

## **Two Essays**

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**Note:** This talk is the one I meant to give at the conference. What follows it – “Bill’s Story” – is a lightly edited version of what I actually said; I felt that his account of the abuse and death of his elderly mother pre-empted my original talk.

# 1. Honey versus Vinegar: The Politics of Walking Softly and Not Carrying Any Sort of Stick at All

Don’t get me wrong. I hate psychiatry as much as anyone I’ve ever met. And I have nothing but respect and admiration for the tireless labours of all who’ve fought to expose psychiatric abuses and bring their perpetrators to justice.

In fact, I’ve done a fair bit of exposure myself over the years and will continue to do so as the opportunity arises. I began in 1986, when I became the editor of *Phoenix Rising: The Voice of the Psychiatrized*. In 1990, I was one of the founders of the Ontario Psychiatric Survivors’ Alliance, which I coordinated until 1992. Like *Phoenix*, OPSAnews gave people an opportunity to write about what they had been or were being subjected to in the name of professional help.

I have interviewed people all over Canada about what’s wrong with psychiatric “treatment” and how to overcome the mess it makes of our lives. I presented excerpts from some of these interviews in two CBC Ideas radio shows (“Analyzing Psychiatry” and “By Reason of Insanity,” broadcast in the early 1990s) and a book (*Call Me Crazy, Stories from the Mad Movement*, published in 1997). The response was overwhelming. Tons of people wrote saying that these stories helped them change their lives – for some, it was the first step in getting off psychiatric drugs.

I have been interviewed many times, on radio and TV and in short films and videos and have written about our issues in newsletters, newspapers and magazines. These days I take part in a creative writing group, and of course I can’t resist denouncing the nefarious practices of the so-called mental health system.

I feel that all of these efforts, along with the many greater accomplishments of other activists, have been effective in raising consciousness – but only when people are ready to listen to and accept antipsychiatry ideas because they are most of the way there already.

Obviously, our stories need to be told, not only because telling them strengthens us individually and collectively, but as a vital counterbalance to the pro-psychiatry propaganda we see every day in the mainstream media – and as part of our struggle for justice.

However, telling our stories is only one of the things that need to happen if we are to protect ourselves and each other from the powerful and well financed agents of social control whose business is to label, medicate, incarcerate and sometimes electroshock people whom society finds difficult to deal with.

As I grow older and more experienced I feel increasingly that the very most important thing I can do is to explore and publicize alternatives to psychiatry – which are exciting, wonderful and as numerous as the other side’s fake diagnoses.

Exposing the outrages perpetrated against us in the name of treatment is vinegar. Somebody’s got to do it, but not all of us have to do it all the time. Finding, and promoting, kinder, gentler and *far more effective* ways of dealing with emotional and mental problems is honey.

The number of alternatives is virtually infinite, and many are simple, obvious, and free of charge. My first rule for helping people in emotional trouble is: *Don't panic*. Panic is usually people's first reaction to us, often when we're already panicking ourselves. And if we're not, and they are, we soon will be. Keep in mind that, no matter how severe the crisis, the nature of crisis is that it will pass.

Rule Two: Give your time/take your time. It was Marg Oswin, a wonderful OPSA volunteer, who taught me that time is the greatest gift one person can give another. Make time for people you're trying to help, and don't try to move anything too fast. Often just listening to someone for longer than they're used to – say, longer than a couple of minutes – and not interrupting or shifting the focus to yourself can be tremendously useful.

Rule Three: Don't make assumptions or jump to conclusions. Not about what's going on with the person, not about what you can do to help, not about anything. Always ask, and never assume that you know what someone wants or needs. Offer a hug or hand-holding if it seems right, but you might want to add something like: "Or do you need space?"

Helping people isn't rocket science, and you don't have to be a professional or even an adult to do it. My favourite example is a time when I was completely out of my mind and went to a friend's house to avoid going home. She was busy – but her three-year old daughter, seeing me crying and confused, started marching up and down the room chanting, "Fresh air and exercise, fresh air and exercise" – and then asked me if I wanted to fix myself a sandwich.

Fresh air, exercise, food, sleep, kindness, peace – the things we need when we're in distress are what every human being needs to be healthy and happy. And every kind of alternative healing and bodywork technique (e.g., yoga, tai chi, Feldenkrais) can serve as a superior substitute for any kind of psychiatric treatment, if we keep in mind that different things work for different people and many may need to be tried before the right one is found.

