

## “The Final Journey: dialogs, dances and dilemmas”

Sharon Gray Siano R.N.

Hospice Liaison Nurse

People seem not to take exception to the metaphor that the act of dying is a journey – just as they consider the act of living to be a journey. But rather, the challenges and discomfort come when the word “final” is attached to the metaphor.

A phrase that I have used to summarize what I believe about my chosen specialty is as follows; “Hospice is...compassionate care for the completion of life”. Much to my surprise, this has been quite a conversation starter as people have read it and begun to discuss the “completion of life” component of the phrase. Perhaps, you too, might be drawn into the debate as to whether or not there is an end to this journey or a completion to this life. However, I would offer that; yes, there is a final portion of this journey – a completion of this physical life that we share with our family, friends and loved ones. It is a time when our physical body succumbs to traumatic injury or to progressive disease and illness. Although the physical symptoms may be challenging and at times overwhelming, it can be a time of quiet peacefulness; a culmination, a completion, of memories and life events shared with those who are present. But is this how we perceive death? How does our social reality effect our perception, our expectations and ultimately our journey? Do we as individuals or collectively as a culture give thought and consideration to how we want to die, or is all of the energy placed on how we can postpone death?

We are fearfully and wonderfully made<sup>1</sup>, and our life journey began most certainly when our life itself began, following quiet paths and busy highways of both the frightening and the familiar. We are unique individuals with distinctly different life experiences; a composition of events, genetic influences, family, religion, culture, and environment which influence and guide us into the development of certain expectations and behaviors. Our world view – our social reality - is a place of comfort, or at least, familiarity because we have learned what is expected, what is “normal”. Matriarchal families, patriarchal families, religious or non-religious, families that value individual autonomy, families that believe in the autonomy of the unit rather than the rights and autonomy of the individual, families that injure and separate, families that nurture and bind together. Each of us define or judge circumstances, services, ourselves and other people as strong or weak, good or bad, worthy or unworthy as a result of our developed social reality. We plan, dream and schedule our lives based on what we have learned – there is an anticipated script. However, the end of our lives is rarely scripted – it is often added there by someone else – someone who knows little or nothing of who we really are or what is in our script. They walk into our lives and change the story with few words and little knowledge of the devastation they may leave behind.

Why are end-of-life dialogs so difficult for health care providers?

How are these difficult dialogs interpreted by patients and how do they effect the patients journey and decisions regarding their care?

What are some of the barriers to adequate communication for patients, families and providers regarding care for a patient with a life-threatening illness?

How can health care providers learn to offer compassionate honesty for patients, throughout the continuum of care, regarding their illness and treatment options?

How is our life journey changed and shaped as we meet with doctors to hear of a devastating disease and a life-limiting prognosis?

How is quality of life defined and by whom?

How do we cope as the familiar becomes the frightening and the fragile dances we share with the people we love become confusing and difficult to follow?

## **Dialogs**

Quality of life is self-determined. This is applicable throughout our life journey; we make decisions and choose paths that bring to our life results and quality that is comfortable and acceptable by our own self-definition. This should be no different when a patient is coping with decisions related to health care. Quality care at end-of-life is highly individual and should be achieved through a process of shared decision making and clear communication that acknowledges the values and preferences of patients and their families.<sup>2,3</sup> Health care providers must understand that the medical interventions, quality of life and overall outcomes of end-of-life care for patients and their families are largely determined through the conversations they share with their providers. When these discussions are avoided or are managed poorly, the quality of remaining life for patients can be seriously jeopardized.<sup>3</sup> Studies support our knowledge in practice that patients are not adequately informed about their options related to end-of-life care.<sup>4</sup> But this again is indicative of the need for improved and continued dialog between patients, families and providers.

There are many factors that influence these so often sub-optimal dialogs. As I have watched and participated in many hundreds of end-of-life conversations with patients, families and providers – I have come to acknowledge perhaps the most powerful of all barriers is that of fear. I see fear manifest itself in many ways, not only in patients and families but also in staff and providers; silence, pride, anger, tears, pain, avoidance. Fear can permeate a patient's journey – but compassionate communication can ease the fear and empower the patient. It is difficult for patients to comprehend why health care providers are not comfortable talking about end-of-life truths and issues. “Why are they afraid – they deal with this everyday and they are the professionals?” When in truth, each individual's social reality influences how comfortable they are in discussing matters related to death. Unfortunately for patients, health care professionals are not excluded from this. I just met with a patient and his family

today who shared with me that they had to change Oncologists because they felt that the last physician was not being honest and open with them – they weren't getting answers to their difficult questions.

A physician's hesitancy to be honest and candid regarding a patient's poor prognosis is probably well intentioned. Among other concerns, they fear that the truth will harm their patient.<sup>5</sup> One physician recently told a patient and their family member that he would not refer the patient for hospice care because he felt that it would depress the patient. What is it that makes even an educated Oncologist believe that by trying to avoid the sadness of impending death that the remaining time will be better for the patient or the family? Health care professionals must come to understand how their perceptions and beliefs may negatively influence the course of care for their patients. The encounter with this physician is an example of communication that is not patient-centered. While perhaps well intentioned, the physician did not seek to understand the needs or beliefs of the patient and caregiver, but rather made a judgment based on his own personal reality and perception of what was best for the patient.

