

**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

June 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

Resource Center Coordinator: [Harriet Whitehead, PhD](#)

Cancer Patient Education Program Director: [Kerry Harwood, RN, MSN](#)

Acknowledgments: The current issue has been put together with the assistance of Jennifer Gentry, RN, MSN, APRN BC-PM and Gwen Dodson, RN, MSN. I would also like to thank Dr. Linda Sutton, Assistant Clinical Professor, Medical Oncology, for past advice.

Contents: Planning for Life's End, Part 1: Advanced Directives



Planning for Life's End

A Tibetan story features a young man who meets the Buddha and is granted one request. The young man keeps it simple, he says, "I want you to warn me when I'm dying; I don't want to be caught by surprise." The Buddha agrees. Times passes and this young man matures. His beard grows, his voice deepens, his muscles fill out and the girls take an interest. Soon he marries.

Time passes. He acquires his own farm and becomes a father. He works hard, acquires more land and soon he is a respected householder in the community. Time passes. The man's hair becomes gray at the temples, his voice more gravelly. His oldest children are getting married and having babies. He is beginning to divide up his land with them. His muscles diminish, he develops a paunch. He requires reading glasses.

Time passes and passes and our man is eventually white-haired and shriveled. His voice has grown squeaky, his hands tremble. He is short-winded, sees poorly and barely hears at all. His grandchildren are now getting married. His farm holdings are completely in the hands of his descendants. One day, the man becomes ill and takes to his bed. In a matter of days he is dead and finds himself on the other side, facing the Buddha. "But, but..." he protests, "You promised you would warn me!"

The Buddha replies, "I've been warning you every day."

For Tibetan Buddhists, the moral of this story is that from the moment of birth we are dying. Life itself is a process of dying, visible – if we are watching – in every decade of our life. The deeper moral is that we are never watching! We are warned and warned but we manage to be caught by surprise nonetheless. When it comes to planning for dying, we mortals are perpetual procrastinators.

But there is a need for plans and a need for knowledge about the end, a need that is not always easy to meet. Doctors of cancer patients are usually the ones who are asked, "How long do I have? If I'm going to die, what should I expect? Are there some stages and signs? Will I wind up in the hospital on a lot of tubes?" Each one of these questions may require an involved explanation. The doctor who warms to the subject, waxing eloquent on cancer mortality statistics or varieties of collapse, may soon notice that instead of a comprehending response, he is seeing his patient's eyes glaze over with dread and despondency. Or she will have learned from experience that too many patients defy the prognosis and die later or earlier, harder or easier, than any of their doctors expected. Easier to back off the dire subject and accentuate whatever positive is still left. Modern medicine makes it easy to

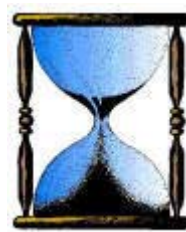
procrastinate. Virginia Morris, in her wonderful book, *Talking about Death Won't Kill You*, writes

Dying is a complicated affair that involves multiple shades of gray. As medicine has developed more weapons, more ways of battling disease and keeping people alive, and more ways of fighting disturbing side effects, the question of when to stop has become more and more confusing... As long as a treatment holds some hope of doing something, as long as one statistic seems favorable, as long as there is one example of someone who beats the odds, how does a person ever say no? How do you ever stop treatment? The fact is, most of us don't.(218,220)

Right. Most of us don't, and this is one reason so many of us will not be at home at the time of death, but in a medical setting with – yes – tubes. Also, as long as one is on treatment for one's cancer, it is all too easy to put off a lot of other decisions as well – wills, advance directives, reconciliations with relatives, the pets, the funeral, the unpaid bills. A tiring list to face while trying to enjoy those sweet remaining months.

I admire the sensible patients who start on their list early, when they still have their energy, and the brave doctors who are able to be blunt and say, "We're running out of options, get your affairs in order." But I suspect that I myself will not be a sensible patient and I probably won't select my doctor on the basis of bluntness. So let's start with a little self-forgiveness and move on from there.

If you've read this far, you're probably interested in the points we'll be covering in this newsletter and the next. In this issue we'll deal with (1) how do we judge how much time is left?, and (2) how do we avoid the "bad deaths" we hear about or have witnessed, the highly medicalized deaths in which the patient is swathed in tubing and miserable at the end? In our subsequent installment, we will concentrate on (3) the practical and emotional needs of the dying.



