



### *Unending Gratitude:*

A compilation zine is made by a community of writers and thinkers. This zine has benefited from a core of daring, witty, and committed authors whose attempts to publicly articulate their lives are truly humbling. Additionally, this project has survived the past 2 years thanks to the tremendous amount of emotional, creative and financial support offered by my friends and family. Every time I fell down one of you was there to pull me up again. You have made the word "community" feel real.

Lauren Denitzio, Cynthia Schemmer, Joe Carroll, Kate Wadkins, Jordan Wishner, Rachel Rubino, Ben Holtzman, Erica Dunkle, Justin Arocho, Jodi Tilton, Jeff Cunningham, Jessy LaHood, Roz Hunter, Sarah Hanks, AEH, John & Mary, Maria Arettines, Kathe Karlson, Mariln Arias, Bunka Choi, Bryan Winston, Jared Santiago, Nevada M., Amanda Bross, Phil Schappert, Mom, Joe, Pat & Ian, Abacus One. Dad.



# The Worst

**COMPILATION ZINE ON  
GRIEF AND LOSS  
ISSUE 2**



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## BOOKS ABOUT GRIEF AND LOSS

Grieving Mindfully: A Compassionate and Spiritual Guide to Coping with Loss by Sameet Kumar, Ph.D.  
 The Mercy Papers: A Memoir of 3 Weeks by Robin Romm  
 Aftershock: Confronting Trauma in a Violent World, A Guide for Activists and Their Allies by Patrice Jones  
 The Body Remembers: The Psychophysiology of Trauma and Trauma Treatment by Babette Rothschild  
 Trauma and Recovery: The Aftermath of Violence from Domestic Abuse to Political Terror by Judith Herman

## ONLINE RESOURCES

.pdf file of the first issue of The Worst: <http://zinelibrary.info/worst>  
 The Sent(A)Mental Project--A Memorial to GLBTIQA Suicides: <http://sentamentalstudios.weebly.com/sam-project.html>  
 Expressive Arts for Grieving People: <http://expressive-arts.blogspot.com>  
 The Icarus Project Radical mental health supports: <http://theicarusproject.net/>  
 Geppetta Puppet Theater; Fables exploring depression, grief, self-harm, trauma & suicide: <http://geppetta.weebly.com/hear-them-howling.html>  
 The Ghost Bikes Project <http://www.ghostbikes.org/>

## RELATED PROJECTS

SICK: A Compilation Zine on Physical Illness by Ben Holtzman  
 The Revolution Starts at Home: Confronting Partner Violence in Activist Communities by INCITE! Women of Color Against Violence; [http://incite-national.org/media/docs/0985\\_revolution-starts-at-home.pdf](http://incite-national.org/media/docs/0985_revolution-starts-at-home.pdf)  
 Support by Cindy Crabb; a zine about supporting people who have been sexually abused  
 Friends Make the Best Medicine by the Icarus Project; on creating community mental health support networks  
 Counterbalance by Kristi; a zine about activist burnout and support  
 When Language Runs Dry, Issues 1 & 2 by Claire and Meredith, about chronic pain  
 Scarsongs a forthcoming trauma reader compiled by the Icarus Project



## RESOURCES AND CONTACT:

THEWORSTZINE@GMAIL.COM  
<http://theworstcompzine.blogspot.com/>  
<http://www.myspace.com/theworstcompilationzine>

## OTHER ZINES ABOUT GRIEF AND LOSS

**MOST AVAILABLE THROUGH STRANGERDANGERDISTRO.COM**

**DORISDORISDORIS.COM, OR CLICKCLACKDISTRO.COM**

**Baby Girl #7 and #8:** Lindsey discusses her mother's illness and death from cancer.

**Dad:** Timothy discusses the death of his father and its impact on his identity and sense of family history.

**Habits of Being #1:** Cynthia documents the struggles of herself and several other womyn to overcome loss and other life obstacles.

**I Dreamed I Was Assertive #11:** Celia writes about what it was like to go through her father's things after he died.

**Introvert #6:** About how Nicole dealt with the death of her 4 month old nephew to SIDS.

**Love Letters to Monsters:** Ciara talks about losing her father.

**Mutant Superpowers and Lithium Pills: Bipolar Adventure Stories:** Sascha Scatter has some really beautiful writing in here about losing his father.

**Vena Cava #5 and #6:** Patsy explores the death of her father from surgical complications.

**What I Saw From Where I Stood:** Eva talks about losing her friend Meg in a bus accident, and how her community responded to the loss.

**You Live for the Fight When That's All That You've Got:** more from Ciara, more intensive coverage of the death of her father.

## INTRODUCTION

The first issue of "The Worst" came out in the spring of 2008. For me, it was like someone had turned on a switch that illuminated a new network of people, stories, and supports, which grew more densely populated every month as the distribution spread.

It has been amazing for me to see the ways in which people have used the zine as a way to tell their stories: reading out loud in public or around the dinner table, giving the zine as a gift to family or friends to break the seal on complex or painful communications, and inspiring people to put pen to paper themselves. There seems to be something irreplaceable about the sharing and speaking of life experiences among those traveling similar paths. Grieving can feel particularly maddening at times, and even more so when you have no reassurance that others also feel as lost and confused as you do.

Confronting the world and my daily life in this capitalist society with a grief zine has also served to illuminate many reminders of why I was compelled to create The Worst in the first place. The years since the publication of the first issue have been fraught with the same reiterations of capitalism's devaluation of human life and concurrent denial of our need to grieve for these losses. We have witnessed capitalist democratic government's choice to sustain economic markets rather than people with the federal bailout of private lending corporations despite the massive foreclosures and homelessness that resulted from unsustainable and greedy corporate practices. Our tax money still funds the mass destruction and murder perpetrated by the U.S. military initiatives in Afghanistan since 2001 and Iraq since 2003, the recently-proposed racist SB 1070 legislation targeting immigrants and people of color in Arizona, and the increasing militarization of America's borders. BP's oil spill created massive destruction of ecosystems and wildlife, "cleaned up" with toxic oil dispersants that have already entered our food chain.



We are caught within the gears of a system that is primed to generate loss, trauma, and grief while leaving us scrambling and struggling for the resources and social supports we need to process this grief. To claim our grief—to claim that our relationships with each other *matter*—within this climate of isolation and denial is itself a radical act.

The only way out of grief is through it. We cannot truly move on from a loss until we have explored its meaning to us, a process we can accomplish by assigning written and spoken words to the experience. *Trauma* is a physical or psychological wound that causes severe and prolonged distress and disruption in a person's life. Similarly, *grief* is a state of deep and poignant distress. While not all grief is defined as "traumatic," the language of trauma studies lends great insight into how we can calm our distress and heal our wounds.

In her book *The Body Remembers*, Babette Rothschild explains that traumatic memories are stored in our brains differently than non-traumatic memories. Our brains typically store memories through a combination of sensory information and more linguistically-based time and space data (20-21). During trauma, stress hormones suppress activity in the parts of our brain involved in creating verbal or "explicit" memory, while the nonverbal or "implicit" memory center keeps right on recording (28-29). Thus, traumatic memories are mostly relegated to the non-verbal, or implicit memory center where they will stay indefinitely, creating distressing bodily sensations, flashbacks, and waves of feeling that are often confusing to us because they are not accompanied by the usual verbal information that might provide us with some insight into our current states (31). Clarity comes when we begin to assign words to these memories; it's a process that literally moves parts of them to new storage places in our brains and into the realm of verbal understanding (Jones, 37). In her book, *Aftershock: Confronting Trauma in a Violent World*, the wise eco-anarcha-feminist Pattrice Jones explains that feelings must be spoken in order for healing to occur. Noting that language is an inherently social activity by which we communicate meaning to others, she concludes: "one general principle of good emotional health is to talk about your experiences and feelings" (38). Talk to your family, chosen family, friends, partners, strangers, therapist, and pets. Write letters, journals, blogs, zines, papers and poems. You may find that once you start it gets easier.

**Tommy Pico** was born and raised on the Viejas Reservation of the Kumeyaay Nation near San Diego, and now lives and eats in Brooklyn. He writes for, and edits, the zine *birdsong* with friends in the Birdsong Collective. [birdsongmag.com](http://birdsongmag.com)

**Kathleen McIntyre** lives in Queens and goes to school for social groupwork. She is a member of the For the Birds collective and a volunteer sexual assault and intimate partner violence emergency room advocate. She is interested in the radical project of putting words to our feelings and exploring the ways we can help each other heal from trauma and loss as a way to strengthen our alternative communities against the necrophilic capitalist mainstream. [theworstzine@gmail.com](mailto:theworstzine@gmail.com)

**Cynthia Ann Schemmer** is a writer and native New Yorker living in Brooklyn. She is currently working on her MFA thesis in creative nonfiction at Sarah Lawrence College and is a member of the feminist collective For The Birds. She has recently released the first issue of an oral history/creative nonfiction zine called *Habits of Being* and has been published in *Feminist Review*, *Drawn and Quarterly*, *For The Birds Blog* and currently works on staff as a nonfiction reader for the Sarah Lawrence literary journal *Lumina*. Her mother is always there, on the page, even if just in the white space. [www.habitbeing.blogspot.com](http://www.habitbeing.blogspot.com); [habitsofbeingzine@gmail.com](mailto:habitsofbeingzine@gmail.com)

**Beth Puma** is a radical educator currently living in sunny Tucson. She is interested in critical pedagogy, cupcakes, fighting fascists, feminism and guinea pigs. She misses her partner in crime, jodi, terribly.

**Jacks Ashley McNamara** is a queer artist, writer, activist, organizer, gardener, poet, and performer living in Oakland, CA. In 2002 they cofounded The Icarus Project, a radical mental health support network and media project by and for people living with the dangerous gifts that our society commonly labels as "mental illnesses," and are currently working on editing a reader about trauma and curating a performance project around queer/trans lives and mental health.

**Mikki "Sprout" Shafer** is a mama, crafter and survivor who lives in Portland with her tot huntress and sweetie bryan. they ride bikes and cuddle and sometimes cry and they love each other very much. to contact her email [bryanandmikki@gmail.com](mailto:bryanandmikki@gmail.com)

**Adelaide Windsome** is transgender artist, puppeteer, and activist living in Philadelphia. Above all things, she believes in embracing melancholy with magical. <http://geppetta.weebly.com>



# ABOUT THE CONTRIBUTORS

**Miss C Bean** hails from the pacific north west, the deep dirty south, and canada. Photography, mixed media collage, writing, and cooking fantastic vegan food to share with her family and friends (and cats) fill her days.

**Krista Ciminera** lives and works in Brooklyn, New York, where she is a bike messenger, musician, and crafty lady. She has a life-long history with disease, dying, and death and uses writing as a way of exploring these topics in a way to better make sense of something that otherwise feels foreign and frightening.

**Jesse Palmer** is an activist in Berkeley, California. He has been a member of the Slingshot collective for 22 years and works as an attorney representing housing coops and non-profits. He still lives at the Cathaus collective house where Jenn died. You can contact the author by emailing [slingshot@tao.ca](mailto:slingshot@tao.ca).

**Sam Boyd** grew up in a small town in the middle of the state of Maine. His favorite body of water to swim in is a river. He now lives in an attic with a half moon window overlooking the hills of Worcester, Massachusetts. He has recently decided to try out the real world again and got a job as a 4th and 5th grade math and science teacher down the road from his house.

**Lauren Denitzio** is a graphic designer and illustrator living in Brooklyn. She received her BFA in Illustration from the Rhode Island School of Design in 2006. She is currently a member of the feminist collective, For the Birds, and regularly collaborates with non-profits and social justice organizations on various visual art and design projects. [blackandredeye.com](http://blackandredeye.com)

**Morrigan Phillips** lives in Jamaica Plain, MA where she works within the HIV/AIDS community and is an editor at Left Turn Magazine. Near as she can tell total happiness can be found in canoeing, good friends, train trips and contributing to the good work in the world that needs doing.

