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The Newsletter of the Advocates for Care Reform

The Association of Advocates for Care Reform is dedicated to improving the quality of life and care for people living in long-term, residential care in British Columbia

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Thank you to our supporters

Help us spread the word!
Please circulate this newsletter among your networks

News from the Board

The past several months have been most active for the ACR Board. Activities related to family councils have been in high gear with major events in two health authority areas (Vancouver Island and Fraser) in addition to the normal facility-based workshops. ACR was also invited to a meeting with the Vancouver Coastal Health Authority on the topic of family councils. We have focused this issue of the newsletter on family councils to reflect and report on these events.

On the advocacy front, ACR was represented at the Vancouver public forum held as part of the provincial government's *Conversation on Health*. ACR also made a formal submission to the *Conversation on Health* entitled "Residential Care?—Who Cares?" The submission is now available on the ACR website (from the homepage at www.acrbc.ca) as well as on the *Conversation on Health* website (www.bcconversationonhealth.ca); we have also sent a copy to all BC MLAs. We highly recommend that everyone interested in and concerned about residential care in British Columbia read another submission to the *Conversation on Health*: "The Two Standards of End-of-Life Care in British Columbia" by Dr. Romaine Gallagher and Dr. Elizabeth Drance. Available at www.bcconversationonhealth.ca, this submission provides a clear outline of the current 'second class' status of palliative and end-of-life care in residential care facilities in BC.

Sadly, we were all made aware of the regrettable situation at the Beacon Hill Villa in Victoria when it made headline news all across Canada. We can only hope that this media attention will serve to raise public awareness of residential care in our province and that the spotlight on the issue will last longer than the typical media 'sound bite', prompting more urgent action for tangible improvement.

In response to the debacle at the Beacon Hill Villa in Victoria, ACR has written to Heather Cook, Director of Residential Services, Vancouver Island Health Authority (VIHA), voicing our specific

concern with VIHA's recommendation for the development of a family council at that facility that it "...must include representation from the Retirements Concepts Leadership team." We have reiterated that it is essential for family councils to be run by and for families with total independence from facility management—a model that has proven most effective and is embedded in the Ontario legislation that strongly supports family councils (Bill 140: Long-term Care Homes Act). Correspondence on this issue has also been sent to the Minister of Health, the Premier of British Columbia and the Leader of the Opposition. We are hopeful that our concerns will be considered.

As we enter the spring of a new year, the time has come to renew your ACR membership and for us to encourage you to consider making a donation to support the work of our association. A very small proportion of those who use our resource materials, attend our workshops, access our website and receive our newsletter support the work of ACR through membership or donations. All of our activities require resources. Perhaps you could consider including ACR amongst the charitable organizations you support? Membership/donation forms can be downloaded from our website (www.acrbc.ca) and charitable tax receipts are provided.

May 2008 bring improved quality of care and life to those in residential care facilities in BC.

With best wishes on behalf of the ACR Board,
Gwen Roland and Kathleen Hamilton
Co-Presidents, ACR



Announcements

1. New Board Members!

We are pleased to introduce two new Board Members, Lyne England (from Victoria, BC) and Ken Lylack (from Maple Ridge, BC) who will bring their family council experience and valuable knowledge and skills to our Board. We are very pleased to have them join the ACR Board. To learn more about Lyne and Ken, please visit our website for their biographies.

2. Membership renewal time is here...

It's that time again... and we invite you to renew your membership in ACR, or perhaps become a new member. Annual membership is \$30 and the membership year is from January to December. Donations are also welcome and tax receipts will be provided.

To join ACR or renew your membership, or to update your contact information:

- Use the new/renewal membership form available from our website at www.acrbc.ca; please include your email address
- Send us an email at info@acrbc.ca
- Call us at 604-732-7734 and leave a message on our answering machine—please speak slowly and clearly and repeat your contact information.

For family council organizations, please be sure to include a contact name and email address.

