Alberta Health Services

Involving Families in *Appropriate Use of Antipsychotics*

Mel's Story

My Father in Law was diagnosed with early onset Dementia in his 50s and passed away last year from this devastating disease. It seemed as soon as he was placed in Long Term Care they started prescribing antipsychotics.

His behaviours were in no way disruptive or aggressive. He would get very scared because the rare type of dementia he had affected the occipital part of his brain first. He went from having perfect vision to being legally blind in a matter of months. He would get very overwhelmed and upset if approached in a hurried/loud manner and would think he was being attacked. He would flail, throw his arms and yell because they would rush at him yelling his name "Melvin, Melvin, Melvin" even though he had only ever gone by "Mel" and really disliked being called Melvin. If you took time with him, spoke to him softly and one person at a time, you could always help him to get changed or toileted etc.

I counted all the antipsychotics/sedatives he was on at one point and he was a on a total of 7!! This included Risperidone, Ativan, Imovane, Haldol and Trazodone. We'd find him literally walking sideways down the hall or bent completely in half stumbling down the hall, he'd be drooling non-stop, he'd sometimes have lip or gum smacking, he'd have repeated falls nearly every single day. It was just awful to see and so unnecessary... `

How do we open the gate ?

Dementia is challenging for families. As in Mel's story, families often feel they're on one side of the fence, staff on the other, and the gate only seems to open from the staff side[1]. Mel's family had ideas to improve his care and concerns about his medications, but felt like no one was listening.

Dementia is challenging for staff. Staff feel overwhelmed by the daily needs of residents, along with the stress, grief and exhaustion of families. How do we open the gate, tear down the fence and work together more effectively? 1 Sienna Casper, ICCR presentation 2013
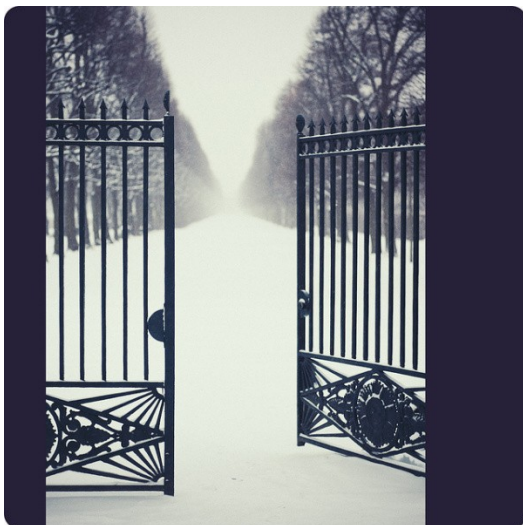
What do Families Need?

No one gets a Dementia 101 course in high school. Dementia is tough! How do families navigate the challenges of communicating and visiting with their loved ones? Betty spends the whole visit asking, "Where's my purse?" Bill can't remember yesterday's visit and says angrily to his son, "You're of no use to me!" Resources such as the Shifting Focus Guide can help!

"How was dad's day?" What are families looking for when they ask this question? They're not looking for proof you're doing your job—but a way to connect with you and the person they love. You open the gate when you:

No one gets a Dementia 101 course in High School

- ♦ Meet the family with a smile and ask if they have any concerns

- ♦ Offer any positives or highlights from the day—a good appetite, enjoyment of the volunteer fiddler, a better sleep, etc.
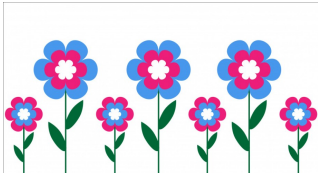
Resources for Families

Shifting Focus: Guide to understanding dementia behaviour

This booklet provides information about the brain and dementia, recognizing and understanding the person's actions and behaviours, and supportive strategies.

For more information and resources see:

www.alzheimer.ca

Alberta Health Services AUA Toolkit

What do Families Bring?

- ♦ Families bring the person's life story

- ♦ Can participate in aspects of care

- ♦ Help make decisions

- ♦ Can be advocates and supporters. Can help us understand the meaning behind behaviours.

How do we shift from Experts to Partners?

- ♦ Discuss options and solutions, versus fix and give advice.

- ♦ Ask, don't tell.

- ♦ Empower versus encourage dependence.

