Chapter Five: Death and Dying

I. Caveats About Death Issues

The figure most often and most conspicuously missing from the insurance charts and demographics is the one I call The Big One, which refers to the number of people out of every one hundred born who will die. Over the long haul, The Big One hovers right around...well, dead nuts on one hundred percent. If this were on the charts, they'd call it death expectancy and no one would buy futures of any kind. But it is a useful number and it has its lessons. Maybe you will want to figure out what to do with your life. Maybe it will make you hysterical.

-Čarlson, Peter, "Working Stiff, The Life and Times of Thomas Lynch, Poet, Philosopher, Author, Undertaker," *The Washington Post*, August 3, 1997

For the last hundred years, death and dying have been taboo social topics of conversation. While the last few generations have watched an increasing amount of simulated violence and deaths on television, and even seen an increasing amount of deaths in homes and on the streets of cities due to violence, there is a steady reluctance to address the topic on an individualized or personalized basis.

Far from encouraging wide-ranging discussions of suicide, murder, death from illness or natural causes, as occurred in nineteenth century Western Europe and continues to occur in many traditional societies and cultures in other parts of the world, many people in the United States seek to deny that death happens, protect their children from witnessing death, and sterilize or sanitize death through confining its happening to hospitals or nursing homes away from home.

Yet ten percent of our population survives the death of a family member each year. Five percent of children lose one

Participant's Notes

parent through death before they are twelve. Close to 50,000 deaths due to homicide and vehicular homicide occur each year. About three times that many deaths occur due to suicide. The complexities in our reactions to these occurrences have many ramifications.

A. The death of a loved one raises concerns about one's own death\

1. When am I going to die?

Anxiety is just as logical a consequence and is, in fact, more common in bereavement than depression and actually paves the way for it.

– Rando, Teresa, *Grief, dying, and death: Clinical interventions for caregivers*, Champaign, IL: Research Press, 1984

2. Am I ready to die?

So you ask about my thoughts on dying. No I am not ready to die, but does God care?...I always thought I would live to be one hundred but now I have been shot and hurt and unable to walk or move without assistance. So, do I think I might die before one hundred years — yes! Do I know that Carly died — yes! Am I ready? No!

Robbery victim, NOVA Crisis Response Files, 1990

3. Am I afraid to die?

"The First To Go"

If I should go before the rest of you Break not a flower or inscribe a stone, Nor when I'm gone speak in a Sunday voice But be the usual selves that I have known.

Participant's Notes

Weep if you must Parting is hell, But life goes on, So sing as well. – Joyce Grenfell

4. Is it better that I die now rather than later?

And then one or the other dies. And we think of this as love cut short, like a dance stopped in mid-career or a flower with its head unluckily snapped off—something truncated and therefore, lacking its due shape. wonder. If, as I can't help suspecting, the dead also feel the pains of separation (and this may be one of their purgatorial sufferings), then for both lovers, and for all pairs of lovers without exception, bereavement is a universal and integral part of our experience of love. It follows marriage as normally as marriage follows courtship or as autumn follows summer. It is not a truncation of the process but one of its phases; not the interruption of the dance, but the next figure. We are "taken out of ourselves" by the loved one while she is here. Then comes the tragic figure of the dance in which we must learn to be still taken out of ourselves though the bodily presence is withdrawn, to love the very Her, and not fall back to loving our past, or our memory, or our sorrow, or our relief from sorrow, or our own love.

– C.S. Lewis, A Grief Observed

5. Am I useful, dispensable, or indispensable in life?

I've wondered since my husband's and my two children's deaths whether I should have died with them. It would have been easier, that I know, at least for me. But would it have been better? I still have two children. I don't know.

Participant's Notes

- NOVA Crisis Response Files, 1996
- 6. Can I be concerned with my death? Someone I loved died if they can do it, so can I.

I worry about how my mother died, I worry about whether or not she was in pain. But, I believe it was an experience that she needed and while I worry about my own transition from life to death to life, I still think I will end up satisfied with the result.

Surviving child of a cancer victim, NOVA Crisis Response Training, 1996

7. Is death wrong?

Americans have always thought death was an option.

- Anonymous

B. Crisis responders need to explore their own concerns about death

Crisis responders should not impose their beliefs on those who are in grief and hence may need to clarify their own reactions to death in general so that they are better able to support victims and survivors rather than be subsumed in their personal issues.

- 1. How do crisis responders feel about each issue if they view it from the perspective of their own death?
- 2. How do crisis responders feel about each issue if they view it from the perspective that someone they love very, very much may die?

II. Acknowledgment of Death

The following premises help adults and children acknowledge the reality of death. When death happens:

- **A.** The body ceases to function it is broken so it cannot be fixed.
- **B.** It is the time when someone is gone from your life forever in life as we know it.
- C. Each person will have his or her own understanding of death based on his or her personal beliefs.
 - 1. Some people believe in life after death and some do not.
 - 2. Some people believe in heaven and hell and some do not
 - 3. Some people believe in a world of spirits and some do not.
 - 4. Some people believe that death is the end of everything and some do not.

III. Fears and Anxieties About Death

The following fears of death are placed in order of lowest priority to highest priority in their emotional content. There are many other fears, but these simply highlight some that are useful for crisis responders to give voice to if survivors are struggling to understand the impact of death on their lives. Once again, it is useful to remind survivors that their reactions may involve a complex reaction to both the death of their loved ones and their own future death.

A. Practical fears

1. Fear for loved ones – there are fears for what may happen to loved ones who have died. What have they experienced and what will they experience? More often this fear is for the loved ones who survive. A dying person may worry about what will happen to his or her loved ones – whether or not they will have financial, physical or emotional resources to cope with the dying person's absence.

Participant's Notes

Even survivors often are ambivalent in their reactions – their grief over the loved ones' death and their fear of their own future.

Ididn't know how to balance our checkbook. Ididn't know whether I could keep our house. I was lost in a world awash with misery. I missed my husband, I missed our strength. I was terrorized by my helplessness.

- NOVA Crisis Response Files, 1988.
- 2. Fear of changes in role, closely related to fear of the practical changes in a loved one's life are the practical changes that occur in a loved one's role due to the loss of another. A wife becomes a widow. A parent becomes a parent of a murdered child. A sibling feels compelled to take on the role of an older sibling who died. All such forced role changes are traumatic and result in emotional stress.

