

# PRACTICAL Palliative Care Today

A Professional Newsletter of San Diego Hospice and Palliative Home Healthcare

Volume 2, Summer 2000

## How Do I Tell My Patients They Are Going To Die?

### Breaking Bad News

*“Almost invariably, the act of communication is an important part of therapy; occasionally it is the only constituent. It usually requires greater thought and planning than a drug prescription, and unfortunately it is commonly administered in subtherapeutic doses...”*

—Robert Buckman

Breaking bad news is one of the most challenging tasks facing physicians today. Often it is done poorly, because physicians have not been trained in the nuances of good communication. Communication is an art, but there is an evolving science behind this skill. Like any skill, it can be mastered with practice.

Breaking bad news cannot be delegated or avoided. It is the patient's right to be fully informed, if they wish, about the extent of their illness and the likely progression of disease. In order to make fully informed decisions they require truthful information about their prognosis and choices available for care. Self-directed care has long been a prime goal of palliative medicine because it really provides the

patient with the control necessary to assure that *their* goals, not necessarily ours, are met as they reach the end of *their* lives.

Robert Buckman has perfected a six-step protocol for breaking bad news that includes the following six stages:

1. Getting the physical context right
2. Finding out how much the patient knows
3. Finding out how much the patient wants to know
4. Sharing information: aligning and educating
5. Responding to the patient's feelings
6. Planning and following through

### Get the Physical Context Right

Patient privacy and comfort are very important. A comfortable and quiet setting is the most appropriate place in which to break bad news. In the hospital, family lounges, if empty, are ideal. Introduce yourself to everyone present. It is important to recognize the patient first, often with a handshake, to indicate their primacy over other family members who may be also present.

Sitting down is an inviolable rule. The patient will perceive the time spent by the physician to be longer if he or she sits during the conversation. Sitting at the patient's eye level or a little lower reinforces patient control. Remove any impediment to good eye contact.

A somewhat relaxed posture on the part of the physician will help ease patient anxiety. Touching the patient may be very comforting to them. If it is not, it will be readily apparent and touching should be discontinued.

Techniques that facilitate and solicit conversation from the patient are useful. These include, but are not limited to, letting the patient speak without interruption or talking over them; and encouraging conversation by gestures, nodding, pauses, smiling, encouraging words and tolerating short silences. *Continued on page 7*

# A Little Book of Doctor's Rules

by Clifton K. Meador, M.D.

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## Rule 98

Some diseases are not treatable, but all patients can be given care.

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## Rule 135

Listen for what the patient is not telling you.

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## Rule 353

Never ignore an experienced nurse's observation.

## From the desk of the editor ...

Having completed our discussion of pain in the last issue of *Practical Palliative Care Today*, we have the luxury of turning to a new topic or theme for this issue. The main topic of discussion will center on communication, specifically how to break bad news in the best manner and how to continue to support the patient once the news is broken.

We have the luxury of teaching this skill to medical students from the University of California at San Diego School of Medicine through the use of simulated or standardized patients. The actresses react to the news with tears and genuine emotion that the students handle with a remarkable amount of aplomb, empathy, and skill. In a way, it's a shame we cannot let each of you readers experience the material in this way, instead of just reading about it.

Also in this issue is an essay on the key components necessary to be a palliative care physician that I hope you will find enjoyable reading as well as somewhat enlightening. A more practical article on managing bowel obstruction without a nasogastric tube may be more directly applicable to your practice.

As in other issues, our *Integrative Palliative Care* column will discuss another integrative intervention: prayer and meditation. And another new San Diego Hospice staff physician will be introduced.

As always, I hope you enjoy this newsletter. Your letters, comments, articles, and any form of feedback are always welcome.



**Michael E. Frederich, M.D., Editor**

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### Meet the Staff

The newest member of San Diego Hospice's full-time physician staff arrived July 1, 2000. He is **Jay R.**

**Thomas, M.D., Ph.D.**

Jay comes to San Diego Hospice as a staff physician who most recently worked for the VA Medical Center in San Diego and held an academic appointment of Assistant Professor of Medicine at the University of California at San Diego School of Medicine.

