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**GUIDE TO
COMPREHENSIVE
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TESTS & PROCEDURES

**COMPLEMENTARY /
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January 2006

from

The Duke Patient/Family Resource Center

The Duke Patient/Family Resource Center is:

- A lending library offering books, audio and video tapes, magazines and free brochures dealing with cancer and certain blood disorders and with issues of coping, survivorship, caregiving, and grieving
- Open 8:30 to 5:00 every day the Morris Clinics are open
- Located in the White Zone, first floor, of the Morris Cancer Clinic, Room 15123.
- Our phone number is 919-684-6955. Our email address is FamilyLibrary@mc.duke.edu



Resource Center Coordinator: [Harriet Whitehead, PhD](#)
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THE MEDICARE PRESCRIPTION DRUG BENEFIT (Medicare Part D)

The hardest part of this thing has been figuring out how to figure everything out
(senior quoted in news article)

It's happened already. Some seniors are already enrolled in a plan that gives them prescription drug discounts their parents never got to enjoy, all at federal expense. Others are still dithering on the sidelines, trying to decide which of the many available plans is right for them. They have until May 15, 2006 to enroll before their premiums start coming with a 1% add-on each month, a penalty for late enrollment.

Meanwhile, who knows what the future will hold. There are enough rumblings around the country and in Congress to suggest that the way the Medicare Prescription Drug Benefit, hereafter called "The Benefit," has been legislated is not very satisfactory and may have to be changed.

"Too confusing."

"A give-away to the drug companies."

"Totally unfunded. Where's the money going to come from?"

These were the initial rumblings. With the first wave of enrollees now reporting their experiences, new complaints have arisen, especially among lower-income enrollees who were promised help with their deductibles and co-pays but, in the first two weeks of the program, failed to get it.



But alongside the rather negative chorus there runs a steady drum roll of hopeful opportunism. The local newspapers, the government, the AARP, keep telling us: It *will* save you money, how bad can that be? Jump on it while it's there, it might get away. Sign up for some plan, any plan, you can always change later. Maybe an earlier generation got by without this, but now expensive drugs loom so large in the treatment of every illness, you have to insure yourself. And so on.

For those of you who are old enough and wanting to join this hopeful crowd, or for those of you who have a parent on Medicare who needs assistance with the decision, and lastly for those of you who have already jumped onto a plan or got your parent enrolled and are now wondering what you've gotten yourself into, we offer our admittedly very limited overview of how the thing works and how to go about getting enrolled.

The emphasis in this newsletter. We will concentrate here only on what is called the "stand alone prescription drug plan," or PDP. That is a plan that doesn't come as part of any other larger insurance package, other than Medicare itself. Except for suggesting useful websites at the end, we will concentrate only on advising people who are not eligible for financial help in meeting the premiums or deductibles. If you are a person with urgent financial concerns, with a very special medical situation, or with an already complicated insurance situation, we strongly advise you to consult one of the SHIP coordinators listed below. We ourselves are very grateful for the help of Lynne Chamblee, the SHIP coordinator at the Council for Senior Services in Durham, NC.

Preamble to an explanation. First of all, what's so confusing about "The Benefit"? Well, there is one wording ambiguity in most of the presentations that threw me off for a while, but other than that, the explanations I've read have not been written in a confusing way. The frequent complaint of confusion seems to stem primarily from the following features:

- The Benefit is designed in a way that makes you wonder: *Why? Why?* Why do you get coverage for part of your annual drug cost, then no coverage at all until you've spent several thousand, then suddenly fabulous coverage once again. This is the famous "donut hole" in coverage, or more politely, "coverage gap."



- Everyone tells you that you have to get on the internet to really do it right. Well, that takes 75% of us seniors out of the game right there. And even seniors who thought they were pretty handy with a computer have been emitting screams of frustration. The do-it-yourself on the internet approach is tough for internet reasons, not just for Benefit reasons. But relax, there are ways around this.