Sadness, depression and grief are all a part of what is intermittently experienced by a patient (and their family) as they hear of a terminal diagnosis and adapt to the many changes it brings. The avoidance of these emotions is neither beneficial nor necessary. Elizabeth Kubler-Ross was the first to introduce the concept of stages that an individual may pass through on this journey; 1) Denial, 2) Anger, 3) Bargaining, 4) Depression, 5) Acceptance.<sup>6</sup> As we are privileged to care for people at the end of their lives, we see that they very often experience each of these stages. Perhaps vacillating from one to another, sometimes even skipping a few completely. Our hope is that each individual will determine their own path to acceptance, in their own time, on their own terms; we are simply honored to be there to support, guide and comfort them. So, as health care providers we should be striving to help patients to cope with the sadness, not avoid it, so they may be empowered to live their remaining time to the fullest on the path that they have chosen.

We understand that while sadness will be at times part of the journey, so also can joy, comfort, peace, resolution and hope. When I asked a physician, who deals with cancer patients on a daily basis, why it is so difficult for him to talk to patients about end-of-life issues, he said that he is "afraid to take away their hope". This is a common barrier, founded in fear, for providers throughout the continuum of care. My response to him and to all providers who share this opinion is that we should NEVER assume that we know where a patient's hope lies. Hope may lie in the obvious; physical healing and restoration of our physical body. However, perhaps a patient's hope lies somewhere else:

Like Patricia, who wanted to continue "aggressive treatment" even though it was ravaging her body, in the hope that it could prolong her life just long enough for her to see her first grandbaby born six weeks later. After the baby's birth, she chose to stop the treatment that was making her so ill because her hope was fulfilled. She died comfortably at home three weeks later, just after her third visit with her grandbaby. Her choices, when we took the time to understand them, were beautiful examples of a patient's autonomous

decisions related to quality of life as well as her hopes desired and hopes fulfilled.

Like Steve, whose body was so devastated by Lou Gehrig's Disease that breathing took most of his energy and the only independent movement he had left was to blink his eyes and move one thumb. This man's hope did not lie in physical healing, but rather in the hope that he could say goodbye to each and everyone of his friends and loved ones at a goodbye party. It was a party, by his request, where the messages he wanted everyone to receive were "Don't worry, be happy" and "Don't sweat the small stuff - and it's all small stuff". Steve died peacefully at home just a few days after his party. I continue to cherish my memories of this courageous man - and his messages.

Like Jack, who had reached his eighth decade of life and had been told that his heart and lungs were so fragile that life could end at any moment. That was okay with Jack, he was "ready to go home". He had a strong religious faith, a belief that Jesus had a spiritual home of wholeness and peace waiting for him after his physical death. He was a priceless soul, a man of wisdom and spiritual strength - I felt nurtured in his presence. Although he had been near death, the decline of his heart and lungs stopped, his health stabilized and he was "graduated" for a time from hospice care. Some months later we were again requested to provide care for him as his health had again begun to fail. As Jack's heart and lungs weakened, his strength declined and his quality of life worsened - he prayed for God to take him home. But He did not. Months went by and he struggled with inner turmoil as he sought to understand why God did not take him NOW - why must he linger when he was ready to die? Through his questions and turmoil he held fast to the knowledge of his faith. Jack's hope was in spiritual wholeness and completeness after death - he longed for it and peacefully received it, when the time came.

As I discuss end-of-life issues with patients and families, I ask many questions - questions that help me to understand the patient's knowledge, hopes, and fears about what they are facing. These questions can also help a patient and family receive a gentle introduction to some of the issues that may confront them during end-of-life. "Can you tell me a little bit about your illness?" "Can you tell me what the Doctors have told you to expect from your illness?" "What has been the most difficult thing about this illness?" "What gives you joy?" "What do you believe happens after this body dies?" "We've been talking about how you are the most important decision maker about your own quality of life - what things are most important to you right now?" "What things are most important to you in the future?" "Are there any specific things that you feel that you need to do or complete?" "What, if anything, are you worried or afraid about?"

Of course, questions are only as good as the time spent listening and acknowledging the answers. So often when patients are ill and in the hospital, few people/providers have much time to actually TALK to them. Oh they get asked questions about pain, nausea, bowel function and the like - but they rarely have the opportunity to talk about what they are feeling or what they fear. What

is perhaps ironic, is that for some patients, I am the one they fear. I am the hospice liaison in the hospital - the person who, for many patients, represents end-of-life itself.

PETER (and Linda)

I first met Peter in the hospital- at the age of 53- eight years after his first skin cancer diagnosis. His journey, even before we met, had been wrought with challenges. He was first diagnosed with melanoma at the age of 45. He received aggressive treatment – and they prayed for healing. Four years later Peter began having trouble walking and they found that it had metastasized to his brain. The doctors told him “surgery would probably not cure” him but “it could prolong his life”. Peter and his wife Linda “decided to fight” so Peter had brain surgery to remove the tumor – and they prayed for a miracle. Radiation treatments to his brain followed after he recovered from the surgery. Nausea, vomiting, right-sided weakness and physical therapy were daily struggles for him and his family. You see, these things just don’t happen to the patient, they happen to the spouse and children who struggle in their efforts to maintain normalcy as life continues on around them. Soon his symptoms subsided and life seemed to normalize. Peter was eventually able to return to work and they felt truly blessed to have received such a gift – their prayers had been answered.

Peter did quite well for four more years with no further reoccurrence of his cancer... until now. About a month ago Peter began to act oddly and could not recognize his family, then he had a seizure. A CAT scan of his brain showed that the tumor had not only re-grown, but now there were a total of four tumors. He had been at home on medicine to reduce the swelling in his brain until he began to get worse. Now he was in the hospital and the neurosurgeon had told them that he could not operate on Peter again – there were too many tumors – there was no further aggressive treatment that they could offer. The doctor suggested they talk to hospice.

