

A sepia-toned photograph of a creek. In the foreground, several thin, dark reeds or branches are reflected in the water. The background shows a bright sun low on the horizon, creating a shimmering reflection on the water's surface. The overall mood is serene and contemplative.

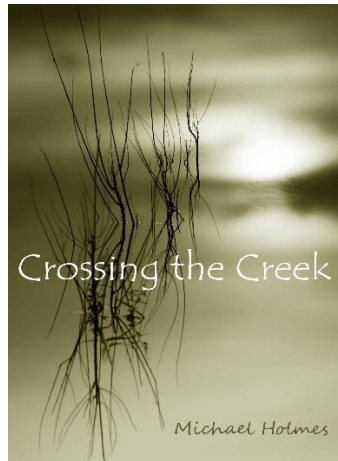
# Crossing the Creek

*Michael Holmes*

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## A Practical Guide to Understanding Dying Process

Michael Holmes, R.N.



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# Table of Contents

<i>Disclaimer</i>	5
<b>Introduction</b>	6
Appetite	8
Bowels	11
Circulation	13
Respiratory	16
Sleeping	20
Confusion	22
Pain	29
Loss of Energy	48
Fear	51
Seeing People Who Have Gone Before	55
Symbology	57
Grief	65
Summary	73

## *DISCLAIMER*

This guide **SHOULD NOT** be construed as a replacement for the assistance of your local physician, hospice, home health agency or palliative care organization. It **SHOULD BE** viewed as a supplement to those things. This guide addresses only general themes and concepts, and represents only the observations, conclusions and opinions of the author.

For specific instruction and assistance with particular tasks, such as how to turn a patient in bed, administer medications or care for a urinary catheter, consult appropriate professionals in your area.

The views expressed in this guide are the opinions and perspectives of the author. They were acquired over years of working with dying people, but do not constitute the only valid perspective on dying process. If the opinions expressed herein clash with your own, stop reading and search for support elsewhere.

# Introduction

This guide is intended to provide dying people and their caregivers with a general description of what they can expect to encounter. While understanding does not eliminate the impact of experience, it can certainly reduce some of the consternation and allay that creeping sense of panic.

All transitions have similar key elements. Also, every person experiences a wide variety of transitions during the course of his/her lifetime. In that sense, there is nothing new in dying process. In fact, each of us develops our own, personal style for dealing with transitions. We tend to stick with that style, whatever it might be, when we face the transition we call death.

If you would like to know how you are likely to handle your own death, look back upon your life and observe how you have handled all your other transitions. Unless you decide to change your approach that is the roadmap you will follow while dying. (For more on this subject, read *Key Elements of Transitions*, also by Michael Holmes.)

While all transitions have similar key elements, this guide, *Crossing the Creek*, deals specifically with the transition of dying. Every person does not experience every sign or symptom described herein, or a person may experience a particular sign

or symptom in his/her own unique way. There is room for infinite variation in how any given individual may experience the dying process.

At the same time, certain general themes are common to all. I have been told many times by caregivers and family members that after reading this book, they then saw it unfold, step by step, in their dying loved one. But even more helpful was that they also knew what each of those steps meant. Rather than being unexpected and frightening, the steps of dying process were anticipated and understood to have a purpose.

It is well to remember that all transitions entail some disagreeable or uncomfortable aspects. Dying process is no exception. No reasonable person expects that life will contain no discomforts, yet some espouse the notion that somehow, death will. This is not a reasonable expectation. Dying process has its difficult aspects regardless of one's level of enlightenment.

Modern medicine has demonstrated a remarkable capacity for mitigating or even eliminating many disagreeable aspects of physical death. At the same time, modern medicine cannot relieve people of responsibility for their own lives. We all prepare for our own death by the manner in which we live our lives. Skilled clinicians can be a great help, but we each bear the ultimate burden of responsibility for how we live and how we die.

# Appetite

## *Appetite decreases*

The patient may stop eating entirely. Indeed, this is to be expected. Progressive loss of appetite is a hallmark of dying process and is a mechanism by which the body keeps itself more comfortable. This is often very hard for caregivers to accept but it is important to listen to what the patient wants and not what you think s/he ought to be wanting. Bodies have been going through this for thousands of years and have worked out effective techniques for keeping themselves comfortable. Pay attention to what the body is saying it wants... or does not want.

As physical bodies progress through the dying process they lose their ability to digest food effectively. If the patient tries to force themselves to eat when their stomach's ability to digest food is diminished, the food just sits there, causing a feeling of being bloated... or like they swallowed a brick. The stomach will likely reject food outright; i.e. vomit, if the patient insists on trying to eat after having lost their appetite.

If the goal is to achieve comfort, then force feeding is a direct contradiction of that goal. Forcing terminally ill people to eat causes them discomfort.



## *Fluid intake*

A dying person will eventually stop wanting to consume fluids as well as solid food. Again, this is how bodies maintain their comfort. Forcing fluids when a body does not want fluids can only cause added misery.

## *Caregiver reactions*

We have been taught all of our lives that how good of a job we are doing as caregivers depends upon whether or not we can get the patient to eat and drink.

However, when someone is in an active dying phase this is absolutely wrong! In the overwhelming majority of cases, people do not die because they stop eating, they stop eating because they are dying. The only reason for an actively dying person to eat or drink anything is for pleasure. If it is not pleasurable then there is no point in eating or drinking. In fact, it is likely to do more harm than good.

There are times when caregivers need to ask themselves: Am I trying to make them feel better? Or am I trying to make me feel better?

## *A Practical Example*

Early in my hospice career I had a lady whose diet consisted of

one maraschino cherry every morning. She craved that cherry and it filled her up. She looked forward to her daily maraschino cherry; she loved it, savored it, it did not upset her stomach and she had no desire for anything more. Eating that one cherry served its purpose; it gave her pleasure... without causing her any distress.

# Bowels

## *Bowel activity slows down*

A decrease in bowel activity goes along with loss of appetite, decreasing physical activity and changes in circulation. Most patients are taking some type of pain medication during their dying process as well, and these medications slow bowel activity further.

Stool softeners and/or laxatives are generally necessary to maintain regular bowel function, but it should be kept in mind that “regular” or “normal” during the dying process may be considerably less frequent than it was while the patient was healthy and active.

For example: If a person has been accustomed to having a daily BM prior to becoming seriously ill, once every two or even three days might be good during their dying process.

## *Cessation of bowels*

As death draws near, total bowel shutdown may be expected. Trying to whip the bowel into action while the rest of the body is shutting down is not sensible and attempting to do so may cause unnecessary suffering for the patient. Again, if the primary goal is to achieve comfort there comes a time when one has to

consider whether laxatives, enemas or manual extraction of stool is achieving more or less comfort for the patient. Your physician or nurse should be consulted to help determine when the time to stop worrying about the bowels has arrived. And of course, the patient is likely to have an opinion on the matter as well.

# Circulation

## *Circulation gradually diminishes*

Circulation shuts down progressively by becoming increasingly centralized. First the outermost circulation diminishes, such as the hands and feet, by becoming cool and perhaps even discolored. Then the legs and arms are affected, and so on.

Fevers may come and go. There may be unexplained sweating, sometimes profuse. There may be swelling of the limbs and other signs of fluid imbalance.

Urine output may fall as the kidneys receive less effective circulation. Then again, the urine output may remain surprisingly high even after the patient has stopped drinking, it just depends on the individual. Fluids shift from one compartment to another within the body and this can sometimes produce a surprising amount of urine in the absence of any fluid intake.