His education and background are very impressive with a BA, *Magna Cum Laude*, from Harvard in Biochemistry (where he was Phi Beta Kappa) followed by a Ph.D. in Biochemistry from the University of California at San Francisco and his M.D. degree, also from UCSF. Jay completed an internal medicine residency at UCSD.

Dr. Thomas is the son of a Presbyterian minister and grew up in North Carolina. He met and married a fellow molecular biologist during graduate school and they have three children.

Jay was seduced into palliative medicine and hospice work through part-time employment during the past year with San Diego Hospice. To say that it was a mutual attraction between Jay and our hospice would be an understatement, and we are thrilled to have him on board.

Jay hopes to combine his strong interests in spirituality, medicine, teaching, and research to San Diego Hospice's rapid growth at the forefront of hospice and palliative care. Please join us in welcoming Jay to San Diego Hospice.

# Managing Bowel Obstruction without a Nasogastric Tube

One of the greatest challenges faced by palliative medicine since its beginning has been the successful management of bowel obstruction without the use of nasogastric tube insertion and suction.

Traditionally, nasogastric suction and intravenous hydration is used to manage patients pre-operatively for up to ten days. However, prolonged nasogastric suction for symptomatic treatment of inoperable patients is not recommended. When surgery is not an option to relieve bowel obstruction, as it often is not in terminally ill or critically ill individuals who have elected palliative care, another approach is needed.

Individuals with incomplete or partial bowel obstruction may continue to be fed. This is particularly true if the obstruction is at the level of the lower ileum or colon. Feedings of small portions of liquids or low residue foods given early in the day may be very well tolerated. This is provided of course that the patient wishes to eat. Individuals with complete or total bowel obstruction or those with obstruction at more proximal levels should not be fed.

Bowel function in partial obstruction is best maintained with softener/stimulant combination agents such as Pericolace or Senokot S administered routinely several times per day. Anti-spasmodics such as Donnatal may help manage pain. Anti-emetics may be necessary should the individual also suffer from nausea and vomiting.

Several other agents, however, are even more useful in managing a bowel obstruction and allow us to remove a very uncomfortable nasogastric tube. The two most exciting medications are octreotide (Sandostatin) and scopolamine.

Octreotide modulates gastrointestinal secretions by reducing gastric acid secretion, slowing intestinal motility, decreasing bile flow, and reducing splanchnic blood flow.

Its inhibitory effect causes a decrease in water and sodium secretion of the intestinal epithelium and thereby reduces distension of the bowel.

In a recent study by Ripamonti et. al.,<sup>1</sup> octreotide at a dose of 0.3mg per day delivered by continuous infusion found that it was possible to remove the nasogastric tube three to five days after starting treatment. There was also a decrease in constant and colicky pain. It was felt that these effects were due to octreotide's inhibition of vasoactive intestinal peptide which reduces intestinal secretions.

Octreotide may be delivered intermittently by subcutaneous injection at six to eight hour intervals or continuously. The dose usually varies from 0.2 to 0.8mg per day total. In our experience at San Diego Hospice, octreotide is the preferred agent for managing bowel obstruction.

Scopolamine is also effective in managing bowel obstruction, but through a mechanism different from that exhibited by octreotide. Scopolamine's anticholinergic activity decreases tonus and peristalsis in smooth muscle, both by competitive inhibition of muscarinic receptors at the smooth muscle level and by impairment of ganglionic neural transmission to the bowel wall. Muscarinic cholinergic receptors have been observed on mucosal cells of the intestinal lumen which explains scopolamine's ability to reduce intestinal secretions.

The study by Ripamonti et. al. found that scopolamine at a dose of 60mg per day is effective in managing bowel obstruction with the nasogastric tube removal possible from three to eight days after starting the infusion. One potential adverse effect of scopolamine compared to octreotide was the higher incidence of dry mouth although this did not reach clinically significant levels.

