

## Disenfranchised Grief: Exploring the Complexities of Hidden Sorrow

What I loved most about him was the contagious nature of his raspy laugh, how he'd throw his head back laughing, and what a thrill it was to make him laugh. I still get whiffs of his sweet cherry tobacco. He smoked a pipe and vaped and loved the attention he received blowing giant clouds of smoke in public places. He was the funniest person everyone, both in and out of the family, knew. He lit up every room and the party didn't start until he showed up. When arriving at family functions, I was met with greetings and usual formalities and always anticipated the question, "Where's Robby?" — a question I will never hear again. Wherever we were, he was never far behind. We were a package deal.

My grief becomes invisible when the world expects me to show up unaffected by the loss of my Uncle Rob. Living in the shadows of the present opioid crisis are all the lives lost and the invisible mourners who live with disenfranchised grief; grief that is not socially accepted by society, as it does not fit into normal conventions. Many assume that the hardest days after death are in the first few weeks of mourning, and after that period individuals should start to resume normal routines with ease. This misleading belief devalues the processes of grief, as initial shock and subsequent stages ebb and flow in different cycles for everyone. The model of the Five Stages of Grief adapted by Elizabeth Kubler-Ross expresses that there is no linear process of grief and individuals can move back and forth between different stages at different points during their grief journey. Losing my Uncle Rob to a fentanyl overdose, just before I moved away to college, unveiled the intricate depths and heartfelt complexity of the grief journey.

My grief journey began on July 21, 2022, when my mother and I were the ones to discover that Uncle Rob had died alone in his apartment due to an overdose. When you hear the words "fentanyl overdose" or "heroin addict", your preconceived notions of drug addicts may

skew your perception. You might think of a skinny man, dirty and old, lying on the side of the road with needles and rain puddles surrounding him. Your imagination would paint you an erroneous picture of my Uncle Rob. Robert Alan Miller was a dapper man who prided himself on dressing in the finest linens and suits from designers like Brooks Brothers and Calvin Klein. He was a man who color-coordinated his closet, quoted authors like Oscar Wilde and Friedrich Nietzsche, savored every sip of matzo ball soup from his favorite deli, and loved Christmas. But, even if my uncle possessed none of those quirky but charming qualities, it would not diminish my right to grieve.

One month following his death, I moved away from home to begin my studies as a music therapy major at Montclair State University. While grappling with the weight of a traumatic loss, I found myself navigating the challenging path of simultaneously fulfilling the expectations of being a dedicated and friendly student. My natural tendency to strive for perfection with my grades instinctively kicked into autopilot, serving as a buffer between my grief and the demands of my schoolwork. I quickly found myself bargaining between rest and good grades.

The combination of sleepless nights plagued by night terrors and dysphoria surrounding my uncle's death made it challenging for me to attend class some mornings. The ambiguity in attendance policies at Montclair State, where professors have discretionary power, intensified my anxiety when faced with the dilemma of choosing between taking care of my mental health or fulfilling my academic responsibilities. During my grief journey, I've learned how common it is for those who have lost someone traumatically to experience night terrors. In fact, "Studies investigating the occurrence of nightmares demonstrated that following a traumatic loss, 45–88% of children and adolescents experienced frequent/severe nightmares" (Eisma, Lancel, Stroebe 2020). This is one of the many layers of my grief that the outside world does not see.

What is more scarring than the nightmares is the sense memory of “the sweet smell of death.” I never understood that saying until I had to clean out my uncle's apartment with my parents...The intensity of what I heard, saw, and even smelled that day will forever be imprinted on my mind. It is difficult to recall everything that happened and in what order that day, but my memories come in spurts. I helped my father bag up the old soiled recliner Uncle Rob died in and rolled it to the dumpster outside his apartment. As I was packing up his collection of designer ties and various clothing, there were mumbles about what could be kept and what had to be left. We were preparing to move and couldn't take much, plus it was impossible to stay in that studio apartment with a discernible smell that lingers after a person expires and isn't found for three or more days. There are times when I can recall only the sweet smell of pipe tobacco, but other times the smell of his death is all-consuming. I remember my Mom and Dad pulling a gallon-sized Ziploc bag from a safe that Dad had finally broken open. We all stared at the bag filled with dime bags of white powder (fentanyl) and new syringes. It became clear but not surprising that Uncle Rob had been using for a while and may have been preparing to unalive himself. I'm actively working through this trauma; but contrary to some beliefs, therapy is not a cure for grief, but rather a space where I can learn to cope. What I saw and smelled in his apartment are experiences I do not wish on anyone, but I share this to shed light on how little a person can know about someone's grief.

While US universities and employers offer attendance policies with bereavement leave, which, like many other countries, is typically limited to five days, this may not adequately provide the necessary time individuals require to process any type of loss, especially when it is a traumatic experience. Factors like age, one's relation to the deceased, and the severity of the circumstances also play a role in how long one may take off from work or school to grieve. In

the article, “An Invisible Grief – Group Work with Bereaved Siblings,” psychologist Barbara Dickson, who lost her brother in an accident, discusses the negative impacts of having a poor social understanding of grief by describing, “In many workplaces and schools, little leeway was given to most bereaved siblings. They were expected to perform as normal, despite the known effects of grief such as lack of concentration, low energy, and intense changeable emotions, which lead to lower school marks and to work performance dropping below previous standards” (2002).

