

Patient and Family Involvement –  
experience from the  
Appropriate use of antipsychotics  
(AUA) project in LTC

Sept 2016

# AHS: Patient/Family involvement

“Upstream”  
(planning)

“Downstream”  
(clinical practice)



## Patient Engagement:

- include the patient/family perspective when **planning** health care delivery (AUA project implementation)

## Patient Centred Care:

- implement practices that enhance the patient experience and improve key outcomes
- gain the patient/family perspective at the **point of care**
  - Inclusion
  - Responsiveness
  - **Partnering**

# What are Antipsychotics?

- Medications designed to treat psychosis (hallucinations/delusions)
- VERY helpful/necessary for:
  - chronic mental health conditions (**Schizophrenia**; some types of depression, etc.)
  - Short term for distressing psychosis (e.g. delirium)
- Commonly used to **'manage' behaviours** in people with dementia (chemical/pharmacologic restraint)  
risperdal; seroquel; zyprexa
- Clearly established **evidence of harm** when used for long-term in older people with dementia
  - Death: strokes/pneumonia; falls, decreased ability to communicate/engage



# AUA: a project in 4 phases

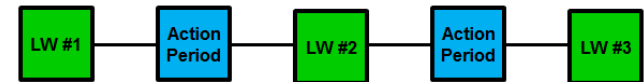
## Phase 1 (2012-13) Plan/Develop resources

- AUA Steering Committee
- AUA Guideline – Expert Advisory Group
- AUA Toolkit of resources – working group
- Outcome Evaluation working group



## Phase 2 (2013-14) Start Small

- 11 Early Adopter Sites (EAS)
- Innovation Collaborative
- 50% reduction in residents on meds



## Phase 3 (2014-15) Scale and Spread

- Provincial implementation to all 170 LTC sites in province (Innovation Collaborates and Education)

## Phase 4 (2015-16) Sustainability

- Two additional LWs (Sleep and Delirium on Dementia)
- Trail resources in Supportive Living

