

EoL Care

CHANGING THE WAY PEOPLE EXPERIENCE DYING AND DEATH
SIDNEY REGIONAL MEDICAL CENTER

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About EoL

One Tough Topic

How Americans choose to die is evolving and in part due to advancements in technology as well as innovations in medicine for how diseases are treated. These changes are contributing to a shift in utilization for those services that are designed to support families and the patient that may either be terminally ill or approaching end-of-life. Instead of wanting to stay and bed and wait to die, the goal now is to live as much as possible until the body will not allow any more 'living.' Many of those that want to 'die at home' only need support services like hospice for a couple of days, compared to in the past where the dying process could take up to 6 months or more. Ironically of the 80 percent of those that state they want to die at home yet only 25 percent do. With more and more choosing to die in a hospital, assisted living, or nursing home setting instead.

What once was considered a taboo topic, the subject of death and dying is becoming the subject of discovery and even conversations during dinner. This resource guide is designed to support you as you take steps to address what most think is *one tough topic*. Yet as challenging as it can be to ponder one's own wants and wishes for when they die, going through this process can be life altering!

Why prepare?

The emotional anxiety and stress that is so often associated with end-of-life has become a more than a topic at dinner. Given the recent chain of events from the pandemic of 2020, the sheer number of lives lost due to COVID is shining a new light on the subject of death.

Like any other stage of life, planning and taking the time to identify your wants at a time when you are able to make choices right for you, removes much of the struggle that last minute planning creates. When properly discussed with friends and loved ones, the mental anguish experienced is much less cumbersome and easier to manage when plans are in place.

Reality Check...

How many times have you not made a decision to avoid hurting someone? Like many decisions in life, taking time to consider what you want to happen when you are dying may appear to be protecting you and those you love by not 'worrying' them about something that hasn't even happened. And yet the reality is choosing to not make a decision, may ultimately place the burden on someone else at a time when emotions are hardest to manage. Planning ahead, even for your own death, may be the best gift you can give to those closest to you.

Realizing your value

Recognizing there is value associated with your life and that you add value to the lives of others, is a quintessential step when discussing the process of death. Why? Because when you understand that you are valued, there is level of fulfillment and acceptance toward knowing you have lived a rich life. Planning for end of life at this point, becomes about the embracing of future events and celebration of life with those you love. Sharing in the legacy you are leaving for those most important to you.

However, if you find that you have more to give, more to live, more to do, going through the steps to plan your ending days can help identify what is most important for you to accomplish and becomes the strategy to which you may more richly live your life.

Types of Care

At Sidney Regional Medical Center (SRMC) our focus is meeting patients at every stage of life to support their health and wellness efforts. When considering end of life, in many ways this may be the most important stage of life where our team can help address the concerns and questions when facing complex illnesses as well as terminal diagnosis that lead to end of life.

ALWAYS PLAN
AHEAD. IT WASN'T
RAINING WHEN
NOAH BUILT THE
ARK

Richard Cardinal Cushing

Team approach

Goals

What this is

Aging & dying expert medical care (not at home)
 Aggressive pain and symptom management
 Mental/behavioral support
 Emotional support
 Planning tools
 Research links

What this isn't

Sidney Regional Medical Center including the staff are unable to provide the following:
 Durable Medical Equipment
 In-home/bedside care
 After-hours care
 Financial support
 Listing of local resources
 Advance Care Planning tools

CCM

Physicians Clinic

CHRONIC CARE MANAGEMENT (FOR ESTABLISHED PATIENTS)

Wellness coaching and check-ins

Annual Wellness Visit

Advance Care Planning/tools

Provide aging awareness educational tools

PROVIDER CARE (TO COMPLEX ILLNESS CARE)

Physician Clinic providers help to manage the questions, concerns and quality of life for their patients

Advance Care Planning resources highlighted

At the time that pain levels increase due to the progression of chronic illnesses or injury a referral may be made to Internal Medicine for further review

For those that are actively dying or with terminal diagnosis and declining health the Sheriff will be alerted

Workflow:

Patients may learn of advancing health concerns or terminal illness through CCM or when seen from their provider.

Education and resources should be given to patient to promote discussion

CIC

What is CIC

Complex Illness Care

Patient can self-refer or be referred to Dr. Smith for Internal Medicine consultation by both internal and external providers.

Patients must be adult age state of NE is 19 years of age or older.

Dr. Smith will assess if there is a need for symptom and pain management for improve quality of life, which at some point may develop to end-of-life care.

Coding for this service falls under the location and is the same evaluation management as all specialty providers use. Workflow will fall into the Internal Medicine queue.

Dr. Smith can do house calls if critically necessary, go to the nursing home and can use virtual visits

when needed.

Visit summaries will aid in the collaboration with our providers to manage the patient wholly.

CIC Workflow:

Patient is referred to Dr. Smith with Internal Medicine.

Appointment scheduled for one-hour consultation appointment

Dr. Smith will determine CIC plan, defining stage of illness.

Additional referrals and prior auths as needed for other things (lab, radiology, prescriptions, etc).

Medication management.

BH

Behavioral Health

Caregiver support

Kristen Rose, LPC, LIMHP will provide:

Caregiver stress support group

Grieving support group

Dealing with anxiety, depression, etc with caregiver, family members

Patient support

Lynn Bournia, LPCC, PLMHP will provide through the Senior Life Solutions program to Medicare participants 65+ therapy for:

Depression/anxiety

Traumatic events/loss of loved one

Loss of interest, energy, change of appetite, and difficulty sleeping

Feelings of sadness, grief, worthlessness, hopelessness

EoL Doulas

EoL Doulas

Family and patient emotional support

Wishes, vigil, legacy planning

End-of-Life Doula Program

EoL Doulas provide emotional support and guidance for the those going through end-of-life:

Helping to define life meaning

Identifying unresolved issues

Use of guided imagery

Vigil planning

Legacy work

Reprocessing the death

Criteria for participation

Contract for interested participants, disclaimer

Process steps

Interview/assessment

Identifying participant current stage

Doula involvement

Identify wishes

Who is to be involved

Outline intensions

Create plan: meaning, legacy and vigil

Vigils

Letter writing

Obit writing

Breakdown walls, active listening

Doula support

Adding in new volunteers

Ongoing training
 Journals/journaling
 Self help
 Business cards
 Liability insurance
 Community outreach efforts
 Coffee shops
 Workshops
 Education opportunities with churches
 Resources
 Who to call when
 Deathdeck.com
 Storymatic Remembery
 Steps for grieving
 Donations
 Other?
 Online and printed EoL Toolkit will include:
 Outreach flyer
 Local resources listing
 Who to contact when
 What to expect when working with an EoL Doula
 EoL Volunteer resources
 Vigil
 Legacy
 Meaning and resolution
 Hand out at events, admissions, reception, providers
 Post internally
 Use with various onsite speaking opts

What are doulas:

Support families and loved ones during and after diagnosis and the dying period
 Introduce a comprehensive, holistic continuum of care concept
 Increase cross-cultural psychosocial/spiritual options for more personalized, family centered end of life care
 Find ways to engage families and friends in ways that are meaningful and life-affirming
 The dying person, and those identified as important to them are involved in decisions about treatment and care
 The people important to the dying person are listened to and their needs are respected.
 An EoL Doula provides compassionate, non-medical, emotional and spiritual support to those and their loved ones who are facing their final transition.
 We empower people to make well-informed decisions about their eol wishes and preparations.
 Doulas often help families open a dialogue about the topics of death and dying, which in our society are not easily discussed.
 EoL Doulas provide unique care to each person and family depending upon their specific beliefs wishes and needs.

We create a space of calm amidst what can be chaos

A holistic approach to end of life care with information to assist you to learn what to expect physically, emotionally and spiritually when a patient is dying. Providing steps that help to manage higher levels of peace for both patient and loved ones

OUR VALUES

Passion

To bring the fervor of our mission and vision to everything we do and to inspire individuals and programs we work with to bring compassionate and clearly structured services to the dying.

Quality

To constantly improve educational and program services so we deliver the very finest products to our organization, community, and individual customers.

Inclusivity

To see that our educational products and program services are equally available to all people, no matter their race, ethnicity, religion, or sexual orientation, in any country or environment, at the same time that we take into account the social traditions and spiritual perspectives of the cultures where we work.

Connection

To serve as an ongoing resource for the growth in knowledge and ability of the individuals we train; for advice to programs we help develop, and for business guidance to the private practitioners who use our program model.