Society lacks even more compassion when the deceased has “completed” suicide or has died as a result of circumstances deemed taboo. We’ve constructed a general perception that life, people, and things must be pleasant, easy, and successful. These standards disregard the complex realities of human suffering and death. The Montclair State University website provides information regarding attendance policies, which appear to be determined by individual professors for each class. However, these policies seem to differ across departments, resulting in a multitude of approaches to handling student absences. This can amplify the stress experienced by students as they navigate the uncertainties surrounding attendance expectations. Most universities fail to consider the whole student when it comes to academic performance. If students are expected to pay hundreds of thousands of dollars for a college education, their universities should not only be concerned with their achievements and completion of course requirements but also the overall health and well-being of their student body. The ability to thrive academically is significantly impacted by one's emotional, mental, and physical state.

Recent studies on college students and grief have found that “Approximately 60% of interviewed seniors had lost at least one family member or friend since the end of their first year in college, and nearly 1 in 4 (22.8%) reported experiencing multiple losses among family and

friends” (Cox et al., 2015). When spouses, parents, children, or siblings lose a loved one, they are afforded a limited amount of understanding and assistance from society. However, when one loses someone like a friend, uncle, or ex-spouse, there is a significantly different standard set for grief and compassion. Recent studies suggest that with common grief (e.g. losing an elderly grandparent to natural causes), symptoms can begin to alleviate after six months. This timeline does not account for the mourning period in complex grief after a traumatic loss (Cox, 2022). The meager but standard five-day bereavement leave in this country fails to recognize the depth of sorrow and healing time required after a loss, rendering it inadequate and counterproductive.

It has been nine months since my Uncle Rob died from a fentanyl overdose and much like other disenfranchised griever, I live in a complicated state of sugarcoating the way I talk about him. The stigma surrounding his death adds a level of shame to my grief that would not be there had he died a “good” death, such as from old age or a health condition. I typically say he died of substance use, as an attempt to preserve his memory and soften the blow. The minute I say “heroin overdose” a stereotype is depicted in a person’s consciousness, and biases are placed where they ought not to be. A complex, sensitive, funny, and artistic man, such as my uncle, does not deserve to be reduced to his darker final moments. An article exploring stigmatized deaths of those who struggled with substance use found that children who had lost parents to addiction deeply struggled with feeling, “unworthy to grieve” (Bauld, Valentine, Walter 2016). Additionally, people think that because I am “only” his niece there should be a limit on my grief. This standard set by society does not reflect the true nature of my relationship with my uncle. Perhaps, if he were my father, there would be more empathy from others.

Uncle Rob was more than just an uncle, at times he stepped into the role of father figure to show up in a manner that he wasn’t always capable of doing for his own nuclear family. As I

grew older I began to see his darker moments. But through it all, we always managed to bring out the better parts of ourselves with each other through humor. Even though I am his niece, I raised the funds and planned his funeral and I went through his things to collect mementos for everyone. More importantly, I did this with great honor. However, this process would have been easier if he had died in a different way. Because of how he died, I'm left with traumatizing mental images, unresolved feelings, and night terrors.

When you lose someone to an overdose, the unknowns are deeply troubling as you must learn to live with never knowing the full truth. Many disenfranchised griever wonder if their loved one's overdose was accidental or intentional. In the podcast "Grieving an Overdose – The Death of A Brother" a woman described the immediate experience of losing her brother to an overdose, "I felt like I was trying to solve a crime, trying to figure out what happened. There were a lot of questions about how he died." Like this mourner, I was left to play Nancy Drew in the months following my uncle's death. The only way I could feel some sort of control was by researching overdoses, and timelines of body decomposition, basically playing forensic pathologist to try and figure out exactly when my uncle had died and how long he had been alone in his apartment. It is haunting.

Additionally, this death has caused me to be hypervigilant and fearful of now losing my mother, Uncle Rob's little sister, to suicide. This fear is unfortunately rooted in reality. According to the journal "Suicide Bereavement and Complicated Grief", "People who had known someone who died by suicide in the last year were 1.6 times more likely to have suicidal thoughts, 2.9 times more likely to have a plan for suicide, and 3.7 times more likely to have made a suicide attempt themselves" continued, "Some may feel closer to their loved one by taking their life in the same way" (Young, 2012). The devastating impact of losing someone to suicide can

reverberate through the hearts and minds of those left behind, casting a haunting shadow that can potentially engulf even the strongest among us.

A student's life can be altered overnight and completely change the trajectory of their academic career. The article "Understanding Bereavement among College Students: Implications for Practice and Research" found that "the lack of support and understanding could make it difficult for individuals with disenfranchised grief to cope with the demands of higher education and the bereavement process" (Bistricean & Shea 2021). The sudden and complex stress of navigating college life and grief can have many negative effects on the human body. A PubMed review explained, "Grieving people have lower levels of certain immune system cells, including natural killer cells and lymphocytes. They also have higher levels of inflammatory markers which can further worsen the likelihood of illness or infection" (Buckley, 2012).

