HM medical guide to dying

Which topic is more troublesome for you: Death or Dying. Many people fear the dying process more than death itself. Commonly expressed concerns are dealing with pain or other symptoms, being dependent or a burden to family or caregivers, and getting the medical care you need. Others are more concerned with death and the psycho-spiritual issues associated with it.

This section concentrates on two main issues: How to have your wishes respected at the end of life (Part 1 *Advance Care Planning ACP)* and how to get the best medical care during a terminal illness (Part 2 *Treating the person).* Both require ACP—Advance Care Planning. Both require considering “worst case scenarios” which include sudden death from an accident, stroke or heart attack. Certain mortal illnesses like dementia occur over an extended period of time. Others like advanced cancer (Stage IV or metastatic) have shorter more predictable time frames and problems such as pain control.

**Part 1 Advance Care Planning ACP and Advance Directives AD**

Advance care planning isn’t just about the end of life. Realistically ACP is about how you live your life right now. Recognizing that death awaits you makes such planning more urgent. You can’t wait until you get a “Round 2 IT.” Making important plans in the midst of a crisis doesn’t lead to the best decisions.

Firstly you need to examine what you want when you recognize that mortality applies directly to you; it is not a theoretical exercise. Using the Go Wish cards can stimulate you to consider things you might not have thought of. The deck of 36 cards include such possible wishes as *To be free from anxiety, To maintain my dignity, To have close friends near.* These cards are particularly useful for couples or families to initiate conversations. They are available at [www.codaalliance.org](http://www.codaalliance.org).

The most important parts of ACP are the conversation that occur with your surrogate, your family and your doctors. Even if you cannot complete an AD it is important that you select a representative who will speak for you if you cannot speak for yourself. This must be someone you trust to present your wishes (so you have to make sure that person understands them clearly) even if someone objects (like a family member who hasn’t come to terms with your dying or a doctor who wants to try *just one more treatment)*.

Your representative isn’t making the decisions. They are simply representing what YOU HAVE ALREADY DECIDED if you can’t speak for yourself. If you wish you can also request that they or some other person(s) speak on your behalf if you don’t wish to speak.

Having conversations about death and dying are neither simple nor easy. Most people avoid having them. There are trained personnel available in many hospitals or organizations who can facilitate such conversations. Unless it is an emergency situation such as in the Intensive Care Unit or Emergency Department, such facilitated conversations take time and persistence.

Here are some questions to ask yourself about an advance directive.

* What do I want and not want at the end of life.
* Who will speak for me. Who should **not** speak for me.
* What is the *one thing* I want my family, friends and health care providers to know about my wishes. Specific areas to consider include medical, legal, financial and spiritual.

I wrote an article called *Repealing Murphy’s Law* (if something can go wrong it will go wrong) which is posted on the website (karunabv.org under Teachings, week 3). It addresses the kinds of things that can interfere with your AD working the way you want. Below I have included the “appendix” I wrote for my own AD to at least show you how I, as someone with medical experience, has approached the topic.

**Appendix 1 to Five Wishes Instructions for my surrogate and family**

I wish treatments that make my life worth living according to the following values listed below. If treatment has little chance (less than 5%) of returning me to a life I deem worth living I do not wish life sustaining treatment started. If it has been started then I ask that it be stopped if there is a less than 5% chance of recovery.

The outcome of serious illness is always ambiguous. I wish decisions made based upon the prudent opinions of my doctors at the time, which should be offered as if they were making the decision for themselves if they were in my circumstances.

**The values that make life worth living.**

I wish to be comfortable physically. Unpleasant symptoms should be treated to allow comfort. If side effects of treatment cause their own problems then I wish my sensorium maintained clear enough to communicate meaningfully with those I love UNLESS I indicate pain levels of 7 or more out of a 10 point scale. In that case make pain control the highest priority.

The most important value is to be able to communicate with those I love. I wish no impediment to that and request my environment support this communication. If I am unable to think or communicate—and have <5% chance of regaining this capacity—life is not worth prolonging.

The next most important value is to be cognizant of my environment and aware of my thoughts and feelings. I have always been a thinker and wish to remain so. If there are illnesses or injuries or anticipated treatments that would prevent me from thinking clearly be aware that if I cross the point where I can no longer understand myself or environment (e.g., dementia, CVA, brain injury, etc.), life becomes much less worth living. I do not wish life prolonged under these circumstances if they are irrecoverable.

I would prefer to remain active but would accept a life limited in physical movement if it could not be avoided.

I do not wish to avoid death but be alive as long as I find life worth living. The problem with death is the saying goodbye to those I love, and their sadness at losing me. I hope to prepare all of us for my death which “will come when it will come.” (Julius Caesar, Shakespeare) I have additional instructions for the different ways I may become incapacitated.

**Sudden event such as accident or stroke that leaves me unable to communicate what I want.**

If the event is so severe that even if I regain consciousness I will be so impaired that I would not regain awareness of my environment, of other persons, or self-awareness I would not wish life sustaining treatment.

It may take some time to determine this and life support may be initiated. If it is the opinion of at least 2 physicians (including a neurologist) that the chances of my recovery to a satisfactory state are <5%, life support may be withdrawn. If they cannot make this determination within 30 days I wish life support withdrawn. If in my surrogate’s opinion and there is family consensus that I am suffering **and** they, too, are in distress at my status, at 30 days from the initial event life support should be withdrawn A satisfactory state is one in which I am able to communicate so that I am understood and I can understand the persons around me.

**Progression of a chronic disease such as malignancy, heart failure, etc. so that I am unable to communicate, that state is not likely to change, and death is likely to occur in </= 6 months.**

I would request to be on comfort care, whether Hospice or not, and symptoms managed well. Symptoms of infection, shortness of breath, pain, and any other distress should be treated but not with antibiotics, transfusion if actively bleeding or other treatments which would prolong my dying.