Collaboration

To partner with and support organizations and individuals that seek to improve end of life care in ways that go beyond the scope of our offerings and will benefit dying people and their loved ones.

Innovation

To stay conversant with the latest developments in the end of life field, while we also lead the conversation forward to constantly reimagine how we approach death and dying.

Integrity

To develop our business in a way that adheres to high ethical standards of practice, strives to deliver services in a timely manner, and supports the goals and dreams of those who work with us.

Service

To make sure that we uphold the true meaning of the word "service" as we work with all our stakeholders, and promote service as a central concept in the doula approach.

BENEFITS**PATIENT & FAMILY**

Greater emotional support & interaction
 Increased sense of control
 Better understanding of signs & symptoms
 Less anxiety, depression, & suffering
 Deeper sense of purpose in last days
 Easier time with grief
 Having the chance to be truly heard

ORGANIZATION OR COMMUNITY

Higher patient & family satisfaction
 Improved community recognition
 More referrals
 Better overall quality of service
 Greater care of the dying
 Enhanced community interconnections
 Rewards of service

Source: http://www.hospicenet.org/html/grief_guide.html

Hospice Bereavement Program

Bereavement services foster a caring group of staff, volunteers and family members who work together to encourage full expression of feelings guiding the bereaved through the difficult and normal grief process

The Hospice Bereavement Program offers appropriate bereavement alternatives to assist caregivers and families of Hospice patients to cope with and process their grief.

Individual and support group services are offered to assist the family through the stages of healing as well as throughout the recovery period.

Bereavement issues occurring both before and after death are included in the Bereavement Plan of Care. This plan includes:

Services offered.

Frequency of services.

Bereavement counseling, if utilized

Bereavement services are offered to families of the Hospice patient for 13 months after the death of the patient and are furnished under the supervision of a qualified professional with experience or education in grief or loss counseling.

The Medical Social Worker and/or designee carry out the following activities after the death of the patient. (Note: In most cases, the Hospice Volunteer is the designee who carries out the activity) Within 24-48 hours, after death of the patient: call the family to offer empathy, inquire about funeral arrangements/Memorial Services, visit as indicated, provide community resources if needed, and arrange for "Bread of Life" delivery. The Medical Social Worker and/or designee will contact volunteers to make bread and will make arrangements with the family for delivery.

Within 48 hours, after the death of the patient, send a sympathy card to family.

Attend wake of Memorial/funeral Services within Hospice area.

Within 1 to 3 weeks after patient's death, visit family and deliver bread.

Medical Social Worker completes a Bereavement Assessment Form

Medical Social Worker invites bereaved to the next scheduled bereavement group meeting and sends notification of support group meetings.

The Medical Social Worker and/or designee shall carry out the post death, one-year, Bereavement Follow-up Program at 6 weeks, 3 months, 6 months, 9 months and 12 month intervals with the following activities:

6 Weeks – Do at least one of the following: Visit, telephone, send sympathy or "Thinking of You" card to survivor or caregiver. Invite survivor or caregiver to bereavement support group or mail information on grief or related material.

3 Months – Write a sympathy note which may include article or booklet on grief. Invite family/caregiver to Bereavement Group meetings and or make a home visit if appropriate.

6 Months – Same as 3 months

9 Months – Same as 3 months

12 Months – Same as three months and provide information on Annual Memorial Service if applicable.

Coordination of Care

Nursing/ER

Nursing Unit/ER

Nursing Unit

Identify patients that would benefit from further review from Internal Medicine for symptom/pain management due to terminal illness, chronic illnesses or entering end-of-life stage while inpatient
May suggest follow up appointments scheduled with Internal Medicine/CIC if patient is going home
May see Internal Medicine providers while in staying hospital

Social worker discusses what services will and will not be provided and provides area resources
Depending on necessity and patient's ability to pay, may consider swing bed, ICF or Comfort Care rooms when more medical attention is needed or preferred

ER

Identify patients that would benefit from complex illness care through Internal Medicine for symptom and pain management due to terminal illness, or entering end-of-life stage
 If patient is actively dying, may require myriad of immediate care
 Provide available local resources if appropriate
 If actively dying, consider contacting Sheriff's department if patient wants to go home

Patients & Families

Making decisions

Deciding what's right for you

Locations for dying

Choices available locally include:

Home/caregiver home

Hospital

Inpatient

Comfort Care

Extended Care

Swing bed

The hospital is certified to offer **short-term** skilled medical and physical rehabilitation care using the acute care beds for patients in transition between acute care and home care or other lower level of care facility. Your physician has recommended you participate in a short stay program to stabilize your condition, complete a pre-determined treatment and to increase your endurance, functionality and independence. Our goal is to provide an environment which is comfortable with medical needs and supportive to encourage you to recuperate and regain as much independence as possible.

Though we are a program located on an acute care unit, your daily routine should be quite different than your hospital stay.

ICF

Comfort Care

ACP

Advanced Care Planning

DNR

Living will

Durable power of attorney

Organ donor

POLST and MOLST forms

Estate planning

<https://www.nia.nih.gov/health/advance-care-planning-health-care-directives#what>

Advanced Care Planning

DNR

Five Wishes

Estate planning

Will

Burial

other

Caregiver support

Caregiver & Patient support

Caregiver

Who to contact when

General timeline for stages and symptoms of dying
 Understanding of pain levels and management of
 Dealing with fear, anxiety, depression, exhaustion
 What to expect during active dying
 How to care for self while caring for someone else
 Access to advance care planning expectations
 Other wishes of dying to attend to
 Local resources for support/respite
 Life Assist Program

Signs & Symptoms

DISCLAIMER

This guide SHOULD NOT be construed as a replacement for the assistance of local medical care. 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.

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.

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.

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.

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 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?

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. 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 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.

Bedsore

One of the chief complications of circulatory shutdown is the tendency towards the development of bedsores. Bedsores, or decubitus ulcers, 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 messaging 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 bedsores. Consult with your doctor or nurse for assistance in determining what might work best for you.

Despite your best efforts, bedsores 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 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 resolitional 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 – 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 affects 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 over abundance 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.

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 patient'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

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 more 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.

TMI & Resources

How to discuss EoL

Local Resources

Who to call when

If you have a concern or complaint regarding your latest visit to SRMC, care you received or quality matter, please let us know by calling our hotline at 1.800.273.8452 or [click here](#) to submit a concern.

Who to contact when:

Living in a rural area doesn't always mean 24/7...planning and preparation are essential to limit the mental stress that can be part of the dying process.

How to discuss concerns with your care team

When to call your doctor

When to go to the ER

Caregiver training and support

Emotional needs

Financial concerns

Planning tools and forms

Common symptoms & stages to watch for during active dying

Local and regional resources with contact information

Who to contact when listing

Who to call when?

When supporting the needs for someone that is facing end-of-life there are times when you may be unsure as to if a change in behavior, physical appearance, or level of severity for the illness should be communicated. Of course, then it is determining what the next steps should be, like who to call and when.

The following list outlines critical health levels and concerns to assist you when changes are less than 'normal' and you would like someone to discuss your concerns with before escalating the occurrence to going to the ER.

Contact numbers for SRMC:

Main number **308.254.5825**

Physicians Clinic **308.254.5544**

Specialty Clinic **308.254.5067**

Walk-in Clinic **308.254.4752**

[General timeline for stages and symptoms of dying](#)

[Understanding of pain levels and management of](#)

[Dealing with fear, anxiety, depression, exhaustion](#)

[What to expect during active dying](#)

[How to care for self while caring for someone else](#)

[Access to advance care planning expectations](#)

[Other wishes of dying to attend to](#)

[Local resources for support/respice](#)

[Life Assist Program](#)

Complications that are concerning

Difficulty breathing, shortness of breath

Fast heart rate

Chest or upper belly pain or pressure lasting 2 minutes or more

Fainting, sudden dizziness, weakness

Changes in vision

Confusion or changes in mental status
 Any sudden or severe pain
 Uncontrolled bleeding
 Severe or persistent vomiting or diarrhea
 Coughing or vomiting blood
 Suicidal or homicidal feelings
 Difficulty speaking, or numbness or weakness in any part of your body
 Unusual belly pain

If you are an established patient with SRMC, the Physicians Clinic is open M-F 8am-5pm. Call 308.254.5544. After hours, please consider calling emergency services at 911 or go to the ER located at 1000 Pole Creek Crossing.

