

**DEALING WITH
DEATH & ILLNESS:
A GUIDE**

Written by Dennis Pezzato, PhD

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Dealing with Death and Illness: A Guide

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Dealing with Death and Illness: A Guide

Preface:

There are times in life when we experience life-threatening illness and/or the death of a loved one. Sometime these situations are anticipated and sometimes they occur unexpectedly. In far too many cases, we are not adequately prepared to deal with the emotionally fraught decisions we must make and execute.

In the case of serious illness, we may often have ample time to learn- as-we-go, seeking advice and assistance from family, friends and health care professionals. These experiences can often be traumatic and devastating emotionally.

However, in the case of a death, whether unexpected or not, often we have very little time to prepare and can quickly become overwhelmed with the number of issues that must be dealt with in a short period of time. And we are faced with these issues in the midst of feeling numb, shocked, and emotionally traumatized by the experience of loss.

In different ways, both are usually emotionally traumatic. Having said that, each process is different in how they affect us and how we deal with them.

In the following pages, I will make suggestions about important things to consider about each of the situations we are faced with, which I have referenced above.

PLAN AHEAD

Illness:

We obviously don't always know if or when we might have to deal with a serious or life-threatening illness but in many cases, we do have warning signs of some type. But the way we "plan ahead" for illness is by preventing lifestyle-related illness from occurring; at least try to decrease the odds of an occurrence by proper diet, exercise, rest, and regular health care maintenance and screening.

Another way to plan is by having some form of health insurance and/ or a health savings plan. Another way to plan is by becoming informed about health care providers and options within your community. Lastly, try to have an emergency fund put aside to help with unexpected costs related to a prolonged illness. Before any serious illness is the best time to do your estate and end-of-life planning.

Death:

This is a topic that, for all sorts of reasons, is difficult for most families to talk about and face. Death and dying is not something that is easy to talk about; the thought of death scares many of us. However, if we do not talk about it and plan for it, we risk making the entire experience,

when it occurs, infinitely more complicated, chaotic, stressful, and emotionally draining.

There are entire books written on just this topic alone, so I will limit my comments to basics. This way, you have at least a good idea of where your planning efforts might be most fruitful.

The focus here is primarily dealing with the death of adults, especially older adults. Whether death comes unexpectedly, by way of accident or sudden illness, or due to the aging process and/or a protracted terminal illness, there are certain things that should be discussed and planned for among appropriate family members.

I think it is safe to say that when folks reach their advanced years, say late 60's, 70's, and beyond, thoughts about deteriorating health and the end of life become more prevalent.

What a great time to make sure we consider looking into what we can do now in order to make the latter stages of our life journey safer, more secure, and in keeping with our wishes. Following are some of the things to consider:

- **Advanced Healthcare Directive**
- **Trust**
- **Will**
- **Five Wishes (A simple way to express your end-of-life wishes)**
- **Prepaid Funeral Services**
- **Organ Donation**
- **Legal and Estate Planning**
- **Long Term Care Insurance or Provision**
- **Down-sizing living arrangements**

RESOURCES

There are many sources available within the county that can provide important information on all sorts of issues. Following are some examples:

- **Area Agency on Aging/ Agency on Elderly Affairs**
- **Legal Aid**
- **Adult Protective Services**
- **Long Term Care Services**
- **Healthcare Professionals**
- **Hospice Agencies**
- **Professional Mortuary Services**
- **Mental Health Professionals**
- **Pastoral Counseling (Faith-based Communities)**

There are also online resources available for information, including some hotline and/ or chat services from the following:

- **Aarp - aarp.org**
- **National Institute on Aging – nia.nih.gov**
- **Consumer Reports – consumerreports.com**
- **Verywell Health – verywellhealth.com**
- **Kiplinger – Kiplinger.com**
- **Alzheimer’s Association – alz.org**
- **Compassion and Choices - compassionandchoices.org**

CHECKLISTS

WHAT TO DO

Illness:

When a loved one (or you) is diagnosed with a serious or terminal illness, you will all likely feel traumatized and overwhelmed; this is normal. You can deal with this and you will get through this.