My experiences in this new life have shown me the reality of our lack of social awareness of disenfranchised grief. Most of the outside world only chooses to see what is on the surface, and I have only met a small number of people who notice my grief. We could benefit from restructuring our current ideology around bereavement to help nurture those who live with this kind of grief. There are days when my schoolwork consumes me to the point where I'm able to operate on autopilot, temporarily forgetting about my grief. I'm able to be funny and enjoy the nonsense of life. But today I was not able to suppress my grief, I cried until my cheeks were red, with a headache and nausea. I experienced the physical manifestation of what lives in my heart, the longing, the sorrow, the guilt. There's fondness and love that exists as well, but grief is like a ball in a box with a pain button. Some days my ball is small, it bounces around, rarely hitting that button; but today my ball was large and all-consuming. It touched every edge of my box and triggered the deeper depths of my grief.

I will carry this grief with me for the rest of my life, but it has given me the opportunity to raise awareness for those who are struggling like my Uncle Rob, and those like me who are learning to carry on in life without their loved ones. What you can't see is my trauma and what you can't feel is my pain, but what is visible is the person I have grown to be because of my Uncle Rob. It's the puffy veins on my hands that resemble his, my nature to clown around to make friends laugh, and my determination to teach people about the importance of showing up in your life with an open heart and compassion. I'm driven to honor my Uncle Rob by fighting for change that could shift our perspective and response to the grieving process. Just as we do with sick days in school, I believe we should allow a certain amount of excused absences for mental health days to support every student's mental and emotional well-being. Giving students the autonomy and right to choose when to care for their mental health would not only benefit work-life balance but would promote academic success. I share my story to make others aware of how little you can know about a person and that by practicing compassion with friends and even strangers, we can create a deeper collective change in how we view and treat grief in society. By fostering a more emotional understanding of the natural human experience of grief, we build a more connected and empathetic world.



### **My Promise to Uncle Rob**

Part of my grief and healing process is advocacy, and I am passionate about speaking out on disenfranchised grief and its impact on a student's life. The week of April 17th, 2023, Montclair State announced that they would offer Narcan Kits on campus. This effort is commendable and could greatly help to decrease death by overdose. However, it is a continuation of the cycle of institutions only focusing on treating the symptoms as opposed to preventatively caring for the root cause.

I believe that facilitating change begins at home. As a Montclair State University student battling disenfranchised grief, I am determined to fight for the implementation of mental health days and a standard set of sick day absences into university policy. As I began my research on this topic I was pleasantly surprised to learn of Hailey Hardcastle, a young mental health advocate who successfully passed House Bill 2191 into law in the state of Oregon in June of 2019. Her bill allows students to take mental health days off from school the same way you would a physically sick day. In her words, "That day off is the difference between feeling a whole lot better or a whole lot worse."

A common argument against the implementation of mental health days is the fear of students taking advantage of this policy, but the way it was constructed leaves little room for speculated negligence. If a student is overwhelmed and emotionally unstable, this law protects them from being penalized for missing a day of school to care for their mental health. Their guardian must inform the school of the mental health day absence and every school is able to track how many students take how many mental health days. If a student seems to be taking a bunch of mental health days, they are then required to have a check-in with the school counselor. Hardcastle explains that "this is important because we can catch students who are struggling

before it's too late." Sometimes the hardest step is reaching out for help and their hope is that this bill bridges the gap and opens up space for understanding and dialog surrounding mental health.

Montclair State's lack of policy surrounding this issue makes for an unfair playing field among student success. Some professors are accommodating and others choose not to be. Also, any biases held by the professor can sway their decision on how they handle specific student absences. Without clearly written bylaws in university policy, it opens the door to discrimination on all fronts. During my first year at MSU, I encountered a professor who only allowed for two absences and any subsequent absence afterward would lower my grade. This professor's rigid absence policy had an adverse impact and contributed to heightened stress levels. People get sick, car batteries die, emergencies happen, and people grieve. The fact that I had to operate from a place of fear for my grade was not helpful to my academic success. I believe this anxiety could have been alleviated if there were a campus-wide policy that protected my right to have not only a few physically sick days but also at least one mental health day.

If Montclair State is worried about their students overdosing and wants to provide Narcan kits to help, I would ask them to also consider their student's mental state as well. I've heard of MSU students who drop from full-time to part-time because they are too overwhelmed by their workload and feel a lack of support regarding their mental health from the administration. A peer in my class who continuously missed class through the semester expressed that in her darkest moments, she would miss class just so she could get some rest and would miss more classes because the thought of being behind in her work would trigger fear paralysis. I think of her and other students in the same boat who could have relief from a mental health day policy, as it would alleviate these symptoms of stress. The implementation of a mental health day policy into the school bylaws would undoubtedly have a profound impact on both the student's well-being

and the university's overall success. On behalf of my Uncle Rob, I will continue to advocate for mental health resources and amplify voices that need to be heard.

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