Ask the Experts: Learning to Live with Grief

Yvette Perreault explores the impact of HIV-related loss and what helps survivors through their sorrow.

Just as AIDS has challenged us to rethink much about individual and community health, so too has it expanded our understanding of grief. For those of us who are long-term survivors and those of us who have been connected to communities ravaged by AIDS, we may know multiple losses.

While there seem to be certain common responses to death, there are also unique factors associated with HIV-related deaths. The impacts of stigma and discrimination, disenfranchisement, lack of spiritual support, fear of contagion, multiple losses, illness-related complications and survivor guilt are tremendous.

In our grief, those of us who survive may feel a greater than usual amount of rage, fear, shame, unresolved grief, guilt, helplessness, insecurity, numbness and pessimism. We may be more likely to experience a loss of intimacy. We may develop new physical symptoms or those we already have may worsen. For some of us, grief can affect our will to stay healthy—we may lose the motivation to adhere to HIV treatment and take care of ourselves. To some, these reactions might be viewed as “symptoms” that signal pathology, but they can also be seen as normal responses to catastrophic events.

At the same time, there are many stories of incredible resilience—of people who are transformed by their loss yet remain steadfast in their determination to continue to love and courageously engage with community. This, too, is part of the legacy of AIDS-related grief.

According to the Public Health Agency of Canada, 76,275 people in Canada have tested positive for HIV since 1985. And, yes, many are doing just fine. But we also know that at least 14,030 Canadians have reportedly died of AIDS-related causes. And there are others in our communities of people living with HIV who have died from other causes—such as cancer, heart attacks, organ failure and overdoses. With each death, a network of family, friends, colleagues and healthcare providers is left behind to grapple with the impact of loss. Many of us find ourselves immersed in what feels like unending waves of loss. This becomes our new normal: We are challenged to live and cope with our loss, with our altered hopes and dreams.
I asked four people with both professional expertise and lived experience to offer their thoughts on grief and grief support. These individuals know a lot about life and loss—and, I believe, about love.

**Al McNutt**

HIV+: 27 years, Chair of the board, AIDS Coalition of Nova Scotia
Truro, NS

When my partner Gary died 21 years ago, I felt guilty that I was still alive. And I still do. I can tell you exactly what he did before he died. There was a poster from *Longtime Companion* (a movie about the early years of the AIDS epidemic) on the wall, showing a scene where everyone reunites at the end. Gary and I had talked about that scene, about how when he died, everyone in his life would be reunited—his mother, me, Rob and Doug, Ralph and Ian, and his ex-partner John. (From the four couples who spent a lot of time together, I’m the only one left.) Before Gary took his last breath, he looked at me and smiled, touched my cheek, touched the poster, and then stopped breathing.

Initially I didn’t feel worthy and took unnecessary risks because I didn’t think I mattered. But then I realized that I had to stay healthy to contribute to society. I decided not to give up. Many of us already feel so beat up and are dealing with lots of pain in our lives, but we have to find our own unique ways of moving beyond that pain.

I have to love HIV in order to love myself. It’s part of me now. We have to co-exist. It’s no longer a loss but an opportunity to live in a fuller, more meaningful way. Life is too short to be dragged down by it all.

As people living with HIV, we have so much to offer. My advice is: Try to step out and face the world head on. Be yourself. Speak out. Your story is valuable. People will listen. Try not to stay in a place of fear. We need you to become the advocates of tomorrow.

Spend time with your photo albums and journals—and keep your vodka and orange juice handy! I have a video of Gary and me line-dancing that I replay, that still makes me cry. I know that pain can stop us from looking back, but the more you visit your story, the more crying you can do and the easier it becomes to remember. Crying is good therapy. It’s important to think about our relationships and who we were in those relationships. What we shared with our loved ones matters.

I have Gary’s urn on the mantle in my office, so I see him every day, along with my dad’s urn and my sister Bonnie’s, who died 40 years ago of cancer. Sometimes I look at the stars and wonder if my dad is up there and whether he’s found Gary and Bonnie. Pain can be unbearable but facing it gives us our own teachable moments, our own therapy. Talk is also good therapy. We’re not so alone in our grief if we can share our stories.