I received a page from the neurosurgeon requesting a hospice consult with Peter and his wife. This meant that the doctor believed that Peter had a prognosis of six months or less and was a candidate for the hospice program. I called the nursing unit to see if family was present since the patient was having some confusion. The nurse stated that the patients’ wife Linda was there and acknowledged that I could meet with her within the hour. When I arrived, the nurse said that Linda had become very anxious and stated that she had to leave – missing my appointment. She did not return my phone calls. The following day, in the presence of an old friend, I evaluated Peter. Peter slowly told me of his journey, of what had recently been found in his brain, of how he was working just a few weeks ago and now how “it looks like they can’t do any more for me”. A few minutes into my visit Linda arrived. Pleasant, controlled, talkative – until I introduced myself. Such an obvious response of fear and panic ensued. She could no longer make eye contact with me while she hurriedly began organizing the snack items and vitamins that she had brought to Peters’ room, giving him directions on what to take and when. As her pace quickened her tone became high pitched and strained as she said “I am just not ready to meet with you - I

can't talk to you – I can't deal with this – I don't want to deal with this.” Before I could respond, the phone rang and she continued her hurried pace as she gave instructions to one of her children who was preparing for a concert performance the same evening. My heart ached for her as I experienced the evidence her pain. I could sense in her that the only way that she was keeping from completely falling apart was to stay angry and in control of things, routines, schedules. I softened my voice and with as much casualness as was appropriate, let her know that I understood that she was juggling a lot and that it was okay, I could continue my conversation with Peter and perhaps she could arrange a time the following day for us to meet.

She was only able to speak by phone the following day, but we were gradually able to talk about end-of-life issues. She was so angry, focusing on the fact that Peter had “beat it” before – “why can't he beat it this time?” “Why is the doctor so sure that another surgery won't help?” And perhaps the most common argument I hear; “ I don't think we are ready to give up yet”. We talked of how patients cannot control the course of disease, particularly now in the later stages. That when we talk to patients about "giving up or not giving up" – it somehow implies to them that we believe they have the power to change the course – but they don't. She briefly cried as we talked about how we are never quite ready to say goodbye to someone we love, and how families play perhaps the most important role in helping the patient prepare. As I began to ask her questions that helped her to focus on Peter and what she believed to be important to him, her anger faded and she began to concentrate on how they as a family could support Peter in his desire not to be back in the hospital. While acceptance of her husbands' terminal illness still remained very difficult for Linda, Peter was able to die at home with hospice care after his discharge home from the hospital.

## RITA

Rita was diagnosed with breast cancer four years ago, had her left breast removed and then received chemotherapy and radiation therapy. She remained free of disease until one year ago when they discovered that the cancer had invaded several bones and a small area of one lung. She began chemotherapy treatments again. I met Rita recently in the hospital after they discovered that the cancer was now in her liver and had spread throughout her lungs. A hospice referral was made and I visited with Rita after reviewing her history. She recounted for me her struggles through treatments and how difficult it was to hear that the cancer was not only back, but was aggressively spreading even while she was on chemotherapy. When I asked Rita what her understanding was of her illness and what the doctors had told her to expect, she said “that I only have a short while to live”. Rita was 42 years old.

As we talked, she shared with me that her husband was having difficulty accepting that her cancer was back and that she had a limited amount of time left to live. She had tried to talk with him, to prepare him, but he always avoided the topic and would tell her to “think positively – you're gonna get better”. This was the ultimate barrier. She cried as she talked of her two children and how she feared leaving them. How could she be sure that they would be okay and that

she would have a chance to say goodbye if she couldn't even talk with her husband and discuss even the possibility that she may die? As I asked how I could help, her husband walked in to her hospital room. He asked her why she was crying and she began to try to explain to him that the doctor had told her that the cancer in her lungs was getting worse. He interrupted her saying, "Shhh, Rita, its okay, don't worry, everything is going to be okay and you are gonna get better and come home." Rita was silent and looked at me with sorrow-filled eyes as if to say, "See, can you see what I've been telling you?" It was clear that she had no words that could provide an answer. Silence hung in the air until I said, "Hello, I'm Sharon, the hospice liaison – Rita and I have been talking about her cancer and some of the things that are most important to her at this time." He stood up straighter and the tone in his voice changed as he said, "What do you mean *at this time?* – it's not like she dying". I allowed the question to linger for just a moment. He glanced at Rita, then back at me as his expression changed and he asked meekly, "Is she dying?" and I gently replied, "Yes." He sat down on Rita's hospital bed and wept. Rita held him as he cried, comforting him with some of his own words, "Shhh, it's gonna be okay -- I've accepted what's happening, but we have to talk – we have to make plans". She beamed with peaceful contentment as he looked at her a moment later, continuing to cry, and said, "I understand ... I love you...I just don't want you to die". That was the truth. It was then that the honesty began and they were able, for the first time, to truly share what was facing them as individuals, as a couple and as a family.

Difficult dialogs and bittersweet moments like these are common throughout this journey as people struggle, grow and prepare to say goodbye. We must remember that our presence, our very willingness to share honestly in their experience, can improve a patients' quality of life and provide with them the sense that they are not alone on this journey.<sup>7</sup>

#### METAPHORS and ENIGMAS WITHIN THE DIALOG:

Some of these I have brief comments or discussion to share, others could encompass another entire paper.

Not curable – this comment, given as a prognosis from physician to patient is far too subtle and for some, benign. I did not see this clearly until I asked a patient what their understanding was of their disease process (which was cancer) and he very pleasantly replied, "My doctor says that they can't cure it." Left with a sense of incongruity between my knowledge of the gravity of his illness and his seemingly carefree reply, I asked him, "What does that mean to you?" He stated, "It means that they can't cure it – I'll have this cancer until I die." This patient, who did not seem to have a less than average intelligence, understood from his conversation with his physician that this cancer could not be cured – but what he did NOT understand was that this cancer would end his life prematurely.

