

Who has the right to control your life?

ROB WIPOND

Caught between archaic, paternalistic laws and deteriorating conditions in care homes, more and more BC seniors and their families are discovering how easy it is to lose basic civil rights that we often take for granted.

We're here to bust an 86-year-old woman out of a nursing home. Kim packs her mother Joan's personal items (some names have been changed to protect anonymity). I survey the quaint room and ask, "Do you like it here?"

Joan replies, "I want to go home."

Instantly, I see why Joan is in trouble. I'll soon learn she's smart and funny, but she looks feeble and vulnerable. Dammit, she looks *old*. You feel an instinct to reach an arm around and reassure her, "I'll take care of everything." You want to *take charge*.

For Joan, that's become the problem.

We walk toward the exit. How hard can it be for a daughter to get her own mom out of a residential care home?

"I thought I could never be shocked again," Kim says later, while her mother meets with a lawyer. As a health care consultant, Kim thought she'd already seen the worst of health care. "But I'm continually reeling."

Archaic laws, few rights

I too was shocked when I first learned how easily seniors can lose their rights.

My friend Jamie had long been friends with Dan, a poor recluse. In 2006, Dan contracted an infection. Jamie got him to hospital. While the 72-year old was recovering, a psychiatrist appeared asking personal questions, wondering if the isolated senior was "capable" enough, or if he needed residential care.

Dan preferred home, and revealed he had savings from which he'd pay Jamie for help in future.

The psychiatrist became suspicious. "He started asking me all these prying questions," says Jamie.

The relationship between the psychiatrist and still-recovering recluse deteriorated, as it became clear Dan's fate was at stake. "Dan was crying a lot," says Jamie. "And then Dan decided he hated [the psychiatrist] and he would not talk to him. This made it all worse."

The psychiatrist suddenly declared Dan mentally "incapable" of making decisions. Dan was forced into residential care; the Public Guardian and Trustee (PGT) took charge of his money.

A similar thing happened to Tony Argieri. Argieri has a neuromuscular disease; he's wheelchair-bound, deaf, and recently lost speech.

But with the aid of specialized computer communication tools, he's lived alone and worked as a government accountant for years.

In some unclear sequence participants disagree on, Argieri *apparently* was hospitalized for a thigh operation last year, a hospital doctor declared him mentally incapable even though Argieri could communicate in slow, awkward handwriting, he was sent to Glengarry nursing home, VIHA stored his belongings, the PGT took control of his money, and his landlord stopped receiving rent and sued.

Eventually, clumsily clutching a pencil and pushing one computer key at a time, Argieri contacted Paul Gilbert, an old friend. Gilbert says Argieri seems like "pretty much the same guy" he's always known. He's been trying to unravel what happened and help Argieri regain control of his life, but has been stonewalled.

Authorities are reluctant to communicate with Gilbert, protecting patient confidentiality. Argieri signed a letter designating Gilbert as his representative, but Glengarry staff countered Argieri wasn't mentally capable of making that decision. Gilbert asked for documents establishing Argieri was incapable, but no one has produced any.

"I was murdered," Argieri types to me.

"It doesn't seem entirely fair," comments Gilbert.

Legal experts agree. The root problem is provincial legislation covering guardianship of people with diminished mental capacity. Canadian Centre for Elder Law (CCEL) lawyers analyzed guardianship laws in 2006. These experts say BC laws, unlike elsewhere in Canada, have "remained virtually unchanged" since 14th century Kings were dictating to lunatics and idiots. BC laws are "paternalistic," they state, "breach procedural fairness standards," and

"threaten Charter rights and freedoms."

In summary, the laws affecting Joan, Dan and Tony are "a disgrace" to democracy, says Laura Watts, CCEL national director. "You flip a switch and you have no rights."

The "switch"? If you're deemed "incapable" by a health professional, control of your life is handed to a court appointee, usually a family



EVERYONE AGREES Joan has some short term memory loss, and can be suggestible, but people disagree deeply on what Joan truly wants and how severely Joan's mental faculties have been affected. So legal battles have ensued. Who has the right to control Joan's life?