Words are not only spoken and written but also heard and read. Jones continues: "one way to help create a healthy . . . community is to listen with empathy when other people talk about their experiences and feelings" (38). Judith Herman reiterates that a traumatic event affects not only our sense of self, but also the "systems of attachment and meaning that link individual and community" (51). Becoming an active listener/reader/witness of other's loss narratives is an essential part of community healing. Being a safe griefspace for another person entails welcoming conversations about loss that are usually deemed taboo: transforming our "worst" experiences into something from which we can and will recover.

Compilation zines can give space for what multiple people need to say, and through the act of writing and "being read" we can discover ourselves in new ways. Likewise, those offering support don't often get the opportunity to read a collection of honest accounts of usually unspoken or nonverbal experiences of loss. The process of reading helps us think about how we could begin to respond to these complex experiences in the safe arena of our own thoughts. Once sensitized, we may be better able to respond to moments when similar feelings and stories are expressed by the people we care about. (The use of zines as a low-cost, accessible medium for this sort of healing activity has exploded in recent years for all types of life experiences from sexual assault to chronic pain—check out the resource list for some related titles.)

This zine constitutes a demand on both mainstream society and the alternative communities we create to hold a space for the very human, very necessary and inevitable work of grieving, mourning, and (when the time is right), helping each other to continue living in spite of tremendous loss. In this second issue I have first and foremost sought to provide a space for new voices to practice putting words to their experiences. I've also tried to seek out new themes and types of experiences in the hope that even more people may find something that resonates and perhaps decreases their sense of loneliness.

We must speak about our losses in order to open up again to new growth. We must engage with others about their losses and their struggles, because it helps us to stop feeling alone and reminds us that we, too, can heal. Society's model of grief containment perpetuates the widespread denial that natural and unnatural deaths are happening all around us. This zine is an invitation to refuse collusion with denial, containment and control. This zine is for everyone who craves an authentic, collective path to healing.

*By Kathleen McIntyre*

SEPTEMBER 2010



# THE CALENDAR

*By Maria Arettines*

I am sitting on a blue and white blanket knitted by a Greek woman I do not know. I have just discovered that my calendar – my 99 cent bright yellow calendar – is gone. Disappeared. Its home for the past one and a half years, my rust infested refrigerator, still remains, but the calendar itself, set on July of 2007, is gone. Right now it is six seasons later, November. 2008.

In the last week of July of 2007 you, Jodi Tilton, died. I didn't have the heart to flip the calendar's page after you were in the hospital, brain tissue hemorrhaged, a machine pumping your heart. You died, August came, but the calendar remained as was. A reminder, a backdrop, a part of the scenery of my kitchen. The magnet that held the calendar also held a drawing of a bird, wings sprawled, crayoned by Conor the week you were in the hospital, and a photo of you and Beth. The photo and drawing are still there, held by that same magnet. But now the calendar is gone. I checked the sides of the refrigerator, under the refrigerator, and even in the cabinets surrounding the refrigerator. Nothing and nowhere. When I realized the calendar was gone my head started swirling, and it wouldn't stop, and it hasn't stopped since.

Right now I am imagining where my calendar must be. I just saw a television special about bald eagles on channel 13. Flying, the show says, is intuitive for the birds. They practice in their nests, hopping up haphazardly, before they take their first plunge and fly. They are not taught what to do with their wings, they just do it. Landing is the most difficult thing for a bald eagle to learn. They showed clips of baby bald eagles smacking into branches, attempting to land, letting us know that this is real.

Last year, I did spend the summer in California, but instead of going to the river and eating JuJu B's at the movies with my dad, I was sorting the many boxes that make up his archives. As I sifted through the fine details of his long and rich life of song and story I began to embrace what may be part of the answer. In all that haste of youth we drive ourselves to tackle each new issue and each injustice as if in our lifetime it must all be solved and we will be the ones to do it. But in reality we have only the time given to us to add to what has been built and leave something more for those who will come next: small victories, stronger movements and in my dad's case songs and stories of struggle and times gone by.

My dad had a song, the chorus of which is, "work'n on a ship, may never sail it, ship gonna sail gonna sail some day. Working on a ship may never sail on, gonna build it anyway". And there it is...the lesson and the legacy. In what I hope are the many long years of my life, I'm going to be working on that same ship as my dad and so many of my friends. I will probably never sail on it, but that's not the point. The point is to be a part of building it. And there's time; time enough to explore and learn and grow. To read every damn book about every damn topic, to study ancient prose and attend every protest, to bake sweet bread and plant blooming lilacs. There is time to breathe and there is time to grieve and time enough to sing songs with friends and make pie and grow a garden. There is even time enough to stop and say to your friends, "My heart is too heavy for this work right now. I need to care for myself and be cared for." And to not walk away, but just begin to work on a different part of that ship we are all building.



didn't want him to have the transplant. It would have meant more time in hospitals, rather than at home among his friends and loved ones. It would have meant poisonous anti-rejection meds and the constant fear of infection. But it was still hard to hear.

I was planning on spending the summer with my dad before heading to the RNC. But eight days after his 73rd birthday and a week before I was to leave, I got a voice message from Joanna asking me to call. Based on the urgency of her voice I knew it had something to do with my dad. I assumed it was another stay in the hospital. It wasn't. My dad had, quietly and after several days on the couch with friends and his Unitarian minister visiting, passed away in his sleep, in his home, next to his wife, among all the things he cherished. There was a pain I felt in that moment that I cannot now imagine having lived through. All the rehearsal in the world had not prepared me for that call.

My family recently gathered in Nevada City to mark the one-year passing of my dad. In the weeks before I traveled home I thought a lot about the past year. I thought of how I am still afraid of my cell phone, actually afraid of it. Whenever family calls I get this sick feeling in my stomach could it be bad news? More often than not I leave my phone at home on my windowsill. I thought a lot about my shame over my shoddy organizing efforts over the last two years and my lack of staying connected to old friends. Why didn't I say something? But mostly I asked myself over and over again "why didn't I go out to be with him sooner? Why did I feel I had to stay in DC and continue to stumble through a shadow of my life?"

Being back at my dad's house this spring, I felt some relief. It was nice to be among family, to be around people I knew for sure understood the quiet and unspoken grief that we all carry around. But we didn't talk about it much. We just enjoyed each other's company, playing music and telling stories. Coming back east to Boston where I now live, I flew out of San Francisco. My Brother Brendan and Joanna came with me and we spent the day before I left on the beach in S.F. We also stayed in the same hotel Duncan and Joanna stayed in while my dad was in the hospital. Being there made me feel wretched. I should have been there at the hospital with my dad too. I should have had that experience they had. In the wake of my dad's death I need to find some answers to the questions surrounding my not going out to California sooner.

I told a friend about the calendar on Wednesday. How I can't let go. One time I looked at the calendar and thought of taking it down. July 2007. A long time ago. I stood and stared eye level with it, contemplating if I should.

But I didn't.

Now it's Sunday, and it's not there anymore. I am imagining where it could have gone.

I am imagining my calendar – my beloved, cheap calendar – with equally cheap wings, flying through the clouds over Bay Ridge. The wings are not fully feathered yet. The bright yellow pages are hazily leaping through the sky, taking off from this three story brick building in Brooklyn and flying upwards. And somewhere, not too far off, you are sitting, laughing a belly laugh. My calendar's pages are flip-flopping in the wind, and months and days do not matter anymore.



# THINKING ABOUT IT

*By Sam Boyd*

I found out today that someone very close to me died over the weekend. Found in a hotel room dead from alcohol poisoning. Maura and I had stopped communicating over the past few months but had been really close. We had an intense, complicated relationship and dated for a short amount of time. I loved her dearly and let her into my heart more than I've let anyone else in during my entire life. So, it is really hard to think about and really hard to process. On the phone my friend told me to feel everything I'm going to feel. When her aunt died she let everything hit her that was going to hit her. For me so far, it has been waves of contrasting emotion. One moment I'll look toward the sky, see a ray of light beaming gold in the air and feel some degree of understanding. I'll be able to make some sense of what happened in some way. See the silver lining, breathe okay. Suddenly a wave of intense sadness will strike me. I'll remember being under the covers listening to Animal Collective boom through the room into the dark, quiet night. Winter howled outside in frigid Massachusetts but we were warm underneath her heated blanket. Small kisses, big eyes, close cuddles, big big hearts booming. The pain of the memory will fill me and be draining and consuming. Different than other pain I've felt before. But I think its good to let it pass through me. Overtake my body for a few minutes. Wait for whatever wave comes next. Feel what I'm feeling completely.

It's hard to be alone. I'm writing this because I can't go to sleep right now. I can't close my eyes and drift off. It is as if I would be facing something too challenging. I'm staying with some friends in Northern California and I'm glad they are around. It is good to be distracted when I need to be. I can't be reflective the whole day, it would simply be much too hard. I wish however my friends would talk to me more about Maura. I find it hard to initiate the conversation myself. I felt almost embarrassed to share what happened. Death is a heavy subject and it is a lot to impose on someone. And I hate to feel like I am imposing. But I can't do this alone, so I share the story, even though it is hard to push the words from my mouth. But I can tell people don't know how to respond. How do you respond? There is no comfort that can be given or reason that can be explained that would put my mind at rest.

the traveling, and all the talking came back to that shelter, to those people and to his town. He wasn't a super star; he was like all the other hard working people who made that shelter possible. He was like the rest of us...maybe he just knew it more then we did.

I tried over the years to spend more and more time with my dad. But looking back it doesn't seem like enough. I was living and working far away in Washington DC. Only now, a year since my dad's death, can I look back and see that I barely registered the impact my dad's health was having on me. During the last year of his life, as I jumped from DC to California tried to stay involved in the local projects I was already a part of like Books to Prisoners and the local Infoshop. I was also helping set up legal support for the Republican National Convention in St. Paul - and I did it all half assed. I just couldn't pull it together and dig out of my worry over my dad's health. No one said anything and neither did I. I passed the days in a mental isolation. I even avoided my garden.

During the last long visit I had with my dad we were told he would needed a heart transplant. This shook my dad to his core. When he spoke about the possibility of getting a new heart, he spoke of his heart with sadness as if he was losing a friend. After all, his heart had been with him through an incredible life.

I didn't have to tell many of my friends that my dad was being considered for a heart transplant. Before I even returned to DC word had spread. There was even a Facebook "Cause" page all about it. It all made me want to hide my worry even more. I was afraid and stretched thin, but still I tried to stay involved. Bumbling as I was, people didn't say anything about my crappy work.

A hospital in San Francisco that specializes in heart transplants asked my dad to come down for an evaluation that involved a month long stay in the hospital. My oldest brother Duncan came to stay with him and my step mom, Joanna. Together Joanna and Duncan stayed in a hotel at night and with my dad in the hospital all day. I talked with them often. But I never went out there; I stayed in DC and continued to stumble my way through various activist projects and social circles. I was preparing for a trip of some sort when I got a call from my dad. After much thought, much deliberation, he decided that he did not want a heart transplant. I knew this was coming. The truth is I



about Celtic mythology and baking bread. Often I would call my dad, and after some short greetings about how we both were doing and how the cats were fairing I would ask a question that would be on my mind. His answers would be more like a story and would incorporate his vast knowledge of all things: histories, arts, poetry, literature, etc. Often I would call from my community garden plot to ask him about planting and growing. I would sit on a little mound of dirt while he would tell me a tale about growing things that would take us far, far from the original question.

I recall one particular question a few years ago. One morning during a summer I was staying with my dad, the New York Times ran an obituary for one of the last commanders of the Abraham Lincoln Brigade. As I sat and read the paper I asked my dad what exactly the Abraham Lincoln Brigade was. I had over the years read a lot about the Spanish Civil War; it holds a special part in the hearts of radicals and anarchists the world over. But I didn't really have a clear understanding of who the Abraham Lincoln Brigade was and why they existed. My dad began to tell me the story of young WWII soldiers returning home from fighting Nazi Fascists only to find their own government supporting the fascist Franco regime. They knew what fascism was and that they had to support the resistance to Franco. Veterans and non-veterans alike shipped themselves out to fight in the Spanish Civil War as the Abraham Lincoln Brigade. As he looked down at the paper he began to cry. As he continued, his voice cracking, the tears dripped off the tip of his nose onto the newsprint.

