

PROJECT SUSTAIN

The Basics of Grief and Multiple Loss:
a Training Manual for Workers in
AIDS Service Organizations



AIDS Bereavement Project of Ontario

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Produced by the AIDS Bereavement Project of Ontario

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The views expressed herein are solely those of the authors and do not necessarily reflect the official policy of the Minister of Health Canada.

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This manual is also available in French.

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Forward

The AIDS Bereavement Project of Ontario (ABPO) is pleased to bring you *The Basics of Grief and Multiple Loss: a Training Manual for Workers in AIDS Service Organizations*.

As a resource to assist community-based AIDS service organizations (ASOs) in enhancing their response to loss, change and transition, ABPO has been working for a decade in Ontario. We have gathered much information on the specific bereavement needs and responses of staff and volunteers working in both urban and rural settings. Our evaluations tell us that our interventions and materials provide workers with the individual and organizational supports vital to assist them in maintaining their spirit and resiliency in this tough field. (You can find out more about ABPO in Appendix IV).

In 1999, we were challenged by several key AIDS agencies in other parts of the country to develop a framework to respond to the loss needs of workers in ASOs outside of Ontario. In meeting this challenge, ABPO initiated and sponsored Project Sustain, a 3-year national pilot project designed to quantify and describe the impact of AIDS grief and multiple loss, provide regional comparison of the unique challenges facing ASOs, and identify and help initiate resilient strategies within ASOs in three distinct regional settings: Vancouver, Winnipeg and the Atlantic. Our key question was: 'In relation to loss, death and transitions, what can be changed and added to better support frontline ASO workers in a manner that is locally determined and ongoingly effective?'

Project Sustain staff and Regional Resource People designed and delivered 45 workshops for 350 participants in 20 pilot sites across 3 regions of this country. We trained 14 Regional Resource People and are left with solid data about AIDS-related loss and resiliency. You can read more about the theory, research tools and results of this exciting and inspiring work in the companion document to this *Training Manual: Project Sustain Final Report* prepared by our evaluator, Val Gervais. We are grateful to those who pushed us and worked with us across many regional differences to make Project Sustain come alive. We anticipate further national endeavours as the concepts of worker resiliency, distilled through Project Sustain, continue to be developed by Regional Resource people committed to this work.

This particular Training Manual is a first step in this area. By providing a thoroughly tested 'how-to' manual accompanied by solid, relevant background material on AIDS-related multiple loss, we are hoping ASOs will find it practical to provide their staff and volunteers with a solid orientation to the reality of multiple loss and community work. We believe this basic grounding in loss can serve as a foundation for deeper explorations of stress and resiliency, both within ourselves and our communities.

We see this as an evolving body of work. We are currently developing training materials that incorporate the loss framework described in this Training Manual as the basis for working with the complexities of organizational change and transitions.

And a note of gratitude to all those who live with HIV and AIDS, who teach us every day through their grace, stubbornness and determination, to those who come to work in our community-based ASOs – the work is tough and surprising every day. And to those who have died of AIDS, our commitment to their legacy is at the very heart of all this work. We lean into the pain of loss so their stories can continue to have meaning and their spirits can help us remember to sing with the gift of life.

Yvette Perreault

“ 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

“While we have the gift of life, it seems to me the only tragedy is to allow part of us to die - whether it is our spirit, our creativity or our unique gloriousness.”

Gilda Radner

“When I work with people, I want something that sings for them. And that's enough. It has to be. Lean into the work with curiosity and humility.”

Yvette Perreault

“The manual is the skeleton, the bones. People provide the flesh. The grief is there. We know that. We know certain questions to ask, but then the creativity comes in applying that to a particular group. Every group is different. The differences are what makes it wonderful. ”

Edwin Scherer



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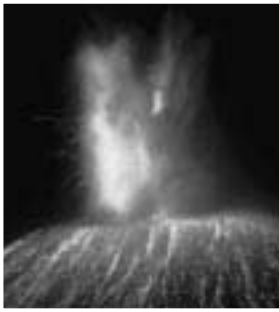


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Introduction

While there seems to be a typical constellation of responses to death, the unique factors associated with AIDS losses increase the complexity of grieving. While some classify this as a pathology, it's seen here more correctly as a normal response to catastrophic events. Our particular grief responses are not a maladaptive reaction to the abnormal stressor of multiple losses and community devastation.