You are told when you marry that you are two people who combine to make one unit; one family with shared love and goals. For forty years the two of you are one. What happens when all of that is subtracted? What happens when one becomes one half? Nobody tells you that.

- A widow, quoted in Staudacher, C., *Beyond Grief*, New Harbinger Publications, Oakland, CA, 1987.
 - 3. Fear of loss of family and friends is a closely related fear. This loss is the companion to missing someone deeply. The question, "when will I see you again?" evokes its poignancy, which is more painful when it is answered, "never in this life again."

My heart was darkened over with grief, and whatever I looked at was death. Where I lived was a torment to me; even my own home filled me with sorrow. Those things which my friend and I used to share together, now that I was without him, tortured me like the lash of a whip. My eyes looked for him everywhere and could not find him. All places were hateful to me, because he was not there. They could not say to me now, "Look he will soon come," as they used to say when he was alive and away from me.

–St. Augustine, *The Confessions*

4. Fear of the perpetrator — If a loved one has died due to murder or homicide, the survivors or covictims may continue to be afraid that the perpetrator will kill them or other family members. This fear is often perceived as silly by law enforcement officials or family and friends, but is very real in the mind and dreams of the survivors.

This fear can exist even if there is no prior connection or tie to the perpetrator or if the co-victim is a witness to the crime. Unless a real threat has been made, the police often do not understand the co-victim's apprehension and are not very empathetic if he articulates it. While the perpetrator is in jail, the co-victim may continue to check on his whereabouts. After the perpetrator is released, the apprehension of the co-victim may increase even if there has been no contact. This type of fear can last a lifetime.

-Spungen, D., *Homicide: The Hidden Victims*, Sage Press: CA, 1997 (forthcoming)

5. Fear of the dying process – this fear includes both the fear of the possible pain of the dying process and also what might be available to comfort loved ones through the pain. There are some who have

Participant's Notes

lived through a "near-death experience" who tell of a sense of peacefulness and resolution. There are others who tell of feeling frantic and a need to return to life. But, no one knows what the process truly will be when lived through or died through to completion.

a. death's peace

I had last night the loveliest dream; My own land shown in the summer's beam, I saw the fields of golden grain, I saw the reaper's harvest strain; There stood on the hills, the green pine-tree, And the thrush and the lark sang merrily. A long and a weary way I had come...

- "The Female Convict," Letittia E. Landon, in *Library of World Poetry*, William Cullen Bryant, Avenel Books, New York, 1970.

b. death's anguish

When I saw his face — marked with terror and confusion — I knew he was dead. I cried because of his pain. He had been killed. He knew it before he died and he felt it. If I could have held him, maybe then it would not have been so difficult. But he was alone, trapped in an airplane. Hung from the skies.

– NOVA, Crisis Response Report, 1988.

B. Fears of impending doom

1. Death's contagion

People who survive the death of loved ones may feel that they will spread the death. Women who suffer the loss of a child may fear that other children, or their own future children, will not live to adulthood. Survivors of those who have died due to fatal illnesses often fear that they have con-

tracted such illnesses. Others in society seem to agree with these fears. They may resist talking about the death, the "contagion," in order to feel less vulnerable to the disease of death.

a. carrying the cloud of death

My mother died of cancer when I was a baby. My father remarried and my stepmother died of cancer when I was four. My father died of cancer when I was twelve. My grandparents raised me after that. When I married, I married with dread – would I have children who died before me? I convinced my husband to adopt a child because I couldn't give birth to death.

– NOVA, Crisis Response Report, 1988.

b. the stigma of dying

No matter how death occurs, survivors of loved ones who die are often left alone by their friends or family members. In cases of murder or suicide, the gap between former friends and family may become too large to overcome.

It's funny, you know, to lose a friend because your father committed suicide. After the wake I went across the street from the funeral home. My friend lived right across the street but he acted as if, "What is your problem?" I guess he was having a hard time dealing with the death himself. He never called me anymore and we just went our separate ways. I couldn't deal with losing a friend. I think the whole thing just freaked him out. He couldn't believe it. I lost two friends because of this. The rest of my friends, they didn't want to hear about it. Maybe it isn't that they didn't want to hear about it, but that it was hard for them to deal with it too...

– Staudacher, C., *Beyond Grief*. New Harbinger Publications, Oakland, CA, 1987.

Participant's Notes

2. The perception of imminent death

It is not unusual for survivors to feel that they too will die in order to sustain their connection to the person who has died. And, in fact, some survivors grieve to death or find a pathway to death through suicidal behaviors.

When Virginia Woolf's mother died, she left behind not only dependent children, but also a grieving and inconsolable husband who frequently shared with his children his own wish to die. Not only were Woolf and her siblings burdened by their father's pain, even worse, they were implicitly charged with the task of making his life bearable.

– Harris, M., *The Loss That is Forever*, Dutton Books, 1995.

C. Fears of the unknown

The fear of what will happen to loved ones, or what will happen in the dying process, and all the practical fears, all are related to fears of the unknown.

1. Fear of God

For many, the fear of the unknown begins with the fear of confrontation with God, or reconciliation with God – and how that occurs. Does God demand an accounting for our lives? Is He or She a final arbiter of our living? Will we face Hell and damnation and what does it take to get to Heaven? Our quandary, and our hope, and expressed by Alfred Lord Tennyson:

For tho' from out our bourne of time and place
The flood may bear me far,
I hope to see my Pilot face to face
When I have crossed the bar.

- Tennyson, "Crossing the Bar"

Participant's Notes

2. Fear of spirits

God is not the only concern of the dying. There is also a fear, for many, that they will see or become part of a spirit world. Those who survive a loved one's death may also fear being drawn into this nether world.

Tennyson addresses this conundrum as well:

Do we indeed desire the dead
Should still be near us at our side?
Is there no baseness we would hide?
No inner vileness that we dread?
Shall he for whose applause I strove,
I had such reverence for his blame,
See with clear eye some hidden shame,
And I be lessened in his love?"
— Tennyson, "In Memoriam"

3. Fear of judgment and finality

The fear of finality and judgment has little to do with the spiritual world, in this context, but may be as important. Most people want to believe that their life was significant by some measure. That measure might be in terms of the children they have raised; the reputation they have made; the legacy they have left – but there is a need to have been significant. Death ends all potential at ensuring that one's life was significant.

Pile the bodies high at Austerlitz and Waterloo. Shovel them under and let me work – I am the grass; I cover all.