It was much, much later when my dad lay in a hospital in Sacramento for another heart procedure that I reflected on that morning on the patio, realizing how much my dad had been thinking about death, even back then. The obituary in the New York Times represented the death of another one of his elders...his obituary would be the same for many people. He was facing his own mortality and that was something I also had to do. My confidence in my dad's miraculous recovery from a dire diagnosis of Congestive Heart Failure was being shaken. I started facing the reality that he had an ever-weakening heart.

The slow decline of my dad's health was marked with more frequent hospital visits, increasing numbers of medications and fewer and fewer shows. Regardless, he was as alive as ever. I took heart as I saw him work enthusiastically to help establish the first homeless shelter in Nevada County, Hospitality House. For my dad, all the stories, all

When I do share what happened my friends listen with tender ears. I don't like one-way conversations and when I pause I sense the awkward, uncomfortable feeling of my friends not knowing what to do. I don't expect them to make me feel fine again right now. I can't feel fine again. Not yet at least. I wish they would keep me talking though. I have a lot inside of me that needs to spill out even though I don't know what it is that I need to spill. I wish they would ask me questions. What's a nice memory of her? What's a cool thing you did together? When was the last time you talked? What do you think she'd say if she could talk to you? Where do you think she is right now? Where was her favorite place? How did she laugh?

I'm feeling weird and I'm sure I'm acting weird. How can I act myself when something like this happens? I am sure my signals are hard to read. Even though death is an uncomfortable subject to talk about there's nothing wrong with being direct. One friend called to tell me that I have her support whenever I need it. She told me to call her when I'm ready to talk. I appreciate how direct she was. It wouldn't make me feel uncomfortable in anyway for my friend to ask what I need. Do I need to be alone? Do I need to be distracted? Do I need to talk about Maura? Do I need to talk about weird, cosmic ideas concerning death?

I don't know how I'll feel tomorrow. I don't know if it is going to get harder or better. Probably both at different times. Maura filled my heart in a lot of complicated ways that I'll never understand. I'm not sure how the space she occupied will change as I think about all of this. Not sure if it will feel empty. Not sure if it will be filled with something else. Not sure if she'll stay there forever. Not sure at all. Today I called a few of my closest friends and they all told me they love me. It felt really great to hear that. To be reminded of the love around me. I wish these people could be with me right now sleeping beside me in a big bed, rubbing my back, big spooning me.





## WORKING ON A SHIP THAT I MAY NEVER SAIL

*By Morrigan Phillips*

For more than a decade, I rehearsed getting that phone call from back home telling me my father had passed away. I was still in high school when my dad was diagnosed with Congestive Heart Failure. The doctors gave dire predictions of an early death in the next 5-10 years. Well, my dad surpassed all expectations and thrived for over a decade with only half a working heart.

My dad was a radical....a radical singer, artist, historian, story teller...so many things. He was U. Utah Phillips. He was also (more often to me) Bruce Phillips the comedian, French fry lover, prankster, gardener, and fierce little league fan. His lessons, many of which I and others learned from watching him on stage, and his grace, kindness, songs and stories are blessedly enduring because he kept on working after his diagnosis.

Through the years the anxiety I felt regarding my dad's health tested our relationship. At times I would go months without speaking to him, angry that he was jeopardizing his health to travel and share his songs. I didn't want to believe that what he was doing was valuable. I didn't want to see that continuing to perform and take part in his trade was what kept him going and made him stronger. I just wanted him to stay put and stay healthy. Over the years the pain and anger that raged in me gave way as I saw the anxiety he felt over the prospect of having to give up his trade. The road kept him connected and energized. The last seven years of my dad's life saw my love for him win over any anger. Our relationship grew stronger.

My dad's knowledge ran deep and a large part of our relationship revolved around my love of learning everything I could from him. He could talk just as deeply about the history of the labor struggles of the Industrial Workers of the World as he could talk



Years ago, a woman I knew said she was going to turn 50 soon, and yet still remembered her father's death like it was yesterday. He had dropped dead while walking in the snow with her and her brother. She was 10 years old.

Listening to her story, in my relatively young grief, I could not imagine how it would be possible for me to carry my dad's death with me for so many years as she had. Simultaneously, I was terrified I would forget him entirely and spend my life searching for the mysterious force that had once simultaneously been my anchor, and also created more damage in my childhood psyche than anything before or since. I felt so disorganized; that this woman was different somehow than me because she had been able to keep the pieces together as she grew and forged her path.

But as I also grew, and survived some of the hardest years of my life, his memory has only become more present. In another strange paradox of time and space, I have forged a sort of makeshift peace with his alcoholism, depression, rules, and toxic behavior, while at the same time rigorously examining the ways in which these same parts of him still affect me, vowing never to forget, lest I drown in lack of awareness and dissociation. I have had to learn to temper the voice of his grandiose praise into a steady and accurate respect for myself. To trust my own writing, speaking, planning, and doing, because he was no longer there to (I believed) perfect the finished products of my mind. I have also claimed within myself the good things he gave me: the part that stays strong, that doesn't give up hope, and that takes such joy in living in spite of everything difficult that life presents. I am still learning how to love without contingencies, how to speak directly on my own behalf without fear of our family crumbling. I continue to work in order to heal the lineage of dysfunction and pain we both lived, and I like to think he would be excited about that if he were still around.

In fact this anniversary, 9 years later, I have come to the realization that without his death, I would never have gained the strength I needed to try and heal myself. I would never have gained the perspective that my Self was drowning in his shadow as well as the urgency to fight my way out of it. Dad, after 9 years it is clear to me how you will always sleep on the line of tension between presence and absence, between loss and healing, between disintegration and creative life. I can meet you and work through "us" in this space and it will be the best and realest bond we've ever had.

## A MOTHER'S INTUITION

*By Mikaela "Sprout" Shafer*

I had never known death. I had never felt its fury. I had never known how badly it hurt. I once thought that death came unexpectedly, swiftly and without notice. For me death was lingering for months. Death whispered in my ear, entered my dreams. Death held me captive.

The winter of 2006 I became pregnant. I felt a great need to keep this baby despite warnings, despite circumstance. I just felt differently that when I was pregnant before and quickly rushed to have it aborted sighing huge heaves or relief. No, this baby was different, I could feel it inside my womb.

According to all technological signs I was having a "normal" healthy pregnancy. I was glowing and growing. The baby was kicking and swimming. I told myself this daily and yet some dark thought in the back of my mind could not relax. I kept feeling sad as if I'd already lost her. My partner would tell me not to worry that our baby was fine we would have a beautiful baby soon. I kept asking "what if she dies" and "what if something is wrong." A mother's intuition is stronger than any technology.

My labor started on October 13th, Friday the thirteenth 2006. I stood up to a small gush of yellowish liquid and a bloody pop of my mucus plug. I felt the cramps getting stronger and stronger until they were contractions. I moaned and rocked through them. I intended to birth at home with a midwife so it was just me and my partner and occasionally a doula. For days I went through the constant waves of contractions. I wasn't dilating but the baby seemed OK. After 3 days I started to get a fever. I started to feel hopeless. I started to worry. I would shout "something is wrong, something is wrong" but everyone would tell me to "shh its OK don't give up." A mother's intuition is stronger than anybody's words.



On the fourth day the midwife took me to the hospital. I was checked it and given antibiotics. I had an infection. I was given pitocin to speed things up. "I need a c-section" I shouted over and over "shh your almost done" they would say.

When our daughter paikea came sliding out the room was quiet. I suddenly felt dizzy and yet calm. I laid down not wanting to look at her. I heard the doctors talking, medical terms I didn't understand. They told me to hold her hand and talk to her. I looked at her and she was blue. Meconium was everywhere. Her fingernails were brown. My face began to get hot as they carried her away. I could barely hold back tears. A nurse came it to "explain" things to me. "everything is going to be OK" they kept saying. They transferred her to Johns Hopkins.

I stayed with her at the NICU for nine days. For nine days I read her stories. For nine days they told me to say my goodbyes. For nine days I sung songs to her. For nine days they told me she was very sick. For nine days I wanted her to live so badly. For nine days they told me there is little hope. For nine days I knew she was already gone.

On the ninth day we sat in a small room with one couch. I wore a new dress and my partner wore a vest he made just for this occasion. The nurse told us it was time and we unhooked our daughter from the machines. I held her and she gasped for breath. Its a body's natural reaction when it is taken off life support. A last attempt at life. We held her hands and held her feet and kissed her. She turned blue and cold. They took her away.

A week later we got her back. A tiny bronze urn sits on a bookshelf. In a way I knew her fate all along. A mother's intuition is stronger than anything.

## MAKING UP FOR LOSS TIME

*By Kathleen McIntyre*

It's hard to explain how a major loss feels after some time has passed—to someone who has never lost anyone or to someone who is 1 or 2 years in. For me, it follows a logic that applies nowhere else in theories of memory, attachment, love, hate, or relationships in general.

As I grow older, realize my father's life seems more finite, his 46 years laid out neatly before me. I've had time to hear most of the stories I missed as a kid and never got to hear from him, I've read all his old books and letters. There will be no new pictures taken, no chance to hear how he weighs in on recent world events, or hell, even the recent events of my own life. He is a life, not a-live. On bad days this claustrophobic assurance of "no more" makes me frantic and so angry that if the life were made of glass, I would just shatter it, its limitations being so useless to me as I grow up alone.

On better days, I am quite content with my father's 46 years, knowing that the layers and double-meanings, metaphors, and understandings are still so difficult to master that it will take me the rest of my own lifetime to really figure him out. On these days, the reality of "all I have left" is so vivid and full of potential, that he feels very alive to me—in the new way I feel him around since he died.

On these days, I want to talk. I am not sick of it, and I have not forgotten. On these days, the old jokes are still as funny, the old wounds still as fresh, and the old stories just like the first time I lived them. It does not feel like I am playing a broken record or grasping at straws. It is this frozen sense of time that I find the most difficult to explain—that his death has taken up so much space in my being, and damaged/rerouted so much of my capacities that engaging with a finite version of his life is truly enough.

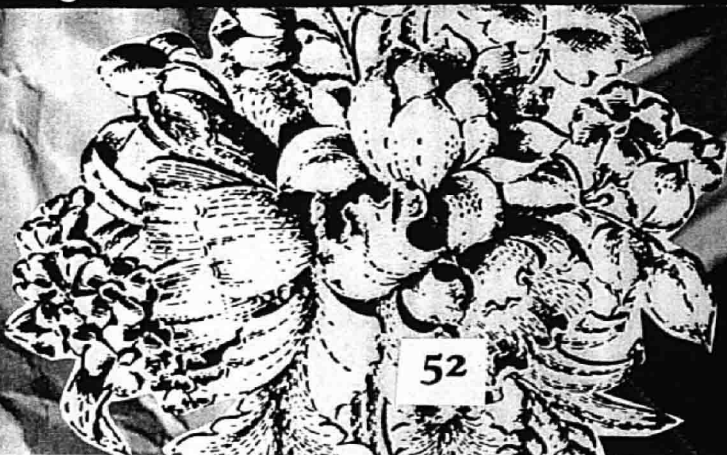
Trying to figure it all out is empowering—like a child feeling proud to have moved a large inflatable ball. Its mass is an illusion—its actually just filled with air, but it's all she's capable of at the time, and it feels alright.



physicians as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal. If artificial life-sustaining means have been commenced, they should be stopped. All care necessary to keep me comfortable and free from pain should be given, even if pain-relieving medications may hasten my death.

To effect my wishes, I designate \_\_\_\_\_ residing at \_\_\_\_\_ or if he or she shall for any reason fail to act, I \_\_\_\_\_ residing at \_\_\_\_\_ (in that order) as my health care agent/surrogate, that is, my attorney-in-fact regarding any and all health care decisions to be made for me, including the decision to refuse life-sustaining treatment, if I am unable to make such decisions myself. My agent/surrogate's authority shall become effective when my primary physician determines that I am unable to make my own health care decisions. This power shall remain effective during and not be affected by my subsequent illness, disability or incapacity. My surrogate shall have authority to interpret this document, and shall make decisions about my health care as specified in my instructions, or, if or when my wishes are not clear, as the surrogate believes to be in my best interests. I release and hold harmless my health care surrogate from any and all claims whatsoever arising from decisions made in good faith in the exercise of this power.