Additional conditions and symptoms that require emergency attention include:

Poisoning
 Drug overdose
 Loss of consciousness
 Major burn
 Severe allergic reaction
 A broken bone with skin protruding through the skin
 Drowning
 Any significant change from normal behavior
 Confusion or delirium
 Decreasing responsiveness or alertness
 Excessive sleepiness
 Irritability
 Seizure or abnormal shaking or twitching
 Strange or withdrawn behavior
 Severe headache or vomiting, especially after a head injury
 Inability to stand up or unsteady walking
 Unconsciousness
 Skin or lips that look blue or purple
 High fever
 Severe or persistent vomiting or diarrhea

When to call for help

Remember, anytime you are not comfortable with a medical situation, you should call for help. By acting quickly, you may prevent a serious emergency and could save a life.

If you are an established patient with SRMC, the Physicians Clinic is open M-F 8am-5pm. Call 308.254.5544. After hours, please consider calling emergency services at 911 or go to the ER located at 1000 Pole Creek Crossing.

Call Us Early. Call Us First.

Patients share their symptoms as soon as they are recognized so your provider can assist to determine which option is best for the situation: a same day office visit with a doctor, a weekend office visit, and/or counseling over the phone may be available.

We encourage patients to call SRMC Physicians Clinic M-F 8am-5pm at 308.254.5544 before going to the emergency room or Walk-in Clinic.

We may be able to assist in:

Managing your symptoms
 Reduce the risk of other complications that might arise when you go to the hospital
 Give you the ability to remain at home with the support of family
 Reduce the stress of caregivers having to arrange a sudden hospital visit
 Prevent unnecessary costs

It is important to call us as soon as you begin to experience symptoms or side effects so we can address your medical needs immediately and avoid unnecessary complications. Here are signs and

symptoms to watch for:

Chills or fever greater than 100.5

Bleeding

Pain at your IV site

Diarrhea

Nausea

Vomiting

Any symptom concerns or questions related to your medical care or prescribes devices

What is the process for after hours calls?

In a case where an end of life patient is having a change in status at home, what are the steps that these patients and their families are going to be encouraged to take? **If this is something the patient/family are not able to manage at home, they will be advised that their only option would be to come to the ER. They can call the ER but where we do not diagnose over the phone, the ER would advise them that they would need to come in. There is a possibility that we may approach the hospitalists to take these calls that would come in, but that discussion has not occurred and need to get Jason's input on this.**

Are Dr Smith and Stephanie going to be on-call for the weeks they are in service? If so, then in that scenario, the call would go to Dr Smith or Stephanie first. Then, the ER may receive a call from Dr Smith or Stephanie letting us know that a patient is coming for _____ type of service in the ER or maybe a direct observation or inpatient admit. **Dr. Smith is not going to be on call for this, and neither will his back up person (we do not know who that is at this point with Stephanie leaving). Possibly the hospitalists for after hours?**

Or

is this something that we treat as a consult? Our ER nurses do not give out medical advice over the phone and I don't know that our ER providers would give advice without evaluating the patient in-person. This scenario is more complicated because the patient will need to get to the ER first and then be evaluated. In the consult scenario the patient shows up in the ER and then we call Dr Smith or Stephanie to come in and consult in the ER (kind of like we do with Dr Graves/Jansen)? Then the decision is made to a) discharge home, b) place in observation or admit inpatient if the patient qualifies for that level of service, c) place in private pay end of life care at the rate of \$_____. **If it is during normal clinic hours/days for Dr. Smith and/or his back up a call could be placed to them while on site to come to the ER and see the patient, but those really would be handled in the clinic space rather than the ER. There will be no on call for this program, unless we do the hospitalists.**

Private pay payment issues

Our current process without this new program is if death is imminent, we may keep these patients because families decide to pay private for the patient to stay here and pass away instead of taking them home again. However, with this "promotion" of end of life care, I anticipate that we may see more end of life patients come through the door. In that case, we need to have a more solid game up front as far as payment. I don't know how many people who decide on private pay actually pay their bill and we could fill up part of our acute care with end of life private pay people who have no intention of paying but don't want their loved one to die at home.

We will also have cases where death is **not** imminent but family does not have resources or the want to take care of the family member. What does that look like then? Once the patient is here, we are "stuck" with them..... **Although we are not promoting end of life, we all know that is a component of the program and we need to address the private pay situations. We currently have the two programs outlined but not set up, so we will need to have Emily check and see when they could be set up by. I can reach out to her now...as for patients who are 'left here' that we are 'stuck' with...this really wouldn't change from what you do today with those patients...this program is not promoting this or would not be supportive of this type of care for their loved one, but if it is happening now, I do not see**

that this program would encourage or direct people in that way at all and would be addressed no differently than they do now. Is that the social worker who helps find their next step?

ACP Tools

Advanced Care Planning

DNR

Living will

Durable power of attorney

Organ donor

POLST and MOLST forms

Estate planning

<https://www.nia.nih.gov/health/advance-care-planning-health-care-directives#what>

Medical Order Forms by State

Physician Order for Life-Sustaining Treatment (POLST)

Medical Orders for Life-Sustaining Treatment (MOLST)

Physician Orders for Scope of Treatment (POST)

Medical Orders for Scope of Treatment (MOST)

The above are all medical order forms that represent the same thing but have different names depending on the state you live. Regardless of the term, these forms are a tool to help physicians and other health care providers discuss and convey a patient's wishes regarding cardiopulmonary resuscitation (CPR) and other life-sustaining treatment. They are designed to be actionable throughout an entire community. The orders are immediately recognizable and can be used by doctors and first responders (including paramedics, fire departments, police, emergency rooms, hospitals and nursing homes). The forms are a medical order signed by the patient, their healthcare professional and a witness.

Click links below to learn more:

www.polst.org

www.molst.org

www.conversationsofalifetime.org/wp-content/uploads/2018/06/What-is-MOLST-POST-POLST.pdf

www.healthinsight.org/tools-and-resources/send/48-educational-resources/639-polst-conversation-guide

Five Wishes

A comprehensive advanced care planning guide for how to approach, talk about and document end of life decisions. Offers a free downloadable workbook with great questions to start the conversation.

<https://fivewishes.org/>

DNR

Five Wishes

Estate planning

Will

Burial

other

Aging Resources

Aging resources

NIA/NIH infographics

AARP Caregiving Resource Center: www.aarp.org/caregiving or **877-333-5885**

Your one-stop shop for tips, tools and resources while caring for a loved one. For Spanish resources visit www.aarp.org/cuidar or call **888-971-2013**.

AARP Advance Directive Forms: www.aarp.org/advancedirectives

Free, downloadable state-specific advance directive forms and instructions.

AARP Care Guides: www.aarp.org/careguides

Take the stress out of caregiving with these targeted, easy-to-use guides.

AARP Local Caregiver Resource Guides: www.aarp.org/caregiverresourceguides

Local resources that help make caregiving easier.

AARP Caregiving Tools: www.aarp.org/caregivingtools

AARP's suite of web-based tools will help you find services, keep track of health records and more.

AARP Medicare Q&A Tool: www.aarp.org/MedicareQA

An easy-to-use online tool that provides answers to frequently asked questions about Medicare.

AARP Health Law Answers: www.healthlawanswers.org

An online tool designed to help you understand what the health care law means for you and your family and where to go for information in your state.

AARP I Heart Caregivers: www.aarp.org/iheartcaregivers

Share your caregiving story and connect with others.

AARP Long-Term Care Cost Calculator: www.aarp.org/longtermcarecosts

Find and compare the costs of home care, assisted living and other services throughout the United States.

AARP Online Caregiving Community: www.aarp.org/caregivingcommunity

Join our community & connect with other caregivers like you.

Administration on Community Living (ACL): www.acl.gov

The federal agency responsible for advancing the concerns and interests of older people. The website has a variety of tools and information for older adults and family caregivers.

Alzheimer's Association: www.alz.org or 800-272-3900

Resources, tools, and a 24-hour helpline for people with Alzheimer's disease and their families.

American Cancer Society: www.cancer.org or 800-227-2345.

From basic information about cancer and its causes to in-depth information on specific cancer types— including risk factors, early detection, diagnosis and treatment options.

American Diabetes Association: www.diabetes.org or 800-342-2383

Resources and research to prevent, cure and manage diabetes.

American Heart Association: www.heart.org or 800-242-8721

Resources will help you better care for someone who has heart disease or who has had a heart attack, heart surgery or a stroke.