Certainly I used to present myself as a person whose goal was to bring down psychiatry. But for me it has become increasingly important to consider the many people who feel psychiatry has saved their lives. Yes, I can shout about how the drugs they depend on are hurting them and the professionals they see should all be in jail. Doing so can feel really good, to *me*. But I'm going to sound like the Antichrist to them, and they certainly won't listen to anything else I say.

But what if I pass on expressing my anger, justified though it is? What if I focus on letting people know that there are choices other than the ones they've had so far?

My experience has been that this offers a better chance of encouraging people who have embraced their labels to look at themselves and their stories in a different light. And of course when I talk about alternatives to people like my younger self – who have had their spirits crushed by psychiatric "help" and have no idea that *real* help is possible – I see their eyes light up and know that I am doing good. More good, I now believe, than I can do by encouraging them to become enraged.

Finally, a word about language. Our movement has been through many struggles about what to call ourselves, and each of us has her or his personal preferences, from "consumer" or "mental patient" to "survivor," "ex-inmate" or "crazy." One of the participants of a focus group I attended in Vancouver came up with something that really struck me: instead of talking about "mental illness" and "mental health," what if we started using the term "mental diversity"? I liked this a

lot. We also spoke about what's wrong with the "recovery" model (that it implies recovery from illness, and that people are seen as having recovered when they shut up and conform – most often when they are turned into zombies due to "compliance" in taking psychiatric drugs. What if, instead of "recovery," we talked about "rediscovery" (of the lively, creative people we were before psychiatry got hold of us) and "discovery" (of new ways of coping with difficult situations and emotions)?

I like to think that Judi Chamberlin would have approved of these terms. Judi is my biggest movement hero. She always told it like it was, but with brilliant tact and a beautiful focus on self-help and alternatives to psychiatry. We lost a giant force when she died this year, and I hope with all my heart that more and more of us will follow in her footsteps, not preaching to the converted, but speaking out in ways that are easy to hear and virtually impossible to argue with.

## 2. Bill's Story

Earlier this week, I had just taken a seat on the Skytrain —Vancouver's equivalent to Toronto's subway — when a pleasant-looking man about my age got on with his bike. He was wearing a helmet, with a flashing light attached. I asked whether he had left the light on intentionally. He jokingly explained that he needed to keep it on because space ships were going to be landing any minute.

I laughed, and we started chatting. He told me he was on his way home from an ecology conference. He mentioned the community development program of a local college, and asked me if I knew the place; he thought I looked like a college teacher. I said I was supposed to have become a college teacher, but my life got sidetracked when, at the age of 20, I got locked up on a psychiatric ward. I also told him that I was soon going to be speaking at an antipsychiatry conference in Toronto.

That was all the opening he needed to launch into the horror story of how his elderly mother — to whom he had always been a loving and dedicated son and, in the final years of her life, a devoted caregiver — had been psychiatrized, debilitated, and finally done in at a private hospital licensed under the Vancouver Coastal Health Authority. We both missed our stops, and rode to the end of the line and back again.

Listening to him, I realized that his story needed publicizing, and it came to me that, ironically, this was more important than what I had been writing about.

"Not only my siblings," Bill told me, "but every lawyer and every doctor involved — and even the Public Guardian and Trustee of British Columbia — had their hands in my mother's pockets. And every court order of the two judges trying to protect my mother's rights was violated. The third and final judge ordered that my mother be declared incompetent to manage her own affairs and must bear the considerable costs for all parties involved."

In 2003, Bill's mother had to undergo open-heart surgery — a quadruple bypass and tissue valve replacement — due to congestive heart failure. She was 83 years old. She came out of surgery suffering from a common yet frequently unrecognized condition known as Post-operative Cognitive Disorder.

At the recovery centre, expecting to go home after a physical assessment in which she met all the necessary criteria, Bill's mother was suddenly subjected to a ten-minute "mini mental status exam" at the hands of a geriatric psychiatrist.

"This person," said Bill, "stated that my mother was completely incompetent and suggested that I fight my brother in court with regard to her affairs. I did not believe what I was being told. I refused to fight over my mother — and was soon to discover from her own GP that crucial information was being withheld both from my mother and from me, her designated medical decision-maker."

I'm going to continue in Bill's voice; together, we wrote what follows over the next two days. It is based in part on sworn affidavits and other evidence that he showed me.

Mom was denied her right to go home. Instead, in February 2004, she was sent to one of the worst extended-care hospitals in the province, where she was held for 18 months.