Scopolamine may be adminis-

tered either subcutaneously by infusion, intermittent injection or through the transdermal scopolamine patch (TransDermScop). The dose of scopolamine usually administered is 0.8-2.4mg per day (much less than that used in Ripamonti's study.)

In fact, if relief is not obtained from the above individual medications, a combination of some of them may be useful to put the bowel completely to rest. An opioid (commonly morphine but others are equally effective) is provided to assure pain relief and to slow intestinal peristalsis. Scopolamine is often used as the agent to inhibit intestinal secretions. An anti-emetic that inhibits chemoreceptor trigger zone activity (commonly a dopamine antagonist like haloperidol or droperidol) is often provided to assure that nausea and vomiting is effectively managed. In fact, all three medications may be mixed and delivered in a subcutaneous continuous infusion to simply decompress the bowel.

Sometimes, corticosteroids like dexamethasone are used to also treat bowel obstruction. Although data from prospective randomized studies is lacking, anecdotal instances of palliation of this problem have been reported.

Utilizing and prescribing these medications and strategies in combination can provide successful management of bowel obstruction without nasogastric tube placement and suction. The comfort that this provides is a great relief to us all, patients and caregivers alike.

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<sup>1</sup> Ripamonti C, et.al. "Role of Octreotide, Scopolamine Butylbromide, and Hydration in Symptom Control of Patients with Inoperable Bowel Obstruction and Nasogastric Tubes: A Prospective Randomized Trial." *Journal of Pain and Symptom Management*. 2000. Vol. 19. No. 1: 22-34.

# Key Components of a Palliative Physician

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**A**s in any discipline there are key components that are necessary to the complete make-up of an excellent palliative physician. In order for physicians to provide the best possible end-of-life care they must be well rounded and that they possess strengths and skills in all three dimensions of personhood-body, mind, and spirit.

*The core or key components required to make an excellent palliative care physician are caring and compassion (spirit), communication skills (mind), clinical competence (body), and courage (body, mind, and spirit.)*

## **Caring and Compassion**

Caring and compassion are synonymous terms. They essentially mean having sympathy for individuals inclining one to be helpful or merciful. End-of-life care requires an ongoing relationship with our patients and families defined as an empathetic response. Although feeling and sharing the patient's suffering experience at some level is important, the palliative physician must not become too emotionally involved with the situation. Some objectivity must be maintained in order to function as a caregiver.

Stoicism on the part of physicians, however, may occasionally go too far. Keeping a safe distance is often communicated non-verbally to patients and families as a non-caring attitude. An occasional appropriately shared tear may be the highest compliment we can extend to a patient as an acknowledgement of understood suffering and compassion.

It is still very true today as it was expressed by Francis Peabody in his famous Harvard Lecture in 1927:

*The good physician knows his patients through and through and his knowledge is bought dearly. Time, sympathy and understanding must be lavishly dispensed, but the reward is to be found in that personal bond which forms the greatest satisfaction of the practice of medicine. One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient.*

## **Communication Skills**

In giving information to dying patients and their families, there is more chance of miscommunication and communication errors because no other time of life is felt to be as stressful as the end of life. For this reason, excellent communication skills are crucially important for the palliative

care physician to possess.

Breaking bad news requires such skill that it is discussed in depth in an accompanying article in this newsletter. But it is not enough just to be a skillful talker. At least half of the requirement is to be a skilled active listener. Its not enough to listen to the patient, however. The caregivers are also very important.

In a recent paper published in the *Annals of Internal Medicine*,<sup>2</sup> it was found that people who care for terminally ill patients say that they feel less depressed and better able to cope with their lives when they can talk to a doctor who simply listens to their problems and their concerns about their loved ones.