One of the first things you should do is to learn as much about the illness or disease as you can; learn about how it progresses, and what to expect in terms of symptoms and treatment.

Create a log or journal that is organized into sections so that you can keep track of appointments, doctors' orders, medications, patient symptoms, medication tolerance, patient behaviors, and all paperwork relevant to all processes; include insurance paperwork also.

Record all important contact information for providers in the journal. Staying organized and having information handy will make the process much easier and less stressful.

Accompany your loved one to all appointments, so that there are two listeners to hear and understand the information. Always write down any questions you might want to ask, and make

sure your questions are always answered before you leave the appointment.

As soon as possible, make sure you have in place all the end-of-life issues addressed in writing; hopefully you have had these conversations and taken care of all the paperwork.

Communicate regularly with appropriate family and friends; determine who is willing and able to help with your caregiving duties. Sometimes being a care giver can be too overwhelming to the point of creating an unhealthy physical and/or emotional situation for the caregiver. Please accept the gift of help when offered, it can benefit everyone involved.

Finally, let me say a few things about the importance of being aware of Hospice Care. Everyone should at least understand what Hospice provides for patients and families. Many of us, when making our wishes known for the end of our lives, would prefer to die at home amidst some comfort and familiar surroundings. This option, instead of a hospital setting, might feel more peaceful in many ways.

To that end, Hospice is an exceptional alternative and a means to ensuring comfort and focused care. Hospice regards death as part of the continuum of life. Hospice care goals are all

about maximum comfort and caring with minimal pain, to whatever extent possible. Their services are provided in the home setting, regardless of the type of home setting. Hospice also provides caregivers with the knowledge necessary to provide the most comfort for the patient.

Talk to your physician early-on about the appropriateness of Hospice care or contact Hospice with any questions you might have.

Death:

When a loved one dies, whether suddenly and unexpected or expected and anticipated, it almost always feels like a shock. Emotionally, it is a shock to our emotional sensitivities; it is trauma and loss. If you have done any planning in advance, that will serve you well and ease some of your burden, both physically and emotionally. If you have not done any planning, then it will be extremely helpful to have some idea of “what to do”.

I suggest that you start out by allowing yourself at least a little time to embrace whatever feelings you are experiencing in the first minutes and hours following the event. Allow yourself to express your grief in any way that feels natural to you. Before you start thinking

about all the things you must do and all the people you must tell, take some full deep breaths and tell yourself that you can, and will, do whatever it takes to get through this time.

Based on information from multiple sources, I have compiled a basic list of things to do. This is not intended to be comprehensive or all inclusive; you will gather your own resources and information based upon your own judgement and particular set of circumstances.

Following are some basics:

- **Get legal pronouncement of death (911 or healthcare provider)**
- **Tell family, friends, and an employer**
- **Execute funeral plans or make a new plan**
- **Gather appropriate legal documents, including a will, etc.**
- **Contact organ donor programs, Social Security Administration, Veterans Administration**
- **Write an obituary (mortuary can help)**
- **Secure loved one's home if necessary**
- **Arrange for pet care**
- **Have mail forwarded**
- **Get 10-12 copies of the Death Certificate**

- **Secure the Will and Executor if they exist/ contact your attorney**
- **Arrange for CPA regarding taxes**
- **Gather all accounts information for notifications (credit cards, banks, investments, life insurance policies, long term care insurance, credit agencies, Motor Vehicles Dept., Voter Registrar, utility companies, digital services, etc.)**

Please check multiple resources for additional information, and don't forget to draw upon family and friends who may have had to deal with these issues in the past; their guidance and experiences can be very helpful.