- Whether you go on the internet yourself or have someone else do it for you, you have to thread your way through several multi-step processes before you arrive at a good choice of plan. As you get close to the end, the information you must provide on what drugs you buy, what dosage, and how often, gets exquisitely detailed. Best to have all those little drug bottles lined up right in front of you as you sit down to begin. And you may be required to think very hard about which drugs you really want on your list and in what quantity. This is where many people bog down.
- The "plans" on which you are trying to decide are all run by private insurance providers and each state has its own list of plans. The more plans there are, the more difficult it is to make a choice. North Carolina has 39 plans, and North Carolinians can count themselves lucky. Floridians have to wade through 102 plans!
- Many of the same insurance providers who are offering stand alone prescription drug plans, have recently been aggressively marketing their own Medicare HMO or Fee-for-Service plans, often under names that resemble the names of the stand alone drug plans. In some cases, they set themselves up in pharmacies, recruiting seniors right there in the pharmacy. Seniors will enroll thinking that they now have prescription drug coverage when they don't. Seniors will enroll thinking that

now their doctors and hospitals are covered by the plan when they might not be.

- The reverse problem can happen as well. A senior might be already enrolled in a Medicare HMO, PPO, or Fee-for-Service plan which happens to cover drugs as well (some do). He or she then wanders into a pharmacy and gets sold a "stand alone" Benefit plan. If no one checks on this, his or her enrollment in the stand alone automatically cancels his or her membership in the Medicare HMO, PPO, or Fee-for-Service. Wonderful!

You can see that the project can be both daunting and slippery. But it might well be worth it. Here is a perspective to help get you started.

Putting it in perspective. It's useful to think of "The Benefit" as *catastrophic drug cost insurance*. The reason for this is the very generous coverage that you get once you've spent your way through the "donut hole." At this point, your Benefit plan starts picking up 95% of your drug costs. For a patient with an age-related chronic disease - a managed cancer, a heart condition, a diabetes with complications - this is huge. A post donut hole drug bill of \$50,000 would drop to \$2,500.

True, you have to spend your way through the beginning co-pays and deductible, then through the donut hole, and this would mean putting yourself out-of-pocket for \$3,600 every year. Then you add on the 5% copays thereafter, say the \$2,500 just cited. A yearly total of \$6,100 may still seem rough but it's a far cry from a yearly total of \$53,600.

If you're already in catastrophe land or have reason to believe you easily could be, "The Benefit" sounds like a no-brainer. There's no penalty for pre-existing conditions. Everyone over 65 is eligible. All you have to do is struggle through the enrollment experience.



But there is a gamble involved here. The plans differ as to which of the less common drugs they cover. And if no medical catastrophe has befallen you, you will have no idea which special drugs you will need when one does. The plan you've enrolled in just for that rainy day may not turn out to be the best one after all.

The decision will be easier for seniors who already take some expensive medicines and want some coverage for those. These seniors will be advised to enroll in the plan that best meets their current needs. There's no point in speculating about the future. If a much more expensive drug need should come down the pike in the

future and their plan refuses coverage, they will have to change plans, but they can do so without incurring the late penalties that befall seniors who never enrolled in any plan. In the meantime, they will have enjoyed some relief from their current drug expenses.

Seniors with few or no current drug expenses have a harder choice. Many will take the attitude that anything can happen at any time and jump on a plan, probably the cheapest they can find, just in case. (This is what I have done.) In every state except Arizona, there will be one plan at least with a monthly premium under \$20. In North Carolina there is one plan for \$13 per month (Humana).

But not everyone will want to go this route. Plenty of seniors will ponder those late charges and think, "I can hold out for another year. The late charges aren't that fearsome, and I'll save the money I would have to spend on premiums." There is also a good chance that the final deadline for enrollment before the late fees kick in - May 15 2006 - will have to be extended. The backlog of seniors needing help from advisors is huge. So there is time for thoughtful delaying tactics. However, if you let 2, 3, even 5 years slide past before you try to enroll, the 1% per month late fee on your premium will make you groan.

How to begin the search and enrollment process. The process may take a day or more to complete, so have some spare time. Have all your pill bottles and/or prescriptions lined up. If you are not able to use a computer, if you are unfamiliar with surfing the internet, if you are hearing or speech impaired, or simply if your mind wanders a lot, you will need the help of someone who does not have these limitations. A more able relative or friend will need to be available for usually more than one day to get the job completed. I will detail below what that person will have to go through to find you a plan.



