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## Living and Grieving Beside Judith

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*When my mother Judith was diagnosed with pancreatic cancer in 2005, I was pregnant with my second child, Rosemary Judith, and was frantically trying to finish up my dissertation on Judith Butler. By the time my mom died in 2009, I had lived with and cared for my daughter Rosemary Judith for over three years and had read, written about, presented on, and taught Butler's *Precarious Life* and *Undoing Gender* many times. This essay is an experimental attempt at juxtaposing my experiences of living and grieving beside three different Judiths: my mom, Judith; my academic muse, Judith Butler; and my daughter, Rosemary Judith. My goal is not to connect these experiences in any easy or seamless way, but to put them beside each other in the hopes of presenting one person's (as daughter/scholar/mother) tentative and unfinished account of grief, loss and the livable and not so livable life.*

My mom Judith died last year on September 30. Diagnosed with a particularly nasty form of cancer—pancreatic—back in October of 2005, she had defied the odds by living for four years: three and a half years longer than expected.

When she was diagnosed, I was pregnant with my second child, Rosemary Judith, and was frantically trying to finish the final chapter of my dissertation. That chapter was about feminist virtue ethics and drew heavily upon Judith Butler's work in both *Precarious Life* and *Undoing Gender*. I wrote part of it on my laptop at the hospital while the doctors were attempting to remove my mom's tumor and half of her stomach.

While Butler writes a lot about grief, my reading of her work in the hospital was not motivated by state of impending loss and my recent realization of how I was vulnerable and, in the words of Butler, undone by my mom's not-

yet-death. Instead it was motivated by my urgent need to make sense of what kind of life my mom could expect to have if she survived this risky surgery; I was searching for an answer to Butler's poignant question in the first chapter of *Undoing Gender*: What makes a life livable (17)?

By the time my mom died in 2009, I had become a mom again—Rosemary Judith was born in March 2006—and I had spent a lot of time living beside Butler's work on grief and the livable life. As I watched my daughter grow from a newborn to a toddler to a troublemaking kid, and my mom slowly, and then rapidly, deteriorate, I had read, written about, presented on, and taught *Precarious Life* and *Undoing Gender* many times. I frequently thought about the livable life and how my mom was able to hold on to so much of it for so long, even as it was being stripped away from her in many big and small ways. As she refused, or was unable, to die over the last six months of her life, after the second round of chemo made her too weak even to walk and I struggled to be a good-enough mother, I wondered about the value and limits of grieving and staying in a state of grief for too long. Does that state of grief necessarily require a temporary suspension of life? And if so, what does this suspension mean for our own livable lives and for the livable lives of those for whom we care?

Judith Butler has been a part of my living with and grieving beside my mom in many ways. It is not so much that her work has comforted me (although it has), or allowed me to fully make sense of my mom's illness and death (what could, really?), but that it has always been a part of this process for me. When my mom was diagnosed I was reading and writing about *Precarious Life*. When my mom died I had just completed a presentation on Butler, *Undoing Gender*, and the virtue of staying in trouble. And for much of the time between those years of diagnosis and death I was reading and thinking about Butler in relation to my own theories about making and staying in trouble.

But just as Judith Butler has been a part of my living and grieving beside my mom, my mom and her terminal cancer have been a part of my living and grieving beside Judith Butler. My reading of, and subsequent teaching and writing about, Butler has been informed in many different ways by my mom, her illness and my experiences of struggling with her impending death. When I was in the waiting room as my mom's tumor was being removed and I was writing about the livable life, I wasn't thinking only about how Butler's articulation of the livable life would shape my ideas about what was happening to my mom; I was thinking about how what was happening to my mom would shape my ideas about Butler's articulation of the livable life and her larger project on grief. My mom, and her experiences living with and dying from pancreatic cancer, powerfully shaped how I read and think about grief and life, and the ways in which loss and life undo us.