As far as my own death goes, I’m not afraid of dying but I worry about leaving my kids (even though they’re now 30 and 34). When they ask, “What are we going to do without you?” I tell them: “Get on with your lives. Carve out your niche in the world. Take on your own advocacy pieces. Never forget the wonderful moments we shared—the hugs, the stories, the laughter…. Those memories are going to keep you going through the hard periods. When my time comes, rejoice in the fact that I’ve had a wonderful journey.”

**Dr. Alejandro Peralta**

Counsellor, Dr. Peter Centre
Vancouver

I have seen people deal with grief as they live with chronic health challenges and deal with losing loved ones. We learn to deal with loss with the inner capacities, strengths and resilience that we have. Each person has to develop their own grief strategy.

I learned Elizabeth Kübler-Ross’ five stages of grief—denial, anger, bargaining, depression and acceptance—but in life, the process isn’t linear (nor did Kübler-Ross intend them to be). Whereas my psychotherapy training followed a more classic disease model (crisis intervention and providing support for a brief period, to reach a specific goal), I’ve learned to focus on where a person is in this moment and help them develop strategies from that place.

At the Dr. Peter Centre, we consciously create community. Giving and getting support is an important part of
people’s mental health. Professionals and community members alike build relationships and trust. We meet people where they are and accept where they are. We spend time together on a daily basis. We establish stability and work from there. We aren’t about “interventions” in a traditional sense. These shared aspects of daily living are our “interventions.” In this way, relating to your counsellor is not outside of people’s day-to-day experience. I go to them, they don’t come to me.

Depression is an aspect of grief, and I believe it is part of people’s resilience. Losses are something people have to live with and depression is an integral part of letting go. Although doctors sometimes prescribe medications to people who are grieving, I believe that people have to go through this part of the process to get to the crux of their unique situation. People have to relate to all aspects of their physical, emotional, mental and spiritual parts to be well.

Our clinical team gets together at the beginning and end of each day. We discuss the issues that arise and how we are doing. Many of us have a spiritual practice, such as meditation. I practice yoga and Buddhism (even though I was born Catholic) and try not to get stuck in the material world. I lost my mother 20 years ago. You have to live through these losses. I’m concerned that we don’t allow ourselves to go through these times with awareness.

I understand my role is to provide companionship to the person I’m lucky to meet. Through that, I, too, mature as a person. My skills and tools are not just my knowledge but my presence, my ability to empathize. As I lend you my strength, I need to keep building my own.

Wayne Fitton

HIV+: 1988, Consultant and ABRPO (AIDS Bereavement and Resiliency Program of Ontario) facilitator
London, Ontario

Grief was a reality for me even before AIDS hit my community. My younger sister died of throat cancer in 1983. I was her primary caregiver for six months after her tongue and the tumour in her neck were removed. I loved her, so I managed my fear and horror. That’s when I saw death for the first time. That experience set me up for the waves of AIDS-related deaths that followed.

In 1985, my best friend John was diagnosed with AIDS. He died nine months later. He was sensitive to the fact that my sister had just died but he needed help. He asked me to set up a care team for him, which I did. As he was dying, he said, “You’re good at this, Wayne, and there’s going to be a lot more caretaking to do in the community, so three months after I die, I want you to volunteer for a new group starting up, the AIDS Committee of Toronto.” So I did.

A year to the day after John died, my friend Barry took his last breath. And on it went for a decade until antiretrovirals came in.

How did I go from supporting one dying person to the other? I was not afraid to be with the dying. I stayed in my authentic relationship with people as they changed—it was still Karen, it was still John, it was still Barry... My tribe was dying and I had to step in. I could do this because I didn’t stay alone. I found places where I could talk and be real. Once I joined the staff at the Toronto People with AIDS Foundation (PWA) and then the AIDS Committee of Toronto (ACT), we had each other as witnesses, we were people “who got it,” who knew what it was like in the trenches.

In 1991 I looked at ACT’s AIDS stats. We said goodbye to 147 clients that year—15 of whom were my clients. That same year, I also said goodbye to a lover and to my dad. And there was more loss to come. Richard, who was my coworker and became like a younger brother, died. When I was at his funeral crying, I wasn’t even sure my tears were for the guy in the casket. That’s when I learned that new loss resurrects old losses.

