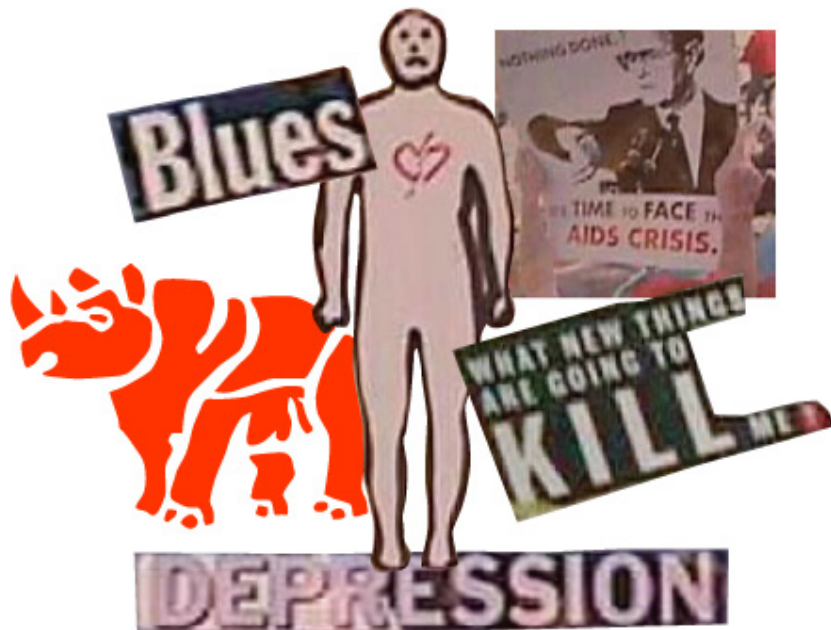


'Survive and Thrive'



Long-term AIDS-related Multiple Loss Survivor (LTS) Intervention Framework



AIDS Bereavement Project of Ontario

Our sincere appreciation to retreat participants who opened themselves to something new and stretched themselves to help us all learn about multiple loss.

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INTRODUCTION

The AIDS Bereavement Project (ABPO) provides community-based AIDS agencies with concrete support in the area of AIDS grief and loss. Funded by Ontario's Ministry of Health, the Project is a unique resource for Ontario groups wishing to look explicitly at AIDS-related grief and loss within their organizational settings. Additionally, from 2002-2005, ABPO received support from Regional AIDS Community Action Plan to develop *“Practical Tools for Surviving and Thriving with Ongoing Loss”* and *“Address the Impact of AIDS-related Multiple Loss and Community Devastation in Long-term HIV Infected and Affected Individuals”*.

Thus far we have found that for workers, there are few tools that combine grief, loss, bereavement and trauma theory, and are informed by the resiliency strategies of long-term HIV-affected community members. Therefore, we have created an intervention framework that incorporates these elements, provides concrete tools for workers, and documents the efficacy of the tools designed. For newer workers providing service to community members, the research and documentation of the lived experience of service users, and the development of practical skill sets to support those experiencing catastrophic loss is essential.

Consultation with Support Workers working in ASOs reveals that long-term survivors of the HIV/AIDS pandemic (both infected and affected) are experiencing depression, isolating themselves, and suffering from psychic numbing and loss of affect consistent with a response to multiple loss. Many long-term survivors are living with the catastrophic loss of community devastation, with serious consequences for their mental, emotional and physical health.

In addition, PHAs who believed they would soon be dying and “joining friends and lovers” are now adjusting to probable long-term improved health as a result of ARVs. Through ARVs, people experience episodic acute illness with AIDS, which creates a cyclical movement through a usually linear experience of life-threatening disease (cite BC research CWGHR). Consistent with grief theory, part of this adjustment includes the need to grieve the many losses they have experienced. These survivors are not necessarily accessing current available supports through the ASO.

Many of the Support Workers in this province are relatively new (under 3 years experience as indicated at a recent OAN Support Workers Skills Building session). As such, they do not necessarily have an experience of HIV disease prior to the availability of ARVs. This can leave long-term PHAs with a sense that their loss-related issues are no longer being addressed by their local ASO. Where the Bereavement Project once focused on the grief-related needs of the staff, many Support Workers are now telling

us that they personally are not dealing with the effects of ongoing multiple loss and do not have the theoretical background or life experience to relate well to the complex bereavement needs of their clients.

While ABPO continues to provide training to Support Workers as part of our mandate, it is now becoming apparent that ABPO, with its combination of theoretical and practical experience, is well positioned to provide direct support to long term survivors and community members as part of a “hands-on” training and mentoring experience for front-line workers.

EXECUTIVE SUMMARY: Outline of Framework Components

In order to increase knowledge of the effects of AIDS-related multiple loss and to enhance ASO and PHA communities' capacity to identify and effectively manage loss and transition-related stressors, the following sections include:

Section ONE: Findings and Materials from Pilot Work

1. A report of the findings from our research into the impact of multiple loss on 135 individuals in pilot communities between 2002-2005. Additional detailed information is in **Appendix A Final Retreat Evaluation Report**.
2. A summary of relevant grief, multiple loss and trauma theories and models.
3. Giving a specific example of a community's experience with the 'Survive and Thrive' model.

Section TWO: How to Hold a Retreat

- 4.- 6. Sharing specific information for designing, promoting, delivering and evaluating a 2-day retreat intervention, including detailed annotated agenda for facilitators.

Section THREE: Integration into Ongoing ASO Activities

9. Summary of relevant information and contextual considerations for ASO Support Workers, Volunteer Coordinators and Educators.

In the **APPENDICES B & C**, you will find the **Multiple Loss Assessment Questionnaire** and '**Tree of Life**', which are practical tools to:

- quantify the number and types of losses experienced, both tangible and intangible;
- provide an initial assessment of the impact on the mental, physical, emotional, spiritual, sexual and social well-being;
- identify the range of current coping strategies and strategies of resiliency utilized by individuals experiencing multiple loss.

SECTION ONE: Findings and Materials from Pilot Work

1. Measuring the Impact of 'Survive & Thrive' Retreats

a) Retreat Format

The retreat allows participants to explore more deeply the multi-faceted aspects of grief, loss and ongoing healing in a safe space with community peers. Retreats spanned two days and were conducted in four regional sites in Ontario, Canada. On-site accommodation and/or local travel costs were covered where appropriate. As well, childcare subsidies were made available for parents to be away from home.