If no friend or relative is available at the moment, there are designated contact people in every county who can give you an appointment with an advisor. Phone numbers are listed below. They will ask you to show up with a bag of all your pill bottles and a good part of the interview will involve determining what quantities you take and how often. Think about these questions as you collect your

pill bottles. They will also want to see your Medicare card and documents from any other insurance plan that may be covering your drug costs.

Lastly, many of the pharmacies, Walmart, CVS, Eckert, have reps on hand from many of the plans to help you through the procedure. Call the pharmacy of your choice and ask if there are Medicare Prescription Drug Benefit reps available to talk with you. If so, take the bag of pill bottles up there and sit down with one. Remember, he or she will be representing only one company, so you may have to be interviewed by several different reps before you find the plan of your dreams. Remember to emphasize that you want *a stand alone prescription drug plan*, not any of the other insurance packages his company may be selling.

Call these numbers for assistance with finding and enrollment.

The North Carolina Senior Health Insurance Information Program known as "SHIIP" provides the most comprehensive training for the volunteers that will be helping hundreds of seniors narrow down their lists of plans and do the enrollment for the plan of their choice. If you get an appointment with a SHIIP volunteer or a SHIIP coordinator, you can feel reasonably confident that they will steer you right. SHIIP assistance will be available up through May 15th 2006, and probably beyond. If not SHIIP, some local programs provide pharmacists to guide people through the selection process. These also are very desirable assistants. Here are some names and numbers.

For Durham County

Council for Senior Citizens
Lynne Chamblee (SHIIP coordinator)
919-688-8247
Lynne or a SHIIP volunteer will meet with you

Durham County Cooperative Extension Service
Deborah McGiffen (SHIIP coordinator)
919-560-0521
Deborah or a SHIIP volunteer will meet with you

Senior Pharm-Assist (serving their clients and the general public)
919-688-4772, ask for Gina Upchurch, Rebecca Keller, or Casey Kaufman

Lincoln Center (serving only Lincoln Center clients)
Dr. Jennifer Philips (pharmacist)
919-956-4540

For Orange County

Department of Aging

Katherine Leith (SHIIP coordinator)
919-868-2087
Katherine or a SHIIP volunteer will meet with you

UNC School of Pharmacy
Medication Management Program for Older Adults
Jena Ivey (SHIIP trained pharmacist)
919-843-2278

For Wake County

Resources for Seniors
Rhonda Townes
919-733-0111

For Chatham County

Council on Aging
Evelyn White or Jeannie Ellington will make the appointments,
then a SHIIP volunteer meets with you.
919-542-4512

Whether it is you manning the computer or another helpful person, here are the steps that person will follow to find you a plan that's most reasonable for you, given the list of pharmaceuticals you now commonly use.

The finding and the enrollment process. For an easy to follow version of the process described below, one that explores the question of financial assistance and enrollment in other drug insurance plans, please visit www.mymedicarematters.org and follow their "7 Simple Steps." Meanwhile, here is a preview of what you or your helper will wind up doing to locate the best stand alone plan (PDP) for you.

1. Get on the internet.
2. Go to www.medicare.gov.
3. Click on "Compare Medicare Prescription Drug Plans."
4. Under "Where would you like to begin?" click "Find a Medicare Prescription Drug Plan."
5. There are two choices at this point. One is the "personalized plan search," the other is a "general search." If you have any other drug coverage, or suspect that you have any other drug coverage (from your spouse, from a former employee, the government or a union), or if your income is quite low, click on the "personalized plan search." Drug plan reps or other professional advisors will automatically do this for you. You will have to provide information that includes your Medicare claim number and any documents you have regarding the other insurance that might already cover you. The result of following these steps is that you may be told that some other program is

better for you than the “stand alone prescription drug benefit.” You will be provided with the details. It may be that your current coverage is already fabulous and you shouldn’t change it.