BC OMBUDSMAN KIM CARTER CLARIFIES she's investigating residential care primarily because so many individuals with unresolved complaints have asked, "Where can I go?"

member or the PGT. But what's "incapability," and how is it determined? If you regularly forget pots on the stove, but still manage everything else, are you "incapable"? Yes or no?

There's widespread "confusion" even among lawyers and health professionals, CCEL writes, because incapability is "vague" and "appears to differ in different contexts." Health professionals often use a Mini-Mental State Examination, CCEL notes, "erroneously" presuming that its 10 to 15 cognitive challenges—to count backwards by seven, spell backwards, and say noifsandsorbut—can effectively determine your right to liberty. Many health professionals, CCEL states, simply dole out "informal," "on the spot" judgements and then testify authoritatively, "in my opinion, this person is incapable." CCEL adds that due process rights are often ignored by health professionals who "perceive 'doing law' as contrary to 'doing health'." Typically, you're not even notified you're losing your rights, in order to "avoid unnecessarily upsetting" poor, incapable you.

Protests easily ignored

Essentially, these laws leave most seniors in care homes powerless. Many residents have already been deemed incapable, and others can easily be so deemed at any moment.

The abject powerlessness of most residents and the contrasting immense power of care providers has long been a feature of nursing homes, but few relatives or guardians worried or intervened much so long as homes appeared to be reasonably respectable places to put loved ones.

However, in recent years, the quality of care and life in BC residential homes has been deteriorating. Relatives are becoming alarmed. They're starting to complain in larger numbers, and more vociferously.

They're complaining about hospital-level cleaning and on-site cooking being replaced by "horrendous" filth and "airplane food" or "TV dinners."

They're complaining about cutbacks and increasing numbers of casual, less skilled workers making providing decent care nearly impossible, even for the many admirable caregivers out there. "Things are not getting done. Pure and simple," elaborates Lyne England, a nurse who chairs the Regional Family Council Advisory Committee (comprised of relatives and friends of people in care). "We know people aren't getting turned. They aren't getting fed in a leisurely manner. They aren't getting toileted as frequently as they should. They're told to relieve themselves in their briefs."

But what residents and relatives are finding is a residential care system which, from caregivers up to health authority executives, has long been accustomed to having King-ly, unchallengeable legal powers and simply ignoring seniors' rights.

BC Ombudsman Kim Carter clarifies she's investigating residential care primarily because so many individuals with unresolved complaints have asked, "Where can I go?"

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THE ONLY OTHER EVIDENCE offered of Joan's delusions is that she believes the care home "is running a prostitution ring." But examining the lodge's own daily notes, it seems Joan's dislike for the lodge is nearly constant, and what she's doing is comparing it to a contemptible brothel where women are confined, drugged and raped...

"There's seemingly no accountability," confirms England. She points to how particular local facilities have, arguably illegally, unilaterally begun bleeding helpless patients for the costs of medically necessary items like briefs or specialized beds yet, after two years of complaints, VIHA still simply comments the practices are "under review."

England also notes that increasing acts of "retribution" by care home staff with seeming impunity has created "pervasive fear" among residents and families alike. "Residents are worried about speaking out because they fear... not having their care provided in a timely manner, or being avoided, or..." England continues by mentioning Bud Maclean, who gained fame when his late wife's meals went to nutrition experts. Maclean says staff informed him that, if he didn't stop complaining, "[We] can put you out of here and you won't be allowed to see your wife." VIHA CEO Howard Waldner ultimately personally acknowledged that staff treated Maclean inappropriately. Nevertheless, says Maclean, little changed.

Phillip Jamieson, a former police officer, BC Police Commission executive, and president of a Saanich family council, observes residential care providers and VIHA act like an authoritarian, self-protecting "cult." "I don't intimidate that easily. I've met murderers," he says. "But I would say [attempting to intimidate] is the way they operate normally... If there's criticism of them, they circle the wagons and shoot inward."

And it was into all of this that Joan and Kim recently walked.

Caught in the system

Joan had been living at home with her son Ted when, in 2006, a doctor's medication error hospitalized her. While she was recovering, unbeknownst to daughter Kim, Ted had Joan designate him as her health care decision-maker. Normally, such representation agreements become effective if the person's ever deemed incapable; unusually, this was "effective upon execution." Shortly thereafter, Ted informed Kim their mother was going into long term care.

