

**SERVICES OFFERED****GUIDE TO  
COMPREHENSIVE  
CANCER CARE****PATIENT / FAMILY  
RESOURCE CENTER****SELF CARE GUIDES****TESTS & PROCEDURES****COMPLEMENTARY /  
ALTERNATIVE CARE****HOME**

## *In the Know*

### **Connecting Patient / Family Library Patrons To Information, Ideas and Resources**

**April 2004**

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](mailto:FamilyLibrary@mc.duke.edu)

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### **The Money Thing Dealing with the Costs of Cancer Treatment**

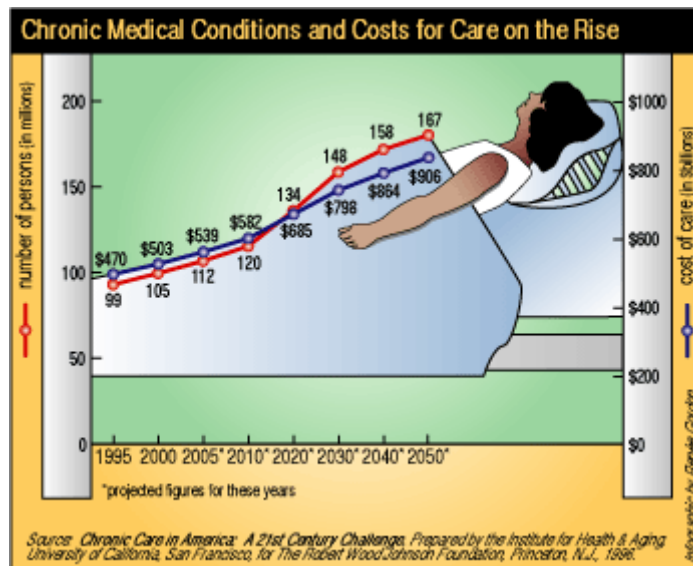


Perhaps the next worse thing to receiving a cancer diagnosis is receiving that first batch of medical bills and realizing that these may be just the beginning. The vision of being cured – finally - but destitute, flashes to mind. Or, worse, of being *sick* and destitute, or of leaving behind a destitute family, or ... but I needn't go on. If it's any consolation, the desperation that often sets in when a person faces catastrophic illness usually clears up in a short few months, and is replaced by a strategic indifference often summed up in phrases like, "I've learned not to sweat the small stuff."

As a patient, your object should be to get yourself to that no sweat point without losing your better judgment and making poor treatment decisions in the first hectic phase. The best advice I ever received, when facing lung surgery for a possible cancer, came from my health professional cousin who said, "Money should be the last thing on your mind at this point." I pass along her helpful words.

But don't stop reading.

Either you, the patient, or someone in your support network – a helpful family member or friend - will have to deal with the money thing sooner or later, probably sooner, and this issue of our newsletter is designed to help you, or them, get a handle. We have worked in consultation with Duke social workers, Renea McCann and Pam Reller; Duke Patient Resource Manager, Betty Watson; and with American Express Financial Advisor, Betty Nicholson, to put together these pointers.



**The money mine field.** We will start from the vantage point of working patients who are not yet eligible for Social Security and Medicare, as they are the ones juggling the most variables. Some notes on Medicare will appear near the end.

As treatment proceeds and the bills start pouring in, many pre-retirement cancer patients find themselves caught between the two pincers of inadequate insurance coverage and loss of income. More money is going out each month, because most people are at least slightly underinsured for catastrophic illness and because insurance companies will (in many cases, sadly) begin raising the premiums and/or finding ways to deny parts of the expected coverage. Meanwhile, less money may be coming in each month, because cancer patients are often unable to work for periods of time, and may even be let go. These two problems tangle together when your insurance coverage comes to you through your employer. How will you thread your way through?