6. If you already know for a fact that you are not low income enough to qualify for special help, and that you are not already covered for drugs by some other plan, just skip to the “general search.”
7. Enter your zip code. Notice that once again they will ask you if you may have other insurance or be “eligible for additional help.” Answer “none of the above,” and “No” to these questions. Fill in your zip and hit Continue.
8. Select your county. Continue.
9. Now hit, “Choose a drug plan type.”
10. Now hit, “Search for Medicare Prescription Drug Plans.”
11. You now may hit “View Plan List”, peruse it and collect the 800 numbers of the various plans. You get the 800 number by clicking on the name of the plan. This will take you to a page that also allows you to check other details of the plan such as which pharmacies are in their network. When you are through, X out of that page, and you’ll be returned to the list of plans.
12. Alternately, before you view the plan list, you may decide to scroll down to where you can enter your drug information. If you think you’re unlikely to be able to enter all your drug information successfully, best to simply collect 800 numbers and start calling the ones that appear attractive to you in terms of monthly premiums, or deductibles. (This is what I did after a few failed attempts to enter my drug information appropriately). You will ultimately be connected to a plan rep who will enter all your drug information on the calculator that the reps are using right there at the plan. This will usually give you a more accurate picture of what your yearly costs will be. I have found the reps for the actual plans to be almost invariably polite, intelligent and helpful. Most importantly, if you are taking any of your medicines at less than or more than the most common rate, the rep will be able to enter the right rate into the calculator, and bring up your true annual costs. (I was not able to do this properly at Medicare.gov, but I may have given up too easily.)
13. When you click on a plan name to find the 800 number for a plan, you will also find a link on the page leading you to a list of the pharmacies in your area that honor the plan. Usually more pharmacies honor than are listed there, and as time goes by more and more will honor, depending on how popular this plan becomes. Or, if you find the little place where you can specify the number of miles you’re willing to drive to get to a pharmacy, and increase that radius, you will find more pharmacies listed. All of the plans I tried were honored by at least Walmart, CVS and Eckerd. If you have a super favorite pharmacy that does not honor the plan you want, you may be

- able to contact them, request that they fill out the paper work for your plan, and have the plan will put them on their network.
14. Ask each plan you call whether they have a mail order delivery that would be cheaper than picking up the medicines at the pharmacy. If so, consider this option.

Your ideal plan should have the following features.

- **IT SHOULD COVER ALL YOUR DRUGS.**

Different plans have different “formularies”, i.e. catalogs of drugs that they routinely cover. If one or more of your important drugs are missing from the plan’s formulary, it’s usually best to drop that plan from your list of choices. However, if the plan has other features that are quite attractive, and/or if the non-covered drug is either quite cheap or relatively unimportant in your life, you might give the plan a chance.



- **OTHER THINGS BEING EQUAL, IT SHOULD HAVE THE LOWEST ANNUAL COST TO YOU OF ALL YOUR CHOICES.** This is why the complicated step of entering all your drug information accurately in the plan’s calculator is one of the most important parts of the whole procedure. If you do this haphazardly, or if your helper or your plan rep gets it wrong, the calculation becomes worthless. This is why our next section will deal with figuring out your drugs.
- **IT SHOULD BE HONORED BY A PHARMACY**

THAT IS EASY FOR YOU TO GET TO, or by mail order services if you live where packages are easily received. As noted above, you can sometimes make this happen by requesting that your chosen pharmacy get on the plan's network. But find out before you leap.

- YOU SHOULD FEEL COMFORTABLE THAT THE PLAN IS REPUTABLE and will not simply go out of business overnight. All the plans have typically been "approved by Medicare," in order to get on the state list, so presumably they all have a minimal level of reputability.

Figuring out your drug usage in order to get your real total annual cost.

The typical plan calculator will assume that if you take, say Lunesta®, to get to sleep, you'll be doing it every night and thus every month you will put in an order for 30 Lunesta®. That 360 Lunesta® every year. But who takes sleep aids that way? Answer: very few people. If you're taking one such pill only every 4th night, your intake will be only about 92 pills per year, or roughly a 3 month's supply. If you don't want your annual drug costs to be miscalculated badly, you'll have to make it clear to the person who is entering your information on the calculator that you are consuming your pills at this lower rate. The more expensive the drug, the more important that you get this right.

Another example: Suppose you prefer to take a 20 mg tablet of your acid controller in the morning and another 20 mg around suppertime, instead of taking one 40 mg tablet once a day. Make sure that the person entering the data doesn't just convert you to the 40 mg tablet without asking. Also make it clear that you're consuming the 20 mg tablets at twice the usual rate. (In general, I found the plan reps I talked to quite incurious about why I take my drugs in the dosages I do. No one said to me, "Honey, did your doctor prescribe it that way?" When I told one rep that I had an alternate source for a certain drug that was far cheaper than the plan's price, she never inquired, "What do you mean by an alternate source?" I conclude from this that you need not be shy in asserting what drugs you prefer and at what dosages.)