[Sign and date, and have witnessed by two un-related persons who are over 18, not named in the living will, and who won't receive any property upon your death. They should confirm in writing near their signatures that you are of sound mind at the time you sign.]



## THIS IS WHAT YOU DO WHEN YOU DON'T KNOW WHAT TO DO

*By Krista Ciminera*

She washed her hands before she put them down her throat, and then she washed them again. She rinsed her mouth out with water, but didn't brush her teeth. Then she laid down on the bathroom floor and thought about vomiting again. Her damp skin stuck to the tiles like it was the tiles. Her body made involuntary motions- she groaned and gasped so that perhaps someone on the other side of the door would think that she was masturbating, or softly crying or slowly dying. And then it began to rain. Softly at first but then hard, definite pangs upon the window pane. Although she agreed that a sunny day might seem insulting, the rain did not fit her mood. It would be better if the sky turned white and the oxygen left the air, and she could live like a fish in a fishbowl inside the bathroom. Everything outside of the bathroom would be dead and she would be, too, if she left.

For a long time she remained like this, not conscious or unconscious, but teetering in a state that lies just beyond definition and is reserved for those in immeasurable pain. For today was Thursday, and on Wednesday her sister stopped living.



The neighbor's dog hung itself, her mother said one afternoon when Julius was a child. There are certain statements, certain occurrences that when spoken of, broke the bones of the skeleton of reality she attempted to construct in her young mind. Her mother had been in the kitchen drinking tea with some of the younger wives of the neighborhood when this was said, and the little girl stopped her idle drawing in the next room, her ears now pricked to their conversation.



"Apparently, the dog was left tied to a door knob, and its nervous jumping tangled the leash around the knob until it suffocated. They found it swinging from the door when they got home." The adults shook their heads forlornly, then shrugged their shoulders in haste and moved onto a different topic. Julius, however, was frozen in her small chair, with a crayon poised slightly above a piece of marked paper, as if two great hands had suddenly taken hold of her shoulders, like the schoolmaster did whenever she was caught drawing during class, afraid of what was before her.

She tip-toed to the large, low window that faced the street and peered out at the neighbor's house in disbelief. It sat on the corner where a new lane began in the middle of her street. It was as unassuming as all of the houses in her neighborhood, but now its familiarity was unsettling. There was a new desperation in its conformity. There it sat, pleading to be like the others, but Julius knew it was not. Forever now it would be marked by mistake, known as the house of the dead dog.

Her fists gripped the windowsill as her mother's words echoed in her head. Vividly she imagined, for she had never been inside this neighbor's house, a darkened hallway with a yellowed door at the end. On that door, hanging from the knob, was the dog. Her breathing quickened as she saw its esophagus, a piggy pink, becoming folded and squeezed like a twisted towel. The mucous and acid, bile and bile coming up onto the tongue and dribbling out of the heaving mouth. Its eyes, at other times demure and dark, were now filled by the life that was rapidly emanating from it. And just as quickly as life filled the dog, it receded into the smoky corners of the hallway. Limp and languid against the door, it swayed in heavy time to the faded beat of its heart.

Her eyes focused momentarily on the faded reflection of her self in the window, and then again she looked past, and this time two of her eyed the house across the street—the child from before and the person she would one day become. Still, the child gave pause. If such a fate could befall upon as innocent of a creature as that, she wondered, what would become of us?



## LIVING WILL AND APPOINTMENT OF ATTORNEY FOR HEALTH CARE DECISIONS

*By Jesse D. Palmer*

To my family, my friends, my physicians, my lawyer and all others whom it may concern:

I \_\_\_\_\_ being of sound mind, emotionally and mentally competent, and understanding the full import of this directive, make this statement of my wishes and instructions concerning medical treatment.

I intend this document to be legally binding. I am a resident of \_\_\_\_\_. I direct my physicians, other health care providers, my family and any surrogate designated by me or appointed by a Court, to carry out the wishes stated in this document. If I become unable, by reason of physical or mental incapacity, to make decisions about my medical care, this document provides the guidance and authority needed to make any and all such decisions.

If at any time I have an incurable injury, disease or illness certified to be a terminal condition by two physicians, one of which is the attending physician, and where the application of life-sustaining procedures would serve only to artificially prolong the moment of my death and where my physician determines that my death is imminent whether or not life-sustaining procedures are utilized, I direct that my life shall not be artificially prolonged and that life prolonging procedures should be withheld or withdrawn, and that I be permitted to die naturally.

In addition to the above, I do not want my life to be prolonged if I have become unconscious and, to a reasonable degree of medical certainty, I will not regain consciousness.

Finally, I do not want my life to be prolonged if I have an incurable and irreversible condition and life-prolonging treatment imposes risks and burdens of treatment that outweighs the expected benefits, even if my death is not immediately imminent.

In the absence of my ability to give directions regarding the use of life-sustaining procedures, it is my intention that this directive shall be honored by my family and



## Conclusion

While death is a natural part of life, the healthcare industry and cultural norms that try to hide death have limited self-determination at the end of life. Just as many people are battling the inhumane corporate machine that is killing the earth and dominating most aspects of human life, we need to struggle so that the healthcare industry serves human needs, not corporate greed, at the end of life. That means fighting for freedom from suffering and empowering each person to decide how much to use, or decline to use, high tech medical procedures at the end of life.

For many people, having a good death may mean one connected to community, not machines. With help from friends as well as caring medical professionals, we can organize our own do-it-yourself deaths.

Promoting self-determination at the end of life doesn't mean cutting off money to people who want to use healthcare to the max — it means giving everyone more options. There is a lot of evidence that the more open the dialog, and the more options available, the cheaper overall end of life healthcare will ultimately be, because many empowered people will not request every last procedure. But the main reason to struggle for a more humanistic culture around end of life issues is to avoid suffering, not just to save money. A lot of the fancy high tech healthcare procedures are causing, rather than preventing, human misery. By engaging in hard discussions about death and learning to think about death as a part of life, rather than as a terrifying unspeakable topic, we can help build a culture that supports individuals where it is okay to ask for help, as well as decline corporate care.

I wish to thank the excellent doctors and other medical staff at Herrick Cancer Center who cared for Jenn and exemplified the best of what the medical system can offer people.

For information on Oregon's Death with Dignity Act, check out [www.deathwithdignity.org](http://www.deathwithdignity.org).

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Mold peppered the ceiling and cascaded softly down walls of the bathroom, claiming its space as a living thing among decay. If Julius remained still, the spores would eventually take hold and slowly paint their place over her body, but even in her sleep she churned by a force that was not her own. The acids in her throat and mouth, fermenting in the folds of her gums and the furrows of her cheek, where now all about her, and the air hissed with a tinged volatility that singed her exposed skin and pinched the deepest parts of her nose.

Slowly she became aware of a noise deep within the apartment that she shared with her sister. At first it acted not like a noise, but as a sight behind her closed eyelids. In the darkness there became small, soft spots of light that slowly began to pain the thick thoughts of her head and prodded her into consciousness.

"Julius!" her sister's voice yelled. "Julius!"

She blinked. The voice continued. A full chest of air propelled her upward and she scrambled out of the bathroom and into the narrow hallway that connected their two bedrooms.

"Rosemary?" she called her sister's name, searching with her eyes in the darkness. "Rosemary?" The voice responded from her sister's room. She faced the closed door of her sister's room, remembering that in the night before the door seemed quite different. It was as if construction had taken place in Julius's short absence, and a new door appeared that opened into a foreign and foreboding place. It gaped at her with the same indifference.

Turning the knob, the door gave way to her sister's bed. On it was a large, long mass of blankets and immediately Julius grabbed them and pulled them off and onto the floor.

"Rosemary!" she cried, her eyes filling with the gray outline of a crumpled sheet. She placed an unsteady hand on the empty bed as her name throbbed in her head. Her heart beat with the force of all her strength and her eyes darted around the room, not seeing but feeling the weight of her sister's voice around her. On the floor, she pushed aside the blankets and searched under the bed.



"Julius!" the voice commanded attention. It was said as if to someone across a crowded room, paired with the waving of a hand intended not as a greeting, but to gain notice. She crawled on her knees to her sister's desk and swept the contents onto the floor. She cried out her sister's name frantically, hurling piles of scattered clothes and books until she lifted her head to a place she had not looked.

There, in the farthest corner, hung a golden cage that swayed powerfully in the air. "Julius!" came the voice from inside the cage. Prudle, the bird, was turning about on his perch. He mimicked his sister's voice perfectly, save for a tinny note that sounded somehow hollow. "Julius!"

Julius uttered a sharp protest and brought her hands to her mouth. Prudle sensed that he was discovered and this threw him into a frenzy as he repeated Julius's name with a heightened fervor, pitching the cage about the corner. The room filled with sharp light and the bird's voice became piercing. Without thinking, she grabbed the black slipcase under the cage that her sister used to cover it at night and tugged it on violently. With hands on either side of the cage, she breathed heavily and whispered, softly, "No."

She felt faint and collapsed onto her sister's bed as a new horror washed over her, more acute than the day before. Her pain could not be contained and contorted her body as the only means of expression, for there were no words that could be spoken to release the thoughts in her head. The twisted sheets mimicked her movements, turning as she thrashed about. How cruel, she thought, now loosely trapped in folds of the sheets, how powerfully lifelike a simple item like linen can become when tossed with such emotion. She fought with them, eyes closed, becoming more entangled, her mouth emitting one long, strangled cry. Pounding one limp fist upon the bed, she yielded to the strength of the sheets and her movements slowly died out.

What once protected her sister's live, warm body now wrapped Julius as if in preservation. And wet like her they became with her tears.

In 1997, Oregon passed the Death with Dignity Act, the first law in the US to permit doctors to legally prescribe lethal drugs to terminally ill patients who request them. The law prevailed over court challenges and Washington State has since passed a similar law. These types of laws are more common in Europe than in the US.

Under the Oregon law, a patient has to be well enough to self-administer the lethal drugs. Patients have to make repeated requests to their doctors over a period of time, orally and in writing. The doctor and another physician have to fill out forms diagnosing a terminal illness with six months or less to live and finding that the patient is mentally competent to make and communicate health care decisions. The doctor has to advise the patient about alternatives, including palliative care, hospice and pain management options. And the doctor has to ask the patient to notify next of kin about the prescription. There are forms that all parties have to fill out and file on the Oregon Department of Human Services website and it is impressive to see all the safeguards built into the law.

Since its passage, Oregon has kept detailed records about how people have used the law, which are reported annually. From 1997 to 2009, 460 Oregonians have taken their lives using medicine prescribed under the Act. Not everyone who requests and gets lethal drugs actually takes them. Just having options can be helpful and comforting to many people.

In 2009, there were 95 prescriptions -- 53 patients took the pills and died, 30 died of their illness, and 12 were still alive at the end of 2009. 98 percent of the patients who took the drugs died at home. On forms asking doctors to assess the reasons patients requested the drugs, the most frequently mentioned end-of-life concerns were: loss of autonomy (96.6%), loss of dignity (91.5%), and decreasing ability to participate in activities that made life enjoyable (86.4%).

I find this law important and interesting -- despite the hyper-state orientation of forms and permissions -- because of the way it opens up end of life options and dialog. The reasons patients request lethal drugs is especially interesting. These people haven't given up on life -- rather, they are empowered and engaged in defining for themselves how they want to live, including when and how they want to die. This seems to me the polar opposite of people caught up in a medical system intent on delivering procedures disconnected from the potential costs of benefits to patients or society. While not everyone will want or use such options, pushing to extend them widens the space to grapple with these issues.



What can we do to make these difficult conversations easier and more common, so more people can have humane deaths surrounded by their friends? The process around Jenn's death was easier because the medical establishment in Berkeley was experienced and supportive of alternatives, because of the type of person Jenn was, and because her community was ready to participate.

