



Converting loss into language

Deborah Golden Alecson MS Special Education

Adjunct Instructor, Excelsior College

DAlecson@msn.com

Deborah Golden Alecson MS is a thanatologist who teaches at Excelsior College in Albany, New York. In this article she talks about how writing and poetry have helped her survive multiple losses. Deborah is the author of *Complicated grief: a collection of poems*, *We are so lightly here: a story about conscious dying*, and *Lost lullaby*, and the recipient of The Washington Irving Book Award for nonfiction in 1997. Her website is www.deborahgoldenalecson.com.

I am a seasoned griever having withstood the blows of three singular losses. The dead grandparents, great-aunts and uncles, pets – these losses were wrenching but nothing like the triad I am about to describe.

Multiple losses

The first loss was the brief life of my newborn, Andrea, who was pulled from my womb via c-section after having sustained oxygen deprivation during a Pitocin-induced labor. My perfect pregnancy in 1989, culminated in a crisis and what did her in was medical malpractice. Her two months of life were maintained in an isolette in a neonatal intensive care unit. She looked like a giant compared to all the other babies, most of whom were premature. In the beginning, she was on a ventilator while needing artificial nutrition and hydration through a naso-gastric tube. She did not have and would never have a suck reflex. There was uncertainty as to whether she was in a PVS or a coma but in either case, her brain was irreversibly damaged. After all the brain scans were done and the meetings with the doctors, it was pretty clear that should she live her existence would be minimal, in fact, she would only be existing. This is when things became unprecedented at the hospital. After enormous soul searching, my husband and I wanted her to be allowed to die; this meant taking away all life support. There was a window with the ventilator, but she was soon able to breathe on her own. We

requested that the hospital stop feeding her. We were assured by the nurses that she would slip into death with no discomfort. I will not give away what happened here. Suffice it to say that it is a most horrid place to be – advocating for the death of your precious baby.

Twelve years later, my seemingly healthy husband, Lowell, at the age of fifty-two got sick to his stomach. It wasn't a virus, it was pancreatic cancer that had metastasised throughout his digestive organs. Literally the moment he awoke from exploratory surgery the surgeon told us that he had two months to live. With that shattering prognosis, we proceeded to live nine of the fullest months of our marriage. Lowell was the choral director and acting teacher at Scarsdale High School in Westchester, New York and we knew practically no one in the community who had died from so deadly a disease at such a young age. During this time, our son was nine going on ten. (Our boy, Sky, was conceived the Christmas Day after Andrea's death.) In hindsight, I see these nine months resembling trimesters that lead to birth. The first trimester was denial and chemotherapy, though I knew without a doubt that it was futile treatment. The second trimester was a shift to palliative care and signing on with hospice. The last trimester was a time for accomplishing his goals, redefining hope, and accepting his imminent death. Lowell was able to conduct his concert choirs in a standing-room-only concert at the High School six weeks before he died. On 28 January 2001 Lowell died at home.

The most recent shock to my system was my eighty-five year old mother's suicide. What made this grief even more complicated was that she was also an abusive parent. In 2012, I was planning to move to the town in which she lived to be closer to her even though we had a rocky relationship. As I put my house on the market she decided to move across the continent. She had a neuropathy that was in fact genetic in origin but she refused to accept this; and instead, she became convinced that the exquisite weather in San Diego, California would cure all her ailments. She knew no one there and had never been there. I knew that her impulsive decision was one of a deranged mind but the fact that she indeed pulled off the move would indicate competency. We barely communicated during the months she was in San Diego living in an independent facility. She had accused me of bizarre behaviors including seducing her second husband when I was a teenager. She became increasingly reclusive and once her house sold back East, she devoted herself to putting her affairs in order. Responding to her wish to see me and my son, we decided to visit her in September for her birthday. She of course knew that we were coming out and while we made plans to do so, she made plans to kill herself. Flawlessly, she pulled it off on 6 August 2013 by swallowing a lethal dose of prescribed medications. When my son and I arrived at her apartment to clear her stuff out, we found her goodbye notes, stamped and addressed for me to mail, and pages of yellow lined paper with instructions about her sources of income, bank account numbers, contact information, people to notify, etc. On the nightstand by her bed she had hand-written the following:

"Seer,

Give us each our own death,
the dying that proceeds
from each of our lives:
the way we lived,
the meanings we made,
our needs."