**Development of dementia so that I am unable to communicate, or recognize family, or not able to improve with whatever current treatments are available.**

I would find this state unsatisfactory and wish life support withdrawn. Life support interventions such as tube feeding, ventilatory support should not be done though oral feeding and oxygen are acceptable.

**Part 2 Treating the person**

Medical care today is delivered by a team. Some teams are organized by the medical system that treats you. Other teams are organized or expanded by the patient and family. Second opinions are routine now and doctors are not upset if you request one. For terminal illness a Palliative Care team is frequently part of your treatment. Palliative care simply means that the person’s needs are specifically addressed, especially symptom control. Some studies show that when palliative care is started at the same time that cancer chemotherapy is begun patients live longer than those who receive only the chemotherapy. Palliative care is NOT HOSPICE and does not imply any expected life span.

Palliative care is not always routinely offered and you may have to request a consult. That is your prerogative and will not interfere with the rest of your disease-focused treatment. Most University medical centers and many hospitals have palliative care divisions.

Optimally, medical care while you are sick and not expected to be cured focuses on treating the person as well as the disease. Treatments are designed to improve the quality of life (QOL) as well as length of life. In some cases there is a trade off. Side effects of surgery or chemotherapy are tolerated because life is prolonged and any decrease in QOL is temporary.

I have written a chapter entitled *Patient experience of Malignant Mesothelioma* for a medical textbook on this type of cancer which starts in the pleura or outside membrane of the lung. It will be published April, 2017 by Springer. Since this is a pre-print I request that you not share this with other people. The book is intended primarily for doctors and I have written it from that perspective. The sections included, however, are relevant to patients as well. The chapter presents what I consider an optimum way to treat patients. At the same time it describes how treating this type of cancer which has a very high mortality impacts physicians as well.

The following sections are rather lengthy. I believe each of them has useful information but would start with *Principles*. The following sections on Treatment plan and End Game offer perspectives on how I would like to be treated if I had a terminal illness

**The Patient’s Experience of Malignant Mesothelioma** in **Asbestos and Mesothelioma, ed. Joseph Testa, MD**

PRINCIPLES

1. Principles of a Patient’s Experience of MM

Successful care of a patient with Malignant Mesothelioma (MM) requires both medical treatment of the disease and understanding the experience of the patient. Both disease and its treatment have associated symptoms that compromise patients’ life spans as well as their quality of life. A comprehensive treatment strategy looks at the psychosocial context and needs of the patient. It leads to a better experience for patients and a more rewarding one for medical professionals caring for them. Several principles provide the basis for understanding the person and developing an integrated treatment plan.

1.1 *Largeness of Life*

The goals of treatment go beyond curing the disease and extending life. From the patient’s perspective simply living more days is not sufficient. That is only one dimension, length of life. Another dimension is the height of Quality of Life (QOL). Prolonging a miserable existence or painful death is of little value to the patient. Medical success, however, is generally measured in the time dimension as Disease Free Survival or survival from time of diagnosis to death. Health related quality of life HRQOL, the vertical dimension, may not be a specified goal though validated measures do exist. (Hollen PJ, Gralla RJ, et.al. 2006) ([Mollberg NM](https://www.ncbi.nlm.nih.gov/pubmed/?term=Mollberg%20NM%5BAuthor%5D&cauthor=true&cauthor_uid=22921241), [Vigneswaran Y](https://www.ncbi.nlm.nih.gov/pubmed/?term=Vigneswaran%20Y%5BAuthor%5D&cauthor=true&cauthor_uid=22921241) wt.al. 2012) Even HRQOL, however, does not capture the true extent of patients experienced QOL since other unmeasured factors are equally important. **(**Clayson H, Seymour J, Noble B 2005) ([Salmon P](https://www.ncbi.nlm.nih.gov/pubmed/?term=Salmon%20P%5BAuthor%5D&cauthor=true&cauthor_uid=9081350), [Manzi F](https://www.ncbi.nlm.nih.gov/pubmed/?term=Manzi%20F%5BAuthor%5D&cauthor=true&cauthor_uid=9081350), [Valori RM](https://www.ncbi.nlm.nih.gov/pubmed/?term=Valori%20RM%5BAuthor%5D&cauthor=true&cauthor_uid=9081350). 1996)

Patients’ daily experience of life includes health related symptoms but also includes issues of satisfying social roles, pleasant or unpleasant emotional states and an intact or damaged sense of self. Quality of life can be measured by the balance between painful or unpleasant symptoms versus enjoyable experiences. Diminishing the distress of any symptom increases QOL.

The third dimension is the depth of meaning or sense of purpose. Without a reason or motivation to go thru treatments that have significant side effects patients may decline them. The intangible and difficult to measure *Will to Live* often depends upon having a reason to live. Sense of purpose or meaning in life is generally considered a spiritual issue, in- or outside of religion. *Man’s Search for Meaning* describes Viktor Frankl’s experience in Nazi concentration camps and has led to a school of psychotherapy that emphasizes the importance of meaning in life for healthy survival. (Frankl, V 1992) The association of meaning and well-being can be traced back to Aristotle. ([Ryff CD](https://www.ncbi.nlm.nih.gov/pubmed/?term=Ryff%20CD%5BAuthor%5D&cauthor=true&cauthor_uid=25435804), 2014) The ability to make meaning in difficult situations gives individuals greater resilience, the ability to cope with adversity and even to survive. Studies of persons with cancer showed that in early stages of disease most were well adjusted. With disease progression only 1/3 remained well adjusted. Established meaning of life, value systems and personal religion helped individuals adjust.( [Majkowicz M](https://www.ncbi.nlm.nih.gov/pubmed/?term=Majkowicz%20M%5BAuthor%5D&cauthor=true&cauthor_uid=25261670), [Pankiewicz P](https://www.ncbi.nlm.nih.gov/pubmed/?term=Pankiewicz%20P%5BAuthor%5D&cauthor=true&cauthor_uid=25261670), 2014)