We believe in miracles – a common statement from patients and families as they try to explain why they are not ready to talk about hospice or end-of-life. This is

also a huge dilemma for a portion of the Christian community as they feel that they are denouncing the power and ability God has to heal them if they consider or plan for death. Never discounting their belief in or desire for a miracle, I share that in my experience working with many, many patients, miracles DO happen – but very often they come to us in different ways and not always in the form of physical healing. Miracles may come in the form of physical comfort and pain relief, healing of family and relationships or in many other numerous ways that may provide spiritual peace and comfort. I also have spoken with the patients’ and families who believe that they should not even consider death because they would be discounting Gods’ ability to heal. If entering into spiritual belief territory feels appropriate and not threatening, then my question to them has been, “If we know that we look forward to be in His presence and that He desires ultimately to bring us to Himself, why then is death viewed as an adversary?” “Isn’t our ultimate wholeness and completion in Him?”

He/she isn’t ready yet – this I commonly hear from providers and I have come to understand that it usually means no one has really talked to the patient about end-of-life issues. There may be several reasons for this; the patient may avoid topics that reflect the life-threatening nature of their condition, or the physician may be uncomfortable discussing possible treatment failure. More often than not, it may be a combination of factors that lead the provider into assuming that the patient is not ready to discuss end-of-life issues. But again, while this is also indicative of poor end-of-life communication skills, its foundation is beneficence.

I’m (he/she is) not ready to give up – this undoubtedly could encompass an entire paper. Why do we feel as if coming to terms with our mortality and actually preparing to die is “giving up”? - as if we somehow are in control of whether our body gives up or not? Like I said – content for another paper.

## DANCES

I often talk with patients and families about how this journey truly is a journey of growth. While it perhaps sounds like a corny cliché, this has been my experience. For the most part, people grow and learn to adapt to circumstances and conditions that perhaps they once thought were unacceptable and intolerable in theory. Their social reality, their script, is changed, and to whatever degree they are able, they adapt. “It is crucial for health care providers to recognize that personal growth can occur during life’s final stage and that it is valued by patients and their loved ones.”<sup>3</sup> Providers can facilitate, support and guide opportunities for growth and communication by becoming skilled in patient-centered communication, providing meticulous symptom management, recognizing the uniqueness of each journey and using our knowledge and experience to prepare patients and families for what lies ahead.

Of course some people will not have an end-of-life experience that embraces growth or tolerates change or even allows them to experience

acceptance and closure. But if we believe that quality of life is self-determined, then we must respect each individual's right to make choices that may even seem incongruous to our idea of a good death.

CATHY

Cathy was forty-eight years old when she was first diagnosed with Stage III ovarian cancer. We had little contact and even less specific knowledge of her battle with cancer as she had all but separated herself from her family; Cathy was my cousin. I had the opportunity to travel to her city for a bio-ethics conference and decided to call her and ask if I could visit. I was pleased that she wanted to reestablish contact and I looked forward to seeing her, even for a few hours before my flight. How shocking it was to see this cousin of mine, who bore such resemblance to my sisters, looking like a patient who was nearing the final stages of her disease process. Her face gaunt, abdomen so swollen with fluid that she appeared pregnant, legs so swollen from her lymphadenopathy that she had difficulty walking. With any amount of exertion she had difficulty catching her breath. As we sat on her sofa to visit, I realized how different this conversation was going to be.

We exchanged distant pleasantries; her house, the city, the bio-ethics conference I was attending. But a new tension entered the room when she asked how I enjoyed my job. There was a sense of awkwardness as I explained how I love being a hospice nurse and how sharing in a patient's final journey is such a precious honor. As I answered her questions, I talked about my frustrations related to doctor-patient communication and how difficult it seems for many doctors to talk to patients about their prognosis and end-of-life care.

We eventually came to a place that I felt it was time to say, "So how is everything going for you – what kind of treatment are you undergoing?" She had been on chemotherapy for nearly four straight years and changed doctors when they chose not to treat her as aggressively as she wanted. She had sought out an experimental trial at a major university but was declined due to the extensiveness of her disease. The previous week she had to have a blood transfusion and was also having her abdomen tapped and fluid removed nearly weekly. Cathy had fought so hard to be as normal as possible, some would say to deny her disease, but I don't think that it was that simple.

Many of the challenges and heartaches patients' face involve the slow dwindling of their independence. Cathy bound her abdomen daily so that the swelling and distention was not quite so obvious. She also went through a twice a day exhausting ritual of three layers of binding to her legs to reduce the swelling, discomfort and appearance of abnormality. If a patient can avoid the external signs of the changes within, perhaps they can stave off the realization that this is truly happening. Is that denial? Or rather is it preservation of a mind that is choosing not to accept or confront the possibility that death may come.

Cathy had a circle of friends and colleagues where she lived, but no one else. Who would care for her, I thought? A person who is fighting to maintain independence has difficulty accepting that the question even needs to be

addressed. She spoke of when her doctor mentioned hospice to her, she said “There was no way that I was ready for that – I still wanted to fight.” The fact that it was spoken in the past tense intrigued me. “Have you thought about how hospice could help you now?” I asked. “No, I think hospice is for when you are ready to die, and I don’t think that I am ready to die.” “The doctor has told me that chemo is no longer working – but I want one more treatment before I stop”. Ambiguity is not uncommon in patients as they face a terminal illness. The script has been changed, but some, with good cause, have trouble with their re-written part. I asked if she had given any thought to what she did and did not want in regards to end-of-life specifics like being resuscitated, but she hadn’t considered her options. Amazing to me for a person who, in my opinion, was so close to death. We spoke frankly about the issues of resuscitation, intubation, artificial-ventilation and the sometimes fine-line of prolonging death rather than promoting and prolonging life. The visit ended with Cathy talking of what her hopes were for her two sons, a sign that perhaps she was indeed thinking toward acceptance and closure. Unfortunately, that never happened.