How much time is left. When the patient is quite close to death, there are distinct patterns. Hospice, which one hopes is on the case by then, will provide caregivers with a list of these. Or you can access this same information by going to:

<http://www.hospicepatients.org/hospic60.html>

To read an even more detailed explanation of this phase, visit

http://crossingthecreek.com/main_index.htm

The period of imminent dying can last from 24 hrs to two weeks. It is unrealistic to

expect that the dying person will be sufficiently aware of or sufficiently concerned about the issues of those who will survive him/ her to provide any meaningful input during this final phase. In other words, all the most important aspects of planning for life's end, including healing relationships, are best attempted well before this point, if that is possible. What we really need, then, is a list of signs that tell us when the patient is getting close to the end, but not as close as two weeks. He or she still has some good time left, time left in which to make arrangements, time left in which to heal relationships, time left in which to enjoy life's sweetness just a little bit longer. But no time left to procrastinate.

When is this? First, let's look at the larger context. When a solid tumor cancer has reached stage IV, it is, with the exception of testicular cancer and certain other quite rare cancers, considered incurable. With drugs and/or radiation, it may nevertheless be "managed" for a while, sometimes for a long while. The doctor can clarify this. The doctor can tell you whether your particular cancer is an aggressive sub-type and thus likely to move fast, or whether its apt to be rather indolent and easy to keep under control. Aggressive cancers usually give the patient less than 18 months. Less aggressive ones may stay under control for from 2 to 20 years. Cancers for which there are as yet no long-term management procedures often have to be lumped with the aggressives, though not invariably.

The non-solid cancers – leukemias and lymphomas – present more ambiguities and there may never be a clear point at which further treatment is considered futile. At the same time, serious crises can sometimes erupt even very early in treatment. It is easy to be caught short with one of these types of cancer. Thus, preliminary, "just-in-case" end of life planning might well begin upon hearing the diagnosis of leukemia/lymphoma or of any stage IV cancer. Whether solid or "liquid", if the cancer is an aggressive sub-type, planning should definitely begin. The more energy-demanding aspects of planning, such as constructing one's will, negotiating financial transactions, taking that longed-for trip, or trying to wrap up a life goal, are best tackled at the earliest point possible.

Remember: Planning does not push you closer to death. Planning does not preclude miracles. Planning *should not* brand a planner as the family pessimist. On the contrary, good planning may aid the battle by relieving patient stress and permitting better caregiver co-ordination.

With a manageable form of advanced cancer, where the time-to-death may be quite long, patients and caregivers must learn to deal with years of uncertainty. Dr. Joanne Lynn, who wrote the useful *Handbook for Mortals*, remarks that as times goes by it becomes very hard to decide whether one is still living with one's disease or now dying from it. There is a tendency to look for special "signs" that the terminal decline has begun. Each crisis – an infection, an unfamiliar pain or swelling, a sudden skin rash – can raise the question all over again: "Is this it?" But the crisis may well blow over, as have many in the past.

There is, in fact, a useful, though indirect way, to approach the problem of how much time is left. Dr. Linda Sutton, oncologist and a former medical director of Duke Hospice, counsels caregivers to avoid worrying about the particulars –