And pile them high at Gettysburg
And pile them high at Ypres and Verdun
Shovel them under and let me work.
Two years, ten years, and passengers ask the
conductor:

What place is this?

Where are we now?

Participant's Notes

I am the grass.

Let me work.

- Sandburg, C., "Grass," in Cornhuskers, Holt & Co., 1918.

4. Fear of being alone

For many people, there is an ultimate terror at being left alone. There is nothing quite so alone as dying – to the best of our knowledge. When you are born, you are connected to your mother. But, when you die, you are connected to no one in this world.

There is nothing short of dying Quite as lonesome as it sound ...

 Kris Kristofferson, "Sunday Morning Coming Down"

D. Fears of loss of connection with life

These two fears may be the ultimate fears of death.

1. Fear of loss of body

There is no culture that condones the mutilation or destruction of the human body – without ritual. There is a sanctity connected with the body, and there is a physical conception of identity that each person carries with him or her to the grave. The idea of the body being torn apart, mutilated or destroyed is abhorrent to the human condition. The loss of body without a chance to say goodbye to it may deeply disturb survivors – some may refuse to acknowledge the person is dead; others may dwell on the inability to bury the person; still others anguish over both the suddenness and completeness of the transition from "being to nothingness."

I search the sky ... in desperate sorrow but can discern no human form ... There is not a trace. No grave. Nothing. Absolutely nothing. In a way they didn't really die. They simply became smoke. How does one bury smoke? How does one place headstones in the sky? How does one bring flowers to the clouds? Mother, Potyo ... I am trying to say good-bye to you. I am trying to say good-bye.

- Isabella Leitner, a survivor of the Holocaust, quoted in *A Global Response to Crisis II*, by Yael Danieli, Ph.D., a chapter of The Next Generation in Victim Assistance (NOVA).
 - 2. Fear of forgetting or being forgotten

Finally, there is the fear that loved ones will be forgotten or that survivors will forget. That fear is based on the truth. It's a truth that most people try to ignore. However, most of us will be forgotten one hundred years from now and we will, over time, forget one another. But, the yearning to remember and to be remembered is strong.

It is often said that something may survive of a person after his death, if that person was an artist and put a little of himself into his work. It is perhaps in the same way that a sort of cutting taken from one person and grafted onto the heart of another continues to carry on its existence even when the person from whom it had been detached has perished.

 Marcel Proust, Remembrance of Things Past translated by C.K. Scott Moncrieff.

V. Anger Over the Death of a Loved One

Many people react to a loved one's death with anger. Anger has many functions in grief, just as it does when people react to trauma.

A. Anger is usually driven by fear, but it may be independent

- 1. People may be angry when their loved ones have died and direct the anger at their loved ones.
- 2. Anger may be directed at people who try to help survivors.
- 3. Anger is also energized by frustrations at people, agencies or organizations who are perceived to be responsible for the conditions under which survivors work.

B. Anger is useful in coping because it helps defuse fear and inhibits other stress

- 1. Anger can conquer pain.
- 2. Anger mobilizes frustration.
- 3. Anger fuels fantasies of renewal.
 - Revenge fantasies.
 - Compensation fantasies.
 - Forgiveness fantasies.
- 4. Anger may help survivors continue to live long enough to find reasons other than anger to survive.

VI. Guilt Over the Death of a Loved One

Many people feel guilt after the death of someone they know or love. At times guilt is felt because it is a way to hold on to someone who is loved. Some people feel generalized guilt after the deaths of others. Guilt seems to be predicated upon the following kinds of issues.

A. Guilt about preparations for death

- 1. Often individuals who have made plans for the death of a loved one and their consequent loss feel badly about having made those plans. For instance, a surviving spouse may feel guilty that he or she insisted upon having her partner sign a will, arrange for funeral plots, or take out life insurance.
- 2. Sometimes survivors have thought about the impact of the possible death of a loved one upon themselves and others and feel a sense of guilt when the death and impact occur.

B. Guilt about lifestyle changes

- 1. Sometimes survivors feel guilty when their lifestyle improves because of inheritance or monetary compensation for loss.
- 2. Sometimes survivors feel guilty because their lives become less complicated as a result of the death of a loved one.
- 3. Sometimes survivors feel relieved about the death of a loved one because of their perception that the person is now without pain.

C. Guilt concerning negative thoughts or feelings about the loved one

- 1. Most people do not have consistently positive thoughts about people they love; most, at some point, lapse into frustration, anger, or even momentary hatred and, upon reflection, those lapses often cause self-blame among survivors.
- 2. Sometimes survivors feel that their negative thoughts induced the death of a loved one.
- 3. Sometimes survivors are anguished over the fact that they acted a certain way towards loved ones, and now, after their deaths, will never be able to tell those loved ones they are sorry, or to ask their forgiveness.

D. Survivor guilt.

- 1. Many survivors feel they should have died instead of the person who did.
- 2. Often survivors feel their survival was a mistake and that the person who died should have lived.
- 3. Some survivors feel that there is a certain amount of suffering and loss allocated to any particular community, and that if they had died or been injured, someone else could have been spared.

E. Guilt usually serves to confuse survivors

Caregivers should try to help clarify the sources of guilt and provide survivors with options for new perspectives. Much of what caregivers can do in response to guilt issues is to listen to the bereaved.

Some of these perspectives include the following.

- 1. Death does not result from a predefined selection process.
- 2. Death cannot be bargained away or defeated by an offer of the exchange of another's life.
- 3. Everyone will eventually die. Planning for death is healthy, not a predictor of when death will occur.
- 4. Relief for a loved one who has died a painful death is not an ignoble reaction.
- 5. Frustrations with a loved one prior to death cannot cause his or her death. You may have thought, at times, that you wished someone dead, but your wish is not an action.

VII. Shame after Death of Loved Ones

A. Shame about how someone died

The shame surrounding how a loved one died is, in one way, vicarious shame. The survivor takes on the shame that the loved ones would have felt. Was the loved one nude when he or she was killed? Were they out of control in front of other people? Were they humiliated in death? Such thoughts and others may clutter the thoughts of the survivors.

B. Shame over relief

Survivors may also be ashamed because they felt relief at the death of a loved one. Sometimes the relief stems from the fact that the loved one was in pain or suffering. But at other times, the shame is because the survivor may feel less encumbered as a result of the loved one's death. There is guilt stemming from the duty owed to the loved one, but there is also shame over the fact that the survivor seems to have put his or her personal feelings above the life of the loved one.