Argentum: www.argentum.org

Information and resources on assisted living options and how to find them.

Care.com: www.care.com

Improving the lives of families and caregivers by helping them connect in a reliable and easy way.

Caregiver Action Network: www.caregiveraction.org or 202-454-3970

Information, educational materials and support for family caregivers.

CaringInfo: www.caringinfo.org

A national engagement initiative to improve care at the end of life.

Eldercare Locator: www.eldercare.gov or 800-677-1116

A public service of the U.S. Administration on Aging that connects caregivers to local services and resources for older adults.

Elizabeth Dole Foundation: www.elizabethdolefoundation.org

Created to help American military caregivers by strengthening the services afforded to them through innovation, evidence-based research, and collaboration.

Family Caregiver Alliance: www.caregiver.org or 800-445-8106

Tools and resources for family caregivers, including the Family Care Navigator, a state-by-state list of services and assistance.

LeadingAge: www.leadingage.org

Consumer information on long-term care facilities and services, and how to access them.

Medicare: www.medicare.gov or 800-633-4227

Provides information about the Medicare program and how to find Medicare plans and providers. Caregivers will also find a tool on the website to compare home health care agencies and nursing homes. The official U.S. government site for Medicare.

National Academy of Elder Law Attorneys: www.naela.org

A professional association of attorneys who specialize in legal services for older adults and people with special needs. Find information on legal issues affecting older adults and a database of elder law attorneys by state.

National Alliance for Caregiving: www.caregiving.org

This organization is dedicated to improving the quality of life for caregivers and those they care for through research, innovation and advocacy.

National Alliance for Hispanic Health: www.healthyamericas.org or 866-783-2645

The Hispanic Family Health Helpline and its Su Familia provide free and confidential health information for Hispanic families.

National Association for Home Care & Hospice: www.nahc.org

Consumer information on how to select a home care provider or hospice.

National Association of Home Builders: www.nahb.org/caps or 800-368-5242

A web-based directory of certified aging-in-place specialists who can identify and/or provide home modifications that make a home accessible, safer and more comfortable.

National Association of Social Workers: www.socialworkers.org

This organization maintains a directory of licensed social workers at www.helppro.com/nasw.

National Clearinghouse for Long-Term Care Information: www.longtermcare.gov

Information and tools to help plan for long-term care needs.

National Hospice and Palliative Care Organization: www.nhpco.org or 800-646-6460

Provides free consumer information on hospice care and puts the public in direct contact with hospice programs.

National Multiple Sclerosis Society: www.nationalmssociety.org

Offers resources and support to navigate the best life through the challenges of MS.

National Parkinson Foundation: www.parkinson.org or 800-473-4636

Events, research progress and resources for those affected by Parkinson's disease.

National Respite Network: www.archrespite.org

A service that helps people locate respite services.

NIH Senior Health: www.nihseniorhealth.gov or 800-222-2225

Fact sheets from the U.S. National Institutes of Health can be viewed online or ordered for free.

Rosalynn Carter Institute for Caregiving: www.rosalynncarter.org

Created to support caregivers, both family and professional, through efforts of advocacy, education, research and service.

SAGECAP: www.sageusa.org/sagecap

An organization providing counseling, information, support groups and more to gay, lesbian, and bisexual and transgender caregivers.

Social Security Administration: www.ssa.gov or 800-772-1213

Help and information on eligibility and benefits are available online from 5 a.m. to 1 a.m. ET Monday through Friday; 5 a.m. to 11 p.m. ET Saturday; and 8 a.m. to 11:30 p.m. ET Sunday. Phone help is available 7 a.m. to 7 p.m.

ET Monday through Friday.

State Health Insurance Assistance Program (SHIP): www.shiptacenter.org or 877-839-2675

Your local SHIP offers one-on-one counseling assistance for people with Medicare and their families.

The Conversation Project: www.theconversationproject.org

Created to help people talk about their wishes for end-of-life care.

Veterans Affairs: www.caregiver.va.gov or 855-260-3274

Provides supports and services for families caring for veterans. Connects caregivers with local caregiversupport programs for veterans.

Village to Village Network: www.vtvnetwork.org

An organization that helps communities start Villages, which are membership-based groups that respond to the needs of older people within a geographic area. Find Villages across the U.S. online.

2-1-1: www.211.org

A free and confidential service that helps people across North America find the local resources they need.

Signs & Symptoms

Caregiver support tools

Grief Support Group flyer

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.

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

Emily Dickinson (1830–86), U.S. poet. Attributed last words. Quoted in: W. H. Auden, *A Certain World*, "Words, Last" (1970).

End of:

Crossing the Creek

A Guide to Grief

Bereavement, Mourning and Grief

Overview

People cope with the loss of a loved one in many ways. For some, the experience may lead to personal growth, even though it is a difficult and trying time. There is no right way of coping with death. The way a person grieves depends on the personality of that person and the relationship with the person who has died. How a person copes with grief is affected by their experience with cancer, the way the disease progressed, the person's cultural and religious background, coping skills, mental history, support systems, and the person's social and financial status.

The terms grief, bereavement, and mourning are often used in place of each other, but they have different meanings.

Grief is the normal process of reacting to the loss. Grief reactions may be felt in response to physical losses (for example, a death) or in response to symbolic or social losses (for example, divorce or loss of a job). Each type of loss means the person has had something taken away. As a family goes through a cancer illness, many losses are experienced, and each triggers its own grief reaction. Grief may be experienced as a mental, physical, social or emotional reaction. Mental reactions can include anger, guilt, anxiety, sadness and despair.

Physical reactions can include sleeping problems, changes in appetite, physical problems or illness. Social reactions can include feelings about taking care of others in the family, seeing family or friends, or returning to work. As with bereavement, grief processes depend on the relationship with the person who died, the situation surrounding the death, and the person's attachment to the person who died. Grief may be described as the presence of physical problems, constant thoughts of the person who died, guilt, hostility, and a change in the way one normally acts.

Bereavement is the period after a loss during which grief is experienced and mourning occurs. The time spent in a period of bereavement depends on how attached the person was to the person who died, and how much time was spent anticipating the loss.

Mourning is the process by which people adapt to a loss. Mourning is also influenced by cultural customs, rituals, and society's rules for coping with loss.

Grief work includes the processes that a mourner needs to complete before resuming daily life. These processes include separating from the person who died, readjusting to a world without him or her, and forming new relationships. To separate from the person who died, a person must find another way to redirect the emotional energy that was given to the loved one. This does not mean the person was not loved or should be forgotten, but that the mourner needs to turn to others for emotional satisfaction. The mourner's roles, identity, and skills may need to change to readjust to living in a world without the person who died. The mourner must give other people or activities the emotional energy that was once given to the person who died in order to redirect emotional energy.

People who are grieving often feel extremely tired because the process of grieving usually requires physical and emotional energy. The grief they are feeling is not just for the person who died, but also for the unfulfilled wishes and plans for the relationship with the person. Death often reminds people of past losses or separations.

Mourning may be described as having the following 3 phases:

The urge to bring back the person who died.

Disorganization and sadness.

Reorganization.

Phases of a life-threatening illness

Understanding how other people cope with a life-threatening illness may help the patient and his or her family to prepare to cope with their own illness. A life-threatening illness may be described as having the following 4 phases:

Phase before the diagnosis.

The acute phase.

The chronic phase.

Recovery or death.

The phase before the diagnosis of a life-threatening illness is the period of time just before the diagnosis when a person realizes that he or she may develop an illness. This phase is not usually a single moment, but extends throughout the period when the person has a physical examination, including various tests, and ends when the person is told of the diagnosis.

The acute phase occurs at the time of the diagnosis when a person is forced to understand the diagnosis and make decisions about his or her medical care.

The chronic phase is the period of time between the diagnosis and the result of treatment. It is the period when a patient tries to cope with the demands of life while also undergoing treatment and coping with the side effects of treatment. In the past, the period between a cancer diagnosis and death usually lasted only a few months, and this time was usually spent in the hospital. Today, people can live for years after being diagnosed with cancer.

In the recovery phase, people cope with the mental, social, physical, religious and financial effects of cancer.

The final (terminal) phase of a life-threatening illness occurs when death is likely. The focus changes from curing the illness or prolonging life, to providing comfort and relief from pain. Religious concerns are often the focus during this time.

The pathway to death

People who are dying may move toward death over longer or shorter periods of time and in different ways.