To complicate this even further, my living and grieving beside Judith Butler and my mom Judith have been shaped by my experiences as the mother to a third Judith, Rosemary Judith. Throughout the past four years my daughter was beside me. I was pregnant with her when my mom was diagnosed and I was writing my dissertation on Butler. I was breastfeeding and staying up with her almost every night while my mom was recovering from her first round of chemotherapy and as I was teaching about the ethical turn in Butler's work. I struggled with her frequent (and very typical for a three-year-old) proclamations of "I hate you" as my mom started falling down too much and as I taught a graduate class on grief and being undone in Butler's *Undoing Gender*. And I marveled at her feisty and troublemaking spirit as my mom's weak body revolted against her almost indestructible spirit and as I began writing about the virtues of troublemaking and troublestaying for both an upcoming presentation and my blog.

This essay is an experimental attempt at juxtaposing my experiences of living and grieving beside three different Judiths: my mom, Judith; my academic muse, Judith Butler; and my daughter, Rosemary Judith. The purpose of this essay is not to connect these experiences or my narratives of them in any easy or seamless way, but to put them beside each other in the hopes of presenting a tentative and unfinished account by one person (as daughter/scholar/mother) of grief, loss and the livable and not so livable life.

### **Being Beside: An Explanation**

Throughout the past four years all three Judiths have been central to my life. They have been beside me, and beside each other, as I have struggled to make sense of and endure grief and impending loss. In addition to the literal ways in which each of them has been beside me, these three Judiths speak to three different roles that I have negotiated simultaneously but not easily or always successfully: the daughter, the scholar, and the mother. Negotiating these different, sometimes conflicting and frequently exhausting roles has been a constant challenge that manifested itself in some unique and troubling ways. At times my roles seemed to complement each other. Being a mother comforted me as I prepared myself for the impending loss of my own mother. Being a daughter losing a mother to cancer opened my scholarship to new ways of thinking and feeling about women's narratives of cancer and illness. Being a scholar provided me with a useful outlet for exploring and reflecting on losing a mother to terminal illness.

At other times, these roles came into conflict and made me doubt my ability to properly inhabit any of them. How can I be a good enough daughter to my mother and a good enough mother to my daughter at the same time? How can

I laugh with my daughter while my mom is lying in a bed, seven hours away, struggling to eat, to breathe? How can I think critically and abstractly about the limits and possibilities of grief and coming undone, when I am in the midst of the process myself? For the past four years, the roles of daughter, mother and scholar have resided beside each other. Just like my living and grieving beside the three Judiths, they are not reducible to each other, yet their existence in relation to each other has shaped my experiences of grief and loss. In losing my mother, I am not just a daughter; I am a mother raising her own daughter. In raising a daughter, I am not just a mother; I am a daughter without a mother. In reading, writing and teaching about Butler's notions of grief and the livable life, I am not just a scholar; I am a mother and a daughter struggling to make sense of grief and the livable life.

## Grieving Beside Judith

### *Fragment One*

... one mourns when one accepts the fact that the loss one undergoes will be one that changes you, changes you possibly forever, and that mourning has to do with agreeing to undergo a transformation the full result of which you cannot know in advance (Butler, *Undoing Gender* 18).

The idea of undergoing a transformation that one cannot know in advance is central for Butler and her vision of social transformation. In *Undoing Gender*, she discusses the value of unknowingness and of not trying to securely and definitively establish one's plan of action prior to acting (227). For Butler, grief is central to this experience of unknowingness and the risks that we take to maintain and embrace it. Overwhelmed with sadness and exhaustion and unable to compose ourselves or to deny our vulnerability to loss, we cannot pretend that we have control or that we can always know with certainty how to act or who we are. In risking unknowingness, we are transformed into individuals who don't know, but who are willing to act anyway.

