“Anti-psychotics and Off-label Prescriptions: Right for Whom? When?”

A Family Member’s Perspective
Leslie Smith
22nd Annual John K Friesen Conference
May 27–28, 2013
My Mother–The Patient

Ruth—one month prior to entering the hospital
Prior to entering hospital she was living at home
Walking with a walker with no difficulty
Calling and speaking to family members on the phone with no assistance
Eating three meals a day, and had a healthy appetite. She weighed approximately 129 pounds
Sleeping from 11:00 pm to 6 am without the need of any medication
She had been diagnosed with Dementia

- Given Haldol sometime during this period
- Eating meals sporadically
- Walking with walker
- To us, she appeared altered

- Received the spinal pain relief injection
- Eating meals sporadically
- Becoming agitated
- Was strapped into her wheelchair, and asked repeatedly to be untied
- Walking with a walker
- Speech became compromised, began mumbling, and had difficulty communicating clearly
- Kept asking me to help her
- Delirium
Hardly able to speak
Began slapping and pounding on the chair
Taking clothes off, losing ability to speak
Was still eating but sporadically
Still taking Haldol 3 times a day, without our knowledge
Arrived to find her agitated, banging, repeating words, taking clothes off
Her left eye was closing
Her joints were stiff

The nurse arrived and said that he had called the doctor, and told him to come to the hospital. When I asked what was going on, the nurse replied.

“It is the anti-psychotic drug!”
To which I asked
“What anti-psychotic drug?”
He said “The Haldol!”

The doctor arrived, and after examining her, immediately took her off Haldol.

He said she should improve in the next 3–4 days, after the effects of the drug wore off. I left, expecting her to recover to her previous state.
Dr. Louis Caplan, Professor of Neurology Harvard Medical School and Senior Neurologist Beth Israel Deaconess Medical Centre

- The most overused drug among patients hospitalized on medical and surgical services and in intensive care units
- One dose of Haldol can be disastrous for patients with Parkinson’s and other extrapyramidal conditions.
- When the sedative effects of Haldol wear off, patients naturally often have rebound hyperactivity. Any sedated individual can become temporarily restless when they are becoming more alert. Unfortunately they then are often knocked down with more Haldol rather than letting the natural course of recovery from sedation transpire.

Alliance for Human Research Protection
She had been transferred to the Acute Ward, staff continually assumed she was from a home, and that she had severe dementia

Found her tied into the bed screaming

This was the first time her screaming was continuous

There was a very marked decline which began around Jan. 11, 2013

She was agitated, banging, screaming, and slapping herself for no apparent reason

Delirium
Off all drugs (Haldol & Morphine)
Visible progress for this time
Eating 3 meals a day
Walking assisted
Toileting
More responsive
Responding to yes, no and saying some sentences.
Started to brighten up
Slapping 90% gone
drinking from cup on her own
(all of the above were being done regularly when at home)
She was still screaming, agitated, banging
She kept saying "I am so frustrated " "Please clear my brain"
Feb. 3–Feb. 9, 2013

- Feb. 3–Given Trazadone for sleep
- Feb. 5–She said “I’m better today”
- Started to brighten up
- Visible progress for this time, eating 3 meals a day
- Walking assisted, toileting
- More responsive, responding to yes, no and saying some sentences
- Feb. 6–fell out of bed while under supervision of 24 hour care worker
- I arrived on Feb. 7 to find her strapped into a chair
Severely impacted bowels
Given Morphine and Nozinan
The explanation from the Doctor on call was that her behavior was due to the Haldol effect
Agitation, screaming, banging, not speaking etc.
He consulted with the on-call Psychiatrist whose explanation was
“Her brain is attached to the Haldol type drug. She requires another drug to bring her out. Like a Heroin addict being taken off Heroin cold turkey which is what happened to her. Haldol should have been weaned off. Nozinan would hopefully do this.”
We were desperate so we said yes
Screaming when morphine wears off
Snowed under and did not wake up for almost 2 days
Feb. 11–Feb. 28, 2013

- Still taking Nozinan
- Difficulty eating without assistance
- Randomly eating meals
- Not walking
- Not toileting
- Very marked decline in overall ability and health
- Overdosed during this time, on morphine (dilaudid), Narcan was used to reverse
- She kept saying "Why don't you people pay attention" and "I just want to say one thing. I want to go home"
Week of Feb 27

No care worker for shift. She was put in the hallway in chair.