Different causes of death result in different paths toward death.

The pathway to death may be long and slow, sometimes lasting years, or it may be a rapid fall toward death (for example, after a car accident) when the chronic phase of the illness, if it exists at all, is short. The peaks

and valleys pathway describes the patient who repeatedly gets better and then worse again (for example, a patient with AIDS or leukemia). Another pathway to death may be described as a long, slow period of failing health and then a period of stable health (for example, patients whose health gets worse and then stabilizes at a new, more limiting level). Patients on this pathway must readjust to losses in functioning ability. Deaths from cancer often occur over a long period of time, and may involve long-term pain and suffering, and/or loss of control over one's body or mind. Deaths caused by cancer are likely to drain patients and families physically and emotionally because they occur over a long period of time.

Anticipatory grief

Anticipatory grief is the normal mourning that occurs when a patient or family is expecting a death. Anticipatory grief has many of the same symptoms as those experienced after a death has occurred. It includes all of the thinking, feeling, cultural, and social reactions to an expected death that are felt by the patient and family.

Anticipatory grief includes depression, extreme concern for the dying person, preparing for the death, and adjusting to changes caused by the death. Anticipatory grief gives the family more time to slowly get used to the reality of the loss. People are able to complete unfinished business with the dying person (for example, saying "goodbye," "I love you," or "I forgive you").

Anticipatory grief may not always occur. Anticipatory grief does not mean that before the death, a person feels the same kind of grief as the grief felt after a death. There is not a set amount of grief that a person will feel.

The grief experienced before a death does not make the grief after the death last a shorter amount of time.

Grief that follows an unplanned death is different from anticipatory grief. Unplanned loss may overwhelm the coping abilities of a person, making normal functioning impossible. Mourners may not be able to realize the total impact of their loss. Even though the person recognizes that the loss occurred, he or she may not be able to accept the loss mentally and emotionally. Following an unexpected death, the mourner may feel that the world no longer has order and does not make sense.

Some people believe that anticipatory grief is rare. To accept a loved one's death while he or she is still alive may leave the mourner feeling that the dying patient has been abandoned. Expecting the loss often makes the attachment to the dying person stronger. Although anticipatory grief may help the family, the dying person may experience too much grief, causing the patient to become withdrawn.

Phases of grief

The process of bereavement may be described as having four phases:

Shock and numbness: Family members find it difficult to believe the death; they feel stunned and numb.

Yearning and searching: Survivors experience separation anxiety and cannot accept the reality of the loss.

They try to find and bring back the lost person and feel ongoing frustration and disappointment when this is not possible.

Disorganization and despair: Family members feel depressed and find it difficult to plan for the future. They are easily distracted and have difficulty concentrating and focusing.

Reorganization

Treatment

Most of the support that people receive after a loss comes from friends and family. Doctors and nurses may also be a source of support. For people who experience difficulty in coping with their loss, grief counseling or grief therapy may be necessary.

Grief counseling helps mourners with normal grief reactions work through the tasks of grieving. Grief counseling can be provided by professionally trained people, or in self-help groups where bereaved people help other bereaved people. All of these services may be available in individual or group settings.

The goals of grief counseling include:

Helping the bereaved to accept the loss by helping him or her to talk about the loss.

Helping the bereaved to identify and express feelings related to the loss (for example, anger, guilt, anxiety, helplessness and sadness).

Helping the bereaved to live without the person who died and to make decisions alone.

Helping the bereaved to separate emotionally from the person who died and to begin new relationships.

Providing support and time to focus on grieving at important times such as birthdays and anniversaries.

Describing normal grieving and the differences in grieving among individuals.

Providing continuous support

Helping the bereaved to understand his or her methods of coping.

Identifying coping problems the bereaved may have and making recommendations for professional grief therapy.

Grief therapy is used with people who have more serious grief reactions. The goal of grief therapy is to identify

and solve problems the mourner may have in separating from the person

who died. When separation difficulties occur, they may appear as physical or behavior problems, delayed or extreme mourning, conflicted or extended grief, or unexpected mourning (although this is seldom present with cancer deaths).

Grief therapy may be available as individual or group therapy. A contract is set up with the individual that establishes the time limit of the therapy, the fees, the goals, and the focus of the therapy.

In grief therapy, the mourner talks about the deceased and tries to recognize whether he or she is experiencing an expected amount of emotion about the death. Grief therapy may allow the mourner to see that anger, guilt, or other negative or uncomfortable feelings can exist at the same time as more positive feelings about the person who died.

Human beings tend to make strong bonds of affection or attachment with others. When these bonds are broken, as in death, a strong emotional reaction occurs. After a loss occurs, a person must accomplish certain tasks to complete the process of grief. These basic tasks of mourning include accepting that the loss happened, living with and feeling the physical and emotional pain of grief, adjusting to life without the loved one, and emotionally separating from the loved one and going on with life without him or her. It is important that these tasks are completed before mourning can end.

In grief therapy, six tasks may be used to help a mourner work through grief:

Develop the ability to experience, express and adjust to painful grief-related changes.

Find effective ways to cope with painful changes.

Establish a continuing relationship with the person who died.

Stay healthy and keep functioning.

Re-establish relationships and understand that others may have difficulty empathizing with the grief they experience.

Develop a healthy image of oneself and the world.

Complications in grief may come about due to uncompleted grief from earlier losses. The grief for these earlier losses must be managed in order to handle the current grief. Grief therapy includes dealing with the blockages to the mourning process, identifying unfinished business with the deceased, and identifying other losses that result from the death. The bereaved is helped to see that the loss is final and to picture life after the grief period.

Complicated grief

Complicated grief reactions require more complex therapies than uncomplicated grief reactions. Adjustment disorders (especially depressed and anxious mood or disturbed emotions and behavior), major depression, substance abuse and even post-traumatic stress disorder are some of the common problems of complicated bereavement. Complicated grief is identified by the extended length of time of the symptoms, the interference caused by the symptoms, or by the intensity of the symptoms (for example, intense suicidal thoughts or acts).

Complicated or unresolved grief may appear as a complete absence of grief and mourning, an ongoing inability to experience normal grief reactions, delayed grief, conflicted grief or chronic grief. Factors that contribute to the chance that one may experience complicated grief include the suddenness of the death, the gender of the person in mourning, and the relationship to the deceased (for example, an intense, extremely close or very contradictory relationship). Grief reactions that turn into major depression should be treated with both drug and psychological therapy. One who avoids any reminders of the person who died, who constantly thinks or dreams about the person who died, and who gets scared and panics easily at any reminders of the person who died may be suffering from post-traumatic stress disorder. Substance abuse may occur, frequently in an attempt to avoid painful feelings about the loss and symptoms (such as sleeplessness), and can also be treated with drugs and psychological therapy.

Life Assist

Life Assist Program

Who-65+ (or others at risk of falling) and home alone for extended periods of time.

What- Medical Alert Systems that call 911, family, or friends at the push of a button. In home devices as well as mobile (GPS tracking) devices are available.

Why- Assisted living is expensive and this is an economic alternative. This device gives you the independence you prefer while providing you peace of mind. This device also gives your friends and

family greater freedom and peace of mind; they will be contacted immediately if an emergency occurs. (List Monthly Pricing).

When-can be worn and used at all times-even in the shower

Where-in the comfort of your home

How-Simply push your button if you are in distress or have an emergency

NIA/NIH Resources

NIA/NIH infographics

NIH Advanced Care Planning Tool

The National Institute on Aging has a great site that uses easy to understand wording to help educate the public on important topics such as defining CPR, comfort care, artificial nutrition and hydration, etc. The advanced care planning page offers starter kits and prompts to walk you through getting your healthcare directives and end of life wishes known.

<https://www.nia.nih.gov/health/advance-care-planning-health-care-directives#decisions>

XX

To make quality of life care resources and services available in the setting most appropriate for that at end-of-life.

INTRODUCTION

Caring for a family member or close friend is one of the most important roles you'll play. It may start with driving your loved one to get groceries or to the doctor. Later, you may find yourself taking more time off from work, preparing meals or handling bills.

No matter where you are in the journey of family caregiving— just beginning to anticipate a need, helping coordinate a big move or taking care of a family member full time—having a good framework to help guide both you and your loved one will make the process easier.