C. Shame over circumstances after someone dies

Sometimes survivors are left in bleak circumstances, financially, physically, and practically as a

result of a loved one's death. This may occasion reactions of shame over new roles, new situations and new challenges.

D. Shame imposed by society's disgust at the survivor's behavior

The social order in many societies demands that survivors endure their suffering without complaining. Behavior that is construed as incongruent with social standards is deemed demented and then isolated.

During 20 years of working with PTSD clients, I have found that, regardless of the victim or trauma, the response of others will follow a predictable pattern. If reassurance and cheering homilies fail to comfort, if subtle warnings fail to quiet the victim, the ultimate trump card is shame: Only shame is powerful enough to squelch the victim's desperate need to be heard. The power of shame is known and sanctioned in the Bible: In the story of Job, neither God nor the community would tolerate even a good and innocent man's crying out against the most outrageous betrayal and unjust violence. ... The shamed person feels both exposed and condemned, uncovered and seen through — in a sense flayed by the community's disgust and contempt. ... Therefore, the best technique for silencing the trauma victim, whose outraged and betrayed sense of self cries out for expression, is shame, which alienates the private, violated self from the social self.

 Jeffrey Jay, "Terrible Knowledge," Networker, November/December 1991

VIII. Death and Loss

A. Death and loss result in grief for victims and survivors\

Although this section is entitled "Death and Dying," and, as such, may be thought of as referring to human death, the experience of surviving a death may be endured following other kinds of losses as well.

Participant's Notes

Employees may feel as though they suffered deaths when they lost jobs. People who are divorced often feel like they survived the death of a marriage or a relationship. Burglary victims suffer small experiences of deaths when they find their property gone. So death can mean many things. Crisis responders should be alert to various kinds of losses and their impacts.

- 1. Precipitation of grief occurs with the recognition of the loss, the absence of someone or something.
- 2. Recognition of loss may be immediate, incremental or may occur years after the loss itself.

B. Kinds of losses

1. Loss of life

The ultimate loss is the death of a loved one. For survivors that loss is one that lasts until the end of their life.

You know poor Mr. Dodsley has lost his wife; I believe he is much affected. I hope he will not suffer so much as I yet suffer for the loss of mine ... I have ever since seemed to myself broken off from mankind; a kind of solitary wanderer in the wild of life, without any direction, or fixed point of view: a gloomy gazer on a world to which I have little relation.

- Samuel Johnson, Boswell's Life of Johnson.

2. Physical losses

a. invasion of body

Dr. Morton Bard has often suggested that sexual assault or incest is the closest thing to death. The forcible violation of one's body through penetration of the body's most rigorous defenses is often overwhelming. It is particularly offensive when committed by a person who is known, trusted or loved. It severs the belief in humanity and community.

A secure sense of connection with caring people is the foundation of personality development. When this connection is shattered, the traumatized person loses her basic sense of self.

- Herman, J., Trauma and Recovery.

b. loss of limb

Catastrophic physical injury is not always manifested through the loss of limb; however, the significance of the loss of a leg or an arm cannot be overlooked. The physical identity of an individual changes with the mutilation or amputation of a body part. Perhaps that is why people who are paralyzed care for the unfeeling parts of their bodies – they have a visceral connection with their former healthy bodies.

The phenomenon of the "phantom" limb is well known. The body remembers the injury and the pain of the arm or leg that is not there. The brain continues to send information to the absent part, but it cannot respond. The pain of a broken bone is infinitely reassuring because the bone can be mended. The pain of something that isn't there is grievous.

Half a man. My legs are gone. Stubs of aching longing are all that is left of my other half. I tell myself that I am whole and I am lucky to be alive. But how do I grieve over the half that is gone."

– Car crash victim, NOVA Case Logs, 1985.

c. loss of ability

The loss of previous mobility, vision, hearing, and talents is often a consequence of catastrophic injury. But it may also be a result of catastrophic trauma. Some people may lose their physical abilities because they have been

Participant's Notes

physiologically harmed. Others may lose those abilities because they have been psychologically harmed. In either case, there is grief over the loss of capacity to perform in a certain way.

She was late for school that morning of June 7, 1979. So Renee Katz, 17, a talented flutist at Manhattan's prestigious High School of Music and Art, stood at the edge of the 50th St. subway platform in Manhattan, waiting to board the incoming E train. "There was a thud," says Katz, now 33. "Then I was under the train. I realized that my hand was severed. I yelled for my mother. I yelled that I wanted to go to college, that I was a musician." ... Although her career as a flutist was over and she has had to learn to write and eat with her left hand, she can now perform after six surgeries and hundreds of hours of therapy, such mundane tasks as shifting gears in her car. "Her life changed in a split second," observes occupational therapist Pat Casler. — People Magazine, April 3, 1995.

d. loss of memory

Sometimes memory is lost through the efforts of the cognitive brain to protect itself. Sometimes it is lost because the brain has been damaged through injury or disease. In any case, it is frightening for survivors to know that they do not remember, or that they will not remember, their former knowledge, lives, or even their reason for living.

Grace knew it was Thanksgiving ... friends would be missing this year. At times she understood why, and felt the pain of the passage. Other times there was only the sense of loss and its questions: What's missing? Where are they? Why aren't they here?

But the questions were fleeting, as was so much else

in her mind. Once her life had been a continuous train of events. Now it was broken into moments. Events occurred disjointedly. She had lost the connectors to give them order.

So she was left with a potpourri of emotions ...

One minute it might be greed, the wanting of things for an eternity that wouldn't be. Another it was anger, or sadness, or fear....

That might have explained the peril she felt, the sense of things beginning to rot, the urgency. Some Alzheimer's sufferers stayed at plateaus for years, some even long enough to die of natural causes. Grace knew that she wouldn't. She could see a daily worsening, could chart the steady diminution of her abilities even with the steady diminution of her abilities."

– Delinsky, B., *Shades of Grace*, Harper, NY, 1995.

e. loss of sensorial perception

Victims may lose capacities of sensorial perception such as the ability to smell or to taste. After some events, there may be a total loss of senses. After others, loss of senses may be discreet and may be associated with the event itself.

f. loss of beauty or image

Survivors of a catastrophe who have had their faces or bodies scarred or maimed often feel as though they have lost their ability to connect to others. People they see may avert their eyes or seek to avoid contact with them because they are ugly.

