

INTRODUCTION

For over 35 years I have worked as a professionally trained human services and health care development consultant, advocate, director, CEO and training facilitator. Many of my most important insights to write this text book however, also came from the teachers in my personal life and as a volunteer caregiver and support worker. The following is a sampling of teachings from these ‘classrooms’ that will be shared more completely throughout this resource. It was in these experiences that I learned and earned the **inner resources** that are essential for leaders and caregivers to not only compliment but to actually effectively implement evidence based best practices.

Thump! Only hours before, Bill had come home from work feeling great. Quite suddenly he felt weak and went upstairs to lie down while Pauline, his partner, finished making dinner. Within an hour his body had shut down—an acute attack of Guillain-Barré Syndrome. The thump was the sound of Bill intentionally falling out of bed, which was the only way he could call Pauline for help. Within the hour he was on life support machines which would keep him alive for the next year. For the first six months he was totally paralyzed, unable to even blink his eyes that were frozen open in terror. For the ten years since that day, each week I visit or drive my quadriplegic friend and his wife to doctors and physiotherapy appointments as we, with humour and mindfulness work through another stretch of rocky road on their unexpected “Freedom 55” retirement journey. I continue to be ‘awe’ struck with how well their relationship is thriving within the frustrations, fears and fatigue because of how they delicately dance back and forth, gently leaning into but not identified with the ever-changing roles of wife/nurse/husband/patient.

Twenty-three years ago as my twin sister and I walked off the court after winning our mixed -doubles tennis championship, I encouraged Polly to push her doctor to find the cause of her recent severe headaches. I can describe in detail the pay-phone booth where I called to get the news that the CT scan had revealed a tumor that would take her life three years later. Her devoted husband, family and siblings fought to save her, but eventually had to let go as she Grace-Fully embraced ‘Thy Will’ with Sacred gratitude for her 49 years. I helplessly watched, now totally consumed by my life-threatening clinical depression that left me struggling for 2 years with debilitating fatigue, extreme weight loss because I was unable to eat, and the constant company of suicidal thoughts.

Bret and Julie met me for coffee and told me that Bret was dropping his tools a lot at work; they wondered if it could be the result of his alcoholism that I had helped coach him through recovery several years earlier. I was with them when the doctor informed Bret he had Amyotrophic Lateral Sclerosis (ALS, also known as Lou Gehrig's disease). For five years Joanne, my life partner, and I volunteered as part of his primary support team. The day before he died, I carried his one hundred pounds of skin and bone from toilet to bed. Unable to speak for over a year, he now gave me that sacred smile of gratitude. He motioned for me to hit "play" on his cued-up CD player, and Louis Armstrong sang us "What a Wonderful World". From abused child to street fighter and alcoholic, he died an enlightened sage.

My phone rang at 2:26 a.m. on a Friday morning. The garbled voice on the other end of the phone was my Dad in the midst of his massive cerebral hemorrhage. We rushed him to the hospital where for an agonizing week his five children struggled with the impossible yet necessary decision to remove life supports from our brain-dead best friend. As I held his hand I encouraged him in his journey to the other side, to be with Mom. Two years after my mother's massive heart attack she had been assured by doctors that she could live a good long life if she stopped gardening, caring for grandchildren, volunteering, cooking family dinners and dancing. Sitting beside my father, I recalled that night twelve years before when his beloved wife, Mur, died on the dance floor and took his heart with her. For twelve years, we his children actively supported him and tried in every way to help him retrieve his soul, but to no avail. Now in our final act of mindful loving care that tore our hearts apart, we helped him find that peace.

As I entered the Hospital for Sick Children with a stuffed animal for a surprise visit with seven-week-old baby Emma who had been admitted for some routine tests, I was met by Biljana sobbing in disbelief that Emma was now on life supports. Grief, fear, despair, hopelessness—no words can describe the heartache of a father and mother saying goodbye to their precious, innocent baby. Although before this day I thought that I was ready to meet these situations, I now found there was no way I could be adequately prepared to support these dear friends through their spirits' terrible black night transformative process except to stay mindfully present, moment after painful moment. As we said good-bye to Emma, her saintly grandmother took a little, well-worn wooden crucifix from her purse, poured some water into a styrofoam cup and blessed it, and with an unlit candle baptized Emma's frail little body. With the love created by this three-generation family, with monitors beeping, alarms going off and loud intercoms paging nurses and doctors to another world, this acute care room had been transformed into a grand cathedral as great as any found throughout Europe. Our experience with Emma started a most sacred ongoing purifying process for her parents and me; I continue to help them be with their ever-present pain and recognize it as a vehicle of awakening.

When I visited Jim's home for the first time I was shocked by the many holes that had been punched through the drywall by his fist. Jim's developmental disability, including fetal alcohol syndrome had kept him helpless to control his impulsivity. In those days, without the required training of workers and Jim, the slightest annoyance could bring him to agitation and then rage within minutes.