This guide is a practical tool to help you care for your family member or close friend. You'll find information, resources and checklists to help you get organized and find the support that you might need. **Words in italics are described in greater detail in the Glossary, and organizations identified with an asterisk are listed in the Resources section.**

The guide follows five important steps that will help see you through your caregiving journey.

Start the conversation. Many people wait until a crisis occurs before they talk about their values and preferences, wishes for health care or details of their finances. If you wait until a fall, accident or serious diagnosis, big decisions may be driven by assumptions.

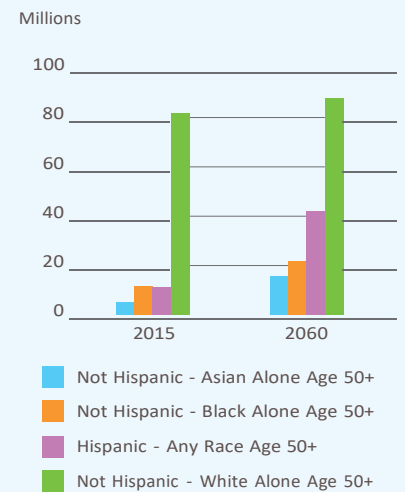
Form your team. No one should try to approach the responsibilities of caregiving alone. While other family members are likely sources of support, don't overlook friends, colleagues, clubs, or religious and other organizational affiliations as resources too.

Make a plan. Putting together a family caregiving plan now will help you respond more quickly and effectively should the need arise. It can also provide some peace of mind. A plan helps everyone get on the same page and keeps the focus on what's best for your loved one.

Find support. Many issues may arise during your caregiving experience that require additional information and resources. Don't hesitate to reach out to organizations and professionals with experience in helping *family caregivers*.

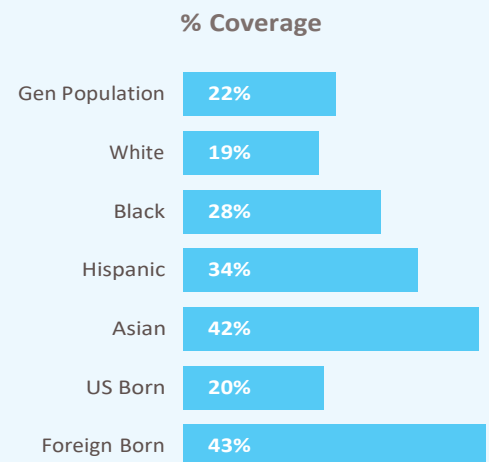
Care for yourself. As a family caregiver, it's easy to forget about your own needs. Keeping up your energy and maintaining your health are critical in order to care for others. It's just as important to make a plan to take care of yourself as it is to create a caregiving plan for others.

Growth and Diversity of the 50+ (2015-2060)



Source: U. S. Census Bureau, 2014. National Population Projections, Population Division.

Incidence of Caregiving for elders (Age 45-55)



Source: Belden, Russonello & Stewart and Research/Strategy/Management, 2001. "In the Middle: A Report on Multicultural Boomers Coping With Family and Aging Issue". AARP Research Report.

Caring for a family member or close friend is one of the most important roles you'll play.

Try not to anticipate what your loved one might say or how they will react. Just get the conversation started. It will likely take place over time. Be open. Express your love and concern and, most importantly, listen.

Respect your loved one's wishes. Every family caregiving plan must center on the wishes of the person receiving the care. A plan should never be made without the participation, knowledge and consent of your loved one. A person with a cognitive impairment should participate as much as possible.

Once you've started the conversation, you may wish to bring in a few other trusted family members or friends to be part of the process.

Before meeting, you and the other family members should consider...

- Who is the best person to start or lead the conversation? What are
- your own feelings and outlook on the situation?
- What are your goals or what is the best outcome you think might happen as a result of the conversation?
- What are you prepared and not prepared to do?
- What is most difficult for you about having this conversation about the person you care about?
 - "I'm starting to think about estate planning. Do you have any advice?"
 - "I just read an article about gathering all your important papers. Sometime can you show me where yours are and what you'd like us to do just in case?"
 - "As time goes on, do you think you will want to stay in this house? It might be difficult with all the stairs."
 - "You mentioned your eyes are bothering you. Is this causing problems with reading or driving?"

We've inserted a goals and needs checklist on page 23

to help you identify concerns related to your loved one's home, health, finances and legal needs.

Review finances. Money can be a particularly sensitive subject, but it's often at the heart of many decisions you'll make with your loved one about housing, health care and other expenses. One thing that family caregivers often find surprising is that most health insurance, including *Medicare*, pays for little, if any, of the costs of care in a nursing home, *assisted living residence*, or help with daily activities such as bathing, dressing or meals. Ask them

to review their bank accounts, investments, insurance coverage and loans. Find out whether they have *long-term care insurance* and funds or assets that can be used to cover potential care needs.

Counter resistance. Your loved one might say, "I just don't want to talk about it." Some people are private by nature. It's also hard for some people to admit they need help, especially if it's from their own children. If your first conversation doesn't go well, try again. Start small, discussing just one aspect of your concerns. If your loved one shuts you out, ask a trusted family friend, doctor or faith leader to approach them about your unease.

It's important to have a point person to keep the process moving and make sure people understand what's been decided. In most families, one person assumes the primary role because he or she lives nearby, has a close relationship, or simply is a take-charge person. Expect that there may be conflicts and don't be afraid to talk through them. Better now than in a time of crisis.

It is also sometimes helpful to engage the help of an outside facilitator, such as a social worker or minister, to help keep everyone focused, manage potential disagreements and communicate difficult subjects during the meeting.

Size up the situation. Figuring out what your loved one's priorities are—where they want to live and the nature of the care needed—will help you determine the next steps. It can lead you to find resources ahead of time. Your loved one may be hesitant to share the details of their finances or health, but approach them with respect and explain your intentions.

caregiving plans beginning on page 34.) For example, if your loved one wants to move in the next year or so, you can assign someone the task of researching locations and facilities. Someone else might offer to spend some weekends helping them sort through their belongings.

A written summary of the plan can reinforce your loved one's wishes and needs. Set up a system for communicating with everyone on the team. The point person should be well organized and an in-depth planner who can work through conflicts between the team members. There are a number of roles that people can help with; for example, you might want an assertive advocate to communicate with medical professionals or insurance companies. Be open to modifications as the situation and team members' ability to help may change. How your loved one's needs unfold may differ from what you expected.

The most effective family caregiving plans are made with the person you are caring for at the center of the discussion. Armed with the information you gathered from going through our goals and needs checklist, you can begin to explore the options available in the community and bring in team members to help manage the workload.

By now, you should also have an idea of the willing caregivers on your team. It's now time to figure out your plan. Be sure to ask your caregiving team members about their preferences for who does what task. For instance, they might be more comfortable with one person handling financial affairs over another. Assigning tasks can take place in a face-to-face family meeting, over a conference call, or through a series of emails.

The plan doesn't have to be extensive or fancy. You can never anticipate every detail or scenario. The plan should include immediate needs as well as the future. Use the goals and needs checklist as your guide. Options for addressing needs will depend on finances, the willingness of your support team and the availability of community resources and services. (See sample

Hire help. If you see that your loved one needs help with daily activities, you can explore the range of home care services available. Some home care workers do housekeeping, meal preparation, laundry and shopping. Others provide more hands-on help with bathing, dressing, and transferring from one position to another, which usually requires special training, a license or certification, depending on the laws in your state. Your agency on aging can help you identify the appropriate services and connect you with providers. They can also help you determine eligibility for publicly funded services. If you work with a home care agency or hire someone on your own, be sure to ask about licensing, background checks, training and costs. Get references to ensure good quality. Visit the AARP Caregiving Resource Center* at www.aarp.org/caregiving for more information on how to hire and find help.

Secure safety. The main goal is to help your loved one stay as independent as possible and in their own home. As your loved one has more difficulty getting around or their vision or hearing fades, some simple changes can be made to make the home safer. Handrails, grabbars, night-lights and adjustable shower seats

It's OK to reach out for extra support. If you've discovered the scope of care that is needed is beyond what you or your team can provide or if you're not sure what is needed, you might consider getting help from an organization in your community.

Locate community resources. A variety of support services are available to people age 60 and over and their caregivers throughout the United States. Your local *area agency on aging* can typically help connect you to services such as home-delivered meals, transportation, *adult day services* centers, care management and more. Check into the services offered in your community through the Eldercare Locator* at www.eldercare.gov.

Consult a professional. Oftentimes a loved one's needs can be complex, especially when health, emotional and financial issues come into play. A nurse or social worker can help you determine what is needed, find services, and arrange and monitor the care. Perhaps your workplace has an *employee assistance program* that can help connect you to professionals and services in your community. You can also find services through the Eldercare Locator.

can make a house safer and more comfortable. The AARP Home Fit Guide at www.aarp.org/homefit offers solutions that range from simple fixes to improvements that require skilled expertise.

Find housing with supportive services. If your loved one has decided that they would prefer to get care in a new residence that combines housing with support services, you can look into the variety of housing options that may be available in your community. Begin by making a list of criteria, such as location, group dining, laundry service and more. Not all types of housing are available in every community. Our Glossary includes common definitions for the different types of housing alternatives available.

Once you know the type of living arrangement desired, visit several facilities, and be sure to talk with residents and their families. For more information about how to choose the right housing option, go to the AARP Caregiving Resource Center at www.aarp.org/caregiving. If

10 Questions to Ask Before Hiring a Health Aide

No one with a need for a home health aide should be afraid to seek necessary care. But how do you ensure that your loved one is in safe hands? Lee Lindquist, M.D., chief of geriatrics at the Northwestern University Feinberg School of Medicine, offers these 10 questions to ask when vetting home-care agencies.

1. How do you recruit home health aides, and what are your hiring requirements?
2. Do you do criminal background checks on prospective aides? How about drug screening?
3. Are health aides certified in CPR, or do they have any health-related training?
4. Are the aides insured and bonded through your agency?
5. What competencies are expected of the aide? Lifting and transfers? Personal care skills (bathing, dressing, toileting)? Training in behavioral management, cognitive support?
6. How do you assess what the aide is capable of doing?
7. What is your policy on providing a substitute home health-care aide in the event a regular care provider cannot perform the services in your contract?
8. If there is dissatisfaction with a particular home-care provider, can he or she be replaced "without cause"?
9. Does the agency provide a supervisor who is responsible for regularly evaluating the quality of home care?
10. Does supervision occur over the telephone, through progress reports or in person at the home of the older adult?

Work and caregiving. Many of those who are caring for a loved one are also in the paid workforce. Find out if your company has policies or programs to support caregivers.

Benefits or services may be available that can help ease your situation. Think about taking advantage of flextime or working from home to help open up your schedule. If you need

more time off, consider asking whether you are covered by the *Family and Medical Leave Act*. Many people are covered by the act, but if you work for a small company or haven't worked for your employer long, you may not be eligible for this program.

Understand the financial impact. Your personal finances can take a hit from family caregiving—from time off of work, cutting back on hours, or passing up promotions to buying groceries and prescriptions. Try to calculate these costs when budgeting. If possible, stay in the workforce to increase retirement income later.

Advocate for you. Let your loved one's doctor know that you are their primary caregiver and you need information on their condition and the treatments prescribed. Ask for training if you are expected to do procedures at home. Some professionals might be reluctant to share information, but most professional offices have a form you and your loved one can sign giving providers permission to discuss their care with you. If your loved one has a durable power of attorney for health, be sure his or her medical providers have a copy in their medical files.

The Caregiver Advise, Record, Enable (CARE) Act, which has passed in many states recently, generally requires hospitals to:

- Provide your loved one the opportunity to designate a family caregiver when admitted.
- Inform you when your loved one is to be discharged to another facility or back home.
- Give you explanations and live instruction of the medical tasks—such as medication management, wound care and transfers—that the family caregiver will perform at home.

You can check if your state has passed the CARE Act and read the latest news about other AARP Advocacy initiatives on www.aarp.org/SupportCaregivers.

Learn more about the CARE Act and get your free wallet card to keep with your insurance card, so you have important information about the CARE Act when you need it. Visit www.aarp.org/walletcards.

Recognize your emotions. How you came into the role as a caregiver can influence how you feel about the experience. Perhaps you have always been close to your loved one and you see this role as your chance to give in return the loving care they gave to you and your family. Others may have been pushed into the responsibility and feel resentful because they are stretched with their own work and children. Then there are those who enter caregiving reluctantly, but discover it's a chance to mend a broken or distant relationship. However you arrived to this responsibility, it's helpful to recognize your emotions.

Take care of yourself. Allow yourself to take a break. Tend to your own needs for exercise, sleep and healthy eating. Find ways to reduce your stress and make sure to take time to have fun! If you take the time to care for yourself, you often return to your responsibilities renewed and better able to provide care for your loved one. To cope, consider tapping into social networks such as www.facebook.com, www.caringbridge.com, and AARP's online caregiving community at www.aarp.org/caregivingcommunity for support.

Caregiving services and support groups. There's comfort in knowing others are experiencing the same ups and downs as you. It may also give you ideas about other strategies and resources available to lighten your load. There are community services that can help you in your journey of caregiving. Don't feel guilty about needing time off or help with understanding complex information; and remember that your loved one may also benefit from having a wider circle of care. Find services and support groups available in your community through ElderCare Locator.*

Social workers, nurses and other professionals can guide you through care choices and help monitor the care when you don't live nearby.

Technology such as *personal emergency response systems*, remote monitoring devices, mobile apps with medical records, and electronic calendar reminders can help you juggle your many tasks as well as provide some peace of mind that your loved one is safe. Organization is essential for the long-distance caregiver. Keep a list of all contact information for doctors, insurance companies and neighbors. It's also important to keep a list of their medications with you.

GOALS & NEEDS CHECKLIST

Use this list to start the conversation about what is most important to your loved ones and what strengths they bring to bear.

Goals	Strengths
_____ To remain healthy and active	_____ Able to advocate for self
_____ To stay/move near family	_____ Adequate savings and/or income
_____ To remain in my own home for as long as possible	_____ Low-maintenance single-story home
_____ To stay active with religious or community groups	_____ Family and friends nearby
_____ To maintain hobbies	_____ Relationships with family
_____ To be around people	_____ Other
_____ To move to a residence with support services	
_____ To move to a more accessible home (one story or apartment with elevator)	
_____ To be financially secure and/or to budget for future needs	
_____ To travel/visit home country	
_____ Other	
Needs	

First determine if there is an immediate need under each area. If there is not a pressing issue, prioritize the tasks to be addressed and develop a timeline.

GENERAL NEEDS ASSESSMENT
 (One for each individual who will need care)

Area of Need	Types of Possible Tasks	Point Person
Home Maintenance and Living Situation	<input type="checkbox"/> Pay rent/mortgage <input type="checkbox"/> Home repairs/modifications <input type="checkbox"/> Ongoing maintenance <input type="checkbox"/> Safety concerns <input type="checkbox"/> Grocery shopping & meal preparation <input type="checkbox"/> Lawn care <input type="checkbox"/> Pet care <input type="checkbox"/> Housekeeping <input type="checkbox"/> Research alternative living situations <input type="checkbox"/> Other: -----	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
Financial Affairs	<input type="checkbox"/> Paying bills <input type="checkbox"/> Keeping track of financial records <input type="checkbox"/> Managing assets <input type="checkbox"/> Applying for and supervising public benefits	<hr/> <hr/> <hr/> <hr/>
Transportation Needs	<input type="checkbox"/> Driving decisions <input type="checkbox"/> Coordinating rides <input type="checkbox"/> Locating transportation services	<hr/> <hr/> <hr/>
Personal Care	<input type="checkbox"/> Coordinating personal care activities <input type="checkbox"/> Help with daily grooming and dressing <input type="checkbox"/> Rides to hair stylist <input type="checkbox"/> Clothes shopping	<hr/> <hr/> <hr/> <hr/>

GENERAL NEEDS ASSESSMENT (One for each individual who will need care)

Area of Need	Types of Possible Tasks	Point Person
Health Care	<ul style="list-style-type: none"> _____ Monitor and record physical and emotional symptoms _____ Arrange medical appointments, transportation, and someone to accompany as needed _____ Submit medical insurance and bills _____ Explain medical decisions _____ Medication management (fill prescriptions, fill pill boxes, give reminders and dispense medications) _____ Perform medical tasks (wound care, injections, and catheter) _____ Obtain medical bracelet and/or medical alert system if needed 	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
Communications	<ul style="list-style-type: none"> _____ Keeping family caregiving team informed _____ Coordinating team visits _____ Daily check-in _____ Obtain cell phone and/or Internet to enhance communication 	<hr/> <hr/> <hr/> <hr/>
Socialization	<ul style="list-style-type: none"> _____ Sending greeting and thank-you notes _____ Arranging for visitors _____ Arranging outings 	<hr/> <hr/> <hr/> <hr/>
Adaptive Devices	<ul style="list-style-type: none"> _____ Ordering, maintaining and paying for adaptive devices _____ Training on how to use devices _____ Other 	<hr/> <hr/> <hr/>

PERSONAL INFORMATION CHECKLIST

(One for each individual who will need care)

NAME

X	Personal Information	Where Is It Kept? <small>(attach copy of documents)</small>	Contact Name
	Social Security Card		
	Birth Certificate		
	Marriage Certificate		
	Death Certificate (for deceased spouse)		
	Divorce Papers		
	Military Records branch of service VA ID#: discharge papers:		
	Driver's License/Organ Donor Card		
	Passport/Citizenship Papers		
	Address Books (names and addresses of friends and colleagues)		
	Lists of church & community memberships and contact information		
	Information on waiting lists or contracts with retirement communities or nursing homes		
	Information on funeral arrangements		
	Pet Care: Vet, Sitter, Walker		
	Beautician/Barber		
	Lawyer		
	Other		
	Passwords		

HOME MAINTENANCE CHECKLIST

X	Home Item	Where Is It Kept? <small>(attach copy of documents)</small>	Contact Name
	Mortgage Company Name: Amount due:		
	Rental Management Company: Amount due:		
	Rental/Real Estate Agent:		
	Gas/Electric/Water Company:		
	Cable/Internet/Telephone:		
	Home Security Company:		
	Neighbor's Contact Information		
	Homeowners Insurance Agent: Insurance Policy #: Homeowners Premium:		
	Garbage Service/Garbage Pickup Day is: M T W Th F (circle) Recycle Service Pickup Day is: M T W Th F (circle)		
	Home Services: <ul style="list-style-type: none"> • Handy person • Lawn care • Appliances 		
	Passwords Computer(s) password clue(s) Phone messages password clue Cell phone		

PHARMACY Name

PHONE #

LOCATION

PHARMACY Name

PHONE #

LOCATION

DOCTOR Name

PHONE #

ADDRESS

DOCTOR Name

PHONE #

ADDRESS

DOCTOR Name

PHONE #

ADDRESS

DOCTOR Name

PHONE #

ADDRESS

DENTIST Name

PHONE #

ADDRESS

HOME CARE AGENCY

PHONE #

ADDRESS

HEALTH CHECKLIST (continued)

X	Item	Where Is It Kept?	Contact Name
	Medicare Original or Medicare Advantage (company name): ID Number:		
	Medicare Prescription Drug Coverage (company name): ID Number: <i>(does not apply to an Advantage plan with drug coverage)</i>		
	Other Health Insurance Policy (Medigap): Company: Premium: Payment schedule:		
	Veterans Health System: ID #:		
	Do Not Resuscitate (DNR) Order:		
	Physician Orders for Life-Sustaining Treatment (POLST) form— if available in your state		
	Living Will/Advance Directives		
	Durable Power of Attorney for Health Care		

TRANSPORTATION CHECKLIST

NAME _____

X	Item	Notes	Where Is It Kept?
	Auto(s):	Make(s):	
	Auto Loan Information:	Model(s):	
	Title for Car(s):		
	Auto Insurance Company:		
	Recreational Vehicles: Title: Insurance:		
	Transportation Services (such as ACCESS van or local cab service):		

X	Item	Where is it kept? Contact Name
	Bank Records (checking/savings accounts) Pin number clues — online banking and accounts with passwords and clues	
	Trusts	
	Will	
	Durable Power of Attorney for Finances	
	Any Rental Agreements or Business Contracts	
	Complete List of Assets & Debts	
	List of Routine Household Bills	
	Federal & State Tax Returns (past 3-5 years): Tax Preparer:	
	Records of Any Personal Loans Made to Others:	
	Financial Planner or Broker:	
	Life Insurance Policy or Policies:	
	Disability Insurance (long- and short-term):	
	Long-Term Care Insurance:	
	Safe Deposit Box(es):	Location(s): Number(s): Keys:

PUBLIC BENEFITS CHECKLIST

Your loved one may have or be eligible for help with paying for food, heating bills, property taxes and more. Use **AARP BenefitsQuickLINK**, www.aarp.org/quicklink, to find out about programs in your state.

X	Item		
	Food Assistance (i.e., SNAP/FNS)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Low Income Home Energy Assistance (LIHEAP)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Supplemental Security Income (SSI)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Property Tax Assistance	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Extra Help Paying for Medicare Part D (prescription drug coverage)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Medicare Parts A, B, and D Premium Support	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Medicaid (help with long-term care and medical care) Number & Identification Card	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Transportation Assistance	<input type="checkbox"/> YES	<input type="checkbox"/> NO

A caregiving plan can be simple or as detailed as you and your team desire. Use this simple planto determine the goals, steps, person responsible and timing together. Try to include a self-care goal for yourself and your team.

Name:

Date Started:

Team Members:

Contact Info:

Need	Steps	Person Responsible	Timeframe
<p>1. Better understand and manage Mom’s medical care</p>	<p>Meet with Mom and doctor</p> <ul style="list-style-type: none"> a. Create chart of medications to be taken when (make multiple copies for team) b. Buy pill organizer c. Get calendar to mark all appointments d. Mom signs form giving doctor permission to discuss medical care with me and my sister e. Take notes at each appointment in journal—get written instructions from doctor f. Confirm follow-up/appointments 		
<p>2. Move Mom to a new home</p>	<ul style="list-style-type: none"> a. Determine amenities/services needed b. Determine budget c. Research locations d. Research facility types e. Sort through stuff to be sold or given away 		
<p>3. For the caregiver: Relax with friends once a week</p>	<ul style="list-style-type: none"> a. Call Mary on Monday for a movie on Friday 		

SAMPLE DETAILED WEEKLY CAREGIVING PLAN

For daily tasks or those done on a regular routine, try something like this weekly schedule (it can be made into a daily or monthly schedule):

Caregiving Week of:

Day	Tasks	When	Person(s) Responsible	Plan
Monday	1. Check whether medications have been taken	End of day	Daughter Mary	Call and review pill box
	2. Go to doctor's appt	1:00 p.m.	Daughter Ann	Drive to appt, get prescriptions, set in pill box
Tuesday	1. Go grocery shopping	After work	Son Al	Call Mom for grocery list at lunch, shop after work and drop over.
	2. Check on medications			Check pill box when dropping off groceries. Look in fridge for spoiled food
Wednesday	1. Check on medications	End of day	Daughter Mary	Call and review pill box
Thursday	1. Check on home-delivered meals on the holiday	Today	Daughter Mary	Call agency to see if meals will be delivered next Monday
	2. Check on medications	End of day	Daughter Mary	Call and review pill box
Friday	1. Check on medical bill payment	Today	Daughter Mary	Make call to insurance provider about payment
	2. Ask Daughter-in-law Peggy to bring lunch on Monday			Call Peggy to fill in for Monday lunch
Saturday	1. Take over supper	Afternoon	Daughter Ann	
	2. Drive to beauty parlor			
	3. Check on medications			
Sunday	1. Manage medications	Evening	Mary	Review medications and place in pill box for the week
	2. Take to faith services	9:00 a.m.	Al	
	3. Arrange for visitor or outing	1:00 p.m.	Niece Beth	Drive Mom to service

[HTTPS://ONLINENURSING.SIMMONS.EDU/NURSING-BLOG/END-OF-LIFE-CARE/](https://onlinenursing.simmons.edu/nursing-blog/end-of-life-care/)

[HTTPS://WWW.AGINGCARE.COM/ARTICLES/COMPARING-END-OF-LIFE-CARE-OPTIONS-198129.HTM](https://www.agingcare.com/articles/comparing-end-of-life-care-options-198129.htm)

[HTTPS://WWW.LONGTERMCARELINK.NET/ELDERCARE/END_OF_LIFE_SERVICES.HTM](https://www.longtermcarelink.net/eldercare/end_of_life_services.htm)

[HTTPS://WWW.HRSA.GOV/SITES/DEFAULT/FILES/HRSA/RURALHEALTH/RESOURCES/HRSA-RURAL-COLLABORATION-GUIDE.PDF](https://www.hrsa.gov/sites/default/files/hrsa/ruralhealth/resources/hrsa-rural-collaboration-guide.pdf)