Sense of purpose is created by the individual but it can be supported or thwarted by others. Understanding what is important to the patient offers the medical team a window into that person’s life. Taking into account what they value helps the team make treatment decisions. When extending life is unlikely and there are few medical options to improve their quality of life, supporting patients’ value system can still make their lives larger. Ways of doing this range from adjusting chemotherapy schedules to let them visit a new family member or attend a wedding. End of life care may be organized around supporting patients and families find closure, which goes beyond just orders for comfort care. Questionnaires have been developed to measure the meaning of life to individuals. There are tools that allow meaning of life to be measured. ([Salmon P](https://www.ncbi.nlm.nih.gov/pubmed/?term=Salmon%20P%5BAuthor%5D&cauthor=true&cauthor_uid=9081350), [Manzi F](https://www.ncbi.nlm.nih.gov/pubmed/?term=Manzi%20F%5BAuthor%5D&cauthor=true&cauthor_uid=9081350). 1994)

Presenting the concept that the goal of treatment is based on a three- dimensional model, *Largeness of Life*, gives both patients and physicians a way to maintain a positive and valuable goal even as the focus of treatment changes. It maintains realistic hope that there is something good possible when prolonging life is a less obtainable goal. It also encourages patients to be active participants in their treatment. This perspective enhances the doctor-patient relationship and often makes caregivers job easier. The most important benefit of presenting care in this manner is that it avoids increasing patients’ despair by being forced to tell them *there is nothing more we can do.* Rather physicians can say *we can help you in a different way.*

1.2 *Nature of Suffering*

Eric Cassel’s seminal article, *The Nature of Suffering and the Goals of Medicine*

(Cassel E, 1982) defined suffering as a threat to the integrity of the person and occurs when an impeding destruction of the person is perceived.

Suffering can occur in relation to any aspect of the person, whether it is in the realm of social roles, group identification, the relation with self, body or family, or the relations with a transpersonal, transcendent source of meaning.

Suffering is distinct from pain though it may include pain. This is particularly true under certain circumstances,

Patients feel out of control, when the pain is overwhelming, when the source of the pain is unknown, the meaning of the pain is dire, or when the pain is chronic... Another aspect essential to an understanding of the suffering of patients is the relation of meaning to the way in which illness is experienced.

To understand fullythe patient experience of MMcare providers must recognize that suffering goes beyond physical symptoms. Threats to self-identity, social and family roles, body image, loss of soverignty or autonomy can be just as debilitating as tumor invasion of ribs or costal nerves. Loss of self is a fundamental form of suffering in the chronically ill. (Charmaz K 1983) That kind of suffering does not respond to morphine and requires a different approach.

1.3 *Family experience*

Persons are different from patients. The patient is described in the context of a disease. They have a relationship both with the disease and health professionals treating them. Becoming a patient does not replace being a person. That distinction may be lost when focus on treating the disease becomes so central and little attention is paid to other issues. Patients expect doctors to use all their technical skills and concentrate on curing their cancer. They appropriately believe that is the doctor’s job. Their wish for health professionals to treat them as persons is also strong. It is unspoken and often revealed only by their disappointment with care.

Persons live in the context of a family and social system that has their own expectations. Persons need psychological support as well as physical care. Persons are defined in many dimensions. They have families who have expectations and may have to make adjustments in their lives if the person is unable to go shopping or drive the children to soccer practice. They have jobs in which they earn the money to provide for their dependents. Persons have activities they enjoy like playing golf, walking along a beach, playing the piano and socializing with friends. When they become patients engaged in treatment of their MM many of these activities are interrupted. Even a threat to such pursuits causes suffering if these things are important to that person.

Family members often provide medical care for loved ones beyond simply driving them to an appointment. If the patient, for that is what they become to family members as well as nurses and doctors, is not eating enough the spouse worries. Families have the same fears of the future the patient does.

1.4 *Team approach*

Patient care requires a team to provide solutions to the complex problems MM creates. This can be most obvious at tumor boards where medical oncologists, surgeons, radiotherapists and other professionals confer and develop a treatment plan. Large medical centers have other resources available such as palliative care, nurse specialists, social workers, physical therapists and support groups. Hospice organizations, for example, are required to provide spiritual care. Personnel trained specifically to do this are part of the team that already has nurses, social workers and a physician.

Developing a comprehensive care plan to address both the medical and psychosocial needs of patients and families requires a team. Not only are multiple perspectives needed to recognize all the problems, multiple personnel are need to provide solutions. Not all physicians treating MM have these resources already available. It becomes necessary to network with other services in the community and form ad hoc teams. This is vital for both patients who need the services and caregivers who can be overwhelmed by trying to provide them.

TREATMENT PLAN

Treatment Plan

3.0 Developing a strategic treatment plan

In the life of patients diagnosed with MM there are several points which offer opportunities for doctors to obtain information about patients and then guide them to better outcomes of the disease. By considering these points and asking patients the right questions, clinicians can intervene to prevent problems. Even if the patient dies, when they help patients maintain their quality of life, families see providers as caring people and doing the best job in a difficult situation.

3.1 Before Diagnosis

Even before the first encounter patients have a history of prior experiences with illnesses and stories they have heard about other people’s experience with cancer. Patients have already developed some ability to cope with significant events, established some kind of support system, and have defined who they are in terms of their roles and activities.

