



***August 17 2010:
Concurrent Disorders: Messages from a
mom and her late son regarding the
prolonged and complex battles of mental
health and addictions; recovery versus
death. When and how do we break the cycle?***

First, I would like to thank you for this opportunity to speak to you today.

I am from Halton Region (specifically Georgetown, Ontario). My name is Betty-Lou Kristy and up on the screen is my late son Peter (Kristy) Beattie. Pete was addicted to prescription opioid pain medication and died of a mixed drug overdose almost nine years ago, two days before X-mas, on Dec 23 2001. He was 25 years old and the absolute love of my life. There are no words to describe the loss of a child and the journey of grief that will be with me the rest of my life.

It is my hope that in sharing some of my own and my late son's personal challenges dealing with both mental health and addiction issues plus representing two polar opposite outcomes: one of recovery; one of death; will highlight the ripple and cyclical outcomes when early intervention and effective care are not available. To try and articulate how the personal boundaries of the "sick" family member becomes malleable and invasive resulting in the whole family becoming "sick" and how that both affects and infects the generations to come as it did from the preceding generation.

To be able to effectively address treating concurrent disorders, all involved from patient/client to treating professionals to government and funders must have a way to conceptualize how pervasive, intrusive and complex the illness of concurrent disorders are with it's propensity to exacerbate, infect and destroy in a cyclical process even the finest of family and society fabric, let alone one that is already tattered, torn and worn.

The image that comes to mind when trying to find some sort of analogy that gives vision and clarity to the complexity of concurrent disorders, is one of an extended family of parents, their children, their children's children and let's throw in some grandparents of the parents as well, who are involved in a serious single car crash where they all end up with injuries of varying degrees. Some have obvious compound fractures and numerous deep bleeding wounds that need immediate attention. Some have internal injuries that are indicating there is something seriously wrong but sourcing, identifying and then treating the unseen root cause of the symptoms can take many twists and turns. Some are on life support. Some have organ failure and need a healthy family member match to survive. Some have brain damage and some have spinal injuries that have left them paralyzed, immobile and vulnerable. Even the ones who were not directly hurt have been badly impacted because they are now the caregivers to the caregivers and don't know what to do and do not have the expertise and skill set required. Some of the survivors are just children and even though they may have not have had life threatening injuries, who is healthy enough to take care of them so the wounds don't fester and become infected? Who takes care of whom? Where do you

start? Where and how do you advocate, try to support and find effective long term care for each family member affected when there are so many multi-layered issues within this family “car crash?!!”

Next obvious question...How do you as providers of the many services we need; identify, co-ordinate, prioritize, streamline and create a flow out of chaos, knowing that this puzzle has so many pieces. You recognize that each piece needs to be put together quickly because there is a storm brewing and the wind and rain are whipping all the pieces of the puzzle all over the place because of disjointed systems that don't allow any one person the whole picture. So basically you as the clinicians, practitioners, professionals end up working in the dark, reacting instead of responding because we all need more than you can personally provide within the current structure. The longer it goes on without an effective coordinated effort, then everybody is becoming overwhelmed and negatively impacted and that is just a festering ground for more chaos and trauma for all involved. The end result is too many ineffective bandages that are not working and all involved are not only losing hope and direction....they are ending up hopelessly lost.

And so our journey begins....

Both my son and I battled with mental illness, alcoholism and addiction with two completely different outcomes. I not only stand before you as a survivor of my own horrendous journey through mental illness, alcoholism and drug addiction, but also as a grieving mother who lost her only child to the exact same thing. The one variable that strongly influenced our different outcomes was the type of drugs involved.

I grew up in a very violent home being the child of alcoholic parents. My mother was in and out of psychiatric wards for her many breakdowns and suicide attempts. My father seemed the saner of the two but he came with his own scars being the product of a family that was riddled with schizophrenia, suicide and all levels and types of addiction. I “escaped” leaving home at 16, then marrying abusive husband number one and then abusive husband number two, all of which had that same mental health and addiction components. I have in my distant past had many admissions to mental health hospitals. I was on this ever changing cocktail of psychiatric drugs and treatment which also included bi-lateral electro-convulsive therapy. I was extremely anorexic, always cutting and self harming, paralyzed with both panic attacks and depression. I frequently acted on my suicidal tendencies. My diagnosis included rapid cycling bi-polar disorder, obsessive compulsive disorder, post traumatic stress disorder, acute anxiety and panic disorders ...and the list went on and on.