But over time, Joan began expressing ever more strongly to Kim that she wanted to go home. And witnessing the same degenerating care conditions many others had, Kim began to think the facility was making her mother not only unhappy but physically worse. Like many, though, Kim found expressing concern wasn't received well.

For example, Joan kept complaining about "feeling drugged" and enervated. Kim worried because she'd seen studies showing overprescribing to the elderly is widespread, particularly of psychiatric drugs for behaviour control in understaffed facilities. Only after much conflict did Kim obtain Joan's prescription list.

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Enhance well-being—retrain the brain

“I was dumbfounded,” she says. Amongst other medications, Joan was being given antidepressants, antipsychotics, addictive sedatives, and powerful opioids. A Texas toxicology firm told Kim the regime was “very dangerous” and indicative of “a serious failure in judgement by her care providers.”

Ted still felt the facility provided good care, and said Joan told him she liked it. Kim said Joan wanted out, and she was willing to care for her. Two of the care home’s doctors have stated that Joan is “incapable” of making her own decisions due to progressing dementia, thereby helping solidify Ted’s authority through the representation agreement.

Everyone agrees Joan has some short term memory loss, and can be suggestible, but people disagree deeply on what Joan truly wants and how severely Joan’s mental faculties have been affected. So legal battles have ensued. Who has the right to control Joan’s life?

Independent experts warn me against taking sides in complicated familial conflicts, and not to presume I can evaluate or fairly represent a person with Joan’s profile to readers. So I take a different tack: examining how the health professionals are rendering those same decisions.

Poring over court affidavits, correspondence, and daily notes of the senior’s lodge staff, I discover a veritable testament to BC’s dangerous combination of rights-stripping laws, residential care system despotism, and deteriorating quality of care.

Questionable uses of power

Two things immediately seem transparent. First, Joan frequently expresses intense dislike for life at the lodge, but the care providers believe they know what’s best and just as frequently dismiss, distort or misrepresent Joan’s experiences and wishes. Second, apparently because Kim, unlike Ted, often expresses concerns about quality of care, the health professionals engage in dubious efforts to cut her out of the picture, much like happened to Bud Maclean.

For example, Kim asked to get a second opinion on Joan’s status from a psychogeriatrician. The lodge doctor simply refused. The doctor even added the remarkable corollary that he personally be present if Joan ever did see a specialist.

Then, while explaining in affidavits why Joan needs to stay at the facility, this doctor paints Joan as having “no understanding or appreciation for what is happening around her” and being “incapable of understanding or appreciating her health care and other personal needs.” Conversely, when their director of care emphasizes Joan’s safety and autonomy at the lodge, she explains Joan easily manages her own washing, dressing, and virtually every aspect of her personal care.

But this director argues Joan is vulnerable due to her having experiences “not based in reality,” like “that she is being drugged”—without mentioning Joan is being administered several mind-altering drugs. Ironically, elsewhere the director blames Kim’s complaints to staff for often making Joan become “agitated” in ways that “require administration of a sedating medication.”

Even more worryingly, Joan accused two staff members of sexually assaulting her. Kim believed her. The lodge didn’t contact police or send Joan to hospital for evaluation. Since its own review found no conclusive evidence, several affidavits then present Joan’s accusation as more evidence of Joan’s “delusions.”

The only other evidence offered of Joan’s delusions is that she believes the care home “is running a prostitution ring.” But examining the lodge’s own daily notes, it seems Joan’s dislike for the lodge is nearly constant, and what she’s doing is *comparing* it to a contemptible brothel where women are confined, drugged and raped: “[she complained the

Without realizing it, you may be stuck in a feedback loop. It may have been brought on by a specific emotional trauma, or cultural conditioning, but if you are experiencing anxiety, frustration, forgetfulness, depression, or lack of sleep, it may be that your brain is habitually operating on the wrong frequency.