A woman who had been stalked, assaulted, doused with kerosene, and inflamed by the match of an offender found herself altered forever. Her ugliness was confirmed by another woman in a grocery store who told her daughter, "If you aren't good, you will grow up to be as ugly as that woman."

3. Material Losses

a. loss of money

The loss of money or property may leave a void for a few days or weeks. Vandalism, often considered one of the least serious of crimes, may cause communities to become fearful and threatened. It is difficult to imagine the desperation of a person who cannot buy food for his or her children. Money and property may represent independence and opportunity. The humiliation of poverty and dependence exacerbates the sadness of loss.

I had nothing. I begged on the streets. It seems odd but I was resigned to that life. I knew its limits. Until, that day when I had been given a five dollar bill. For one moment, I felt rich and then I was shoved down on the street and beaten. My five dollars was gone and I knew my life was worth less than five dollars.

- Victim, NOVA Victim Service Report, 1987.

b. financial losses

More serious financial losses may mean that a person who had felt secure a future retirement has been rendered penniless.

Telemarketing schemes in the last few years have robbed many older people of the chance for a secure retirement. Floods, earthquakes and other natural disasters often destroy homes and happiness. Despite victim compensation programs, the financial impact of trauma can leave survivors destitute. They may face loss of job, income, property, and find themselves in thousands of dollars of debt due to medical expenses and the costs of rehabilitation.

c. loss of sentimental property

The loss of photographs of a loved one, a wedding ring, or some other item of memory may be the source of inconsolable grief.

- **d.** loss of pets pets are a significant addition in the majority of American lives. The death of a pet may be grieved as deeply as the death of a loved one in the family.
- **e. loss of friends** when people have to move from their friends and thus have, at best, long distance contact, there is often grief.
- **f. loss of home** some studies suggest that the home is identified deeply with an individual's sense of self. Destruction of home may symbolically destroy an individual and his or her family.
- 4. Intangible Losses
 - **a.** loss of trust there is often a sense of loss in the ability to trust other people after a major tragedy.
 - **b. loss of faith** sometimes people lose their faith in God whether temporarily or permanently.

Ihad become a great enigma to myself and asked my soul why it was so sad and why it caused me so much distress. And my soul did not know what to answer. If I said, "Trust in God," my soul very rightly did not obey me, because the dearest friend whom it had lost was more real and better than the fantastic god in whom it was told to trust. Only tears were my consolation, and tears had taken the place of my friend in my heart's love."

- St. Augustine, *The Confessions*.
 - c. loss of identity crises may cause some people to lose their sense of identity. Incest survivors sometimes talk of grieving over who they might have become but for the chronic sexual abuse.
 - **d. loss of history** and its connections to the future disaster, death and change create a hiatus in the present. Nothing that has happened in the

past will ever be viewed again except through a vision colored by the disaster. And there is no prediction of the future because of the bedlam of change.

e. loss of time

While history and its connections to the future seem to have gone through a time warp, so does the sense of the future. There is for many a sense that time goes by without them and that time lasts for years. When they "wake up," they are old and growing older and there is no way to recover the past.

f. loss of values

For some, victimization by crime causes them to want to victimize others. And some of those people are sickened by that change in their attitudes and values.

g. loss of confrontation with death

In the face of conflicting values and losses, some people lose their will to live. In most cases, this does not mean that they actively will seek to die. However, they may not seek to survive when confronted with death in the future.

h. loss of feeling

People may talk of having no ability to respond emotionally after a tragedy.

i. loss of innocence

If a disaster was caused by a human crime or accident, the human perpetrator may be perceived as being evil. The confrontation with evil causes some people to feel they have lost their innocence.

j. loss of hope

Tragedy may throw people into despair. All the intangible losses accumulate and become overwhelming, and people lose hope.

IX. Confronting Grief

Some literature on death and dying describes the grief response in terms of one pattern. There are actually many responses to death, dying, grief and loss. There are also unique responses to dealing with grief. Many make a distinction between grief, which occurs when the perception of loss is understood, and mourning, which involves actively working to reconstruct life after loss. Identifying losses is important in order to understand what is being grieved. There are different responses to loss occasioned by disaster and that suffered due to anticipated causes. The sadness may be similar but the responses to loss reflects different types of suffering. The following outline reflects some of those differences.

A. Understanding sadness after loss

- 1. Sorrow is expected after death or loss, and is not pathological. Usually, it is overcome after a period of time. It is not useful to try to delay or impede the process of individuals in their efforts at regaining functioning and control over their lives. Sigmund Freud, "Mourning and Melancholia," in *The Standard Edition of the Complete Psychological Works of Sigmund Freud*, Strachey, J., ed.& translation, London: Hogarth, 1953
- 2. Sorrow is accompanied by the need to accomplish three goals. One is to free oneself from the terminated relationship with the person or object that has been lost. A second is to realize and adjust to the world without the person or object that is missing. Finally, there is an effort to establish new (not replacement) relationships with others. Eric Lindemann, "Symptomology and management of acute grief," *American Journal of Psychiatry*, 1964.
- 3. Realization of loss results in immediate responses of numbness, yearning and searching for the person or object lost, despair, and reorganization of one's life after loss. Bowlby, J., *Attachment and loss*, New York: Basic Books, 1980
- 4. Sorrow involves four tasks: the acceptance of the

reality of the loss, living through the pain, recognizing that the loss is forever, and accepting that the loss is in the past and that life goes on. Worden, J.W., *Grief counseling and grief therapy: A handbook for the mental health practitioner*, New York: Springer, 1991 (2nd ed.)

- 5. "The Six R Processes of Mourning" (from Rando, T., *Treatment of complicated mourning*, Champaign, IL, Research Press, 1993)
 - Recognize the loss.
 - **React** to the missing.
 - **Recollect** the missing, the relationship, and the meaning of the relationship.
 - **Relinquish** attachments to the world before the loss including assumptions that no longer hold.
 - **Readjust** to a new world without forgetting the old.
 - **Reinvest** in the world around you.

B. Anticipatory grief

1. Natural anticipatory grief

In this manual, natural anticipatory grief is illustrated by grief over the expected death of an aged loved one. While natural anticipatory grief after such a death is often experienced with less shock than sudden, arbitrary death, there are factors that can make the anticipated death of a loved one traumatic, such as an especially close relationship or a survivor left with a vanished social support system.