Cathy came to California to stay at my mom and dad's home just two months after my visit. My mom, Cathy’s aunt, had welcomed her into their home and would care for Cathy as she died. However, Cathy hadn’t yet come to terms with what was happening, but she had evidently come to the realization that she could no longer manage on her own. She had two grown sons who longed to repair their relationships with her and say goodbye. They could see the changes in her and tried to talk with her about necessary decisions, but she continued to spend most of her time avoiding meaningful conversation. She was estranged from her father and other members of her family, including a brother, but gave no indication that repairing those relationships was important. Perhaps it is most painful to watch patients suffer the pain and consequences that come as a result of NOT making decisions. The dance was a difficult one.

Cathy, who had been fiercely independent, was now living in a bedroom of someone else’s house, with only a few of her belongings. While her lack of decision making was respected as her right, there were other things where she had few rights. She was no longer safe to drive and was denied the ability to do so, she could not smoke in the house with the oxygen and she was reliant on other people for her care. All very necessary for her safety as well as the safety of others, but nonetheless, very difficult.

Within weeks of her arrival, Cathy was hospitalized. The staff tried to talk with her about end-of-life decisions and she avoided them, said she’d talk about it tomorrow when I was due to visit. I visited and she avoided making any decisions or discussing her changing status. Her boys grieved as they saw her drifting away but continued to experience her evasion of any opportunity to have meaningful conversation. Her estranged father visited and she kept silent, never speaking to him, a precious chance at healing lost. She finally made a decision about her care when an oncologist came into her room and had a very straightforward conversation with her and told her that she was dying, soon. He then told her something that I will be forever grateful for, he said, “There comes a time Cathy when we are no longer prolonging someone’s life, but rather, we are prolonging their death.” She then, still with some ambivalence, decided not

to have resuscitation and to go home with my mother. But even with that decision made, and being so close to death, she still wasn't sure about accepting hospice! My mom explained that the only realistic way for her to be cared for in the home environment was with the assistance of hospice. She agreed, and came home that afternoon. The following day she started a rapid downhill course and I went to help care for Cathy.

Most patients who have struggled and fought so hard to avoid death usually come to a place of peace, a place of acceptance. Cathy did not. I stayed up with her into the night, trying to ease her breathing from the excessive pulmonary edema – but there was no comfort to be had for Cathy. She was anxious, but was so weak that she could no longer talk. As I wiped her face with a cool cloth and quietly sung to her, she remained agitated. As I held her hand and gently said, “Cathy, you have been so brave and fought so hard, its okay now just to rest” – she removed her hand from mine, opened her eyes to look at me and made an angry face. That was the last time she opened her eyes. A few hours later, she restlessly died. As I personally struggled with why I couldn't make the journey better for this person, my own family member, I reminded myself – quality of life and conversely death, is indeed self-determined.

#### MR. WALKER

I called him Mr. Walker - not Ed, which was his given name, but Mr. Walker. Although he had a humble existence living in a small, run-down motel room, he commanded a sense of natural respect. Some thought of him as a hermit who had little time and few words for people. He claimed he had no family. The only friend he had was a woman who also lived in the motel and came by a couple of times a week to check on him and bring him his whiskey, cigarettes and a few groceries.

Mr. Walker had lung cancer. My very first visit to see him was when he made it clear to me that I would never get him to stop smoking or drinking and I should expect him to “get it over with” if he should ever not be able to care for himself. I wanted to make sure that I understood what he was trying to communicate, so I applied a gentle tone to my question as I started to seek clarification. My wonderful, gentle communication efforts were cut short as I heard, “Look, its simple, when I can't wipe my own ass anymore I'm going to use this gun and blow my brains out” he said, as he pulled a handgun from the pocket of his beloved recliner chair. I was speechless. While I had never had a gun waved before my face, I did not feel a sense of danger from this man, he was simply matter- of-factly informing me of his intentions. Of course, I then needed to establish that Mr. Walker had no immediate suicidal ideation's, which, after our visit, I felt confident that he did not. He enjoyed his life as it was; watching TV, smoking, drinking, sleeping in his recliner chair, and being independent. He told me that he did not WANT his life to end, only that he wanted me to understand what was important to him and what he would not want to endure.

As a hospice team we reviewed the circumstances and the social worker helped me draft a plan to support Mr. Walker but also protect his safety. It took several visits to establish a solid rapport and relationship of trust with Mr. Walker. He had evidently fired other nursing agencies that had provided care for him after they attempted to impose their values and norms upon him. Mr. Walker could not be imposed upon – but I found that you could bargain with him. After he began to trust that my goal was not to come into his home and try to change him, we reached a bargain. I did not tell him that he had to change his plan, but rather, I requested that he talk to me or call hospice at any time of the day or night BEFORE he would consider going through with his plan. He didn't have to think but for a moment before he agreed.