WHAT NOT TO DO

Illness:

Don't panic or act in haste. Do not fail to follow the instructions of your health care providers. Do not forget to write questions down prior to doctors' appointments; and get your questions answered before leaving. Do not be in denial about the reality of what is happening. Do not forget to take care of yourself during the process of taking care of someone else.

Death:

Don't panic or act in haste. You will navigate your way through this loss. Do not make major decisions regarding large purchases or sales during the first 6-12 months unless these transactions were pre-planned and/ or must be done quickly because there are no reasonable alternative choices. Don't commit to giving possessions unnecessarily or on impulse; these decisions should be well-thought- thru over time, so as not to set oneself up for future regrets.

Do not consider taking unsolicited advice from a source unfamiliar to you without proper vetting and scrutiny; don't make decisions early in the process without the help of a trusted loved one or friend, unless these decisions were actually set in advance of the death.

ASKING FOR HELP

Asking for help can be difficult and awkward for many of us, despite the fact that most of us would drop everything to help someone who asked us for our help during a crisis or challenging time.

The reality is that none of us has ever gotten to where we are today without help from numerous others in our lives; most of that help was unsolicited, I'm sure.

So, here we are in a most challenging situation of having to deal with serious illness or death, and we are probably hesitant to ask for help. For many of us, help is immediately offered without our even having to ask; still, too often we decline to accept that help.

Consider this: when we graciously accept help from others, we are giving that helper a gift of allowing them to give their gifts of love, compassion, and consideration. It is a wonderful opportunity for everyone to express love and kindness.

Having help can make a huge difference in the way we manage our challenges and our emotions throughout this process. It can also impact how we recover and heal from the trauma of illness and loss.

LOSS, GRIEF, and HEALING

Grief is an emotional reaction to loss, any loss. Most commonly, most of us think of loss by death; the death of a loved one or friend. But

there are many kinds of loss that can trigger grief. Let's look at some common kinds of loss:

- **Loss of physical abilities which accompany illness or aging**
- **Loss of memory or cognitive abilities due to illness or aging**
- **Loss of children from the home (empty-nesting)**
- **Loss of family members due to estrangement**
- **Loss of spouse or partner due to divorce or separation**

As you can see, there are many kinds of loss that can be traumatic emotionally and be a natural cause of grief. Additionally, there is a thing called “anticipatory grief” that we might experience while witnessing a loved one or friend deal with a serious or terminal illness. That means we are grieving for current and ongoing losses as well as anticipating future losses and even death.

Now, let's look at some typical questions that someone who is grieving might ask:

How long will I grieve?

No one can say how long your grief will last, and no one has the right to tell you how long it should last. In general terms, we need to allow

at least two years to go through the grieving process; expecting to have intense grief for about a year, and less intense grief for about another year. The pain you feel can change in intensity almost moment to moment; it can ebb and flow.

Sometimes you may almost feel calm, and other times you may feel an unbearable pain. This unpredictable ebb and flow will gradually subside. Grief lasts longer than society generally recognizes, so try to be patient with the process; doing so may help to ease some of the accompanying stress.

How can I deal with my feelings of guilt?

Guilt can be a normal part of grieving for many of us. It surfaces with thoughts and feelings of “If Only I...” In general, you need to believe that you made the best decisions you could with the information you had. Don’t be afraid to express your feelings of guilt to a friend or confidant. That person can probably help you take a more objective view of things. Unresolved guilt can make you feel miserable for years and might result in causing physical and emotional symptoms of distress. Hindsight and/ or second-guessing is counter-productive in these situations.

What do I do with my anger?

Anger is a human emotion which is easily expressed, and therefore, a common reaction to loss of any kind; that can especially hold true when a loved one dies. Anger, like guilt, needs to be expressed through healthy and acceptable means. It may be embarrassing or painful to admit that we are angry with God, others, or even the loved one who has died. But this realism will bring anger out into the open where it can be managed. Extreme anger should never be turned inward and repressed. Anger is best handled by bringing it into the honest light.

Can I just ignore my grief?