Patient histories customarily include past medical illness, family history and sometimes social or lifestyle history. This information gives some picture of the person but is incomplete. The context of the person’s life is also important. This includes occupational history, a description of the family and social environment in which they live and their educational level. Additional information is needed about socioeconomic status, spiritual or religious practices, drug and alcohol use, and particularly the ways the person has responded to stress in the past. With this information providers develop a more complete picture of the human being and can recognize areas of their strengths and vulnerabilities.

Clinicians also have their own history. Their training and prior experience with mesothelioma is likely to determine the treatment choices they prefer. Their prior experience with patients generally lead to certain expectations of patients. Their conscious and subconscious attitudes toward cultural, racial, gender, socioeconomic and physical appearance of the patient can influence they way they treat certain individuals. The doctor’s communication style including body language, style of interpersonal interactions and her or his definition of the patient-physician relationship also affect how that patient will be treated.

Persons do not prepare to become patients but physicians can and do prepare to care for them. Many elements of professional style are unconscious. Doctors prior exposure to mesothelioma and to patients have already set some habits and affect current behavior. The attitudes toward patients as well as expectations of themselves are malleable and can be consciously modified. It is natural to want to repeat experiences that turned out well. The experiences that have created doubt, remorse, or a sense of failure can be starting points to develop other behaviors that are closer to the clinicians’ vision of what they want to become.

When subconscious behaviors are brought to awareness they can be examined and future conduct modified. Optimally this is viewed as a part of continuing medical education. A potential danger of such self-examination can be unwarranted and sometimes brutal self-criticism. Too often doctors pass off their exemplary behavior as “just what is expected” and don’t acknowledge the good they do. Calling attention to one’s self might be viewed as bragging. Receiving praise from colleagues can become an occasion for brushing off compliments rather than simply saying thank you for the comment. Doctors strive to improve their medical skills. That same motivation can be used to develop more proactive and effective ways of working with patients.

3.2 At the Time of Diagnosis

Patient expectations of whether they will live or die are often set at the time of diagnosis. This is based on *how* they are told as well as *what* they are told. Previous experiences of illnesses affect their beliefs about what is likely or possible for themselves. This is particularly true for stories about other persons’ experience with mesothelioma and other cancers.

A common presentation for pulmonary mesotheliomas is pain and shortness of breath with a chest X-ray showing a pleural effusion. A therapeutic thoracentesis may be done in the emergency department to relieve symptoms. Patient or family questions may lead the one doing the procedure to mention the possibility of cancer. The mention of cancer can bring patients to the psychological edge of a cliff with a profound need for more information. The patient or family members may importune the provider with a barrage of questions. Their questions cannot be answered at this point because the information isn’t available. Only their fear is present. Sensing that fear can pressure the provider to offer reassurance. If handled well, the patient may accept that there are several possibilities and that an organized diagnostic process is beginning. When told they will have to wait for answers they may be left with more fear, more confusion and sometimes less trust in the medical system.

Optimally the patient will be referred immediately to another clinician, either primary care or specialist, with experience in pulmonary disease. The prompt referral can prevent the patient from feeling completely helpless and adrift in a complex medical system without guidance.

The roles of the clinicians as well as the sequence in which they see the patient may determine how they present information to them. The thoracic surgeon may be required to do the biopsy if prior thoracentesis and cytologies were not diagnostic. They may then become the physician who first tells the patient the diagnosis. If someone else has already played that role then the surgeon may be required to discuss both the surgical procedure and prognosis.

The first doctor to tell the patient they have a mesothelioma is in a critical position to influence the patient’s course. That clinician must assess where the patient and family are emotionally. Whether they are the provider who manages the patient’s emotional needs or not, the way patients are first told their diagnosis has a profound effect on future encounters.

Some patients will be in such shock they are unable to process factual information. At the same time accompanying family may have myriad questions and need or even demand answers that only lead to more questions. Acknowledging an individual’s emotional state can help build trust. That person then feels recognized and their position legitimized. There are several ways this situation can be handled.

*This news must come as a shock. It can be hard to take in all the details. Many people have lots of questions. Tell me what you know about this rather rare type of lung cancer. Perhaps I can then answer your questions in an organized fashion.*

Depending upon the responses, clinicians can direct the conversation to the one in most distress letting the others know they will have their questions answered later.

Until the most pressing emotional needs are addressed there is little room for information about treatment or prognosis. Sometimes providing such information can’t wait until a later appointment and the physician must find out who is best equipped to receive it. An anxious patient still needs reassurance but this may come from another person such as a nurse or family member. Letting them know you understand their situation and will address it as soon as you can may be enough to give them some relief.

Presenting the diagnosis in this way creates the basis for trust that the person is seen and important. That helps diminish the threat of being alone in a dangerous situation. Other areas of potential suffering can be addressed later as the clinician gets more detailed information about the patient’s life. Such questioning builds further trust because it indicates the clinician is interested in the person not just the disease. Other providers may ask the questions and gather information that can predict the patient’s coping abilities, support resources, and areas of vulnerability where additional measures will be needed. The goal of this process is to develop a strategic treatment plan that prevents as much suffering as possible and empowers the patient and family as they go thru treatment.

*Tell me what you understand of what you’ve been told.*

*What have you heard or read about mesothelioma?*

*Sometimes the statistics can seem pretty grim. Yet there are some people who unexpectedly do very well. Do you think you might be one of them?*

*Most people will need help at home after surgery. Who can you call on to give you help while you’re recovering?*

*Everybody has been in situations where they felt overwhelmed. What helped you cope with things when you faced difficult situations before?*

Chemotherapy and radiotherapy may considered along with surgery. Presenting the case at tumor board can help make such decisions, allowing integrated treatment. It is also an ideal time to involve social workers or other therapists who can provide patient and family support if care is needed.