3. Health Canada Medication Alert: CBC News Investigation

A Health Canada warning (from June 2005) about the dangers of the use of atypical anti-psychotics for seniors with mild dementia was the subject of a recent CBC News investigation (January 7, 2008; David McKie). These drugs include: Risperdal, Zypexa, Seroquel and Clozaril. For further information go to: www.cbc.ca/news/background/seniorsdrugs/off-limits.html

4. Hospital Food: CBC Radio Series

A one-week series on hospital food recently aired on CBC Radio's Sounds like Canada with Shelagh Rogers (January 7-11, 2008). Interviews were conducted across Canada with patients, family, staff and food providers. Food issues in residential care were discussed as part of the series and ACR provided some comments and observations. An excerpt from the ACR contribution was read on the Friday, January 11th program. You can listen to the series on the CBC website at: www.cbc.ca/soundslikecanada/interviews.html. Past shows are archived on the site for a limited time.

5. Residential Care Educational Tools

The website for the Murray Alzheimer Research and Education Program (MAREP) at the University of Waterloo provides an interesting selection of research and educational tools relevant to residential care. For instance, they have a video vignette series (available in DVD, VHS and CD-ROM) entitled "Managing and Accommodating Responsive Behaviours" which illustrates ten of the most intense behaviours experienced by staff working in long-term residential care facilities. The series provides formal care givers with practical strategies for managing a host of behaviours, including pacing and wandering, general restlessness and agitation, trying to get to a different place, grabbing onto people, constant requests for attention and help, repetitive sentences and questions, cursing and verbal aggression, making strange noises and screaming. A resource guide accompanies the video. This education tool is geared towards educating front-line staff and can be delivered as a facilitated session or as a self-study tool. Please visit www.marep.uwaterloo.ca to learn more.

6. Free Information Fair for Caregivers

Annual Caregivers Information Fair

Saturday, March 15, 2008

Vancouver Public Library, Central Branch (Library Square)

350 Georgia Street

10:00 am to 3:30 pm

Sponsored by the Caregivers Association of BC (CABC), the fair will feature information booths and speaker presentations throughout the day. Topics will include: How to Access Community Health Services; Resources for Caregivers; Difficult Emotions that Caregivers Face: anger, guilt, abusive thoughts, resentment... and how to deal with them on the caregiving journey; and, a performance by the 'Raging Grannies'! Check the CABC website for updates (www.caregiverbc.ca).





Family Council Update

The past year has certainly been an eventful time for ACR's family council activities. We are pleased to report on two major family council events—one in each of the Vancouver Island and Fraser health authority regions.

In June, a workshop was held for facilities in the Nanaimo area at the Bebin Park Recreation Centre. The event attracted twenty-five participants from four facilities, including family members, staff and facility management. We were most heartened by the support for family councils by one facility that sponsored family members to participate.

In September, ACR together with the Fraser Health Family Council Task Group sponsored a Family Council Conference in Maple Ridge. The venue, refreshments and lunch were kindly provided by Holyrood Manor. Please see the Information Exchange section of this newsletter for more information on the event.

In addition to these major events, Family Council Workshops have been held at the following facilities over the past several months:

- Highland Lodge, Langley
- Mt. St. Joseph Hospital - ECU, Vancouver
- Delta View Life Enrichment Centre, Delta
- Normanna Home, Burnaby
- Menno Place, Abbotsford
- Czorny Alzheimer Centre, Surrey
- Fairhaven United Church Home, Vancouver
- Dogwood Lodge, Vancouver
- St. Vincent's – Langara, Vancouver
- Langley Gardens, Langley
- Dania Home, Burnaby

We are pleased to have been invited to these facilities and welcome the newly formed family councils among them to the growing network of family councils throughout the province.

Facilities and family groups interested in organizing a family council or revitalizing an existing one can contact ACR by phone at 604-732-7734 or by e-mail at info@acrbc.ca to book a Family Council Workshop. We would also like to hear from existing family councils to learn more about their activities in order to share this information with other family council groups.