We were interested in understanding the initial and sustained impact of the retreat on persons attending and subsequently designed a comprehensive evaluation plan that consisted of a questionnaire and qualitative reflection tool ('Tree of Life') conducted at three intervals: 1) prior to the retreat, 2) three weeks following; and 3) three months following the retreat. Of the 70 persons who attended the retreats across Ontario, 67 completed the evaluation materials. Evaluation findings are considered in the context of HIV and multiple loss and are summarized below. You may obtain a detailed '*Survive & Thrive*' Final Evaluation Report by emailing us at yperreault@fifehouse.org or see Appendix A for a full report, including selected evaluation graphs.

b) The Collective Experience

The majority of participants were male (79%), HIV positive (86%), and self-identified as gay (64%) or straight (19%). On average participants were 40 years of age (range: 34-63) and among HIV positive persons, have been living with HIV for 12 years (range: 6-18). In addition, 56% of participants volunteered at their local AIDS Service Organization, with a small proportion (9%) currently employed as ASO staff.

In our evaluations we were interested in documenting the loss-history among Long-term Survivors. Across Ontario sites participants indicated experiencing an average of 157 deaths related to HIV in their lifetime; and 76 deaths not related to HIV.

Participants also indicated having experienced a number of 'significant' losses throughout their lifetime, such as: male relationships, partners/lovers, friends, family, career, income, health, body image, independence – to name a few.

All retreat participants indicated that they have experienced Physical and Emotional Effects from their grief/loss. While Physical Effects from grief/loss are difficult to discern due to correlation with side effects from HIV treatments, all participants

indicate they have experienced “insomnia, fatigue or inability to sleep” that they personally associate as related to their grief and/or loss. The top 5 Emotional Effects participants relate to their grief/loss include: Depression, Anxiety, Stress, Anger/Frustration and Hopelessness.

A total of 88% indicate having received professional support in the past for issues related to HIV status, sexuality, relationships, family and grief and/or bereavement. Similarly, 84% of participants indicate currently receiving support from such sources as: ASOs, friends, counselor or psychologist.

The vast majority, 86% of participants report having a ‘personal faith/belief system’ of some kind (we did not ask religious or spiritual denominations or affiliations). Among those indicating they have a personal faith/belief system, 77% indicated that their grief/loss related to HIV has changed their belief system in some way (i.e. heightened, shattered, sought new faith/belief system).

c) Evidence-based Impact of ‘Survive & Thrive’ Retreats:

In the interest of understanding the initial and sustained impact of the retreat we asked participants to complete evaluation materials three weeks and three months following the initial retreat. These evaluation materials consisted of the same questions that were asked prior to the retreat and the reflective ‘Tree of Life’ exercise. The ‘Tree of Life’ exercise engages participants in a reflective process, composing written statements about where they see themselves in their lives right now.

Figure 1. ‘Climbing the Tree of Life’



The page includes the statements, “Picture yourself as a child on this tree. Circle the child which best represents where you feel you are at this moment in your life.” In

essence, the child which the participants choose supports them to align with a distinct positioning of their present perception of 'self' - or **self-perception**. The actual handout used in the retreats is in Appendix B Tree of Life; it includes the prompting statement, "How does this child represent what is going on in your life at this point?", followed by six blank lines to solicit from participants a written snapshot of their self-perception.

Participants' Tree of Life statements were analyzed for thematic content at three weeks and three months following the retreat. Combined with the **attitudinal measures** from the questionnaire, our evaluation findings demonstrate a balanced understanding of the Grief Journey (see page 14) for those who attended the 'Survive & Thrive' weekend retreats.

(i) Prior to the retreat, participant's tended to perceive themselves as:

- 'isolated' and 'withdrawn' as a means of coping with the effects of worry, grief, loss, financial stress, etc.
- as though they were 'watching life from a distance'
- feeling 'lonely, despondent and hopeless.'

A number of participants indicated that they had 'illness fatigue,' described in the literature as being worn-down emotionally, physically and psychologically from living with a long term, episodic, debilitating disease, many indicated that they saw this as 'coming to terms with living with HIV'.

Others indicated feeling 'beaten by HIV' yet wrote about the necessity of a 'positive attitude', or 'taking one day at a time'.

Participant statements convey the understanding that while living with HIV has Long-term Survivors feeling on the periphery of community, family or social networks and results in them feeling lonely, despondent or hopeless, they have nevertheless come to accept this as the reality of living with HIV.

(ii) Three weeks following the retreat, participants report feeling:

- 'less depressed', 'less lonely', 'less guilty for still being alive', 'less worried or concerned about their future'; and 'less like withdrawing from social activities'.
- In addition, participants also indicate that their grief/loss no longer affects their sex drive as much as before.

Considering how participants perceived themselves 3 weeks after the retreat, many participants indicated that they felt like they had:

- 'fallen from the tree' and were now 'struggling to get back on',
- some state that they were on an 'emotional roller coaster', and were 'feeling exhausted, less able to cope and fragile.'

These responses are not surprising and are in accordance with the Journey of AIDS-related Multiple Loss, outlined on pages 13-16. At this stage, participants have begun a process of change and reflection.

(iii) Three months following the retreat, participants report feeling:

- 'happier about the way life is going'
- and continue to feel 'less depressed', 'anxious', 'lonely', 'less guilty for still being alive', 'less afraid of dying'; and that 'sex continues to be more important in their lives'.

Participants also indicate the importance of

- 'recognizing their losses' and
- 'understanding their feelings'.

Considering how participants perceived themselves 3 months following the retreat, most participants described feeling:

- 'angry', 'depressed', 'alone', 'tired of life with HIV' and 'sad about so many losses.'

Some described feeling:

- 'stuck', 'having trouble getting going', 'being at a cross-roads in life', where they were 'looking back and to the future to seek answers.'

Again, these responses continue to validate the experience of participants in the context of the 'Grief Journey'. This highlights the importance of continued support because Long-term Survivors increase community engagement as a result of the retreat.

Summative Statement:

"Before the retreat I had seen myself as pretty 'on-course' with my life. I'm positive, and this affects every aspect of my life and relationship I have with others. I do not really see myself as a part of any 'community' or 'circle' per se. I've just come to accept this as my 'lot in life'. After the retreat my perspectives changed – I saw everything, including myself, differently. It has been a challenge to move from accepting this 'lot' - to a place where I actually take an active role and responsibility for my life. Since the retreat, I have felt angry, depressed, frustrated, elated, ecstatic, happy ... (at least I am feeling these emotions now!) ... I am, simply, a thousand times happier than before."

Retreat Participant

2. Grief and Multiple Loss Theory

a) 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 linear 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. The stages are numbered to correspond to Worden’s Tasks of Mourning (see c)).