Of course, communication for communications sake is simply not enough. The content communicated is critical. Providing as much information as individuals can understand about prognosis, disease progression and pathophysiology, as well as explaining about medications and interventions is critical for the patient and the family. When individuals really understand the treatment plan it is amazing how compliance improves, resulting in successful palliation of symptoms and suffering.

## **Clinical Competence**

Clinical competence is perhaps the most readily identified skill necessary to possess in order to be an excellent palliative care physician. Being especially knowledgeable in the areas of pain and symptom management is crucial to the total care of the patient because patients suffering physical symptoms are unable to focus and deal with psychosocial

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<sup>2</sup> Emanuel, E. *Annals of Internal Medicine* 2000; 132:451-459.

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and spiritual problems.

This is particularly the role of the palliative physician whose skill and training is focused on managing physical symptoms. This skill extends beyond that of the routinely licensed physician, however, because there is a specific database that relates just to palliative medicine.

For example, evolving information about mechanisms of neuropathic pain and the role of the NMDA receptor is part of this specific database.

Knowledge of NMDA antagonists is often crucial in managing this most challenging symptom. The management of nausea and vomiting using a mechanistic approach is also illustrative. Often refractory patients will respond to combination therapy utilizing medications having different sites of action due to multifactorial etiologies causing their nausea and vomiting.

With the avalanche of new textbooks, articles, and other sources of information, it is increasingly difficult for the non-specialist physician to keep up with all the latest techniques of excellent pain and symptom management. For this reason, it is highly recommended that palliative medicine consultation be sought as indicated to palliate patients whose symptoms are not responding to commonly known interventions.

### **Courage**

Courage is perhaps the most important of the key components of a palliative care physician. Defined as the ability to disregard fear or the ability to be brave, courage is required in this field of medicine probably more than any other.

Overcoming paranoia about prescribing adequate amounts of opioid analgesics and the perception it is somehow hastening the death of the patient is necessary. The fear of heightened scrutiny by governmental licensing bodies and government restriction or denial of one's ability to

prescribe medications have been concerns for many palliative care physicians. The fear of pressure in this area, although diminishing, is still very real for some physicians.

Fear may also exist about referring patients to hospice and other palliative care programs because of the recent attention to “inappropriate referrals” of patients who live

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too long to suit the government. Both focused medical reviews and the Office of the Inspector General through “Operation Restore Trust” have added to the fears of sanctions for fraud and abuse as they relate to the referral process. To date, no physicians have been sanctioned or penalized for inappropriate hospice referrals.

Of course, most of the government's concern surrounding this issue can be disregarded because there is no intent to defraud by referring patients for hospice care. Once the HCFA reviewers understand that physicians cannot accurately prognosticate when a patient will die due to idiosyncratic individual variation, these types of allegations will hopefully disappear. Then, we can all get

back to the job of providing the best palliative care possible without undue worry.

It also takes courage to prescribe medications for off-label indications. Although there is data about the efficacy and safety of medications prescribed in this fashion, the PDR does not describe the chemistry and applicability of most pharmaceuticals, only the approved indications. In fact, we would be unable to palliate most symptoms successfully without prescribing medications in this manner.

The most courageous acts provided by palliative care physicians, however, are largely outside the regulatory realm. These are those that deal honestly and openly with issues of death and dying. It takes a lot of courage on the part of any physician to honestly discuss a life-limiting illness and to attempt to accurately prognosticate not only life expectancy but course of disease. Being prepared to deal with the resultant emotions of the patient and family as well as the emotions of the physician, himself, is a large part of this intervention. Just dealing with death itself takes courage. Every patient that dies takes a little part of the palliative physician along and reminds that physician of his or her own mortality.

### **In Conclusion**

Having recognized and discussed the four key components of being a competent palliative care physician—caring and compassion, communication, clinical competence, and courage—it is important to recognize another need of physicians who practice in this demanding specialty. That is simply *self-care*. It is critical that we pay attention to the need for down time and respite for ourselves from the demands of this form of healthcare. Regular time-off is crucial to the success of any palliative care practitioner who should not deny this important need.

