Family Practice Grand Rounds

Terminal Care

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DR. JON STERNBURG (Assistant Professor of Family Medicine): The subject for today's Grand Rounds is terminal care. We are concerned with how we care for patients who are dying, and we want to address several specific aspects of this special care. We would like to share our personal involvement with two patients and to encourage you to discuss your own concerns and experience.

DR. WILLIAM SCHEIBEL (Assistant Professor of Family Medicine): Close attention to details in caring for a terminally ill patient may make the difference between a very peaceful death or a very traumatic one, as will be demonstrated by a following case history.

DR. STERNBURG: We would like to come up with specific strategies that can be employed in caring for patients. Two case histories will be used to help illustrate some important points. Mr. A. was a 74-year-old retired dairy farmer who first presented to the Family Practice Clinic in 1979, and several months later he was diagnosed as having adenocarcinoma of the stomach. Subsequently, he developed primary hepatoma, a cancer that was unrelated to the cancer of the stomach. Ultimately, he went into hepatorenal failure from his cancer and died in the hospital 18 months after the diagnosis.

DR. SCHEIBEL: Mr. B. was a 55-year-old white machinist who was diagnosed with small cell carcinoma of the lung in October of 1980. He had a long course of chemotherapy and died seven months later. I will give more details as we go through the presentation.

DR. STERNBURG: I would like to list the is-

sues for discussion, starting with the diagnosis. How should a physician tell a patient he has a terminal illness?

DR. LYNN PHELPS (Director, Family Practice Residency Program): Ordinarily the patient has a pretty good idea what to expect. There is a biopsy, an x-ray reading, or something that is going to settle the diagnosis. So, the patient is anticipating the diagnosis and sometimes the physician doesn't have to say much beyond confirming the patient's suspicion. But that does not mean you should walk in and say, "You have cancer; you are going to die in two weeks." The patient needs to be given some hope along with the diagnosis. The old method, of course, was to try to keep the diagnosis from the patient; tell the relatives, but don't tell the patient because he can't handle it.

DR. MARC HANSEN (Professor of Family Medicine): It is important to be sure what questions are being asked, which may be quite different from what you would expect. After confirming the diagnosis, you can continue to get information about what the patient really wants to know. For example, the patient may be worrying about what is going to become of his family, or if dying is going to be painful. The physician has to identify and deal with these kinds of questions.

DR. BALDWIN LLOYD (Associate Professor of Family Medicine): Each person has a different appreciation of what he or she is experiencing, and you cannot generalize about how you break the news of a terminal illness to the patient. The better you know a patient, the easier it is to sit down with him and tell him what will happen.¹ Before embarking on definitive studies, most patients will tell you they want to know what is going on, they want to be told.

DR. STERNBURG: What if they don't let you know, or what if you are not sure? In the case of

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Mr. A., I thought he wanted somebody who would be honest with him, but I didn't have a clear sense of how detailed he wanted me to be.

DR. LLOYD: He obviously had some pretty worrisome symptoms by the time you made that diagnosis, so I would begin by giving him a differential diagnosis that would include cancer and see how he reacts.

DR. HANSEN: It is important to decide who is to perform this task. Often a surgeon or someone who has done a procedure that leads to the diagnosis feels obligated to tell the patient what is happening, which may not benefit the patient, since that person would probably know the patient less well than would his family physician. Such a discussion needs to be coordinated among the physicians.

DR. STERNBURG: So, one physician caring for the patient should give the diagnosis.

DR. HANSEN: Yes, or at least there ought to be a plan of how to give the diagnosis and who is going to do it.

DR. LLOYD: I hear criticisms from patients, their relatives, and patients in the adjoining hospital bed about physicians coming in and saying very bluntly, "Well, you have cancer," and leave it at that. It takes a certain amount of finesse to sit down and establish rapport with a patient before giving such a diagnosis. One should avoid just blurting something out; that action indicates the physician's discomfort more than anything else.

MS. BERNIE TREICHEL (Nurse Practitioner, Department of Family Medicine and Practice): Hearing an unfavorable diagnosis is highly anxiety evoking for the physician and the patient. After saying "cancer," time is needed for the patient to assimilate its meaning. Patient responses may be influenced by their past experiences of friends or family members with similar diagnoses, their fatigue from diagnostic tests, and their perception of future well-being and function. This is a time for considerable support.