Many times the natural anticipatory grief response occurs in response to mini-strokes, dementia, Alzheimer's disease or increased fragility. Reactions often occur in the following pattern:

- a. Initial shock happens in reaction to changes that are recognized in the loved one during life.
- b. Sporadic bouts of sorrow occur as family and friends acknowledge that their loved one will die in the near future.
- c. Family and friends begin to prepare and plan for final loss and the expected change in their roles.

- d. Upon death, detachment is filled with sorrow/missing/loneliness. However, in anticipatory natural death, this phase is usually relatively short.
- e. After the death of the loved one, the survivors implement the plan for change. There is a gradual acceptance of the immutable fact that death is a natural consequence of life.
- f. Remembrance is usually a planned affair and memorials may or may not be apart of such process.
- 2. Unnatural anticipatory grief

This refers to the process of grieving over a death that follows a terminal illness when the dying person is still young, middle aged or youngold. This process involves the following overlapping phases.

- a. Denial: characterized by an unexpected loss syndrome but occurring during the life of the dying person and precipitated by the announcement of the terminal illness. Sometimes the denial phase is complicated by loved ones who do not know how to function during a "long goodbye."
- b. Protest/anger: this phase is often manifested by survivors bartering with God, with doctors, with anyone who might delay the death for the person who is diagnosed as dying. It usually occurs prior to death due to the fact that the delayed dying process means that the survivors begin to work through some grief prior to the actual death.
- c. Despair will follow the protest and anger prior to death because despair is the corollary of hopelessness.
- d. Disengagement occurs, since most people cannot sustain the impact of despair for long periods of time, and so they go in and out of extreme grief in order to survive.
- e. Finally, there occurs a preparatory period and planning for final loss.

If the loved one and the dying person go through this period separately, without communicating their respective feelings, it will inhibit survivors from being able to cope.

Death following separate preparations will usually cause additional shock, anger, sorrow and detachment.

Death following mutual communication and planning will help the survivor respond to death with detachment, implementation of a plan for survival, acceptance, loneliness and focus on remembrance.

f. Reconstruction

Reconstruction after the loss of a loved one is extremely difficult. When one has had to live through the anticipatory period in which loved ones and others have recognized the incumbent death, there may be special sorrow. The anticipatory period may not have been perceived as real. The person may have been perceived, accurately, as irreplaceable. Greater intimacy may have been gained during the anticipatory process than ever before. What those who have a chance to say good-bye to others have is the potential tenderness of goodbye. Communication during this anticipatory period is the key for reconstructing lives of survivors. Lack of communication is the pitfall for people in estranged relationships.

C. Traumatic grief

For many survivors the impact of sudden, random death and the consequent grief has an enduring pain that reflects different patterns than anticipatory grief. The survivors usually experience a traumatic reaction to the manner of death or loss which they must confront before they can even begin to grieve over the loss. After the trauma reaction they then confront the death itself. These reactions are not linear but more like an ongoing volcanic reaction which throws them back and forth from different emotions and feelings.

- 1. Denial and shock still are manifested in confusion, avoidance, and refusal to participate in acknowledgments. Unremitting crying, physical pain, weakness, nausea, sleep disturbances, and loss of appetite often occur. However, the denial and shock are paralleled by the other emotions that follow.
- 2. Rather than protest, most survivors concentrate on anger. They know their loved one died. Their denial and shock occur in response to death not in the expectation of death. There is no longer anyone on whom one can rely to defy death no doctors, no lawyers, no God. So protest becomes anger but anger aimed at self, loved one, God or the world. It usually manifests itself in irritability, lack of concentration, frenzied activity, and eventually fatigue.
- 3. Despair follows anger. There is depression, hopelessness, agony. Survivors often experience an inability to think or act. There may be an urge to recover what was lost, but a recognition that there can be no recovery.
- 4. No one can maintain the sense of despair that exists after the suddenness of loss. So, as in the response to anticipatory unnatural grief, there is a time in life where many people need to become detached. Being engaged in everyday living is too painful.
- 5. Reconstruction of life. Reconstruction of a new life can only take place after there is an integration of the trauma event with the incipient grief, as well as with the acknowledgment that things well never be the same and that their survival continues despite the pain.

D. Duration of grief

1. Some people have said that death that is expected or "natural" is survived with a relatively shorter bereavement period than that which is not expected or is the result of a sudden disaster. There is no way to predict the length of the grieving process for anyone who has survived the death of a

Participant's Notes

close loved one. It may be that when survivors have had an opportunity to prepare for the coming death of loved ones, some of the grieving is done while the loved ones are still alive. In such cases, the acute grief process in the aftermath of death may last no longer than two years. In sudden, tragic death, particularly when complicated by the additional trauma of murder, a transportation crash, or terrorist attack, the acute grief process may last for as long as five to seven years. The important thing for caregivers to realize is that as long as the survivor is beginning to focus on the present and the future, in addition to the past, there is movement towards a possible new life.

The worst thing about grief is the length of time during which the experience lasts. For the first weeks one is in a state of shock. But the agony lasts long after the state of shock comes to an end. After a year, or about two, the agony gives way to a dull ache, a sort of void. During the night in one's dreams, and in the morning when one wakes, one is vaguely aware that something is wrong and, when waking is complete, one knows exactly what is."

- Lord Halisham of St. Marylebone, A Sparrow's Flight.
 - 2. After the acute grief process, there will continue to be spasms of grief a loss is forever. For most people, grief eventually subsides and a new life can be constructed. However, most will also suffer spasms of grief during the rest of their lives.

Tonight all the hells of young grief have opened again; the mad words, the bitter resentment, the fluttering in the stomach, the nightmare unreality, the wallowed-in tears. For in grief nothing "stays put". One keeps on emerging from a phase, but it always recurs.

5-30

Round and round. Everything repeats. Am I going in circles, or dare I hope I am on a spiral?

But if a spiral, am I going up or down it?

How often – will it be for always? – how often will the vast emptiness astonish me like a complete novelty and make me say, "I never realized my loss till this moment?" The same leg is cut off time after time. The first plunge of the knife into the flesh is felt again and again.

They say, "The coward dies many times"; so does the beloved. Didn't the eagle find a fresh liver to tear in Prometheus every time it dined?

– C.S. Lewis, A Grief Observed.

