



# ACR NEWS BULLETIN

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*This issue provides information on*

- 1. Fact Sheet # 2: Antipsychotic Medications In Long Term Care***
- 2. ACR AGM Held October 6, 2012***
- 3. ACR Dissolution - Reflection on where we've been, and done, and what's next...***

## ***Fact Sheet #2: Antipsychotic Medications in Long Term Care***

We're pleased to provide the attached Fact Sheet #2 (November 2012) on this most important topic to the distribution of the Bulletin and for reference, on the ACR website: [www.acrbc.ca](http://www.acrbc.ca).

The use of antipsychotic medications in Long Term Care is problematic as reflected in various care incidents, research papers and their 'black label' warning issued by Health Canada (2005), for their use in older adults with dementia.

Our goal is to provide family and friends of those in residential care with an overview of how and why antipsychotics are used on older adults with dementia in residential care and to provide information on what they need to know and do to advocate for appropriate care options for their loved ones.

We strongly encourage widespread sharing of this Fact Sheet to help raise awareness about the troubling use of antipsychotics in Long Term Care and non-pharmacological care alternatives.

We anticipate a future News Bulletin that will expand upon some of the topics covered in the Fact Sheet.

## **ACR AGM (October 6, 2012)**

Dissolution of ACR was on the Agenda of the AGM held in Vancouver on October 6, 2012.

The motion to dissolve ACR was passed. The implementation process will take some time and will be guided by the ACR Board. In the meantime, we will continue to provide News Bulletins and undertake systemic advocacy.

## **Reflections on where ACR has been, and done and what happens next...**

ACR – the Association of Advocates for Care Reform has been around since 1991 supporting the development of family councils and improved quality of care and life for those in residential care facilities in BC.

Along the way ACR has worked to raise awareness on the realities of residential care, feedback on care and quality of life concerns and recommendations for improvements. A publication 'Alone in a Crowd? – Social Isolation of Seniors in Care Facilities' (1997) was an eye-opener on the perspective of life in residential care from those who live there - the residents. These findings were well received and, still, today, are often referenced. A project to support research for an updated publication was on our 'wish list' – perhaps someday there will be a sequel.

The Family council initiative had a boost in 2005 when Gaming Commission Funding supported the establishment of a new website, development of a Family Council Handbook that covered the basics of developing and sustaining a Family Council, Family Council Conferences, and the publication of our first ACR Newsletter, 'Caring' in addition to a variety of other resource materials.

Subsequently, additional supplementary material was developed once a need was identified – for example a brochure on 'Visiting', revised sizes of the original Family council poster as well as an efile version for Facilities and Family councils to print off as needed.

Family council information sessions and workshops were held on weekends in the early years. When the response dwindled and with the new material available as a result of the Gaming Commission Grant, we began to hold Family Council workshops in a variety of formats. This included: community based workshops with attendees and staff from various facilities in the area; workshops held in specific facilities; workshops sponsored by a Health Authority (e.g. the Interior Health Authority sponsored two workshops; one held 'live' in Penticton and the other via webinar broadcast throughout their region), 'tune-up' sessions provided as requested by facilities; 'general discussion sessions' with existing Family Council members, facility groups and staff who were interested, but sceptical and wondering what Family Councils were all about.

## Family Council Conferences

ACR had its first Family Council Conference (September 2007) – the first of what was hoped to be an annual event, held in locations throughout the Province.

- **Sept 2007**, the first Family Council Conference took place at Holyrood Manor in Maple Ridge who kindly offered to co-sponsor the Conference.

The Conference focus was: **'Moving into Residential Care - Collaborating for a smooth transition'**. This panel presentation and discussion brought together a Facility Administrator, Social Worker, Nurse and Family member:

Karen Baillie (RN, BScN, MHA, CHE) Executive Director, Haro Park Centre;  
Leanne De Romeri (BA, MSW, RSW), Czorny Alzheimer Centre;  
Cherry Harriman (RN, BScN, Diploma in Gerontology), Manager, Health Services, Peace Arch Hospital – Extended Care;  
Gaby Marcano, Family council member, Holyrood Manor

- **Sept 2008**, the second Family Council Conference was held at Normanna Home in Burnaby who kindly offered the use of their facility. Sessions included:

**'Pay Less Tax – What families need to know about disability and medical expense claims'** with Eileen Reppenhagen, CGA, aka 'The Tax Detective', and

**'Overview of Legal Tools that authorize decision-making on behalf of another (eg. Powers of Attorney, Committee, Living Wills, Representation Agreements)'** with Andrew Rebane, Managing Partner, Valley Law Group, Abbotsford BC.

We turned to rental facilities, when finding a host facility was unsuccessful.

- **Oct 2010** the third Family Council conference was held in Vancouver at the Unitarian Church. The theme was: **"What Do We Want for Older Adults in BC?"** with:

***Keynote Speaker: Carly Hyman, Manager of Systemic Investigation from the Office of the Ombudsperson of BC.***

and, a panel presentation in the afternoon:

**'Communication in Residential care – a cornerstone of quality'**, with

JoAnn Perry (RN, PhD) Associate Professor Emerita, UBC;

Barbara Purves (S-LP(C), M.Sc., PhD) Assistant Professor, School of Audiology and Speech Sciences, UBC;

Lyne England (RN) and Gwen Roland (Past President of ACR)

- **August 2011** Our most recent Family Council conference (held with financial support from the United Way of the Lower Mainland) addressed both 'care' for family and friends on their journey, as well as 'care' for the residents.