DR. KAREN PRIDHAM (Associate Professor of Family Medicine and Nursing): If you tell the patient alone, how that patient tells other people may present a real dilemma. The patient, for instance, may feel comfortable knowing he has cancer, but he may feel that his wife or family may not feel comfortable knowing.

DR. SCHEIBEL: I think Mr. B. illustrated several of these points. He was hospitalized for increasing weakness and fatigue. Because he had spastic paralysis, which previously had been fairly stable, our initial consideration was a neurological disorder. But, because of a low serum sodium on an admission screening test, we also began considering other diagnoses. His clinical course was consistent with inappropriate antidiuretic hormone. There was a small area of the left lung field that appeared to be abnormal; however, we couldn't be sure what this vague density represented. On the sputa, testing for malignant cells. and the bronchoscopy, which was done subsequently, the diagnosis of the small cell carcinoma of the lung was made. Dr. Longenecker (secondyear family practice resident) did a very good job of first talking with the patient as soon as the pathology reports were back and then immediately bringing in the patient's wife to rediscuss the diagnosis with both of them present.

Once a patient is told he or she has cancer, little else that you say at that initial interview may get through to him. I think, therefore, it is important to arrange for frequent follow-up visits, especially in that initial period. Questions that come up can then be answered, and close contact can be maintained with the family, who will have a great number of questions as well.

MR. JIM McGLOIN (*Psychologist*, *Department of Family Medicine and Practice*): Preparation for the interview in which you give the diagnosis begins as you start the workup. You can then gauge the patient's level of anxiety along the way. For example, you can see whom he might like to have with him during that interview.

DR. SCHEIBEL: It is important that the primary care physician be the one to discuss the diagnosis with the patient. One convenient approach may be to have the initial interview with the patient and then expand the interview to include the other family members the patient wishes to have present during the discussion of the diagnosis.

DR. ADA FISCHER (Visiting family physician): I have found from clinical experience and personal experience, with the death of my mother and a brother recently diagnosed as having cancer, that people know what they have at the time of admission to the hospital. The physician's point of maximum impact is when the decision to admit the patient is made. I usually sit down with patients and go over their options and diagnoses. Cancer may be one of those options, and at that time it is Continued on page 998

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important to paint a picture of hope in case the diagnosis turns out to be cancer. I found this approach to be more useful in helping people than waiting until there is a final diagnosis, because on admission the patient identifies the worst possible thing that can go wrong and homes in on it. Neither my mother nor my brother really heard anything once the word cancer was said. Patients know, so acknowledging the possibility of cancer at the beginning of the workup is important.

Another point is whom to include when telling the diagnosis. Patients' families often say, "Don't tell the patient." I point out that I must tell the patient. My contract is with the patient, not with the family. There is always a reason why the family doesn't want the patient to be told. Often it is because they think they are protecting the patient. Their fears must be identified as well as the patient's because they have to help the patient work through this. Patients are often much stronger and more willing than their families to cope with what they have. I have never known a patient who did not know he had cancer. They know from early on.

DR. STERNBURG: Given the diagnosis, how does the physician relate to the patient's prognosis? Once the diagnosis sinks in, both patients and families want to know what it means, especially how long they are going to live. In fact, in the case of Mr. A., I was pressured to give a specific number of days because the family had to come a great distance to see him for the last time. My approach was not to make a guess, but rather to say, "I really don't know. I can't predict. Let's take it one day at a time and see what happens. It doesn't look good right now." As far as the family coming in, that's a tough decision the family will have to make.

DR. SCHEIBEL: The precise course of cancer cannot be predicted. Although you have an idea about prognosis by the type of cancer, it is best just to convey to the patient how serious it is and not to give a specific time limit, even though the family expects it. Television and other media portray people being told specifically how long somebody has to live, and many people think that physicians can do so. Families want to know in order to mobilize the rest of the family, especially when they are from out of state, to see the patient the weekend before he dies. Even the patients themselves will often ask. Dunphy has observed Continued on page 1000

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that higher socioeconomic class and personal aggressiveness correlate with an increased desire for knowledge of the disease process.² Patients may have business affairs to settle before their death. Such people try hardest to determine the length of time they have to live. One strategy to use with these people is to reverse the question and ask them how long they really would like to live. Not only does that direct the topic back to the patient, but it elicits what terminal patients want to accomplish in the immediate future. It is also a useful tool to help them reach their goals.