**Different starting points, different paths.** There are essentially two paths to follow through this mine field, one if you are officially “poor” and the other if you are not. If you are officially poor, many state and federal social services open up to you, including Medicaid. Medicaid is a state run program and varies, in generosity, from state to state. I know that in North Carolina, a Medicaid patient usually has extensive medical coverage and will be eligible for a Medicaid bed in a skilled nursing facility if that becomes necessary.

The federal government defines where poverty starts, and the bad news is that it starts at quite a low level. The current rule of thumb is that you are in federal poverty if, as an individual, you have a monthly income of \$748 or less. For a couple, the sum is \$1,010; and for a family of four, \$1,533. There is a separate calculation regarding your “resources,” i.e. things you own other than straight income, but I am unable to provide you with a website for this estimate. Generally, *one*

house for a family and *one* car for every working person, is not included in the resource count.

The good news about these figures, or better news at any rate, is that many social services become available to people who are at 200% of the federal poverty level, or 150%, or 120%. There are some services – such as Temporary Assistance for Needy Families - that do not refer to the federal guidelines at all but use their own assessment procedures.

You can assess your federal situation for 2004 more precisely by going to the following website:

[http://www.workworld.org/wwwebhelp/poverty\\_guidelines\\_federal.htm](http://www.workworld.org/wwwebhelp/poverty_guidelines_federal.htm)

Click on "Current Guidelines."

If you find that you are officially poor, you will follow the social services pathway outlined below. If you are not, you will follow the financial strategizing pathway outlined below. If you are not YET officially poor, but may soon become so because of medical expenses, read up on both pathways since they are going to converge. Seniors on Medicare with limited means and other assistance issues should check out both pathways and the Medicare resources cited below, under Big Mama Medicare. Before we get to either pathway, however, there are certain things everyone should do.

### **Things Everyone Should Do**

Rich, poor, and anywhere in between, you can help yourself enormously by making certain arrangements.

1. Keep track of your medical “purchases” and insurance coverage in detail.
2. Get your insurance company to set you up with a case manager.
3. Set up a payment plan with your medical provider.
4. Discuss the situation with your employer and exploit all employee services. Ditto for your spouse’s employer if your insurance coverage comes from there.
5. Give relatives and concerned others a diplomatic way to help out.
6. Push the envelope on those bills; more things are negotiable than you think.



**Keeping track.** If you're the lucky, but rare person whose insurance coverage picks up every charge that comes down the pike, with AFLAC covering the co-pays, well, you might not need to do any keeping track. But if you're one of the underinsured majority, you'll open your first set of bills and EOB's ("explanation of benefits" from the insurance company) and collapse in confusion. The bills will show items you never heard of, even doctors you never heard of, but who have submitted their charge. The EOB will show that while the insurance company paid for X#\$!kl)!03, they want you to pay for 49K\*\*C2!4. It's all in code and even when it's in English, it will be none too clear.

It will be ever so handy, if, when calling up your provider and your insurance company for clarification, you had in hand some notes showing the dates of your medical visits and what you think happened during these visits. (This includes what you thought was going to be done to you under anesthesia.) All it takes is a simple pocket notebook, carried to every outpatient visit. As the nurse is drawing blood, count the number of vials she fills up and ask if each one is for a different test. They are? Then write down, "[X number of] blood tests," getting the name of each from her if she's chatty.

Keeping track becomes trickier when you are in the hospital, as you may be anesthetized, pain-medicated, or simply too ill to notice when various procedures are performed. Moreover, there are different billing systems that kick in, depending upon your medical condition. Nonetheless, you can avoid some misunderstandings if you have a relative or friend keep track of the exact time of admission and discharge and the hours or days spent in special, more expensive, facilities such as the recovery room, after surgery, or the Intensive Care Unit (ICU). Timing errors can add enormous sums to your bill.