D. Special grief issues

1. Crisis and trauma reactions complicate the grieving process.

In sudden, random, arbitrary death, grief is often delayed due to the initial crisis reaction. Individuals are often consumed for months or years over "how" their loved one died. As a consequence, they may avoid confronting the loss and put off grieving for a long period of time. No one can help survivors catch up with the reality of the death, they experience their own internal timetable, which may be affected by external forces, but it will always be governed by the internal emotional concerns of the survivors.

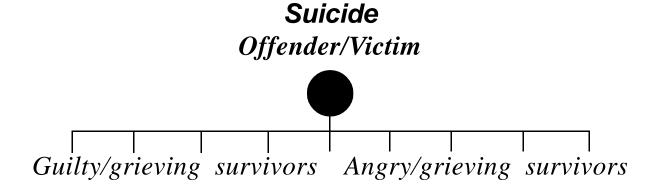
- 2. When death is sudden, often survivors grieve over the fact that they did not have a chance to say a formal good-bye to the person who died.
- 3. When there have been difficulties in the relationships between the survivors and the person who has died, it can exacerbate sorrow.
- 4. People grieve differently based on their attributes and the relationship they had with their loved one see the chart at the end of this chapter.
- 5. Some relationships are overlooked or minimized in the aftermath of death. The overlooked may

- include former spouses or partners, step-children or -parents, adopted children where biological children also exist, foster children, grandparents, godparents, aunts, uncles, and so forth, teachers and students, employers, and colleagues. It is wise to spread the comfort net as wide as possible after a traumatic death.
- 6. At times survivors may feel they are denied a grieving process. They endure illegitimate grief. It is not recognized by society, nor is it acknowledged as valid. There are several reasons for this phenomena. The significance of the relationship may not be recognized between the survivor and the person who is dead. The death or loss may not be acknowledged by the survivor's support system. The victim may have been stigmatized, and so is thought unworthy of grief. The loss may be minimized as not important. The survivor may be stigmatized for grieving.
- 7. Attributes of a particular death may also affect the grieving process.
 - a. Anytime a loved one dies, and the victim had been tortured or the dying process is protracted, expect an additional level of grief.
 - b. Death due to intentional human cruelty usually causes additional anger and outrage.
 - c. Suicide causes particularly complex reactions in the surviving loved ones. Grief is often accompanied by a sense of betrayal, guilt, and misunderstandings. For some survivors, the "Understanding Suicide as a Homicide" Chart (next page) is helpful. Suicide may be thought of as a homicide in which the perpetrator is also the victim. The survivors can grieve and remember with love the victim while at the same time feel outrage at the perpetrator.

Understanding Suicide as a Homicide

Both deaths leave guilty, grieving, angry survivors:

Homicide Offender Victim Guilty/grieving survivors Angry/grieving survivors



While NOVA has used this construct with survivors of homicides and suicides for years, only recently did a paragraph from William Styron come to our attention that illuminated the analogy even more. Styron struggled with severe depression and almost committed suicide one night when in the darkest of despairs. He wrote:

A phenomenon that a number of people have noted in deep depression is the sense of being accompanied by a second self — a wraithlike observer who, not sharing the dementia of his double, is able to watch with dispassionate curiosity as his companion struggles against the oncoming disaster, or decides to embrace. There is a theatrical quality about all this, and during the next several days, as I went about stolidly preparing for extinction, I couldn't shake off a sense of melodrama — a melodrama in which I, the victim-to-be of selfmurder, was both the solitary actor and lone member of the audience. I had not as yet chosen the mode of my departure, but I knew that the step would come next, and soon, as inescapable as nightfall. (emphasis added)

- Styron, William, "Darkness Visible", in *Sacred Sorrows*, eds., Nelson, John E., Nelson, Andrea, Jeremu P. Tarcher/Putnam: NY, 1996)
 - 8. While patterns of grief are similar, everyone grieves differently. It is important to remind survivors that their grief will be manifested differently than their surviving loved ones. If survivors are not aware of this, grief in the aftermath of death can destroy even very loving relationships.
 - 9. Spasms of grief continue for a lifetime. They may be caused by trigger reactions to traumatic memories but they are also caused by benign, routine memories and recollections of joy.

E. Commemoration

- 1. Most people feel a strong need to commemorate the life and the death of their loved one. In part this relates to the need to confirm that the loved one is not, and will not be, forgotten. In part it relates to the physical and emotional need to act on the overwhelming feelings of grief.
- 2. Just as everyone has their own way of grieving, everyone has their own way of remembering.
- 3. Methods of commemoration

- a. Fixed memorials are those most commonly associated with death: a tombstone, a statue, a plaque, a cross, or other physical thing that symbolizes the individual's life or death.
- b. Sometimes a person is remembered through living memorials such as a scholarship fund, an activity (memorial walks or games), or the dedication of a survivor's life work.
- c. There are times when there is a purposeful attempt to memorialize someone's life through an "eternal" symbol such as the eternal flame over John F. Kennedy's grave.
- 4. Times for commemoration
 - a. In the aftermath of disaster, the first memorial usually takes place through a memorial ceremony within the first week of the event.
 - b. Some communities have a memorial at the end of the first month or at the time of a holiday if one occurs shortly after the tragedy. Some religions have ritual memorials of someone's death every month for a year.
 - c. At the end of six months after a disaster or a death, survivors often reach a point of deep depression. To help endure that period of time, some communities hold six month memorials.
 - d. The first year after a disaster is one that may be marked with long-term stress reactions throughout the community. These reactions are often termed "anniversary" reactions. Even though some people may not want to think about the tragedy, it is likely that many people in the community and the media will focus attention on the disaster.
 - e. After the first year, it is likely that the following "anniversaries" will draw attention to the disaster: the 5th, 10th, 15th, 20th, 25th, and 50th.
 - f. It should be noted that many people experience more depression at the end of the second year after a disaster than at the end of the first year.

This seems to be due to the fact that the second year after the disaster many people, not affiliated with the disaster, forget about it. Survivors often feel abandoned and betrayed.