DR. FISCHER: Patients do not simply ask the question, "How long am I going to live?" That is merely what we hear. They want to know what the quality of life is going to be with this illness, for that will dictate what they are able to do and what they are going to accomplish. Another unstated portion of their question is. What can you offer me that will enhance the quality of my life? You have all these medications, but are they really going to make it possible for me to spend time doing the things that I want to do? Such questions direct you in dealing with the prognosis. If I have little to offer to patients, then I tell them that they will do well at home with their family. Most people have no experience of death at home; society fears dying. We don't want people to die on our couch or in the nursing home, so we shift them into the emergency room. The questions then are. When is he going to die? Is he going to die at home in my arms? Is he going to die where the children can see him? Physicians get around these real issues by giving only the prognosis.

DR. STERNBURG: This raises a critical issue: What are patients most afraid of when they are dying? Knowing their particular fears may help us individualize treatment plans to help them be less afraid. Certainly one of the specific fears patients have is pain; another, perhaps more important, is abandonment.^{2,3} What most impressed me about Mr. B. was that, when he came into the hospital, he was furious about a mistake on his name band. which indicated a physician other than myself taking care of him. He said, "This has got to be changed-it's got to say Dr. Sternburg." At first I thought it was unimportant, but he made an issue out of it and wanted to make sure that I was there, that I was going to be the one who attended to him. By just being available and seemingly not abandoning the patient, I was offering something. Subsequently, after running the gamut of noneffective chemotherapy with substantial side effects, he came in every week until his debilitation required home visits. These postchemotherapy visits were probably more important because he learned he would not be abandoned.

DR. PRIDHAM: I think a counterpoint of that is fear of abandoning others. Again, it depends on the stage of life. Leaving others can be devastating.

DR. STERNBURG: How would you address that?

DR. PRIDHAM: Well, it is necessary to help the patient identify the fear and define the resources available to his survivors to do what needs to be done.

DR. STERNBURG: That issue came up with Mr. A. and Mr. B. We talked about what was going to happen when Mr. A. died. He mentioned that the will was settled, he had chosen the pallbearers for his funeral, and the funeral home arrangements had been made. It was at this point, when in listing things it seemed as if there was nothing else left to do, he started crying.

Final details were well-arranged, and I think he was scared. We addressed the specific list of things to be done, what would happen to his wife and children when he was gone, and agreed to his wife getting medical care at the clinic after he died. I would attend not only to her grief, but also her other medical problems.

DR. FISCHER: My experience has taught me that people with terminal illnesses need to be told it is alright to die. Often, in spite of suffering and misery, they have a tremendous need to hold on for other people. It can be very hard for family members to let go; it was very hard for me to let go of my mother, I would have taken her anywhere or done anything. Finally, I worked through the grief process, realizing everybody deserves a rest and that I was trying to save myself. Even for physicians, death is a hard thing to deal with. Dying can be the most peaceful thing that happens to people.

DR. SCHEIBEL: That is a very good point. It is also a very difficult one for physicians to accept because for physicians death is equated with defeat. We have failed by not reversing the disease process in that patient. Equating death with defeat must be overcome to be able to be comfortable and effective in dealing with the terminally ill patient. Continued on page 1002

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Brief Summary: Before prescribing, please consult complete prescribing information, a summary of which follows:

Indications: IMODIUM is indicated for the control and symptomatic relief of acute nonspecific diarrhea and of chronic diarrhea associated with inflammatory bowel disease. IMODIUM is also indicated for reducing the volume of discharge from ileostomies.

Contraindications: IMODIUM is contraindicated in patients with known hypersensitivity to the drug and in those in whom constipation must be avoided.

Warnings: Antiperistaltic agents should not be used in acute diarrhea associated with organisms that penetrate the intestinal mucosa, e.g., enteroinvasive <u>E. coli, Salmonella, Shigella</u>, and in pseudomembranous colitis associated with broad-spectrum antibiotics.

Fluid and electrolyte depletion may occur in patients who have diarrhea. The use of IMODIUM does not preclude the administration of appropriate fluid and electrolyte therapy. In some patients with acute ulcerative colitis, agents which inhibit intestinal motility or delay intestinal transit time have been reported to induce toxic megacolon. IMODIUM therapy should be discontinued promptly if abdominal distention occurs or if other untoward symptoms develop in patients with acute ulcerative colitis.

Precautions: In acute diarrhea, if clinical improvement is not observed in 48 hours, the administration of IMODIUM should be discontinued. <u>Abuse and Dependence</u>: Physical dependence to IMODIUM in humans has not been observed. However, studies in monkeys demonstrated that loperamide hydrochloride at high doses produced symptoms of physical dependence of the morphine type.