Ramier Maria Rilke

And, in an almost empty refrigerator, there was a bottle of cheap pink champagne that my son and I opened immediately.

Surviving loss

How have I survived such cumulative loss (and this doesn't including what's yet to come: my aging and dying)? Each triggered a spiritual emergency in which I fully immersed myself, and I was able to convert my grief, pain and despair into prose and poetry. I was born with the gift of written expression and it has been my buoy for the sea of turbulence that has been my life. I also was advised by a brilliant therapist with whom I went into serious psychoanalysis in my early twenties to keep a journal and write every day. I do.

Lost lullaby is a book about my daughter's brief life and the ethical, legal and social issues that compounded our attempts to

do the right thing for her. Up until this book, I was writing a great deal of poetry, dabbling in fiction short stories, and I ran a reading series for writers of prose and poetry in a cafe in Park Slope, Brooklyn. My identity as a writer, up until my daughter's birth, was hinged on getting recognition as an artist. It was for me an exalted identity to have. Except for my miserable childhood and existential angst, I had nothing of great importance to share with the world at large.

Soon after Andrea died, I knew I had an important story to tell and my doubts were whether or not I was a good enough writer to do it and her justice. I was fortunate to have found an agent who believed in the book so I persevered. I also was invited to the Hastings Center as a fellow to do research. This was my major introduction to the world of medical ethics. While in the basement of the Hastings Center, after having felt nauseous for several days, I learned that I was pregnant with my son.

I was fueled by a great deal of anger and indignation when I wrote *Lost lullaby* during the first year of my son's life. Though I now understand that there were prior and current legal cases to consider, specifically the Terri Schiavo case (BBC News, 2005) at the time I didn't understand why our request for her to be allowed to die was not granted. A great deal of my grief was converted into exposing the hypocrisy of surrogate decision making. It also helped that I had a healthy and vibrant son to care for, born in the same hospital where thirteen months earlier Andrea had died. *Lost lullaby* was the recipient of The Washington Irving Book Award given by the Westchester Library Association in 1997. It also fell into the hands of a couple in California who were going through an almost identical situation with their brain-damaged newborn. The book was read by the family members as well as the doctors in the neonatal intensive care unit and the parents' wishes were acted upon.

This is a poem included in the book at the end of the chapter I entitled 'Loss of Hope.'

For Lowell

Our love fused in my womb grew
as microscopic matter and
the imaginings of our minds.

First months like motion sickness
followed by calm
then helium belly that bulged
with creature kicks
until the being had a sex, then name,
and we called her Andrea.

We prepared her place on earth:
toys shelved in greeting,
drawers filled with soon-to-be belongings,
an empty cradle rocked in anticipation.

We labored for two days
and still she couldn't budge,
stuck in the canal facing
her own peculiar direction.

An emergency too late
pulled her blue from my body.

Our little girl lies silent
staring in a place we never prepared,
with a tube threaded through her throat
to keep her alive when dead to the world.

The following poem was included in the chapter I entitled
'Despair.'

For Andrea

Even before I felt the kindling of life
flutter in my belly, I knew your presence
as a vision of cells separating into being.

I loved the thought of you: your beginning,
sacred genetic intermingling:
mommy's eyes and daddy's mouth,
generations of traits transformed in utero.

then came subtle shoves of limbs
flexing through ribs,
occasional hiccups, then feet
protruding with fists through my skin.

You were a person to me.

My darling little girl,
I am dumb to explain your fate,
powerless to stop what you've become:
gone from your body
that breathes to feign life.

You are an innocent
with a soul like a halo
that encircles and waits
to merge with your body.

I so wanted you, baby,
to love and hold
feeding from my breasts.

Now all I want
is your corporeal death.

We are so lightly here: a story about conscious dying was self-published nine years after Lowell's death. I had showed it to my first agent who, by the way, racked up glowing rejections from all the major publishers for *Lost Lullaby* (I got the book on my own to the University of California Press) and she said the topic was not hot. She couldn't imagine there being an audience. The writing of the book was cathartic and I relied on my journal notes. I purged. I sobbed. I wrestled with the right words. I wrote the book because I am a writer, but more importantly because Lowell is a role model for dying well. The book is almost a guide.

