Healthcare **Communication** Review

On Building Health Partnerships: Food-for-Thought, Practical Tips, Resources

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END-OF-LIFE
& PALLIATIVE CARE

End-of-Life: Choices for Patients & Loved Ones

It's a sad day when patients learn they have a life-threatening illness. It's sadder still if treatments for their particular conditions are of limited or questionable value and/or have harsh side effects. When that happens, patients often face a choice between aggressive treatments or palliative care – in other words, between treatments aimed at extending life or those aimed at the relief of suffering caused by physical pain and other sources of distress. Although it is often possible to achieve both, by choosing one over the other, individuals are often stating which is most important to them: living a little longer (even at the expense of comfort) or living more comfortably (even at the expense of days, months or years). Neither choice would be wrong.

Another choice that patients and/or their families may face is whether or not to involve loved ones in the decisionmaking process. Here, again, the "right" answer to this question will vary from person to person and from family to family. While excluding loved ones from this process might, at times, be best, including them is often better for all involved. Why? Because the idea of impending death often signals a time of great emotional turmoil. (Both individually and as a society we do not easily handle death and dying.) Because this is a time when practical as well as emotional support is greatly needed. Because the decisions we make in this regard often affect others, especially those that love us. And because, even when the prognosis is unspoken, everyone knows, or suspects, that death is near.

Silence leads to isolation and often serves no one. To shut loved ones out of the process (whether it's patients shutting out family or family shutting out patients) not only denies the dying much-needed support, but denies them the opportunity to put their 'house' in order; to support or repair relationships; to minimize conflicts; and to reach a point of being at peace with oneself – to leave this earth having achieved a state of harmony or, even better, to have achieved that harmony and find that one has also gained more time. Who wouldn't want that? ☐

In Search of More Time: Considering Chemotherapy & Clinical Trials

It's often hard to give up on life. Perhaps that's why, as reported by Breast Cancer Action, more people tend to choose any treatment that might prolong life – even those that carry only the slightest hope for success (measured by adding just one more week or month of life) and even when the treatment regimen is difficult.[1]

Searching for details of treatment options, however, is not just for those patients who are unsure of what they want to do. Understanding what might lie ahead can be of great value even for those who want treatment regardless of the consequences – if only because "to be forewarned is to be prepared." And to be prepared enables patients and their families to take steps that can help make the experience a more comfortable one – both physically and emotionally.

See **Time** *pg. 6*

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From the Editor

The 1995 report of the SUPPORT study, funded by a grant from the Robert Wood Johnson Foundation, showed that much is still lacking in the end-of-life care available to patients and their families in the United States. A more recent study, conducted by the Hastings Center, looked at why improving end-of-life care has been so difficult. While not downplaying the work yet to be done, a summary of their published report of this study, (November-December 2005 *Hastings Center Report*), noted that the last 30 years have shown some progress. They note, for instance, that people have a greater decisionmaking role in their end-of-life care and, although the suffering of patients is not yet adequately addressed by the medical profession, palliative care – the prevention and relief of suffering – has been recognized as a medical specialty. Indeed, they report that an ever-increasing number of hospitals are establishing palliative care units and over two thousand doctors and ten thousand nurses/nursing assistants have been certified in this field.

This is good news. Even so, the Hastings Center reported that much needs to be done to improve end-of-life care. The question is: 'how?' Because the matter of death and dying is a complicated one (for individuals and their families, for healthcare professionals and for society as a whole) the Center calls for social changes as well as changes in healthcare delivery.

To a large extent, the changes that have been made so far are a result of litigation and our legal system. The concepts of patients' rights and informed consent, for instance, are a result of federal and state laws. While the legal system has been, and remains, an important part of bringing about much needed changes, the Center has concluded that other paths are needed as well. It recommends that change efforts should focus more on shared decisionmaking and communication among patients and their loved ones. Care for dying people, they say, would be much improved by a system that not only takes into account the values and needs of individual patients, but also works to help patients, their families, and healthcare professionals make difficult decisions.

This view is, of course, totally in sync with our own goal of promoting health partnerships by helping patients, their advocates and professionals build relationship and shared-decisionmaking skills. To that end, this issue offers articles that will further readers' understanding of some end-of-life options; of dealing with pain; and of comforting dying loved ones or patients. We also offer reviews of resources that will, we think, be very helpful to those professionals and non-professionals who care for and support the dying. As always, we hope you find this issue of value.
Be Well. *Judith Greenfield*

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In Search of Comfort: Understanding Hospice Care

By Kathy A. McMahon

Having the great privilege of working with New York State's Hospice providers, I continue to be in awe of the caring and compassion I see every day. Hospice is unique… providing both patients and their families with the support, help and guidance they need to meet the challenges of serious illness. The aim is to be sensitive to their needs, emphasize quality of life, and assist patients to live as fully and comfortably as possible.

Trained hospice teams–physicians, nurses, home health aides, social workers, spiritual caregivers and volunteers provide skilled and compassionate care. Hospices:

- Embrace all patients coping with advanced illnesses,
- Emphasize quality of life and comfort rather than cure,
- Promote personal choice and individual dignity,
- Respect the traditions/wishes of patients/families,
- Provide care in patients' homes but, when needed, can provide care in nursing homes and inpatient settings,
- Use current treatments and medications,
- Address physical, social, emotional, spiritual needs,
- Provide care and support to the bereaved.

Q: How can my family member get hospice services?
A: Anyone can refer patients to hospice–family members, friends, physicians, nurses…anyone. When that happens, the hospice will evaluate the patient to see if he/she is eligible for hospice services. To be eligible, a doctor must be willing to certify that the patient has a prognosis of six months or less (if the disease runs its normal course) and the patient must no longer be receiving curative treatment. To find a hospice in New York State, call 800-431-8988 or 518-446-1483. Or visit **www.hpcanys.org** and click on "find a Hospice." To find hospices in other states, go to **www.hospicefoundation.org** or **www.nhpco.org**.

Q: How is Hospice paid for?
A: Insurance coverage for Hospice is available through Medicare and, in New York State, through Medicaid. Also, most private insurance plans, HMOs, and other managed care organizations include hospice care as a benefit. Hospice is also covered under New York State's Family Health Plus and Child Health Plus Programs. In addition, through community contributions, memorial donations, and foundation gifts, many Hospices are able to provide patients who lack sufficient coverage with free services. Other programs charge patients in accordance with their ability to pay.

Q: Can I have Hospice if I don't have a primary caregiver at home?
A. Yes! In the past, some hospices required a primary caregiver in the home. This is no longer the case in New York State. Unfortunately many physicians and other potential referral sources don't know this. Talk to your local hospice about how they can accommodate the patient if there is no primary caregiver in the home.

Q: What if I don't have a home?
A: Hospice is a philosophy of care, not a place. It can be provided wherever the patient lives – at home, in a nursing home, or in any accommodation or shelter. In addition, Hospice Residences – 8-bed, home-like facilities – are beginning to be built in New York State. Check with your local Hospice to see if they have, or will have, one.

Q. Can Hospice provide palliative care to patients who have longer than 6 months to live and who are receiving curative treatment?
A. Yes. In 2002 NYS Hospice Licensure Law was amended so that Hospices can provide palliative care to patients with advance, progressive illness outside the six month prognosis while they are receiving curative treatment. This is not covered by Medicare or Medicaid, but it does allow patients to pay privately for the service or for HMOs and insurance companies to contract with the Hospice for palliative care services. Contact your local Hospice for more information.