Bodies are composed largely of water. As they move through the dying process and circulation shuts down there are bound to be effects which are noticed by both patient and caregiver. Remember that these effects, while abnormal in a healthy person, may be quite normal for a dying person. One of the most difficult truths for inexperienced caregivers to accept is this: in most cases, some degree of dehydration will help to keep the patient more comfortable.

## *Bedsores*

One of the chief complications of circulatory shutdown is the tendency towards the development of bedsore. Bedsore, or decubitus ulcer, are caused by prolonged pressure; that is, failure of the patient to move periodically.

A person does not have to be in bed to develop a bedsore, they only have to remain in a fixed position for more than a couple of hours at a stretch.

Bedsore can usually be prevented by repositioning the patient at least every two hours. Keeping the skin clean and dry, and gentle massaging with a good lotion are helpful preventative measures. If the patient is unable to reposition him/herself, someone else must do it for them. The patient does not necessarily have to be moved far with every turn, just enough to change their pressure points.

Various types of special mattresses and pads are available to help prevent the formation of bedsore. Consult with your doctor or nurse for assistance in determining what might work best for you.

Despite your best efforts, bedsore may occur during the dying process. Some dying patients are so debilitated that even mild pressure for relatively short periods of time can lead to the development of a decubitus ulcer. If you observe a developing

bedsore; i.e. a persistent reddened area or blister, contact a professional for assistance.

### *Comfort Goals*

The goal in palliative care is to prevent bedsores from becoming a serious threat to comfort. In palliative care there is sometimes a delicate balance between keeping the patient comfortable in the present while avoiding situations which might cause more discomfort in the future.

For example: Moving the patient periodically may cause discomfort. At the same time, not moving the patient can cause serious bedsores and lead to considerable discomfort in the future. The application of good palliative care requires a fair degree of skill and experience. Determining when to discontinue certain aspects of care can mean the difference between comfort or discomfort for the patient and peace of mind for the family. While the term “palliative care” seems clear and uncomplicated on the surface, achieving it is not always so simple. Consult a professional for advice in these situations.

# Respiratory

## *Pulmonary congestion*

Fluids may accumulate in the lungs, but this can usually be avoided if fluids are not forced on the patient... especially IV fluids.

Patients and their caregivers often express a fear of dehydration, yet some degree of dehydration is preferable during the dying process because it tends to keep the patient more comfortable. Being fully hydrated while dying often leads to lung congestion and shortness of breath. Dying people have enough to worry about without having to struggle for air.

## *Airway Rattling*

What was once called “the death rattle” is actually an accumulation of excess fluid and mucous in the upper airway which “rattles” as the patient breathes in and out. Certain drugs can be given to help dehydrate the patient and thus, clear up this rattling. However, these drugs may cause discomfort by themselves; things such as excessively dry skin, mouth and eyes. It is far better to avoid overloading the patient with fluids in the first place than to get caught up in the hazardous game of alternately forcing artificial hydration and dehydration. In most



cases, natural is better.

If upper airway rattling does occur it can be quite loud and disturbing for caregivers to hear. Fortunately, it is seldom as troublesome for patients as it is for caregivers. By the time this phenomenon manifests the patient is usually in semi- or full coma and is not really aware of any physical discomfort.

Suctioning is seldom recommended because it usually causes more discomfort than it alleviates.

To relieve upper airway rattling by suction it is usually necessary to do deep suctioning; i.e. suctioning all the way down into the main stem bronchus or “windpipe.” This requires at least one and often two highly experienced clinicians. It also tends to be very traumatic for the patient no matter how skillfully performed because of the highly sensitive nature of the windpipe. Then, even if successful deep suctioning is accomplished, the rattling will likely return within ten to twenty minutes anyway.

Since upper airway rattling is usually more unpleasant for caregivers than for patients, it may be helpful to remember that the primary goal is to keep the patient comfortable, not the caregivers.

## *Breathing patterns*

As the dying process evolves, certain respiratory patterns may appear. One common respiratory pattern is called Cheyne-Stokes (pronounced: Chain Stokes). This is a regularly, irregular pattern; i.e., the patient takes several breaths, then stops, then takes several more breaths, then stops again, and so on. This is an irregular pattern which repeats itself regularly. The pauses between breaths can be quite long; perhaps half to three-quarters of a minute, sometimes longer. Family and caregivers often find this very unnerving but it seldom is a clear indicator of anything specific... other than the patient is quite ill, which everyone was presumably aware of already.

A respiratory pattern which sometimes appears just hours prior to actual death is a regular, fairly deep, panting pattern. This pattern is driven by the autonomic nervous system after much of the rest of the brain has already shut down. Caregivers sometimes mistakenly think this pattern indicates recovery rather than approaching death because it is so regular and appears to be effective.

A final, or “agonal,” respiratory pattern is called “fish out of water” breathing. This is an ineffectual gasping of the mouth with little or no actual intake of air.

This agonal “gasp” occurs very near physical death.

The final breaths taken at the moment of death are frequently deep, cleansing breaths or “sighs.” Sometimes there are two or three, sometimes only one.

# Sleeping

## *Sleep/dream patterns*

Sleep and dreaming are very important parts of the dying process. Patients sometimes complain about how much time they spend sleeping and comment that they feel like they are wasting what little time they have left. This could not be further from the truth. Much of the necessary work of the dying process takes place during a sleep/dream state. This is not wasted time at all, it is vitally important.

## *The purpose of sleep*

The work of dying process has to do with resolving all the unresolved issues of one's lifetime. This is a huge job and requires considerable effort. It is very important work because death is a transition that prepares us for the next phase of life. It is not smart to enter the next phase of life loaded down with a bunch of unresolved junk from the last phase. Dying process prepares us for the next phase by helping to resolve all of our old junk. This resolutional work can be broken down into different categories, but suffice to say it is a huge task.

The sleep/dream state is very useful in accomplishing these tasks because it gets around the limitations of time and space. It is much easier and more effective to review an unresolved

episode in one's lifetime (which may have occurred several decades previous) while in a dream state than in a waking state.

In the sleep/dream state, one can accomplish a virtual return to the time and place in question.

Ordinarily, we suppose that time travel occurs only in science fiction movies. Not so. The minds of dying people move around in time and space as a matter of routine. Dying process utilizes this capability in order to accomplish its larger goal; to prepare us for the next phase of life.

Interestingly, the normal sleeping pattern during the dying process is virtually identical to the normal sleeping pattern of newborns; off & on around the clock. There is no night or day for newborns or dying people, just dozing off & on, day & night. Sleeping pills seldom have much effect on this pattern since during this phase, this pattern is the norm.

On the whole, total sleep time increases. This gives the patient time to get his/her work done. The nature of that work may or may not be recalled by the patient while awake. Then too, the patient might not be willing to share this information as it may be very personal.

Whether the patient is able to remember the content of his/her dreams or is willing to share them with others is really not important. What is important is that the work of review and resolution get done. Whether or not this is being accomplished can generally be surmised by observing the patient's overall

progress; whether s/he seems to be moving toward a more serene state of mind or is staying stuck in negativity.

Even patients who claim not to remember the content of their dreams will usually reminisce about their lives when they are awake, especially upon first awakening. Virtually everyone who goes through a dying process reminisces about the important events and people in their life. These reminiscences can be important clues as to what is going on in the dreams s/he may not remember (or wish to share.)