Families should never be considered visitors

Talking about Responsive Behaviours & Antipsychotic Medicines

When?

- **Pre-admission meetings**

- **Admission Conference: expectations with disease progression**

- **When responsive behaviours occur, to look for the reason for the behaviour and alternatives to medicine**

- **When it is believed an antipsychotic could be helpful and appropriate**

- **Care conference medication reviews, to discuss reducing or discontinuing antipsychotic medicine**

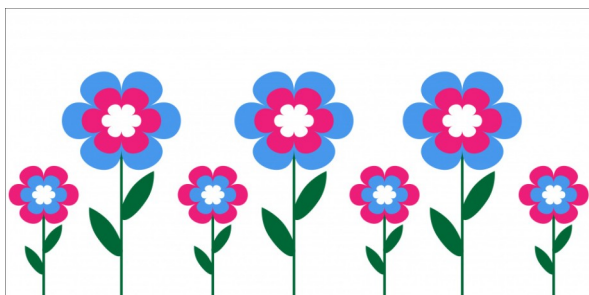- **Family council presentations**

- **Ongoing informal updates**

Open communication will help avoid the distress of *surprise phone calls!*
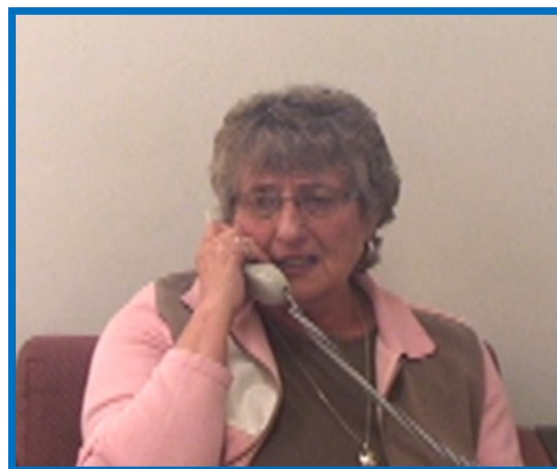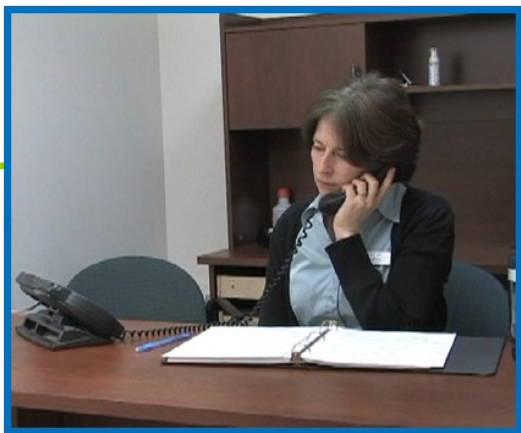
Resources for Staff

See the AUA Toolkit for Resources including:

- **Responsive Behaviour Brochure**

- **Antipsychotic Medicine Brochure**

- **AUA Family Conference Tracking Record**

Mel's Story, continued

When Mel became palliative in January last year, it was a fight to get nursing to call his Doctor to stop all his meds. In the end we had his GP stop everything as Mel became so weak, was no longer eating and drinking, became bed ridden as his dementia was in the late stages. Some of the nurses would question [having no medications] by saying, "We'd like to call the Doctor as he should be on something to help him settle."

I'd just look at them and say, "Are you serious? Look at him, he's not moving at all, he can't eat or drink."

They'd say, "Well when we change him he fights us and yells." Well of course he would when you don't explain what you are doing and he is terrified. I would come in and help change him, wash his face, change his position etc. and he would be fine.

We were blessed in Mel's final days as he had an excellent LPN and team of Nursing Attendants looking after him. While it was sad when he passed away we felt an immediate sense of relief as we knew he would no longer be suffering and would be at peace.

We ask you to think of Mel. Think of Mel when you are providing care to your clients or patients with Dementia. Think of him when you are going to give your "agitated/difficult/aggressive" patient that prn dose of antipsychotic.

Think of him when you see signs that a patient is overmedicated.

Our hope is that through this story and the AUA project that greater awareness and light will be brought to this topic. Mel would have wanted us to share his story and we hope that it can help to make a difference in the care and quality of lives of others like him.

Remember to think of Mel….

*Identifying information
changed to protect privacy*