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Nursing Mothers: It is not known whether IMODIUM is excreted in human milk. As a general rule, nursing should not be undertaken while a patient is on a drug since many drugs are excreted in human milk.

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If vomiting has not occurred, gastric lavage should be performed followed by administration of 100 gms of the activated charcoal slurry through the gastric tube. In the event of overdosage, patients should be monitored for signs of CNS depression for at least 24 hours. If CNS depression is observed, naloxone may be administered. If responsive to naloxone, vital signs must be monitored carefully for recurrence of symptoms of drug overdose for at least 24 hours after the last dose of naloxone.

In view of the prolonged action of loperamide and the short duration (one to three hours) of naloxone, the patient must be monitored closely and treated repeatedly with naloxone as indicated. Based on the fact that relatively little drug is excreted in urine, forced diuresis is not expected to be effective for IMODIUM overdosage.

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DR. STERNBURG: While attending Mr. A. in the hospital, I checked to see how comfortable he was and if his nursing care was good.^{3,4} I sat down on the bed with him, took his pulse, and touched him by lightly palpating his abdomen. That worked well because it gave him time to talk about whatever was on his mind. Although the regimen differs from care of the acutely ill, the time commitment is similar for a terminally ill patient as it is for a patient with pneumonia.

DR. SCHEIBEL: We were able to support Mr. B. at home because he had a very capable wife and he wanted to stay at home. Terminal patients need hope. In his case using chemotherapy helped to provide hope, and up to several days before his death, he still wanted chemotherapy. Patients may grasp at anything as a means of fighting for life, and they need a lot of support, especially upon withdrawing. For example, Mr. B. became so weak that he needed help to get out of bed, required a wheelchair and a commode at the bedside at home, and needed the services of visiting nurses. We attended very closely to his personal needs, especially because his wife was becoming fatigued. We made routine weekly house calls as well as extra visits for any acute problems such as edema of his legs, which required an urgent home visit because Mr. B. and his wife were very concerned about what the edema meant. He finally realized his condition was deteriorating when I arrived to help move him so that one of the Care Cabs could take him to the hospital for his chemotherapy. He had been bedridden for two weeks and could not maintain a sitting position. I returned the next day and spent almost an hour talking with him. Then he and his wife also had a very long talk.

DR. STERNBURG: It is hard for both the patient and the primary care physician when chemotherapy is not successful; everyone is enthusiastic when the oncologist can provide treatments and protocols. When treatment options are exhausted, however, the family physician must begin making final preparations. One of the final preparations is deciding whether to obtain an autopsy. Discussion of this should occur before the patient dies so that he can participate in the decision. When I made one of the house call visits, I sat down with Mr. A. and I said, "There is not much more I can do, but Continued on page 1005



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there is an option that is going to become available at some point and I would like your input. That is, when you die, should we perform an autopsy?" Before I could even start to explain, he said, "Give me the paper, I will sign it now." I said, "Wait a minute and let's discuss it," because I felt he did not know all the implications of what I was suggesting. I pointed out the opportunity for his family to learn the definitive nature of his illness and information that might be useful to the family in the future, and for physicians to be provided with a better understanding of the complicated nature of his illness. He was glad he could make a contribution by allowing an autopsy, and he and his wife then talked easily and enthusiastically, not only about the autopsy, but also about the funeral arrangements, his will, and other final plans. Without this participatory discussion, the decision would have been made after the death, and I believe the family would have denied it. This is a functional approach for the family as well as the patient.

DR. SCHEIBEL: It also seems to express indirectly and symbolically that it is all right for the patient to die. Approval came from you and his wife in this case.

DR. STERNBURG: Does anyone else have a different attitude or another way of approaching the topic?

DR. ANN GRUNWALD (Second-year family practice resident): It seems to me that the physician must know the patient very well in order to do that.

DR. STERNBURG: You are right. It is important to know your patients, not only to sit down and talk about an autopsy, but to talk about any problems in the family.

DR. WILLIAM SCHECKLER (Chairman, Department of Family Medicine and Practice): There are several potentially compounding variables that need to be considered concerning autopsy. First, a patient donates his or her body to the Medical School and an autopsy cannot be done. Second, in many protocols, not just for cancer but for other diseases, an autopsy is required. Therefore, the subject should be addressed early. Telling the patient that if he should die, we would like to do an autopsy to see what happened can be an effective means of making it understood to the patient and spouse beforehand. Autopsy should be discussed early to avoid uncertainty when a patient dies. Third, in a teaching hospital the primary physician has another physician on call for him. The house officer, who often doesn't know the family very well, may ask for the autopsy. The physician who knows the patient and the patient's family best, rather than the most junior physician on the service, should be the one who explains the reasons for autopsy.