Somewhere in all this chaos when I was just turning 30 years old, I met a stable man who truly loved me and my nine year old son. He is still my husband today 24 years later. It was only through the home he provided, his love, stability and fortitude to stand by me and my then nine year old son....did I finally start the healing process.

I battled back with all I had and started to break free of it all. Finally Pete was going to have the healthy mother that he so needed!!!! Sadly by now as I was rising up to take control of my life ... my son was now falling into that same pit I just got out of.

By age nine his highly developed verbal, comprehensive and creative skills transversed an acute intelligence, depth and passion. This was in sharp contrast to his earlier diagnosed learning disabilities. As he continued struggling with learning, his self confidence and self esteem plummeted over the years. Frustration and anger morphed into depression, his anxiety and panic attacks grew out of control. This sensitive, loving and entertaining kid with the deep desire to accomplish something great in his lifetime was rapidly descending into self destructive tendencies that tarnished both his

personality and behaviour. The crushing anxiety/panic attacks and depression that started in his early teens continued to get worse with each passing year. Pete was suffering with carpal seizures from the most extreme form of panic/anxiety attacks and he was now experiencing auditory, sensory and visual hallucinations.

As a young adult in his early twenties he was boxed in and fighting for survival. Pete, like his mother, fell into the trap of escaping the pain and confusion through both alcohol and drugs. The alcoholism that started with his first round of drinking at age 14 very quickly consumed him as it was his coping mechanism. His drug addiction was to the prescribed opiate pain killer's percocet and oxycontin.....and deep into the abyss did he fall with this addiction. Pete soon became more afraid of living than dying.

After many suicide attempts, Pete died of a mixed drug overdose while a patient in the acute care section of a psychiatric ward. Pete was not allowed off ward but his hospital roommate was and his drug of choice was snuck in for him. The lethal combination of opiates mixed with the newly prescribed high powered psychiatric drugs, administered on ward was missed. Even with my two warnings to staff that day, my plea to watch out for my son, to both chart my warnings and verbally tell the next shift in about this potentially dangerous situation, the autopsy and coroner investigation proved Pete was dying for over six hours on ward before the final aspiration and his death. The staff did not notice till after Pete had been dead for 45 minutes.

This is the first time that I have publicly disclosed the circumstances surrounding Pete's death but I feel this is the target group that could use that info in a productive way and understand that I am not doing so vindictively. I would like to try and be part of that solution by bringing it to the forefront in the appropriate manner to the appropriate audience. (I have no intention of indentifying the hospital involved, that would not serve any purpose, but having identified that my late son and I are from Georgetown, I feel it is necessary to clarify that the hospital involved was NOT from my Mississauga/Halton LHIN area NOR a CAMH facility.)

I myself suffered one broken hand, one broken nose, a terrifying incident being lost and one serious drug overdose reaction that almost killed me in four separate incidences that happened as an on ward patient of several psychiatric wards/hospitals. My younger sister (also concurrent disorders) who was hospitalized for a psychotic break which manifests as aggressive paranoid ranting and behaviour was completely ignored and admonished by staff when she was trying to express that her tongue was swelling and she couldn't breathe properly. She was told to get a drink and go lie down. Several hours later they found her and a "crash" team was called and they were able to save her life. It was not explained to her or any of her family that a new med they had put her on had the potential for one serious side effect, an allergic reaction that causes the tongue to swell to the point that it blocks the breathing passage. Being a board director and bereavement facilitator for Bereaved Families (Halton/Peel) has allowed me to hear many stories of MH&A systemic failures that have either directly or indirectly caused serious incident or harm to patients/clients when they were at their most vulnerable. This is NOT limited to hospital settings; sadly it has involved many MH&A treatment environments.

As part of this presentation I was asked "If you could change one thing about the system, what would that be?" My answer is that patient/client safety is high on my priority list of what needs a radical systemic change as we need to protect our vulnerable.