My most recent book, *Complicated grief: a collection of poems* written after my mother's suicide is a whole other animal. The day after my son went back to college, and I was teaching the subjects of physician-assisted suicide and euthanasia for my Ethics of Health Care course, I fell apart. I had kept it together for about a month, attending to my mother's affairs as so many of us have done. The rug was completely pulled out from under me. I couldn't concentrate to teach and took a leave of absence. I sought therapeutic help and began churning out poems while sitting hour after hour before the flame of a single candle in disbelief, grief, anger and shame. What I was not prepared for was the chucking up of childhood memories – the reliving of the abuse in my mother's hands. My estranged extended family was even more estranged and many people who were in my circle at the time did not understand what I was going through. They thought I should be relieved or something. It was bleak and I wallowed in the muck pushing out poems when I was able to get up off the couch and sit before my computer. And of course, all the other losses surfaced. While writing the poems, I did consider whether or not they would be good enough for publication. The one book that helped me cope was given to me by my therapist, *Your turn for care: surviving the aging and death of the adults who harmed you* (Brown, 2012). Laura Brown's book was revelatory in helping me understand my grief process and I felt even in the thick of it that I wanted to help others. Here's a poem that I wrote on 2 December 2013.

My Mother's Suicide - Number Two

it's a whimpering grief
not one of convulsions
it limps along
it doesn't wail
or moan
it's an atmosphere
of dim light and murmurs
it doesn't shred the heart
but there is some bleeding
in sleep it invades
I am lost or in danger
then mornings of long transitions
breathing deeply beneath the covers
it's a grief that is compared
to all the other griefs

no cries to God
 no angry gestations
 just sitting on the couch
 beseeching the flame
 of a single candlestick
 it's a low grade fever grief
 that feeds on childhood memories
 that reel through
 as I watch the quivering
 dot of light
 in my darkened living-room
 there is no retching separation
 or incomprehensible loss
 of a source of love
 there is emptiness
 stretching back to my birth
 a smoldering grief
 no 'why me'
 but a steady red heat
 beneath who I am
 and will become

As fate would have it, my professional life mirrors my personal one. However, my original calling, that of a writer, serves both. I went from being an autism specialist to a thanatologist, getting through the door via medical ethics after *Lost lullaby* was published. My BA degree is in philosophy with a concentration in ethics so my attraction to the study of moral principles preceded *Lost lullaby*.

I live each day as if the absolute worse thing that could happen can happen to me. I am not exempt. Life has taught me this. I live each day with the hope that it is a good day to die. And if it isn't, I ask myself why not and what still needs my attention.

How Do Normal People Do It?

how do normal people do it
 casket and funeral home
 lines of chairs to be filled
 rabbi leading services
 prayers
 candles lit
 the comforting of one another
 accolades, praise
 silly stories
 sudden gasps
 one's mother/sister/friend is dead
 feeling grateful for one's childhood
 being gathered in this net

 moving as one to the burial site
 together in the absence
 the pain of the loss

lowering her into the grave
 pebbles tossed
 not our way
 no gentle into that good night
 rather you taking your life
 police and the medical examiner
 official reports
 counting the pills left in a bottle
 delays on the certificate of death
 pending more evidence

then the shell shocked gathering
 of relatives at risk
 a lost collection
 of denial and guilt
 the package of ashes
 the instructions you left

ours is a family of broken branches
 scattered beneath a leafless tree

To conclude

To conclude, it was a high school English teacher who was the first to praise a poem that I had written and that poem was one stanza that expressed how utterly alone and anguished I felt. My father had authored a couple of nonfiction books and my step-mother was an award winning journalist in New York City. I grew up watching people write. All three of my parents appreciated art in its myriad manifestations. In my mother's home, I heard Miles Davis and in my father's, Puccini. My father, also an artist, worshiped Rembrandt and my mother, Picasso. I was a reader and sought out literature that gave me a connection to a larger life and that affirmed my range of emotion.

As I mentioned earlier, the greatest influence on me as a budding writer was my psychotherapist Dr Robert Melniker (now deceased) who told me that I was a born writer: feedback that was essential for my fragile self-esteem.

Writing is my method of making sense of life and since my life has included such staggering losses, I have been able to convert the pain through written expression, and then let it go. ■

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