DR. FISCHER: I have some problem with the concept of autopsies. In my culture, which is a black society, an autopsy is considered to be a desecration of the dead. It can be very difficult to get people to discuss autopsies or what you do with people once they are dead. Funerals are important events for many in the black society. I have a theory that they are important because many black people live through a long life with nothing, and the funeral is a time to go out in style. A movie called Imitation of Life shows that quite well. We need the autopsy to seek new information. I have never had a family refuse an autopsy of someone who had a rare disease or a disease that had implications for their children. Autopsies are, in some instances, a desecration of the dead. I don't request them unless I feel that they will enhance medical knowledge. Because of fiscal constraints in some states autopsies are not done unless there is foul play.

A final point about dying. I find often that patients are much more of a comfort to me when they are dying than I am to them. They say, "Well doctor, you have done all you can and it is time for the Lord to take over." That interests me.

DR. STERNBURG: I agree. I didn't mean to imply that an autopsy ought to be done because the patient died. It ought to be done for two reasons: for the family and for enhancing medical knowledge. In some communities, hospitals do offer an autopsy free of charge because of the accreditation incentive. You are right, we ought to be careful about how we use that incentive. My point was that we must plan ahead. One way to facilitate the process is to let the patient participate in that decision before the end.

DR. SCHECKLER: There are exceptions for not doing an autopsy. The patient may have had an operation prior to death or the patient's culture might dictate that autopsy is unacceptable.

DR. FISCHER: Another consideration in making final preparations is the expense of chemotherapy and other treatment. Terminal illness may

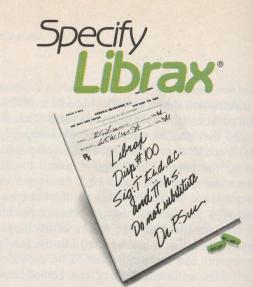
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drain the cash reserves of a family to the point of their having to sell possessions. Sometimes patients are unwilling to do this. Dignity is another important requirement. A patient may decide to refuse pain medicines because they "cloud the senses" or chemotherapy because it may cause hair loss.

DR. SCHEIBEL: Attending to details when you are expecting death is important. In the case of Mr. B., we had already discussed performing an autopsy and arranged to notify the university so that, when necessary, the autopsy would be done free of charge. One morning, Mr. B. very quietly died. Mrs. B. knew that he had just died and called the clinic answering service to notify us. She received an unexpected response. She was told to call the emergency medical service immediately, and the physician on call would meet her at the emergency room. Mrs. B. was in a state of shock and called the emergency medical service. On arrival, they tried to resuscitate Mr. B. and transported him to the hospital emergency room, where he was pronounced dead on arrival. Dr. McHenry (second-year family practice resident), who was called, knew it had been prearranged for Mr. B. to die at home. We thought Mrs. B. had panicked, but the real reason did not emerge until we had a conference with Mrs. B. We asked why she called the emergency medical service instead of contacting Dr. McHenry directly. Out came a flood of anger at the emergency medical service and the clinic answering service for having to watch the traumatic attempts to revive her dead husband when she knew there was no hope for his ever getting better. That provided us with a valuable learning experience.

DR. STERNBURG: That conference is also a time to present any findings from the autopsy or to talk about the death, as well as other things going on in the family, such as concerns about the wife being left alone or the availability of nursing services in the community. At our clinic we have nurse specialists, but a visiting nurse service, religious groups, or a hospice group might be helpful as well.

DR. SCHEIBEL: Because of the grieving process, the family will often have many questions they are not able to ask at the time of death. Several weeks later they are more likely to ask questions. Time helps put the whole thing into perspective. I have the impression that a follow-up Continued on page 1008



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Please consult complete prescribing information, a summary of which follows:

Indications: Based on a review of this drug by the National Academy of Sciences—National Research Council and/or other Information, FDA has classified the indications as follows:

"Possibly" effective: as adjunctive therapy in the treatment of peptic ulcer and in the treatment of the irritable bowel syndrome (irritable colon, spastic colon, mucous colitis) and acute enterocolitis.

Final classification of the less-than-effective indications requires further investigation.

Contraindications: Glaucoma; prostatic hypertrophy, benign bladder neck obstruction; hypersensitivity to chlordiazepoxide HCI and/or clidinium bromide.