I can imagine things being a lot more difficult when children are trying to relate to elderly parents across cultural divides, when the healthcare system is less supportive, and when the person dying doesn't get information about alternative options or doesn't feel comfortable asking if there is another way.

I don't have any brilliant ideas about how to change this dynamic other than trying to stimulate discussion about death and dying.

I think it can help to talk about end of life issues with your friends and loved ones before there is a crisis even though this is far from easy. One tiny part of opening discussion may be getting people to sign living wills. A living will is a document you can sign instructing your loved ones what you want done if you become seriously ill or injured and can no longer communicate your wishes about medical care. They usually appoint one or more persons to make decisions on your behalf. A person who signs a living will may, for instance, request that their body not be kept alive artificially when there is no hope of recovery. They permit people to limit the excesses of the high tech healthcare system.

When you sign a living will, you have an opportunity to talk with the people you are appointing to make medical decisions on your behalf about your wishes and your values around end of life issues and how you want to use the healthcare system. This can stimulate discussion and cultural development all around. I've put a sample living will at the end of this article and on-line in case you want to try this.

## *Death With Dignity*

Even more taboo than openly discussing end of life issues is the movement to permit terminally ill patients to obtain lethal drugs to hasten their deaths. This allows terminally ill people to have some measure of control over their deaths. I see this as lying along a continuum of contemporary responses to the end of life -- from using high tech medical care to aggressively extend life, to declining care, to using palliative care and hospice to control suffering at the end of life, and extending to a patient ending their life before they would otherwise die naturally to avoid prolonged suffering. The common goal is self-determination and empowering each person to decide what is right for them. No one path is right for everyone so the key is opening a variety of options.



*By Lauren Denitzio*



By Caitlin Nagle

As I write this, my grandfather is dying. By the time I finish this, he may already be dead. The moments that elapse between a person knowing someone to the point at which you know someone who has passed, is a river hard to navigate. That is the popular metaphor, right? Time is like a river? I understand the metaphor in the sense that, time is fluid, as are memories, which play in reverse.

My Grandfather, Henry, is not even my biological grandfather. My grandfather died of a heart attack when I was a child. He left my grandmother before I was born; in the videos I have seen of me interacting with my biological grandfather, he seems distant. Henry, my Papa, has been a constant in my life. When my parents divorced, my grandparents took over the parental roles. I spent every holiday with them, I spent every summer with them, as an adult I now live two subway stops away from them. He is eighty-five years old and grew up in Brooklyn. His eyes are hazel. He is of average height and weight. Most weeks he can be seen walking around the east village by my grandparent's apartment, he visits fruit stands but doesn't paw the produce. These are some facts about him. I love my grandfather. I can't describe him; to list his personality would be to trivialize him.

Knowing that my grandfather is in a hospital in Florida, his lungs and heart failing, while I sit here in my apartment, is fucking breaking my heart. I can't reach my arms long enough to touch him. Even a plane won't get me there fast enough. I am so overwhelmingly terrified of what it will mean to miss him. These minutes are ticking by and I don't know if he is still alive. I have felt this dread before; a few years ago my dad took my sister in I into our kitchen to tell us that he had bad news. I felt this tightening then. My papa with his heart so big.

participating in these discussions. Learning to have these discussions is much more about changing general cultural norms. Dying people may not feel comfortable talking honestly with their families because they don't want to scare the people they love, or themselves. Caregivers don't want to honestly discuss death issues with the dying because they don't want to seem like they are giving up hope. The mutual fears and inhibitions are making difficult transitions harder for everyone involved.

I can remember, as Jenn's cancer spread throughout her body, how we both avoided talking about her impending death, even when it would have helped to be able to discuss it openly. We were lucky to finally have frank discussions towards the very end, but it was never easy. Her doctor greatly helped in the process by telling Jenn at a particular point that there were no more realistic treatment options and that her focus should switch to palliative care -- care designed to manage pain rather than fight her cancer. Jenn was so used to fighting that I think she would have tried more long-shot treatments right up until the end had her doctor not given her permission to pull back and change her focus from fighting to dying.

While it would be easy to confuse this transition with giving up, I think of those last few weeks of Jenn's life as particularly meaningful for her. We began visiting outdoor places she loved and scheduling visits with her friends so they could say goodbye. She wrote a will to provide for her cat. We talked about what she wanted done with her body. She gave away her camping gear and materials she used as a high school teacher -- symbolically wrapping up loose ends. Jenn could have missed some of these opportunities to wind up her life had she kept on fighting and trying more treatments until the very end.

At a housemeeting a week before she died, Jenn discussed her wishes regarding her care and the role hospice would play in permitting her to die at home. She asked housemates not to panic and call an ambulance when she got sicker because she didn't want to be taken to a hospital or connected to tubes or wires. She signed a do-not-resuscitate order so that if paramedics were called, they would not take extraordinary measures to revive her. Her doctor prescribed pain medication, anti-anxiety pills and other drugs to limit her suffering as much as possible. An acupuncturist made home visits to reduce annoying hiccups and itching. Most of all, we scheduled her friends to sit with her 24 hours a day during her last 5 days.

While there was no way to avoid all of the suffering that one's body goes through as it shuts down, all of this planning, communication and support helped Jenn depart in a fairly humane fashion.



## Death Panels

A tragic detail of the past year's struggle over healthcare reform was the moment when a proposal to pay doctors to consult with patients about end of life care was demonized as calling for "death panels" intent on "murdering grandma". The proposal was immediately dropped from the bill, squashing a chance to have an honest discussion about how corporate, Western medicine mis-handles death. Under Medicare, the government healthcare benefit for people over 65 and disabled people, doctors are not paid for these complex and time-consuming consultations, which can be crucial for dying patients. But doctors are paid for procedures, regardless of whether these procedures are helpful or just prolong a dying person's suffering while providing no real benefit.

Whereas death is inevitable for all of us and a normal and natural part of life, modern health systems can sometimes treat death in a dehumanizing, mechanical way -- a problem that modern technology should somehow seek to "solve." Rather than being able to end life at one's own pace, people are put through increasingly desperate, painful and invasive medical procedures to buy a few more days or hours.

The hopeless struggle to defeat death costs not just quality of life for patients, but accounts for a huge portion of healthcare expenditures. The five percent of Medicare patients who die each year consume about one-third of Medicare expenses, with aggressive treatments during the final month of life eating up almost a third of that sum, according to government statistics. The mainstream healthcare system is in crisis not just because millions of people lack coverage, but because the cost of coverage is increasing so rapidly. End of life care is a big part of this increase. As medical technology gets better and more complex, there are more and more ways to spend a lot of money at the end of life.

There is not an endless pool of money to pay for healthcare, especially as the population ages. Money spent on expensive end of life care that doesn't improve a dying patient's quality of life is not available for other care.

Cultural attitudes about whether it is always appropriate to use every available medical technology to prolong life has to somehow evolve along with technology. This requires opening space to honestly and earnestly discuss end of life issues, which is precisely what was closed down with the "death panel" rhetoric.

## Learning to Talk

Learning to talk about death is not about government programs or changing the medical system -- although it certainly would help to make sure doctors could be paid for

He had not died, my mother had. A story for another time perhaps, probably not. I will never be able to understand what I felt relief for in those seconds that passed before I had to call the morgue to release my mother's body. Either way, I felt like shit and I feel like shit now. My papa said to me at the wake, "I loved your mom, she was a very special lady." I wonder if that is all you can really say about someone you love, dying? I hate knowing that there is no worse pain than losing a loved one. I hate that I cannot have more time with my grandfather and my mom. I can sit here and think about them and write this but I can't touch them. For months after my mom passed away I would have these panic attacks, they would start with me thinking about my mother's skin and furiously rubbing my hands together. I would try to remember the last time I touched her, the last time I slept near her, and I could never recall. One day while unpacking some of her books, I found a photograph of she and I asleep next to each other. I don't remember how that made me feel. I still have the photo but now I can't really look at it.

On my grandfather's desk there is a picture of he and I with my arms around his neck, I am hanging off him and we are both laughing. I am afraid to think about that picture for too long.

A half-hour has passed and I have not heard from my family. I don't know what time it is.

My Grandfather died this morning at around 8:45 a.m.





## FOR LOSS

*By Tommy Pico*

"It doesn't spoil/my time is what spoils my time."  
-Matthew Zapruder, "Aglow"

I can't remember if it's my first memory or my first dream: My mom's baggy red "Wild Bunch" jacket (the reservation's all-female softball team). We're at a funeral, standing around with my aunt Cossie. A casket. Marble. Mounds of earth. Early morning it's a cloudy day and people are standing around drinking coffee and sniffing. People are lining up to view the body; it's an old face. Handfuls of dirt, everyone, before the gravediggers begin to pile it on. And then the real wailing: no vanity no self-consciousness. The kind of unfurling in a child's laugh. This is the only thing happening and the only thing real, and the earth is slowly swallowing this person forever. I remember I feel lost awful, I wail. I remember feeling a grief that was not mine, but was. My community's.

*I remember eating cereal with you,  
Watching weekday morning cartoons,  
Waiting for the school bus.*

*My brother is 12 years older than me  
So I never really competed for my parent's affection  
Before you lived with us,  
And everything you did pissed me off,  
Especially the scrape of your front teeth*



## LEAVING THIS WORLD WITH A HUMAN TOUCH

*By Jesse D. Palmer*

Death is a hard topic to face or write about with any honesty, modesty or accuracy. Five years ago, I held my best friend Jenn as she died from cancer. Her death was sad, overwhelmingly difficult and yet it was also somehow beautiful, natural, humanizing and reassuring. Her final moments were nothing like what you see on TV. Rather, they were raw and animalistic, unmediated by culture or language, almost like a reversal of birth. Since seeing her death, I haven't felt afraid of my own death.

While her life was cut short to only 35 years, it seemed like she had a good death. She didn't want to lose autonomy or be connected to a bunch of tubes or wires, isolated in a scary hospital. And so she actively directed her own death process. With help from her doctors, housemates and hospice, she was able to end her life totally naturally with no extraordinary medical intervention, in her own bed, in her own room, cared for by her friends and loved ones.

We're all going to die but most people feel inhibited talking openly about death because of cultural taboos. Discussing death openly and in detail can seem negative or scary -- like if we don't talk about it, maybe it won't happen. But with a high tech, profit-driven medical care system, our culture needs to figure out how to honestly discuss death, both so the dying can have as good a death as possible, and to stop runaway end of life costs from bankrupting the healthcare system for the living.

We need to build a culture that discusses the death process so each individual can decide for themselves when more advanced healthcare makes sense, when it is time to give up the fight, and even when it might make sense to request lethal drugs to hasten our own death to avoid prolonged suffering.



in the dark of the night  
she could not wake up  
she dreamt of how she saw  
him last lying in pain how  
foolish was she not to know  
that he was dying  
she thought of how small he  
must have felt as he tried so  
hard just to save her name  
she thought of how she  
should have stayed and  
asked him all the things that  
she never wanted to know  
or what it felt like to feel  
your bones falling apart  
breaking down in nothing  
if he knew where she would  
end up if she was going the  
right way in the dark of  
the night she wondered  
if she would ever wake up

but still she wished to  
she wished the dream of  
places that she had once been  
in places that she could  
only visit in her sleep  
in her sleep from that she  
did not ever want to wake up

in the dark of the night  
she is someone she once  
was in the dark of the night  
she feels loved.

Against the cold, metallic spoon,  
The slurp of milk with every goddamn bite.

It is cold in Brooklyn in my windowless room and  
I just learned that you wrapped your car  
Around a telephone pole.

Full night cry, I think of spoons.