Those grieving around AIDS may show greater amounts of rage, fear, shame and lack of resolution. They may suffer increased feelings of helplessness, loss of intimacy, self-destructive behaviour, insecurity, numbness and pessimism. Please consider, then, these extras: social isolation, stigma, lack of spiritual support, fear of contagion, homophobia, survivor guilt and disenfranchisement (see footnote 1).

If any of this sounds familiar to you, then, the training manual you are holding will be a great relief. It clears a very practical path through the dark and tangled subject of grief and loss. It aims to transform how you are feeling. It will help you bring hope back to the people with whom you work and volunteer.

If you are unfamiliar with Canadian experience of AIDS losses in the 1980's to mid-90's, this manual is a digestible way to absorb our learnings from that time. With the increasing complexity of AIDS, there is a relevance of these perspectives and tools for many facets of the on-going work. These include the constant loss of the known brought on by the illness-related challenges, inconsistent drug-side effects, including sudden deaths, working with marginalized and diverse client populations – all of this compounded by organizational transitions.

Most of our workplaces neglect to deal effectively or even recognize the deep impact of grief, loss and transition on both their paid and unpaid workers. What this amounts to is establishing a brand new occupational hazard. The ability to accompany clients and engage well with community members on their own intense grief journeys is severely limited. (Refer to the useful background article 'AIDS Grief: Out of the Closet and into the Boardroom' in Appendix III).

This manual will equip you to bring basic theory and support to three specific groups at AIDS Service Organizations (ASOs): staff teams, Volunteer Coordinators and their volunteer pool and community workers interested in the impact of loss on AIDS affected communities. The information here can also be more broadly applied to any workplace dealing with a 'death surround,' cycles of loss or constant change. For many, the workshop provided here may be the first validation of and support for the reality of their experience.

Transitions are difficult for everyone. The familiar is past and the new is not yet known. Meanwhile, the present is a limbo or 'neutral zone' where people may not recognize themselves. A shared understanding of the real impact of loss, change and transition is a bridge to recognizing and respecting our essential humanity.

Though this manual will definitely interest individuals, the grief work that organizational groups need to do is best done in groups. Individuals need to do their own grief work, but individuals organize into groups, and a grieving organization is a living organism with different needs and dynamics.

The aim is to maintain the health of both co-workers and workers in the face of multiple loss and anticipatory grief. A healthy ASO will be better able to meet the needs of those using their services, to model strategies for holding steady in the midst of catastrophe and to mobilize affected communities to regain a healthy sense of themselves.

Developed for Project Sustain and drawing on the expertise of the staff of the AIDS Bereavement Project of Ontario (ABPO), each section is designed to be easily implemented, with a clear rationale for the activities recommended and a timeframe for each.

At the heart of this manual is one very flexible workshop. It can be tailored to fit a short [S] (half-day), or long [L] (full-day or two half-day) timeframe. Overheads for each workshop section are included, as well as handouts and worksheets that can be photocopied. The authors highly recommend that the workshop is guided by a team of two facilitators.

This manual is a work in progress. The format will allow you to load in more information as it's provided. ABPO staff are continually striving to improve the quality of our work with ASOs. We cannot do this without your help. We will greatly appreciate any feedback you have for us about the manual, especially as to format, clarity and ease of use.

The AIDS Bereavement Project of Ontario wishes to thank the AIDS Community Action Program of the HIV/AIDS Division of Health Canada. Your generous support/funding has made this manual possible.

For more information about the history and evolution of Project Sustain and details of the AIDS Bereavement Project of Ontario, please refer to the companion document: *Project Sustain Final Report*.

Footnote 1: The term 'disenfranchised grief' deserves some clarification. It refers to grieving that doesn't have the supports the general population usually offers, e.g. a relationship may not be recognized, the loss may not be acknowledged and society does not give the grieving person the role of mourner. This may mean that loved ones are barred from the hospital room, or AIDS doesn't get mentioned at the funeral.

Perhaps the best advice for coping with grief that's not validated and supported comes from philosopher Albert Camus. After the loss of his close friend, the poet Andre Gide, Camus said, 'Those deprived of grace simply have to practice generosity among themselves.'