Doctors aren't expected to provide patients with price information and many don't even know the prices of their procedures, but you can ask your doctor who else in the medical team will be submitting a charge in regard to your surgery (e.g. the anesthesiologist, the pathologist, other consultants). You can also ask for the full official title of a medical procedure, e.g. "radical prostatectomy," "bilateral salpingo-oophorectomy," and inquire at billing what the ballpark figure for that procedure is.

After several rounds of comparing your notes with the bills, the bills with the EOBs, and both with the answers you get when you call up for clarification, you will begin to get the hang of spotting questionable items. Mistakes are often small, but for some reason, they're never in your favor. And small things add up.

For an excellent little lesson on billing errors and how to get the jump on them, go to [http://www.thehealthpages.com/articles/ar-\\$hosp.html](http://www.thehealthpages.com/articles/ar-$hosp.html) (the source of my illustration above).

**The insurance case manager.** Most insurance companies will appoint you a case manager, at your request, if you are judged to be facing a catastrophic illness and there is reason to believe you will have many issues to discuss with them. Examples of issues to discuss are: payment for experimental treatments, miscommunications between the company and your medical providers, billing mysteries, and how to do appeals when coverage is denied. Having an established contact person who knows the details of your case can, if he/she is a good guy, save you hours of re-explaining and waiting on hold.



**The payment plan.** If you have a lot of liquid assets sloshing around, sure, you can pay as you go. But most people will need to stretch things out a bit. Maybe \$1,000 per month, maybe \$100, depending on your finances. If you're a Duke patient, call up Customer Service at 1-800-782-6945 and speak to a billing rep. This is the person with whom to negotiate a monthly payment plan that is right for you. Negotiate as strongly as you feel necessary to arrive at a realistic figure. As long as you are able to stick with your plan, you will avoid being dunned by a confusing assortment of collection agencies. If no plan seems realistic to you, request a "charity care" form from the billing rep, fill it out and submit it. Duke has discount plans for the truly needy.

The billing rep is also the person you speak to when you're waiting for an insurance adjustment, before paying the bill. There is often a gap between when the first version of the bill is due for payment and when the insurance company and the provider arrive at the second, and truer, version of the bill. One patient told me, "Let those bills cook down for a month or two before you pay." But you may not be given this month or two unless you insist each time.

**Your employer.** It's a scary moment, and you might want to wait until your medical situation has been fully spelled out to you, but sooner or later you must tell your employer what is going on. To try to continue working when intermittent illness causes missed days, late arrivals, and such, could put you in danger of being fired by an employer who might

have been sympathetic if he/she had understood the situation.

While employers in North Carolina technically have the right to fire at will, the legal environment isn't conducive to their readily doing so, especially in the case of sick persons with whom a jury would probably sympathize. Large employers, like Duke, IBM, and the state, seem – from the patients I've talked to – willing to bend over backwards to see a cancer patient through the crisis. Options include long medical leaves, reduction to part-time work, donations of leave time from other employees, and financial counseling. If your insurance comes through your employer, it is obviously important that you work something out. Even Wal-Mart, which is not known for its generous employee insurance plan, is rumored to try harder when one of their own faces a major illness.

The small employers, who are themselves more impacted by their employee's need for leave time or work load reduction, are the ones most apt to let you go just when the income is most needed. It is unlikely they have offered you insurance in the first place, so this would not be an issue. If you are looking at a situation like this, it would be a good time to read up on your rights under the Americans with Disabilities Act, (ADA). Their website for learning more is:

<http://www.usdoj.gov/crt/ada/adahom1.htm>

Look for the publication entitled "Questions and Answers: the ADA and Persons with HIV/AIDS" Many of the points in this publication apply to any job-threatening serious illness.

A patient and his/her caregivers may also be able to tap into their rights under the Family Medical Leave Act, which covers all federal employees. Websites to visit on this topic include:

<http://www.dol.gov/esa/whd/fmla/>

and

<http://www.opm.gov/oca/leave/HTML/fmlafac2.asp>

A third resource, both for insurance issues and job discrimination issues, is the Patient Advocate Foundation. Their number is 1-800-532-5274, and their website is: [www.patientadvocate.org](http://www.patientadvocate.org). They will mail out a pamphlet entitled, "First My Illness, Now Job Discrimination." We will have several copies of this in the Resource Center.