*Up until the last year, when she could barely speak, my mother and I loved to talk. Frequently our conversations were inspired by my mom's curiosity and her wonder about the world and ideas. Having been a teacher for over 20 years, she asked lots of questions and always liked to learn more about what I was reading or what I thought. Her curiosity was not motivated so much by a desire to know, but by a desire to feel and experience as many different ways of understanding as she could. She found joy in contemplating the why and how and seemed to be energized by what she didn't*

*and might never know. Somehow she had held onto the wonder that children seem to have, but often lose as they grow up. I inherited that wonder from her and I witness it in my daughter Rosie J everyday.*

To acknowledge that we don't know, that we are uncertain about how to proceed, doesn't always produce anxiety and isn't always best understood in relation to grief. To be open to undergoing a transformation of who one is in ways that one can never anticipate isn't always to risk unknowingness. It is an invitation to wonder, to be curious and to imagine the world in new and mysterious ways. My experience of being beside my mom as she was dying transformed me, to be sure. But it was more her persistence in life and my memories of how she envisioned uncertainty and unknowingness in terms of wonder and joy instead of anxiety and loss that transformed me, not her death and my grief over her loss.

### *Fragment Two*

*The attempt to foreclose that vulnerability, to banish it, to make ourselves secure at the expense of every other human consideration, is surely also to eradicate one of the most important resources from which we must take our bearings and find our way (Butler, *Undoing Gender* 23).*

In *Precarious Life*, *Undoing Gender*, and *Frames of War*, Butler repeatedly emphasizes the importance of grief and vulnerability. She discusses the value of grief in relation to those who have been denied the right to grieve their loved ones and/or have had their own lives considered unworthy of grieving, and therefore not fully human. She also describes how grief, as a state of being and as a non-violent response to others, is urgently needed if we are interested in arresting cycles of violence (Butler, *Precarious Life* xii). Much of Butler's discussion of grief is in the context of two specific historical, cultural, social events: the AIDS crisis and GLBTQ communities' inability to grieve their lost loved ones, and the U.S. government's quick and very violent response to the 9/11 terrorist attacks in New York City. In these situations grief is the thing needed because grief has been so unjustly or unwisely denied and/or foreclosed.

But, even as Butler devotes considerable attention to specific contexts in which grief needs to be promoted, she has grander aims for how and why we should value grief. She believes that grief is a valuable state to be in, and is an important part of what it means to be human. Grief, and the vulnerability and sociality of the self that it reveals, help to guide us as we struggle to develop less violent ways to exist in the midst of and beside others.

*I was always so tired. I had been living with my mom's impending death for three years and she was really starting to look bad. My dad warned me that it would probably get a lot worse. My daughter had just turned three and was entering a new phase, the "I hate you" phase. With no warning and for no apparent reason, she would matter-of-factly state, "I hate you." It was really hard to hear. I wondered, how can I be a good mother when I'm sad all of the time? What is it doing to my daughter to live in the shadow of this death and my grief over it? Were her repeated declarations of hate more than a phase that all three-year-olds go through? Was she trying to warn me that I was failing as a mom and remind me that I was more than a daughter losing a mom, but also a mother who needed to care for her daughter?*

While I agree that being in a state of grief is valuable and can help to remind us of our vulnerability in the midst of others, it can also place unrealistic and unhealthy demands on us. It is difficult to balance the need and/or desire to grieve with the demand to care for others. Are there other resources, aside from grief, that can guide us as we navigate the difficult terrain of being a daughter losing a mother and a mother raising a daughter?

*The first two years of my mom's terminal illness weren't too bad. Even though she had been diagnosed with a death sentence (six months to live), she was able to qualify for surgery and undergo chemotherapy. She experienced a miracle recovery, welcomed two new grandchildren into the world, and traveled to Paris and Sydney. Then the tumor came back. Slowly she deteriorated. First one of her wrists became numb so she couldn't do any of her artwork. Then her anxiety and the morphine she had been taking daily for two years made it almost impossible for her to read. Then she started falling down a lot. Suddenly one day she couldn't walk. My sisters and my dad arranged for hospice at home. We thought she was about to die, but we were wrong. She looked terrible. She couldn't talk. She could barely eat. She slept a lot. Yet she continued to live. To me she was already gone. I wanted desperately to grieve her loss, but I couldn't; she was still alive. I was tired of being in a state of grief, yet unable to grieve; tired of witnessing her suffering and feeling helpless and unable to alleviate it. Four years of waiting, with uncertainty, for death is a long time.*

