Department of Social Services or Medical Assistance Services

- If your insurer is Medicare, or if your insurer is Supplemental Security Income, it is regulated by the U.S. Social Security Administration.
- If your insurer is Veterans Benefits or CHAMPUS it is regulated by the Department of Veterans Afairs, Veterans Assistance Services.

TAB F PAGE

Tab F Expense Logs for Deductibles

Date:	Type of expense:	Amount you Paid:

Tab F Expense Logs for Deductibles

Date:	Type of expense:	Amount you Paid:

Tab F Expense Logs for Deductibles

Date:	Type of expense:	Amount you Paid:

Tab F Expense Logs for Deductibles

Date:	Type of expense:	Amount you Paid:

Clear Plastic Sleeves to Store Tax-deductible Out-of-Pocket Expense Receipts

Tab F