Meanwhile, my brother began to pursue extremely acrimonious court proceedings, at the urging of the health authority and the doctors. On the advice of the BC Public Guardian and Trustee, my mom retained a lawyer for herself. Thereupon, the attending physician, together with the Senior Geriatric Psychiatry Consult (for all five residential care facilities on site) certified, detained and drugged my mother and of course made it impossible for her to be represented by a lawyer.

Simultaneously, this Senior Consult was retained by my brother, to whom he provided two highly questionable affidavits for the court fight. He also influenced other psychiatrists to deem my mother incompetent. The manipulation of medical facts was instrumental in forcing my mother into institutionalization.

Over the next six years, Mom's rights were systematically violated by the doctors, the health authority, and my siblings.

The process of enfeebling my mother began right away. Nurses cranked up her bed so that Mom could not safely get to her feet. And they would not assist her to the bathroom. In the first week I discovered that Mom (continent and walking when I brought her there) had been left lying in diapers full of feces and urine. When I complained to the nurse, I was told, "This is not a recovery centre."

The surgery had necessitated that a vein be removed from Mom's leg. Over the course of 18 months of enforced inactivity and consequent lack of circulation, the remaining quarter-inch of the 30-inch incision, which had otherwise already healed by the time she got there, was "nursed" into a festering, open wound. The raging infection was not addressed until three days after it was reported. By then, extremely potent antibiotics were required.

It was only later that I was told outright: "It [the infection] is in the bone — and is going to keep coming back." I contacted Infection Control and then a senior health authority executive.

All along, my mom had wanted to go to a particular facility in her community. But on August 17, 2005, the health authority forced her into what they first told us was a non-profit facility and then said was a residential care home. However, it turned out to be a private hospital with a 43% rate

of chronic alcoholism, where formerly high-functioning professionals — doctors, lawyers and judges — can drink themselves to death.

It needs to be said that my sister actively portrayed my mother as an alcoholic, even delivering a mickey of gin to her in the hospital while Mom was suffering from delirium. In fact, my mother hardly ever drank at all.

Throughout all that happened, my siblings were using and telling lies about both my mother and me. They were supported by medical and psychiatric personnel and by the authorities in going against my mother's wishes — notably, the documented fact that my mother had declared me her medical decision-maker and next of kin.

Staff behaved in a manner that was untruthful and manipulative from the very moment I escorted my mother into this private, for-profit facility — where, I must point out, there is no formal complaint mechanism, nor do family members have any means of legal recourse under the Hospital Act when a resident dies.

However, for the first time in a year, I was able to take Mom out. I took her for a walk every morning that first week. I brought her daily paper to her. I proved to them that, contrary to what they'd been told, my mother could walk and was continent. And, I proved to them that she was not mentally incompetent — she could read and write and keep a calendar.

We went out to dinner on the Friday of that week and to church on Sunday. From there we went home, where we began to plan the celebration of her upcoming 85th birthday.

On the Monday morning, I got an enraged phone call from the administrator, informing me that my mother was legally detained in the facility and couldn't leave the building. I replied, "You are lying to me. We've been out every day, as you well know."

When I asked if the Geriatric Consult was involved in this, she lied about that as well. And when I cited proof that she was lying again, she shrieked, "I've got news for you. This is a private care facility. I can bar you from this facility. And you will never see your mother's face again."

All my mother and I had ever asked was to be able to spend as much as possible of our remaining time in each other's company, in an atmosphere of dignity and respect. And this was categorically denied to us.

Forced to accept the fact that we could no longer go out together, we established a routine of activities within the building, visiting whenever we wished. We made many friends among the residents and staff.

In 2006, my mother told me she wanted to visit our home on Easter Sunday. She instructed me to speak to the attending physician, because she did not trust the administrator.

I requested, in writing, a compassionate leave for the home visit and was treated extremely rudely. Thereafter, our peaceful enjoyment of each other was systematically attacked every time I visited, eventually to the point of phony police calls.

As a professional who has actually advised policing agencies, I hold the police in high regard. And I have been able to prove that, in every single instance of complaints made to them about

us, the police were being lied to, and that any allegations were false. In fact, in a number of instances, police investigations clearly established that criminal offences had been committed against both my mother and me and that serious violations of court orders had taken place.

Please note that it is against the policy of British Columbia's policing agencies to investigate police complaints from either residents of care facilities or their family members. They will only respond to calls from facility staff.