Lastly, those with any permanent disability, cancer-related or not, and who are now without a job yet still able to work in some capacity, might want to check out the Ticket to Work program, through their website at [http://www.ssa.gov/work/Ticket/ticket\\_info\\_BenAd.html](http://www.ssa.gov/work/Ticket/ticket_info_BenAd.html). Information on this program can also be obtained by calling 1-800-968-7842.

**Give others a way to help financially.** It can feel wrong to even close relatives to be flat out asked for money, and many patients are





embarrassed to even try. But if you're living on the financial edge and it's clear that people want to help, one way that can make it easier is to ask each person, or group, to commit to paying one of your bills, for a certain period of time. One can take the heating, another the lights, another the car insurance premiums. It makes sense to suggest this at the point shortly after the full seriousness of your diagnosis has rippled through your network. Ask too soon, before it becomes clear that this illness will be financially overwhelming, and you risk being accused of crying wolf. Wait too late and the helpful impulses may have receded.

A word to family members who may be reading this: patients can feel tremendously dispirited if they're told things like, "You spend your money first, then you can ask for ours." Nothing raises stress levels (and reduces survival chances) like feeling you're out there on your own in a time of failing health. Even modest financial assistance is psychologically uplifting.

**Don't be afraid to negotiate!** It's not just the payment plan at the doctor's office where this advice applies. How about your other bills? The rent, the mortgage, the utilities, the car payments, the childcare center, the credit cards. Often when creditors hear the word cancer, they soften enough to restructure your debts. It can't hurt to broach the subject.

In this same vein, when the insurance company denies coverage, don't hesitate to launch the appeals process, or to repeat it, if necessary. Each time, your appeal must be reviewed by a different team, and a later team may take a more generous view. To get some sense of where insurance companies tend to prove dilatory and what sort of legal language rings bells with them, a useful website is [www.AppealLettersOnline.com](http://www.AppealLettersOnline.com). There you can download a sample letter for each of three common situations. These are letters written from the point of view of your medical service provider rather than you, the claimant, but they are informative for either party. You might want to show the relevant one to your service provider.

### The Social Services Pathway



For anyone federally poor, or even close to that status, the Duke social worker is a key contact. He or she connects you to the array of services available through the North Carolina Dept. of Health and Human Services. (He or she will be able to look up the relevant agency if you

live out of state). The social worker connects you to Medicaid and/or Social Security Disability, food stamps, energy assistance, pharmacy assistance, housing assistance, child care, transportation, three months worth of cash assistance – whatever seems relevant to your case. It may be that other persons in your family are eligible for some sort of benefit because they have problems of their own, and financial relief on that front helps to take the stress off the family all around. Most Duke social workers also serve as individual and family counselors. It's nice to be able to talk to someone who knows who the other players in the family game are and how money fits into the picture. Every floor of the hospital has a social worker, and there will be a social worker on duty at the outpatient clinics. Just ask.

The North Carolina Dept. of Health and Human Services has a website at <http://www.dhhs.state.nc.us/>

If you live in Wake, Durham, Person or Orange counties, you can call the Dept. of Health and Human Services "Infolinc" line at 1-800-831-1754. Just state your needs and answer their questions about your situation. Even if not eligible for the types of services mentioned above, you may nonetheless get good advice on finding needed items such as wheelchair ramps, medical equipment, nursing homes or specialized rehab services and local support groups. It gives you a starting point.