**T**he San Diego Hospice Integrative Palliative Care Team continues to organize and draw together individuals within San Diego Hospice and the community to further learn about and apply integrative medicine techniques to the care of our terminally ill patients. The word *integrative-versus complementary or alternative-* was specifically chosen because these therapies are integrated into the plan of care to complement traditional modern American palliative medicine. They do not stand alone. In this issue, prayer and meditation are discussed.

The Committee on Prayer and Meditation of the Integrative Palliative Care Program at San Diego Hospice was established to support patients, families, and staff members with prayer and meditation. The committee pools community resources in many practices of meditation and prayer, provides a variety of teachings related to prayer and meditation, and is creating methods to research the effects of prayer and meditation on comfort for the dying and their families.

One might say that there is, “an impulse to engage in an act born of our longing to transcend the confines of self-reference which addresses the depths of human need. Whether or not this is done in silence, and whether it is called meditation or contemplation, or prayer, or employs an object, does not seem particularly important. What matters is that we find a way to address that universal yearning, however one defines it, or whatever form it takes.”<sup>3</sup> Through this act we become receptive to enlightened presence, the omnipotent love and compassion that exists for all beings.

Each quarter a special event is scheduled. In November 1999,

Mettanando Bhikkhu, a Buddhist monk from Thailand, presented, *Meditation for Ourselves and for the*

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*Prayer and meditation have a long history in the experiences of humankind...*

*They connect us with the ineffable mystery of life and death, guide us through life's passages, and can provide comfort and meaning for the dying person and their family and friends.*

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*Dying Person*, and in April 2000 presented, *Meditation, Prayer, and Dying from a Buddhist Perspective*. He will tentatively return to San Diego Hospice in August to train staff members to use meditation tech-

niques which can be helpful for the dying person.

In order to maintain diversity, guests from other traditions will be invited to share their experience, wisdom, and knowledge with San Diego Hospice staff, patients, and families. For example, in October 2000, the Martin Luther King Community Choir will present a concert in the Keck Conference Center.

Prayer and meditation have a long history in the experiences of humankind. They are interwoven into the fabric of the individual and his or her culture. They connect us with the ineffable mystery of life and death, guide us through life's passages, and can provide comfort and meaning for the dying person and their family and friends. San Diego Hospice provides an environment where such practices are welcome.

Time for communal prayer and meditation is available at San Diego Hospice at 11:00 a.m., Monday through Friday in the Inpatient Care Center Reflection Room. Each session is led by a chaplain or other staff member. Staff, family, and patients are invited to participate.

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<sup>3</sup> Tricycle. Spring 2000. P 66.

Repetition, reiteration, and reflection not only confirm to the patient that you are listening closely, but also help draw them out.

The empathic response includes identifying the emotion that the patient is experiencing, identifying the origin of that emotion, and responding in a way that tells the patient that you have connected the two. The physician needs to convey honesty, compassion, and caring while remaining hopeful and informative.

Give patients information at their own pace. It is usually best received if a supportive person (often a family member or close friend) is present. The timing of the news is important. It should be given at a time that is convenient for the patient which may not be convenient for the physician. This may require delivering the news before the physician is completely comfortable doing so. Sufficient time should always be allowed for questions and venting emotions.

The worst scenario would be to break bad news over the telephone while the patient is alone and in a gruff, uncaring, factual manner with no time for questions and no arrangements for follow-up.

### **Find Out How Much the Patient Knows**

After setting the physical context, the next step in breaking bad news is to find out how much the patient knows or suspects. This information is obtained in only one way—by asking the patient directly. The patient's understanding about the impact of illness on their future is the most important piece of information, not their ability to understand details of pathophysiology or specific medical terminology.