Car crashes and Indian country: there are studies. "Accidental" deaths. "Risk-taking behavior." Diabetes and of course alcoholism. Other drugs there was a big meth craze for awhile in I think the 80's. Guns, suicides. I know someone who drank motor oil in 8th grade. And of course a loss, an ancestral loss. Hair and blood. I came to an understanding that people die, lots, before I learned how to read (oh and I started early). My family and I, we went to every funeral that ever happened on any reservation in the county (at least) and San Diego County has the most reservations of any in the United States. But they are all small and very spread apart so. Dusty car trails and the windows rolled up. Where were we going now, Yuma this weekend Santa Ysabel next weekend. Someone up in Cocopa passed. Campo. Manzanita. My parents were something like prayer leaders, lit candles through the all-night wakes. Rosaries sorrowful mysteries, dusk-to-dawn. My mother would sing the old Spanish songs. Fire pits. Stealing cigarettes from the clubhouse. I don't feel comfortable telling everything because some things are for us, only. But be assured there is a ceremony to each one. (Things you will never know). It's weird: when I was a child, wakes were kind of fun. There was an element to them. It'd see all my cousins. *SIT DOWN. BE STILL BE QUIET!!!* What did I know? Climb that tree with all the limbs cut off. Remember that one time Popei fell asleep up there? Seeing who could stay up the latest. And then without fail someone caught you— *INSIDE THE TRIBAL HALL! Listen to the rosary pay your respects!* People would get up and tell stories about the dead, and everyone cried. Hard. Even grown men (you see where I'm from it isn't a weakness).



*You were eating microwave buttered popcorn  
(that smell has always made me nauseas)  
And the blue of late-night TV blinks across your cheeks  
In the dark in the waiting room in the hospital.  
When we hear wails from the next room,  
You know.*

*And you know.  
Inhales quick diaphragmatic,  
The single popcorn kernel fall from your lips,  
One, trembling at your fingertips.  
They had you make the call:*

*"Let my daddy die."*

Sometimes I am very business very serious, like— I am no fun at all. And it's true, sometimes it's hard for me to "have fun." Childhood wasn't a kingdom for everyone. Sometimes I joke with my friends that I'll be the last man because I'm the only one who can take it, because I've already known so many people to die. They laugh but I'm not so sure it's a joke. So sometimes I'm serious, not so new and curious. I'm not cold. But I understand the impulse: pulling back because loss is so painful, so personal and monumental (and inevitable!). But somehow, apples ripen. Car breaks sound the exact same as they always have and the Mister Softee jingle still bores through the park.

*I didn't make it to your funeral because.  
Because I was too busy being a Brooklyn hipster.  
(I have never admitted that to myself before)  
If I close my eyes real tight. I can almost  
See your face, like it's like the stars  
You can only see in your periphery,  
And someday. Sometime soon I guess,  
I won't remember your face  
From knowing you, at all.*


In the end, I feel like in order to escape the emotional loneliness I feel every single day, I must throw myself back in the environment where this all began. You have to start at the beginning to get to the end, you know? Maybe by leaving this concentrated city and having days upon days of time to myself, with my family, without any distractions, I will be able to dig deep into the caverns of my mind and dissect all the pieces that have been dormant for the past two years, and after an indefinite amount of time my brain will yawn and stretch and say, "Oh, good morning."

While I may always be seen as the "young one", I know I can find my voice and write this out for all to read. Actually, I just did, and I will again and again and again. I am not going to shatter. Talking about death is made out to be this taboo thing, so no one brings it up in fear of breaking you. Everyone forgets about it except you. You will never forget. You will always remember, and although your body isn't eternal, your will is. It is unstoppable.



*This piece was written in September 2008, two years after my mother's death. It was the first piece of writing I had produced about the subject, so I view it as a significant progression in my grieving and writing process. A lot of the feelings have changed drastically and some decisions were never carried through (grief and love are constantly evolving forces). While it's hard for me to read this today (mostly for literary reasons), it was definitely a catalyst to healing. There was a time I thought I'd never be able to put this experience down on paper, but after writing "The Young One" I haven't been able to stop. And for that, I am glad it exists.*





on our relationship. I know it is frustrating for him to deal with me, because when things get bad, my mentality is that they will never get better. On top of that, I get upset and annoyed that he isn't filling any of the voids my mother left. I even say hurtful things in order to have him feel what I am feeling: pain. They are never terrible things, but little quips that are just enough to cause a prick. I am having a particularly tough time living without all the things she contributed to my life. Rather than pinpointing these voids created in her absence and thinking of ways to personally deal with them, I dwell on the fact that she is gone and expect my partner to be able to fill them. It's an impossible expectation.

None of this applies solely to him. I've noticed that I've done it to the closest people in my life. It's a terrible habit that the new "me" has picked up. I hate this new me. I am a different person than I was three years ago and I feel it every day. I can't completely remember the old me, but I do know that she didn't cry this much, that she was much less serious, and that her heart wasn't as heavy. I feel like I never have anything to say anymore. I am quiet and bored when I was once outspoken and full of ideas. Something needs to bring that girl back.

Whether or not I am ready to acknowledge my mother's death is not the decision of anybody else but myself. It's not a matter of wanting, but rather a matter of being mentally ready to release her. I know that hypothetically I am ready to do this, and I feel that by moving back home I will get the closure I need to do it. I will form an improved relationship with my father, with better communication, and create a new feeling in that home. I will learn that it is okay to cry to my family, because no matter what, we are all feeling the weight of this loss. I will learn to cope with the voids left with her passing, and I will fill them with new strengths and new cures. I won't put as much pressure on my partner, because I will learn to support myself and not fully depend on others to keep me emotionally stable. I will visit her grave regularly and I will talk to her at night and say, "Hi, Mom. I am going to graduate school for creative nonfiction! Aren't you proud? You are the only topic I ever want to write about because I miss you so much. We all do."

Recently I went to Paris with Lauren Wilkinson and we went to the catacombs. I'm not a big monument kind of person; I much prefer the raspberry tarts to the Eiffel Tower. But the catacombs were different you know—rooms of stacks of bones, surprisingly sans graffiti, and down much farther than I'd imagined. And of course! All the imaginary lives: who these people were, who they were too shy to talk to, who they were too busy for. *This was Regina and her favorite thing about the morning was the curl of her lover's arm.* And then back to the light and afterwards I was pretty grave. And Lauren, without turning without a blink, says: "Woah. We really don't have any time to waste."

*I see flashing lights down Graham Avenue—  
Someone is in shock, someone will feel the loss.  
I see flashing lights down Graham Ave.,  
Too far down to make anything out.  
But someone is in shock will feel the loss.  
I hear the sirens down Graham and someone  
Down there is lost.*



# GRIEVING INTESTINES

*By Beth Puma*

The ripples of her death still affect me as they vibrate into the nooks and crevices of my day to day. When Jodi died I made some serious changes in my life, including moving across the country. A new friend, in my new city once very bluntly asked, "What was so special about this girl that everyone that knew her is fucked up by her death?" The question although an innocent and sincere one, left my insides burning. I didn't shit for days—which brings me to my piece.

Jodi had a serious autoimmune disorder called colitis that fucked with her digestion and did not allow her body to absorb nutrients properly. She lived with the disease everyday, often with bloody, violent diarrhea, drastic weight loss, and a hardened and tender stomach. For years it was managed by diet. In 2007 there was a series of flare-ups that disrupted Jodi's independence and autonomy. She reluctantly decided to try a new medication. It lowered her immune system so her body wouldn't attack her own body anymore. It backfired. She caught some type of bug because of her compromised immunity. She was dead in three weeks.

She was angry at her body. It had betrayed her. I was angry at her body too. My body began to change during and after her death. It began responding stimuli in a way that mimicked Jodi's colitis symptoms. As my community grieved for the loss of the rock that was Jodi, my body dealt with her death by attacking itself. I didn't realize it at the time my body mourned Jodi in a very different way than my heart and brain. After so many doctors and so many tests, I have come to some peace with myself that my stomach problems were caused by my grieving intestines.

The week Jodi was in a coma in a hospital was the first time I noticed a violent change in digesting. I wasn't eating too much, but my stomach was too twisted. I wasn't sleeping, as I found myself in vigil in the ICU waiting room. My face was swollen from crying. I started to shit my brains out. I haven't had diarrhea since being a little girl, but throughout my week stay in that waiting room I found myself lunging for the toilet. To be honest, under normal circumstances I was among those who would avoid shitting in public at ridiculous costs. My body was sleep deprived and nutrition

miles and miles away as I stared at my mother's leathery face. It reminded me of a baked potato on the verge of bursting in the microwave, just begging for some fork to be the hero and pierce through its tough skin to release the steam. I looked at her wilted hands crossed over her body and thought about the last time we spoke, after she seized and right before she fell into the coma. She had sat up in the hospital bed and held my head between her two boney hands. "I love you so much it hurts," she slurred. She was so drugged up, and I couldn't stand it. She kept holding my head for what seemed like hours and kissed my face repeatedly. I didn't cry at the time, but I don't think I will ever be able to control myself from crying when I think of that moment now.

I felt my Grandmother grab my arm, and I was brought back to reality. I was instantly angry as I realized I was looking at my mother's lifeless body. I was told that the service would be closed casket since she had lost an unhealthy amount of weight and also had a black eye from the fall of the seizure. No one wanted to remember her like that. Yet there she was, puckered and orange, with no trace of black and blue. I looked at my father and asked him why no one had said anything to me. He said people needed closure and he should have told me. I looked around the silent funeral home as I stood with my back to the coffin weeping loudly. I could read everyone's thoughts: "What a shame, and so young."

Talking to my family about my mother's death has been troublesome for me. My brothers each have families of their own and my father has recently started dating. While I am still trying to understand my feelings, they have all reached acceptance. My brothers both tell me I can talk to them about it always, and I appreciate that, but it isn't so easy. I feel as if bringing it up only reopens the wound, especially with my father. I know that I will start crying uncontrollably to the point where I hiccup myself into a frenzy while they stand by and console me. I don't want to be the coddled young one anymore.

I avoid talking to my family and instead seek salvation in my partner. A constant source of support and love in my life, I break down to him regularly. I understand that unloading all of my emotions onto him without help from my family is a strain



I am a very sensitive and emotional person, I acknowledge this. I am my mother and she is gone. We understood each other because I was created from her heart and flesh. Now being the only female in my immediate blood-related family (father and two brothers), I am faced with a more concentrated edition of my own emotions in a less emotional environment. Everyone still grieves, but they grieve less, or differently, since they have all dealt with the situation. My grieving process has been stunted due to a few reasons, one of them being me moving out of my parent's house to Brooklyn a month after the funeral in order to avoid dealing with it. I didn't want to be in that home, when really it's exactly where I should have been. The lack of support from my family the past two years has seriously affected my acceptance of her death, and there's no one to blame but myself.

Another reason I believe I have emotionally fallen behind is due to always being seen as the "young one" in my family. The youngest of three children, I am at least 12 years younger than my two brothers. Throughout my mother's illness I was often left in the dark because it was believed that I would take the news the hardest. While that was true, it also led me to believe that death just wasn't in the cards. I was told things were fine when they weren't even close to being fine. I would find out she had been admitted into the hospital for serious issues, like a seizure caused by the disease spreading to her brain, three weeks after the fact. I was never told these things while they were happening because my family didn't want me to see her at her worst. Also, because my mother wanted me to graduate from college that year and coming home every time her condition worsened would prevent me from doing so. As you can imagine, when I was told that she was in a coma and the doctors didn't expect that she would be coming out of it, I was shocked. I was beyond shocked. I was completely outraged, yet at the same time, it was too surreal to actually believe after a year of being kept ignorant by my family and my own denial. She was put into hospice immediately and three weeks later she died.

The entire wake my Grandmother kept crying to me, "What are you doing to do without your mother?" as we sat in the first row looking at her body. I knew what she really meant: how am I, a weak girl, still so young, going to get on in life without my mother? I blocked her crying out. There was just a faint hum from

deprived, adrenaline searing through my veins. I had very little control over my bowel movements. Of course while on the hospital shitter, completely mortified, with very little strength to even stand, my head raced at the realizations that this was only a glimmer of what Jodi had to deal with when her colitis flared up.

Jodi died that week in July. I tried to regain my sanity. I slowly attempted to put nutritious food in my body, slowly trying to find a regular schedule—for me that is always a way to try to put myself back on track. My stomach troubles subsided for the time being. I am a teacher; I really don't know what I would have done without a summer vacation to buffer my healing process. I traveled to different cities, looking for hugs from friends and vegan cake and adventure to nurture me. I did a lot of writing that summer, and made the decision that at the end of the teaching year, I was going to move.