Financially strapped cancer patients should also check out [www.cancercare.org](http://www.cancercare.org)

Or call 1-800-813-HOPE (4673). Or get your social worker or health professional to download their application form from their website at <http://www.cancercare.org/Files/OpenFile.cfm?id=8255>

Cancercare.org can link you to its own financial assistance programs. They cover such things as pharmaceutical needs, transportation, child care, home care, chemo and radiation needs. Some grants are geared toward specific cancers.

Lastly, read about Social Security Disability below.

### **The Financial Strategizing Pathway**



**Explore Social Security Disability.** At some enlightened point in U.S. history, it became established that the aging, who are no longer in the work force, need and deserve some sort of ongoing affordable health coverage. Medicare came into being, serving the retired population aged 65+ and supplementing the Social Security benefit. If someone who has achieved this official “senior” status should come down with cancer, or any other expensive illness, a lot of the financial load (though not all of it) is lifted.

But what about younger people who have become “functionally” senior i.e, no longer able to handle gainful employment and hit with mounting medical expenses, through no fault of their own but simply because a devastating illness – such as cancer – has intruded? Wouldn’t it be nice if one could hurry age 65 along and become an official senior, receiving a monthly social security benefit and Medicare?

One can. It’s called Social Security Disability and you don’t have to be federally poor to qualify for it. That’s why I put it first under the financial strategizing pathway. A social worker can help you explore this option. It does not hurt to apply as soon as one becomes no longer capable of the work one normally does. The clock starts ticking with your first application. If it takes three tries to finally get approved, as it sometimes does, the benefits check will arrive six months from the time of that first application. Twenty-four months on the benefit will have to pass before the Medicare part kicks in. Clumsy, but you get there eventually.

**Get a financial advisor.** If you’re not near the poverty level, get a financial advisor. It used to be only folks with over a million to spend ponied up for these services, but now, with reasonable annual fees, just about anyone can afford them. I’m extremely far below the million mark, but I have one – Betty Nicholson, from American Express Financial Advisors. Even as a well person, I was surprised at what a difference she has made in my financial life. Remember to shop around for an advisor. Ask trusted relatives or friends for referrals. Many advisors do not charge for their initial meeting. When you call an advisor, always ask for their fee schedule and get a written quote before you commit to their services. Here are some actions that are likely to be suggested:



1. Take a “snapshot” of where you are right now, financially. You may be able to work this out by yourself but it will be less stressful if you use the services of a more experienced friend, relative, or professional. At any rate, construct a list of your current assets and order them in terms of liquidity, i.e. How easy and/or practical they

would be to cash in. Now might be the time to convert underperforming mutual funds to more liquid, but still remunerative, investment vehicles, such as the stock index certificates that many brokerage houses sell. Now might be the time to sell the motorcycle or the speedboat. Amass a little war chest of liquid assets to face the onslaught of bills.

2. Do a cash flow summary to see what your annual expenses are – *all* of them. Don't overlook the eating out tab, yard-care tab, or all of those products and services you normally subscribe to. If pinched, ask yourself, Could I do with fewer cable channels? With fewer magazines and newspapers? With an answering machine instead of voice-mail? Little things add up.

3. Seek out low impact forms of debt, e.g. reverse mortgages if your house is paid off, or debt consolidation loans, to replace high impact forms, such as credit card debt.

4. Remember to incorporate all of your changes into your tax planning. Talk to your tax advisor to see what makes sense in your specific situation. Usually, high medical expenses will lead a person to itemize deductions, and there are other things that can be itemized while you're at it, e.g. interest paid, employee job expenses, charity.

5. Check your life insurance policy for permission to arrange a viatical settlement. Under such a settlement, you receive cash for a percentage of your policy's value. In some cases, the insurance company simply resells your policy to a speculator; in other cases, you can receive some cash without surrendering the policy. This is a plan to consider implementing when the end is not very far off. A useful book to consult beforehand is *Cash for the Final Days: A Financial Guide for the Terminally Ill and Their Advisors*, by Gloria Grening Wolk & Ralph Nader.