Warnings: Caution patients about possible combined effects with alcohol and other CHS depressants, and against hazardous occupations requiring complete mental alertness (e.g., operating machinery, driving). Physical and psychological dependence rarely reported on recommended doses, but use caution in administering Librium[®] (chlordiazepoxide HCl/Roche) to known addiction-prone individuals or those who might increase dosage; withdrawal symptoms (including convulsions) reported following discontinuation of the drug.

Usage in Pregnancy: Use of minor tranquilizers during first trimester should almost always be avoided because of increased risk of congenital malformations as suggested in several studies. Consider possibility of pregnancy when instituting therapy. Advise patients to discuss therapy if they intend to or do become pregnant.

As with all anticholinergics, inhibition of lactation may occur. **Precautions:** In elderly and debilitated, limit dosage to smallest effective amount to preclude ataxia, oversedation, confusion (no more than 2 capsules/day initially; increase gradually as needed and tolerated). Though generally not recommended, if combination therapy with other psychotropics seems indicated, carefully consider pharmacology of agents, particularly potentiating drugs such as MAO inhibitors, phenothiazines. Observe usual precautions in presence of impaired renal or hepatic function. Paradoxical reactions reported in psychiatric patients. Employ usual precautions in treating anxiety states with evidence of impending depression; suicidal tendencies may be present and protective measures necessary. Variable effects on blood coagulation reported very rarely in patients receiving the drug and oral anticoaqulants; causal relationship not established.

Adverse Reactions: No side effects or manifestations not seen with either compound alone reported with Librax. When chiordiazepoxide HCI is used alone, drowsiness, ataxia, confusion may occur, especially in elderly and debilitated; avoidable in most cases by proper dosage adjustment, but also occasionally observed at lower dosage ranges. Syncope reported in a few instances. Also encountered: isolated instances of skin eruptions, edema, minor menstrual increased and decreased libido—all infrequent, generally controlled with dosage reduction; changes in EEG patterns may appear during and after treatment; blood dyscrasias (including agranulocytosis), jaundice, hepatic dysfunction reported occasionally with chiordiazepoxide HCI, making periodic blood counts and liver function tests advisable during protracted therapy. Adverse effects reported with Librax typical of anticholinergic agents, *i.e.*, dryness of mouth, blurring of vision, urinary hesitancy, constipation. Constipation has occurred most often when Librax therapy is combined with other spasmolytics and/or low residue diets.



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Table 1. Terminal Care Issues
Diagnosis
Mortality
Inconceivable to die of natural causes
Death is bad, frightening, calls for retribution and punishment
Grief and shame are not far removed from anger and rage Anger at deceased is disguised or repressed which only prolongs
period of grief
Families usually exclude children
Speak freely with patients about diagnosis of malignancy without
equating it necessarily with impending death
Leave door open for hope—patient is vulnerable and expects the worst
Sense of empathy as important as quality of care Prognosis
One cannot predict the precise course or outcome of cancer
Impossible to make a rigid prognosis of specific time
Variable course for disseminated cancer
May ask patient how long they want to live Be honest
Patient Fear of Abandonment
See patient regularly
Reexamine and reappraise at each visit
Touch patient—pulse, palpation, etc
Care does not end with withdrawal of extraordinary forms of
treatment
Daily living—commodes, hospital bed, bath, stool softeners/ laxatives, nutrition
Pain relief
Patient need for hope
Preparations for Death
Spiritual support
Funeral arrangements
Will
Autopsy request
Support groups Visiting nurses/allied health care providers/counselors
Hospice
Religious
Neighbors and friends
Conference After Death
Present autopsy findings
Answer questions after family has had time to reflect
Helps survivors have perspective of entire illness Assess status of remaining family

conference is a very useful tool for both the family and the physician to complete the discussion about a deceased patient.

DR. STERNBURG: I appreciate all of your comments and have outlined a summary of key points to be aware of when caring for terminally ill patients (Table 1).

References

1. Kyle D: Terminal Care. J R Coll Gen Pract 21:382, 1971

2. Dunphy JE: Annual discourse-On caring for the pa-

tient with cancer. N Engl J Med 295:313, 1976 3. Cassem NH, Stewart RS: Management and care of the dying patient. J Psychiatry 6:293, 1975 4. Rosenbaum EH, Rosenbaum IR: Principles of home

care for the patient with advanced cancer. JAMA 244:1484, 1980