Keynote Speaker: Jan Spilman, MEd. BC Registered Clinical Councillor ***Caring on Empty ? - Wellness for family and friends of those in residential care***

Afternoon topics:

***The Eden Alternative – A Gift for Residents, Families and Staff:*** with Lori Amdam (RN, MScN, Dip Health Care Mgt.)

***Music Therapy – Caring In Tune:*** with Susan Summers (MMT, MTA) Music Therapy Department , Capilano University

Family Council Conferences were all very well-received. Attendees left with information, insight and greater awareness about diverse topics. As well there was an opportunity to meet with other family members and friends of those in residential care, and exchange ideas about the activities and workings of other Family Councils. Most left with a few personal 'aha' moments to share with other family and friends as well as their Family councils.

## **Systemic Advocacy**

On the advocacy front, ACR has pursued various issues and topics relevant to the quality of care and quality of life in BC residential care facilities. This included:

- a submission to the BC Conversation on Health
- a submission to the BC Ombudsperson's systemic investigation into Seniors' Care in BC and meeting with their Systemic Investigations Team.
- detailed feedback on the changes to the Continuing Care Regulations sent to the Ministry of Health
- support for an independent, funded Seniors' Advocate for BC
- letters sent on various specific topics and care concerns to the Ministry of Health, Health Authorities, the Ombudsperson of BC and others.

as well as, advocating for full and timely implementation of the BC Ombudsperson Reports: **The Best of Care: Getting it Right for Seniors in British Columbia (Parts 1 and 2).**

(Contact: [www.bc.ombudsperson.ca](http://www.bc.ombudsperson.ca) 250-387- 5855 Toll free: 1 800 567-3247)

## **Why Dissolution?**

A primary objective of ACR was to support development of Family Councils in residential care facilities throughout BC. An essential component of that was the establishment of legislation in BC that enshrined the existence of Family councils in BC Law.

This has happened, albeit, to a limited extent in BC, as the Continuing Care Regulations now references Family Councils. Unfortunately, the existence of Family Councils in BC is not as strong as we would like, because unlike in Ontario, it is found in 'regulations' pursuant to an Act, not in the Act itself, nor, is the substance of the regulation, as strong as in Ontario.

## **Progress, yes. Good enough? No ... not yet.**

Another objective of ACR was the improvement to the quality of care and life in residential care facilities in BC.

Through our contact with and feedback from the many Family councils that used our online materials or attended an ACR Family Council workshop, we have heard of successes in improving care and quality of life for the residents of "their" residential care facilities.

We've heard of improved food services, improved access to activities (including evening and weekends), increased 'outings', increased cleanliness, resolution of some building and outdoor area maintenance concerns, establishment of 'procedures' for more effective feedback to management and staff.

Information sessions sponsored by Family Councils and speakers at meetings have helped families become better informed and equipped to work collaboratively with staff and management to effect improvements, and for individual family members to advocate more effectively on behalf of their loved ones. In addition, there has often been an increased awareness by family and friends of some of the realities, complexities and challenges of the 'workings' of a residential care facility, including the role of Health Authorities and the Ministry of Health in funding and staffing ratios.

We have been heartened, and often amazed at the scope and variety of positive changes that Family Councils have achieved within 'their' facility – to improve care and quality of life for residents and to support their friends and family members – and, as a group, to support staff and management. Lastly, their role in helping families and friends of new residents feel welcomed and supported during the difficult 'admissions and transition' phase of having a loved one move in to residential care must be recognized. All accomplished by the few or many, who voluntarily form and run the Family Council.

However, with regard to systemic care concerns, improvements have been elusive. Substantive and sustained improvement, here, often remains beyond the scope of the best efforts of the most well-meaning and caring individual facility.

## **What's next?**

We feel that, although much is left to be done, the time has come for ACR to pass the torch to the many individuals, community organizations and groups, and governments, that have the potential to do it.

A future ACR Bulletin will address further some thoughts on 'what can be next'.

## **As for ACR and Family Councils?**

We are exploring ways to ensure that our Family Council materials remain available via our website and to provide information on various sources of additional information and support. In the meantime, we are presently continuing to prepare ACR Bulletins, reference materials (including some updates) for our website and to undertake systemic advocacy.

We encourage and hope that existing Family Councils will reach out to new and struggling FC's to offer suggestions and support – maybe even some 'joint' activities (e.g. speakers, information exchange) and advocacy around common care concerns.

## **For now...**

**we invite you to read: [Fact Sheet #2: Antipsychotic Medication in Long Term Care](#) , and encourage all, to share this important information widely.**

*What we do for ourselves dies with us. What we do for others and the world remains and is immortal.*

Albert Pine

**Disclaimer** This bulletin contains material that is meant to be informative, thought-provoking and promote dialogue. This material is for information only and should not be construed as an endorsement of the views expressed; products or services mentioned and should not replace consultation with the appropriate qualified professionals. Individuals who require medical, legal or other expert advice should consult with the appropriate qualified professional. ACR does not endorse any specific approach to care. The views and opinions expressed are not necessarily those held by the ACR Board of Directors and staff.

ACR website: [www.acrbc.ca](http://www.acrbc.ca)