Two Last Words: If I could dispel just one myth about Hospice, it would be that choosing Hospice means giving up hope. Hospice actually fosters hope – it helps patients reclaim the control they have over the time they have left. It helps them understand that even though death can lead to sadness, anger, and pain, it can also lead to opportunities for reunion, reminiscence, laughter, and HOPE – hope that Hospice will enable a patient to live his or her life to its fullest. It is not uncommon for patients entering Hospice to experience an improved sense of wellbeing and comfort as a result of pain management and symptom control issues being openly discussed and effectively resolved and from a sense of control gained from defining their own goals of care.

Finally, Hospice is not meant to be "brink of death" care. If you or your loved one has a life limiting illness, seek an evaluation from Hospice as early as possible. The care and comfort Hospice will bring to you and your loved ones are invaluable. The Hospice staff truly believes it is an honor and a privilege to be invited into your lives and your homes to help care for your loved ones. Take advantage of the caring and compassion they can bring to your family.□

Palliative Care and Pain at the End of Life

By Marcia Levetown, MD

Palliative Care

Palliative care is about the relief of suffering; it is applied most often to patients with chronic and irreversible or terminal conditions. While suffering may arise from many sources, including emotional, spiritual/existential, and social distress, perhaps the most recognized source is physical – most often represented by pain. Other symptoms can be equally or even more distressing, including shortness of breath, profound fatigue, feelings of abandonment, concerns about being a burden or doubts about whether the patient's life was well-lived. Palliative care addresses *all* these sources of distress *and more*, but for now we will discuss physical pain.

Pain

Pain is common in all life-threatening conditions, not just cancer. The SUPPORT trial, conducted in the early 1990s, studied over 9000 patients with limited life expectancies. It showed that patients with chronic lung disease, heart disease, infections in the blood stream, as well as cancer, all have a very high incidence of moderate to severe pain. Unfortunately, most physicians and other health care providers have not been taught to diagnose and manage pain. In fact, most practicing physicians have neither heard of palliative care nor received training in it, leaving them powerless in the face of patients' pain and feeling they have "nothing left to do" when disease has overtaken their patients.

Pain CAN be controlled. Nevertheless, patients continue to suffer unnecessarily. Patients and families should not be satisfied with the response "we have given all the medication we can" if the patient is still in pain. One of the biggest barriers to pain control is ignorance among laypersons and professionals regarding the terms 'physical dependence', 'tolerance' and 'addiction', as well as disproportionate fears of side effects from strong pain medications.

Physical Dependence

If a patient has been taking a medication for weeks or longer, and its use is suddenly stopped, the dose is dramatically reduced, or a reversal agent is used, a predictable set of symptoms, based on the medication, will occur. This is a PHYSICAL issue, not psychological, and does not imply addiction, or that the patient is a bad person. It occurs with many classes of medications, including steroids and anti-seizure medications.

Tolerance

With time, the dose of medication needed for the intended effect increases. This also is a physical phenomenon and is related to the medication itself, the route of delivery, the usual duration of its activity. Tolerance is less of a problem with opioids ("narcotics"), than was initially thought – especially for medications that are long-acting and taken by mouth. Need for large increases in dose usually means the disease itself is getting worse, rather than tolerance.

Addiction

Addiction is a disorder affected by genetic, social and psychological attributes of the individual. It is NOT CAUSED by medications, however, the misuse of medication is a sign the patient has an addiction problem. Addiction is NOT related to the dose or duration of treatment, nor the presence of withdrawal if the medication is stopped (see dependence, above). It is about using the medication despite self-harm. This is exceedingly rare among the terminally ill, especially those who have never previously had addiction problems. Patients may 'watch the clock' or insist on higher doses of medications. In the face of terminal illness, this frequently represents poor pain control. The goal is improved function and increased ability to participate in and regain some enjoyment of life. If the medication only makes the person withdraw, the patient insists on its continued use, he or she may have an addictive disorder. Some patients have co-existing pain and addiction. Their treatment is difficult and is best managed by practitioners experienced in the care of such patients.