As someone who spent the last four years grieving for a mother dying an excruciatingly slow and painful death, I am not interested in mining the ethical and transformative possibilities of grief. I don't want to keep grieving; I want to *stop* grieving, and I want to think about what other resources I have to guide me as I attempt to recognize and live with my vulnerability. What about humor, joy or even wonder? Are there ways to think about risking uncertainty and

our unknowingness that are not connected to grief as something that is only negative and that always signals loss—of control, of autonomy, of stability?

## Living Beside Judith

### *Fragment Three*

I think one is hit by waves, and that one starts out the day with an aim, a project, a plan, and one finds oneself foiled.... Something takes hold, but is this something coming from the self, from the outside, or from some region where the difference between the two is indeterminate? What is it that claims us at such moments, such that we are not the masters of ourselves? In what are we tied? And by what are we seized? (Butler, *Undoing Gender* 18)

Central to Butler's understanding and promotion of grief is the idea that grief interrupts life as we know it or as we *think* we know it. Hit by waves of sadness and loss, we come undone and are forced to recognize our own dependence on others and our vulnerability in the midst of those others. This recognition is described in relation to loss: the loss of certainty, loss of autonomy, and loss of control. Butler envisions these feelings of loss as having the potential for opening us to new ways of being human and of forming connections with others.

*The social worker told us we needed to let our mom know it was okay to let go. We needed to tell her she had our permission to die. One of my sisters planned a big dinner for mom and the three of us readied ourselves for the painful conversation. Just before dinner I turned on some music—The Sound of Music. Spontaneously I, sometimes with my two sisters joining in, performed the entire musical. At one point, maybe while I was singing “The Lonely Goatherd,” I realized that this was one of those big moments in my life. My mom may have been dying, but she was laughing too. Well, at least her eyes were laughing. And we were all having a lot of fun. Towards the end of the album, when Mother Superior sings “Climb Every Mountain,” I hit the high note! I mean, I really hit the high note—vibrato and all. We laughed and laughed and then brought our mom her dinner, forgetting all about the painful conversation we were supposed to have.*

Sometimes life interrupts grief, not the other way around. Our best intentions of grieving properly are undone. Our attempts at making sense of how grief is supposed to be are troubled by life's persistent refusal to stop happening. For our belief in self-mastery and autonomy to be interrupted by someone or

something greater than us doesn't always just signal loss and demand that we grieve; it can also signal life and joy, and invite us to laugh and to live.

*My mom was diagnosed with stage four pancreatic cancer in mid-October 2005. I was about 18 weeks pregnant with Rosie. A few days before I drove to Chicago to see her, maybe for the last time, I had an ultrasound. I found out that my baby was a girl. When I arrived at my parents' house, I told my mom that she was going to have another granddaughter named after her: Rosemary Judith. I was fairly certain that my mom would never meet Rosie J; the doctor had indicated that she might only have six weeks left. Six months later, my mom took a break from chemotherapy to visit us and meet her new granddaughter. From the moment she was born, Rosie exuded life and joy. Her spirit and joy of life were amazing and infectious; she compelled you to engage with her and the world, whether you wanted to or not.*

There is something else that resides next to (beside) and in addition to (besides) grief as we struggle to make sense of our human vulnerability and the ways in which we are done and undone by others; joy is another “one of the most important resources from which we must take our bearings and find our way” (Butler, *Undoing Gender* 18). While Butler briefly mentions the importance of joy, in the form of pleasure, she focuses her ethical and political project almost exclusively on grief. As I learned the night I sang with my sisters and as I am repeatedly reminded as I look at Rosie J, grief and joy reside in the midst of each other and sometimes in spite of each other.