We took time to say goodbye and to go to memorials. We stopped and recognized the presence of death. We created spaces to tell our stories. We learned about sudden temporary upsurges of grief [see “STUG,” below] and respected the power of a grief hit. I longed for a day when I wouldn’t be dealing with grief. But that didn’t happen. So I became an expert at this thing called grief. Death and grief are now a part of who I am every day.

A STUG (sudden temporary upsurge of grief) often occurs at significant times, such as anniversaries, when feelings of grief return with an intensity that surprises people. These upsurges of grief don’t usually last as long as the first experience of a “grief hit” and individuals often learn to manage their memories and feelings.

I appreciate that I am living with loss. I will never “get over it.” Grief has become an active part of my identity, not
something to recover from. I claim grief as a link to those I've loved and lost. I am not sick or crazy. I honour my grief because I cared about these people.

What has helped me along the way? Theory and language to locate myself have been crucial. Words and concepts to describe what I'm experiencing in my heart and body validate my experiences. I have found ways to express my fear, sadness and rage so I'm not carrying the emotional pain in my body. If I did not attend to my grief in a sustained way, I would have gotten sick.

Long-term survivors like me who lived through the '80s and '90s and watched our worlds implode don’t do well in isolation. Many of us are in shock about still being alive, and we need to process our stored-up grief; otherwise it gets in the way. To maintain my health, I need to connect with a network of people who are willing to sit down and explore what our grief looks like.

Develop your own healing process. Find people who can listen and validate you. Don’t spend time talking with people who try to “fix you.” I continue to do my personal work so I can sit well with others. Newly bereaved people need healthy role models and mentors more than they need therapy.

**Betty Ann Rutledge**

Volunteer Outreach and Training, Scarborough Centre for Healthy Communities, Palliative Care Toronto

I started doing grief work shortly after Sept 11, 2001—the day much of the world was grieving. And I started doing AIDS work, including facilitating a weekly support group, the year my best friend Ted died of AIDS and my mother died of cancer. Oh, I know grief. I’m only 48, but I’ve had as much loss as an 80-year-old.

I know that grief occupies every level of my being: physical, emotional, mental, spiritual, social and sexual. I know that there are times when I am in a “hit of grief” and it seems like I will always feel this way. Even though I feel like I’m going crazy, I’m not. This is normal for me. My grief and how I manage it are uniquely mine.

Grief can feel unbearable. It’s like being parachuted into a foreign land with no map, compass, language facility or tools to navigate a relentlessly complex terrain. As bereaved people, we are charged with the monumental task of trying to figure out the “new normal” of our lives. Many of us have felt that we wouldn’t survive our losses, but we have.

Fresh grief is so unimaginably painful that we immediately respond by throwing up a blanket of protective denial. That blanket can hang around for days, weeks, months or years. Even when the veil begins to dissipate, it can return when the pain becomes too much to bear.

Early grief may look something like this:

- You wake up in the morning and for those first few fuzzy moments of consciousness, you forget. Then you remember, “They really are gone.”
- Moments of intense fear and panic—“I can’t survive this.”
- Deep lethargy and lack of motivation—simply crawling out of bed and brushing your teeth can seem like a huge, and some days impossible, task.
- Confusion, frustration, anger.
- Sadness and unbearable pain.

How we deal with these thoughts and feelings are as unique as the grief itself. Some people throw themselves into work, a project or an activity. People who, in the immediate aftermath of a loss, create a memorial website, start a foundation, write a book or train for a marathon are sometimes described as *instrumental griever*. Then there are those of us who tend to experience grief most intensely on a feeling level—sometimes referred to as *intuitive griever*. In those early days, many of us feel badly that we are so unable to participate in the world in any kind of “normal” and “acceptable” way (and fear that we will never be able to again), that we may withdraw into ourselves and retreat from a world that is so out of sync with the state we are in. I know how hard it is to resist that tendency to isolate and how vital it is to try to reach out to something, someone, anything that will keep us remotely connected to life.
If you are a multiple loss survivor, the good news is that we know we can survive this, because we have survived it before. (The bad news is that we also know just how bad it can get and how deep that pit of grief is that we must fall into, swim around in and then slowly crawl out of).