I was also asked to cover what has helped in recovery, what worked and what has mattered most in moving forward. I decided to leave that to the end as Pete's tragedy will always be my tragedy, even

in the face of my triumphant recovery, which was ripe for relapse having to deal with losing a child and knowing that my prolonged battle with concurrent disorders is part of what set Pete up for his.

Looking back, there were so many missed opportunities for intervention, particularly early intervention. For both my late son and I, the non-operative phrase that seems to be indicative of the barriers to effective care was “lack of choice.” We were expected to fit the system which was like trying to forcibly push a square peg into a round hole. We were expected to deal with one issue at a time and that not only enflamed our other outstanding issues, it made whatever treatment we were getting absolutely futile and always lead each of us to a complete unraveling. One step forward and six steps back became exhausting for both of us as we never seemed to be able to secure all the services we needed, when we needed them!!

It all felt very punitive in nature.

I ended up being locked up in detention home, deemed to be incorrigible when I was 13 yrs old. I was NOT incorrigible. I was petrified, abused, traumatized and fighting for my very life and sanity within the insanity that was my childhood. My extremely intelligent nine year old son who was diagnosed with learning disabilities was acting out at school, but the principle decided that Pete simply had behaviour problems and a case of the “druthers”....”He would druther be playing than in school.” Unfortunately due to this man’s ignorance /bias he blocked Pete from being classified as (what they called back then) “an exceptional” child and that resulted in Pete not getting any of the recommended and specialized school programs that he needed to be able to learn due to his learning disabilities. This set Pete up for a lifetime of embarrassment, self worth and self esteem issues as he tried to cope with learning and failed miserably. I could NOT find safe affordable housing so my kid and I could escape the abusive marriages. My only choice was to stay because I was afraid that if I ended up on the street they would take my child away. My father dies when I am 25 years old and that triggers suppressed memories and flashbacks which completely blocked any type of healthy bereavement because I am dealing with yet another level of trauma and nobody made that connection for me. My deteriorating mental state was deemed to be that I was an alcoholic and drug addict and needed to get my shit together and make a choice. My kid ended up with charges and in jail, then saddled with a criminal record from a psychotic break fuelled by his mental health and addictions.

I seriously can not make a list of what actually helped or worked for either one of our journeys with concurrent disorders. They both were fraught with so many ineffective, patchy and what seemed to be experimental guesswork, that not once could we find any confluence in treatment processes. One of the most invasive deterrents’ to ideal care was that mental health was treated as a separate entity from addiction and the very real bias against addictions in the mental health field. That obviously has improved a LOT but it is still very real in many settings. The other still outstanding issue is the polarizing divide within the addictions field regarding abstinence based care VS harm reduction. Also, to this day, the STIGMA surrounding MH&A still has the power to hold us hostage and we need to call it what it is—discrimination... and all do what we can to abolish it once and for all.

Dealing promptly and effectively with concurrent disorders can only be delivered by teams of teams, all following the same framework and protocols from intake appraisal to outcome measurements. There also needs to be a plausible means of information sharing that respects privacy issues BUT also provides a seamless connection to all of the services a person and/or families dealing with concurrent disorders may need. This must also allow for individual needs and individual expression of what recovery looks like to be met while working collaboratively with-out anybody losing there autonomy. This applies for all sides involved from patient/client, caregivers, MH&A providers such as clinicians, doctors, nurses, LHINs, community agencies, funders, front liner workers and responders such as

police, fire, and ambulance. Plus it must extend out to our school boards, teachers, social workers, judicial system, housing etc.

We all need effective tools and systemic frameworks that nurtures self empowerment and enables everybody involved to have their needs met. No matter how diverse and complex. You can't provide what we desperately need of you, if you are stuck racing against time, working in oppressive failing systems that diminish your capacity to deliver effective services. You only end up as burned out and frustrated as we do.

To close I would like to answer the final question I was asked to address. **“What has mattered most in moving your recovery forward?”**

Days like today! Being a Person with Lived Experience who is invited to share mine and my late son's journeys with concurrent disorders and being able to provide our life and death outcomes. You help me re-invest in life when you not only listen to me BUT you hear me (and in hearing me...you hear my late son's voice as well). This allows me to be part of the solution and that is the most integral piece that keeps me moving forward in my recovery.

I thank you for this honour.

Betty-Lou Kristy (betty_pdb@msn.com) and the Late Peter (Kristy) Beattie