Grief can be painful, and if so, it can demand a lot of effort. It can be tempting for some to want to ignore it and hope it passes. In our society we are generally taught to suppress our pain and tears and “be strong”. We would do better to learn from some other cultures who have a more open and demonstrable way of grieving.

Unresolved or incomplete grief does not go away. Interestingly, many of the things we call social or behavioral problems had their beginnings in unresolved or incomplete grief or emotional trauma. Grief should not be ignored; it is a necessary part of the healing process following loss.

What is the key to surviving the loss of a loved one?

It is important to realize that the early days of grief are spent becoming aware of the “existence of non-existence and anguish”. The beginning of the survival process will follow that awareness and might be one of the most difficult tasks we will ever face.

However, I know that we are all equipped with the ability to journey through the process. We are all equipped to face the pain that accompanies the grief, but we must give ourselves permission to embrace all the emotions that come naturally; these are authentic, and part of who each of us is at our core.

Try to acknowledge that adapting to the changes that may accompany loss will take time, maybe even a long time. With your personal strength and courage, and the help of others, you will heal and move forward in a positive way. In time, you will emerge from pain to peace. These are choices we all have the power to make.

NORMAL GRIEF REACTIONS & MANIFESTATIONS

Normal Grief Reactions:

- **Bodily or Physical distress of some type**
- **A preoccupation with an image of the deceased**
- **Guilt relating to the deceased or circumstances of the death**
- **Anger, Irritability, or hostility**
- **Inability to function normally**
- **Lingering sadness**

Manifestations:

Feelings:

- **Sadness**
- **Anger**
- **Guilt**
- **Anxiety**
- **Loneliness**
- **Fatigue**
- **Helplessness**
- **Shock**
- **Relief**
- **Numbness**

Physical Sensations:

- **Hollowness in the stomach**
- **Tightness in the chest or throat**
- **Oversensitivity to noise**

- **Breathlessness**
- **Muscle weakness**
- **Loss of energy**
- **Dry mouth**

Cognitions:

- **Disbelief**
- **Confusion**
- **Preoccupation**
- **Sense of presence of the deceased**
- **Hallucinations**

Behaviors:

- **Sleep disturbances**
- **Appetite disturbances**
- **Absent-mindedness**
- **Social withdrawal**
- **Dreams of the deceased**
- **Avoidance of memorabilia**
- **Sighing a lot**
- **Restlessness or over-activity**
- **Crying**
- **Treasuring memorabilia**

***NOTE: Please consult your PRIMARY CARE PHYSICIAN if any of the above trouble you, seem excessive, or interfere with your normal functioning.**

SOME FINAL THOUGHTS

There are so many things in life that are difficult or even impossible to anticipate or plan for; consequently, we are all-too-frequently caught by surprise by our circumstances; then we must make some decisions in a pressured or hasty manner. In many cases, it is difficult to know about the resources that exist and how to access those resources.

In the cases Illness and Death, that is fortunately not the case. There is an abundance of resources available to us; we just need to make the choices that lead us to the information that will allow us to plan for these expected and unexpected occurrences.

My hope is that the materials provided in this booklet might provide you with some knowledge that can save you untold amounts of distress, distress which can tax you emotionally, physically, and spiritually.

DR. DENNIS PEZZATO

Dr. Pezzato is a Behavioral Specialist who has also written our Caregivers Guide and six self-help books that are geared toward helping others with their life skills.

He has, for many years, done cancer counseling for both patients and caregivers, served on the Area Agency on Aging Advisory Board, is an RSVP volunteer, conducts caregiver support groups, and been a volunteer and consultant with both the Alzheimer's Association and Kauai Hospice.

Dr. Pezzato believes that it is important to prepare for life's most difficult challenges, such as caregiving, dealing with serious illness and death, by gathering information and increasing our understanding of what each of these challenges can entail.

By doing so, we can increase our chances of better dealing with these difficult times with less distress, chaos, and emotional trauma.

NOTES