# Confusion

## *Confusion – Disorientation*

Dying process is a lot of work. Generally speaking, that work is resolitional in nature and accomplishing it involves moving around outside the constraints of time/space. While this is an extremely useful and effective technique for resolving one's life issues, it can also be very confusing.

We think of time as being concrete, predictable and constant. When we are dying we discover that reality is different than we had previously supposed. We begin moving around in time/space in ways we never imagined possible. One might say that this takes place "only in the mind," but then, as a person experiences physical death s/he becomes increasingly aware of the preeminence of the mind.

Aphoristically, human beings are composed of body, mind and spirit. As the body dies, mind and spirit emerge more powerfully. As the acorn disappears, an oak emerges. While this speaks to the majesty and wonder of life it can also be very frightening and confusing, especially for the individual experiencing it directly. It is particularly frightening and confusing when neither patient nor caregivers realize that moving about in time, while dying, is normal. When patient and caregivers do not understand this

they are prone to conclude that the patient is “losing his/her mind,” and the prospect of losing one’s mind is very frightening indeed. When this begins to occur anxiety levels rise precipitously.

It is important to understand that moving about in time/space, and thus being somewhat confused, is a natural and normal aspect of dying process.

*Example:* A dying man lies sleeping. He is actively dreaming and reliving (as if he were really there) an experience which occurred in 1930. He is reliving an interaction he had with his mother when he was only six years of age. Then suddenly he awakens to see his forty- five year old daughter standing at his bedside. Do you see how this could be confusing?

To be six years old and talking to your mother one instant, then seventy-four years old and talking to your middle-aged daughter the next instant is a very disconcerting and disorienting experience. This is what it is like to be dying; drifting in and out of a sleep/dream state and wakefulness, not always sure which is which, and moving about in time/space as though we had simply pulled up anchor. We say that the dying are “disoriented” and strictly speaking I suppose that is accurate. They are experiencing something that is innately disorienting and they are disoriented... quite naturally. That does not necessarily mean there is something wrong with them; e.g. suffering from too little oxygen



or too much medication. Dying is naturally confusing, so it is quite natural to be confused while dying.

As the constraints of time/space fade away (along with the physical body) mind and spirit emerge and are possessed of a greater degree of prominence and freedom. Think of it: what if you had the capacity to move about in time/space at will? Freedom on that level can be, at least initially, both frightening and confusing. As we become more adept at dealing with what we are; i.e. consciousness, we become more aware of our amazing capabilities. But this, by its very nature, is frightening... so we try to avoid it whenever possible (slightly tongue-in-cheek.)

Dying people are not losing their minds, they are struggling to grasp a more comprehensive perspective of reality. They are not disoriented because their perceptual capabilities are being diminished, their perceptual capabilities are, in fact, expanding... which is intrinsically disorienting. The disorienting effects of dying have more to do with sensory overload than with sensory diminution.

### *Buried emotions and confusion*

Another task in dying process that can be quite confusing has to do with the review and resolution of denied or buried emotions. Ironically, frank confusion can actually be helpful in resolving

buried emotions.

Burying unwanted emotions does not make them go away (although most of us hope that it will.) Most of us bury, hide or ignore a fair amount of unwanted emotion during the course of our lifetime. Dying process exhumes significant buried emotions and presents them for review prior to our moving on. If the patient attempts to use his/her intellect to block the emergence of these emotions, dying process simply brushes the intellect aside and the patient becomes “confused.” While this phenomenon is upsetting to patient and caregiver alike, it does help address the overall goal of resolution in spite of the patient’s reluctance to undertake the task.

This phenomenon may also manifest as “crazy dreams;” i.e. dreams that seem to make no sense. While these dreams and/or confused states may seem pointless and are discomfiting to patient and caregiver alike, they do elicit certain emotions... the very ones that were buried and needed to be felt and resolved prior to moving on.

### *Convenient confusion*

Some patients welcome confusion as a means by which they can express emotions they were never allowed to express previously. Social constraints frequently impinge upon the healthy expression of emotion, so it is not so surprising when someone utilizes confusion to side-step these social constraints.

This is generally a subconscious choice.

*Examples:* A male might subconsciously embrace confusion so that he can cry; something which he may never have felt free to do in a non-confused state for, as we all know, “big boys don’t cry.” Because of this social constraint, males tend to have a good deal of unresolved sadness and fear which needs to be expressed prior to moving on.

A female, on the other hand, might subconsciously engage confusion so that she can express her pent-up anger; something which may have been forbidden heretofore. Society dictates that no lady “in her right mind” would cuss and yell at her loved ones (even if they have it coming.) One possible solution to this dilemma is not terribly complicated; simply get out of your “right mind,” then cuss and yell and give ‘em hell!

Obviously this can be quite a shock to family and caregivers, and just as obviously it does not necessarily mean that the person on the receiving end (the one catching all the hell) is guilty of anything other than they just happened to be in the line of fire at the wrong time. But dying people do tend to “go off” emotionally at times, and while disconcerting, it may be just what they need in terms of off-loading an overabundance of previously unexpressed emotion. Confusion can sometimes be just the ticket a person needs to give themselves permission to vent, thus resolving previously forbidden emotions.

Many a time have I listened to a distraught family member confide, “This is not my Mother! She was always so sweet.” Or, “This is not my Dad. He was always so strong.”

Actually, what often emerges during dying process are the parts of “Mom” and “Dad” that they were never allowed to express, but were there just the same... part of who they are.

Implications for the living; i.e. the lesson to be learned regarding the healthy expression of all our emotions is, I should think, obvious.

### *Confusion about confusion*

Some of what may be erroneously perceived as confusion by caregivers is really the symbolic language of the dying (see the section on “Symbology” included in this text.)

Yet another confusing aspect of dying process has to do with the expanded perceptions of dying people, often confused with “hallucination” (see section on “Seeing People Who Have Gone Before” included in this text.)

### *True confusion*

Of course some confusion may result from metabolic imbalance, neurologic damage, lack of oxygen to the brain or reactions to medications. In some cases these kinds of confusion may be reversible. Determining whether a particular patient’s “confusion” is normal or abnormal may require considerable skill and familiarity with dying process by an experienced professional. Generally speaking however, a lot of what is interpreted by the less experienced as confusion or hallucination is actually normal and natural... and may even be helpful to the patient.

# Pain

## *Utilizing pain*

Pain is a highly complex issue with biological and psychological aspects, components and implications. Every individual is unique, so determining the likely cause and most effective intervention must be done on a case by case basis by skilled professionals. This section does not pretend to be an exhaustive dissertation on pain or pain control but does, I hope, shed some light on basic pain control and how the dying process may play into an individual's perception of and response to pain.

Pain is sometimes utilized by dying patients and their families (unconsciously of course) in an attempt to counter some of the more frightening aspects of dying process. This is not done because dying people like pain or because their families do not care. It happens because dying process is not well understood and people's natural instinct, when faced with something new and frightening, is to opt for that with which they are more familiar. When it comes right down to it, we are more familiar with pain than we are with dying process, so in an odd sort of way we are more comfortable with pain than we are with death. If for no other reason, this points to why we need to learn more about dying process.

*Example:* Moving about in time (quite normal during dying process) is confusing and can be very frightening, especially in situations where there is a poor understanding of the dying process (which unfortunately is more-or-less general.) Seeing “dead” people (also very common among the dying) is the type of thing that can throw a person for a loop and scare the heck out of them in the bargain. But pain can be used to divert one’s attention from these phenomena, to a limited degree... and I repeat, only to a limited degree... thus dampening the impact of the fear. Again, we are more familiar with pain than we are with dying, so when it comes right down to making choices, we may be inclined to opt for the pain.

