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WHAT I WISH I KNEW: WHEN SOMEONE YOU LOVE SUFFERS FROM A SUBSTANCE USE DISORDER

Thank you for inviting me to speak this evening.

As you heard from Erica McNamara's generous introduction, following my mother's death from alcoholism, I made a documentary titled *My Name Was Bette: The Life and Death of an Alcoholic* that uses her story to examine women's risk factors for developing the disease, delaying treatment, and relapsing. I made the film with my sister's help and support. *My Name Was Bette* is used in treatment centers across the nation and has been viewed by more people around the globe than Kryss and I had ever imagined. We are truly honored that Bette's story has been instrumental to so many in their journey to recovery and healing.

We are also honored that hundreds of people who love someone with a substance use disorder have reached out to us to thank us for sharing our family's story and to share their own. Substance use disorder is deeply isolating, due to the pathology of the disease and to the stigma that still surrounds it. My sister and I understand that being in communication so many people who love someone with a substance use disorder is a rare privilege and a precious and powerful gift.

Although each story is unique, many we've heard share similarities. We have learned and grown from our own experiences and from those shared so generously with us. Tonight I wish to share some of what I've come to learn about loving someone with a substance use disorder. Please take whatever is useful from this talk and leave whatever isn't. Again, every situation is unique; please trust your own truths and your own path, just as I am trusting mine.

Discovery One: You are not alone.

We know the statistics. We know that more than 20 million Americans have a substance use disorder. Virtually everyone we marry loves or at least knows someone with a substance use disorder.

Yet, as I've just noted, given the pathology of the disease and the stigma that continues to surround it, so many of us feel alone in our journey. Please break out of your isolation. Reach out to the Reading Coalition Against Substance Abuse (RCASA); attend an Al-Anon meeting; seek guidance from a social worker or therapist; ask your close friends if you can share your experiences. Supports are available all around us.

Discovery two: It's not your fault.

It's not your fault that your loved one has a substance use disorder. It's not your fault that your loved one won't seek treatment or has relapsed. Once again: it's not your fault. You know that in your head. You would be quick to say it to anyone else in a similar situation. But it's surprisingly common for those of us who love someone with a substance use disorder to wonder if we had noticed sooner, or intervened differently, or done this, or not done that, the situation might be different. Please lay down that burden.

I ask you to extend to yourself at least the same level of acceptance, compassion, and gentleness that you would extend to a friend, or a client, or even a stranger who loves someone with a substance use disorder. As you navigate the complexities of your relationship with your loved one, please be at least as generous of spirit with yourself as you are with others.

This is especially important because somewhere along the way, you or someone involved in your situation will inevitably misstep, or make a misguided decision based on incomplete information, or be forced to choose a least worst option. Allow yourself the grace to do simply the very best you can in demanding and continually changing circumstances where there often isn't a clear "right" answer.

Discovery Three: Be angry at the disorder, not the person who has it.

It's not your fault that your loved one has a substance use disorder. But it isn't your loved one's fault either. Virtually no one chooses to develop a substance use disorder. Although there might be indicators like family history that someone might be susceptible, there's no way to know who will or won't develop a disorder. One person can drink or use and not become addicted; another can't.

A therapist colleague of mine gives substance use disorder the name "Slick." I found this way of envisioning the disorder incredibly helpful. It helped distinguish between the times I was interacting with my mother, Bette, and with "Slick," her disorder. I quickly came to realize that my mother was in a classic abusive relationship with "Slick." Early on, "Slick" promised her the world and showed her a "good time." But as her relationship with "Slick" developed and solidified, "Slick" isolated her from family and friends, as she tried to hide her drinking; "Slick" controlled her schedule, as she became increasingly dependent on alcohol and needed to plan around her drinking; and controlled her money, as she needed to purchase ever greater quantities of alcohol, pay for medications and treatments for conditions related to her drinking, and pay hefty legal fees, fines, and other penalties related to her legal problems.