Patients are confused if they hear markedly different views about the need for and success of various treatments. Developing and articulating a clear plan can prevent this. If there are multiple options or treatment pathways possible acknowledging this ahead of time may help patients tolerate ambiguity or uncertainty. Maintaining dialogue with patients reassures them that their needs will be addressed and can help answer even unasked questions.

Patients are most vulnerable when discussing prognosis. They know their future is threatened but not the magnitude of the threat. Doctors likewise are vulnerable to the dilemma of giving unrealistic or false hope versus painting too bleak a picture and giving false despair. Care providers generally want to allay patient fears and maintain hope. One danger of giving too optimistic an outlook is damaging trust and the patient-physician relationship when adverse events happen. The danger of presenting too dismal a future is that false despair can destroy hope and decrease patients’ motivations to receive possibly life-prolonging treatment.

Evasive answers to patient questions about prognosis or just giving numbers without context is also unsatisfactory. Few patients understand the statistical concept of *median survival* and only hear that death is inevitable if numbers like *50 % are alive at one year* are offered. It takes skill to tell patients that even if the glass isn’t half full there is still something at the bottom that is worthwhile. Acknowledging that prognosis is a statistical concept and doesn’t apply to individuals can allow patients to consider they might be in the small group of longer term survivors. At this point it is useful to ask patients more questions about how they see their future.

*I recognize that only some people have prolonged survival. Do you think you might be one of them?*

*What would you need to help you be in that group?*

*If you don’t think you’ll be one of the lucky ones, what do you want to do? Would you want to try some treatment and discover whether it works for you?*

*Should we try to help you live as best you can for the longest time you can?*

Some patients will make decisions because that is what their family wants, not what they want. Though that type of reasoning can be authentic for them it raises the possibility that these patients may not be genuinely motivated to go thru treatment and suffer side effects. It also raises the question about whether there will be family conflicts at the time that Advance Directives become a dominant issue.

Ethically physicians have a fiduciary obligation to respect patients’ requests. Pointing out that there might be conflicts between the patient’s and the family’s goals shifts the need to establish consensus back to the family, not to the doctor.

There can also be conflicts within the physician treating the patient. Doctors are trained to fix problems (Gawandi, 2014). Specialists have developed skills in their particular field, surgery, chemotherapy or radiotherapy. Doctors’ desire to do something, especially the modality they do best, may influence the way they make decisions and present options to patients. Doctors need to be aware of their own bias to insure patients’ needs are foremost.

3.3 During Treatment

Managing side effects, being aware of impact on family and maintaining hope are the main issues during treatment. Each modality has its own constellation of side effects and impacts various individuals differently. The balance between patients’ coping abilities, the intensity of side effects and the success of supportive interventions determines both how much patients suffer at the time and how they view the future. The most common side effects are pain, breathlessness, fatigue or low energy and limited activities. Pain and shortness of breath are most amenable to medical treatment.

Pain management is part of every doctor’s responsibility. Complex pain syndromes, however, may require palliative care involvement. Not all pain responds to opiods. Fear of overdose often results in under-dose and unrelieved pain. Patients describe pain differently to doctors than they do to nurses and especially how they describe their pain to the family. Getting multiple assessments of the pain’s intensity is often necessary. The pain scale from 0 to 10 is not linear but more S-shaped. Values between 5/10 to 9/10 tend to be more proportional to actual differences in the degree o pain. Reports of pain at 9/10 or 10/10 often reflect anxiety. Pain reports of greater than 4/10 generally require treatment. Patients and family views on pain and pain management are often based on misinformation. Correcting such beliefs often can improve pain control though not everyone will take the medicine to diminish their pain.

Fear amplifies almost any complaint, especially pain. Providing explanations before treatment, giving information on the expected duration of pain (post-operative pain for example) and exploring the meaning patients and families place upon pain can both reduce its intensity as well as strengthen coping skills. Correcting assumptions that any pain means the mesothelioma is growing diminishes the pain and makes it less frightening.

Families watching their loved one in pain often feel helpless and such experiences are very stressful to them. Teaching patients and families techniques like guided imagery or meditation gives them some sense of control and empowers them. Teaching stress control techniques like Mindfulness Based Stress Reduction or MBSR addresses many of the global symptoms of being ill. Such courses are widely available in hospitals and other health systems.

Decreased energy and diminished capacity to maintain customary activities and roles is common with any treatment. Such inability to do what previously has defined their lives is a source of suffering beyond physical symptoms. Patients can no longer be the person they thought they were. Such interruptions in personhood can’t be prevented but their impact can be mitigated. Often side effects are time limited and patients can be reassured that their disabilities are temporary. They and their families can be creative and find substitutes for many activities. Cooking in the kitchen can become menu planning and having help while shopping. Supervising others doing the cooking may return a sense of agency and control. Managing business activities by phone or online seated at home is better than just watching TV. Colleagues and co-workers can visit and bring work with them.

The most difficult yet most widely effective is dis-identifying with certain roles. We are foremost human beings and may perform in the role of parent, manager, salesperson or teacher. The most common way we identify ourselves is *I am a doctor* though we are equally a *son* or a *sister* or a *parent*. Keeping this perspective opens up the possibility of deeper exploration of who they really are. This philosophical question may bring individuals to seek the help of others who have wrestled with such questions themselves. It also makes it more likely that substitutes for previously pleasurable activities can be found. If appropriate, guidance from clergy or counselors is possible.