I hate to be redundant but think this point bears repeating: People seldom choose to have pain consciously. It just sort of turns out that way as a result of a series of reactions and misunderstandings.

*Example:* If a patient and family are not aware that confusion regarding time and space are normal for the dying, they may blame it all on the medication(s).” Next, both patient and caregiver are inclined to either stop the pain medication(s) entirely or to severely reduce the dose. This seems logical enough in the short run and is done with the best of intentions, but will likely yield a poor result. With less pain medication on board, the patient experiences... you guessed it... more pain.

Another complicating factor has to do with the fact that these phenomena (getting lost in time/space and seeing “dead” people) often occur in a dream state... but this makes them no less real for the patient. In fact, dreams tend to become increasingly vivid during dying process. Once again, both patient and caregivers are inclined to blame all of this on the medications and either reduce or stop the dose.

*Example:* Once, while talking with a gentleman who was very near death and sleeping most of the time, I asked him how he distinguished between the “real world” and his “dream world.” He replied that it was very difficult. I asked him which world he was in at that very moment. He told me that he was not sure. I asked if he was feeling any pain. He thought about it for a couple of seconds, then replied that he was, in fact, having some physical discomfort. I suggested that that was a definite clue and he acknowledged that I had a good point. But let me get back to how pain can be used to allay confusion associated with dreams.

Stopping or severely reducing one’s pain medication leads to higher levels of pain which inhibits sleep. This, in turn, inhibits dreaming. In the short run this may seem to be a successful strategy: no sleep, no dreams, no confusion, no fear... just pain.

Many people prefer some degree of pain over a feeling of confusion and fear. Unfortunately however, it is more



complicated than simply preferring one difficult sensation over another, for the added pain not only interferes with the perception of fear, it also interferes with accomplishing the true goals of dying process; the resolitional work.

I believe that when dying process is properly understood, it becomes apparent that the purpose of pain control should be to allow the dying to focus on and get their work done rather than merely to make them feel good. At the risk of sounding hard-nosed, I am afraid I must report that my work with the dying has lead irrevocably to this conclusion: for immortal beings such as ourselves, there is no rest. Sorry, but eternal life means just that.

There are times when life is toilsome. For some strange reason we suppose this will not be true during or after death. It has not escaped my notice that people tend to be in favor of eternal life only so long as it does not involve any of the difficult characteristics of being alive. In life, increased awareness never fails but to demand an increase in responsibility. Except for all the perfect people (an extremely rare variant of the human species) the rest of us are saddled with the responsibility of tending to our own self-improvement. We would be foolish to assume that these undeniable facts of life do a complete 180 degree turn around by the simple expedient of becoming "dead." If you suppose that dying results in continued life with more awareness, but no concomitant increase in work and

responsibility, well... I suspect you are in for a surprise. But I digress.

*Note:* Obviously, there are patients who have adverse reactions to pain medications. In addition, every patient responds to particular medications in his/her own way. Consult a professional to help determine whether a patient is truly having a bad reaction to a medication or is merely experiencing normal dying process.

### *Pain and attention*

Dying process is all about resolving unresolved issues. Resolving issues requires one's full attention. When the patient is experiencing significant pain, s/he cannot focus attention on resolving his/her life issues. Imagine trying to have a serious conversation with a close friend or counselor while experiencing a severe toothache. It simply does not work well.

Pain can hook one's attention and stubbornly hang on. In this way, pain subverts normal dying process by preventing the mepatient's attention from being focused on relevant issues. Therefore, pain is not only unpleasant, it interferes with the tasks of the dying process.

*Example:* A man accustomed to being in control is dying. As the process evolves, he naturally begins to drift back in time to review a particularly difficult episode in his life. This particular man had been a prisoner of war in the Philippines during World War II. Japanese soldiers forced him to be on burial detail where he frequently found himself burying his friends under the most horrific circumstances.

When reliving this horrible episode in his life he breaks into torrents of tears and cries, "... and they weren't always dead!"

These awful memories come to life in his dreams, but he wishes they would go away. He begins to think it is the morphine that instigates these dreams, so he reduces the dose. Now he has more pain (of course) and he sleeps less. The dreams are diminished along with his sleep, and he believes he has solved his problem.

At first this strategy seems to help, but as his dying process progresses, the vivid dreams return. He becomes fearful because he cannot control what is happening. He is afraid to fall asleep. He believes that showing fear would constitute an even greater loss of control so he unwittingly converts his fear into anger and lashes out at the people around him. He is in pain, frustrated, fatigued, frightened, angry, desperate, increasingly belligerent and irrational. His family feels helpless and frustrated, and they too are convinced that the morphine is "making him crazy." They support his decision to stop or reduce his pain medicine

and the downward spiral of misery and frustration continues unabated.

However, it is not the medicine that is causing the dreams, it is merely dying process trying to resolve some of the more difficult experiences of his lifetime.

Pain may initially seem preferable to some of the phenomena that are normal in dying process, but in most cases those phenomena are actually helpful. Again, the idea is to resolve and off-load our junk before moving on. Losing track of time, seeing dead people, experiencing increasingly vivid dreams and reviewing the significant events of one's life are normal aspects of dying process which are purposeful. These phenomena offer (and very persistently I might add) the opportunity to reach a state of resolution regarding the events and deeds of one's life prior to moving on.

Allowing the level of pain to increase may impede the patient's perception of these phenomena for a little while, but it cannot stop them, and ultimately we need to understand their value. At best, utilizing pain to mitigate dying process only works for a short period of time. Eventually the dreaming and confusion resume anyway, even when the patient is wide awake. When this occurs the patient experiences both the waking state and the dream state simultaneously; i.e. s/he is truly hallucinating.

This is doubly confusing and certainly worth avoiding, if possible.

It is important to remember that while pain can be used to mitigate certain phenomena of dying process, it cannot stop that process. Many patients suffer unnecessarily by trying to stop normal dying process phenomena by utilizing pain. This is invariably done out of ignorance; a lack of awareness that a central aspect of dying process involves an in-depth life review. As usual, implications for the “living” ought to be obvious. While with the dying I am frequently struck by the realization that death teaches about life.

It is also instructive to realize that even patients who have no pain, and therefore take no pain medicine, experience the same confusion about time/space, have just as vivid dreams, see equally as many “dead people” and engage in as realistic a life-review as those who are on pain medications. Pain medications rarely cause these things to happen. They may allow these normal experiences to occur by the simple expedient of controlling pain, but rarely do they cause them. Consult experienced professionals to assist in making these determinations.

*Pain and lingering*

While pain can be used to mitigate certain phenomena associated with normal dying process, it ultimately cannot stop that process from occurring. Having said that, now let me add that pain can actually be used to stay “alive” longer... not forever mind you, just a little longer.

It is possible for a patient to remain “alive,” (or more accurately – to remain attached to a physical body) a little while longer by employing the tactic of focusing his/her attention on physical pain. In other words; if you want to stay physical for as long as possible, if you want to eke out every last second, a marginally effective way of accomplishing that goal would be to allow your pain level to rise higher and higher, then focus all of your attention on that pain.

You are where your attention is. If you can keep your attention anchored to a physical body, you might be able to stay in that body a little longer... but only a little longer.