While she was sitting there, she took her shirt off, and was naked from waist up

She had not eaten breakfast, as there was no one to feed her
Feb. 28, 2013

- I personally hired “Nurse Next Door” to care for her
- The shifts were from 8–10, 12–2, 4–6
- 7 days a week
- Objective:
  - To feed her
  - Toilet her
  - Walk her
She said "I am not crazy"
Still agitated
Due to her inability to communicate, it was unclear if she was in pain, or frustrated
The Doctor said it was pain
The family felt it was more frustration
Drinking, and sighing
Was drinking on her own from a cup
Risperdal was started
Was taken off Nozinan
Snowed under
Unable to drink from cup
Two days ago was drinking on her own from cup
Stopped eating prawns
Non responsive
Does not recognize family
Mar. 22, 2013

- Was not eating
- Starving to death
- Medication stopping her from eating
- Unable to walk, or toilet
- Complete decline in all abilities
- I tried to contact and communicate with her Doctor. Sent fax, left messages to ask questions
- Response was “We cannot reply to a fax, you have to make an appointment. We can’t bill you with a fax”
BRISLEY—Ruth Alice

Today we say goodbye to our beloved wife and mother. There are no words to describe the depth of our love for you. There are no words to describe how much you will be missed. There are no words to describe how your beautiful warmth and love has affected us all. Heaven is a place of perfect peace; heaven is a place of perfect love; heaven is a place of perfect protection. The heaven we describe is a home for you now. And there is no better place of peace, no better place of love and no better protected home than behind and within the walls of our hearts. Our sweet Ruth Alice Brisley passed away on April 2, 2013. She was 81. Her loving family includes husband Michael Brisley, adoring children David Smith, Jeff (Leslie) Smith, Leslie (Rick - “Huggy Bear”) Smith, David (Liz) Brisley, Karen (Stu) Sparke, also her brother Cecile and sister Verna. She is predeceased by step daughter Debra. Our mother was a living smile. Her love of life and love for her family was total. When we close our eyes we see and feel her joy. She would never miss a chance to make our day better. She loved her family; she loved her friends; she loved the beach; she loved to garden; she loved prawns and O’Henry’s. She was quick of wit and had a subtle mischievous side. A special thank you to the Palliative Care Unit at Nanaimo General Hospital. Ruth was a member of the Masonic Family. A celebration of life will be held Saturday, May 18th from 11:00a.m. to 1:00p.m. at St. Paul’s Parish Hall, 100 Chapel Street, Nanaimo B.C. If possible please RSVP to: rizzle@shaw.ca Mom, we love you beyond measure.
Contributing Factors To Her Care

- No consistency in care givers, which led to incorrect assumptions, and improper treatment
- When she needed to use the bathroom, the response from the care giver was “She has a brief!"
- She was not given any exercise, or walks throughout the day
- Caregivers would spend all their time on their iPhones, instead of focusing on the patient’s needs
- In one instance, the nurse shoved the medication in her mouth for bowel movement. Instead of having a bit of patience, or allowing me to give it to her, the nurse threw it away, because my mom would not take it. This resulted in her having severely impacted bowels two days later
- When questioned about the medication, the nurse responded with "That's all you are going to get into someone like her"
How Can WE Better Patient Care?

- How can you combat continual staffing changes?
- Lack of time to spend with patients? (that results in patients left unattended)
- How do you change the attitude towards aging patients? When the consensus is we should be spending money and attention to younger people who contribute to society?
- Prescribing medication that does not help the patient, but does make it easier to control them?
- How do you prevent unnecessary deaths in elderly patients?
- Lloyds Storey 2 weeks later