Another example: The plan reps and assistants will always recommend a generic version of your brand name drug if one exists. This saves you the time and energy involved in finding out the information for yourself. Saying Yes to these generics greatly lowers your annual drug costs. However, if you've already had a disappointing experience with the drug they are recommending, you can hold your ground and insist on the brand name drug.



Another example: Cancer patients on Medicare will need to understand the distinction between drugs covered under Medicare Part B, which are typically cancer drugs administered in a clinic, hospital or doctor's office; and cancer drugs that can be taken at home, which may or may not be covered under Part B. Separate these two lists, because if you have Part B, this is usually better coverage. Save Part D, "The Benefit", for all your other drugs. To help sort this out, visit the cancer patient oriented website given at the end of this segment, or consult with a SHIP advisor.

Another example: Many of the plans will give you your drugs more cheaply if you order a 90 supply by mail order. Inquire about this and see which of your drugs can be managed this way. The more you can do by mail order, the lower your yearly costs.

Real total annual cost. This is the figure you need from each plan in order to get yourself the best deal. This cost includes your premiums, your deductible and the portion of the drug bill that you will have to cover each year. *Each year the cost ball starts rolling all over again.* So you really don't need to know whether you're going to fall into "the donut hole" each year or not. You probably will. Anyone using at least one daily blockbuster brand name drug - Lipitor, Nexium, Plavix etc. - probably will. But all you need to know is that Plan A has this situation worked out a little better than Plans B, C and D. Plan A will then be your choice.

The one special case to watch out for concerns the one plan in North Carolina that provides coverage WITH NO DONUT HOLE. This is the Humana Complete Plan. The monthly premium for this plan is about double that of the other plans. Also your co-pays for the fancy brand name drugs will be higher than on some other plans. Nonetheless, if you regularly have yearly costs totaling \$3,600 or higher, call them up and have them put your drug list through their calculator. Even with the higher premiums and co-pays, Humana Complete may turn out to be your cheapest option.

A number of North Carolina plans - Aetna, Cigna, Unicare, Pacificare, Blue Cross/Blue Shield - will continue to discount your generic drugs for you, even after you've fallen into the donut hole. If you rely frequently on generics, this could make a difference for you. Note, however, that the monthly premiums on these plans are on the high side.

It's doubtful that you will need to compare more than half-a-dozen plans. Many of the plans have higher than average premiums for what seems to be worse coverage, so these can be put on the back burner and consulted only if the cheaper plans aren't covering one of your important drugs. If you have a complex drug list, there may be only one plan that covers everything you really really want. If a number of plans come up, try to winnow your list down to 4-5 plans, so you

don't wind up in a state of exhaustion over the whole process.

Once you have your winnowed list, either pick one and call up to enroll, or call them all back again and ask for their enrollment package. The SHIP assistants and pharmacy assistants who help you winnow your list are not allowed to tell you which plan to choose, so this step is on you!

GOOD HUNTING!

Useful websites.

North Carolina SHIP website giving contact persons in every county of North Carolina:

<http://www.ncdoi.com/Consumer/Ship/ShipVolCoordinators.asp>

For assessing how much help you can get if your income is limited, here is an easy to follow Powerpoint presentation.

<http://leahy.senate.gov/issues/medicare/lowincomemedicare3.html>

The wonderful website recommended above with the 7 simple steps.

<http://www.mymedicarematters.org/>

A website oriented to cancer patients:

http://www.cancer.org/docroot/MIT/MIT_3_1_Medicare_Part_D.asp

A word about ambiguous wording. I mentioned earlier that there was one area of wording that kept tripping me up in the presentations I read about the Benefit. This concerns your yearly costs and when you fall into the donut hole. Many websites explain that you fall into the hole when your drug costs for that year hit \$2,250. *True, if understood correctly.*

Your costs hit the magic \$2,250 when what you've paid PLUS what your plan has paid totals that figure. At that point, you personally will have forked over only \$750, while the plan will have forked over \$1,500. Then the coverage gap opens up, and you will have to personally spend \$2,850 more (for a total of \$3,600) before the catastrophic coverage sets in.