Just as I was, a lot of friends were struggling with Jodi's death in different ways—some were even suicidal. At the time I thought they were having a "harder" with it. Looking back, grief is not measurable and not comparable. One person's experience with loss affects them in a completely different way than another's. You can't measure yourself up against another person's grief. I tried my best to be this stone matriarch to my group of friends. I still cried myself to sleep, desperately needing to be held by supportive partner or a comforting friend, but I listened to every phone call and read every email from others who were struggling with her passing. Many times, I swallowed my tears and sadness in an attempts to be a good friend. But this stuff doesn't just go away, and the grief began to harden against my intestinal walls.

September rolled around, and I started teaching again at a new school—a job that Jodi had encouraged me to pursue. I cried my first day of the job, in front of my new boss, because the flood of Jodi's death had overtaken me. Teaching is a very stressful gig, but compounded by the fact that I had lost my best friend made it extremely difficult to act like I had it together to a classroom full of 3rd graders. I started to have severe pains in my abdomen. I could feel food moving through my stomach and intestines like rocks making their way down a chute. I started having a lot of trouble shitting. I wouldn't shit for days and days at a time. There were times my abdomen would grow hard and swollen. Again, my emotions were foggy, and at the time I didn't realize that Jodi had had similar symptoms.

I hated doctors, and still hadn't entirely figured out how to navigate the insurance system so I didn't go to the doctor right away. I tried to take control of my diet, pumping it full of fruits, vegetable and whole grains. I tried to avoid (to some




degree) sugars and vegan baked goods, that I had probably relied on a bit too much as therapeutic. I drank tea and more water. Nothing was working. When I finally did shit, it was violent, painful and quick, like vomiting rocks. Usually by day 3, I lost much of an appetite, not wanting to clog the pipes any more. At one point I took some laxatives (something I greatly feared) but nothing happened. Still, I did not go to the doctor.

Then one day, a few weeks into the school year I was racing to catch the L Train to work. It was a hot day, and my bag was heavy, and I was booking it—it was still early in the year and I was trying to get to school an hour early still. I jumped on a very crowded Dekalb stop subway car, trying to surf the train, as there was nowhere to grab onto. I had a decent breakfast that day, woken up the same time I always do, but I felt completely lightheaded. My vision had started to go blurry, and I lost my hearing for a moment. As soon as I got off at Graham Avenue, where my school is I dodged into a bodega to get some orange juice. I felt better, but was totally freaked.

The next day the same thing happened, except I had to get off the train before my stop for work. I was seconds away from calling for help, which is a terrifying experience when you are alone in a subway station. People often think of New York City as a place, where if people were to fall sick on the ground, others would step right over them. I don't actually believe this, but my body pumped itself with terror. I fumbled through the subway station to the nearest bodega, again my vision blurring. I drank some orange juice, my hearing and vision restored itself, but was shaken. I sipped on the orange juice, nervously chewed on the plastic straw and waited for the next westbound train when I had a flashback. A day or two before Jodi was hospitalized she had told a story of how she gotten lost on the subway around her work. She said her medicine was making her woozy and foggy. She ended up 20 blocks south of her job, and a 1/2 hour lunch turned into a 2 hour outing. She doesn't remember how it happened, but when the fog lifted she remembers be shaken with all the what ifs. I started to cry as I made my way to work.

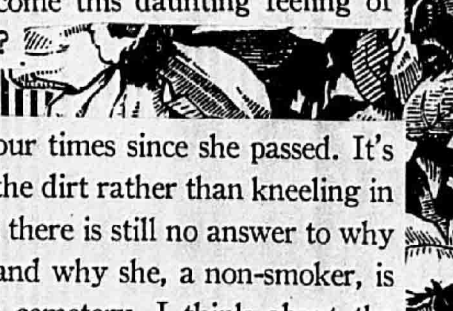
It didn't end there. I got to work, with very little time to prepare before I had to pick up my class. 3rd graders are not forgiving if you come to work not ready to go. I rushed to do my morning prep, and felt nauseated. I threw up all the orange juice I had just drank and my head rushed. It felt like I was throwing up straight whiskey or battery acid. I heaved all over the floor near my teacher's desk. I have thrown up a few times in my life (well more than a few) and several times from an over indulgence in whiskey. This was a different kind of burn, as if I couldn't get air while expelling. I



dropped to my knees in disbelief. I looked up at the door of the person who must have discarded these books and I thought about knocking on it so I could explain to them how unusual this situation was. Maybe they'd like to get some coffee with me because I really needed someone at that very moment to spill my guts to. Instead, I sat on the curb as I fingered through the damp pages of the book. I cried the hardest I had since the funeral at the sheer idea of living in such a weirdly coincidental world.

It's been over two years and four stages since my mother passed and over three years since my parents sat me down to tell me that she was diagnosed with lung cancer. Yet, even after two birthdays and two anniversaries, I still wallow in the fourth stage of depression. The hardest part of grieving at this stage is realizing that while everyone else has forgotten, I still remember. Unlike them, I will never stop remembering. No matter how supportive my friends and family are, I still feel completely isolated because I am a bottomless pit of regrets, nightmares, longings, and relentless attempts at keeping my mother alive. This loneliness is mental rather than physical. While I am constantly surrounded by my closest friends and my immediate family, I often still feel completely alone.

I understand that there is no "normal" amount of time to grieve and that each person is different when dealing with death, but my process has been seriously delayed. My question is, how do the grieving overcome this daunting feeling of emotional loneliness, and why was I left so far behind?



I've only been to the cemetery where she is buried four times since she passed. It's just too real. It confirms that her limbs are buried in the dirt rather than kneeling in it planting tulips in our backyard. It reminds me that there is still no answer to why her own seeds are prematurely planted in the earth and why she, a non-smoker, is gone with no explanation. Every time I go to the cemetery, I think about the funeral and all events leading up to it. The year before her death was filled with hospital rooms, medications, seizures, black eyes, drug highs, comas, my senior thesis, and eventually the funeral. I want to be able to think of other memories — the good ones.



# THE YOUNG ONE

By Cynthia Schemmer

In her book, *On Death and Dying*, Elisabeth Kübler-Ross outlined the five stages of death and grieving experienced by the terminally ill and their family members:

First Stage – Denial and Isolation

Second Stage – Anger

Third Stage – Bargaining

Fourth Stage – Depression

Fifth Stage – Acceptance

I first heard about this book at a grief discussion at Bluestockings Radical Bookstore in the Lower East Side of Manhattan this past spring. It was led by a good friend of mine who had recently released a self-published compilation zine on grief and dying. She asked me to contribute, knowing that my mother had recently passed, but I just couldn't bring myself to do it at the time. I wasn't ready to document my experience, turning an awful nightmare into an even more awful reality, so instead I listened to the contributors read excerpts and talk about their own experiences. For the first time since I had lost my mother, while I listened to their stories of heartache and struggle, I didn't feel alone. It felt like we were all a part of a secret society that night, like we should have had a secret hand sign that meant, "Don't worry, me too."

When the discussion ended, I took the subway back to Brooklyn by myself. I was alone again. My entire life was filled with little moments used to distract my brain from reality. I decided the next day I would go out and buy Kübler's book and it would be my first step towards recovery. As I walked home and thought about my impending release of emotions, I noticed a bag of books on the curb with a sign that read, "FREE." I peeked inside and let out a gasp that made my lungs ache. On the top of the pile lay *On Death and Dying*. I didn't know what to do with myself as I

tried to make it through the day, I was still new to this school and still trying to recover from the first impression, and but felt completely in a haze. I talked to my assistant principal, who quickly and compassionately found a cover for my class, and arranged for a teacher to drive me home. I made an appointment with my doctor, and terrified of having to take the subway alone again, I took the \$30 cab ride from Brooklyn to Manhattan.

I explained all the weird symptoms I was having to my doctor. There was a lot of scratching of her head, as all the symptoms were severe, but no conclusive connection. My doctor is not a pill pusher, and made some suggestions. She told me to do XYZ with my diet to help with the constipation and follow up in two weeks. I listened carefully, took notes, even though I felt like I had tried these things already.

The vomiting, faintness, and inability to go the bathroom continued. I felt lethargic. Eating was difficult. Most smells nauseated me. I didn't want to eat anything at potlucks. I didn't want to meet my friends for a beer at a bar. I stopped going out for a while. I would stay home on Friday and Saturday nights, clutching my side desperately wanting to call Jodi on the phone. She was (and still is) programmed in my phone. I don't know what it is like to have colitis, but everything in my abdomen was pulsating with memories of her.

I followed up with the doctor. I was referred for blood work and to a GI specialist. My GI doctor scheduled a colonoscopy. It was horrific prepping experience. You have to take drink this horrible medicine (that is pharmaceutical salt water as far as I am concerned) that flushes out your system. I had a really difficult time stomaching the stuff, mostly throwing it up. I sat alone on the tiled floor of my bathroom, too embarrassed to call any friend, crying. I was crying about everything: the shaking from vomiting and shitting but mostly because these are the parts of her illness that Jodi very rarely shared. I felt alone, and guilty that she had been alone for these aspects too.

I argued with insurance companies. I kept seeing doctors. I was in pain. I lost weight, but my stomach was always hardened. There was no conclusive answer. I finally decided to talk to my therapist about these physical symptoms. I had been seeing her to sort out a few things and we were working through various aspects of Jodi's death. She very bluntly responded, "Well, you do have a problem with holding your shit in. You are trying to control yourself from losing your shit."



I evaluated this answer over and over in my head on my subway ride home. It had been over 7 months since she had died. I had thrown myself into a new job trying to occupy the thoughts of sadness, guilt, and longing for my friend that crept into my head when I was least expecting it. I was working hard (at the negligence of myself) to be a supportive friend and partner to all the others who were suffering. I would cry with friends, but very rarely verbalize that I felt like falling apart. So I kept swallowing and swallowing the sadness. It made sense that every time my intestines would writhe in pain, I thought of her. In a morbid way I felt connected to her past the grave. I don't know if that is fucked up to say. I had only the tiniest glimpse of what she experienced.

When I started treating these physical symptoms more holistically, I started to see improvement. I made it a point to talk about Jodi's death and how it was affecting my body with my therapist. A close friend and I started going to yoga every week for the first time together, partially because exercise and taking care of the body became super important to me after her death, partially because it was a way of a supportive friend insisting I made it out of my house outside of work. When I acknowledged that her death was still earthing itself into my day to day, with a few changes in diet and exercise, my symptoms began to ease. However, I had to prioritize my healing from her death. It is not that I stopped listening to others or focusing on my job, but I forced myself to make time for myself to cry: to *allow* myself to cry. I allowed myself to admit that I didn't have to be strong for everyone-not even for myself. Most of all I started making those phone calls to friends when I felt sad. Slowly my abdomen muscles relaxed. The faintness stopped.

No doctor was able to give me a direct answer, with direct responses about the pain I was suffering. Of course, none of my doctors knew Jodi, they hadn't known the joy of her laugh, her snarky comments, her commitment to her friends. None of them knew the trauma of watching her sit in a hospital bed slowly losing her motor functions and violently falling into a coma before dying. I am no doctor, but the only thing that has given me peace with this scary time in my life, is that my body found a way to force itself along the grieving process. Perhaps I was crazy. Perhaps though, I desperately missed my best friend.

When I ignored aspects of my grief over her death they found a way to manifest themselves. They found a way to infiltrate my daily life, affecting even the most basic of functions. My intestines grieved, even when my body would not allow it.

When I wake in the raw pink dawn of the real world  
my eyes are burning. Through the kitchen window  
the land is frozen solid and it glows.  
I check for a message from a woman who loves me  
which you would hate, because she is a woman.  
I light the stove and remember  
you were the first woman who broke my heart.  
I was told, over and over, that you loved me  
by my father, who could not make you stop.  
Even if I could not see it  
this was love: contempt, rage, hysteria, despair.  
Clearly love was a painful thing, or it did not exist at all.  
Love could not be demonstrated, it could only be described  
like Santa Claus or Cinderella. Love did not feed you  
or touch you, or learn who you were becoming.  
Love required excuses and objections. Love required a defense.  
Love could not be felt, or seen; it was invisible  
like death, or the future.