Whether this is your first significant loss or not, nothing can prepare you for the swirling mass of chaos that losing someone you love throws you into.

But there is hope. I believe that we all carry within ourselves the capacity to heal. But there is no recipe for healing, no 10 steps to “get over” your grief. (And, by the way, I never want to “get over” losing any of my loved ones! I simply want to find a way to keep honouring the deep love and connection we shared, the gifts given and received, in a way that helps lift the thousand-pound weight from my heart.)

The gift of healing can come in small and often surprising ways: a phone call, an email, someone unexpectedly reaching out to say, “I am here for you”; a song, a quote, a smell, a gentle reminder that they are still with me, watching over me; the comfort of being able to share my true self with someone who really “gets it” and gets me; the look in someone’s eye who has travelled this road and knows the journey is a lifelong one but is willing and able to walk with me for a stretch of time.

I would have chosen to learn these lessons any other way, but there it is and here I am. And amazingly, I feel like a better, stronger person. In my quietest moments, I can hear the sound of my heart slowly and persistently repairing itself around the hole of loss that is now a part of me forever.

There is no formula that works for everyone. But we do know that some things help us learn to live with grief:

- **Take it one day at a time**—and some days, one moment at a time.
- **Connect with people** who understand what you’re going through.
- **Get information about grief**, so you know that what is happening to you is a normal, natural response to your loss.
- **Focus on simple things**—like breathing in and out.
- **Move**—even a little bit. Walk, stretch, try to stay in your body.
- **Eat healthfully**—and forgive yourself when all you can do is eat chocolate.
- **Connect with what gives you hope**—for example, nature, meditating, praying or joining religious services. Or seek the support of a spiritual leader.
- **Honour the way in which grief moves through you**.—If you are a physical person, perhaps dancing or running will soothe you. If you are a creative person, drumming or drawing might comfort you.

Every day will be different. Every moment will bring a new challenge. But with the right support, information, space and time, you will live into this new reality. You will not be the same as you were before your loved one died, but it won’t always feel as awful as it does in this moment.

Yvette Perreault is director of the [AIDS Bereavement and Resiliency Program of Ontario](http://www.ontario.ca/content/dam/ontario/programs/aids-bereavement-resiliency-program网页).
Disclaimer

Decisions about particular medical treatments should always be made in consultation with a qualified medical practitioner knowledgeable about HIV- and hepatitis C-related illness and the treatments in question.

CATIE provides information resources to help people living with HIV and/or hepatitis C who wish to manage their own health care in partnership with their care providers. Information accessed through or published or provided by CATIE, however, is not to be considered medical advice. We do not recommend or advocate particular treatments and we urge users to consult as broad a range of sources as possible. We strongly urge users to consult with a qualified medical practitioner prior to undertaking any decision, use or action of a medical nature.

CATIE endeavours to provide the most up-to-date and accurate information at the time of publication. However, information changes and users are encouraged to ensure they have the most current information. Users relying solely on this information do so entirely at their own risk. Neither CATIE nor any of its partners or funders, nor any of their employees, directors, officers or volunteers may be held liable for damages of any kind that may result from the use or misuse of any such information. Any opinions expressed herein or in any article or publication accessed or published or provided by CATIE may not reflect the policies or opinions of CATIE or any partners or funders.

Information on safer drug use is presented as a public health service to help people make healthier choices to reduce the spread of HIV, viral hepatitis and other infections. It is not intended to encourage or promote the use or possession of illegal drugs.

Permission to Reproduce

This document is copyrighted. It may be reprinted and distributed in its entirety for non-commercial purposes without prior permission, but permission must be obtained to edit its content. The following credit must appear on any reprint: This information was provided by CATIE (the Canadian AIDS Treatment Information Exchange). For more information, contact CATIE at 1.800.263.1638.

© CATIE

Production of this content has been made possible through a financial contribution from the Public Health Agency of Canada.

Available online at: