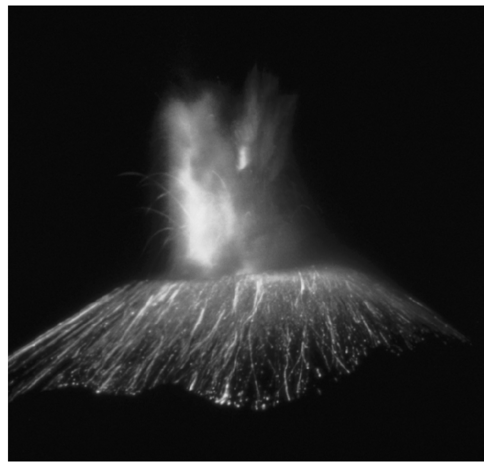


## Appendix I: List of Overheads and Handouts

- Definitions Related to Grief and Loss
- Holistic Health Framework
- Signs and Symptoms of Grief
- Common Myths About Grief
- Truisms About Grief
- The Three Questions
- The Grief Journey
- Grief Journey Definitions
- Tasks of Mourning
- Common Avoidance Patterns
- Issues in Multiple Loss
- Grief Overload
- Core Loss
- Coping Strategies
- Stages of Change Theory
- Aspects of Closure

# DEFINITIONS OF ATTACHMENT, GRIEF &LOSS

## Attachment

- a bond of affection or loyalty
- requires an investment of emotional energy
- to grieve is to honour the profound truth of the attachment

## Bereavement

- the state of having suffered a loss: physical or symbolic

## Grief

- the process that allows us to say good-bye to what was and to get ready for that which is yet to come

## Anticipatory Grief

- the process stimulated by awareness of impending loss/death

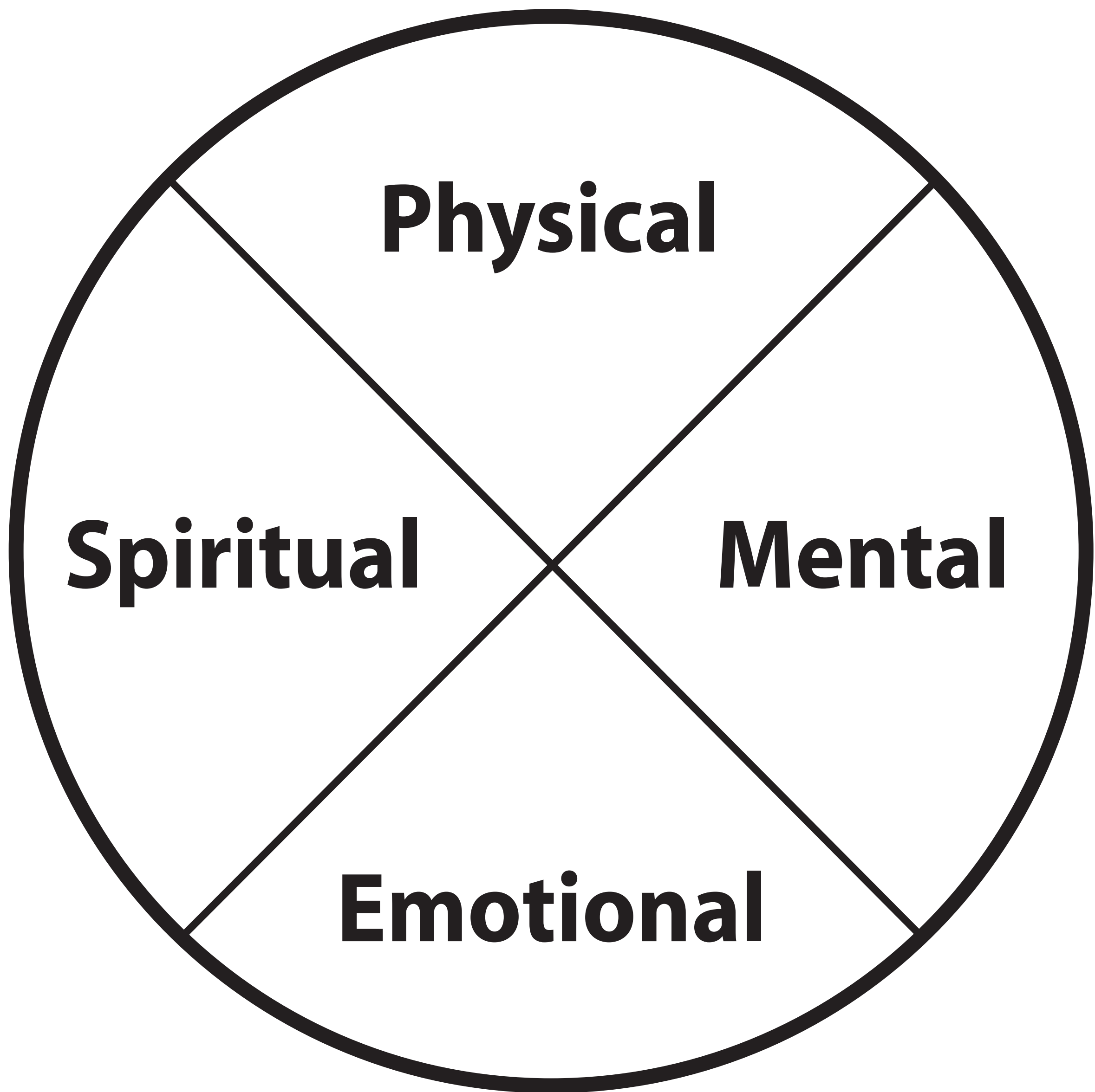
## Mourning

- any public shared expression of a person's thoughts, behaviours and emotions related to the loss

## Multiple Loss

- experiencing constant and sustained loss, often while **anticipating** further losses

# HOLISTIC HEALTH FRAMEWORK



## SIGNS & SYMPTOMS OF GRIEF

### 1. Physical

- I'm exhausted
- I have spasms in my back/my neck is seized up
- My head aches all the time
- I can't shake this flu
- My ulcers are acting up
- My Jaws are so sore – I must be grinding my teeth at night
- I have such a tightness in my chest/difficulty breathing
- Sometimes I don't care about sex, then I have the urge to have sex a lot
- My stomach feels like its in knots half the time

### 2. Emotional

- I'm always on the verge of tears
- Those kitten commercials make me weep
- I'm so irritable I've been biting people's heads off lately
- I'm just pissed off at everything and everybody
- I can't feel anything – I'm numb – I'm not really connected
- I'm having nightmares
- I don't want to feel
- I am anxious all the time these days

### 3. Mental/Attitudinal

- I just can't seem to concentrate/my mind is not here
- I walk into a room and forget why I'm there
- I completely forgot about that meeting yesterday
- I can't slow down/I can't stop my mind from racing
- I can't get to sleep even though I'm exhausted
- I just want to be distracted

### 4. Spiritual

- What am I doing here? There's no point in doing this work
- These deaths are relentless/the suffering is so enormous
- Why is this happening to me? to us?
- This is not how life is supposed to be
- I can't make one more new friend
- No use in making attachments which won't last
- I so desperately want some joy in my life/want peace of mind
- I'm not creative anymore

## Common Myths About Grief:

- **all losses result in the same type of grieving**
- **bereaved individuals only need express their feelings in order to "resolve grief"**
- **to be healthy after the death of a loved one, just put that person out of your mind**
- **the intensity of mourning is a testimony to your love for the deceased**
- **grief should be over in a year**
- **grief declines in a steadily decreasing fashion over time**
- **sudden, unexpected death is the same as losing someone to an anticipated death time alone heals all wounds**

# Some "Truisms" About Grief and Bereavement

- **Bereavement is a normal, natural experience - although traumatic and disruptive.**
- **Response to loss is not a uniform phenomenon-variability must be recognized. Some show intense distress and others don't.**
- **Grief has no timetable. A major loss tends to resurrect old issues and conflicts for the mourner.**
- **Grief is not a linear process, but more of a spiral as mourners revisit aspects of grief again and again.**
- **Grief is experienced within a social context. Society's view of death and expectations of "appropriate grieving" influence expression of loss.**
- **The goal of grief work is to grieve "well" not to grieve "right".**
- **Support is about stimulating the mourner's own coping skills.**
- **While grief and loss are an inevitable part of life, most people lack a language and an understanding of grief that would help them identify and cope with normal, natural responses to loss.**

# THREE ESSENTIAL QUESTIONS:

## WHO AM I?

{as my assumptions about the world and
myself are thrown into question by the experience}

## WHO HAVE I BEEN?

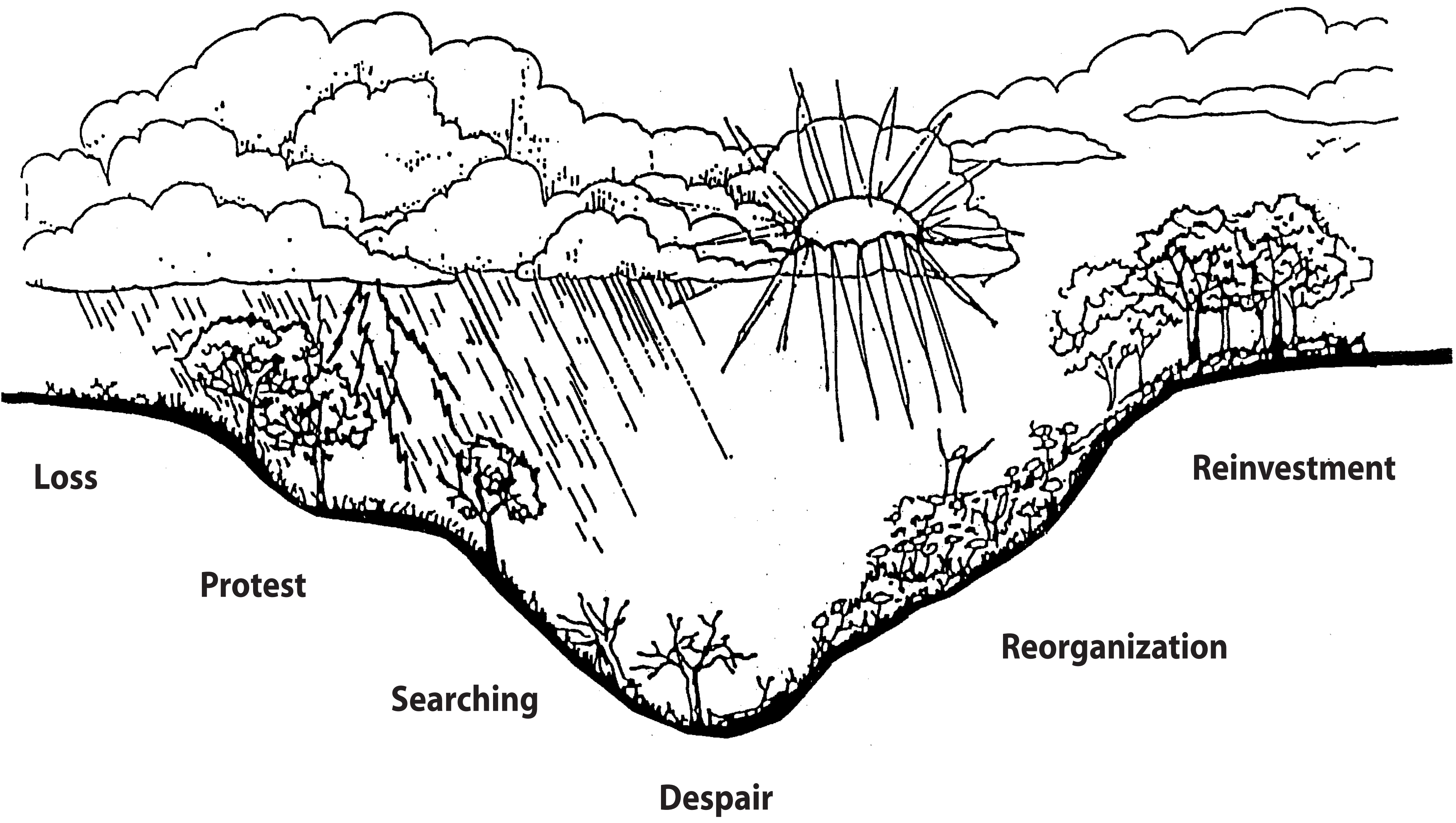
{as I search for anchors in my own past experience,
and prior losses come into my awareness}

## WHO AM I BECOMING?

{as I integrate the changes that
this experience brings to my life}

# The Journey of Grief

devised by Bess Will



# GRIEF JOURNEY DEFINITIONS

## Loss

Assumptions shattered. The initial responses to a loss are:

- Shock, numbness, confusion, disbelief, anger, some physical symptoms

## Protest

Protesting the acceptance of the loss. Anger at:

- Caregivers
- The 'unfairness of everything'
- The deceased
- The self

} anger at self/the deceased can become shame/guilt

## Searching

The felt experience of the missing

## Despair

The 'Pit'

- hopelessness
- agony/anguish
- depression

## Reorganization

The 'slippery slope'

- bursts of energy
- fatigue
- detachment
- indifference

## Reinvestment

- able to recognize and consolidate gains from the period of active grieving
- new, sustainable interests
- the ability to talk about the loss without experiencing the pain and anguish
- the experience of meaningfulness, purpose and hope for the future

# TASKS OF MOURNING

## 1. To Accept the Reality of the Loss

- Must talk about the circumstance surrounding the death.
- Negation: not believing the significance or the irreversibility of the loss

## 2. To Experience the Pain of Grief

- Emotional acceptance occurs when the survivor no longer needs to avoid reminders of the loss for fear of experiencing intense pain or remorse.
- Negation: not to feel resulting in increased physical or psychological problems

## 3. To Adjust to an Environment in which the Deceased is Missing

- “secondary losses” need to be identified and mourned
- Negation: not adapting to the loss and promoting helplessness

## 4. To Withdraw Emotional Energy & Reinvest in Another Relationship

- feelings, thoughts, memories, and gradually worked through
- Negation: people may get stuck at this point and later realize that, in some way, their life stopped at the moment the loss occurred

## To Complete the Tasks it is Necessary to:

- Vent feelings, talk about the relationship and feelings of loss
- Validate all aspects of the relationship, including normal ambiguities
- Resolve any guilt that arises
- Internalize the memory while reinvesting feelings

# COMMON AVOIDANCE PATTERNS

## 1. Postponing

Seeks to avoid the pain by deciding to look at the loss at a later date:
**"I'll deal with it later- it hurts too much right now."**

## 2. Displacing

Refuses to believe that grief is an issue:
**"My anger at you (and myself) has nothing to do with grief!"**

## 3. Replacing

Reinvests prematurely (new relationship, overwork):
**"Having John come into my life so soon after losing Gary is a gift! People say it's too soon; but what am I supposed to do? Turn him down?"**

## 4. Minimizing

Cognitively dilutes feelings through rationalization:
**"You've got to just put it behind you and keep going, there is no good crying over spilt milk, and anyway, we can't change the past; what's done is done and that's just an end to it. No point wallowing forever in self-pity. Always look on the bright side, that's what I say."**

## 5. Somaticizing

Unexpressed feelings manifest as physical symptoms; chronic fatigue, muscle strain, gastrointestinal difficulties, migraines etc.

# ISSUES IN MULTIPLE LOSS

## 1. Grief

- Unresolved and anticipatory grief: can't bounce back
- Increased rage or guilt and physical symptoms
- Denial/delayed reactions
- Self-destructive behaviours

## 2. Survivor Guilt

- Sympathetic "dis-ease symptoms" which mimic the infected

## 3. Burnout: Individual

- Numbness-isolation
- Inability to emote/cold – not emotionally present
- Pessimism-fatalism
- Insecurity-despair

## 4. Burnout: Workplace

- Decrease in productivity and morale
- Increase in conflict, absenteeism and turnover
- Difficulty setting limits
- Decrease in positive feedback and informal supports

## 5. Response Similar to Trauma Syndrome

- Wild swings between numbing and flooding
- Loss of feelings of safety and belonging in community

# GRIEF OVERLOAD

## 1. Living with the Death Imprint

- Indelible, intrusive, distressing images
- Re-experiencing "trauma"

## 2. Range of Responses

- Uncontrollable emotional states
- Disassociative mental states

## 3. Psychic Numbing

- Loss of normal affect & emotional responsiveness
- Loss of interest & involvement in work & interpersonal relationships

## 4. Not Believing People Genuinely Care About You

- View the world as hostile
- Loss of sense of safety in community

## 5. Struggle for Meaning

- Impulse to "bear witness," to speak of the experience
- Difficult to find language to convey what one has experienced

# CORE LOSS

# COPING STRATEGIES
**(Short version)**

## "I can't stand it… and I can't stop it… but I can deal with it!"

**Listed below are suggestions for self-care coping strategies:**

- Stay involved, connected
- Develop support systems to deal with stress
- Create forums for discussion of feelings
- Self-expression
- Take HIV/AIDS vacations if possible
- Participate in rituals (e.g. AIDS vigil)
- Re-commit to life and unmet goals
- Work to find new meaning to life and to disease
- Deal with anger so it empowers not depresses – **exercise, counselling**
- Celebrate the gift of humour
- Attend to closures in a continual way
- Short-term solutions ineffective when working long-term with HIV **– Need Enhanced Coping Skills**

# STAGES OF CHANGE THEORY

| Stage of Change | Awareness |
|---|---|
| **Pre-contemplation** | "I don't really think there is anything that needs changing right now, not really, any way, I can't and there's no point…" |
| **Contemplation** | "Ok, well, I'm not sure I want to change this about my life all I know is I wish things were different…" |
| **Preparation** | "I know this has to change, I just don't know how to go about it." |
| **Action** | "I'm ready to make changes and will get help and support to do that…" |
| **Maintenance** | "I've already made the changes I need to; now I need help in sustaining them…" |
| **Termination** | "I have incorporated changes into my life and those changes are now a part of how I live in the world…" |

# ASPECTS OF CLOSURE

(adapted with permission: Susan Aaron, Psychodramatic Bodywork)

1. **Gains & Achievements**
   What I have gained/achieved as a result of this experience

2. **Appreciations**
   What I appreciate about myself and/or others

3. **Unfinished business**
   Naming what is unfinished helps to leave it behind

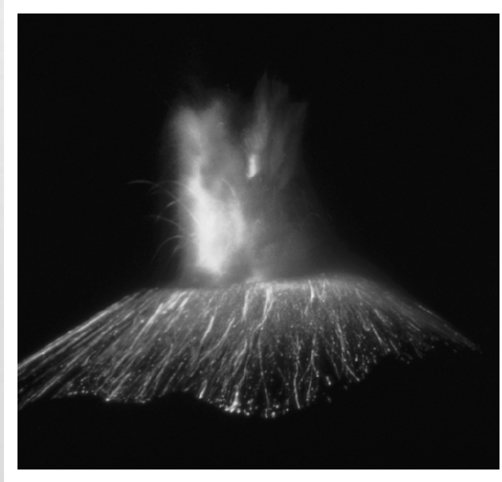
4. **Regrets**
   Any regrets I carry from this time

5. **Resentments**
   What I resent about this experience

6. **Ghosts of closures past**
   Other similar experiences/closures that are present for me now

7. **Moving on - what's next?**
   As this experience is ending I can name what is beginning, and what I will carry forward

8. **Ritual**
   Any deliberate action which has meaning in relation to closing on the experience



## Appendix II: Worksheets for Participants

- Understanding Your Loss History (A) [S]
- Understanding Your Loss History (B) [L]
- Building Capacity
- Evaluation Form

# UNDERSTANDING YOUR LOSS HISTORY (A)

(Short Version) [S]
**adapted from *Grief Counseling and Grief Therapy* by J.S. Worden 1982

Our cultural, ethnic, religious and philosophical upbringing shapes our attitudes towards death, dying and loss. Our early experiences with loss leave us with messages, feelings and beliefs we will carry throughout life. To prevent our being controlled by our unconscious and conscious reactions to our past, it is important to recognize and acknowledge explicitly how these loss experiences have influenced us. This awareness can also help us identify and reinforce useful coping strategies. Take a few minutes to complete the following questions. Put down whatever first comes into your mind. Through this exercise, you will investigate your early learned response to losses, including death. You may begin to identify a pattern of response.

1. An early, significant loss ***not*** due to death was:

2. What others around me said or did that was helpful or not was:

3. How I felt was:

4. The first ***death*** I can remember was the death of:

5. I was age:

6. What I remember from that time:

# UNDERSTANDING YOUR LOSS HISTORY (B)

(Long Version) [L]
**adapted from *Grief Counseling and Grief Therapy* by J.S. Worden 1982

Our cultural, ethnic, religious and philosophical upbringing shapes our attitudes towards death, dying and loss. Our early experiences with loss leave us with messages, feelings and beliefs we will carry throughout life. To prevent our being controlled by our unconscious and conscious reactions to our past, it is important to recognize and acknowledge explicitly how these loss experiences have influenced us. This awareness can also help us identify and reinforce useful coping strategies. Take a few minutes to complete the following questions. Put down whatever first comes into your mind. Through this exercise, you will investigate your early learned response to losses, including death. You may begin to identify a pattern of response that is present for you now.

1. An early, significant loss ***<u>not</u>*** due to death was:
2. What others around me said or did that was helpful or not was:
3. How I felt was:
4. The first ***death*** I can remember was the death of:
5. I was age:
6. What I remember from that time:
7. My primary style of coping with loss is:
8. The way that learned behaviour manifests now is:

# BUILDING CAPACITY

The experience of grief affects the whole being. In order to be better prepared for the work of grief, and to cope with its challenges, it is helpful to be as healthy as possible ***by your own standards***. The following exercise invites you to consider where you can work on self-improvement for your own sense of esteem. ***This sheet is for you alone***, will not be asked to share it.

Esteem may be defined as "Holding in high regard" and when applied to a person may be broken down using an holistic focus to determine where changes may be made in order to build capacity.

With **1** meaning "**very low regard**," **3** meaning "**about average**" and **5** meaning "**very high regard**," please answer the following questions:

How do I regard myself in:

| | | | | | |
|---|---|---|---|---|---|
| **The emotional realm?** | **1** | **2** | **3** | **4** | **5** |
| **The physical realm?** | **1** | **2** | **3** | **4** | **5** |
| **The mental realm?** | **1** | **2** | **3** | **4** | **5** |
| **The spiritual realm?** | **1** | **2** | **3** | **4** | **5** |
| **The sexual realm?** | **1** | **2** | **3** | **4** | **5** |
| **The social realm?** | **1** | **2** | **3** | **4** | **5** |
| **The political realm?** | **1** | **2** | **3** | **4** | **5** |
| **The professional/workplace realm?** | **1** | **2** | **3** | **4** | **5** |

**Other? (please name)** ____________________________________

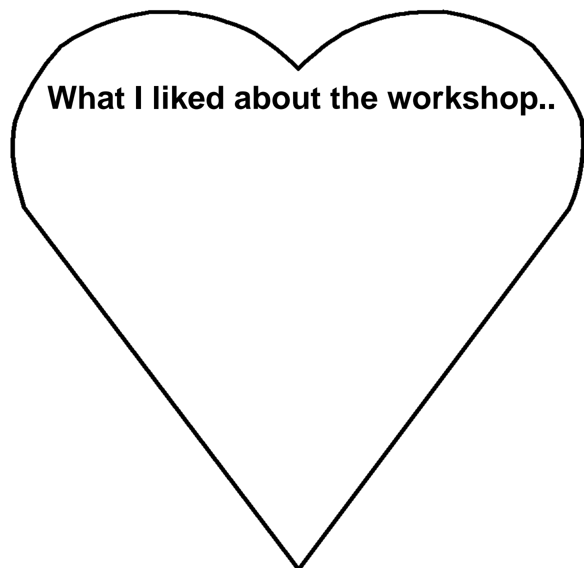
Consider in which of these areas of your life you wish to make a positive change. What can you include in your life that will enable you to feel even better about your whole self? If it feels right for you to do so, please complete the following sentence to provide focus and name your intent.

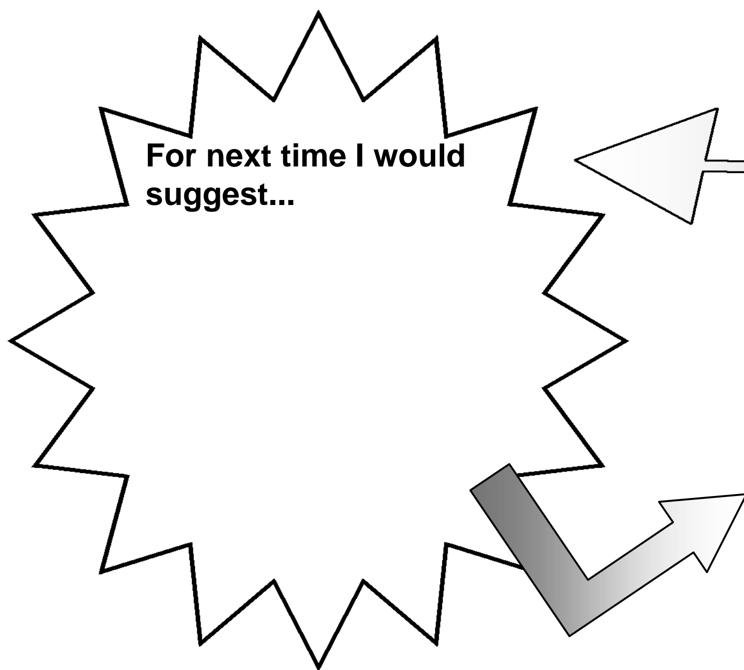
**The positive change I will include in my life is:** ______________________

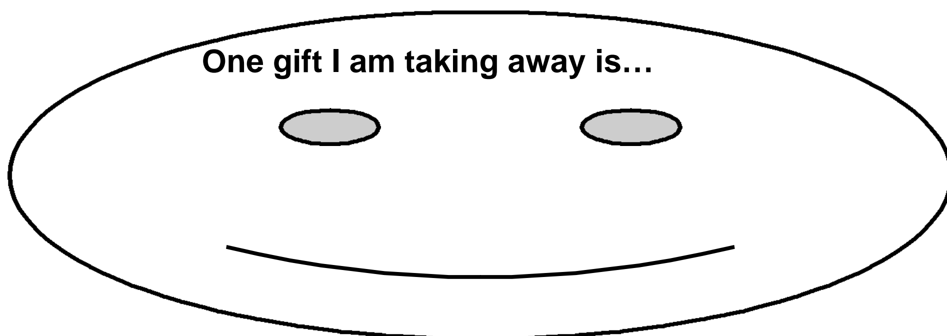
____________________________________________________________

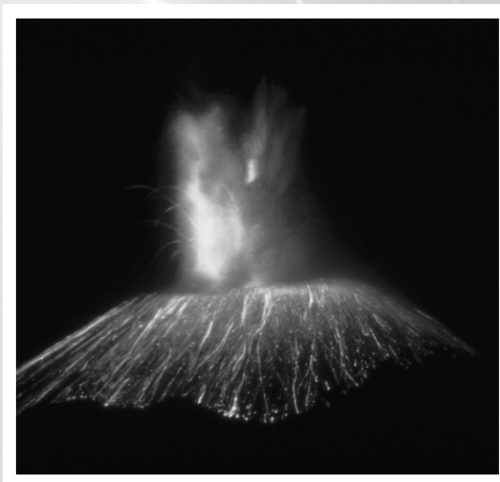
____________________________________________________________

# EVALUATION









## Appendix III: Additional Training Resources

- AIDS Grief: the Bereaved Caregivers
- Understanding Your Loss History (Complete Version)
- Four Tasks: Theory and Guide for Helpers
- Multiple Losses in HIV/AIDS
- Responses to Organizational Change and Transition

# AIDS Grief: " Out of the Closet and Into the Boardrooms" – The Bereaved Caregivers

YVETTE PERREAULT, AIDS Bereavement Project of Ontario, Toronto, Ontario, Canada

As of this writing, over 15,000 Canadians have died of AIDS. Each one of these deaths represents a life that touched countless networks of family members, loved ones, neighbours, co-workers, acquaintances, and the many paid and unpaid caregivers who accompanied these individuals through their battle with AIDS. With those 15,000 deaths comes the legacy of loss -the tens of thousands of bereaved among us who grieve, actively, quietly, publicly, and privately. The impact of grief is profound and pervasive, yet most of us lack accurate information about this fundamental human condition and were not taught coping strategies to help us heal. In many circles, grief is barely discussed, particularly if the loss is due to AIDS. Mourners are left isolated, confused, and scared.

The AIDS Bereavement Project of Ontario provides community-based AIDS agencies with concrete support in the area of AIDS grief. Funded by the Ontario Ministry of Health, the project is a resource for Ontario groups wishing to look explicitly at AIDS caregiver grief. The bereavement project works with groups to design workshops, train paid and unpaid workers, and assist management in assessing and enhancing individual and agency coping strategies.

### Time Alone Does *Not* Heal All Wounds

Tragically, many of our workplaces and professional associations do not attend thoroughly to the occupation-related grief needs of caregivers. Without knowledge and appropriate interventions, workers are left suffering enormous stress, often believing they have a "burnout problem" that they cannot personally remedy with a "stress management" program. When we as caregivers are not supported in acknowledging and working through the impact of these deaths, our ability to perform effectively in our jobs becomes diminished. It is virtually impossible to be fully present to the many HIV/AIDS-related losses faced by our clients, colleagues, and communities when their stories strike at the chords of our own undealt-with grief.

Just as AIDS has challenged us to rethink much about palliative care, so too has the disease expanded our understanding of grief, particularly as it relates to multiple and continuing losses. While there seems to be a natural constellation of responses to death, there are unique factors associated with AIDS that increase the complexity of grieving. The impact of the social isolation, stigma, disenfranchisement, lack of spiritual support, fear of contagion, multiple loss, homophobia, illness-related complications, and survivor guilt is tremendous (1,2,3,4,5). Among the manifestations of grief associated with AIDS are a greater than usual amount of rage, fear, shame and unresolved grief (3), feelings of guilt, helplessness, loss of intimacy, increased physical symptoms, self-destructive behaviours, insecurity, numbness, and pessimism (5).

In any general study of bereavement, these symptoms might signal "pathology". But this type of reaction can also be seen as a *normal* response to *catastrophic* events rather than a *maladaptive* reaction to a normal stressor (6). It is not that AIDS grief is uncomplicated, but the application of yet another medical or psychiatric label to large segments of communities struggling valiantly for acceptance and legitimacy is simply not helpful. We have found it more useful to place the lived experience of grief into a conceptual framework consistent with the activist nature of the fight against AIDS. *However complex, AIDS grief needs to be understood as normal grief in an abnormal time.*

Multiple loss is a grief whose content and course differs from grief responses subsequent to a single death. It occurs when people are experiencing bereavement overload and have no time to fully express their loss before another occurs, resulting in each grieving process compounding the one before. Issues in multiple loss include: (7,8)

**Grief**

- unresolved and anticipatory grief
- learning to live with death as a constant companion
- preoccupation with one's own mortality

**Survivor Guilt**

- "Why am I here and they're not?"
- struggle to make meaning out of what one has witnessed

**Individual Burnout**

- loss of normal emotional responsiveness
- numbness and isolation

- uncontrollable emotional states
- disassociative mental states, disconnection from self and others
- pessimism and fatalism, view of the world as hostile
- insecurity and despair, loss of safety in community

**Workplace Burnout**

- loss of interest and involvement in work
- decrease in productivity and morale
- increase in workplace absenteeism
- difficulty in setting limits
- "callused" worker unable to connect with others
- projection: avoid hearing the horror by interrupting people or distracting them from accounts of pain

**Responses Similar to Post-Traumatic Stress Disorder**

- wild swings between numbing and flooding
- nightmares and flashbacks, distressing, intrusive images of death
- relentless anxiety, uncertainty over who is next
- self-neglect, self-destructive behaviours

There is an emerging body of work related to therapeutic interventions for individuals bereaved as a result of an AIDS death (see references). We actively encourage grieving individuals to seek out therapists, mental health professionals, and community supports skilled in the specificities of AIDS grief and multiple loss. At the AIDS Bereavement Project, our primary interest is the impact of sustained losses on *communities* and *groups* of people organized to respond to AIDS. We challenge boards and executive directors to view grief not simply as a "personal problem" but rather as an "occupational hazard". We ask:

- *What are the unique manifestations of grief in your workplace?*
- *How well are you preparing your workers to live with the eventuality of overwhelming loss and constant grief?*
- *What systemic responses, policies, procedures, and concrete supports are in place to offer paid and unpaid workers timely, appropriate interventions prior to burnout and diminished effectiveness?*

We often say, *"If you're managing an AIDS agency, you're managing a grief agency."*

Caregivers in AIDS agencies differ from other social service and palliative care workers in significant ways: (9)

- AIDS caregivers usually form a counselling relationship long before the point of death, unlike palliative care workers;
- It is more likely that AIDS counsellors are in the same age cohort as their clients, whereas most palliative caregivers are not, since AIDS affects a younger population than cancer;
- Gay AIDS counsellors share experiences and struggles around sexual and gender identity, social marginalization, and often a seropositive status - a host of issues not likely shared between palliative caregivers and patients;
- Unlike cancer, AIDS is often seen as a deserved punishment for immoral behaviours;
- Conventional training leaves AIDS workers painfully unprepared to deal with grief saturation;
- Classic stress reduction strategies (shorter work hours, fewer clients) do not address the central condition of those who provide psychosocial care to an HIV / AIDS population, namely the multiple deaths and related processes of grief for those who have died;
- AIDS caregiver grief is usually suppressed or appears in other contexts, such as continued organizational crisis/worker dissatisfaction. It has often snowballed into grief saturation, with problematic effects on the well-being of caregivers, staff continuity, and agency health.

Just as many in the palliative care community did not actively *choose* AIDS, most community AIDS workers did not choose to become so intimate with death and dying. As one Support Worker expressed it during a workshop:

> My area of expertise was not hands-on care with dying people – I came with an advocacy and social change background. Now I have tons of experience in palliative care, not as a chosen profession but because it was the logical conclusion to my longstanding relationships with sick friends. I believe our support services should respond to the entire spectrum of HIV/AIDS - including helping people die. I certainly would rather be cared for by people who know me as more than a patient! Here I am in my late 3Os, forced to grapple with death in the same way as my grandparents - it is out of the order of things. This should not be happening to me at this stage of my life. What people don't understand is that this is not simply a job for me. As a gay man, it is about my community life as well. Eight guys in my building are sick. I am on a care team for one of my best friends. My co-worker is HIV+. Most of my political mentors are dead. My universe is full of holes. I have no idea how to plan for tomorrow, either personally or professionally. My whole world is AIDS. Even if I decided to leave, where would I go?

All too often, caregiver grief is confused with personnel issues or organizational development matters. These workers exhibit behaviours consistent with the effects of multiple loss:

- A compassionate support worker who is usually able to leave work behind has slowly become "with-out boundaries". She is taking work home and developing inappropriate friendships with clients.
- An executive director who once prided himself on running a tight, efficient ship now appears short-tempered, authoritarian, and seriously lacking visionary leadership.
- A volunteer co-ordinator, formerly a great planner, has become frantic- there is a lot of frenetic activity in the department but no measurable accomplishments and lots of detail falling through the cracks.
- A health promotion co-ordinator who seems to have lost his heart for the work - he uses the same script for every speech and no longer responds with humour and flexibility. He used to joke around a lot.

**Costs of Unaddressed Agency-Wide Grief**

These behaviours have collective and cumulative effects on AIDS organizations beyond the damage done to individuals. These negative organizational effects include the following:

- absenteeism, illness, high job turnover
- unpredictable results on the job
- decrease in productivity
- brittle, fragile, angry workers, emotional outbursts
- inability to set limits and say no, not using lieu days or taking vacations
- poor morale, flatness, lack of creativity
- employer costs: higher benefit premiums, costs of relief staff, costs of hiring and training
- disruption to clients and communities

While there are good reasons for AIDS caregivers to look at grief from an organizational perspective, we continue to encounter significant obstacles. We enumerate them below.

**Grief Myths**

- Grief not understood: "Isn't grief when you're crying over someone?"
- Impact minimized: "I hardly knew those clients - we weren't really intimate." "I'm sure my irritability has nothing to do with grief."

**Grief in the Workplace Myths**

- Not seen as relevant: no orientation to grief as part of training about HIV / AIDS. Seen only as an issue for support services.
- Will deal with grief once a critical number of deaths have made the impact noticeable - but no integrated response.
- Seen as a personal issue: "Professional objectivity and distance should keep workers from attaching. If they're having a reaction, it is an outside issue."
- "It's too big - a messy Pandora's box of emotions which doesn't belong in the workplace. If we open this up, it will take an unrealistic amount of time and money."
- "The current crisis within the agency has nothing to do with multiple losses nor with the recent death of our board chair - it is a side issue."

**Specific to AIDS**

- Many workers are also HIV+, making it difficult for people to rely heavily on colleagues to counteract stress.
- There is a concentration of losses in communities where people normally go for respite and replenishment.

We may summarize this section by repeating, *Short-term solutions are ineffective when working long-term with HIV.*

**BUILDING** A **STRATEGIC RESPONSE TO AIDS GRIEF** (10)

*"We do not expect management to place workers in situations where they will be handling dangerous materials without proper training, equipment, and supervision. Should a worker hurt herself/himself on the job, agencies recognise their responsibility to support and accommodate that employee. Why is grief so different? Our sorrow and turmoil are directly related to stressors/losses experienced on the job. Surely workers could be better equipped and supported to respond to this element of risk and danger inherent in AIDS."*

- board member of an AIDS service organization

In the second section of this paper we consider how AIDS agencies may use prophylaxis and treatment at the organizational level when threatened with the risks of chronic and elevated grief as described above. Based on our experience with the AIDS Bereavement Project, we offer a series of recommendations divided among the following headings: planning process, assessment, acknowledgement of loss, training and skill building, support, structural and systemic changes, mechanisms of appreciation, and ongoing process.

**Planning Process**

- Include all staff and key volunteers. This counteracts the feelings of helplessness common to loss saturation.
- Set up a diverse team to canvass the agency about their bereavement needs.
- Leadership involvement is critical, as future organizational strategies may include revision of policies and benefits and other workplace changes-
- Every group has its organizational culture which must be acknowledged and respected.

**Assessment**

- What problems require solutions? Be realistic about the situation but also dare to dream. One of the most significant, albeit unexpected, outcomes of our work is the reported sense of team unity and mutual support which arises from the experience of looking at grief together.
- Identify confounding organizational issues to be dealt with separately. Workers may be reacting to downsizing and financial constraints. While the emotional impact of this can be dealt with in a session on grief and loss, the structural aspects are best kept for another forum.
- Clarify staff expectations of the organization; providing bereavement support is not intended to turn the agency into a therapy group for staff.

**Acknowledgement of Loss**

- Look at loss through the experience of people at all levels of the organization. What is the grief of the administrator? Of the receptionist? Of the volunteers? Note that loss is not only about death but relates to other transitions: staff turnover, program cutbacks, changing offices, expansion.
- Rituals are vital: notices, memorials, quilts, candle lighting. Create "shortforms" for discussing complex, painful issues in a way that allows workers to express them- selves and yet continue with their work.

- Examine structures which impede the necessary flow of information for the acknowledgement of loss on an agency level, e.g. rigid confidentiality policies.

**Training and Skill Building**

- It is necessary to orient all workers to grief at some level, including the board.
- Recognize and appreciate a wide range of normal responses to loss: our responses are unique and culturally determined.
- Train workers to identify their individual patterns of grief. Do they know when they are grieving? How do they communicate that to others?
- Supervisors have a central role in creating a supportive environment.
- Training serves as a collective acknowledgement that grief is not a personal weakness. It also serves as a common framework for discussion and strategy development.
- Train on a holistic level. Include a broad range experiences such as working with emotions, with the body (massage), and with the spiritual aspects of grief and healing (visualization and hope systems).
- Present information on aspects of hardy personalities -those who successfully adjust to stress through "control, commitment, challenge, and connectedness" (11).
- Make grief and loss a part of the everyday discourse among caregivers.

**Support**

- Develop a range of supportive interventions: individual debriefings after a death, quality supervision, formal bereavement groups, team retreats, etc.
- Offer programs internally and on work time.
- Provide external support: employee assistance programs. Dealing with current losses can resurrect old losses.
- Encourage contained opportunities for emotional expression, including anger.
- Reconnect people to life-enhancing elements: joy, humour, celebrations.
- Attend to closures in a continual way. We tend to minimize the lesser losses and transitions and focus only on significant losses, but through attention to the smaller goodbyes we prepare for the greater ones.

**Structural and Systemic Changes**

- Requires commitment of the employer to accommodate acute and chronic stress of grief. Someone needs to champion this cause and keep grief on the agency's agenda.
- Redefine and review bereavement leave, mental health days, dependent-care leave policies-
- Evaluate benefits and internal support systems. Is supervision adequate?
- Look at stress-relieving practices: job variation, flex time, unpaid leave.
- Integrate grief awareness into the philosophy and core values of the agency: grief work is part of a holistic health strategy and promotes healthy workers and a healthy agency.

**Mechanisms of Appreciation**

- Death can too often feel like a failure. Balance the strain of loss by deliberately creating opportunities for positive interactions with workers.
- Set aside regular times to talk about accomplishments and goals.

**Ongoing Process**

- Develop a system for integrating grief awareness into the orientation process of all workers.
- Information to be distributed regularly and programs offered routinely to staff, volunteers, and board: do not wait for the crises.
- Provide for a regular review of bereavement strategies: What else do we need?

Ultimately, the goal of developing an agency response to multiple loss is the creation of healthy agencies and the creation of healthy, resilient, creative workers. Just as communities have mobilized to understand and respond to HIV / AIDS, we believe that communities can organize successfully to meet the emerging challenge of grief. But first "grief" has to come out of the closet as an identifiable individual reality, as an agency problem, and as a community norm.

The legacy of loss is both individual and communal. Grief work is bearing witness to our personal and collective stories. Grief work is "re-membering" together and building a connection with our sorrow and hope to sustain community vitality.

*Heal the community by healing the individuals and in this way, resurrect the sense of community fundamental to the mental health of the individual.* - Herman Kaal (12)

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# UNDERSTANDING YOUR LOSS HISTORY

**⇒ Take a few minutes to complete the following questionnaire.**

**⇒ Put down whatever first comes into your mind.**

**Through this exercise, you will investigate how you respond to a variety of losses, including death. You may begin to identify a pattern of response.**

- **Our cultural, ethnic, religious and philosophical upbringing shapes our attitudes towards death and dying.**
- **Our early experiences with loss and death leave us with the messages, feelings, fears and beliefs we will carry throughout life.**
- **To prevent our being controlled by our unconscious and conscious reactions to past experience, it is important to recognize and acknowledge explicitly how these experiences have influenced us.**
- **This awareness can also help us identify and reinforce useful coping strategies.**

* Taken from Grief Counselling and Grief Therapy, by J.W. Worden, Springer Publishing Company, Inc. New York, New York, 1982.

## Describe an Early Significant Loss NOT Due to Death
## (An object, an event, a role, a relationship, etc.)

1. **What were the circumstances? When did it occur? Where was it? Who was involved?**

2. **How did you feel? What were your reactions, positive and negative?**

3. **What were you advised or told to do? What did you do to cope with the experience?**

4. **What do you think you learned about loss as a result of this experience?**

## Describe the First Death You Can Remember

1. **What were the circumstances? When did it occur? Where was it? Who was involved?**

2. **How did you feel? What were your reactions, positive and negative?**

3. **What were you advised or told to do? What did you do to cope with the experience?**

4. **What do you think you learned about death and loss as a result of this experience?**

## Describe Your First Funeral

1. **What were the circumstances?  Where was it? Who was involved? What happened?**

2. **What were your reactions, positive and negative?**

3. **What were you advised or told to do? What did you do to cope with the experience?**

4. **What do you think you learned about funerals and memorials as a result of this experience?**

# Describe Your Most Recent Loss Due To Death

1. **Who was the Person?**

2. **What were the circumstances?**

3. **How did you feel?**

4. **How have you coped with this loss?**

## Describe the Death which was the Most Difficult for You

1. **Who was the Person?**

2. **What were the circumstances?**

3. **It was difficult because…**

4. **How have you coped with this loss?**

---

## Of the important people in your life who are now living, the most difficult death for you would be the death of…

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**1. Who is the Person?**

**2. It would be most difficult because…**

## Please complete the following sentences:

**1. My primary style of coping with loss is…**

**2. I know my own grief is resolved when…**

# *Loss, Change and Transition*
# *Four Tasks ¾ Theory and Guide for Helpers*

William Worden (1978) defines grief as *"**A universal human response to loss**."* It is an experience involving complex emotions, spiritual states, behaviours and thoughts. He presents a workplan design intended to lead the individual from disintegration to re-integration.

> ***"Grief is the process that allows us to say good-bye to what was and to get ready for that which is yet to come"***

Basically there are 4 tasks involved in supporting someone through a loss:

## Task 1: Accept the reality of the loss - by moving from denial and avoidance to recognition of the loss.

***Discussion: Shock is healthy and denial is a normal reaction when things change. The relatively brief experience of shock helps a person to begin to adapt to the loss. This experience will usually last a few minutes or a few days. If it persists, it may become maladaptive and work against the person suffering the loss.***

**DO** accept people in their apparent denial of the loss, change or transition. "It's hard to believe".

**DO** accept how difficult it is for them to accept the loss or change. "It doesn't seem possible that this is happening." "It is really tough."

**DO** encourage people to talk about their experience of the loss or change - then LISTEN. You are listening for their story of attachment - help them determine what is the meaning of the loss for them? If the loss is of a loved one or pet, encourage them to remember the shared times in the past and to tell the story of the events surrounding the death. Talking about it can help make it real.

**DO NOT** rush in to set them straight or forcefully encourage them to accept reality.

**DO NOT** support false hopes and misconceptions. You can say softly, "Yes, you really want it to be different, but this is how it is and I am truly sorry about your loss.".