Two Types of Pain

There are 2 main types of pain, pain in the muscles, bones and organs (nociceptive pain), and pain in the nerves, spinal cord and brain (neuropathic pain). The medications used for nociceptive pain depend on the severity of pain. For mild pain, acetaminophen (e.g., Tylenol) and non-steroidal anti-inflammatory agents (NSAIDs) (e.g., Advil) are used. For moderate pain, combinations of opioids and NSAIDS or acetaminophen are used (e.g., Vicodin, Percocet). For any kind of severe pain, pure opioids (e.g., morphine, methadone) are used. There is NO MAXIMUM dose of a pure opioid. Thus, if the pain is not better with the initial dose, the dose should be increased until relief occurs. How fast the dose can be increased depends on how the medication is given (faster for IV compared to by mouth) and which medication is used.

See **Pain**, *pg. 6*

Palliative Care: How Family and Friends Can Help Relieve Suffering

If you've ever suffered even brief periods of anguish over problems with money, relationships, work, or any other non-physical source of distress, then you might begin to be able to understand the suffering that is common to people who are at the end of their lives. While one of the first concerns patients and all their caregivers might have often relates to physical pain, it's vital to understand the full range of suffering that often occurs and the great role that family and friends can play in helping to relieve it.

Sources of Suffering

In the weeks and months that lead up to their loss of life, patients often suffer other great losses as well. Loss of health may prevent them from living life as usual – sometimes causing them to lose their sense of self. If they had been working at a job and cannot continue – they may lose financial security as well. They may also lose the company of some friends and family whose feelings of discomfort in the face of looming death may lead them to avoid their dying loved one. When that happens, patients often experience isolation and loneliness. Patients' concerns about being a burden to loved ones (economically, emotionally and physically) may also weigh heavily on them.

> *While some sources of suffering may be inevitable, others are not. In particular, friends and family can often make a real difference by being there...*

How Friends and Family Can Help

While some of these losses may be inevitable, others are not. In particular, friends and family can often make a real difference by being there for their loved ones. How? In a recent article for the Hospice and Palliative Care Association of New York State, Jack Gordon, then Chairman of the Hospice Foundation of America, outlined some of the ways friends and family could help.[1] While this will likely vary from person to person, he reports that dying patients often want their friends to:

- Be there, even though it may be hard to do
- Be honest – they know when you're not
- Allow them to express and process strong feelings
- Laugh and/or cry with them
- Hold hands, hug, touch, them, if that's what they want
- Be quiet when there, if that's what they need
- Offer practical help with simple chores, childcare, etc.
- Support other family and friends who also suffer.

Advocating for Dying Loved Ones

While many patients are able to die at home, some may spend their last days, weeks or months in a hospice, hospital or nursing home. While hospice caregivers are especially trained to identify and meet the various needs of the dying in a compassionate way, professionals who care for the dying, in any setting, are generally very caring and conscientious. Even so, there may be times when patients are stressed by interactions with a particular aide, nurse or doctor.

If that happens, friends or family members can help loved ones here as well. The question is: how? Your first instincts may be to angrily confront or, perhaps, to bypass the staff person – going directly to an administrator. Another way to address the problem, however, might be to first go directly to the person in question, to identify the problem from the patient's point of view and ask for his or her help in solving it. In other words, instead of an 'Us' versus 'Them' (patient and advocate versus staff) view of the problem and its solution, you might take an 'Us' versus 'The Problem' approach (patient, advocate and staff versus the problem).

'Us' versus 'the Problem'

This approach, as described by Leonard Marcus and his colleagues (experts in conflict resolution and healthcare negotiation), calls upon people to not only voice their own concerns, but to listen to, and discuss, what others have to say.[2] This approach won't work unless both parties are open to it, but you can only find that out by trying. If you do, you might start by first taking the time to figure out how to broach the subject in a non-threatening way.