People who re-train their central nervous system through neurofeedback (also known as “biofeedback for the brain”) find that they are better able to focus, have more energy, are less reactive, and sleep more soundly. The process is non-invasive and, in the case of acupuncturist Walter (Skip) LaFleur of Simple Remedies on Cook Street, involves a program similar to a computer game where people learn to control the video display by achieving the mental state that produces increases in the desired brain wave.

Some call it “aerobics for the brain.” Electrodes, gently attached to the head, connect to a device that measures electrical impulses in the brain, amplifies them, and then records them. To concentrate on a task, specific parts of the brain must produce more high-frequency beta waves. To relax, the brain must produce more low-frequency theta waves.

“This process allows people to re-train their central nervous system for optimal performance,” says LaFleur. “Once you can get the brain frequencies more functional, people experience better sleep, and dramatic improvement in memory. Kids’ grades increase a lot, and behavioural problems stop. Self-esteem improves, and this starts a chain reaction of improvement in all aspects of a person’s life.”

Simple Remedies has been providing Victoria with practitioner-quality supplements, naturally derived and organic, for over five years. They also have on-site nutritionists and body work in addition to herbalists and acupuncturists. And now, after years of intense training, LaFleur is offering this well-documented, drug-free answer to much of what plagues mental health in our modern-day society.

“This process releases people from the imprisonment of emotional disabilities. It allows them to respond rather than react,” he explains. “If the internal workings of the mind are smooth, if there isn’t anxiety, resentment, or fear, then the person is in a much better state of overall health,” says LaFleur, a graduate of the American College of Traditional Chinese Medicine in San Francisco (1985).

Treatment sessions are 30 minutes. The person sits in a comfortable chair watching a screen, and might fly a spacecraft through a 3-D labyrinth, or drive a race car through a cross-country course. There is music, movement, and it’s all affected by minute electrical impulses from the brain. Amazingly, this kind of “play” leads to documentable improvements in some of the most vexing mental maladies.

“It works, and the research and testimonials prove this,” LaFleur says matter-of-factly. “And unlike pharmaceuticals, this is 100 percent positive.” For more information please refer to: EEG-info.com or search “Neurofeedback” on YouTube.



Skip LaFleur helps a client to “retrain” her brain.

Walter (Skip) LaFleur

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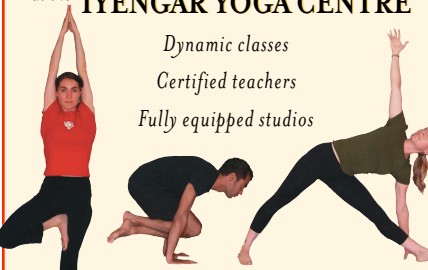
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“WHEN THEY SAY JOAN IS INCOMPETENT and not able to comprehend what’s going on, I find that to be absolute nonsense... I see a collusion between health personnel and family members and legal entities which shouldn’t be happening in that way.”

—Carol Pickup, former nurse, hospital trustee,
Saanich councillor and CRD director

-pills] were knocking her out... You can’t hold me here against my will. I’m not a prostitute... I’m tired of being raped by you people!... I’m in a brothel... they treat me like something off of the street here...”

The health professionals frequently find other creative ways to exculpate themselves, and undermine Kim and her relationship with her mother.

For example, innumerable staff notes describing Joan’s moods are indistinguishable from common side effects of her medications: agitation, drowsiness, memory loss, sleep disturbance... Nevertheless, despite Kim having raised concerns often, *not once* in hundreds of staff notes can I find a suggestion Joan might be experiencing any drug side effects. On the contrary, at one point, staff discussed Joan’s increasing difficulty sleeping and supposed the cause was Kim visiting too often. The facility’s doctor then “prescribed” that Joan only be visited twice weekly for two hours.

When Joan hand-wrote a letter stating she didn’t want her visits with Kim or anyone restricted, the lodge concluded it was “unlikely” Joan had the mental capability to write the letter herself, and ignored it.

Yet Carol Pickup had witnessed Joan writing it. Trained by Seniors Entitlement Services as an advocate, Pickup was formerly a nurse, hospital trustee, Saanich councillor and CRD director. Pickup has been meeting with Joan for a year. “When they say Joan is incompetent and not able to comprehend what’s going on, I find that to be absolute nonsense,” comments Pickup. “I see a collusion between health personnel and family members and legal entities which shouldn’t be happening in that way.”