Having met and spoken with other victims, I now know that it's a systematic practice to use the police to threaten anyone who complains about what's going on in a care facility. Genuinely caring family members are regularly barred from the premises. Everything foisted upon my mother and me was designed to put in place a decision-maker prepared to allow the facility to carry things through to their ultimate end, sooner rather than later.

A woman located here in Vancouver, who had become a friend of mine, and who is probably the top geriatrics expert in North America, has stated outright: "The majority of people in residential care facilities die of conditions that are the result of their institutionalization."

I believe that family caregivers such as myself are rightly perceived as a threat to the residential and palliative care system, because we naturally abhor witnessing the enforced enfeeblement of our loved ones and the ultimate removal of the means of sustenance of life: food and water.

The question of whether or not my mother was competent has absolutely no bearing whatsoever on the bonds of love, trust and caring that were the foundations of our relationship. My mother taught me everything I knew about caring after my father had a heart attack when I was 12. My sole wish was to offer her the same degree of dignity and respect that she gave him.

On the other hand, societal attitudes towards the elderly, and especially those deemed demented, have been dehumanized to such a degree that many family members see no value in their elderly relatives' lives. I have met people who were happy to pull the plug, and often financial interests appeared to play a significant role.

Just before Mother's Day 2006, Mom and I were sitting together in the foyer. I inquired about proper treatment for her recurring leg infection, and the administrator's reply was, "If your mother is dying — if she's been sent to Emergency — we won't tell you. We know your brother won't tell you. And we will only tell your brother."

My mother and I endured and grew used to threats, intimidation and denigrating ploys from all quarters, including the facility owner and her husband. Throughout it all, even when they not only despoiled my mother's body, destroyed her health and drugged her; but also robbed, physically assaulted and used police force against both my mother and me, they were never able to break the bond of caring and respect between us.

They robbed my mom of her home, her church, her community. They denied her the therapy and residence she desired. They knowingly and deliberately committed one illegal and unethical act after another.

On December 11, 2009, after two weeks of unsuccessful attempts to contact my mom by phone, I found out from a short-term contract employee not in on the game that my mother had suffered a stroke and been sent to Emergency the previous day.

I rushed to the emergency ward, and found my mother lying alone, emaciated, refusing food and medicine, and terrified of any contact with the staff. We had not seen each other for more than a year. Within half an hour, my mother was eating and taking her medicine, only from my hand. We begged them to provide us with a bed in a facility where I could be at her side.

On December 16<sup>th</sup>, the social worker told us they would do nothing to help us. I called my friend, the geriatric specialist, and was promised my mother would not be sent back to the private care home. I was instructed to request a geriatric assessment. However, it turned out that there was someone in a serious conflict of interest hiding in the background. When that came to light, the medical director arrived and threatened both my mother and me. On December 19<sup>th</sup>, we were suddenly given 45 minutes' notice that my mother was being sent back to the private care facility, against her will.

The 45 minutes collapsed into five when they realized that I had called the press.

I escorted my mother down to the ambulance. With the stretcher halfway into the ambulance, I was told, "You can give your mother one last kiss." When I leaned over to kiss my mom and say goodbye for the last time, Mom grabbed my finger and refused to let go. Within minutes 911 had been called, and three cars pulled up, sirens wailing. When I said it was the government doing this to us, the ambulance worker replied, "You're about to meet Mr. Campbell's government, right now."

The police jumped from their cars, shouting, "Let go of your mother." And I said, "I am not holding onto my mother. My mother is holding onto me." I was on my knees on the pavement, in the freezing cold, so as not to appear aggressive. The police negotiated with my mother to bring her back inside. More and more officers arrived. They surrounded us near the exit door. A female officer assaulted my mother, ripping her fingers from mine. I saw my mother's finger bent backwards at a 90-degree angle as her hand slammed down beside her.

We were offered one chance to say goodbye. Holding her, I could feel Mother's mortification at the fact that her dying wish — to have me at her side — was to be denied, with the complicity of the Vancouver City Police.

We never saw each other's faces again.

Not only the health authority, but the Ministries of Health, Attorney General and Solicitor General — and office of the Premier, who was my MLA — refused outright to do anything to help us. The care facility failed to provide any legitimate opportunity for me to see my mother before she died.

On January 6, 2010, I was informed that they had already ceased the provision of food and water and that my mother was in fact dying. They were no longer getting her out of bed, and I would not be able to speak to her on the phone.

On January 7, after the fact had been withheld from me for more than 12 hours, I received a telephone message saying my mother was dead.