The Transition to Residential Care; Reflections from one Family Member's Personal Journey

*As presented by Gaby Marciano,
Family Council Member, Holyrood Manor, Maple Ridge*

Throughout my career as a Psychiatric Nurse, I have worked with seniors with challenging behaviours. This experience has given me a degree of insight that many people do not have, and that I probably wouldn't have otherwise. But, even so, it did not ease the pain of placing a loved one in a residential care facility. I can only imagine how much more difficult it must be for those who have had less exposure to the health care system. I would like to share my story, in the hope that my experience may help others.

My intimate involvement with the health care system as a family member, as opposed to as a professional, and, specifically with residential care, began about seven years ago when my mother was first diagnosed with dementia. At that time, she was living in a remote community in the Kootenay area. Widowed and remarried, my mother lived with her husband when dementia first began to change her life. At the early stages of the disease, my mother and her husband relied on home support and respite care. However, as my mother's dementia progressed, it became increasingly clear that she would need additional care.



At that point, I intervened and brought my mother to live with me in the Fraser Valley. Once I obtained status as my mother's 'committee', I was able to take control and make decisions on her behalf and in her best interest.

What is a committee?

A committee (pronounced caw-mi-tay, or caw-mi-tee, with emphasis on the end of the word) is a person appointed by the BC Supreme Court to make personal, medical, legal, or financial decisions for someone who is mentally incapable and cannot make those decisions.



One of the first major decisions I had to make was to move my mother to a residential care facility when her condition progressed to the point that I could no longer care for her on my own. Fortunately, she was placed in a nearby facility, which enabled me to visit regularly and continue my involvement in her care. In addition to being active in my mother's care at the facility, I also involved myself with the family council, which I found to be a welcome source of support and an educational resource, as well as an effective means to advocate for my mother's care and well being.

The move to residential care is not something most families talk about or anticipate. Some families plan effectively for the future of their loved ones by having open discussions and agreeing on future plans. Some take advantage of home support and assisted living options, and progress smoothly through the transition to residential care. In these cases, life in a care facility is often anticipated and accepted without further concern. However for the majority of us, the process of moving a loved one to residential care can be much more of an upheaval. And many of our elders have preconceived notions about what living in a residential care facility might mean. Many recall 'nursing homes' as undesirable places to 'end up', and have reservations about the transition.

Through my experience, I learned that there are many issues to deal with when placing a loved one in care. Like many families before me, I learned that:

- The transition may not occur as we envision, regardless of how prepared we are.
- Placement rarely occurs at a convenient time in our lives.
- Placement often occurs in an unpredictable way, for example, it typically follows a crisis, like a medical emergency, an injury or an illness.
- Other family member's reactions are not always as we expect them to be.
- Whether the transition is gradual or abrupt, there are many adjustments to make and there is a need to adapt quickly—not only for our loved one, and our family members, but also for ourselves.
- Everyone's experience is individual and different, but what we do have in common is an expectation of quality care for our loved one.



I also learned first hand that once the decision is made to list a loved one for placement in residential care, a bed often becomes available within days and there is little time to adjust. There are many aspects to consider in relation to this reality:

- Immediately, we have to become familiar with the admission process.
- We have to focus entirely on the needs of our loved one and make informed decisions in a short space of time, either in collaboration with family members or alone, about extremely important issues such as their health, finances, home and belongings.
- Many times there is resistance to the loss of control over personal decisions, especially when there is no time to get used to this major change. We must deal with our loved one's feelings about their lack of control, which can manifest in negative behavior towards us.
- Often the transition to residential care is from an individual's home to a shared room. In this case, moving to a care facility can seem like an even greater departure from independent living.