His staff told me that when he attacked them, typically the incidents would last for about an hour from the time that he threw his first punches and was finally physically restrained. This sometimes lasted longer when he had a panic attack from being restrained. About once a month they had to call 911 police who would immediately put him in mechanical restraints and take him to emergency psychiatric treatment where he sometimes waited in handcuffs for 3 hours to be triaged and sent home, now severely traumatized and without treatment.

As we were sitting in the kitchen I heard a loud noise behind me and Jim came rushing into the room. He lunged at one of the support workers who quickly stepped out of the way. I moved in front of him to attract his attention. I asked the others to leave immediately. I started to talk to him softly but firmly, "Hey Jim, It's Ok". I also started to intend his calmness by saying to myself "be calm my friend, be calm". I had just started this process when he threw his first punch at me. I cross blocked it and stepped aside, while continually talking to him, "It's OK Jim it's OK". He swung again and I blocked it and kept intending calming. My awareness of being in this situation was constant, like white noise in a crowded mall it helped me to stay calm and therefore focused. I also just stayed aware of my body sensations and intended calming of them as well.

I kept eye contact as best I could and started an internal intention of us being connected and 'grounded'. This is a strategy that I learned from one of my mindfulness instructors. She would say "Stay mindfully connected to the other person as if they were your best friend. If you break connection, both of you have already lost". Each time I blocked, I renewed this intention and softly repeated "It's OK Jim, It's OK".

This went on for maybe five minutes with several more blocks with arms and legs. When he stopped, I looked at him with my arms open and softly said "It's OK Jim, you're just having a bad day". I asked him if he wanted a drink, he said "No". I could see that he was confused, so I asked him to show me his room (a safe and familiar place). He walked away and I followed and was soon enjoying looking at pictures of his family.

Within 3 months of our working together with Jim and his staff, most incidents now never get to aggression and those that do are quickly resolved without restraint or police. Because Jim's life could now be filled with interesting activities he has become 90% less agitated.

These personal stories and many more throughout this book share a little of what I have learned from these teachers about being a competent and compassionate leader, support worker and caregiver regardless of how I am feeling at the time. Their most important teaching has been that we will require personal emotional maturity, mindful presence, and discovery/development of our innate compassion if we ever hope to effectively implement best practices to meet their needs (and our own) authentically and compassionately without burning-out, freaking-out or tuning-out.

What must we as leaders, care givers and supporters do to prepare to meet these challenges?

Our Challenges and What To Do

Human and Health Care services are struggling to meet the ever increasing service needs of residents, and patients with ever decreasing financial resources. Most caregivers and leaders are committed to wanting to meet these challenges. With demands for leaders and caregivers to do more with less time and fewer resources (i.e. be more efficient) however, and further due to societal changes, shifting family values, work and personal life stress etc., there are strong indicators that more leaders and caregivers are burning-out, freaking-out (losing it) or tuning-out. In addition, it appears that authentic compassion is not as prevalent. When compassion is evident, compassion fatigue appears to be a constant threat. This is often coped with by unknowingly becoming less concerned (tuning-out) about the residents'/patients' support needs beyond good physical care. Some even rationalize this lack of concern and compassion as being 'a good professional' by not getting too 'involved'. This is somewhat understandable as a stress management strategy but it is not a satisfactory response to meet this human services and healthcare crisis.

These leaders and workers are generally not incompetent or uncaring people. The alarming rates of burn-out, freak-out and/or tune-out and the growing dissatisfaction of service recipients do attest to this crisis. Studies conducted by OPSEU and other organizations report that a minimum of 50% of support workers and 25% of nurses are regularly physically assaulted by residents and patients. OPSEU also reports that one third of all reports to WSIB of injury due to attacks, come from social services and health care workers. The full consequences of these working conditions are however even more serious. The report goes on to say that "workers who are subject to constant verbal abuse or who work with constant fear of assault are chronically stressed. They are at high risk for serious digestive disorders and heart disease. A daily dose of emotional stress can lead to serious physical and psychological problems. Common symptoms include chronic fatigue, fear and anxiety, depression and substance abuse, and possibly even symptoms similar to those seen in post-traumatic stress disorder".

These conditions then lead to workers mistakes including missing and not effectively responding to the early signs of resident or patient agitation and anxiety that often lead to aggression if not properly addressed.

As you read the comments below (representative of a minimum of one third of all workers and leaders), I think you may recognize the feelings of some of your colleagues; you may even recognize your own feelings from some point in your career:

“This is not what I thought being a caregiver would be like! I’m struggling to find the meaning and purpose in what I do anymore. I don’t have time to offer most residents/patients the care and compassion that they so much need; I just run from one to another doing the basics. I had no idea it would be this way, so impersonal, so mechanical. How can I really care for the ‘whole’ person when I have to be this efficient and I get so little time with them? Most days now I just come in and cover my shift because it’s just too painful to really care about them anymore. My supervisor seems oblivious to my discouragement and how I have just ‘tuned-out’. I’ve told him numerous times but I’ve stopped bringing it up”.