XII. Hints for Helping

A. Suggestions for Survivors

- 1. General decisions For most, it is wise to put off important decisions. This is not a time to decide to sell a home, get married, or seek a divorce.
- 2. Prepare for the "firsts" Everything that is done after someone dies becomes new. There will be the first time a survivor has dinner after their loved one died. There will be the first time that a holiday occurs without the loved one there. There will be the first birthday and so forth. Each first marks a time of "going on" and, for many, a time for grief.
- 3. Prepare for the roller-coaster of grieving Some survivors resent the term "healing," but the process of reconstructing a new life in the wake of disaster has a similarity to the physical healing of the body after a deep wound. It does not happen in a linear way. People have good days and bad days after tragedy.
- 4. Don't set unrealistic expectations.
- 5. Express reactions through writing, talking, physical activity, whatever is most comfortable. Cry, laugh, rage. . .
- 6. Avoid dwelling on personal guilt It's hard not to think of the possible ways that you might have avoided the tragedy, but there is little use in dwelling on what might have been.
- 7. Stay in touch with your doctor to monitor physical reactions. It is not unusual for a person who is grieving to be vulnerable to illness and unhealthy behaviors.
- 8. Educate yourself on specific issues related to this death. Reading about grief is a way of validating your own experiences.

Participant's Notes

- 9. Maintain or develop routines.
- 10. Stay in touch with the living: pets, plants, children, and friends. Many times the necessity of feeding a pet or watering a plant can be a life-connecting experience.
- 11. Communicate with your loved ones who have died write to them, talk to them, pray to them.
- 12. Take time to be sad.

B. Hints for caregivers

- 1. Ask how survivors are doing and listen to their answers.
- 2. Allow people to talk when they want to but don't attempt to force them to talk. Don't force conversations.
- 3. Ask about memories of the deceased.
- 4. Accept all feelings and reactions as valid even when they are frightening.
- 5. Be prepared to hear "worse case" scenarios in a non-judgmental fashion.
- 6. Don't be in a hurry when talking to survivors. Let them know that you will be there for as long as is necessary.
- 7. Don't be afraid of silences.
- 8. Don't betray confidentiality.
- 9. Make arrangements to be with survivors but at their convenience. Don't drop in unexpectedly. If you telephone, ask if the person you are calling has time to speak to you.
- 10. Explain clearly what will be expected of survivors and what they can expect of others.
- 11. Ask survivors how you can help but offer practical options: obtaining information on problems they are facing, mowing the lawn, preparing food, caring for children on a specific date, arranging transportation. Let them decide if they want help before you take action.
- 12.Don't intrude in the house of a survivor without permission.
- 13.Be supportive but don't try to make the survivor feel "good."

Participant's Notes

- 14. Send written notes to show you care.
- 15. Discuss traditions and holidays and how they might be handled.
- 16. Create special tributes for both the survivors and their loved ones at difficult times such as holidays or memorial dates.
- 17. Learn and use the names of the deceased in conversations about them.
- 18.Remember to celebrate the life of loved ones who have died. Don't simply dwell on the deaths. Remember birthdays and death dates of the deceased.
- 19. Attend memorial services and funerals when invited or when they are open to the public.
- 20. Offer to help with death notifications to others.

XIII. Preparing for Death

Caregivers should prepare for their own deaths if they are to be effective in dealing with the deaths of others.

- **A. Financial arrangements** Make estate decisions through wills, trusts or other legal arrangements so that your heirs do not have to face these issues. Even if heirs resent your decisions, the fact that you made them will help avoid personal disputes.
- **B. Death and after-death arrangements** Make funeral decisions and decisions about how you want your body dealt with so that family and friends know your wishes.
- **C. Relationships and communication** Don't let relationships go uncared for while you live. Let people know that you love them.

XIV. Conclusion

Death is an inevitable fact of life. The survivors face grief and sorrow, but the words of theologian Dietrich Bonhoeffer give comfort to some:

Nothing can make up for the absence of someone whom we love, and it would be wrong to try to find a substitute; we must simply hold out and see it through. That sounds very hard at first, but at the same time, it is a great consolation, for the gap, as long as it remains unfilled, preserves the bonds between us. It is nonsense to say that God fills the gap; He does not fill it, but on the contrary, keeps it empty and so helps us to keep alive our former communion with each other, even at the cost of pain.

Participant's Notes

ls	ssues that A	ffect Differe	nt Relationsl	nips After De	eath		
Survivor	Relationship of Deceased to Survivor						
Attrib- utes:	Spouse/ Partner	Child	Sibling	Parent	Friend/ Peer		
Survivors Generally	Companion Connection with life Sexual changes Social isolation	Immortality Identity crisis Social Isolation No chance for life	"Special one died" Love/hate New roles	Orphan Time to grow up New roles	Non-family Isolation		
Male	Long term health problems Workaholic Abandon family Angry outbursts	Failure to protect Weakness Lack of control Avoids other children	Depends on gender of sibling Male: may take on role Female: may interfere with male/female relations	Loss of role model Jealousy of siblings Regret over relationship	Loss of confidente Loss of generation		
Female	Short term health problems Income issues Feel abandoned	Break in family circle Inability to nurture Failure to protect	Male: may interfere with male/female relations Female: may take on role	Loss of role model Jealousy of siblings Regret over relationship	Loss of peer support Loss of generation		
				•			
Child	N/A	N/A	Death anxiety Ghosts Forgetting Survivor Guilt	Dependency Abandonment Betrayal of trust Anger	Death anxiety Ghosts Forgetting		
Adoles- cent	Depression Despair No one can understand Immortalize loved one Suicide Intellectual- ization Sublimation Risk-taking behaviors	N/A	Death preoccupation Suicide Substance abuse Jealousy/competition with deceased Anger Risk-taking behaviors	Instability Low self-esteem Judgmental Anger Move to adulthood Risk-taking behaviors	Death preoccupation Isolation Sense of abandonment		

Issues that Affect Different Relationships After Death (cont.)							
Survivor	Relationship of Deceased to Survivor						
Attrib- utes:	Spouse/ Partner	Child	Sibling	Parent	Friend/ Peer		
Young Adult	Psychological symptoms Death anxiety Compulsive self-reliance	Loss of hope Loss of future Shattered dreams	Breaking of alliance Survivor guilt	Loss of friendship Loss of past No one to turn to	Similar to spouse or sibling		
Middle Age	Sleep disorders Abandonment Overwhelmed by new role	Loss of family Acquisition of grandchildren No chance of grandchildren	Death anxiety Loss of generation	The aged orphan	Similar to spouse or sibling		
	· · · · · · · · · · · · · · · · · · ·						
Elderly	Physical symptoms Loss of hope Often die too Loss of connection with life	Similar to above	Similar to spouse	Mixed relief The aged orphan	Similar to spouse or sibling		