Eventually my mother's relationship with "Slick" made it impossible for her to continue working as a nurse, which she adored. In the end, of course, "Slick" inflicted grave bodily injury on her and, in my view, eventually murdered her.

I learned to redirect my anger away from my mother for "taking up with Slick" and toward "Slick" for abusing my mother. I did remain angry at my mother for never "leaving Slick," but gaining clarity about where to direct my anger helped me navigate the complexities of loving someone with an active substance use disorder.

Discovery Four: You need support and perhaps treatment, too.

Frankly, this discovery pained and infuriated me. I found it incredibly difficult to accept that substance use disorder is in fact a “family disease,” and that the unhealthy dynamics that are inherent to the progression of the disease are “contagious.” I was born to parents with active addictions and there’s no way around saying this – they were abusive to themselves, to each other, and to us. Every day my sister and I were exposed to toxic dynamics and that took a heavy toll on us. When it became evident that I badly needed therapy in my teens, and again in my twenties, and again in my thirties, and at points in my forties, I was furious. My parents’ substance use disorders had already inflicted so much pain and loss. I found it grossly unfair that I needed to devote immense emotional energy, limited time, and hard-earned resources into treatment to work through the damage, and at times I strenuously resisted doing so.

However, I came to accept that I absolutely had to get help in order to develop truly healthy relationships with myself and with others. I can tell you that therapy and other treatments didn’t simply help me reclaim my life; they helped me build a new life filled with joy that I didn’t even know was possible. In other words, it’s been worth it.

I came to understand and accept my need for therapy and treatment through the disease paradigm. Here’s what I mean. My mother was an Emergency Room nurse; she, and thus we, were frequently exposed to contagious diseases. Over the years, I had several mantoux skin tests to check for tuberculosis after she was exposed (the disease was more prevalent then). If one of those tests had been positive, I would have needed treatment. Period. I came to see my “exposure” to substance use disorder similarly. I had in effect “contracted” a variation of substance use disorder, and I needed treatment for it. Period.

In other words, although I understood that my parents’ substance use disorders were not my fault, or even my responsibility, attending to my own dysfunction was – and still is – absolutely my

responsibility. Seeking treatment was the only way to prevent myself from growing increasingly “ill” and from “passing on” the dysfunction I had “acquired” to others in my life.

Discovery Five: It’s okay to step away from those you love in order to heal yourself.

Those of you who know my story know that my mother never achieved sobriety. As I noted earlier, the complex pathology of substance use disorder includes isolation. My mother isolated herself from everyone who loved her, including me. However, at times, I also needed to isolate myself from her.

Let me return for a moment to my example of tuberculosis (TB). If my mother had contracted TB and refused treatment, she would have been contagious and no one would have criticized me for not taking her in or for not visiting her while she had an active case of the disease. In fact, in that situation, many people would have found it irresponsible of me not to stay away, particularly when my children were young.

I saw my family’s situation as analogous. When my mother’s alcoholism was particularly active, or when my own defenses were under assault, in order to maintain my own “treatment regimen” and my hard-earned mental health, I needed to create distance between us. This distance was not about refusing to enable her. It was about me – about meeting my responsibility to myself and to my own family.

If you have seen my documentary, you know that my mother had profound needs as a result of her disorder, particularly at the end of her life. You also know that I was able to assist her with some of those needs but not with others. People who have viewed my story and been on a similar journey of their own understand two things: one, you can’t help someone who won’t let you do so; and two, you

can't help someone beyond your own capacity to do so. You have to recognize and accept their limits and yours.

Many people – most people, in fact -- will respect the decisions you make around setting boundaries and limits and will understand that those decisions arise from need, not from hard-heartedness or malice. Unfortunately, though, some people will not understand and some will judge you. When I find being judged, I remind myself of that tuberculosis example. I also say to myself, and sometimes directly to the person who is judging me, “You haven't lived my experience.” That sentence helps me validate my own reality and also not judge others in return for theirs.