6. Get started on estate planning if this is a rapidly developing terminal illness.

One point, in all this, is to smooth out the impact of these looming large expenses. You don't want your future cash flow chart to look like the python that just swallowed a goat. No, you want it to look like a smooth, even python, albeit one that is larger in circumference. A slow and even liquidation of assets will also help you avoid tax hardships and allow some room for timing the market. The other point, of course, is to accomplish the financial planning you would want for your family if you become unable, or less able, to provide for them.

## **Big Mama Medicare**



During the time my father was undergoing treatment for prostate cancer, I remember looking at his Medicare EOBs and being tremendously soothed by the end of the statement where it would say, "Amount You Owe: 0." How often do we get to see that?

But then I read more closely. The doctor visit with tests might be charged at \$700. Medicare would have picked up \$275. Since my father owed nothing, what happened to the remaining \$425? It appears that the doctor, bless his heart, simply swallowed it. Well, doctors around the country seem to be growing tired of swallowing, and are starting to refuse Medicare patients. Seniors are finding themselves minus a doctor just at the time they need one most. Medicare has become, indeed, "Mediocre health insurance."

I cannot find any suggested solutions to this impending crisis, but it would seem wise to run out and buy supplemental insurance if you are still reasonably healthy and have not done so. If you are facing a cancer crisis, however, the rates for supplemental may rule out that option. Your financial advisor may be able to lay out some options for you.

While waiting for me to figure this out, you might benefit from visiting some excellent websites aimed at seniors and Medicare recipients. These are

**Medicare.** You can go to big mama herself at <http://www.medicare.gov/> The most useful thing I found here were up-to-date locators for physicians, medical suppliers, home health providers, and nursing homes in one's area. You can type in your city, or your zip, how many miles radius is acceptable, etc. These providers are said to all participate in the Medicare system, and I was reassured to find virtually every provider in the Durham area that I've heard of still listed.

**Elder Law Answers** at <http://www.elderlawanswers.com/>. This website will give you a crash course on Medicaid, Medicare, Social

Security, Social Security Insurance (different from plain Social Security and relevant to the disabled), Disability Planning, Long-term Care, Estate Planning, Nursing Homes, Retirement Living, and Medical Directives. It provides useful on-line calculators for resolving, for instance, how much of your spouse's nursing home bill can be transferred to the state if your income is at a certain level. There are links to discussion forums, state laws, pre-selected attorneys, and relevant breaking news.

**The National Committee to Preserve Social Security and Medicare** at [www.ncpssm.org](http://www.ncpssm.org) offers us a lovely resource - Mary Jane, an expert on the system who has been answering seniors' questions for 17 years. Click on the button on the left called "Ask Mary Jane." Complex tangles do not phase Mary Jane in the slightest. She can even tell you whom to call when your local Medicare office proves non-responsive to your repeated phone calls.

### **Resources in Our Collection**

- Cancer Survival Toolbox: Finding Ways to Pay for Care* (audiotape), occurs in a big kit with other useful audio advise, or as a single.
- Americans with Disabilities Act: Legal Protection for Cancer Patients against Employment Discrimination* (American Cancer Society brochure)
- Working It Out: Your Employment Rights as a Cancer Survivor* (National Coalition for Cancer Survivorship brochure)
- What Cancer Survivors Need to Know about Health Insurance* (NCCS brochure, very clearly written)
- The Activist Cancer Patient: How to Take Charge of Your Treatment*, by Beverly Zakarian (chapters on drug approval issues and managed care issues)
- Cash for the Final Days: A Financial Guide for the Terminally Ill and Their Advisors*, by Gloria Grening Wolk & Ralph Nader.
- Cancervive: the Challenge of Life After Cancer*, by Susan Nessim & Judith Ellis (chapters on insurance problems and employment issues)
- Coping with Workplace Issues* (videotape)
- The Complete Idiot's Guide to Managed Health Care*, by Sophie M. Korczyk and Hazel Witte

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