Extending dying process by focusing on pain is something that occasionally occurs to dying people who have an inordinate fear of death. Everyone fears death, (see the section on “Fear” included in this text) but what I am referring to here are those dying people who have an inordinate fear of death. These people may prefer higher levels of pain to death and may actually focus on their physical pain so as to squeeze every last minute out of their physical existence. There is an obvious price to pay, but it can be done.

*Example:* I knew a gentleman who was severely injured in a terrible motor vehicle accident and, as he hovered near death, realized he could go either way. He later said that he gladly embraced a perception of physical pain because he realized that it would lead to keeping him “alive.” He did not want to move on just yet, and he knew that physical pain gave him a point of reference, or focus, in the direction he wanted to go.

*Another example:* While working in Intensive Care, I long ago observed that when a critically ill patient’s ultimate survival was in doubt, the advent of a significant increase in physical pain frequently presaged a “turn for the better.” Conversely, one of the cardinal signs of a patient’s imminent crash is a sudden sensation of “feeling good.”

*Yet another example:* Seeing dead acquaintances may not necessarily be reassuring. One Vietnam Vet who had a near death experience met his dead mother and several of his dead Vietnam buddies. He knew perfectly well they were all “dead” and he was determined he was not going to join them. Despite the fact that he had no physical discomfort while in this non-physical state, and regardless of what this experience may have implied in terms of his own views on immortality, he was bound and determined to return to his physical body at any cost. He gladly embraced a considerable degree of physical discomfort in

order to “stay alive.”

On the other hand, pain may be what convinces some dying people to “let go.” Some dying people conclude that if remaining physical means experiencing significant pain, “The heck with it, I’m outa here!”

The wishes of the individual play a huge role in determining which way they go; into the nonphysical realm or to stay in the physical realm (what we generally refer to as being either “dead” or “alive.”) Depending on the individual, pain may have a significant impact either way.

Clearly, how a particular person relates and responds to pain is highly individualized. Pain might enable one patient to hang on while convincing another to let go. The latter instance is sometimes confused with euthanasia.

Pain can hook a dying person’s attention so tenaciously within the confines of the physical realm that s/he may have difficulty focusing their attention on the next, nonphysical realm. In other words; pain can capture a dying person and hold him/her hostage. Again...not forever, but for a little while.

When pain medications are administered and the pain is brought under control, the dying person can then focus their attention on the next, nonphysical realm, then move on at his/her leisure. Unfortunately, this is sometimes confused with



“pushing the patient over the edge.” I fear there are many professionals and family members who labor under the false guilt of thinking that they put someone “out of their misery” when all they really did was to relieve the pain. My experiences with hundreds of dying people have led me to the firm belief that what actually occurs in the majority of these types of cases is that the patient finally received sufficient pain medication to break pain’s tenacious grip upon their attention, thereby freeing them up to move on. These patients do die sooner, that is true, but not because the pain medication killed them. They die (move on) sooner because pain’s cruel grip upon their attention was finally broken.

### *Addiction*

Some people fear becoming addicted to their pain medications. Addiction is extremely rare when narcotics are used to control real pain (or other noxious symptoms such as shortness of breath or excessive anxiety.) Recreational use of drugs can easily lead to addiction, but very few dying people use drugs for recreational purposes. Addiction in the terminally ill is basically a non-issue. If that is something that concerns you, all I can advise is, let it go.

## *Mental clouding*

Some people are reluctant to take medications because they feel that it clouds their mind. Remember, pain clouds the mind too.

It can be very difficult to think clearly when experiencing significant pain. Try solving a cross-word puzzle while someone pinches your finger in a pair of pliers or sticks needles in your toes. Trust me on this one, it doesn't work well.

Sometimes one has to choose between the lesser of two evils. Would you rather have your thoughts clouded by pain or from taking a narcotic to control that pain? Most people do not labor long in contemplating this dilemma before choosing the pain-free approach. However, in certain situations a person might elect to experience a higher level of pain for a short period of time in order to participate more fully in a particular activity.

*Example:* Imagine you are dying but there is someone you really want to see. Who is it? This person resides far away and it will take some time for them to reach your bedside. You consider cutting back on your pain medicine in order to keep yourself more awake and your attention focused within the physical realm. You really want to see this person very badly and you are perfectly willing to pay the price.

This is a common practice among dying people and is a good example of how pain can be utilized to accomplish certain, practical goals.

### *Balancing medications and pain*

In the majority of cases a satisfactory balance can be struck between pain and mental cloudiness, and thankfully, that balance is not terribly difficult to establish. Narcotics, while dangerous when used for recreational purposes or as a substitute for healthy coping skills, are very safe when used to control pain (and other noxious symptoms.) Finding a good balance takes some skill, but it is not a precise science that yields excruciating pain on the one hand and overdose on the other. There is room for error without having to be fearful of disaster. Balancing pain and narcotics does not require the skill of a space shuttle pilot, it is more on the level of the skill required to drive a stick-shift. Also, in most cases, when a good balance is achieved there is little if any mental clouding for the patient. Despite the fact that people tend to worry over this issue a great deal, in the real world it is hardly ever a legitimate concern. From what I have seen, the vast majority of what is interpreted as mental cloudiness is actually part of normal dying process and has little if anything to do with drugs. Pain and pain medications tend to cancel out the effects of each other.

## *Pain and forgiveness*

Controlling pain is a means to an end. The purpose of dying process revolves around resolving all of one's life-issues. That is an enormous task and is accomplished much more easily when pain is properly controlled.

*Note:* Certain points begin to take on some poignancy at about this stage of understanding dying process:

What we do during our lives really does matter in the so-called end.

How we judge ourselves during our dying process influences the course of our dying process and is a function of how we have learned to judge everything and everyone during the course of our lifetime.

We can, if we choose, get a leg up on resolving our life-issues before we are actively dying, thereby reducing our workload at that time.

Compassion and forgiveness can help dying people to be more loving towards themselves. The functional mechanisms are not always clear, but those who care for the dying cannot escape the suspicion that, at least in some cases, there seems to be some sort of connection between one's judgment style and one's suffering. Offering acceptance and understanding can be a

powerful elixir, for both the dying and the not-yet-dying alike.

Being forgiven (and forgiving) does tend to ease suffering. Being “nonjudgmental” is something of a misnomer in that we all must make judgments in order to survive. The real question is how we judge; i.e. with love, understanding, empathy and compassion... or with harshness and condemnation. Whatever the case may be, we learn to judge during the course of our lives, then have to live with that learned behavior while we are dying.

Religious ceremonies focusing on forgiveness can be extraordinarily helpful. Rituals that are meaningful to the patient are often effective where other tactics have failed... and in some unaccountable way, lessen perceived pain. The urging of religious “authorities” can sometimes convince people to cut themselves a break; relax more, take their pain medicine as prescribed, feel less fear and in short, have a less difficult time.

Still, there are those who would prefer a fair amount of pain to an in-depth review of their own life and deeds. Not to mention, an aversion to sorting through all those buried emotions. This may manifest as a fear of sleep with a concomitant tendency to refuse pain medications (so as to “stop the nightmares.”)

## *Honoring the patient's wishes*

It is clear that pain is a complex issue. One of the most important tasks for professionals is to assess the complexities of the individual patient and provide that patient with adequate information for making informed choices. When dealing with conscious, adult patients who are able to communicate their wishes, it is neither the clinician's nor the family's role to make choices for the patient, only to provide him/her with sufficient information to make informed choices on their own.