Assume, for instance, that your aunt complains about a particular nurse who, she says, handles her roughly and is insensitive to her needs. You might begin by telling the nurse that you want to alert him to some of your aunt's concerns and ask for his help in resolving them. Then tell him how your aunt feels, followed by asking for, and discussing, his view of the situation. Finally, work with him to help figure out how to fix the problem. If, at any point, you need to repeat these steps, that's OK. Discussion can reveal previously unconsidered aspects of the situation, resulting in the need to step back and take another look at it. Indeed, it often works that way.□

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[1] "Your Friend Needs Help" by Jack Gordon appeared in a special pullout of the November 14, 2005 issue of *The Legislative Gazette.* Contact HPCANYS at 518-446-1483 for a copy of the pullout.

[2] Leonard J. Marcus et al. *Renegotiating Health Care*. San Fransicso: Jossey Bass Publishers. 1995.

Pain, *continued from pg. 4*

Mild to moderate neuropathic pain is treated with drugs best known for other uses; these include anti-depressants, anti-seizure medications (anti-convulsants), some medications that lower blood pressure and local anesthetics.

Other Barriers to Pain Control

In addition to concerns about addiction, healthcare providers also worry that patients may stop breathing when they receive high doses of opioids. It is true that opioids slow breathing, but if the patient is breathing 60 times a minute because of the pain (8-12 is normal), slowing breathing is a benefit. Moreover, studies of both adults and infants indicate that pain is a powerful stimulus to breathe. In addition patients who are dying and have been given opioids to relieve the sensation of shortness of breath when they are taken off breathing machines (ventilators) actually live LONGER than those who are not given the medication. Caution is advisable, and patients should be monitored for their level of alertness and breathing rate while increasing the dose, but not increasing the dose out of fear when a patient is in pain is unacceptable. The dose of opioids recommended in textbooks is the safe starting dose for patients who have never received opioids, NOT the dose that is going to relieve the pain. The latter is individually determined by the patient and their illness.

Sometimes, for terminally ill patients, there is a choice between the relief of severe pain and alertness. Patients in severe pain generally prefer to be asleep rather than experience pain; they are unable to enjoy the company of family members while enduring such agony. Many families have a hard time understanding this and beg physicians to keep the patient awake. A stimulant (like Ritalin) can sometimes be used for this purpose, but it is not always successful. It is thus important as a family member to take the opportunity to say "I love you", "I forgive you" and "I will miss you but I will survive-thanks for a good life with you" before the crisis of agonizing pain hits.

No one should die in pain. Fears of initiating addiction among the terminally ill are misplaced. It does not happen. Be an advocate for your loved one – he or she will not personally have the energy to insist on pain relief. Unfortunately, there is a lot of ignorance among healthcare providers about pain management. If the current team is unable to get the pain under control, insist on others being consulted. Your final memories of your loved one will be ones you can look back on with pride rather than regret. Insist on effective pain control for their benefit and for yours.□

Time, *continued from pg. 1*

Patients who are considering established treatments (such as chemotherapy) or experimental treatments (such as those being tested in clinical trials) can usually get information by asking their doctors and doing some research. Of course, knowing what questions to ask and what to look for is not always obvious. Fortunately, help is out there.

When considering chemotherapy, for instance, visitors to the Breast Cancer Action web site will find suggested questions that relate to treatment goals, success rates, side effects, speaking to others who have undergone the treatment, best place to have the treatment, and what to expect if the treatment is declined.[2]

When considering experimental treatments and clinical trials, patients and their families would also be well advised to ask questions. Two important sets of questions to ask relate to the nature of clinical trials (what they are and how they work) and what taking part in those trials might mean for particular patients. An Internet search can help patients and their families here as well. (Those who do not have access to the Internet from their home, should remember that many public, school and hospital libraries provide this service to the community and librarians are available to explain how to use it.)

A starting point for this search might be the government web site, **www.clinicaltrials.gov**. This site provides links to information that explains and describes clinical trials. It also provides links to help visitors who are looking for trials that might pertain to them or a loved one. Other resources may be found through this site as well.