The Grief Journey



b) 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	<i>Projected/externalized grief</i> – "I'm furious at the stupid photocopier; my anger has nothing to do with grief!" or <i>Internalized grief</i> - "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."

c) Worden's Tasks of Mourning with Negation of those Tasks:

* Depicted on previous page, The Grief Journey.

1. To Accept the Reality of the Loss

- The mourner must talk about the death, body, and funeral.
- Negation is 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 is 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 coincides 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 is 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 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*

d) 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 below, 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. (*Adapted with permission: Susan Aaron, Psychodramatic Bodywork)

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.

e) Elements of AIDS-related Loss

(i) Stigmatization: Blame of self and blame and judgement by others affect an individual's ability to work through the bereavement process.

- 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)

(ii) 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
 - More difficulty accepting the reality of the loss
 - More disorganization through life
 - Anxiety
 - Pessimistic future outlook

(iii) 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. Complicating factors in AIDS-related Multiple Loss include:

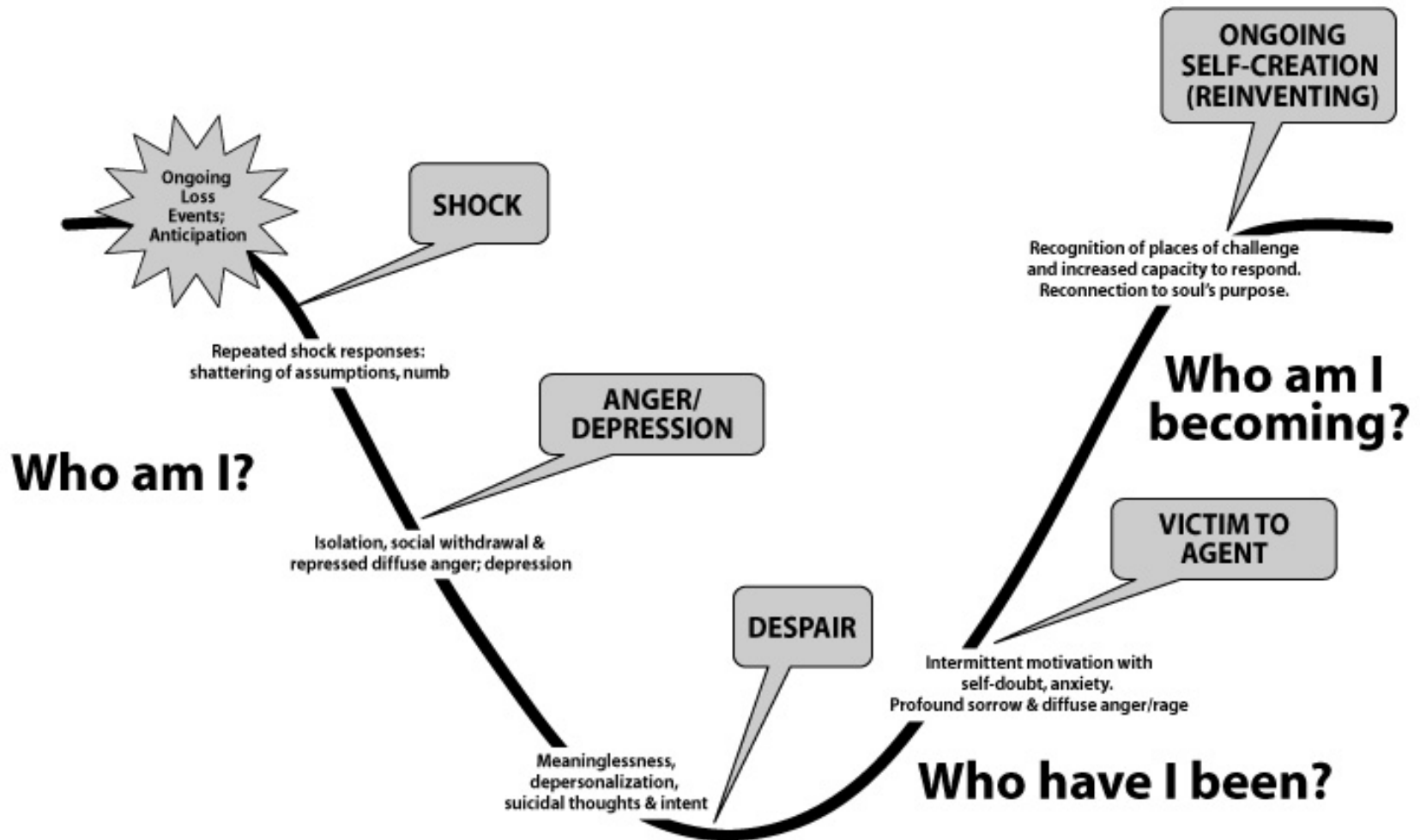
- **Attachment creates meaning:** An individual’s experience of attachment to loved ones provides, “for us the centre of the universe, the place where all the threads of our life, of our world, come together”, what we love “appears to us as something indispensable”. (Ortega y Gasset , 1961).
- **Multiple 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).
 - is 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.

(iv) Journey of AIDS-related Multiple Loss – See diagram following page.

The Journey of AIDS-related Multiple Loss



f) The Challenge of Multiple Loss within the Basic Hierarchy of Human Needs

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

(i) 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 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”.

(ii) 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.

(iii) 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:

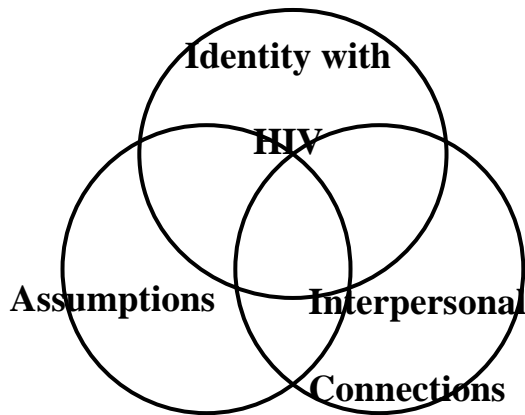
- Helpless to prevent the death of loved ones
- Helpless to eliminate the pain and demise of PHAs
- Helpless to prevent collective, community-wide losses
- Helpless to escape a world saturated with AIDS

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

g) 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, re-infection and
- Psychological threat – of annihilation

3. Emerging Theory: Multiple Ongoing AIDS-related Loss and Community Devastation (Multiple Loss Journey)

a) Working with the Impact of AIDS-related Multiple Loss: 'Complexity of Losses'

Identity disruption is the key distinguishing element of the impact of Multiple Ongoing AIDS-related Loss and Community Devastation (referred to in text as Multiple Loss Journey, see diagram page 25). Identity disruption is both normal in multiple loss and profoundly alienating, because it forces the daunting question: "Who am I now?". Therefore, we use the Multiple Loss Journey to help people explore the impact of their losses on personal identity.