#### *Fragment Four*

... it becomes a question for ethics, I think, not only when we ask the personal question, what makes my own life bearable, but when we ask ... what makes, or ought to make, the lives of others bearable (Butler, *Undoing Gender* 17)?

Butler connects her theorizing of grief to the question of what makes life bearable and livable. Distinguishing the livable life from the basic material conditions that make life possible, Butler wants to think about how and when lives are and aren't deemed recognizable and worthy of life and of being grieved (39).

*I was never afraid to lose my mom. Okay, that's not true. Before my mom was diagnosed I couldn't imagine how I could ever live without her. Her death was the one I feared most, even more than my own. Yet once I learned she would die soon, it wasn't her impending death that made me come undone; it was her life and what it*

*would mean for her (and for me) if she lived, without half of her stomach, always haunted by death, not knowing when the cancer would come back or when she would no longer be able to walk. As sad as knowing she would soon die made me, I knew I could handle her death. But I wasn't sure that I could handle her painful, yet inevitable, journey towards it.*

Butler contrasts her notion of the livable/bearable life with the good life and argues that the good life is only available to people whose lives are already possible and recognizable and who don't have to devote most of their energy to finding ways to survive and persist. For her, the question of the livable life must necessarily precede the question of the good life, because to strive for a good life, one must first be recognized as having a life.

*My mom started falling down a lot. It wasn't safe for her to be alone. The decision was made to begin hospice care. She was no longer living with cancer; she was dying from it. She had entered the final stage. Any thoughts about a cure or remission—that hope for a good life to be achieved again in the future—were replaced by practical discussions of how to ensure that she continued to have a comfortable life that was free of pain. The good or even livable life were no longer possible for her. The best she could hope for was the bearable life. And what she could expect (and eventually did reach) was something that seemed even less than the bare minimum requirements of life. Yet, even as I witnessed her decline and the resultant shift from good to livable to bearable to unbearable life, I can't really make sense of her experiences of those last four years (or even the last six months) as just surviving until the inevitable. Up until those last days, years after she was supposed to die, she lived and, in moments, however fleeting, flourished. She enjoyed life, she laughed, and she loved her daughters, her grandchildren and my dad.*

What makes for the livable life? How do we distinguish that life from ones that are merely bearable or others that flourish? Who gets to make this distinction and how do they do it? My mother's living and dying with pancreatic cancer pushed at the limits of my understandings of life and how and when it is possible.

### **There Is No Conclusion, Only Another Fragment To Place Beside The Others**

There is a more general conception of the human at work here, one in which we are, from the start, given over to the other, one in which we are, from the start, even prior to individuation itself, and by virtue of our embodiment, given over to an other: this makes us vulnerable

to violence, but also to another range of touch, a range that includes the eradication of our being at the one end, and the physical support for our lives, at the other (Butler, *Undoing Gender* 23).

Butler devotes her attention in *Precarious Life*, *Undoing Gender* and *Frames of War* to how the recognition of our vulnerability in the midst of others often results in very violent, yet always failed, attempts to deny or conceal it. But she offers, albeit briefly, the possibility of another way of thinking about and responding to our vulnerability as caring for and being in loving proximity to one another.

*The night before her big surgery, the one that would determine whether she lived (for how long?) or died (on the operating table?), my mom was scared. She really hated doctors and hospitals. And she didn't want to die. My oldest sister asked her if she would like to cuddle with her three daughters on the bed. She agreed, and together we—the three daughters and Rosie J, still in my womb—lay beside Mom. We held her as we waited, not knowing what would happen next.*

My living and grieving beside my mom Judith and my daughter Rosemary Judith has enabled me, through joy and sadness and life and loss, to bear witness to the potential of this second non-violent meaning of vulnerability and to imagine the ethical potential of grief to be found not so much in what we have lost—a loved one—but in what we have gained: the recognition that we have the potential to love and be loved, to care and be cared for.

## References

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