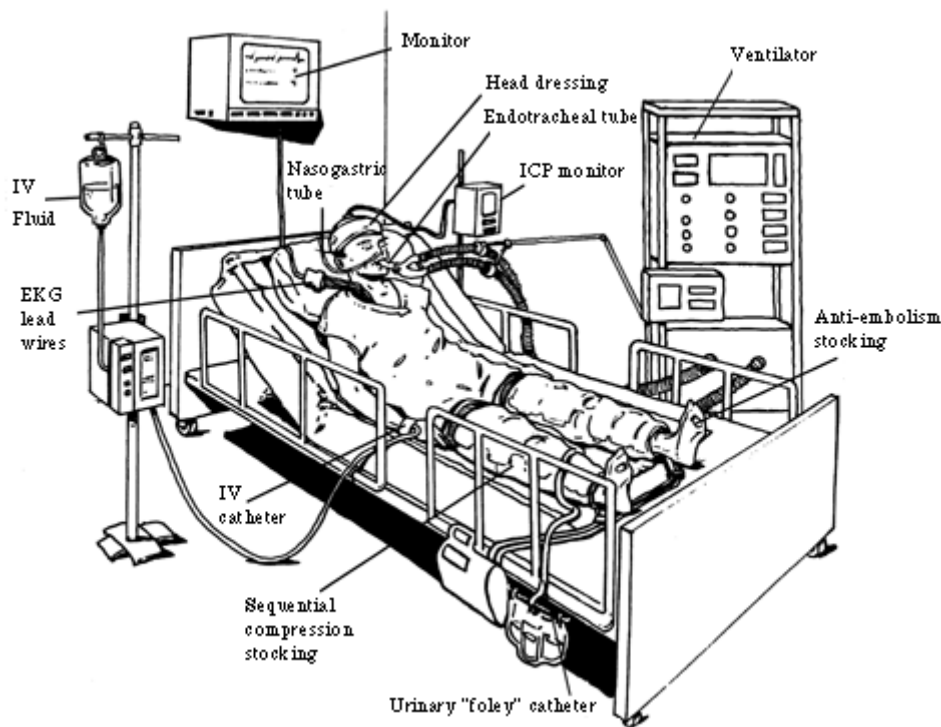
because these are the hardest to predict – and concentrate on the general, which is level of functioning. A patient whose cancer is worsening rather than improving will be gradually losing function. He or she is quite simply doing less and less of what he/she normally did in life. It's a bit like old age speeded up. Anywhere from 70% to 80% of function is lost in the last three months of life.

There will have been many ups and downs in functioning over the course of the months and years. Some have been treatment caused. Some have been treatment alleviated. Others involved infectious processes that the patient could overcome. But with progressive stage IV disease, the ups and downs sooner or later become downs and downs. Retreats to the couch become longer, work days have to be reduced to half-days, then to no days; the lawn doesn't get mowed any longer nor the car's oil changed; the patient often isn't answering the telephone and becomes tired if the visitor stays beyond an hour. The new treatment the doctor is trying just isn't kicking in or is proving too harsh for a weakened body. Scans show more and more disease. Weight loss, appetite loss, and weakness become quite apparent. There get to be more and more symptoms to manage. The patient requires more and more help. Visits to the ER increase as do hospital admissions. There is often an acceleration of crises toward the end. As one caregiver put it, "This disease began as a mist, deepened into a fog, and ended like a tornado."

While any one worsening can be questioned, if you were to keep a record over a few months of the time the patient spends "out of commission" in one way or another, you would see how things are trending. I'm told some doctors use the rule of thumb that when the patient is spending more than 50% of the daytime hours lying down, he/she is within three months of death.

Certainly any sustained downward trend should alert the caregivers that now is a good time to call those out-of-towners who've been delaying their visits, and to initiate any conversations that may have been procrastinated: the will, the advanced directives, the funeral plans. If the patient pulls out of the dive, fantastic! If not, everyone is prepared.

The over-medicalized non-natural death. The American ideal of the "good death" is to pass away quietly at home, surrounded by loved ones and not hooked up to any machinery. In fact, nowadays 80% of Americans die in a hospital or a nursing home, usually hooked up to at least one piece of equipment, typically an IV drip or an oxygen tank. And some patients who insisted on a death at home may wind up being rushed home by ambulance with no time left to get situated before death intervenes. It might be wisest, then, to relinquish at least part of the ideal and reconcile ourselves to a somewhat more "medicalized" image of the end. The presence and care of loved ones is not ruled out by this, and the patient's pain and breathing difficulties are better managed in a somewhat medicalized situation, such as under Hospice care. The question is, how "medicalized?"



Hooked up to a lot of tubes

(Copyright protected material used with permission of the authors and the University of Iowa's Virtual Hospital, www.vh.org.)

Each patient's preference is a little different on this issue, and each end-of-life scenario plays out with somewhat different last minute particulars, so it will be hard to establish general rules. What I will do here is give you a range of particulars to examine, and link you to more extended discussions elsewhere, the goal being to enrich your understanding of what might and what might not be desirable in end-of-life care. We begin by itemizing the most commonly dreaded pieces of "machinery" that make up "life support."