Over the many weeks that followed, he gradually declined in strength. He charted his own course as he refused oxygen so he could continue to smoke and then seemed a bit perplexed when I didn't argue with him but simply told him that he could change his mind at any time. He later accepted oxygen and learned to reduce his smoking so he could use his oxygen more often. As he weakened and was not able to get up and walk around like before, Mr. Walker developed bed sores on his buttocks from sitting in the recliner chair that he refused to leave. These wounds needed to be cleaned and bandaged several times a week and I feared that this would be an indicator to him of the intolerable conditions he had foreseen. It was not. Mr. Walker grew, and though his script was changing, he was changing with it. Mr. Walker died in his recliner chair, his gun still tucked in the pocket, having never been used. He taught me great lessons in autonomy, humility, respect, and the art and value of striking a bargain.

Meaningful, effective communication in any relationship is at times difficult and seemingly unattainable. In the professional context, communication skills are the tools by which we exercise caring and compassion.<sup>7</sup> In our personal relationships, communication is the dance by which we share ourselves, our emotions and our desires. As we dance to the script, it is familiar and comforting. But when the script has been changed, our reality is altered and the dance becomes unfamiliar. One of the many profoundly moving moments in end-of-life care is when a patient or family find peace even as the dance changes.

## ROBERT AND JACKIE

Jackie was on hospice at the age of sixty-three because her physician discovered that her breast cancer had spread to her brain. Although she had had chemotherapy and also had received radiation therapy to her brain in an attempt to reduce the growth of the tumors, we anticipated that she would only live 2 to 4 more months. Robert and Jackie were an amazing couple who after thirty-four years of marriage, were still clearly in love and intent on making each other happy. It had been hard on both of them as Jackie was becoming more forgetful and was getting increasingly frustrated with Robert – and quite frankly everyone. Over the last two weeks, she was having a harder and harder time walking and was frequently falling, but she continued to refuse to use the walker

even though we were all worried about her safety. She was struggling as she realized she was losing her ability to walk independently. Jackie also was having difficulty in safely managing her own medicine as she became more forgetful. We tried to simplify her medication regimen and wrote down a schedule for her to follow to help her maintain control, but she was no longer safely able to do it alone. It was very difficult when, a week later, Jackie acquiesced to using the walker, and Robert started helping her with her medicines.

My next visit was very different; this time there was a great amount of tension, even from Robert. Jackie questioned the medicines Robert handed to her, wondering if they were the correct ones, then she snapped at him because he had forgotten to bring her the coffee that she had asked for thirty minutes before. Robert, very out of character, angrily mumbled as he got up to get her coffee. Neither of them uttered a “thank you” or a “here you go” as he handed her the cup and then again left the room. I excused myself, leaving Jackie to visit with a neighbor who had just arrived, and I followed Robert into the kitchen. I asked him how things had been going and he got a bit teary and explained that things had not been good and that he didn’t understand how they could be angry with each other when they don’t have much time left. We proceeded to have a conversation that helped me to understand them both better and ultimately helped them understand their changing dance and emotions;

Robert was five years older than Jackie, twenty-four when they married. He had worked hard as a civil engineer, planning for their retirement together, but Jackie’s cancer challenged all that he had imagined for their future. He became her caregiver through her surgery and the months that followed when she was sick from the chemotherapy. She was so grateful, and easily expressed it, to have his love and his help through such a difficult time. When Jackie grew stronger, retired early and was free from cancer for several years, they rejoiced together. Then they found that the cancer was back and the script changed again. Jackie did not seem grateful for his help now, but lately she seemed angry most of the time. Robert only wanted to comfort her, to fix all that he could for Jackie, and he couldn’t understand why it wasn’t working- or why she didn’t seem to appreciate his efforts. Robert was also dealing with his own pain, which was evident as he told me through his tears, “ It wasn’t supposed to be her, it was supposed to be me.”

This was when a part of his script became clear. He went on to share that he had a major heart attack several years ago, not long before Jackie found the lump in her breast. It seems that Robert had always believed, especially after his heart attack, that he would be the first to die – that was his script. I listened a while longer before I asked, “How can I best help you?” He answered, “I just want to love her.” We spoke about how difficult this journey is for the person who is preparing to leave – that it is not her choice and how powerless that is, and also how powerless it is to love them and feel like we can not make it better for them. We heard the front door close as the neighbor left from her visit and we went back out to join Jackie. As we began to visit, I remembered a wonderful poem of sorts that I had with me, and because Jackie was an individual who loved things written down (the more lists the better), I decided that this might be a helpful tool. As I sat and read this to them, the tension faded as they began to

see and understand this journey, and their changing dance, in a different light.

## **Bill of Last Rights**

The dying voice sounds an ongoing request for basic human rights, last rights that belong to the dying because they are still among the living. Caregivers of the dying need to continually remind themselves of these last rights, perhaps reading them before and after each visit.

### **The right to be in control**

Grant me the right to make as many decisions as possible regarding my care. Please do not take decisions from me. Let me make my own decisions.

### **The right to have a sense of purpose**

I have lost my job. I can no longer fulfill my role in my family. Please help me find some sense of purpose in my last days.

### **The right to reminisce**

There has been pleasure in my life, moments of pride, moments of love. Please give me some time to recollect those moments. And please listen to my recollections.

### **The right to be comfortable**

The pain involved in dying is multifaceted. Although not all of my pain can be taken away, please relieve whatever portion you can.

### **The right to touch and be touched**

Sometimes I need distance. Yet sometimes I have a strong need to be close. When I want to reach out, please come to me and hold me as I hold you.

### **The right to laugh**

People often – far too often – come to me wearing masks of seriousness. Although I am dying, I still need to laugh. Please laugh with me and help others to laugh as well.

### **The right to be angry and sad**

It is difficult to leave behind all of my attachments and all that I love. Please allow me the opportunity to be angry and sad.