We start by acknowledging the multi-layered work of inquiry into the complexity of emotional, mental and spiritual issues facing long-term survivors. This grounds what can be an overwhelming task of opening up multiple loss issues which include:

- Loss of self, including loss of identity and assumptive world
- Loss of significant people, places, things, hopes, and dreams (tangible and intangible losses)
- Loss of a 'Community of Meaning'
- Losses because of a social and political context of stigma and marginalization

Two key ingredients to begin the process are:

- the power of questions, that help people opening on all levels rather than distracting with problem-solving or dissolving into story-telling,
- using time/people's personal history to help create the container for the process with the three questions:
 - What is Lost?
 - What is Left?
 - What is Possible?

Conscious, focused grief work, like the work of learning to drive a car, requires practice and determination. The work of addressing the impact of multiple loss includes heightened self-reflection and *"requires introspection and increased levels of self-awareness"* (Sprang and McNeil, 1995). Also, 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

Further theoretical support for addressing multiple loss through group work comes from David Nord, *"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

b) Normalizing: “The times are crazy, *you* are not”

The following are key elements in group discussion and theory presentations:

- 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

c) Constructing a Timeline

This exercise can be used as a preparatory process to help people look at their loss history. Typically after 2 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.

d) Structuring Peer Discussion with the Multiple Loss Journey: “What is Lost?”

The theoretical model which was developed through the ‘Survive and Thrive’ project by Yvette Perreault is called **Multiple Ongoing AIDS-related Loss and Community Devastation**, see page 28. It was created to support long-term survivors working in a group process, by identifying seven significant stages and tasks related to those stages. Group exploration of these stages supports participants’ deepening self-awareness through recognition and validation of personal experiences and learning from others. The first four stages fall under the “What is Lost?” process, as follows:

1. Attaching

- Task: In the complexity of losses, acknowledge difficulty attaching.

2. Ongoing Loss Events

- Impact: Shattering of assumptions.
- Impact: Numbness, flooding and disorientation.
 - Task: Normalize confusion.
 - Task: Give language to help make it real, (including 1-1, peer, professional support).
 - Task: Use symbols, metaphors, and rituals.

3. Periods of Anger/Depression

- Impact: Social withdrawal and repressed, diffuse anger.
 - Task: Help with full range of feelings.
 - Task: Help express anger.

4. Despair

- Impact: Meaninglessness, hopelessness.
- Impact: Depersonalization, suicidal thoughts.
 - Task: Identify which part of self needs to die? Help mourn.

e) “What is Left?”: Support for Maintaining Functional Balance

The next two stages are:

5. Victim to Agent

- Impact: Intermittent motivation, self-doubt, and anxiety.
- Impact: Profound sorrow and diffuse anger/rage.
 - Task: Explore what you believed to be true about yourself.
 - Task: Assess and make a plan
 - Task: Support the shift in identity to recognize the power of personal agency.
 - Task: Engage in peer support to establish new role of witness and community member.

6. On-going Self-Creation

- Impact: Conscious involvement in re-inventing self.
- Impact: Must recognize places of challenge - how they have dealt with that in the past.

- Impact: Increased capacity to respond, making more emotional energy available for new identity creation.
 - Task: Examine personal history (of coming out, of immigrating, of dealing with HIV diagnosis), and recognize how any shift in identity that has contributed to who they are now.
 - Task: Support reflection on survival/discovery of growth to this point.
 - Task: Identify current challenges and capacities.

Establishing Functional Balance is a model to support these stages and includes the following behaviours:

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

f) “What is possible?”: Transformation of Identity

At this stage, the personal identity reconstruction process is well underway, opening up new questions such as, “What is possible? What has meaning for you? What is your soul’s desire?”

7. Transformation

- Impact: Establishing reconnection to soul’s purpose.
- Impact: Desiring meaningful, purposeful engagement in life.
- Impact: Constructing a narrative that includes the meaning of loss in new orientation to the world.
 - Task: Creating rituals which support saying goodbye, again, to the person that was and welcoming the new.
 - Task: Consolidating learning by identifying strategies used to get here, with the understanding this journey is a meandering one and we will revisit places again.

Multiple Ongoing AIDS-related Loss & Community Devastation



4. Ottawa Case Study

The AIDS Bereavement Project, in collaboration with the AIDS Committee of Ottawa, held a weekend retreat in October, 1999, entitled *“We are defined by our purpose and possibility, not our pain”*. A flyer inviting people to this exploration of living with the legacy of community devastation was posted within the agency and within two days, 21 individuals had enrolled, 18 of whom were PHAs, most of whom had been infected for over ten years. All participants had experienced multiple AIDS-related losses since the 1980’s and 5 were currently actively involved as volunteers with their ASO. The retreat setting was considered essential to serve as a container to maintain the necessary focus for the intense exploration of complex and multi-faceted loss.

Bereavement Project staff, using their expertise and knowledge of AIDS grief, were able to support participants by:

- Normalizing the experience of multiple loss
- Enabling participants to begin to disentangle the complexity of multiple loss in order to focus on one prominent loss, thereby beginning the process of developing mastery with regard to the mourning process
- Providing a theoretical framework which supported individual experience
- Facilitating discussion of the impact of community devastation
- Empowering individuals to acquire “life enhancement skills” and begin the process of mourning
- Helping individuals develop a vocabulary with which to communicate their experience of multiple loss
- Ensuring ongoing support (in partnership with ACO support staff)

Follow-up discussions with the Director of Support Services at ACO indicate that, subsequent to the intervention, many participants accessed supports for their grief work. The result of this initiative has been that a core group of attendees chose to meet monthly as a support group, periodically requesting additional support from ABPO facilitators. The initial group contained HIV+ women as well as HIV negative individuals who identified with the term, “Community Devastation”. The women and one of the two negative men stopped attending after the second intervention. The monthly group has periodically opened to new members who are then invited to attend the workshops. The monthly group consists entirely of PHAs who are gay men with an approximate average age of 45. Participants are reporting a “rekindling of

hope”, the “ability to feel again after five years” and “a sense of rebuilding community”.