1. The ventilator (or respirator). This is the machine that pumps air into failing lungs and requires that a tube be installed in the patient's windpipe. Here is Virginia Morris's account of the issues involved.

Machines are not nearly as efficient as working bodies, and being on a ventilator is not the same thing as breathing. The tube is irritating, and the sensation of having air forced into one's lungs is uncomfortable. Also, the ventilator itself is only the beginning. Usually patients who are on a ventilator cannot eat or drink, so they must receive nutrition and hydration artificially, which means more tubes, discomfort, and possible complications. They typically cannot speak. They have to receive medications by tubes. They almost always need a catheter, which is inserted into the bladder. These patients are also under tight medical surveillance; their heart rate, blood pressure, and other vital signs are monitored vigilantly. Because they cannot cough, secretions must be sucked up regularly and the lungs monitored, for there is the possibility of developing an infection. They often have their wrists tied down so they won't dislodge any tubes. And they are typically given sedatives and muscle relaxants to ease the discomfort, so they are not fully alert, if they are alert at all. It's not a pretty scene. (133)

2. The feeding tube. There are two types. One is threaded through the patient's nose and down her throat. A second type is surgically inserted through the abdomen. They provide a way to nourish when the patient cannot swallow.

Both can be irritating or bothersome and thus must be defended against dislodgement. Either can produce a reflux that the patient then aspirates bringing on an aspiration pneumonia crisis. Both can become the source of local infection. Here is a link to recent studies that spell out the issues regarding feeding tubes, concluding that they are inappropriate for the dying. http://www.ncmedsoc.org/non_members/longterm_feedingtube_physician.pdf

A shorter version of the study is available at

<http://www.mywhatever.com/cifwriter/library/eperc/fastfact/ff84.html>

A description of how the nasal feeding tube is placed can be found at

http://www.rad.bgsu.edu/patienteduc/feed_tube_placemnt.htm



Nasal feeding tube (from website above)

3. The rectal tube. Yes, indeed, there is such a thing, though it's use is not common. It may be applied if chronic diarrhea, in a disabled patient, is causing skin erosions. This is a palliative function and must be considered seriously, but it does constitute one more thing to defend against dislodgement.
4. The IV drip for hydration, minimal nutrition (glucose) and medication. Another tube, but one quite essential to palliation.
5. The oxygen cannula or mask with it's tube leading to the oxygen source. The cannula wraps under the jaw and around the ears and inserts at the openings of the nostrils. If poorly fitted the cannula can be quite uncomfortable, while a mask directly interferes with eating, drinking, and speaking. Over a period of months, oxygen blowing into the nostrils through a cannula can erode holes in the nasal septum, and oxygen from any source eventually causes a fibrosis of the lungs. On the other hand, struggling for breath is one of the most distressing symptoms a patient can experience, and most patients and families will opt for oxygen support when the need becomes apparent.



Nasal cannula

6. Pain medication pump. When pain is very severe, the patient may be outfitted with a little pump that attaches to an inserted line going into the veins. The pump may be worn on a belt, if the patient is ambulatory, or positioned near where the patient is lying. The press of a button delivers a metered dose of the drug and sets off a timer that prevents further presses from working for a set number of minutes. An excellent palliative tool. (Check the rules on whether a particular type of pump can be legally used at home).

We have now listed 6 things that can be tethering the patient to the bed and constricting him or her to primarily one lying position. (There are yet more, but the rest are a good deal rarer). Excessive medical tethering often renders it impossible for loved ones to be physically affectionate with or even to touch, the dying patient, or for the patient to express his or her wishes. The final element in the non-natural death scenario is to have medical teams rushing to resuscitate a dying patient whose organs are trying to shut down. This is often the image conjured up when people speak of death without dignity.

The advanced directives. One is advised to use “advanced directives” to control what will happen to the patient, medically, as the end draws near. There are three principle ones.