I had other ideas. This was wrong.  
Life was supposed to be different. It should be fair  
and somewhat rational. There should be rules  
and predictable outcomes. Hungry people  
should be fed, sad people  
should be held, rich people  
should be generous, sick people  
should be healed, all people  
should be free. Clearly, I was crazy.

Clearly, I did not understand the way things work.

Tree-hugging liberal bleeding-heart leftist weirdo freak  
radical dyke wingnut bohemian dreamer.

When you died, perfect, of gangrene and booze  
you taught me that the world is sick and needs healers.  
You never even had to say the words.





# LOVESONG FOR MAMA

*By Jacks Ashley McNamara*

I can only seem to grieve for you in my dreams when things happen that should not happen – my father appears with a woman groomed and coached to look exactly like you, back when you could walk, and tells me to call her Kim, which was your name, even though she is young, blonde, and obedient which you were not.

I start screaming like a child in a war zone to make sure everyone knows that my mother is dead and this is disrespectful, don't you think? When morning comes, in the dream, I expect a man who loves and terrifies me to kiss my cheek and try to know my mind. Instead they have brought a doctor and enclosed my wrist in a plastic band marked with the first date I was held down by three nurses and given a shot for my own good. I was two. Now I am not allowed to speak.



## DEAR ERIC

*excerpts from a letter to a lost friend.*

*by Adelaide Windsome*

FEBRUARY 2007

I remember when I first met you in 2003. I talked to you on the phone and you gave me directions to the church Food Not Bombs served at. My first sight of you was through three stacks of milkcrates you were carrying you were carrying to the basement. Your beard stuck out from the sides.

I remember how you stood out in the hectic kitchen. You rode the chaos like bodysurfing a wave or a seed in the wind. Everything always ended up where it should. You stopped coming shortly after I started.

I remember my twentieth birthday. Taking all your stuff to a friend's house down the street. By this time you were having lots of trouble physically and mentally. Your space seemed to mirror this with years of stuff scattered everywhere. Teeth in your shoe. Political buttons caked together with rust. Fliers and bank statements pouring out everywhere.

Though we knew the nature of the disease, it was depressing and frustrating not to see you get better despite our efforts. You can know something is true, but sometimes your heart or some part of you does not believe it.

For two hours I was there holding your hand. You were quiet and sleeping. At some point I heard a deep breath and a pause. I look up. Another deep breathe and then nothing...

I walk around the room and cry. Eventually I walk out in search of a doctor. I try and have a calm demeanor. I don't know why. My friend just died. I manage to squeak out to a nurse that you had stopped breathing.



I sit in the room and cry. I check your pulse again and again. I am in a state of disbelief. I see your lips turning a blueish purple.  
I don't know what to do?  
What to do...

Eventually I leave the room. Someone is waiting so they can go in and clean up. They comb your hair and I can't recognize you.

I sit outside your room crying. An elderly woman walks up to me. Her name is Nancy and she has Alzheimer's. She used to be a swimmer.

"Are you a boy or a girl?"

"I dunno... What are you holding?"

"Oh I don't know... It's a bowl I suppose"

"Did you make it?"

"YES!"

(more crying)

"Well I guess you can come with me...if you want."

Thank you, Nancy. For saying the right things, for saying something.

I miss you so much. I miss our walks in the arboretum, eating bagels, laughing maniacally. The fantastic things you said, the amazing things you did throughout your entire life. You will always be an inspiration to me. Making my life resistance, being persistent, and knowing my boundaries.

love  
adelaide

They found her overdosed on insulin. From one of her friends we learned it was probably an accident- they had been taking insulin to lose weight. I think this fact more than anything fills me with sadness. People deal with trauma in different ways, and now, after 6 years have passed, I think her way of dealing with all the fucked up shit that had happened to her was to try and live in a prescribed normalcy that is perpetuated in this society. In my own life, I support radical mental health, which is not to say it fixes everything that wrong, or that aspects of traditional mental healthcare are not valid. I don't know... I wish she had a place where she could have freaked out if she needed to and it would have been ok. I wish she would have known there are other avenues to surviving in this world than the path she chose. Or the path she was told would be best for her by doctors in sterile white rooms (go to school, fall in love, get married... put the past behind you) or whatever it was.

Life is full of wishes. And I wish she could have painted and gone to shows and had better boyfriends than the ones she had. I wish she could have become a nurse. I wish she would have known how beautiful she was. And I wish I could say that time and space makes it easier for the ones still here. When she was still alive I saw her boyfriends mirror each other- I saw her grow sad time and again, slice her arms, go for stays in fairfax mental institution. Every time she reacted to her sadness in the same way, she received the same treatment. Isn't that the first sign of insanity? Doing the same thing over and over and expecting a different result? And maybe a different approach would have helped. But who knows... I wish radical mental health collectives were more known about. And I see them growing, cropping up, and I have hope. There's a long way to go, but there's still hope.

In two years I will go back for my high school reunion. And I will see the classrooms where we stole kisses, and held hands, and cried, and held each other. Only they will be different rooms with different stories than ours. There will be no "remember when..." followed by laughter. There will be no shared memory of specific instances. There will only be mine, which I will probably keep to myself to avoid making other people feel uncomfortable. And perhaps afterwards I will finally go say goodbye at her marker in the cemetery down the street.\*

\* Since writing this I decided to bail on my high school reunion. The friends I want to see and I are going to New Orleans instead.



KELLY

*By Miss C. Bean*

It wasn't as if it was one of those horrible breakups preceded by months of growing bitter and hateful. It was time and place and circumstance. Moving into new lives, new places. And there was never any intention of staying together. Which was not to say we didn't love each other. It was not the first time for either of us, and it would not be the last.

The last time I saw her we sat on my couch drinking beer in an awkward silence. "I think you're the only woman I have ever loved. And I did. And I do, and it's just..." she says. It's time and space and circumstance. And our love stays in the memories of youth. In the spaces of healing and tenderness where it began.

I don't remember who called me that night, a few weeks before Christmas, three years after that conversation on my couch. I remember sobbing under the covers, clawing at the skin on my arms, trying to scratch some sense of reason out of the situation with my fingernails. Screaming into pillows. Staring numbly at the computer screen at work during the day. My partner bringing me boxes of tissues. Later, me calling Megan and talking for hours and hours. Talking through the sadness and loneliness. Me deciding not to fly back for the service because I did not want to say goodbye amidst classmates, many of them who weren't even really friends of hers in the first place. I can't equate a high school reunion with saying goodbye to someone I love. Sometime I will go see her marker and say goodbye in the way society prescribes, but now I say goodbye to her by reading old letters, seeing her in dreams, talking about her with friends.

## *Brief thoughts on Grief and Activism 2010*

A few months ago, I revisited artwork, poetry, and photography from the year 2006. I never kept a written journal relying on other mediums to capture the essence of the past. The above letter was the most explicit piece I ever wrote.

During this year, I came out as transgender to my family and community and experienced a relapse into suicidal depression.

Throughout this, I care partnered full-time with Eric Weinberger, who at that point had late Alzheimer's disease. There were five of us working with Eric, twenty-four hours a day, and a number of people who supported us through the process by helping make meals or just making time to talk. The simple gestures mattered the most.

As someone confronted with such emotional turmoil, I felt too selfish and needy to ask for support or communicate exactly what I was dealing with. All my friends were activists. I did not wish to be burden upon other people's ability to organize more effectively than me. There was no outlet for release or respite. In response, I internalized a lot of self-hatred.

In many ways, I owe Eric for saving my life.

Eric was in a wheelchair for much of that year. Bringing him to events and protests was difficult since most of the time a flyer never said whether or not a space was accessible, many times it was not. So many people, even people who once knew him, simply ignored Eric or talked down to him because he communicated differently. Whatever state Eric may have been in, he felt that.

Ableism is an issue frequently un- or ill considered.

### *Two things I learned from 2006:*

1. I cannot participate in activist project that ignore self-care and anti-oppression as a vital part of the process. This is not a bridge you can simply cross when you reach it.
2. Grief irrevocably changes who you are.



Eric hanging out at  
Jamaica Pond in Boston.



After Eric's death I expected to fall back into a lifestyle I had previously: attending meetings, working on projects, and traveling to different conferences and actions. I tried working with several environmental groups who were not eager or unwilling to connect to issues of self-care and anti-oppression. This model of activism had not been sustainable for me and now I realized that.

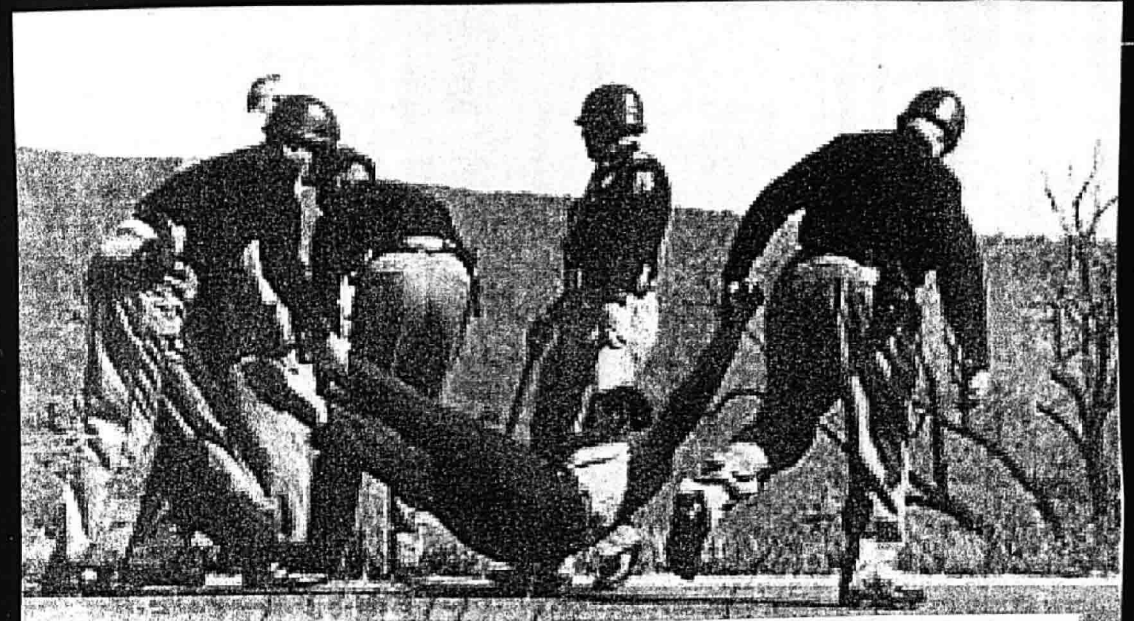
These days, I create lots of artwork and performance stemming from a lack of empowering language around mental health issues and as an outlet to discuss social justice. I find solace in fairy tales and fables, and find fiction connects to a different kind of audience. I call this activism even though it looks very different from how I originally learned to be an activist.

Nearly four years later, I still cry sometimes when I think of Eric and will forever draw strength and inspiration from his indomitable spirit.

Grief will change us; grief will fuse with our hearts. Still, we have the ability to facilitate this change in a positive manner, for survival and to honor the past.

### *About Eric:*

Eric was a dedicated lifelong activist. He participated in the Civil Right Movement down South working with groups such as Congress for Racial Equality (CORE) and Student Nonviolent Coordinating Committee (SNCC). He went on to organize with anti-war and ant-nuclear movements in the 70s and 80s. While in Boston, he became a pillar in Homes Not Jails and Food Not Bombs. Eric was a mentor for countless younger activists and carried himself with a humble dignity. Check out the link below for a full biography of Eric's amazing life: <http://boston.indymedia.org/feature/display/195669>



Eric being arrested during a march from Chattanooga, TN  
to Jackson, MS during the Civil Rights Movement.