The most useful measurement of the impact of treatment is functional status. Asking about broad areas of life including family activity, hobbies and social events is just as important for measuring suffering as finding out how far a patient can walk without stopping or whether they get dressed and out of bed for most of the day.

The effect of treatments on families can be complex. A family member may be required to do technical things such as dressing changes or managing a chest tube. They may also be need to clean up the bed if the patient is incontinent or interrupt their schedule to drive their father to doctors’ appointments.

Both patients and families think about the future as well as cope with the present. Though the patient deals directly with physical symptoms, families imagine what their loved one feels. Their imagination of how they would feel in the other’s shoes may be much worse than what the patient is actually experiencing. Patients may have doubts about their future. Families have both doubts and are doing anticipatory grieving, even if only subconsciously. A spouse may be imagining life without their partner and perhaps feeling guilty for doing so.

Generally the care team focuses on the identified patient. Families and caregivers also have significant distress and needs of their own. Social workers and counselors can become important resources for everyone. There are specific tools to measure the degree of distress for all involved. The NCCN has published guidelines on Distress Management including a *Distress Thermometer* and a listing of various sources of distress ranging from physical symptoms to worries about child care, dealing with a partner and depression or anxiety. As with the pain scale, global distress numbers of 4/10 or greater require attention. The specific sources of distress can guide the type of referral needed. Studies show that over 40% of lung cancer patients have significant distress. (Holland JC, Alici Y, 2010)

3.4 Living with Active Disease

Both patients and their families live now with the question “When?” rather then “If?” Depending upon the degree and type of denial thoughts of death and dying are present in their minds. Appropriately used denial can be a useful coping strategy. Without acknowledging the total impact of an event individuals can process parts of the situation by digesting smaller pieces and not become overwhelmed by the whole. This is the suggested strategy of *how to eat the elephant: one bite at a time*.

Unless this process becomes a way of avoiding preparing for the outcome, the care team can be patient and not confront the person. If certain actions or decisions must be made in a specified time frame the care team has to find a way to let the individuals hold on to a portion of their denial and yet confront the other facts necessary for a decision. Doing this takes skill and practice. Some team members may be better at handling this task better than others.

Pathologic denial presents a different problem. Clinicians must assess the probable consequences patients and families will face if they don’t develop other coping strategies. During this active phase of the disease the goals are to maintain the best global quality of life possible. If denial is creating more suffering, conversations about worst-case scenarios can be introduced. Even if it is presented as a theoretical problem or “what advice would you give another person?” suggesting additional ways of coping can be introduced and encouraged.

There are different styles of coping. Often physicians and nurses who must act or make treatment decisions will tend to confront problems directly. There can be a tendency to push this style on patients or families who are not yet prepared to adopt this style. Understanding that the person is actively chewing on the last bite of the elephant and intends to take another bite soon makes *expressive* denial acceptable. Expressive denial is what a person may say to others. It is the *internal* denial that prevents the person from taking necessary actions that becomes problematic.

Even if the most significant physical symptoms have diminished, patients still may be suffering. They have had to accept their *new normal* that does not include their previous activities and roles. The distress associated with this situation may not need formal psychological counseling. Talking with other respected individuals like clergy, good friends and family members or reading from the large selection of self-help books about coping with cancer may be sufficient.

Some physical symptoms may remain and need to be treated. Asking patients about symptoms that prevent certain activities allows focusing on the most important areas. A common complaint is low energy. Letting the patient know that simple walking rather than running or that lifting small weights rather than heavy weights can improve energy may take away the common psychological resistance to exercise which has been shown to improve both energy and mood.

Another common problem is persistent pain and misinformed beliefs about pain management. The fear of addiction or overdose has increased as there is more media attention to such issues. This can affect physicians as well as family members or patients and can lead to underdosing needed medications. Pain that prevents desired activities should be prevented or treated. Side effects like constipation can be easily avoided. Inappropriate beliefs about opiod toxicity can be addressed. Ultimately the larger context of the problem as end of life care can put these issues in perspective.

END GAME

4.0 End Game

There is no defined start to when the End Game begins. Loosely it is the time either professionals or patients realize they are nearing the end of life. Patients may not be actively dying but they recognize that treatments are failing. Doctors may know that the life expectancy is short even while therapy continues to offer some chance of prolonging life. For patients the End Game has clearly begun when they decide to stop treatments to prolong life and concentrate on comfort care. The paradox is that they should already have been receiving measures to comfort them and prevent suffering long before this.

4.1 Physicians recognize that further treatments are not beneficial.

Doctors are in a curious bind. They have several sets of values which conflict with each other. Medical ethics includes the principles of *Do No Harm, Benificence or Do Good,* and *Patient Autonomy.* There are personal human values also. *Do the best I can* is expressed as not wanting to exclude a chance to help even if it is of low probability. *Avoid failure* is a value expressed as avoiding self- or patient-criticism for giving up. The expectations held by doctor and patient alike are never to stop trying for a cure or at least a longer life. If you do give up you are somehow a bad person. *Maintain the doctor-patient relationship* is a value which is manifested by trying to give patients hope because this is what they need.

Conflict can occur when professional training and experience tells doctors that the patient is going to die regardless of treatment but feel they *have to do something, they can’t just stand there.* What doctors have been trained to do is to fix problems. Rarely are they trained to deal with situations they can’t fix. (Gawandi A, 2014) Perceived patient expectations seem to demand that the doctor must do something to help them. Yet doctors don’t feel they have anything to do that will truly be beneficial except perhaps to maintain the fiction of hope. (Gilligan T, 2012)

Depending on whether the physicians’ personal beliefs or the cultural ethical beliefs are stronger at the moment, treatment may be offered. To resolve cognitive dissonance doctors support their decision by increasing the probability of success and decreasing the impact of side effects. Thus the End Game is delayed because there is something seen as beneficial to do.

Different outcomes are possible, however. Physicians can either be trained in other ways of helping patients or refer to those providers already trained. Sometimes this is a palliative care team or a Hospice provider. In all situations providers can use the existing doctor-patient relationship that has been built on trust. This relationship can be more powerful that doctors realize. Like other important relationships it requires honesty, openness and the willingness to be vulnerable. Patients do not always expect to be fixed. They may be more appreciative of the relationship than disappointed when even best efforts didn’t work. Physicians may confuse the fact that a treatment failed to produce the desired effect with a sense of personal failure.

4.2 Patients recognize that further treatments are not beneficial

Patients likewise are in a bind. What if they decide to forgo further treatment? The implications of disappointing family, doctor and their own expectations can be overwhelming. Patients likewise want to do the best they can, avoid failure and maintain relationships. In addition they may begin to understand they are actually dying and that death is not far away. Practical and existential fears arise whether it is death itself or the process of dying that is most present.

Patients may long ago have reached the conclusion that treatments are not offering benefit commensurate with cost. Willingness to continue depends on hope that treatment will give something valuable. If the person’s quality of life is too low and there is little expectation that it will improve, a *what’s the use?* feeling develops. Something else that will provide better quality of life with fewer side effects becomes preferable. If there is no belief that something else will make life worth living, then allowing a natural death becomes an option.

In those situations patients face the problem of telling family that they want to stop treatment. Patients may have gone past any sense of personal failure or disapproval for not trying harder but families may not have accepted those conclusions. For them, patients stopping treatment can be perceived as a failure. The family *didn’t do enough, they didn’t try hard enough* and hence are to blame for the patient’s decision. Though family may have witnessed the suffering, they have not experienced it personally and not reached the conclusion *that’s enough!*

It’s hard to face a disappointed or disapproving family. Patients are dependent on them for support. They may fear abandonment if they don’t conform to family expectations. Depending on the communication style in the family this process may be more or less difficult. If the care team perceives there is coercion then someone may need to facilitate the conversation. This can be particularly important with end of life decisions in which patients may want to end life support and families cannot let go.

Patients fear abandonment by their doctors. *Will you still take care of me if I don’t take the treatments?* There are times when doctors either directly or indirectly tell patients they can’t take care of them any longer. Patients’ may place more importance in the doctor-patient relationship than they express directly. Asking if their doctor will continue to care for them if they stop treatment makes them too vulnerable to rejection. Given the asymmetric relationship the onus falls upon doctors to reassure patients they won’t be abandoned. Even when patients are referred to other caregivers, it is a simple act of courtesy to send a note to patients letting them know the doctor is still thinking of them.

Only infrequently do doctors, patients and families reach the conclusion simultaneously that there is no benefit from continuing treatments. Defining the goals of treatment as having the *Largest Life* possible at the beginning of treatment provides an opportunity to maintain hope, quality of life, and consensus between parties throughout the disease. Life-prolonging treatment can be presented as a balance between having a longer life but, at least temporarily, a decreased height of quality of life. Such a cost-benefit analysis is both truthful and accurate. Expressed this way both caregivers and patients can be flexible in their assessment of benefit. Patients and families provide the source of adding the depth of purpose and meaning in life. Assistance from religious or spiritual advisers and counselors can also be important. Increasing sense of purpose or even legacy may remain a way to increase the largeness of life when nothing else will.

4.3 Difficult conversations: Responding to requests for non-beneficial treatment

In California case law has determined there is no obligation for doctors to provide *non-beneficial* treatment. The choice of wording, *non-beneficial*, is important rather than *futile.* It is easier to define a specific treatment for a specific purpose as not having benefit if the ethical values of *doing good* and *avoiding harm* are considered. The ethical value of *patient autonomy* does not present a compelling reason to give such treatment since the law does not require doctors to do so.

In spite of this analysis, conversations about refusing to accede to patient or family demands for treatment are still difficult. If they are handled sensitively they need not result in angry denunciations of each other. It can prevent patients or families storming out of the room to find another care provider who will agree with them. This situation can be defused if each party recognizes and acknowledges the feelings and points of view of the other. Patients or families may need to maintain hope to avoid dealing with fear of dying. Both hope and fear look at an imagined future. Hope sees a desired outcome and fear sees an undesired outcome. Depending on the strength of individual coping styles movement away from needing hope may not be possible. Nevertheless, dealing with emotions directly can allow parties to agree to disagree on a specific course of action.

4.4 Difficult conversations: Discussing changing goals of care

The immediate goals of care frequently change. An underlying longterm goal may remain while decisions about doing surgery or changing chemotherapy shift the goals of care to post-operative recovery or weighing the chances of response versus side effects. The bigger goals of prolonging life or maintaining quality of life are not in conflict. Their immediate priority does change. Side effects are tolerated if a longer life is the highest goal. Patients’ needs for comfort remains, there is just a bargain between one goal and another.

For both patients and doctors there may be a sense that accepting quality of life as the highest goal means eliminating treatments that prolong life. Defining hospice as the treatment for *less than six months life expectancy* has made hospice seem like a place you only go to die. Hospice in some minds means abandonment and hopelessness. Palliative care, which may be less widely available than hospice care, is given regardless of life expectancy. Nevertheless, it may carry the same stigma as does hospice. The belief may be that palliative care is given when there is nothing else to be done. Though incorrect, some physicians may still hold this view. Palliative care was recognized as a medical specialty with board certification in 2006 but is yet not familiar to the public.