1. The DNR (“Do Not Attempt Resuscitation”) order is placed in the chart of an hospitalized patient, or carried by patient and family on visits to the emergency room. This directive is usually available on every floor of a hospital as well as in emergency rooms. What the unmodified DNR prevents is *only* cardiopulmonary resuscitation (CPR). It does not prevent emergency care if the patient is found to be rapidly deteriorating from some other cause, e.g. hemorrhaging, choking, spiking a fever, etc. If it is a hospitalized patient’s sincere wish that other lethal conditions be allowed to go untreated, he/she or his/her health agent must make this clear to the medical team and modifications can be made to the DNR. (The most frequently mentioned modification of this sort is that a patient with advanced dementia not be treated for pneumonia.) It should be noted that the majority of patients who experience cardiac arrest in the hospital have a heart condition already. It is also the case that on average only 17% of those resuscitated from an arrest will survive to be discharged.
2. The Durable Power of Attorney for Health Care is a form that designates a particular person to be the patient’s health agent and make medical decisions for a patient should the patient be unable to communicate his/her wishes. You may designate more than one person, with a signed form for each one. Some forms include extra lines for extra designees. *This form is not the regular power of attorney and does not give the designated party power over the patient’s financial affairs.* The signing must be certified by a Notary Public.

3. The “Living Will” or “Declaration of Desire for a Natural Death.” This is the form that requests “no extraordinary means” if the signer is either “incurable and terminal,” or in “a persistent vegetative state.” This signing must also be notarized.

The last two forms, specific to your state of residence, can be downloaded from the internet by going to

<http://www.partnershipforcaring.org/HomePage/>

and following their directions. They are also available on every floor of the hospital at Duke as well as in many of the Duke clinics. You might want to pick up an example, while you are visiting, to take home and ponder.

Making intelligent use of advanced directives. It takes some careful thinking and discussions with all concerned to decide how best to use the directives to shape one’s end-of-life medical care. The Living Will says, “use no extraordinary means,” but what is an extraordinary mean and when should one forgo it? When is the patient actually “terminal?” Should the ventilator – which tends to top the list of unwanted medical devices – be always taboo, or are there some circumstances under which one might want to resort to it temporarily? Should transfusions be added to the list of extraordinary means? How about emergency surgery for bowel obstruction?

It is always best when the patient gives his or her care-providers and family members some general guidelines. Examples might be,

A. “Don't let me die if there's a decent chance I could be restored to my previous state and live on for at least [specify a time period] longer. If it means being temporarily hooked up to machines, that's OK. But if I wind up stuck indefinitely on life support and can no longer communicate with others, I would prefer to have the life support withdrawn.”

B. “I want above all to die at home with my family around me. But I would like to have medical care to prevent pain and suffering as much as feasible. “

C. One AIDS patient, cited by Virginia Morris, wrote: “ I am committed to endure any treatment that can reasonably be expected to permit me to live a life in which I retain my personality and my ability to contribute in some way to the world around me. Don't keep me in a painful or vegetable state, or in a state with no reasonable hope of recovery to a productive lifestyle. I must be able to be more than a patient who is entirely dependent, in a sustained unconscious state, or devoid of the capacities for meaningful human interaction, thought, or feeling.” It was this paragraph that guided his family to refuse further antibiotic treatment once brain infection had destroyed his sight, his hearing, and his ability to speak.

A second consideration concerns the Health Care Power of Attorney. The designated person may be called upon to make a very tough decision, so it might not be the best idea to entrust this position to an overly emotional or a dithering sort of person, even if that person is close kin. Sometimes a trusted family friend, especially one who communicates well with medical people, is a better choice than

a family member.

Use of the Duke Palliative Program. Should you or your declining loved one be hospitalized at Duke, an excellent option becomes available, which is to have a consultation with the Palliative Care Program. Besides adding new dimensions to symptom management, the palliative teams hold conferences with families and care-providers to assist patients, families, and care-providers when there are difficult decisions to be made or complex symptoms to manage. Understanding and establishing treatment goals and help with advance directives are included in this service. The attending physician must be asked to put in a request for the Palliative Care Program.



Hospice nurse with patient. Courtesy of Wuesthoff Health System and Brenda Spakes.

Use of Hospice. Hospice is the preeminent program for palliation and assistance at the end of life. The service is typically covered by your insurance or Medicare. Hospice nurses visit the home – or nursing home - as appropriate and are on-call 24/7. Typically a hospital bed is brought for the patient and any further equipment necessary for comfort and care, e.g. oxygen equipment, a lift chair if the patient wants time out of bed but has trouble rising, all necessary medications. Social workers are available to handle family concerns and a chaplain is on call as well, if the patient or family request this service. Several of the local Hospices have an in-patient facility where a person may be brought to manage a pain crisis or a temporary gap in caregiver support. With these wonderful services available, one is left wondering why the average patient comes to Hospice only in the final month of life.

Probably the main reason is psychological. Hospice must be ordered by one's doctor. The doctor, by writing for Hospice, is in effect announcing to all concerned that he/she feels the patient has no more than six months to live. This is a tough barrier for doctors to cross and many procrastinate bringing the subject up. Patient and family members often do not want to raise the jarring subject either, so things drift along. Even once Hospice has been called, families may balk at finding they can no longer call 911 in an emergency, but must call the Hospice nurse instead. Hospice takes over all medication as well, usually counseling the patient to give up

preventive prescriptions such as blood pressure and cholesterol medication, since after all... In other words, the Hospice decision looms as the most fateful (“fatal?”) of any the patient and family can make. And yet one of the most common reactions, once Hospice has come and done its work, is tearful gratitude and regret that the decision had not been made earlier.

How to get around this impasse? When symptoms are getting out of control, when the patient is needing more and more help, when you seem to be racing from crisis to crisis, what about saying to yourself, the patient or family, “Let’s go on Hospice *for the time being?*” Most Hospices are not averse to dealing with a conditional situation as long as it falls within the medical guidelines. Hospices can and do discharge some patients from the service when a good reason for doing so comes along. Dr. Linda Sutton used to tell patients, “If they come up with a new treatment for your cancer, we’ll gladly drive you to the doctor!” You are not trapped.

Summarizing. In cases of either highly unpredictable cancer or advanced and worsening cancer, a knowledge of end-of-life options and planning oriented to these options can take a burden off both patient and caregivers. This planning can sometimes be tearful, but it will set in motion processes that ultimately soften and make endurable those final days. In the words of Virginia Morris,

Imagining the dreaded dragon is not simply an exercise in tears; it prepares us. It forces us to imagine the unimaginable – what would we do, how would we act – and it starts us on an interesting grieving process that is sad but also wonderful. Wonderful because we wake up in the morning and can seek out the beloved person we’ve imagined losing, spend time together, hug, laugh and play. Hallelujah. We still have time together. (105)

Recommended Books in Our Collection

Talking about Death Won't Kill You by Virginia Morris. A sensitive close-up look at end-of-life decisions that urges readers to "reclaim the forgotten art of dying well." Especially good on communication issues and why we procrastinate planning. Graphically down-to-earth about medical procedures. Many and varied case examples.

Handbook for Mortals: Guidance for People Facing Serious Illness by Joanne Lynn and Joan Harrold. A wide-ranging look at the issues surrounding serious, probably fatal, illness. These cover coping with uncertainty, organizing support, managing symptoms, what to expect as the disease progresses, advanced directives, making difficult medical decisions, and grieving.

Dying Well: Peace and Possibilities at the End of Life by Ira Byrock
A beautiful series of portraits of Hospice patients and their end of life concerns.

Ready to Live, Prepared to Die by Amy Harwell. An inspired, faith-based self-portrait of cancer survivorship and sensible how-to book on living a foreshortened life to its fullest.

Living with the End in Mind by Erin Tierney Kramp and Douglas H. Kramp
The young parents of a young child faced the wife, Erin's, terminal illness by extensive thoughtful planning and reflection on their goals and the future needs of their child. The result, contained in this book, is an ambitious "checklist" that the reader is invited to make use of for his or her own situation. While some may find the list as a whole too daunting, there are nuggets in it for everybody.

How We Die: Reflections on Life's Final Chapter by Sherwin B. Nuland
A well-written doctor's-eye-view of the dying process in different forms of illness, including cancer. An excellent chapter on "Hope and the Cancer Patient." His cancer examples are too limited, however, to give the reader a reasonable understanding of how things might proceed in his or her own situation.

[home](#) • [contact](#) • [site map](#) • [search](#)
[Duke University](#) • [Duke University Health System](#)
[Privacy Notice](#)
webmaster@canctr.mc.duke.edu



Designated by the National Cancer Institute