The American Cancer Society also provides clear and extensive information about clinical trials along with suggested questions for patients to ask themselves when they are considering whether or not they should participate in trials. Though their focus is helping cancer patients, this information is relevant for all types of diseases and can be found by going to **www.cancer.org**. Once there, find the search box and enter "Clinical Trials: What You Need to Know."

As always, discussing what you find with your doctors can help answer the many questions that may arise from your search. They can help you make sense of what you have learned and what it might mean for you. They are part of your care team. Take advantage of that.□

[1] See "Chemotherapy: Making the Decision," *Newsletter # 9*, Breast Cancer Action at **www.bcaction.org**.

[2] See citation 1.

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For the general public and healthcare professionals!

REVIEW: BOOK & AUDIO TAPE

Where Souls Meet: Communicating With the Seriously Ill
By Dillon Woods, M. Div.
www.livingwithquality.org • $12.95

If you are among the many people who avoid a dying friend or family member because you don't know what to say or do, this book can help. The author, a former monk whose work and personal life led him to write this thoughtful guide, provides readers with insights and tips that will help them "be there" for their loved ones.

Woods begins by identifying the needs of the dying, and providing details about how to meet these needs. A key to all this, he says, is listening, *really listening* – something he learned from his mentor. She taught him the importance of listening "*the way you would want to be listened to.*" Taking your cues from your loved ones is another piece of advice he offers: "*…if someone is talking to you and you notice a theme keeps reoccurring, that is something I would ask them more about. Let them talk it all out.*"

But reading the "how to" advice in these pages may not help make us comfortable enough to visit and help a dying friend or loved one. For this reason, early in the book, Woods advises us to increase our comfort levels by thinking about, and coming to terms with, our own eventual deaths. Questions we might ask ourselves when we do this are provided in the appendices, as are recommendations for meditation tapes and other practical tips for both professional and non-professional caregivers.

Much of the book, though, provides specific, highly practical suggestions for being there for the terminally ill: how to practice listening skills; how to be non-judgmental; how to know when to touch or not touch; what to say and do; how to help those who want to take an inventory of their lives by reflecting on past experiences and events; how to recognize when the end is near; and so much more. This is a book whose impact can extend well beyond the death of a loved one. Our advice? Read it!

REVIEW: VIDEO

Like Rembrandt's Draperies:
A Portrait of Cathy Tingle
Filmmaker: Robin Gate
www.lifeworksvideo.com • $154.00

If our ability to comfort and care for dying friends, family, or patients depends, even in part, on our coming to terms with our own mortality, and if coming to terms begins with addressing many of our own issues around death and dying, then watching Cathy Tingle's story may be a good place to start.

Cathy was what some might call a "free spirit" – living mostly off the land, reveling in nature and seeking nothing more in life than health and happiness for herself and her children. Working with children and a variety of other jobs that included grave digging and cutting tobacco, she was very happy. Different though her lifestyle may have been, her journey through her illness was one that will likely feel familiar to many viewers. Like a growing number of people, she strove to cope with her illness and play an active role in making decisions about her care.

From her own words, as well as those of her friends, family, and oncologist – we learn about her life before and during her illness and of lessons learned by all. Issues touched on in the video include the importance of support from family and friends and, from the perspectives of both Cathy and her oncologist, the value of a doctor-patient relationship grounded in compassion and respect.

Healthcare establishments interested in in-services for their staffs, would be well advised to purchase this video, which comes with a detailed curriculum guide that suggests strategies and discussion topics. Because its price is out of the average person's range, patient advocacy groups might think of purchasing it and showing it to their constituents. Whether a professional or not, watching it may help the viewer learn, as did Cathy's friends, to "*...not be afraid to be afraid and to get close to the things we are afraid to be doing,*" because "*… it makes you less afraid of death.*"