Some patients, for whatever reason, may prefer to maintain a certain level of pain. That is their choice. It is unfortunate when dying patients make choices based on poor information, but once given good information their choices should be honored.

## *Pain-free terminal illness*

Not all terminally ill patients have pain. In fact, comfortable death is quite common. Not so surprisingly, these patients may demonstrate increased levels of denial regarding their true condition. We tend to associate the severity of an illness with our pain level. When comfortable, we assume things are not very serious... certainly not critical. Terminally ill patients who have little or no pain may conclude there has been some kind of mistake in their diagnosis and simply refuse to take it seriously.

## *The semi- or unconscious patient*

Medicating the semiconscious or the unconscious terminally ill patient can be one of the most difficult tasks faced by clinicians or family members. In the absence of accurate feedback from the patient, determining whether s/he is having pain may require an educated guess. Even conscious people toss and turn, make scowling facial expressions and call out when they are asleep and dreaming. Semiconscious and unconscious people are no different. This may or may not indicate that they are experiencing physical pain. It may mean nothing more than that they are having a bad dream, and of course narcotics cannot cure bad dreams.

Dying people spend a great deal of time in a sleep/dream state. Much of that time is spent in reviewing the significant events of their lives. If a dying person is unconscious and reliving some frightening event from childhood, s/he may very well toss and turn, make scowling facial expressions and call out. This may give the impression that the patient is experiencing physical pain when in fact, s/he may not. Administering higher and higher doses of narcotics may do more harm than good in some cases by preventing the patient from being able to wake up.

On the other hand, most people would rather err on the side of being sure the patient is not suffering. These situations can be

intensely difficult for family, caregivers, friends and professionals alike, and they bear witness to the value of highly skilled and experienced clinicians in the palliative care field.



## Loss of Energy

*“I feel so weak”*

A universal symptom among dying people is a feeling of losing energy. Some people have pain and some do not. Some people have nausea and some do not. Some have more confusion than others. But everyone who dies complains of feeling a loss of energy. Basically, they feel that way because they are losing energy. It is not possible to experience a loss of physical energy and not feel like you are losing energy. Neither is it possible to overcome this sense of losing energy by taking vitamins or any other medication. In short, feeling a loss of energy while dying is unavoidable.

It is my feeling that “being physical” requires a great deal of focused energy. When the physical body dies, that energy loses its focal point within the physical realm. This naturally leads to a sensation of “losing energy.”

*A pragmatic view of death*

Consciousness may very well survive death. Indeed, I am quite certain that it does. Being around death has helped convince me of this because everything about dying process points towards a continuation, rather than a cessation, of life.

It is a case of: if it looks like a duck, acts like a duck and sounds like a duck, it just may be a duck. The more time I spend around it, dying process looks more and more to me like continuity of life, acts like continuity of life and sounds like continuity of life. Conversely, it cannot be understood, indeed it makes no sense whatsoever, unless viewed within the context of continuity of life.

Regardless of one's religious background, the astute and pragmatic observer of dying process cannot help but to be convinced of human immortality. Ironically enough, dying process itself is the chief argument for human immortality. But I digress...

Maintaining a physical body requires an enormous degree of focused energy which can only be kept up for a limited period of time. Being physical at all is miraculous, but sooner or later it must fade away. Maintaining the focused energy required to manifest a physical body could be compared to holding both of your arms straight out to your sides horizontal to the ground. At first it seems easy, "Hey, I could do this forever!" Well, not exactly. After some time it becomes a struggle. Finally, it becomes impossible.

As the energy required to maintain a physical body fades, the

dying person inevitably feels as though s/he is losing energy.

There are no health foods, no vitamins, no IV's, no pills and no secret techniques that can change this. That is just the way it is, and that is why the one universal symptom among the dying is a feeling of losing energy.

# Fear

## *A universal emotion*

Everyone has some fear of death. There are no exceptions. The degree of fear an individual feels about their own death varies from person to person of course, sometimes considerably, but everyone has some fear of death.

People who are not currently facing death are often inclined to claim they have no fear (the living are very brave!) Some dying people claim to have no fear of death, but frankly, I have never seen a person facing death who acted unafraid. You can say whatever you want but how you act tells the tale. Anyone can say that they have no fear of death, but acting that way is another matter entirely.

Early in my career of caring for dying people I came to this rather shocking realization (that everyone fears death) and remarked to a group of other professionals that I had stopped believing people who claimed to have no fear of death. I said, "The only person I might believe if they were to say such a thing would be Jesus, or maybe Buddha." Then someone else at that meeting spoke up and said (referring to Jesus), "Yes, but He was afraid too." Since that time, when someone claims to be stronger or more evolved than the likes of Jesus, I take it with a grain of salt. The one situation which I had hoped would prove

to be an exception to this rule (that dying process always involves some degree of fear) would be those cases when the dying person had already died; i.e. had a previous near death experience. I was disappointed to discover that this did not bear out. True, these people have less fear and a much better understanding of what dying process is all about, but it does not exempt them from the rigors of an in-depth life-review, nor from being human (having human emotions.)

### *Accepting our emotions*

When a dying person accepts that s/he may experience some fear, then that fear can be handled much more easily. Allowing oneself to feel the fear and then seeking the support of friends and loved ones is the most effective way to handle the fear of death. When approached in this way, the fear of death can be resolved in a relatively short period of time and with a minimum of fuss.

Everyone has fear, even brave people, it's just that brave people have developed some skill at dealing with their fear. Another way I have heard it said is; courage is not the absence of fear but the ability to act in the face of fear.

The entire dying process does not involve fear. Fear is only one part of the overall process. That part, however, always shows up sooner or later. If we burden ourselves with the unrealistic

expectation that we will not be afraid of our death, we put ourselves in an impossible position. Denying our fear only makes that fear worse.

More than once I have seen “religious” individuals who, when dying, were shocked to discover they had some fear of their own death. Worse still, they interpreted this to mean that they had insufficient or flawed faith. Nonsense! All it meant was that they were human.

The fear of death is much easier to deal with and transcend when we admit that we have it. If a person were to catch the flu and then deny that s/he had the flu, the symptoms would be more severe and last longer than if the flu were acknowledged openly and relief sought. Similarly, the fear of death is tough enough to manage without letting it run rampant by attempting to ignore its presence. When we deny our fear it only crops up in some other guise (such as a more acute perception of physical pain, or an inexplicable sense of anxiety.) Deceiving ourselves about our feelings will not make our feelings go away, it only makes them more unmanageable.

## *The magic of human contact*

One of the most effective salves for the fear of dying is the presence of other human beings. It is not necessarily what a person may say or do, but their very presence that makes the difference. We often feel at a loss for words when faced with tragedy, but sometimes saying nothing at all has the best effect. I know that in my own case, when things go awry (with irksome regularity) my wife's presence has a decided calming effect on my angst. She does not necessarily have to say anything to have this effect... in fact, her speaking sometimes makes it worse!

There is something truly magical about one human being simply "being there" for another. Never underestimate the power of your being. Resist the urge to feel ill-at-ease if you can't think of the perfect rejoinder... it might be best to stay quiet after all.

# Seeing People Who Have Gone Before

## *Seeing the other side*

Nearly everyone has heard of dying people seeing or talking to people who are already dead. This is so common as to be expected at some point in virtually everyone's dying process. Whether we can explain it or not is irrelevant. It happens, and it happens consistently. It is not the prerogative of people who are not yet dying to pass judgment on the validity of the experiences reported by people who are dying. When dying people report seeing dead people, then the rest of us had better pay attention.