### **The right to have a respected spirituality**

Whether I am questioning or affirming, doubting or praising, I sometimes need your ear, a non-judging ear. Please let my spirit travel its own journey, without judging its direction.

### **The right to hear the truth**

If you withhold the truth from me, you will treat me as if I am no longer living. I am still living and I need to know the truth about my life. Please help me find that truth.

### **The right to be in denial**

If I hear the truth and choose not to accept it, that is my right.

Author - unknown

For Robert and Jackie, hearing these words, seeing them written, validated for Jackie the pain and grief that she had been feeling and also empowered Robert with understanding of Jackies' complex, yet simple needs. They shared apologies, cried and then laughed together as they talked of some of the recent things that had angered them. While they still had times that they tripped over each other's feet, the dance became easier. I smiled to myself the next time I visited, when in their kitchen I noticed the "Bill of Last Rights" posted on their refrigerator.

### **DILEMMAS**

There are many dilemmas that arise throughout this journey, effecting patient, family and providers. Some that are ethical, some moral, some logistical, some that are simply painful because they challenge and endanger who we believe that we are and all that we have ever known. But however difficult the journey, each of us need to hold fast to the knowledge that we always have something to offer to those who are suffering; the gift of our ingenuous presence. Sometimes a quiet touch and the silent conveyance of compassion and empathy are often times more therapeutic than all of the academic knowledge accumulated over the years. While not all providers are comfortable with communicating end-of-life issues, skills can be learned and practiced – but communication of facts without presence is inadequate.

When I teach this concept to staff and physicians they often ask for clarification. So I explain that five minutes can be spent in a patients' room in two ways; 1) walk in hurriedly, avoid eye contact, do not call them by name, stand at the bedside, ask closed ended questions, give the information you have for the patient, check your watch and leave. 2) walk in hurriedly, make eye contact, call them by name, sit at the bedside, ask open ended questions, inform the patient that you have information to share with them before you share it – this gives opportunity for the patient to decline, continue to make eye contact, ask if they have any questions and after answering them, thank them and leave. Which method exhibits presence? Both methods conveyed and gathered information, but only the second method truly should willingness to be present, and the patients recognize and feel the difference.

Apart from compassionate communication, improving a patient's opportunity for growth and closure at end-of-life is also intimately linked to

meticulous symptom management. A patient may not be able to experience all that is possible or enjoy relationships if they are struggling with uncontrolled pain, nausea or other quality-robbing symptoms.

## JEAN

Unfortunately, Jean's story is not an uncommon one. I met Jean in the hospital after she was admitted for "pain out of control". For weeks she had been suffering at home with pain in her back and legs related to the cancer which had invaded so many of her bones. While she was taking pain medicine, it just was no longer enough. Jean was a teacher and desperately wanted to keep working as long as possible. She was scared to increase her pain medicine for fear that she would not be able to function as a teacher, but she could also no longer tolerate this amount of pain. As I questioned her about her pain, she cried as she told me that for the first time in her life and battle with cancer that she felt that life was no longer worth living – she just wanted to die because the pain was so severe.

Such tragic circumstances; her pain, left out of control unnecessarily had brought her to this place of darkness where she could not eat, could not sleep and worse yet, could not see the value in the life she had remaining. I held her hand and let her talk about her fears of dying and leaving her young children and that perhaps her even bigger fear was that this horrible pain would get even worse and that she would die a miserable death. I reassured her that the priority right now was to get her pain controlled so that she could get some restful, solid sleep. I worked with the physician to readjust her medicines and provide her with some relief and was pleasantly surprised to find her sitting up eating breakfast the following morning after having had her first restful night in many weeks. Jean was so grateful – by the following day she was looking ahead and wanted to talk about how she could make some special memories with, and for, her children during the time that she had remaining. With assistance from hospice, Jean was able to remain in pain control and never again had to question whether her remaining time with her family was worth it – she made every moment count.

One of the most complex dilemmas that can face a health care provider is when someone says, "don't tell." This brings about a myriad of complications and ethical issues for all that are involved.

If we consider that quality of life is self-determined, this implies complete patient autonomy in theory. I have shared patient stories that reflect self-determined quality of life by omission or commission, so to say. That is, people have a right to make choices, or to avoid make choices, all of which impact their quality of life – therefore, it is self-determined. However, if we are to honor a patient's autonomy, we must assure that they are receiving all information necessary with which to make an educated decision, or that they have been offered the information and defer decision making to an agent. As a hospice and palliative care professional, one of my goals is that whatever choices a patient

makes, whether seemingly incongruous or not, they be made based on honest, complete information and treatment options, offered to them by caring health care professionals.

This, of course, takes a full circle back to issues of providers' comfort and skill in communication and discussing end-of-life issues. So what becomes of patient autonomy when a family member says, "Don't tell"?

It becomes imperative to ask of the family member why they believe that not informing the patient would be the right thing to do. I have had families take a "don't tell" position for a variety of reasons. For example, family members reveal that in their culture, it is not appropriate, even disrespectful, to give news of a terminal condition to the patient. Some cultures believe that this knowledge will cause the patient to forfeit any remaining will to live and rapidly die. In this circumstance, it is important to express consideration and honor for their culture while offering insight as to the medical ethics that surround issues of patient confidentiality and autonomy in our culture. A compromise that I have offered shows respect for cultural norms and also honors our obligation to protect the patients' right to their information. I explain to the family that we honor the patients right to name an agent, a proxy decision-maker for themselves, but we must first ask the patient if they would like the information (test results, diagnosis, etc.). While this particular circumstance is not the norm for "don't tell", I have had three such cases, twice the family has understood and the patient has deferred the information to a proxy, and the other case the patient chose to receive the information and be her own decision-maker.