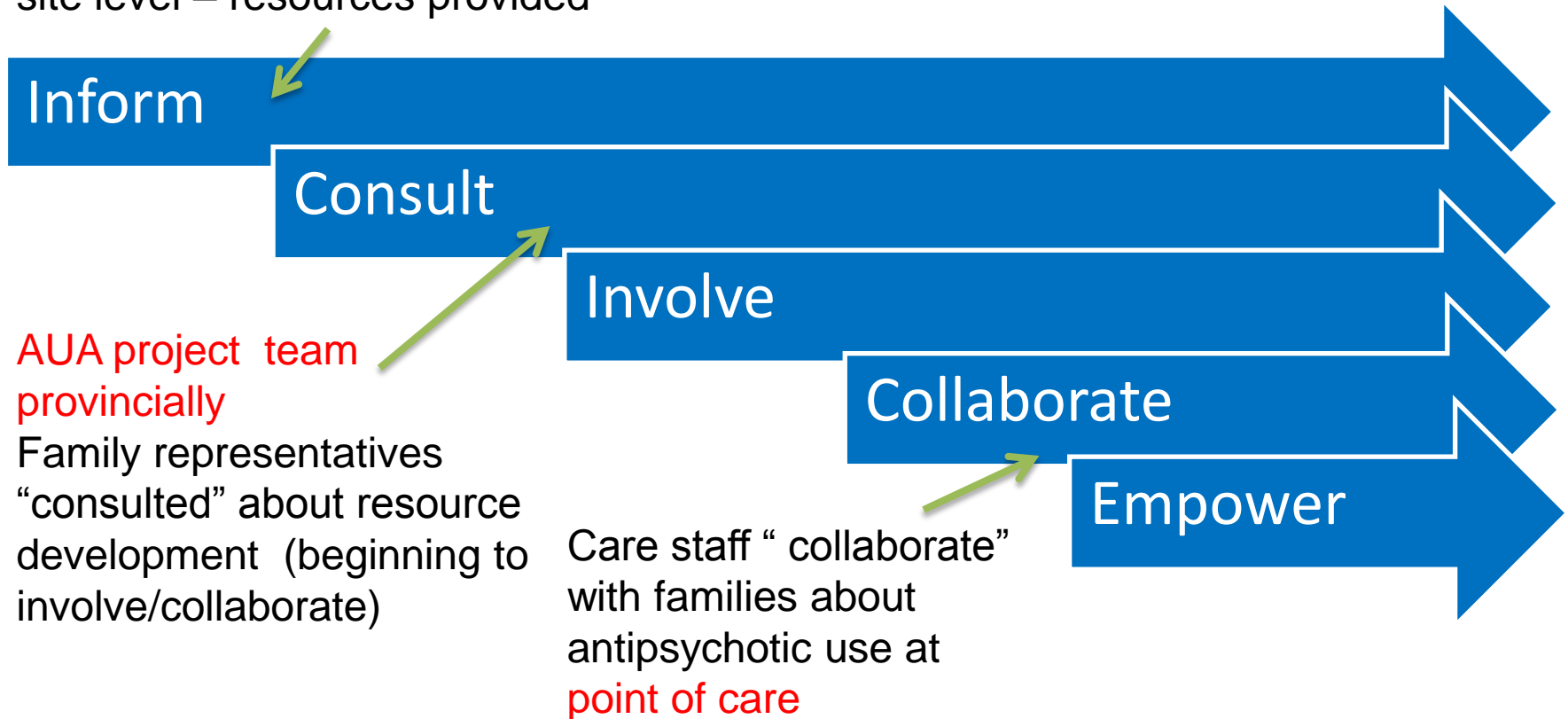


# Summary: Family engagement in AUA

Appropriate Use of Antipsychotics (AUA) Project stages	Engaging family – project level – <b>planning/feedback</b>	Engaging family at site level in AUA project	Skilling LTC staff to engage family	Engaging family about antipsychotic use in LTC sites
<b>Phase 1:</b> - AUA steering ctte - AUA Guideline - AUA Toolkit (staff) - MyHealth.Alberta.ca	<b>Family Advisor on AUA Steering committee</b>		Developed Staff module on engaging family and resources to use at site	Consent required in Guideline  Developed: - Family resources
<b>Phase 2:</b> 11 EAS LTC sites	Family reps invited <b>3 family reps</b> (posters, letters, interviews, etc.)	Media stories	LW#1 - med review steps LW#2 – why engage family? LW#3 – resources for family engagement	Engage in care-planning around responsive behaviours
<b>Phase 3:</b> 170 LTC sites	<b>Family focus groups</b> held to get feedback on the family resources <b>(lead by PERG)</b>	Letters phone calls  Present to Family Councils	LW#1: stakeholder (families at site); med review, consent; <b>MEASURE family engagement</b> LW#2: <b>FAMILY resources</b> LW#3: <i>meaningful activities</i>	<b><u>AUA OUTCOME Evaluation:</u> family reported improved resident Quality of Life, participate in medication discussions</b>
<b>Phase 4:</b> Sustainability	Presentations made to <b>family councils; Family advisor collaborated in planning LW content</b>	Sites asked to invite family to LWs	LW#4: Sleep - decrease sleeping pills LW#5: prevent delirium	Encouraged sharing resources with family
<b>SPREAD: EAS for Supportive Living (SL)</b>	Sites asked to invite <b>family rep involvement</b>	Letters Family Councils	LW#1, LW#2, LW#3, LW#4, LW#5	Planning engagement for provincial spread in SL

# Levels of engagement

Site AUA Teams encouraged to “inform” about **AUA project** at site level – resources provided



# Engaging Families in PLANNING

## Strategy

- Encouraged sites to invite family to be on SITE implementation planning committee (phase 2)
- Project team engaged with family at project planning stage in developing resources for staff/families (phase 3/4)
- Offered family council presentations on antipsychotic medications (phase 4)

## Lessons

- provide more support/direction for teams regarding family advisors
- GOOD collaboration; resources suitable to share with family (not many came to sessions)
- GOOD response to presentations made to family councils

# Encouraging Patient/family centred care

## Strategy

- Set expectation for obtaining consent in **AUA Guideline**
- Developed resources to support conversations about behaviours/antipsychotics
  - Pamphlets
  - Self-study module on how to have conversations

## Lesson

- Not all clinicians ready to engage with family on prescription decisions (yet)
- Concern about maintaining safety in sites when behaviours put others at risk of injury
- Feedback from families: not all WANT to be involved in discussion “leave that to dr”



# Family engagement: Lessons learned (so far)

- we are learning as we go AND trying to role-model and encourage good engagement in sites
- ‘easiest’ stage: involve families around care decisions (help with care-planning behaviours; use of antipsychotics)
- Look for the ‘interested’ family to engage in planning – respect their skills!
- Sitting on committees may not BEST way to use families (going to try more focus groups next)