## *Adding to the fear*

Sometimes dying people are reluctant to speak of their perceptions because they are afraid of being labeled "crazy." It can be an enormous relief for them to discover that they are normal and that their perceptions are accepted by those around them. I have had the experience of saying to a dying person, "So... have you seen your mother yet?" Then have them turn to me in astonishment and reply, "How did you know?"

Unfortunately, the reports of dying people are sometimes written off as "hallucination" or "senility", or blamed on "a lack



of oxygen to the brain”, or “too much medication”, or “metabolic imbalances.” This attitude (unfortunately, all too common) is a practical example of how the fear of death in living people may cause them to act cruelly towards dying people. This is a genuine shame for at least a couple of reasons. First, it is cruel, and second, it ruins the opportunity to learn from the dying. What dying people are experiencing is quite normal and really very wondrous from a spiritual point of view. It provides the living with a vicarious peek through a crack (which only the dying can see) into a larger reality.

### *What we can learn from the dying*

Caregivers to the dying are in a position to learn a great deal. The dying process is the most intense learning experience in life. Therefore, caring for people as they move through that intense learning experience is very educational. Learning about death from people who are dying is important for us all, collectively and individually.

# Symbology

## *Describing the indescribable*

As people approach death, they begin spending more time “on the other side...” so-to-speak. Contrary to popular belief, (and Hollywood representation) dying process is usually a gradual process. Sudden, unexpected death is tragic because it bypasses normal dying processes.

Normal dying process is purposeful; it enables the dying person to approach his/her transition at their own pace. As dying process evolves, the person experiencing it moves back and forth between being fully awake and alert, asleep and dreaming, and perhaps semi-conscious or even unconscious. The patient may become increasingly withdrawn, or more accurately, “internally focused.” When not awake and conscious they are frequently restless; moving their fingers, hands, arms and legs about aimlessly, or “picking at the air.” It is also common to hear them moaning, mumbling or even crying out. All of this is indicative of how hard they are working as they process all the unresolved issues of their lifetime.

Some people maintain a remarkably high degree of waking consciousness throughout their entire dying process, approaching their actual crossing wide awake.

This is rare but can be quite astounding and uplifting for everyone involved. Typically, these people suddenly see something (which we, the “living,” cannot see.) Their faces light up, they throw their arms forward in a gesture of joyous longing, and then they leave (that is, they “die.”)

As a person moves through the dying process, their statements (if they can be understood) may become increasingly symbolic in nature. This is because what they are experiencing and perceiving has less and less to do with the physical world.

Our language is based upon our familiarity with the physical world. Describing a non-physical world in physical world terms is difficult. Since dying people have no words for what they are perceiving, they tend to speak of it in symbolic terms... or metaphors.

The great spiritual leaders in history have also had to rely heavily on metaphors in their teachings... they too were faced with the daunting task of describing the non-physical using physical world jargon. This is where the naive get themselves all balled up; i.e. applying literal interpretations to metaphorical descriptions.

*Example:* One gentleman I worked with (who was very near death at the time) gave me the impression that he had reached the point where he was able to perceive where he was going. I asked him if he “had seen the next world yet.” He replied that

indeed he had. I asked him to describe it for me. He thought and thought, then started to say something but stopped and said, “No... that’s not it.” He thought some more and started to make another attempt at giving me a description, but stopped short again. Finally he said, “Okay, two words: large and potent.” Then he added, “But that doesn’t explain it either.” After that he gave up trying to describe the indescribable.

### *Individual symbolic language*

Symbolic language may be unique to the individual. When people get close to crossing over, they begin to conceptualize how they will get there. Some people talk about catching a train, others mumble about having enough change to purchase a bus ticket, some talk about crossing a river, still others may mumble something about riding in a truck.

*Example:* I grew up on a farm. When I am dying, I will naturally gravitate towards language and expressions typical for farm boys. While growing up on the family farm I loved to play in the creek. As anyone who has spent time playing in creeks will attest, a creek forms a natural barrier. You can only cross a creek in certain places. I used to love jumping from rock to rock, crawling along logs or even building bridges in those places. When I am dying, people around me should not be surprised to

hear me mumbling something about “crossing the creek.”

*Another example:* A person born in the big city would tend to use terms and expressions typical of city life. My wife was born in a large, Eastern city near the ocean. She loves the ocean and loves sitting on an ocean beach, staring out into its vastness. I was born in the Midwest and love sitting by a campfire in a forest, staring into its vastness. I doubt my wife will “cross a creek” when she dies. What she perceives, and how she conceives, of her crossing will be different... yet the same. Every person is unique and likely to make unique conceptual connections. Symbolic language is metaphoric, and we can only speak of that which lies beyond our current experience in metaphorical terms.

A given individual’s choice of metaphors may be difficult to interpret, but there are common threads. If the listener is familiar with the dying person’s background the meaning behind a particular statement may be quite clear.

*Yet another example:* I knew a gentleman (he was dying) who loved mules. He had owned and ridden mules all of his life and he put a great deal of stock in a good mule. As he was dying he kept talking about riding his mules along a canyon wall. He would talk about the difficulties in finding a trail that would lead down into the canyon and up the other side. I am quite sure he

crossed over when he discovered the trail by which he could get his mules to the other side.

### *Common symbols*

Some symbolic terms are actually quite common. One of the most common of all statements made by dying people has to do with “going home.” Regardless of age, color or creed, when people get close to death they tend to conceptualize dying as “going home.” How they get there may vary a great deal, but the idea that dying involves “going home” is really very common. Another very common statement usually goes something like this: “Get me up”, or “Help me up.” The exact verbiage may vary, but the general statement is common.

I take this to be an indication that the dying person is perceiving someone “on the other side” and is requesting assistance. Whether they actually receive any assistance (beyond simple encouragement) is an open question. Self-determination does seem to be an important element in actually crossing over.

### *Self-determination*

It seems to me that self-determination does play an important role in deciding when a dying person actually gets down to the nitty-gritty of crossing over. It has been my consistent

observation that those people who “wait for God to come and get me,” (to paraphrase a not- uncommon remark) spend more than the usual amount of time waiting. In other words, waiters wait. Those who take it upon themselves to get going, get going... but only after having completed their processing.

### *Completing the process*

Dying process, like any process, has particular stages, or tasks. A process cannot be completed more quickly by skipping over some of its tasks. For example, one cannot grow corn faster by skipping over the time and energy it takes to do the planting and watering and weeding. Similarly, I cannot elect to duck coming to terms with my life and then merrily cross the creek. Process is just that... a process.

Once the dying process is completed the individual may elect to move on... or wait, whatever strikes his/her fancy. Sooner or later physical bodies become uninhabitable. After that there is no more choice in the matter and the person is basically evicted.

### *How long?*

One of the most common questions asked of professionals caring for the dying is, “How long? How much longer? How long can this (dying process) go on?”

Professionals are reluctant to answer this question for the simple reason that the chances for their being wrong are very, very high. In fact, it is the close family and friends who know the patient best, and therefore have the best insight into how s/he will react. Dying is a transition. Life is full of transitions and people acquire their own transition-coping style during the course of their lifetime. By reflecting upon how the patient dealt with such things as adolescence, early adulthood, mid- life crisis, empty nest syndrome, divorce, loss of someone close etc., etc., one might extrapolate some understanding into how they will handle their dying. Routine habits may also provide some clues, and no one knows these things better than close family and friends...they are the experts. Example: When we go out, my wife heads straight to the truck. I run around inside checking to see if the lights, TV and radios are all turned off. I stand around scratching my chin wondering what I am forgetting, then meander about aimlessly hoping to see something that might jog my memory. For people who are legally blind, such as myself, you can imagine how involved this process can become. By-n-by my wife comes back in wondering just what the heck is taking so darned long. Between the two of us, guess which one is more likely to linger?