According to Wikipedia (**ref Wikipedia on line 9/9/2016)** *Palliative Care is a* [*multidisciplinary approach*](x-dictionary:r:'Multidisciplinary_approach?lang=en&signature=com.apple.DictionaryApp.Wikipedia') *to specialized* [*medical care*](x-dictionary:r:'Health_care?lang=en&signature=com.apple.DictionaryApp.Wikipedia') *for people with serious* [*illnesses*](x-dictionary:r:'Disease?lang=en&signature=com.apple.DictionaryApp.Wikipedia'%23Terminology)*. It focuses on providing patients with relief from the* [*symptoms*](x-dictionary:r:'Symptom?lang=en&signature=com.apple.DictionaryApp.Wikipedia')*,* [*pain*](x-dictionary:r:'Pain?lang=en&signature=com.apple.DictionaryApp.Wikipedia')*,* [*physical stress*](x-dictionary:r:'Stress_(biology)?lang=en&signature=com.apple.DictionaryApp.Wikipedia')*, and* [*mental stress*](x-dictionary:r:'Stress_(psychological)?lang=en&signature=com.apple.DictionaryApp.Wikipedia') *of a serious illness—whatever the* [*diagnosis*](x-dictionary:r:'Diagnosis?lang=en&signature=com.apple.DictionaryApp.Wikipedia')*. The goal of such* [*therapy*](x-dictionary:r:'Therapy?lang=en&signature=com.apple.DictionaryApp.Wikipedia') *is to improve* [*quality of life*](x-dictionary:r:'Quality_of_life?lang=en&signature=com.apple.DictionaryApp.Wikipedia') *for both the patient and the family.* Derived from the Latin word *pallium*, to cloak or to mitigate. This broad definition corresponds to the concept that the goals of medicine are the relief of suffering. (Cassel 1982) Palliation has always been part of medical care, whether given as willow bark tea or NSAIDs for arthritis. Oncologists offer palliative care when they give an antiemetic for chemotherapy induced nausea, a standard practice.

More recently palliative care has been shown to increase survival in advanced NSCLC when given at the time of diagnosis along with chemotherapy. (Temel JS, Greer JA, 2010) When palliative care is presented from this perspective it becomes a logical part of treatment rather than an abrupt change in treatment. If changing the goal of care to emphasize quality of life is presented not as a failure of prior treatments but of extension of treatment already given, patients may have less resistance. If they are reassured that this is continuity of care and not abandonment the conversation becomes less difficult.

At times the conversation may be more difficult for doctors than patients. Physicians may identify their value to the patient in the surgery they perform or the chemotherapy they provide. They may not have the same training or skills to deal with this situation as they do in their specialty. Some individuals may have chosen to enter medicine to become a healer in the image of Marcus Welby MD, the hero of the medical drama TV program in the 1970’s. They may want to respond to the more human needs of patients but are disappointed when they become simply an interchangeable technician brought in only to do a technical job.

4.5 Avoiding failure: Death is not the enemy.

In spite of patients fighting hard to *beat the cancer*, doctors doing everything they can to cure the disease, and families supporting their loved ones to the best of their abilities, median survival for pleural mesothelioma is about one year. With so much effort spent to extend survival it is easy to perceive death as a failure. The culture supports this conclusion. If we think in terms of *waging a war on cancer*, when patients die it means we have lost the war. After a diagnosis of cancer dying means different things to different persons.

Cultural cancer mythology in the past has suggested that somehow patients were at fault for developing cancer if they didn’t handle stress effectively, didn’t find existential meaning in the disease, didn’t die heroically or died without resolving life issues. Some patients have even felt they were being punished by getting cancer. Dying then became a spiritual as well as medical failure.

There can be shame attached to dying. Patients have their own expectations of themselves. When they cannot (literally) live up to these expectations they may judge themselves harshly. If the failure is perceived more personally, patients may feel guilty. Cultural issues may have them lean more toward one emotional response than the other. The language of medicine also seems to blame patients saying they *failed treatment* if they didn’t respond rather than the treatment failed them.

One of the most painful losses is the loss of a dream. Death of the body may be more easily accepted than the loss of an imagined future. There is pleasure in planning a future retirement, seeing grandchildren grow up or anticipating the activities put off because there wasn’t time. Dying takes away the enjoyment of such planning as well as the actual experience of these anticipated events. It is almost as if death has become a thief stealing the future.

Sometimes patients feel they have let their family down if they don’t perform as expected. This dynamic often plays out over meals. When patients are not hungry and don’t eat, families see the rejection of food as a rejection of their love. Family dynamics are complex. They are often filled with expectations arising from past history. When death cuts short the opportunity to fulfill such expectations both family and patients may see the other as failing them.

There is no simple way for clinicians to discover all the psychodynamics involved. If opportunities present themselves, however, there may be moments when asking questions about what is expected by individuals can reveal critical information. Counseling patients and families about other ways of perceiving what is happening may relieve the sense of failure. Unspoken expectations may be apparent early in the course of the disease. Addressing them promptly may prevent future conflicts.

Physicians particularly may feel that death is a defeat. Medical training emphasizes interventions that change the outcome of the disease process. Cardiac arrest is treated with drugs and defibrillators to prevent death. Surgery is performed to remove localized cancers to extend lives. The medical profession seems to forget, however, that the death rate for persons being born is 100%.

This is the paradox doctors face. They are trained to prevent or delay an inevitable outcome, death. When that outcome is taken personally, death is an enemy. Doctors develop various coping strategies to face death without it becoming a failure.

4.6 Conclusion

Caring for the person with mesothelioma has great challenges as well as the possibility for doing great good. The complexity of understanding and responding to the human being who has the cancer requires a broad understanding of who that individual is and who the care provider is as well. An expanded model of how patients may be perceived allows the development of treatment strategies that prevent suffering and bring greater satisfaction to patients, families and physicians alike.