# Engagement Resources

Google: “AUA Toolkit”  
(external AHS webpage)

- Resources for staff to use to engage families about medication use/behaviours/consent
- Module for staff on engaging families in conversations about antipsychotic use

**Appropriate Use of Antipsychotics (AUA) Toolkit**  
For Care Teams  
Seniors SCN

The Alberta Guideline on the Appropriate Use of Antipsychotic (AUA) Medications (2013) and accompanying resources provide health care professionals with direction regarding assessment and management of responsive behaviours associated with dementia.

The AUA Toolkit Working Group reviews all resources, and will continue to identify promising and leading practices for the Toolkit.

The AUA project is sponsored by the Seniors Health SCN in collaboration with the Addiction and Mental Health SCN.

**Are You New to AUA?**

- AUA in LTC Summary

Questions/Feedback?  
We'd love to hear from you.  
Email [aue@ahs.ca](mailto:aue@ahs.ca)

**AUA News & Ideas**

- Improved sleep in LTC! March 2016 project bulletin
  - View more, bulletin archives
- Curbside Consultations - contact us to find out more
- Published Stories & Articles

**Pick of the Month**

Dementia Care Matters (David Sheard) This site is well-worth exploring! Check out the published articles, videos and books!  
How person-centred are you? Appraisal Form

**Resident Success Stories**

Alberta reducing harmful drugs to dementia patients  
Watch the video... (2:57) Global News

Archived Success Stories

- Dementia patients are "Coming Alive"
- Her eyes sparkle again
- New perspective for dementia patients (video)

**About Us**  
AUA Project Background and Acknowledgements

**Contact Us**  
For further information:  
[aue@ahs.ca](mailto:aue@ahs.ca)

- ▶ Appropriate Use of Antipsychotics (AUA)
- ▶ Responsive Behaviours: Assessment & Care Planning
- ▶ Responsive Behaviour Prevention: Dementia Friendly Environments
- ▶ **Involving Families in AUA**
- ▶ Meaningful Activities
- ▶ Quality Improvement (QI) Project: Reduce Antipsychotics
- ▶ QI Project: Prevent Delirium on Dementia
- ▶ QI Project: Support Sleep in Dementia
- ▶ **Dementia Education Resources**

<http://www.albertahealthservices.ca/scns/auatoolkit.aspx>

# Family resources on behaviours and antipsychotic use

MyHealth.Alberta.ca

The screenshot shows the MyHealth.Alberta.ca website interface. At the top, there is a navigation bar with links for Home, Health Information & Tools, MyHealth Videos, and Health Care Locator. Below this is a search bar containing the text 'antipsychotic'. To the right of the search bar, there are social media icons (Facebook, Twitter, Email) and a 'Share' button. Below the search bar, there is a 'Refine results' section with 'By Category' and two categories: 'Health A-Z (5)' and 'Medications (10)'. The search results are listed below, with the first result, 'Antipsychotic medicines', circled in green. A green arrow points from the text 'Family resources on behaviours and antipsychotic use' to this circled result. The search results include:

- [Antipsychotic medicines](#)  
myhealth.alberta.ca/health/pages/conditions.aspx?Hwid=pl1027
- [Antipsychotic Medicine](#)  
Antipsychotic medicine can sometimes help people with dementia for a short time if they ... to find the best ways to meet the person's needs without using antipsychotic medicine ...  
myhealth.alberta.ca/Alberta/Pages/Antipsychotic-medicine.aspx
- [Dementia: Responsive Behaviours](#)  
People with dementia often use behaviours such as wandering, pacing, cursing and calling out to ...  
MHARelated True Antipsychotic Medicine 3 False ...  
myhealth.alberta.ca/Alberta/.../Dementia-responsive-behaviours.aspx
- [Bipolar Disorder](#)  
Looks at illness that causes extreme mood swings, ranging from mania (feeling overly ... with counselling and medicines like mood stabilizers, antipsychotics, and antidepressants ...  
myhealth.alberta.ca/health/pages/conditions.aspx?Hwid=hw148751
- [Dementia: Medicines to Treat Behaviour Changes](#)  
myhealth.alberta.ca/health/pages/conditions.aspx?Hwid=hw138091
- [Perphenazine/Amitriptyline - Oral](#)  
This medication is used to treat depression occurring with other mental/mood disorders ... a tricyclic antidepressant (amitriptyline) and an antipsychotic medication (perphenazine ...  
myhealth.alberta.ca/health/.../pages/conditions.aspx?Hwid=fdb9047
- [Aripiprazole - Oral](#)  
Aripiprazole is used to treat certain mental/mood disorders (such as bipolar disorder, schizophrenia, Tourette's ... Aripiprazole is known as an antipsychotic drug (atypical type ...  
myhealth.alberta.ca/health/.../pages/conditions.aspx?Hwid=fdb4274