## *Task 2:* Experience the pain of the loss by:

***i) Discussion: In order to effectively adjust to a loss, change or transition, people will react emotionally and may reach a place of deep feeling. This will manifest differently for people: some may keep their emotions private and others may express them outwardly. There is nothing to fix here. Feeling is part of the process. It helps people to relive and repeat their story of attachment and loss. In the event of a death, they will often recount many times the details surrounding the loss.***

**DO** speak directly to the person and address them by name as it helps orient them in the here and now: "Yes, Mary, I'd wouldn't mind seeing that last photo of George again.".

**DO** act in a relaxed and accepting way. Continue to be yourself.

**DO** address the loss directly- say the name of the deceased or mention the transition explicitly: "Now that you require a visiting homemaker to help you with household tasks….".

**<u>DO</u> LISTEN**

***ii) Discussion:  People need to work through the fear that normally occurs anytime our lives have major transitions and significant losses.***

***People can experience waves of agonizing feelings and may worry that they "will not make it" or may ask "how long will this anxiety go on?  They may be reminded in small but poignant ways of their loss.  Nights can be particularly long and painful.  If it is a loss due to death, they may see or hear or feel the presence of the dead pet or person. These experiences may be comforting or disturbing, but they are not that unusual. They are part of saying goodbye. Other cultures are more accepting of these paranormal experiences.***

***They may worry about being forgetful, absentminded, unable to concentrate or make decisions.***

**<u>DO</u>** acknowledge the fear and encourage the taking of small steps, "one thing at a time", and "one day at a time".

**<u>DO</u>** give reassurances that having these intense feelings is not unusual and is normal part of moving through loss and change.

**<u>DO</u>** give reassurance that in time, the pain will lessen. How much time is difficult to say. The intensity of the pain diminishes, but the experience of loss continues for long time - perhaps years.  Anniversary dates, birthdays, holidays, music, places, other losses, may trigger acute grief responses again. This does not mean they are going backwards.  The waves of pain will subside and "good feeling" times will increase.

**<u>DO NOT</u>** hurry people along by suggesting it is time they snapped out of it.

**<u>DO NOT</u>** say the fear is foolish.  Loss is incredibly disruptive.

***iii) Discussion: It is necessary to identify and come to terms with any self-blame or guilty feelings about the loss itself. If there are feelings of guilt, there is seldom any logic to it. It is never satisfied by explanation and indeed may escalate if denied.***

**DO** accept the expression of guilt and express that it's natural to feel guilty. We often have some degree of ambivalence in our attachments.

**DO** acknowledge that they wish things had happened differently: "You would have liked to have more time". Encourage people to talk about any regrets they may have about the situation.

**DO** reinforce the good things. People need this reassurance and can better receive it after experiencing your acceptance of their negative feelings.

**DO NOT** rush in and say: "Now stop it- this thinking is foolish".

***iv) Discussion: Expressing and "letting go" of anger is also a significant part of the process. Anger may be directed at the fact of the loss, anger at God for causing this to happen, anger at caretakers who didn't do enough, anger at others who have not "lost" someone or something, anger at events over which we have no control.***

**DO** encourage people to ventilate feeling: "How are you feeling about all this?" They may unload hostility by exploding angrily, expressing quiet bitterness, and breaking into tears. It is not always comfortable to sit with someone when they are angry- be careful not to get caught up in their distress.

**DO** try to be sensitive to any indication that people want to deal with negative feelings. Sometimes people have been taught to focus only on the "positive" and are suppressing the more difficult, painful reactions.

**DO** listen non-judgmentally.

**DO NOT** give advice about being busy, getting involved and forgetting the past and making the best of it.

**DO NOT** attempt to talk someone out of it, do not defend God or the care-providers or shame the person about their reaction.

## Task 3: Adjust to a new environment where the lost person, part of self, object etc. is missing by working through feelings of loneliness and awkwardness, reaching out to others and remembering one's own resiliency.

***Discussion: This task requires working through feelings of "loss of part of self". People may worry that after the loss they will not be the same. To some extent, this is accurate- many things will be different after a loss. However, it is important that people begin to consciously become aware not only of "what is lost", but also of "what is left"***

***There may still be times of extreme exhaustion and preoccupation with feelings of loss which inhibit initiative- taking. Life seems to have no flavour. Self-confidence is shaken. However, this may be balanced by swings to positive feelings of being alive and moments of looking forward to something. Sometimes this can result in feelings of guilt "I shouldn't be happy"***

**DO** encourage gently the giving and acceptance of simple social invitations, even if they don't seem enjoyable at first.

**DO** accompany people on first outings and assist with the practical tasks associated with the loss (sorting through papers, cleaning out closets, setting up new furniture arrangements, etc).

**DO** acknowledge that some sorrow may always be there, but the intensity will lessen and the duration will lessen. If it is a loss to death, examine what the deceased might have wanted for the one left behind.

**DO** explore with people what has gotten them through tough times before in their lives and then help them identify and build on these internal strategies of resiliency.

## Task 4: Withdraw emotional energy from that which is lost and re-invest in new beginnings, relationships and activities.

***Discussion: This is a time of "making meaning" of what has been and discovering "what is possible" in this new time. It is not unusual for people to feel "disloyal" about enjoying new people and activities or discovering that one appreciates certain aspects of a new situation.***

**DO** gently encourage new beginnings such as joining groups, taking courses, entertaining.

**DO NOT** push or be too eager.

**DO NOT** "gush" or be overly enthusiastic about efforts of the person to re-establish social ties and begin new projects.

**DO** support ways to remember and honour the past and to celebrate accomplishments and steps forward.

## AIDS Bereavement Project of Ontario

# Multiple Losses in HIV/AIDS

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### The Grief Journey

We begin all work in loss by outlining the "Grief Journey" and the tasks of grief that make it possible to shift along the path. Conceptualizing grief as a journey allows us a sense of purpose and movement, with names for aspects of a process that can at times feel overwhelming. While this journey is based on a single loss model, it can be a useful tool in working with multiple loss as the experience of successfully working through a core grief can provide a sense of mastery and accomplishment which results in the internalisation of skills for further grief work. While simplified in the l inear form of a journey, most people report a kind of "meandering through" the peaks and troughs.

All grief work is based on attachment and honours our capacity to feel, care and love as human beings. Working through grief ensures we do not have to lose these highest qualities of our being. See Grief Journey, page 120.

### Common Avoidance Patterns

Because grief work involves emotional pain, often intensely felt, it is understandable how we would want to avoid the experience. Unfortunately, the emotional pain of grief work is unavoidable. Listed below are the most common ways people will (often unconsciously) seek to avoid the work of grieving. Most of us will use predominantly one strategy, with others periodically coming into play. Recognizing how I avoid provides new choices: *"Do I wish to continue avoiding my work; or am I ready to begin?"*

# COMMON AVOIDANCE PATTERNS

Developed by Dr. Alan Wolfelt, 1987

**Postponing**
"I'll deal with it later - it hurts too much right now and I feel like I'm falling apart."

**Displacing**
*Projected/externalized grief* - "I'm furious at the stupid photocopier; my anger has nothing to do with grief!" or *Internalized grief* - "I'm feeling so unhappy and I get mad at myself for little things." (making no connection to a recent loss).

**Replacing**
Premature reinvestment (new relationship, overwork) - "I'm just going to refocus my energy and feelings into these new projects", in an attempt to keep the difficult feelings of grief at bay.

**Minimizing**
Cognitively diluting feelings through rationalization - "I wasn't that close to him" or "I'm just the volunteer, so I can't be grieving."

**Somaticizing**
Unexpressed feelings manifested as physical symptoms - "My aching chest and exhaustion have nothing to do with Dad's death."

## Worden's Tasks of Mourning with Negation of those Tasks:

### 1. To Accept the Reality of the Loss

- The mourner must talk about the death, body, and funeral.
- **Negation:** not believing through prolonged denial involving either denial of the facts, the significance of the loss or the irreversibility of the loss.

### 2. To Experience the Pain of Grief

- It is impossible to lose someone you are attached to without feeling some pain. The survivor will have to deal with the pain at the time of the loss, or will confront it many years later; but s/he will have to deal with it!
- Emotional acceptance occurs when the survivor no longer needs to avoid reminders of the loss for fear of experiencing intense pain or remorse.
- **Negation:** not to feel resulting in increased physical or psychological problems.

### 3. To Adjust to an Environment in Which the Deceased is Missing

- Survivors are not usually aware of all the roles played by the deceased until well after the loss occurs. This is the task where "secondary losses" need to be identified and mourned. A secondary loss may be defined as "a physical or psychosocial loss that coin cides with or develops as a consequence of the initial loss." Examples would include the role of the "cook" in a relationship, which may have belonged to the deceased; or the identity of a mother once a child has died. Each of these secondary losses initiates its own grief and mourning reactions, "every physical loss will engender psycho-social loss".
- **Negation:** not adapting to the loss and promoting their own helplessness.

### 4. To Withdraw Emotional Energy and Reinvest in Another Relationship

- Mourners sometimes believe they are dishonouring the dead if they withdraw emotional attachment. They may fear another loss if they reinvest.
- When "all the feelings, thoughts, memories, and expectations that bound the griever to the deceased are gradually worked through by being revived, reviewed, felt, and lessened" (Rando, 1984), this task may be considered complete.
- **Negation:** people may get stuck at this point and later realize that, in some way, their life stopped at the moment the loss occurred.

### To complete the tasks it is necessary to:

| | |
|---|---|
| **VENT** | Vent feelings, talk about the relationship and feelings of loss |
| **VALIDATE** | Validate all aspects of the relationship, including normal ambiguities |
| **RESOLVE** | Resolve any guilt that arises |
| **INTERNALIZE** | Internalize the memory while reinvesting feelings |

## Elements of AIDS-related Loss

### 1. Stigmatization: Affects bereavement and the working through of grief

- AIDS makes People living with HIV and AIDS (PHAs) "other" because AIDS is seen as:
- Deadly, incurable and progressive
- Cause of immense suffering
- Transmissible (therefore PHAs are dangerous)

### Herek & Glunt (1998) Gallup Poll results (U.S.) showed more than 50% Americans agreed with the statements:

- "Most people with AIDS have only themselves to blame."
- "It's people's own fault if they get AIDS."

### Survivors, receive little support for their grief

("You knew what you were getting into.") and are made "other" as the attribution of stigma and blame protects the "normals". (Goffman, 1963)

### 2. Grief: "The process and work of adjusting to irrevocably lost objects, relationships, and dreams."

- Because our AIDS losses are not supported, we may sometimes " act as if the loss did not happen" (Worden, 1991). This both aggravates the pain of our grief, as well as hindering the process of adjusting to a world where loved ones and dreams are gone. Permanently.

### Unresolved Grief and Complicated Bereavement may be:

- Chronic (extended or excessively intense)
- Absent (fending off usual grief-associated emotions, "I'm fine")
- Delayed (normal symptoms arise after a long period of absence)
- Distorted (interpersonal: isolation, excessive irritability, avoidance, other changes in interpersonal dynamics)

### And may show up as:

- Social withdrawal
- Preoccupation with detail of the death
- Pessimistic future outlook
- More difficulty accepting the reality of the loss
- More disorganization through life
- Anxiety

## 3. AIDS–related Multiple Loss: AIDS losses are not only the people

Grieving arises from lost communities, personal dreams, material goods, hopes and expectations, as well as people. See page 121, the Journey of AIDS-related Multiple Loss. Complicating factors in AIDS-related Multiple Loss include:

### Attachment creates meaning:

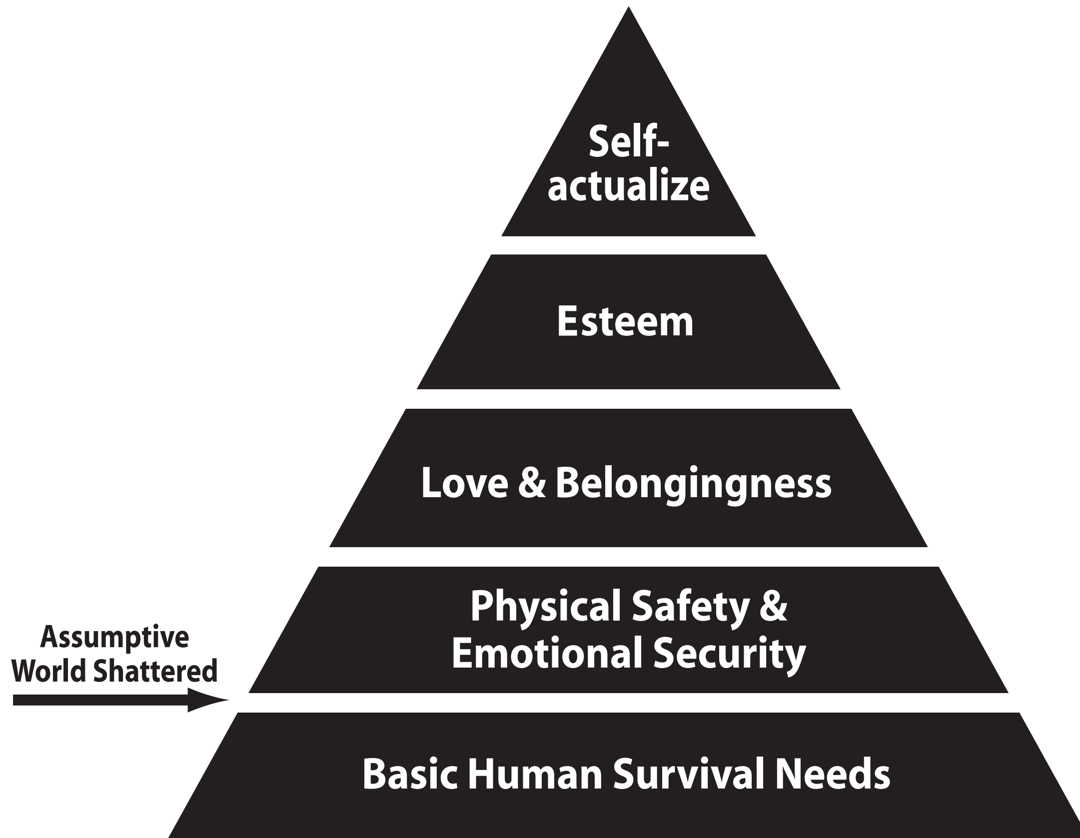
An individual's experience of attachment to loved ones provides, "for us the centre of the universe, the place where all the threads of our life, of our world, come together", what we love " appears to us as something indispensable". (Ortegay Gasset, 1961).

### Multiple loss attributes:

- Quantitative: Ongoing, continual and relentless
- Qualitative aspects of the disease process:
  - has a protracted nature.
  - entails high levels of anxiety and uncertainty due to the episodic nature of health and sickness (the roller coaster).
  - characterized by horror, fear and sadness; due in part to disfiguring symptomology.

### Impact of Community Loss:

- Social networks devastated; community-wide trauma leaves no-one "untouched" or in a position to help.
- The impact on the gay and lesbian communities, "includes the social, cultural, political, sexual and spiritual aspects of community…the entire community reels under the impact of loss" (Nord, 1997).
- Community events (Pride Day, Halloween, etc.), as well as individual anniversaries, provide the opportunity for "re-grief" experiences.




Maslow's Hierarchy of Needs sets a model of progressive human development, where moving towards self-actualization requires meeting of all other human needs.

**1. Individuals' coping mechanisms in the face of multiple loss can create the following behaviour patterns:**

- **Chronic Denial** – In order to remain functional: pervasive emotional shutdown and/or fervent hyperactivity. "No big deal, shit happens, so what".

- **Depression** – "Feelings of hopelessness, helplessness, sadness, cognitive impairment, somatic complaints, and problems falling asleep, staying asleep, and waking early; suicidal ideation, including thoughts about taking one's life, plans for doing so, and actual attempts". (Martin & Dean, 1993)

- **Self-punishment** – Reactive depression, not accompanied by a fall in self-esteem, may in some instances be a form of self-punishment related to survivor's guilt.

- **Anhedonia** – "The complete and pervasive absence of meaning." The experience of someone watching their life like it was a TV show, without being engaged, sexually, behaviourally, or interpersonally.

- **Powerlessness** – Evoking feelings of inadequacy. Grief is often accompanied by feelings of shame: "I am flawed" and feeling of guilt: "I behaved wrongly".
- Suicidal and death thoughts related to:
- Anxiety
- Fear of Death
- Bodily Mutilation
- Separation
- Fear of Loneliness
- Isolation
- Ignominy
- Rejection
- "I can't take anymore"

- **Anxiety** – A normal accompaniment to terminal illness, "exacerbated (by) continual change and loss…as part of an unstoppable process" (Nord, 1997), accompanied by "Who will be next?".

- **Alcohol and Drug Abuse** – Healthy grief resolution is impeded by substance abuse and it "perpetuates complicated mourning" (Rando, 1993). Martin (1988) found a "significant dose-response relationship between the number of bereavements and recreational drug and sedative use". Although emotional responses may be more accessible when drunk, the attribution to the substance "it was the booze talking, not me" does not allow for the integration of the mourning experience. It is like drinking salt water when thirsty; initial feelings of relief followed by increased difficulty.

- **Social Withdrawal** – A common response in single loss and in multiple loss this need to withdraw to may not subside with time.

- **Diffuse Anger** – While a single loss response is accompanied by anger, multiple grief events bring multiple angers, including:
- Anger that values and beliefs seem empty and unhelpful
- Anger that losses are beyond any normal expectation
- Anger at being left alone
- Anger at family of choice or origin
- Anger at those dying and deceased for being infected
- Anger at medical personal and caregivers for being ineffectual
- Anger at AIDS and opportunistic infection
- Anger at society for ignoring and mistreating those with AIDS
- Anger arising from personal helplessness

- **Survivor Guilt** – "Why not me?" may be accompanied by sorrow for our own survival (this does not need to be rational). Helplessness in the face of unrelenting loss, "There is nothing I can do." leads to a desire to make meaning of the experience, "There must be a reason I survived".

## The Shattering of the Assumptive World

Our assumptions form the basis for our security in the world and how we understand and make meaning of our experiences. We are largely unaware of how we base our reality on assumptions, as they form the background from which we operate in the world. For example, we assume that gravity is a constant, that the sun will rise and set and that there is some purpose to our existence. Prior to AIDS, a reasonable and unexamined assumption within the to-be-affected communities was "the people to whom I am attached will not be systematically and randomly eliminated by a protracted and disfiguring disease process within the next decade".

Since the "individual self is interpersonal at its "very core", multiple loss is a "threat to one's very identity" (Uroda, 1977). Each loss is another blow to the self within a social network of meaning. The need to make meaning then becomes deeply felt.

## Learned Helplessness

Another common response to multiple loss is "chronic passivity" (Van der Kolk, 1989) coupled with a tendency to isolate. Survivors of AIDS related losses adopting this strategy may be willing to engage in the painful work of examining the impact of multiple loss when the accumulation becomes more unbearable than re-exposure to memory. Therapeutic work is difficult for us as survivors because emotions may be feared as the heralds of trauma. Living in the reality of an ongoing traumatic process brings into question the value of opening to an emotional response when a death surround characterizes our daily existence.

**Learned helplessness as a response to lack of control.**

**A Survivor's reality is that s/he is:**

- Helpless to prevent the death of loved ones
- Helpless to eliminate the pain and demise of PHAs
- Helpless to prevent collective, community-wide losses
- Helpless to escape a world saturated with AIDS

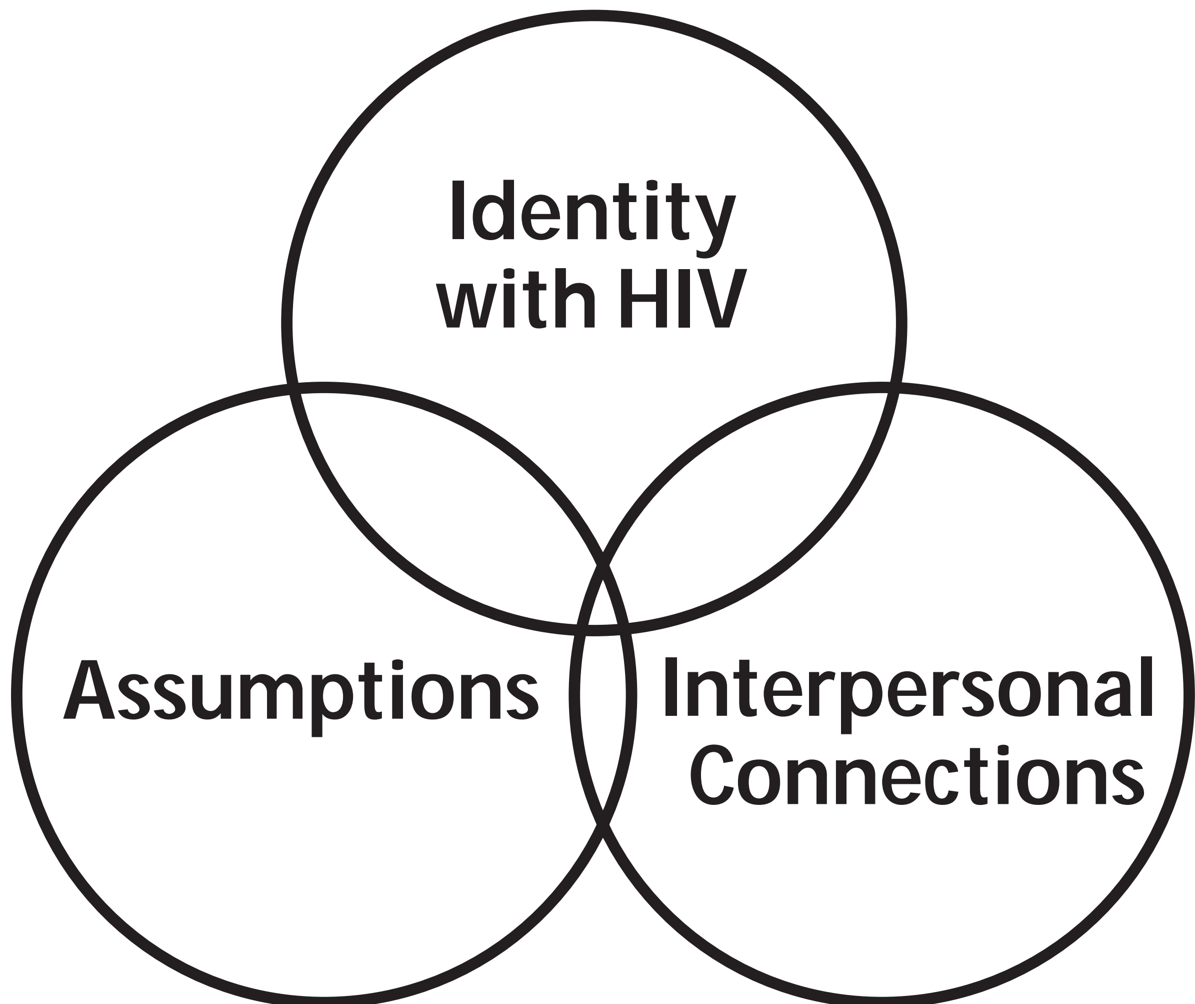
**Incompetence and defenselessness arising from these tangible areas promotes a perception of helplessness which may show up as:**

- Chronic reactive depression
- Helplessness to maintain emotional balance
- Helplessness to respond capably to ongoing loss
- Helplessness to find motivation to develop and implement a future vision

**Disruption of Identity**

A survivor's sense of self is forever altered as they continue to be challenged to live purposefully and deliberately. Identity disruption occurs at 3 levels:

1. **Identification with HIV status,** whether positive or negative, influences the self-concept.
2. **Assumptions** about the universe are shattered.
3. **Interpersonal connections** are disrupted as they occur in the context of a death surround.




**Sexuality is altered in that it now includes the components of:**

- Physical threat – of infection, reinfection and
- Psychological threat – of annihilation

Identity disruption is both normal in multiple loss and profoundly alienating, forcing the question: "Who am I now?" The beginnings of the answer can come from an exploration of the impact of the losses.

## "Where do I start?"

There is often one overshadowing death (lover/best friend) that indicates a starting point in grief work. Particularly if the relationship was conflicted or ambivalent, the need to grieve may present itself more forcefully.

Using the journey of Grief as a road map, allowing your road to wander and meander, and working the four tasks of grief while focusing on one significant loss will lead to developing the ability to process other losses. The process is like developing a new "personality sub-routine". Conscious, focused grief work, like the work of learning to drive a car, requires practice and determination. Eventually, it becomes almost unconscious – not requiring as much time energy and attention, freeing us up for other creative ways of being.

See page 122, Interventions in AIDS-related Multiple Loss. The work of addressing the impact of multiple loss *"requires introspection and increased levels of self-awareness"* (Sprang and McNeil, 1995).

## 1. Normalizing: "The times are crazy, you are not"

### The process of normalizing both:

- Recognizes that extreme responses are required for extreme circumstances, and
- Recognizes the abnormality of the circumstances.

### This recognition honours the need to bear witness, which can help us:

- Stop feeling guilty about feeling guilty
- Stop feeling anxious about feeling anxious
- Liberate more creativity and spontaneity for the healing process
- Shift from a pathological identity to an empowered one
- Shift from being oppressed to being challenged
- Shift from victim to survivor

## 2. Constructing a Timeline

Typically after two or more significant deaths, survivors will adopt a strategy of refusing to mourn, which may include not attending funerals, etc. (Nord, 1997). In order to begin the long-term commitment to uncovering the meaning of the losses, a timeline can help separate out the different losses. The timeline should include all losses including those that are intangible and global (e.g. community, sexuality, fun, safety) not just death events. This then invites the process of methodical storytelling.

### 3. Expressions of Recollections

Emotional responses are "generally constricted initially" (Sprang and McNeil, 1995). Inviting individuals' expression of what they have lived, which dips in and out of the mundane and the intense, allows for expression without becoming overwhelmed.

### The experiential value of bearing witness:

- Ensures the experience will never be forgotten
- May include writing books/articles, attending support groups, creating lasting memorials
- Prevents AIDS having the final victory of total eradication

### "Disenfranchised grief is best dealt with in a social setting." (Nord, 1997) The experiential value of working in groups:

- Validates losses
- Builds community
- Provides a setting to consistently 'lean into' the pain of grief
- Affords the certainty of being witnessed
- Helps in sharing feelings to receive support
- Counters alienation/isolation (others hear and support)
- Lessens survivor guilt
- Aids in the search for meaning
- Fulfills a need for catharsis
- Fosters a sense of choice and control

### 4. Support for Maintaining Functional Balance (Between attaching and detaching)

- Requires ongoing self-monitoring
- Involves neither total immersion or total avoidance
- May include twisted humour as a healthy coping strategy

## Aspects of Closure

As human beings we invest energy in our attachments to people, places, experiences, beliefs and things. Whether positive or negative (an apartment I love, a job I hate), moving on from an attachment requires paying attention to what is being left behind. For example, if leaving a workplace there may be a card and/or party to mark the transition. Often this is the time when appreciations are shared and the card/party is a ritual element in the closure.

### After moving on, a person may realize:

- "Oh, I never got to tell so and so that I regretted…"
- "I really resented the way they dealt with me when…"
- "I guess I never really told them how much I gained as a person in that job…"
- "I wish I had told them how happy I was to be moving on to this new position…"
- "What I didn't like about that surprise party was that it felt just like the surprise party for my twenty-fifth birthday – when my ex showed up and caused a huge scene – his ghost was haunting me all night and I just couldn't relax!"

Because these aspects are not spoken to, they remain as unfinished business, carry an emotional charge, and will need to be spoken of or attended to. It is not uncommon to hear someone speaking of their resentments towards a workplace situation, even years after they have left, because they did not have the opportunity to close well and name the resentments at the time. Unattended closures can then become more emotional baggage to carry around.

The "Aspects of Closure", listed on the following page, identify the areas that may carry an emotional charge associated with an ending. Typically, one aspect will be more present than others (appreciation, resentment etc.). Speaking to all aspects as fully as possible makes for an experience of closing which is as complete as possible.

## Aspects of Closure

**Gains & Achievements**
• What I have gained/achieved as a result of this experience.

**Appreciations**
• What I appreciate about myself and/or others.

**Unfinished Business**
• Naming what is unfinished helps to leave it behind.

**Regrets**
• Any regrets I carry from this time.

**Resentments**
• What I resent about this experience.

**Ghosts of Closures Past**
• Other similar experiences/closures that are present for me now.

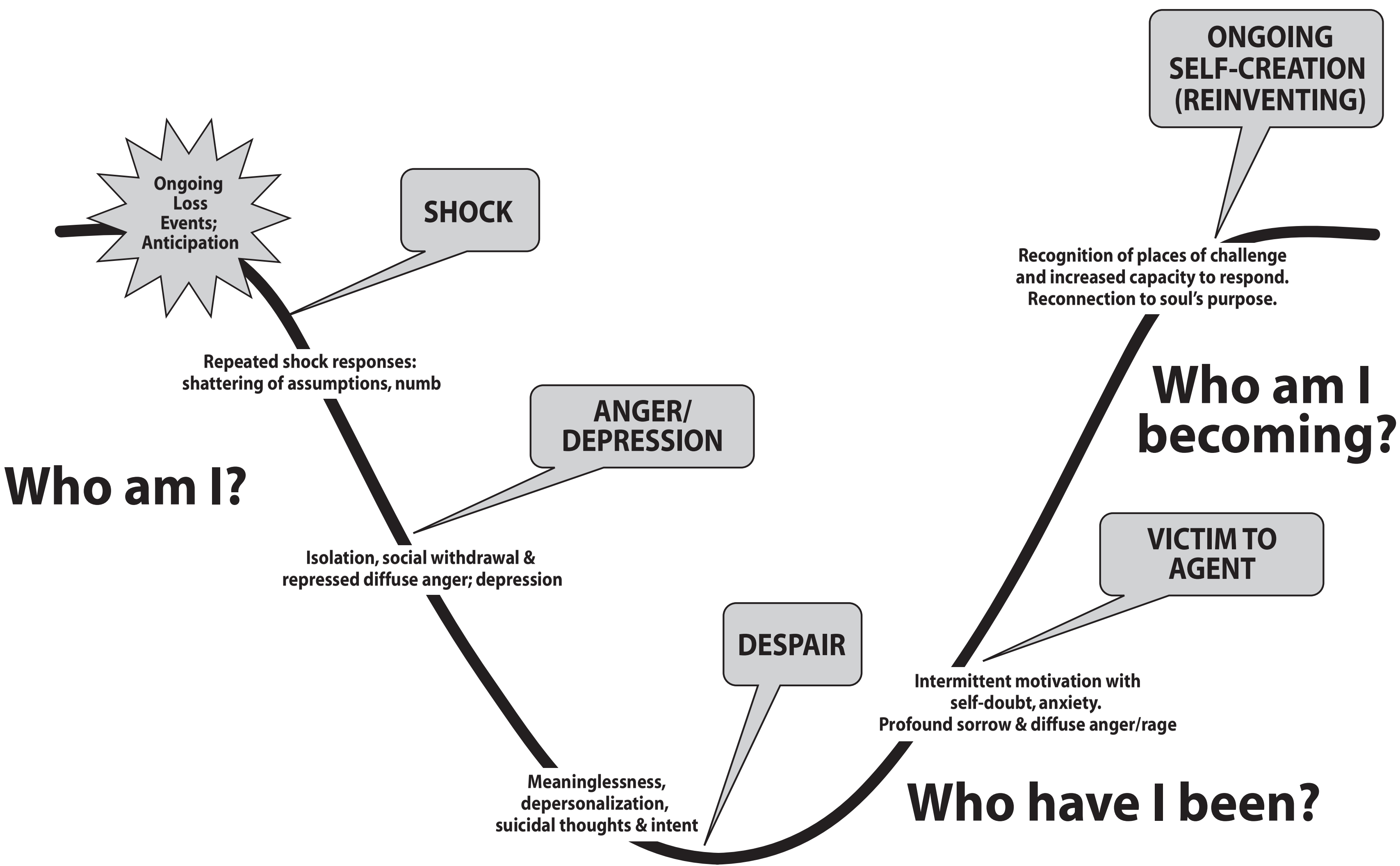
**Moving on; what's next?**
• As this experience is ending, I can name what is beginning, and what I will carry forward.

**Ritual**
• Any deliberate action which has meaning in relation to closing on the experience.

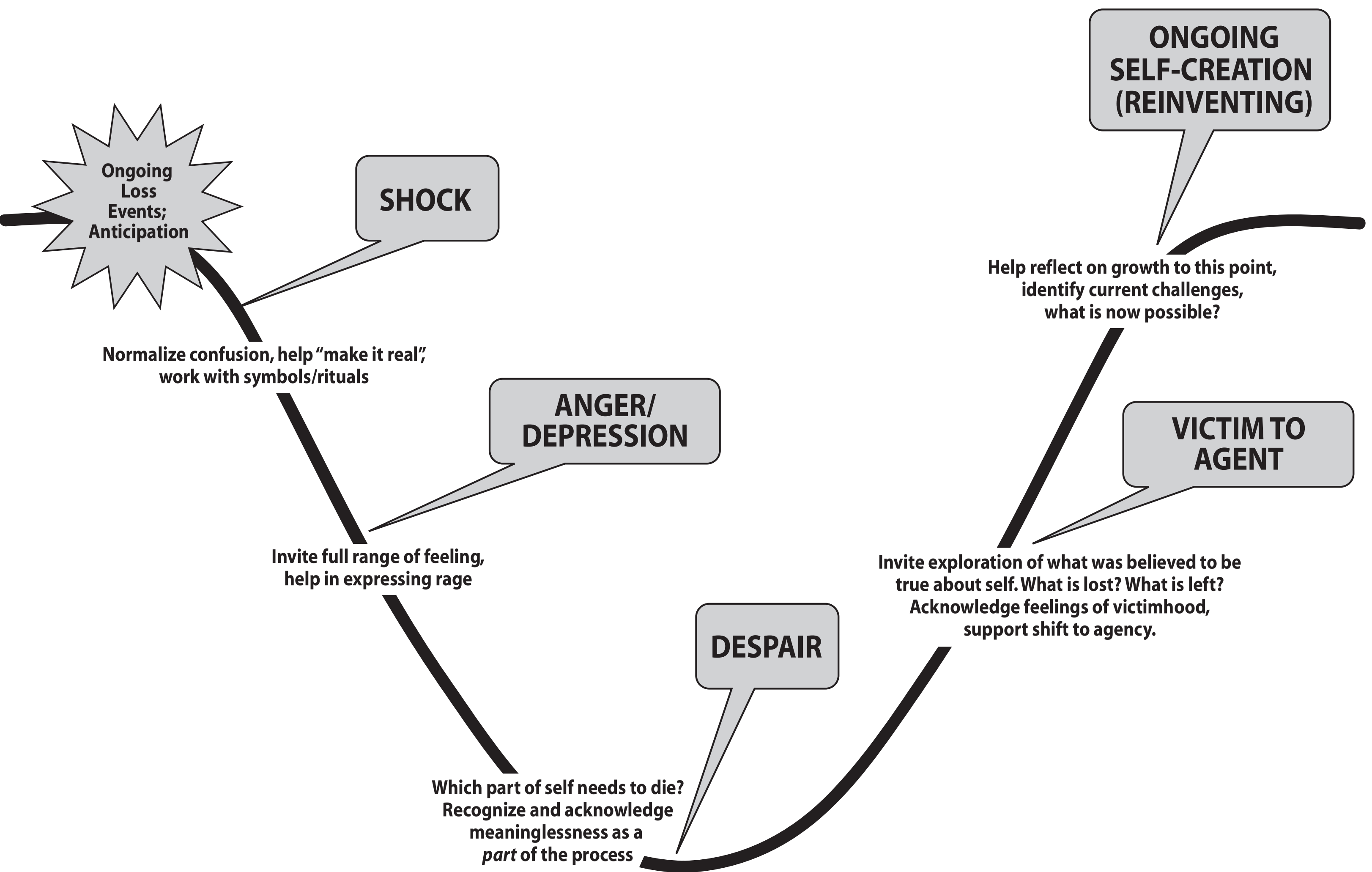
Adapted with permission: Susan Aaron, Psychodramatic Bodywork

# The Grief Journey

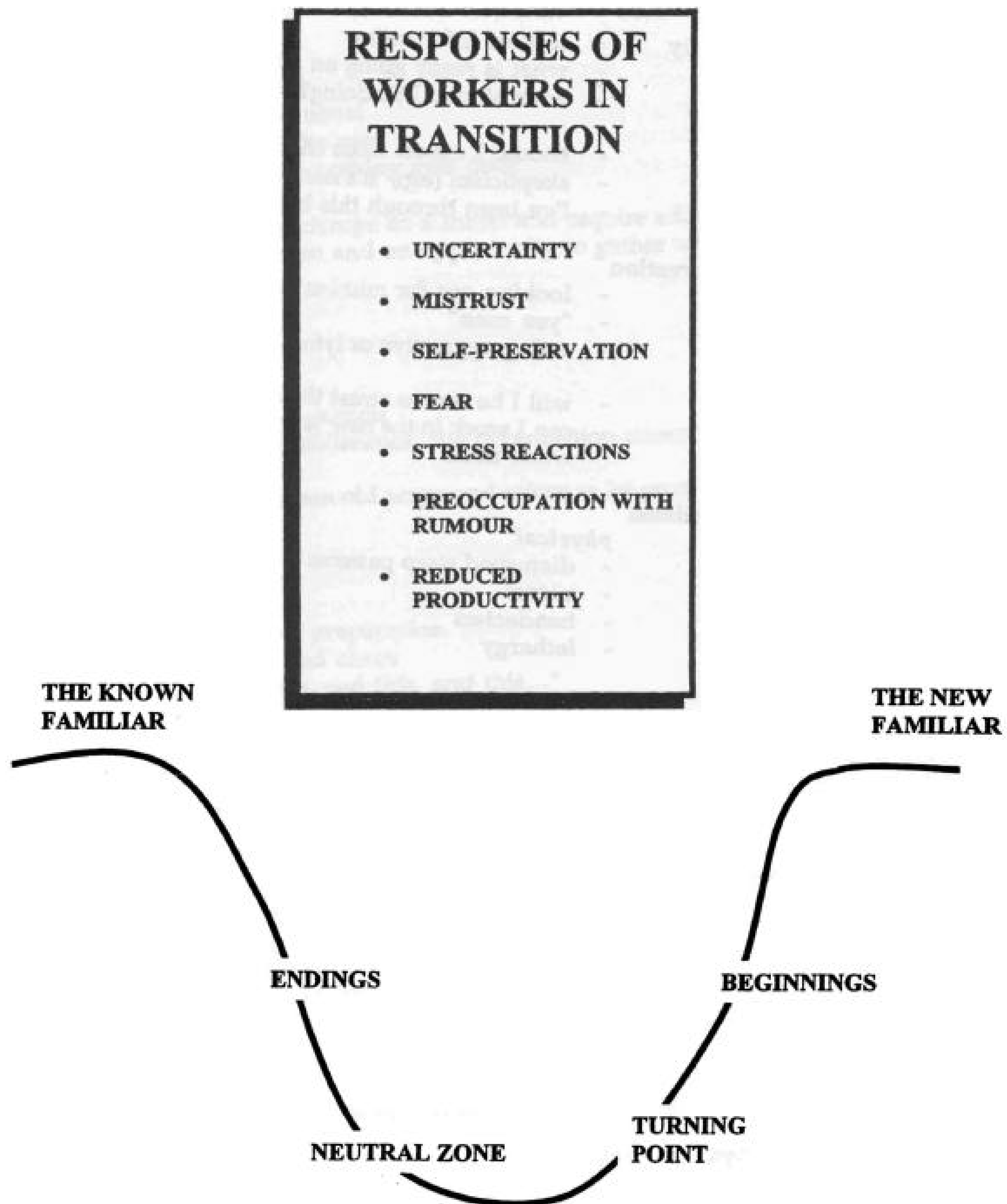
# The Journey of AIDS-related Multiple Loss



# Interventions in AIDS-related Multiple Loss



# Responses to Organizational Change & Transition



# Predictable Ways for Individuals to Act During a Restructuring

- **uncertainty**
  - Lack of information
  - "What is really going on here?"
  - "What should I be doing?"

- **mistrust**
  - "Should I expect more changes to come?"
  - Skepticism (e.g., "It's not going to work. I've been through this before!")

- **self-preservation**
  - Looking out for number one
  - "Yes men/and women"
  - Acting aggressively or lying low

- **fear**
  - "Will I be on the street tomorrow?"
  - "Can I work in the new way or in a new work unit?"

- **stress reactions**

  ***Physical***
  - disturbed sleep patterns
  - ulcers
  - headaches
  - lethargy

  ***Psychological***
  - anxiety
  - depression
  - feeling helpless and powerless
  - irritation with family and friends

- **preoccupation with rumour**
  - Rumour and gossip
  - Misunderstandings regarding senior management's goals and aspirations

- **reduced productivity**
  - Decreased concern for work tasks

People Tech Consulting, 1994

# Managing Organizational Change Model

***Phase One*: Denial**

- Withdrawal
- Business as usual
- A focus on the past
- Activity, but nothing gets done

People experience change as a threat and require additional emotional support, information and an opportunity to gather with others to talk.

***Phase Two*: Resistance**

- Anger, blame
- Anxiety, depression
- "What's the difference, the organization doesn't care anyway."

People try to maintain old ways and refuse to let go of the past.

***Phase Three*: Exploration**

- Energy, over preparation
- Confusion and chaos
- "Let's try this, and this, and this…"
- Lot's of energy and ideas but a lack of focus

There is sadness over the recent loss, but people begin to see the value of what is coming. They start to consider the pros and cons of the change. People begin to take risks and explore new ways to look at things.

***Phase Four*: Commitment**

- People begin to work together
- There is cooperation and focus
- Committed individuals are looking for the next challenge

People are ready to establish new routines and help others to make the change work. People take risks such as changing methods and endorsing new decisions.

People Tech Consulting, 1994

# Bridges' Transition Model

***Phase One*: Endings**

- Transition starts with an ending
- Letting go of the old reality and old identity

***Phase Two*: Neutral Zone**

- 'No-man's-land' between the reality and the new way
- The old way is gone but the new way does not feel comfortable yet

***Phase Three*: New Beginnings**

- The only way to make a new beginning is to first create an ending, and then spend some time in the neutral zone

*William Bridges, Managing Transitions, 1991*

## Letting Go of Resistance

- Identify who's losing what
- Accept the reality and importance of people's belief that they are losing something
- Don't be surprised at overreaction
- Acknowledge the losses openly and sympathetically
- Expect and accept the sign of grieving
- Define what is over and what is not
- Mark the endings
- Treat the past with respect

People Tech Consulting, 1994

# Reminders For Managers

**Communication**

- Encourage open, interactive communication amongst all individuals in order to identify and solve problems early. Ask people to express their concerns. If you make a decision that is in opposition to concerns expressed, explain your rationale behind the decision.

- Provide employees with concrete examples of what you are telling them.

- If you encourage risk-taking, communicate this to everyone. Similarly, communicate to them that along with risk-taking comes mistakes and that is okay as long as you are being flexible, innovative and thoughtful. Be prepared to share an example of when you took a risk that resulted in a mistake and how that situation was handled.

- Celebrate achievements and milestones in order to maintain motivation around the change. Share these achievements with everyone and not just the individuals who were responsible for the achievements.

- Communicate regularly with everyone, verbally and/ or in written form. Have regular staff meetings, walk around and get to know people, ask people to identify one thing they like about what is going on around here and one thing they wish they could change.

**Availability**

- Be visible. Keep your door open, tell people that they can drop by at specified times {e.g., first thing in the morning), walk around and ask questions.

**Trust**

- Work hard to build, maintain and restore lost trust (if you have lost it at points along the way). Let people know about things as soon as possible, be upfront with bad news, tell them you do not have the information if you don't and they request it.

- Let people know that there is a transition period in which we need to negotiate situations and new ways of doing things. Let them know that you likely cannot anticipate everything that they may need, want and/or require. It is not done with intent but due to a lack of awareness of all the issues and details. Is there a way that they could help to rectify the situation?

People Tech Consulting, 1994

**Individual Reactions**

- People may intellectually accept a change and speak about it positively. However, if you question further, you will likely notice that people are struggling with a number of issues in their hearts. For example, people are likely asking the following:

    - ❑ How will things be done around here? New rules? New reporting structures? What do I have to do differently?

    - ❑ What are the consequences if I cannot perform as expected? Will I know when I am at that point?

- Ask yourself if there is anything you can do to address these questions.

- People accept change differently and move through the change process at different rates. Do not assume that everyone feels the same as you do or the same as any one person that you have identified.

**Pace of Change**

- People want answers quickly -they dislike ambiguity and uncertainty. However, they do need to learn how to deal with increased levels of ambiguity. If you do not have an answer or have not established a procedure, tell them so, so that they do not think you have a secret agenda or are insensitive to what they might be experiencing.

**Teambuilding**

- Let people know that you are interested in building a team and not just an organization of individuals. Do not speak in abstracts. Instead, clearly sketch out what and how it will look.

- Reinforce when you see people or groups of people seizing opportunities, acting hopeful and being curious. Share concrete examples of this with the rest of the organization.

- When people raise issues it is not always necessary that management resolve the problem on their own. Invite employees to deal with the problem -solicit their efforts.

People Tech Consulting, 1994

**Monitor Change**

- Accept that there will be resistance to change. Learn to manage it by keeping abreast of it and letting people know that you are aware of it.

- Expect problems. Go looking for trouble. Reward people who identify problems and breakdowns. You cannot lead others if you are the last to know. Utilize their help in finding solutions to the identified problems.

- Track the change process by doing ongoing, informal soliciting of opinions. In addition to keeping you in touch with current organization issues, it communicates your concern for the well-being of the organization and the individuals within the organization.

People Tech Consulting, 1994