So Joan eventually got her own lawyer. He determined she was legally capable and “consistently” wanted Kim as her health care decision-maker. Joan signed a new representation agreement.

Finally, Kim brought Joan home.

The next day, while Kim, Joan and Lyne England (of Regional Family Council Advisory Committee) were chatting, police arrived. The care home’s doctor had trumped the new representation agreement: he’d suddenly declared Joan dangerously mentally ill under the Mental Health Act. So three police officers crashed the ladies’ tea party and escorted Joan to an ambulance.

“It was a nightmare!” cries England.

Joan, however, never entered the psychiatric hospital. A new psychiatrist conducted an MMSE test and, after ten minutes, pronounced Joan indeed mentally ill but miraculously improved enough to immediately be placed “on leave” from hospital—and incarcerated back at the lodge she’d just left.

This psychiatrist’s “treatment plan” listed the names of everyone in the extended family allowed to visit her, and curtailed visits from Kim, her husband, or anyone they might send. No reasons were given.

Today, Joan remains at the lodge. Litigation continues.

Solutions ahead?

“Who in god’s name would think this was possible, that people could actually put you away like this?” cries Kim. “I want my mother to live the way she wants to live. I want her to have a voice.”

While she’d never witnessed psychiatric abduction before, England says she’s seen many cases where seniors’ rights have been similarly trampled by caregivers who either believed they knew best, or had hidden, sometimes exploitative intentions.

“It’s not unusual,” says England. “Do you hear a lot about it? No. Unless you happen to be an advocate for people in care.”

And what happens if the lead doctor is engaged in malpractice, or mistaken? Ultimately, doctors regulate themselves, and are historically more likely to defend than sanction

one another. Meanwhile, court actions require one doctor to testify against another. But doctors weigh such actions exceedingly carefully because, like clashes of titans, challenging each other frequently would ultimately weaken the powers of them all.

Mercifully, though yet to be proclaimed law, many improvements have recently been made to BC's guardianship laws. These give us more rights to compose advance directives, enforce family mediation and, crucially, maintain control over parts of our lives even if deemed incapable of managing other parts.

"It's a very big deal," says CCEL's director Laura Watts. "This is law that affects every single person." She's "very pleased," but adds "unknowns" remain.

It's still unclear, for example, how capability will be determined, how detailed the process will be, and who'll be on evaluation teams.

Watts also notes few professionals or lay people truly know or follow current laws. "I haven't seen a plan for a public education roll-out. My fear is that disconnect will only get bigger."

She also regrets one law remains unchanged, still trumping all these new laws—the one that recaptured Joan. "The Mental Health

Act is in dire need of a complete overhaul... It's a very, very big stick, and I don't think it's at all reflective of the modernization of the guardianship legislation."

Under BC's Mental Health Act, you can be confined and your life carefully controlled merely if you're in danger of experiencing "mental or physical deterioration"—technically, you can be committed for aging.

But CCEL's Robert Gordon advises overhauling this "appalling" law is unlikely. "This is heresy," he says. "[Health Minister] George Abbott will probably run screaming from the room... It's red hot."

Gordon says most health professionals regard the broadly discretionary powers as a "comfy blanket," and resist incorporating civil rights. "People in the health care system... find great comfort from having the Mental Health Act."

Regardless, there are other ways to strengthen seniors' rights.

"Every person occupying a long term care bed should have an advocate," says England adamantly. She feels we also need more family councils independent from VIHA, a provincially-empowered seniors advocate, and "whistleblower protection" for caregivers.

While publicly-funded facilities provide

information about resuscitation and TV hookups, England would like to see them pledging regular meals and baths. "There's no contract for care when you take your loved one to a long term care facility and you leave them there."

Phillip Jamieson, the ex-cop, suggests a charter of rights for people in care. "Even a prisoner in a facility has certain rights," he comments.

Kim believes we also need to question our indifference to seniors. "If any one of us had this happen to them, would we want people to just walk away and say, 'Well, you're old, that's what happens to you?'"

Rob Wipond is looking for someone to advocate for him when he's committed. He has also posted links to references at www.robwipond.com



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