# Key success factors for AUA project

- Leadership support: province, zone, sites, units
- Care Team engagement: local efforts
- Measurement: local tracking/system monitoring
- Lots of communication (project bulletins, media releases) – story telling!!!
- Resources made available to ‘all’ on AUA  
Webpage – tools/strategies developed to help with local implementation
- Family engagement



# Family Presence

Troy Stooke

- Resources for families to help negotiate “being present”

**Families are more than visitors.  
They're partners in care.**



# SUGGESTIONS FOR HOW PATIENTS, FAMILIES, ADVISORS, AND CITIZENS CAN ENCOURAGE FAMILY PRESENCE



## AT THE POINT OF CARE

- Ask healthcare providers to use words that everyone can understand, not medical jargon. Ask that instructions are written down, and meeting materials are sent in advance.
- Request healthcare providers pay attention to concerns expressed by patients and families.
- Encourage practices that will enhance communication between patients, families and healthcare providers such as "NOD" (Name, Occupation, Duties) and "Teach Back" (e.g. "Can you tell me in your own words how you would explain what we've talked about, to a friend).



## ORGANIZATIONS

- Suggest that healthcare organizations update policies and practices to enable family presence, access, or rooming-in 24/7 (for the support person) versus visiting hours (for guests).
- Ask healthcare providers about practices that increase patient and family participation as partners in care. Some examples are:
  - › ["Shared decision-making"](#) a collaborative process that allows patients and their providers to make healthcare decisions together.
  - › Family sharing the patient's cultural, emotional and spiritual preferences
  - › Family Presence at assessments, or hospital "rounds", or care planning meetings
  - › The opportunity (not the responsibility) for family to help with routine or comfort care
  - › Staff support and guidelines for families to be present during difficult, painful or invasive procedures, during critical illness, as well as pre-and post-operatively.
- Find out how patients and families are acknowledged and included in conversations about care, safety, quality improvement, service planning as well as system design, research and evaluation.
- Discover the best 'point person' to have these discussions with. It could be a health care provider or manager, a patient representative, a patient/family advisory council, a patient experience department, or quality improvement team.



## SUPPORT AND RESOURCES

- Find out about the ways your local healthcare organization listens to patients including the process for concerns or compliments and/or a patient and family advisory committee.
- Learn about other resources from the [Institute for Patient- and Family- Centered Care](#) such as the Family Presence Guide: [Better Together Pocket Guide for Families](#).
- The [Canadian Foundation for Healthcare Improvement](#) has a [full toolkit](#).
- Learn how [Better Together](#) can help you!



# WHAT CAN PATIENTS AND FAMILIES DO?



## ASK

- › Get to know the names of the healthcare providers and what they do.
- › Ask questions, clarify your assumptions, be respectful as you ask for information "Could you help me understand why..." or "How can I help?"



## KEEP TRACK

- › Use a notebook or the back of this document or whiteboard in the patient's room to write down questions, answers, names, history, tests, observations, etc.
- › Choose one person as the main contact to share progress with family and friends, and tell the doctors and healthcare staff as well as other family members.



## CONTRIBUTE

- › Families have important information that healthcare providers might need to know to provide good care. Find out when the care planning meetings and patient rounds will occur and ask to be present.
- › Contribute your knowledge to planning care and the discharge plan.



## ENSURE SAFETY

- › Write down information about all medicines. This might include medication name, purpose, how often it is taken and how much.
- › Ask for instructions in writing, in words you understand.
- › Clean your hands.
- › Speak up and tell the healthcare team if you are concerned about a change in your loved one's well-being.



## PROVIDE COMFORT

- › Discuss if, and how, family members might help with routine care.
- › Discuss opportunities for a family member to be present during critical illness, uncomfortable procedures, or just before and right after surgery.