Based on this prototype, the Bereavement Project staff used the outline to develop the ‘Survive and Thrive’ proposal in order to expand the work into three other communities. Information on multiple loss developed as part of the initial Ottawa retreat package was then used as the basis for workshop presentations for the PHA Caucus at the OAN sponsored spring 2001 session resulting in positive evaluations from participants who identified ‘this gives us language to begin speaking together what has been going on privately inside’.

Inter-relationship of Theory and Practice

Consistent with multiple loss theory, the majority of participants attending the initial retreat were experiencing varying degrees of depression and isolation. Interventions were designed to facilitate a sense of, “I am not alone in this” and to allow some of the confusion and strong emotions to be normalized, thereby affording participants the opportunity to become more comfortable with their lived experience of distress.

Evaluations reflected some success with regard to these intents:

- I have developed a sense of *community* this weekend.
- There is a *community* here.
- I can *let myself flow* with the situation.
- I am leaving with a lot of *contentment*.
- I don’t want this moment to end, I respect and care for all of you and I thank you; *I have gained friends today*.
- I feel *grateful* to have been part of this experience.
- It is an *honour* to witness life, and I have this weekend.
- I *solved a very big piece of the puzzle* for myself.
- It has been a great joy to *be here and be still*; I feel incredibly nourished.
- I realized *my purpose in life* is in my work; my soul is in my creativity.
- I have learned to what *I need to pay attention*.
- I have achieved some *tranquility* of mind I will take with me.
- I learned something about trust this weekend *from everyone*.
- The retreat was very good – it brought back something I repressed for forty years and I *realize I need a lot of help*.
- I leave with a sense of *joy*, it has brought me to a place of knowing who I am becoming; which is exactly where I wanted to be.
- I am leaving with *connectedness* and my right to receive love.

- I have learned to accept change.
- I feel enlightened, nourished, joyful and at *peace*.

Consistent with the “Journey of AIDS-related Multiple Loss”, the group identified needing help in working with Anger. ABPO staff provided a one-day workshop with the continuum of anger as the focus.

In January, 2001, the session was again consistent with theory, as participants continued to work with multiple loss. ABPO staff were invited to facilitate a one-day workshop to address the emergent theme of despair, meaninglessness, motivation and suicide. The intervention included normalizing the above, understanding suicide as “a part of self wanting/needing to die” and focussing on today’s challenge with support.

In October, 2001, a two-day retreat at the same location as the initial workshop. The focus was on emotional expression and spiritual growth; especially for those who were at peace with dying (acceptance). “What does it mean to be living now?” Interventions focussed on normalizing the above and facilitating an articulation of current self, higher self and the work needed to connect the two. This work is understood in multiple loss theory as ‘re-inventing’.

In May, 2002, another retreat happened which was part of the overall provincial ‘Survive and Thrive’ activities and involved the research component. As always, the challenge of this work for facilitators is to be open to, respectful of and adaptable to the needs of group members as they present themselves. Initially ABPO had been contacted to provide a weekend workshop on the theme of, “Too much Loss, Too much Change”. Two days prior to the workshop one of the group members died and his funeral was scheduled for the Saturday morning. This death was the first among group members, except for the suicide of a man between interventions #1 and #2. An additional challenge for the facilitators was the integration of 4 new members: 3 women from the women’s group and a gay man.

The on-going support group sessions have varied in frequency with informal on-going contact amongst some members. The peer facilitator accessed resource materials from ABPO in order to support deeper learning and discussion about grief and loss at the support group meetings. When there was a delay in the coordination of a 2003 retreat, a letter was written to the Board of the AIDS Committee of Ottawa, advocating for the importance of this resource for the people in the group.

SECTION TWO: How to Hold a Retreat

5. Advance Retreat Planning:

a) Host Responsibilities

It is important that Retreat Coordinator(s) be designated. These people will be responsible for either implementing or delegating the following tasks, assisted by

Appendix I Retreat Planning Checklist:

- i) Conduct community outreach through publicity and personal networking.
- ii) Provide information and direction to facilitators, as per b) Participant Group Assessment.
- iii) Find a location as per b).
- iv) Logistics coordination: setting start and end times for the retreat, providing materials and supplies.
- v) Make catering arrangements, including meal planning:
 - cover high protein needs for breakfast and lunch,
 - allergy and health concerns, i.e. have fresh fruit at all meals,
 - have clean water available at all times, herbal teas and other refreshments.
- vi) Act as a liaison to Executive Director (if the ED is not the key contact).
- vii) Prepare a list of resource people available locally if participants wish to access more support following the workshop.

b) Location and Set-up

Location is crucial when doing grief and loss work. The room needs to be large enough for all participants to sit comfortably either at tables or in a semi-circle. They need to be able to see the presenters and each other throughout the workshop. There needs to be enough room for an overhead projector, a flip chart and two or three extra tables - one at the front for the presenters, one or two elsewhere in the room for materials, books and refreshments. If the session will include work with the Resiliency Map, an open area of about 7 square metres (21 square feet) will be required.

Other space needs include:

- comfortable chairs
- convenient storage for coats
- access to an outside area for smoke-breaks

- room needs to be well ventilated, but not with intrusive noise from fans or other heating or air conditioning noises.
- private and quiet, preferably with no agency traffic, phone or other interruptions.
- washrooms need to be close by.

c) Participant Group Assessment

As part of hosting an event, the Retreat Coordinator(s) should schedule a phone meeting with the facilitators prior to the workshop in order to discuss the questions below:

- i) What do you know about the participants individually and generally: connection to ASO, personal and community connections?

- ii) Are there any mental health issues, such as depression or suicide risks?

- iii) What losses to death have they experienced lately (both personally and for community)? How have those been dealt with? What other transitions/changes are occurring in their lives? Anything coming up?

- iv) Have people participated in previous workshops on grief and loss? What was their experience of that? How does this community normally handle death, anticipatory grief or change?
- iv) Any other types of retreats? What seems to work for people in this group: do they like to debate talk? Do they regularly express emotions with one another? Do they play together?

- v) What doesn't work for this group?

- iv) How does this retreat fit into the organizational vision and community development strategy? What follow-up plans are in place?

d) Introduction Session

If a majority of participants have no previous exposure to grief and loss work, then it is useful for an ASO to organize a community forum about AIDS-related multiple loss. It should be held 3-6 weeks prior to the scheduled retreat. There are presentation and discussion materials in Appendix D. If it is possible to have

the retreat facilitators for this event, then this helps people make a safe connection to the more intensive retreat environment. It is also an option for an agency facilitator, i.e. Support Worker or Volunteer Coordinator, to introduce the materials and the retreat in an existing group session.

It is essential that workers do personal outreach to community members to encourage participation.

- ✓ Making contact with agency volunteers who are long-term survivors is key, so that they can extend personal invitations to people who have become isolated or disconnected.
- ✓ Remember to do outreach to board members and consider asking around about previous board members.
- ✓ Having an e-mail version of the poster and registration form makes it easy for friends to pass along the information.

6. 'Survive and Thrive' Retreat Template

a) Two-day Retreat Agenda Outline: DAY ONE & DAY TWO

DAY ONE

- 1. Welcome:** Participants arrive to a full breakfast, an average of 20 participants.
- 2. Check-Ins:** Names and intent for attending this retreat, concerns about the event. Themes from the introductions may include a great fear of "not belonging here" accompanied by a deep desire to be "welcomed in". Expect diversity among these participants and support people finding a way to make room for the differences, in order that everyone can feel they belong in the circle.
- 3. Building the Container:** Introduce the premise of the 'Survive and Thrive' multiple loss work; review housekeeping items and develop Group Guidelines.

Sample 'Survive and Thrive' Group Guidelines

Generated through group discussion, "How can we interact to create a supportive, safe environment? What helps you to participate?":

- Speak in “I” statements, refer to own experience, not we.
- Room to be messy, emotions are okay (get things out).
- Ask before offering support.
- “Generosity of spirit” (non-judgemental attitude), active listening rather than problem-solving
- Confidentiality = personal stories not up for gossip
- Humility and curiosity “allow yourself to be surprised”
- Take care of yourself, physical needs met, let others know if taking a break.
- Right to pass.
- Participate at own level of comfort.
- Room for de-briefing, things to ‘parking lot’.

4. Loss Assessment Component: Explain and distribute the Multiple Loss Assessment Tool (see Appendix B & C) and invite to participants to complete questionnaires. Once completed, participants are asked: “How was it to do this questionnaire?”

5. Presentation of Loss Theory – Single Loss Journey and Interventions and Experience of AIDS-related Multiple Loss This helps to situate participants in their own journey. Also, discuss early loss responses and Common Avoidance Patterns. Provide basic information packages. This is not an easy session- even presenting simple theory about loss can elicit strong, but unfocused reactions in some participants. Be prepared for an emotional ‘explosion’ during this section, where participants may require individual attention to help them stay steady.

6. Key Exercise: Making a Body Map Collage – Depicting the Impact of Multiple Loss. See page 39 for complete exercise information and checklist, have materials already set-up on a side table. Introduce the exercise and ask participants to answer the following question in some visual way:
“Depict the impact of loss- physically, emotionally, mentally, spiritually, socially and sexually.”

Participants will take the remainder of the day to complete these vivid depictions. Those who choose not to create visually are asked to prepare to share their experience in another way for the following day’s group work; these presentations included movement, storytelling and work with the grief cloak.

7. **Round of checkouts** help people to end the day, along with a breathing exercise and brief visualization to help close the big feelings.

DAY TWO (Everyone returns for breakfast.)

1. **Check-In:** “How was your evening? What was your response to beginning to open to the reality of losses yesterday? “. For some, the night may have been a challenge, but this helps to bring insight into what people do when they are faced with the stress of loss.

2. **Collage Presentation:** Facilitator invites participants to tape their collage on a flip chart and to take their time in telling their story - as storytelling is the first task of mourning. Participants were reminded that this might move them to the place of feeling and to be conscious of their patterns of response.

- ❖ How might they be inclined to ‘get in their own way’ by minimizing their emotions through laughter, shallow breathing to avoid emotions, or speaking rapidly, so as to make the story less real?
- ❖ Remind participants that this process is not immediately about change. Clarify that it is an invitation to be aware of their responses, as they reflect on the impact of living with losses.
- ❖ Ask participants, “What got you through the tough times?” when the intensity began to build.
- ❖ Encourage people to become aware of their strategies of resiliency as they speak about their losses.
- ❖ Create room for people to celebrate the gains they had made in their lives, as a result of working with loss for a long while.

Once a participant speaks, questions and comments are invited from others. We traditionally keep these types of reflections for ‘debriefing’ after an exercise, but in this case, we support the spontaneous interaction of the group. This meant people had an opportunity for specific feedback immediately following their disclosure. This seemed to help people ‘settle’ after revealing their loss impact.

Challenge: A key question is asked at the end of each presentation: “What is your **current** challenge?”

This exercise takes the day to complete. The collages reflected both the negative and positive impact of loss and are usually very full.

3. Debriefing is usually short, as offering time for participants to speak after each presentation extends the session. Format for debriefing was maintained:

- ❖ How was it to do this exercise?
- ❖ How was it to speak?
- ❖ How was it to listen to others?
- ❖ Anything to check out with others in the room?

4. Closure to the 2-day retreat: We closed with a breathing/centering exercise to help people reflect on their gains and connections with themselves and one another. We used Angel cards as parting gifts and ended with a round responding to “What are you leaving with and what are you moving onto tonight?” Participants were then given sheets reminding them about the 2 follow-up sessions.

b) Follow-up Sessions

(i) Three-week Follow-up

Hold an evening session for participants, two-three weeks following the retreat. Meet with staff to debrief from the 2-day retreat, review recent events and plan this session. The components included:

- ❖ **Providing a meal for participants followed by Check-in**
- ❖ **Evaluation and Closure Agenda -**

1. ‘Reflections from the 2 days’:

- a) What had you expected?
- b) What was your experience of the 2 days?
- c) What happened for you after?

2. Written Evaluations completed: Participants may fill in the Multiple Loss Assessment again. Workers make follow-up contact with those who were not present and mail out the form.

3. Next Steps and Closure: Participants identify preferred format for future work, which can include: more full-day sessions, continuing with deep work, looking at multiple loss in greater theoretical depth, and/or more focused individual work in order to build on people’s stated “current challenges” and how to move forward in their lives.

(ii) Three-month Follow-up

Participants can fill out the Multiple Loss Assessment for the third time. Facilitate discussion to support participants to reflect on changes and similarities in their perceptions and understandings from the original retreat. The main question for group discussion, “How are you continuing working with your ‘current challenge’?” General structure of the day is similar to the retreat, with specific discussion of any follow-up activities.

7. Co-facilitator Preparation: Retreat Materials and Exercises

a) Key Points

- i) Communicate with the Retreat Coordinator to confirm all logistical arrangements as per 4.a) Host Responsibilities.
- ii) Discuss any parameters around who should participate, specifically related to any mental health concerns.
- iii) From the Participant Group Assessment questions 4.b), develop a sense of what is possible with this group and how that can complement the organization’s overall vision for supporting and developing an on-going community response to AIDS-related multiple loss.
- iv) Consider the staff and board of the local ASO. Check to see if it is possible to do a brief presentation to them on AIDS-related multiple loss. Select relevant materials for the theory section and Appendices to create an information package.
- v) Establish a strong, clear connection with your co-facilitator. It is likely that participants will bring stories involving significant and traumatic loss. Balance yourselves with your current life experiences and your working relationship, including current stressors and support needs. Enjoy yourself and enjoy the participants, remembering that the central process of the retreats revolves around authentic communication.

Within individuals and various communities and cultures, there are layers of distinct strategies of resiliency to cope with ongoing loss. Part of the work of facilitation is to offer participants your observations of their creative and unique grief strategies – however odd some practices may appear, they have an adaptive function that helps mitigate the impact of loss. Your relaxed, open, non judgmental tone can help people become

more curious about why they do what they do and be willing to create even more effective individual and organizational strategies.

vi) Take notes. As co-facilitators, it will be easy for one of you to take notes as the workshop unfolds. Notes should include who was present, their role, the words they use to describe themselves and their losses, comments about coping strategies, how an exercise progressed, particular attention to the range of information in debriefing an exercise, emotional tone and when a room goes 'flat' or feels charged or energized.

b) What to Expect: Notes for Facilitators

Check-in

The retreat begins with a circle 'check-in' forming the basis of introductions for all present. Facilitators at ABPO preface the check-in with a brief overview of 'Survive & Thrive' history; and establish the following guidelines to set the foundation for the safety and security of participants for the duration of the retreat.

Group Guidelines to increase a sense of security and safety

- Confidentiality - "what is said here, stays here."
- Leaving is okay - let facilitators or staff know
- Use "I" statements - "speak from your own experience"
- Use Non-judgmental tone
- Respectful listening; respect emotional space of others
- Ask before touching people
- Room to be "messy" - but not here to attack each other
- Room for differences to emerge- tenderly
- Self-Care – "Ask for what you need"
- Participate at own level- "room to pass during exercises or discussions"
- Facilitators to keep things on track and to help people "land their planes" so the work can progress, allowing all present to contribute.

Multiple Loss Assessment Questionnaire

The completion of the Loss Assessment is voluntary. Whether completed or not, this tool, particularly the 'Tree of Life', facilitates an entry for participants to begin reflecting on personal experiences and the impact of grief and multiple loss

in various aspects of their lives. Facilitators recognized the need for sensitivity with participant responses to the completion of the loss assessment tool. For some this exercise may be the first time they have reflected on their lives in this way and a variety of responses can be anticipated.

The time scheduled for de-briefing the experience of filling in the Loss Assessment is essential. For these times, having a third person on-site in a support role can help with giving one-on-one support to people can use some help in getting grounded in the face of big emotions.

Anticipated Responses

- It was easy and tough- both; mixed emotions throughout
- Sex questions were difficult- as an HIV+ woman, it isn't easy to find sexual partners
- I've lost many friends not necessarily through death but through living in a boarder town where I had to stop seeing people because of government/boarder restrictions
- I've lost friends because I stopped working and don't see them anymore
- I'm not afraid of dying but I'm afraid of getting sick and impact on family/friends
- I'm afraid of looking sick ("don't make me take the ugly drugs")
- HIV is all about loss of lifestyle, identity and an illness that brings poverty
- Faith/Beliefs: need to make spirituality clear...what are you referring to?
- This made me think about things I've never put in front of me before
- It's hard to tell whether or not the things in my life are related to HIV "Is this HIV shit or what?"
- Blame is not simple - I'm mad at others, at my government, at my community
- This gets me in touch with my sorrow and loss and that's rough
- Really liked the 'Tree of Life,' it was easier to work with than all the questions

[Lunch]

Presentation of Loss Theory

The day resumes with the presentation of multiple loss theory in the context of HIV (See Appendix E for materials). In locations where an introduction session was conducted prior to the retreat, facilitators would discern if a brief review was necessary for those present; conduct the review if necessary, and then proceed to the next exercise.

Body Map Collage Exercise and Presentation

Knowing our own experience and accepting the reality of it is considered the first task in mourning. It is very helpful for facilitators to put the question on flipcharts in a couple places in the room. This will help people connect more clearly to the question, “Depict the impact of loss- physically, emotionally, mentally, spiritually, socially and sexually” in their collages. Through being in an environment with other multiple loss survivors, people can open to look at their losses in a new way. Let participants know that on the following day, they will be invited to present their collages. Determine your role in supporting people as they make the collages by traveling around the room. The remainder of the day is spent completing the collages.

[Day 2]

After a brief check-in, participants individually volunteer to tell the ‘story’ associated with their collage. Participants are encouraged to take their time telling their story, with facilitators reminding them that they may come to a place of ‘feeling’ and to be conscious of their patterns of response.

Through this exercise facilitators and individuals can become aware of isolated thought patterns and tendencies to minimize emotions through laughter, shallow breathing or speaking rapidly so as to make the story ‘less real’. There was nothing for participants to change here; this came as an invitation to be aware of their responses as they reflected on the impact of living with losses

We encourage people to become aware of their strategies of resiliency as they speak about their losses. Participants are asked such questions as: “What got you through the tough times?” We also created room for people to celebrate the gains they had made in their lives as a result of working with loss for a long while.

Debrief

The following questions may assist in debrief discussions:

- *How was it to do these exercises?*
- *How was it to speak? (particularly for those speaking with long time acquaintances in the room as well as for those who spoke from a different experience, i.e. HIV- long time frontline worker or volunteer)*
- *How was it to listen to others?*
- *Anything to check-out?”*

- *What do you see as your strategies of resiliency?*
- *What gets you through tough times like these?*
- *What resources do you now have?*
- *What types of coping strategies would you like to add to your repertoire?*
- *How has loss changed you?*

Even with thorough debriefing it may be difficult for people to make meaning of this experience immediately. In many instances, time did not allow for the group to explore these questions in great depth.

Closure

We found that a physical exercise using simple yoga-breathing techniques was helpful to close from the intensity of the experience and to gain grounding. Participants were then encouraged to reflect upon their gains from the experience and the connections with themselves and one another.

We also found that ‘parting-gifts’ were important for participants to take away as a tangible item from the experience. We used Angel Cards [Anna: Do you have an example of this to place in the Appendix?] as parting gifts. We ended with each person responding to:

“What are you leaving with and what are you moving onto tonight?”

Participants were then given take-away materials reminding them about follow-up sessions (if planned) and Support Resources.

Contextual Impact

It is important to note that the retreat weekend does not exist in a vacuum. Individual and global events can impact the retreat in very significant ways. In one of our retreats the morning commenced with the Space Shuttle disappearing. When we later confirmed it had exploded on re-entry into the atmosphere, we stopped the work to include a round of the impact of this disaster on participants.

c) Retreat Materials and Exercises

(i) Reflective Exercises

The Multiple Loss Assessment Questionnaire and qualitative reflection tool ‘Climbing the Tree of Life’ are initially used together; however, they are

presented separately because they work with distinctly, with the Assessment Questionnaire gathering information and beliefs and the 'Tree of Life' opening up emotions and self-perception. From the experience of the pilot retreats, participants requested extra copies of the 'Tree of Life' for use as an ongoing personal check-in. Distribute copies at the end of the retreat for people to take home, supporting them through self-reflection and integration. From a facilitator's perspective, the challenge of utilizing the combined tool is to create a strong container through group guidelines and personal modeling and story-telling that reveals your own struggles with loss and patterns of resiliency.

(ii) Multiple Losses in HIV/AIDS Participant Materials

Through 10 years of work with people infected and affected by AIDS, ABPO has integrated many sources of research into grief, loss, trauma and transition. Various theories have been confirmed and sometimes revised by the lived experience of people impacted by AIDS. A summary of the helpful ideas and models that were presented in Section ONE has been compiled for distribution to participants. In Appendix E, the materials are ready to be copied into a package and also to make overhead transparencies.

(iii) Body Map Collage Exercise

In Appendix F are two versions of the Body Map, one masculine and one feminine, to make copies for participants. The idea for these maps came from the book, "One Day I was Fine...A Book about Grief and AIDS" published in 1995 by the Newfoundland and Labrador AIDS Committee. The primary principle behind working with the visual image of the self is that the impact of multiple loss is more complex and felt than what can be captured in statements. The narrative story of people's experiences gives one perspective, carries the details, but may likely fail to communicate the layers of impact that any given experience might have, given a person's inner terrain of other losses and trauma and current life situation. Another aspect of narratives is that they transport people back in time, whereas the goal of this exercise is to help people to become more aware of what burdens they are currently carrying from their losses.

Materials Check List

- Large strong paper (at least 45 cm/18" square)
- Body Maps in two formats
- Wide variety of Magazines (i.e. POZ , Advocate, assorted glossy)
- Enough scissors and glue sticks for each person
- Craft materials (i.e. markers, sparkles, stickers, stencils, string)

SECTION THREE: Supporting Long-term Survivors within ASOs

8. Recommendations for ASO Support Workers, Volunteer Coordinators and Educators

a) Long-term Survivor Integration Process: Helpful Indicators

Based on the image of the Journey of Multiple Loss on page 17, general thematic areas were used to sort the “Tree of Life” assessment tool data. This provided a model with which to better understand people’s lived experience of multiple loss. Elements of the LTS healing process may include people describing the following states of being:

- ❖ *“Fallen”*
State of detachment from community.
Opening to reconnection to life.
- ❖ *“Struggling to get back on”*
Active involvement towards reconnection.
Opening to healing.
- ❖ *“Exhaustion/fatigue/fragile”*
The physiological and psychological impact of doing healing work.
Opening to change.
- ❖ *“Less able to cope”*
Result of changing coping strategies, a necessary stage.
Opening to new expression.
- ❖ *“On an emotional roller-coaster”*
Opening up to suppressed feelings and personal pain.
Opening to learning of new coping and resiliency strategies.

b) Implications for Support Workers & Volunteer Coordinators

When working with LTS Clients:

- ❑ Maintain awareness of LTS Elements of Healing, making the connections in order to validate and help normalize an individual’s experiences.

- ❑ Improve awareness and familiarity of effective ways to support people as they are changing their personal and community support structures and coping strategies, (i.e. supporting people feeling “stuck”).

- ❑ Recognize that as individuals move through the healing process, a deepening and intensification of feelings and reactions is an expected and natural outcome of multiple loss work.
- ❑ Focus attention on identifying models of support that can strengthen individual's resiliency strategies and help people sustain changes over time.
- ❑ Maintain awareness of the personal impact of multiple loss and stages within the process, considering personal coping strategies, growth, and understanding of individual grief and loss issues.

ABPO has also facilitated several weekend retreats for AIDS Committee of Toronto Volunteer Department targeting volunteers who are impacted by multiple loss and community devastation. Many of the participants who attend these retreats are long-term PHAs who volunteer as part of their health-maintenance strategy. The evaluations of these sessions have indicated an extremely positive impact of normalizing the reality of complicated and ongoing grief. Participants benefit greatly from identifying and hearing from others a broad, varied, albeit sometimes strange, range of coping strategies - these represent creative ways people work through the pain of loss with a determination to make meaning of their sorrow.

c) Implications for Health Promotion and Prevention

Legacy Work: Long-term Survivor Support = Nurturance of Living History

Community, organizational and individual understanding and recognition of the impact of multiple loss in the context of HIV health promotion and prevention strategies:

- Better services to community members through strengthening of loss awareness and addressing the impact AIDS-related grief has on a Long-term Survivor's ability to sustain practices related to health promotion and healthy sexuality
- Creating opportunities for Long-term Survivors to re-invest in themselves and each other
- Addressing the experience of isolation among Long-term Survivors through increased opportunities for community involvement

- Improved appreciation of the role of multiple-loss in depression and integrating strategies of resiliency in programs designed to improve quality of life

Build bridges to members of marginalized communities:

- Peer support is essential to individual's processes of the transformative experience of consciously examining the impact of multiple loss and choosing to expand one's coping strategies.
- Getting Long-term Survivors together to share living histories provides social support and meaningful peer contact, facilitating language and meaning from the pain of past and ongoing losses. This assists people in developing an appreciation of purposeful engagement in the present and for the future.

APPENDICIES

- A. Final Participant Evaluation Report**
- B. Multiple Loss Assessment Questionnaire**
- C. Tree of Life**
- D. Intro Session Participant Materials (Basic Loss Theory)**
- E. Multiple Losses in HIV/AIDS Participant Materials**
- F. Body Map**
- G. 'Survive & Thrive' Retreat Agenda**
- H. 'Survive & Thrive' Retreat Poster and Registration Template**
- I. Retreat Planning Checklist**
- J. Useful Resources**