Some dying people want to move on without completing their tasks... this is problematic. Others complete their tasks but decide to wait awhile... this is their choice. Some people decide



not to go at all... eviction can take some time. Those dying people who complete their tasks and then decide to move on, move on.

# Grief

## *The process*

Grief, like life and death, is a process. Everyone experiences grief, including caregivers and professionals. Grief runs a general course but is not necessarily linear. In other words, a person can be in an acceptance stage one day and jump back into anger the next. In fact, people tend to hop around from one stage to another quite frequently.

Grief is actually very pervasive. We grieve more regularly than we may realize. We grieve every loss or disappointment that we experience. The intensity of the grief depends upon the intensity of the loss, but we generally are not aware of our grief until it becomes intense. When grief does become intense, it may seem overwhelming and we fear that we will never be free of it again. The intensity of our grief may ebb and flow, but it is a part of who and what we are. Not only do we grieve our losses after they occur, we grieve our losses before they occur in anticipation of their occurrence.

The contributions of Elizabeth Kubler Ross have been invaluable in helping people to understand grief and its stages. I have taken the liberty of expanding upon her list of stages by including some categories of my own which, while not true stages per se, do represent emotions commonly associated with grief. I have also

presented them here in no particular order so as to de-emphasize the impression that grief is supposed to unfold in a strict, linear fashion.

*Stages, or Common Emotions of Grief (in no particular order)*

ACCEPTANCE

SHOCK

HOPE

DENIAL

SADNESS

CONFUSION

RELIEF

BARGAINING

DEPRESSION

ANGER

FEAR

BLAMING

The intensity of our grief reflects the intensity of our loss. We can expect to go through at least some of these stages with every

loss but if the loss is severe we may go through virtually all of them. Sometimes, when we avoid dealing with the feelings associated with the little losses in everyday life, the big losses we encounter act as triggers for the release of accumulated grief.

“I can’t forgive my friends for dying; I don’t find these vanishing acts of theirs at all amusing.” Logan Pearsall Smith (1865–1946), U.S. essayist, aphorist. *Afterthoughts*, “Age and Death” (1931).

Some of the emotions associated with normal grief are surprising. For example, it is common to feel anger towards the person who has died. It is also common to feel relief that they have died. These emotions may be confusing for friends and relatives of the deceased; they may be unexpected, do not always seem to make sense and may trigger feelings of guilt. Still, they are common and normal in most cases.

Interestingly, we are sometimes surprised to discover what a feeling actually feels like. We might wonder what it would feel like to lose a parent. We might think we could anticipate how that would feel, then be entirely shocked by the actual experience. Even professionals who deal with death and dying routinely may be astonished at how it actually feels when it happens to them. Anticipating a feeling and feeling a feeling are two very different things.

Some of the emotions of grief are more difficult to deal with than others. Anger, especially anger felt towards the deceased, may be difficult for some people to acknowledge within themselves.

Anger can also be difficult to accept in others. At such times it may be helpful to remember that the emotion being expressed is just a part of the grieving process and that it is better to get the emotion out than to hold it inside.

Sadness is another difficult emotion. It is not uncommon for concerned family members to request a sedative (usually for someone other than themselves) when sadness becomes intense and tears are flowing freely. Actually, weeping is healthy when intense loss is experienced... even for men. Burying an emotion merely delays its expression and may even lead to protracted or complicated grief with more harmful, long-term consequences.

If a person threatens harm to him/herself or to others in response to their grief, then s/he does need professional assistance. Barring that, the frank expression of grief is a good thing and should be encouraged.

The healthiest families are the ones that encourage appropriate expression of emotion. The emotionally supportive family encourages its members to recognize and communicate their individual feelings. This allows everyone within that family to resolve his/her grief and move on with their lives.

### *Allowing space for grief*

In a normal grief process every individual jumps around from one

stage to another. Consequently, it is not reasonable to expect that everyone in a family will experience the same emotion at the same time. In fact,

It is seldom that everyone is on the same page when grieving the loss of a loved one. At any given moment one family member might be angry, another in bargaining, another in shock and still another in acceptance. Then, an hour later, they might all switch emotional places. It is good to recognize this and allow each other room for individual expression of grief.

## *Children and grief*

Children should also be included and encouraged to participate in expressions of grief and loss. They should not be forced to participate, but they should be allowed to participate if they so desire. Grieving is a part of everyday life and therefore, good grieving skills should be taught to children by the adults in their lives. For children to learn good grieving skills they must be able to see good grieving skills being practiced around them.

Shielding children from loss and learning how to cope with it deprives them of the opportunity to learn how to deal with life.

Children should not be banished from seeing death or dying people. Their imaginations can and will create far worse images than reality could ever produce. Reality may be tough to deal with at times, but the imagination can be a lot worse.

## *How long does grief take?*

There is no time limit on grief. How long it takes to grieve a loss can vary greatly and depends on a wide variety of factors, not the least of which are: the severity of the loss, the support available to the individual experiencing the loss, and his/her skill at working through grief process. Strictly speaking, one never “gets over” a serious loss. One learns to cope, one learns to

integrate that loss into a larger meaning, but one does not forget.

### *Sharing loss*

Human beings are innately social and need to share at least some of their feelings in order to process them effectively. Spending time alone is important after experiencing a loss, but it may be just as important to grieve with someone as well. The need to recall the stories of our losses is important. It is a normal and effective way of processing grief.

Some people may find grief support groups to be helpful in accomplishing this task. Others may pick out a close friend with whom to share his/her feelings. Still others might utilize a professional counselor as a sounding board for venting their feelings. Clergy can be very useful for this purpose, as can prayer and meditation. Hospices provide grief counselors.

### *Learning to grieve*

It is important to remember that grieving is something we all do from time to time. Learning to grieve effectively is an important life-skill which we need to learn and pass on to our children. It enables both them and us to cope more effectively and to comprehend the meaning of our world more clearly. When grief



is intense, we can quickly become overwhelmed by the magnitude of our emotions and begin to think that there is something wrong with us; that we are the first and only one to ever feel this way. We may lose sight of our profound connectedness to the human race and our commonality of emotion. As we move through feelings of isolation, we can expect to feel a need to reconnect with other humans. A time-honored way of accomplishing this is to share our story.

There is a time to be alone and a time to reconnect, a time to experience solitude and a time to be nurtured.

## Summary

The real goal of dying process is to resolve all the events of our lifetime so as to be ready for the next phase of life. It is a huge task, but dying process is designed to help us accomplish this goal.

We are never entirely prepared for the transition of death, even though we accumulate a great deal of experience with transitions throughout the course of our lives. Indeed, we each develop our own personal style for coping with transitions. And yet, when death does arrive, we are overwhelmed by its enormity.

Transitions are essentially periods of accelerated learning and spiritual growth. Though we find them to be frightening we long for their benefits; to return Home.

Emily Dickinson, who found poetry in the most common occurrences, said just before dying:

*"Let us go in; the fog is rising."*

(Emily Dickinson U.S. poet. 1830-1886)