“Martin, one of the residents has a developmental disability. He really scares me. As soon as I see him getting agitated, I’m afraid that he’s going to blow up and hurt me. Last year, one of his punches landed on my face, and I still feel that trauma. Nothing in my training prepared me to manage the fear that keeps coming up; worst yet, I know that my fear makes his agitation worse. As a result, he gets more aggressive and sometimes needs physical restraint to ensure everyone’s safety. I know that it traumatizes him to be even more likely to have challenging behaviour in the future. I keep thinking that there must be a better way to manage both Martin’s and my fear so we both stay safe and no one needs restraint. I’m so ‘on edge’ and frustrated.”

"Mrs. Porter is so demanding! I know it's because of her dementia, but it still upsets me. She reminds me so much of my mother when I was growing up that I have a hard time responding to her bark. Often I just ignore her, or sharply remind her of who I am and all I do for her; then, hours later, I feel terrible about how I treated her. It seems like I'm two people some days. A part of me says and does things that I later deeply regret. It's so frustrating, and I feel so guilty. If only I could catch myself being disrespectful in time to stop it. How can I keep my heart open to her when she most needs my support? My manager says it's just part of the job and that I need to try harder to stay calm. I'm taking more sick days off than ever because of the stress".

In the above scenarios, and many others that occur in most hospitals, long term care facilities and community living support services, each worker and their manager/leader/director is doing his or her best to ensure optimal services for patients, residents, and clients. The majority of these leaders are caring and trained in conventional management practices and leadership styles. As a result they are doing their best to balance workloads and allocate shrinking financial resources as strategically as possible to minimize service delivery problems and maximize effective and efficient use of their human resources. Working conditions are not likely to improve much more given service demands, fixed staffing levels and limited financial resources. This means that the best possible practices for "what to do," "how to do" and "when to do" are for the most part "as good as it is going to get" under these conditions.

In spite of this, many staff, like those in the opening examples, report for work some place on the continuums of the three "outs" – burn-out (self and others), freak-out or tune out (indifference). This of course means that less than optimal care and support services are being offered by these workers but it also impacts co-workers and the support environment in general.

Burn-out: Staff members who are burning out can suffer from chronic or low-grade depression, anxiety and a host of other mood disorders that can last for years. Although not totally debilitating, they dramatically impact the caregivers' ability to offer the level of care and support that they so desperately want to offer. These caregivers entered this field of service because they wanted deeply to make a difference in the lives of people they care for and support.

Tune-out: Eventually the Martins and Mrs. Porters bring workers to a place of indifference, which I call tune-out. The workers unknowingly armour their heart in a desperate move of emotional self-preservation. They learn the skill of being "professionally warm". At the first sign

of anyone breaking through their heart's wall of protection, they emotionally withdraw and rationalize their behaviour with distractions, like socializing with or gossiping about co-workers. They move into deeper and deeper denial of many of the real needs of patients, residents and clients. These tuning-out workers also sometimes unknowingly begin to spend more of their time with the patients, residents or clients who are less needy, more appreciative and in the worker's mind maybe even more deserving of care. At some deep, unconscious level some of these staff members have decided that to deserve good care you must be a good patient or resident.

Freak-out: At other times they just lose it, freak-out and feel terrible afterwards.

Stop for a moment and picture these staff members: one under the constant cloud of depression, another deeply discouraged by guilt and lack of confidence, still another too disheartened to be able to respond adequately. Imagine for a moment the energy and attitude that each one brings to this vital work. Also imagine the possibility of significantly greater risks resulting from their errors and poor judgments. **And yet, few of them are incompetent or uncaring.**

It has long been recognized that the majority (e.g. 75%) of service delivery problems like mistakes, not following best practices, care recipient legitimate complaints and unsafe working conditions etc. results from a minority (e.g. 25%) of the organization's service recipients and 'outs' workers – victims of (in many cases) preventable and resolvable inadequate practices and working conditions.

Causes and solutions are of course complex and multi-faceted. New legislation, policies, more 'Core Competencies' training or more ridged staff accountability is clearly proving to not be the whole solution.

Mindful and Emotionally Mature Managing & Caregiving (MEMMC) is working to eliminate this unnecessary human suffering of leaders, caregivers, care recipients and the associated financial costs to agencies and hospitals through both prevention and more effective interventions. **MEMMC offers the essential mindfulness and intrapersonal emotional maturity for leaders and caregivers to follow best practices, experience meaning and purpose from what they do, be authentically compassionate and still be safe and efficient.**

In addition to the majority of staff who need direction, development, accountability and encouragement, these special needs staff also require leadership that can effectively prevent and manage the "outs". The workers also require tools and insights to be more resilient (i.e. immune to burn-out, freak-out and tune-out). **Mindful & Emotionally Mature Managing & Caregiving (MEMMC)** is designed to give leaders those skills and prepare them to pass the skills along to their team members.

In this way, both caregivers and care recipients will most often have their mutual needs for safety, dignity and kindness met.