It is more common that the family has greater difficulty in providing a reason for their desire to withhold information. Often times it is simply their perception of how the information will effect the patient and the family desires to protect them. Quite often, in these circumstances, we can educate the family as to the adverse effects of withholding information from an adult who has the right to be their own decision-maker. We may also need to gently make them aware that while they believe they have a moral right to determine what information their loved one receives, they do not have a legal right.<sup>8</sup> The only exception to this would be if the patient has completed a new (2001) Advance Care Directive for Health Care and marked the box that gives their agent or proxy immediate decision making ability even though the patient may still have decision making capacity. This newly re-formatted legal document is an excellent option for patients who, for whatever reason, wish to have someone else assume their decision making prior to their loss of capacity.

A more common dilemma for providers, patients and families is in making decisions about life-prolonging or life-sustaining treatments. These decisions can be heart wrenching and difficult.

## GLADYS

Gladys had been a diabetic for decades and over the last few years she had been experiencing many complications that are common to diabetics. She

suffered from terrible neuropathy that caused penetrating burning and tingling in her hands, legs and feet. Two years ago her kidneys stopped working and she had to start on hemo-dialysis three times a week to clean her blood. When I met Gladys she was in the hospital, no longer able to walk or even get out of bed. I saw her daily for a week to evaluate her pain, she cried nearly every visit and spoke of how she did not want to “live like this” anymore. Soon her pain was controlled and she was resting more comfortably and willing to receive more visits from her husband and friends. Soon she began to have worsening bedsores. Her nephrologist told me that he felt she was in the end stages of her renal failure and diabetes and he spoke to her briefly about end-of-life options and asked if I would continue the conversation.

As I spoke with Gladys, she shared the things that brought her joy; gardening, reading, needlepoint and listening to music. She felt that the only thing that she could now enjoy was music – Gladys had lost most of her sight several months before. When we talked of things she did not want, she decided that she did not want life support or life-prolonging measures and that she did not want to be in a nursing home. She then asked what dying would be like if she were to stop dialysis and, how long would it take to die. I was not surprised by her questions because she had given every indication that she knew her body was slowly dying and that her quality of life would not improve but only worsen.

The next day when I saw her she told me that she had decided to stop dialysis. She then began to cry and told me that I could not tell her family because they would not understand or approve of her decision. I reminded her that her husband had told her two days before, while I was visiting, that he would support her in whatever choice she made. She cried and shook her head and said that he didn't really mean it. I promised her that I would not tell them until she was ready. That night she did something that no one but I understood – she ripped out the dialysis catheter which had been sewn into her chest- the only access that they had to give her dialysis was now gone. She told the staff that it was an accident, but I knew better. Now Gladys was able to peacefully and painlessly slip away and enjoy having her family at her bedside – but she did not have to explain or justify her personal choices - and neither did I.

## IN CLOSING

There are many more very important stories, memories of journeys that are unique to each patient and each family. We as health care providers are written into their script for only a short time, but they each touch our lives with the intimacy of the journey they share.

Maggie Callanan, author of Final Gifts, offered the analogy that hospice and palliative care professionals are “like child birth coaches at the other end of life - we help to ease the transition from one place to another”.

May all health care providers strive to coach the final journey with passion - bringing honesty and empathy to the dialog, comfort and guidance to the dance and integrity and wisdom to the dilemmas.

“As death approaches we do not need to turn away in fear. Instead we can choose to celebrate life and join hands with those we love. We can sing and dance and make merry in the face of the lengthening shadow. We can take the time that remains to add a few magical moments to our book of memories. And when the twilight falls and the moon rises and the one we love passes from us, we can take solace in the knowledge that we embraced and said good-bye.”<sup>9</sup>

---

## REFERENCES

- <sup>1</sup> Biblical text. Psalm 139:14.
- <sup>2</sup> Steinhauser K, Christakis N, Clipp E, McNeilly M, McIntyre L, Tulsy J. Factors Considered Important at the End of Life by Patients, Family, Physicians, and other Care Providers. *JAMA* 2000;284:2476-2482
- <sup>3</sup> Pearlman R, Cole W, Patrick D, Starks H, Cain K. Advance Care Planning: eliciting patient preferences for life-sustaining treatment. *Patient Education and Counseling* 26 (1995) 353-361.
- <sup>3</sup> Larson D., Tobin D. End-of-Life Conversations: Evolving Practice and Theory, *JAMA*. 2000;284: 1573-1578
- <sup>4</sup> Silveira M.m DiPiero A., Gerrity M., Feudtner C. Patients' Knowledge of Options at the End of Life: Ignorance in the Face of Death. *JAMA* . 2000;284:2483-2488.
- <sup>5</sup> Morrison MF. Obstacles to doctor-patient communication at the end of life. In: Steinberg MD, Youngner SJ, eds. *End-of-life Decisions: A Psychosocial Perspective*. Washington, DC: American Psychiatric Press; 1998:109-136.
- <sup>6</sup> Kubler-Ross, E. *On Death and Dying*, NEED PUBLISHER AND DATE INFO
- <sup>7</sup> Larson, D. *The Helper's Journey: Working with People Facing Grief, Loss and Life-threatening Illness*. Champaign, Ill: Research Press; 1993.
- <sup>8</sup> Randall, F. Downie, R.S. *Palliative Care Ethics: A Companion for all Specialties*. Second Edition. New York, N.Y: Oxford University Press; 1999.

---

<sup>9</sup> Menten, T. *Gentle Closings*. As quoted by McNees, P. *Dying: A book of Comfort*. Garden City, NY: Guild America; 1996.