The patient's response should be analyzed for factual and emotional content and for the style of the patient's statements. The patient may start by denying that they have been given any information at all. This may represent denial or may be an attempt to test the physician to see if the information given in this encounter matches information previously given. This may also

lead to feelings on the part of the physician that “nobody ever tells their patients anything and they never get any news unless I deliver it.” This type of thinking is a trap that should be avoided at all costs by the physician.

Analyze the style of the patient's response. Note their manner of speech to assess their emotional state, educational level, articulation ability, and vocabulary so that you may attempt to match their style and level of understanding.

Remember that only seven percent of emotional communication is conveyed verbally. Be alert for revealing non-verbal clues.

### **Find Out How Much the Patient Wants to Know**

Before you launch into delivering bad news, it is critical that you ask the patient how much they want to know. There are no characteristics that accurately predict whether a patient desires disclosure and how much information they desire. You simply must ask them.

An individual patient may not be ready to hear all the bad news you want to deliver in one setting. They may be closed to detailed information or more information after only a few words. If this is the case, it is always best to break off the conversation and make plans to return later to continue the discussion when the patient is again ready.

### **Share Medical Information**

*Aligning and educating* are the first steps in sharing information. *Aligning* is the process through which information is lined up and added to the patient's current baseline knowledge. This is done by reinforcing parts that are accurate, correcting or discarding inaccuracies, and using the patient's own words if possible. *Educating* involves applying a slow and steady guidance over the interview, observing the patient's responses as you do.

Giving information in small doses works best. If there is a large gap between patient expectations and the reality of the situation, you can often

facilitate understanding by firing a “warning shot.” Using the word, “cancer,” is preferred to using words like “tumor” and “malignancy.”

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Although it may seem cruel to use the harsher term, it provides a greater understanding for the patient. After hearing the warning shot, however, most patients will be unable to focus and understand other information as their minds race to comprehend the ramifications of this term. It is often best at this time to give the patient time and space to digest the bad news and to schedule another time for additional conversation and information sharing for later.

When sharing medical information it is best to avoid medical jargon. Jargon often makes patients angry causing them to feel belittled and isolated. Check reception frequently, asking, “Do you see what I mean?” Allow the patient the opportunity to speak in order that they may feel they have an element of control over the conversation.

*Continued on page 8*

Reinforce the information given frequently. This can be done by getting the patient to repeat or explain the general drift, by repeating important points yourself, and by using diagrams and written messages. The most successful communicators blend their agenda with that of the patient. Elicit the shopping list (the patient's agenda), listen for the buried, perhaps unasked question and be prepared to be led.

### **Respond to the Patient's Feelings**

To foster a supportive dialogue, respond to the patient's feelings. Emotions that are communicated by the patient need to be acknowledged through the empathic response, as detailed earlier in this article. This will reduce the patient's distress and is one of the most reliable methods of demonstrating effective listening. This avoids any perception of professional insensitivity or unsupportive attitudes.

We do not have to be completely stoic in relating to our patients. Neither can we be productive if we are emotional basket cases. A nod, a smile, an occasional tear, and a warm hand can be very effective in communicating during those moments when words fail us.

### **Organize and Plan**

The final step in breaking bad news is to not take away all hope for the patient. This is done by demonstrating an understanding of the patient's problem list and focusing on the fixable as opposed to the unfixable. Make a specific plan or strategy and explain it to the patient in simple terms. An algorithm or decision tree may be too complex to present at this time. Instead, a promise to deal with each problem as it arises and a promise to never abandon the patient are more helpful.

Identify and support internal and external resources and coping strategies the patient may already possess and others they may wish to develop. If family is distant, the patient may need to be strongly encouraged to consider help from friends whom they may be reluctant to ask for specific assistance. Community support agencies may also be appropriately involved.

As a last step, give the patient the opportunity to ask questions. Make a definite plan and schedule a follow-up conversation. This really helps the patient feel they will not be abandoned and that there is hope for the future.

Breaking bad news requires as much if not more skill than any other task in medicine. If done correctly, it has the potential to heal. If not, it has the potential to wound or to keep an old wound from healing.



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