Confusingly, some websites will say that costs will have to build to \$5,100 before catastrophic coverage sets in. *True, if understood correctly.* Take the \$3,600 that you will have to personally spend, and add in that \$1,500 the plan has had to spend and you get \$5,100.

Just keep this firmly in mind: For any given year, you will have to spend no more than \$3,600 out of your own pocket to get to the catastrophic coverage. After that, the plan will pick up 95% of the subsequent drug bill.

AMAZON.COM REVIEWS OF OUR RECENT ACQUISITIONS



Before we order a new book for our library, we generally check the reviews of ordinary readers on Amazon.com. The editorial reviews at Amazon are useful too - they will give you an idea of whether the book is credible and responsibly put together. But readers from the general public give you responses that are much more from the gut. These responses are better predictors of whether the book will be popular with our own readership. Here are three examples.

My So-Called Normal Life
by Erin Zammett

First Reviewer: I had been following Erin Zammett's story in Glamour magazine since her diagnosis. Every three months I would look forward with anticipation and hope about her latest entry. Her writing style was so real, and she wore her emotions and feelings on her sleeve. She had nothing to hide from her readers. Cut to this summer, I was vacationing in Maui with my husband, right there, at our hotel was the girl from the pictures that I had read about for all these years. We spoke and she told me that she was on her honeymoon and that she was doing and feeling great. I told her that I loved her articles in Glamour. She then told me she had written a book. I quickly bought it, and didn't put it down til I had finished it. (I even tried to read while driving) This book is a must read. Erin is truly an inspiration to many people. Keep fighting and stay strong!

Second Reviewer: I was laughing & crying hysterical at the same time. I couldn't put it down and didn't want it to end. A fabulous easy read. Erin has a great outlook and is a very funny writer. I can't wait for her next book!

The Breast Reconstruction Guidebook, Second Edition
by Kathy Steligo

First Reveiwer: This was just what I needed, when I needed it. Kathy Steligo gives us her first hand experiences, adds quotes from other women who have been through the different procedures and combines it all with medical facts and figures to help the rest of us make sense of the confusing and often very scary reality of breast reconstruction. I'm sure her advice on handling insurance company issues is also keeping me from making mistakes that I would later regret financially!

This book has been tremendously helpful for both my decisions of prophylactic mastectomy and post-cancer treatment reconstruction.

Having breast cancer is not something any of us choose, but when we take what life deals us and use our experiences to educate others, that is truly noble. Thank you Kathy and all the women in your book, for having the courage to face cancer head on and the decency to help the rest of us by sharing your experiences and the knowledge you gained from your journeys past cancer, to reconstruction. I wish you all health and happiness.

Second Reviewer: All oncologists and plastic surgeons dealing with breast cancer patients should thank Ms. Steligo. She's just made their jobs a lot easier. This book gives an objective review of all reconstructive options, so women can make the decisions that are right for them. Every woman facing mastectomy should read this book, whether she's considering reconstruction or not.

**Help Me Live: 20 Things People with Cancer Want You to Know
by Lori Hope**

First Reviewer: In the past, when people around me had cancer I tried to be supportive, but really, I was a completely clueless moron, which I didn't realize until a few years ago when I went through cancer myself. If this book had been around earlier it would have helped me be a little less clueless. And if had been around when I had cancer I could have given it to my friends and family to help them understand better ways to be supportive, and to help them understand why I was going to have to hit the next person who told me I had to maintain a positive attitude!

The stories and the author's own experiences cover a wide range of reactions and ways of dealing with cancer. It's kind of like a cheat sheet for combatants and non-combatants alike. So whether you are a cancer patient or a survivor, or a spouse, parent, sibling, friend, co-worker, or acquaintance of someone who has been touched by cancer, I think you will find this a helpful book.

Second Reviewer: Thank you Lori Hope! This book couldn't have been published soon enough. It's a great read, and a great reference guide for all of us dealing with cancer. "Help Me Live," is a tool box brimming with words of compassion, wisdom and straight forward advice. I wish I had this guide to help me in the past. However, I'm grateful that this heartfelt book will serve me well, now and in the future.

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