Discovery Six: It's also okay to come close to those you love.

We who love someone with a substance use disorder are urged not to become enablers. This is excellent advice. However, it isn't always as straightforward as it sounds. I just explained why there were times that I needed to step away from my mother. However, there were also times that I needed to come close to her and perhaps even “enable” her in some people's eyes.

After several years of near-total estrangement from everyone, my mother reached out to me in the last months of her life to help her navigate the court system following her second DUI arrest. My mother was not in treatment at that time, and she did not intend to seek treatment. I had some very difficult decisions to make. Here are two of them.

I decided to take my mother to court at least for her first appearance. When I picked her up that first day, it was extremely evident that she was in the end-stage of her disease—and she did in fact die just a few months later. I knew then that I would stay at her side throughout the time that she faced the legal consequences of her alcoholism. Was I enabling her? Perhaps. Would I do it again? Yes.

On the way home from court that first day, she asked me to stop at the liquor store so she could buy alcohol and cigarettes. You can imagine how I felt. However, she was sweating profusely and shaking. It was evident that she was having withdrawal symptoms and that she if she didn't have a drink soon, they'd escalate quickly and dangerously. Furthermore, I was certain that if I took her straight home, the moment I left, she would get into her unregistered and uninsured car, and drive herself to the liquor store, putting herself and others at even greater risk. So I stopped at the store and cried while she hobbled inside. Was I enabling her? Yes. Would I do it again? I think so.

Being present for my mother through this final crisis at the end of her life put immense strain on me and my family. And I probably became an enabler to an extent. But it also allowed us to have conversations that gave us some closure and some peace. I'm grateful that I had that opportunity; not everyone does. I am grateful that I allowed myself to come close to her at the end.

Discovery Seven: Stay present in the moment.

Try to resist the urge to rehash the past – with your loved one and within your own mind. If your loved one is still actively misusing substances, do your best not to live in fear about the future. If your loved one is in recovery, do your best neither to live in fear of relapse nor to imagine unrealistic “happily ever after” scenarios. Whatever the situation, do your best to remain present in it without abandoning realistic hope that things will improve.

In those final weeks of my mother's life, I was surprisingly present—in my rage, my anxiety, my grief, and even my gratitude that we had some time to make amends. Frankly, they were excruciating weeks, and I was kind of a mess. But I subscribe to the words of poet and philosopher Robert Frost: “The best way out is always through.”

Being present in the moment also allowed me to accept the help, support, and love that so many people offered to me. I wasn't alone. Being present allowed me to connect within myself, with

my mother, and with others. Being present allowed me to be honest and authentic. And I believe that was tremendously helpful to healing.

And that brings me to the final discovery that I'll share tonight.

Discovery Eight: You can heal.

Of course, healing is an arduous, thrilling, mysterious, ongoing, and ever-transforming process. My healing began when I confronted the reality of my parents' substance use disorders and their impact on me. With help, I have learned to mourn the loss of my relationship with their true and best selves. With help, I have learned to accept my anger and to channel it -- if not productively at least not harmfully. With help, I have learned to recognize and feel grateful for the gifts that I received from my parents -- like my sense of humor, my passion for my career, and my love of nature. I have also learned that for many of us, healing continues -- and sometimes even accelerates -- after our loved one dies. We don't have to heal on a "timeline." Healing happens as it will, when it will.

Paradoxically perhaps, loving someone with a substance use disorder has also taught me that a healthy and joyful life is built in the myriad of small and seemingly insignificant decisions we make each and every day -- about how we treat ourselves and each other, how we use our time, and where we put our focus and energy. So, despite it all, I'm grateful to have loved people with substance use disorders. I've come to realize that -- although I fail at this to some degree every day -- they've taught me how to live and how to love.

Thank you.