At the same time that all of this is going on, we are trying to come to terms ourselves with the change in the nature of our relationship with our loved one —from spouse, or son or daughter—to a role now more defined by care-giving. While we try to help our loved one adapt, and accept their new surroundings, we try to remain positive and reassuring when we visit. Yet many things are going through our minds:

- Will they receive quality care?
- How will they fit in?
- Will their interests, activities, and mobility be maintained?
- Will there be enough social contact and mental stimulation?
- Will their spiritual, cultural and language needs be met?
- How will their medical needs change?
- Is there a need to change doctors?



And meanwhile, we need to discuss the details of care with facility staff, as well as seek out supportive and specialized services, such as dietary, dental, physiotherapy, and podiatry care services and recreational programs.

Some additional pressures we may face at this time include:

- Extra workload, due to time taken away from our home and our job.
- Family pressures, including our family's reaction to our loved one's decline in health and family members experiencing feelings of neglect due to the demands on our time. Sometimes family members act out towards us in anger or withdrawal. Family configurations differ, and relationships are not always harmonious or stable.
- Compounding our feelings of stress, are our own feelings about the loss of our relationship to our loved one, and how it affects us.
- In some situations, our loved one's spouse or caregiver may have their own serious health issues to cope with.
- We have to concern ourselves with details such as 'health directives' and 'end of life' issues to make sure these things are in place.

Throughout the admission process, the bulk of our time and energy is spent dealing with specifics and details. We strive to be understanding, and to be patient, supportive and helpful to our loved ones in order to help them adjust. In this scenario, we really don't have the time or energy to focus on our own

feelings and needs. We may get to the point where we feel quite drained. Often we experience feelings of loss, failure, inadequacy and helplessness. Yet while we are so focused on the needs of our loved one, we must remember to observe and respect our own needs. We, too, need support and understanding as well as a chance to vent and express our feelings and concerns, our doubts and fears. We need to regain a sense of empowerment in this new and unfamiliar situation with our loved one, and to do more than just visit to overcome the sense of isolation and displacement we may feel. We need to come to terms with the reality that we are now the 'voice' for our loved one, and in this new role we want to be effective in advocating in their best interest.

Ultimately, we need to adjust positively to all of the changes that are being presented, while helping our loved one to do the same. This is not always an easy task. As we get to know the facility staff, routines, programs and other family members, we need to build trust as we rely on facility staff to look after our loved ones to our satisfaction. Our roles may be different but our goals are the same and all of us – whether facility staff members, family members or residents – need to feel valued in our individual roles. As well, we need to understand the scope and limitations of our roles, and to strive for a harmonious, respectful and interactive relationship with each other.

My experience taught me that getting involved with the care facility's family council is the most effective way to bridge the gap between family members and facility staff. The family council provides the opportunity for family members to engage with the facility in a collaborative relationship. The family council provides a supportive venue to share information. And through developing relationships with other family members, we begin to realize that as unique as each of our own situations is, we have many things in common with each other.

Family councils allow family and friends to play an important role in improving the quality of the care environment through providing a mechanism for advocacy, support and education.

1. Advocacy

- Family councils provide a means to discuss, process, and communicate concerns to facility administration on a regular basis, and to collectively advocate for resolution and change on issues arising within the facility that affect our loved ones.

2. Support

- At each care facility, there is a wide variety of family situations represented. The support of other family members can be a valuable resource that can be provided and accessed through a family council. Telling our own story helps us to come to terms with frustrations, conflicting emotions and unresolved issues. Hearing other people's stories helps give us a healthy and more balanced perspective. Through the family council we also have the opportunity to volunteer and become involved in programs occurring in the facility. And the family council provides a venue to celebrate successes at the facility and express appreciation to support and encourage best practice in care.



3. Education

- Getting together on a monthly basis as a family council group provides the opportunity to discuss topics of interest that have current applications for our loved ones and ourselves. It also allows us the chance to become knowledgeable about issues that will affect us eventually. As we advocate for our loved one in care, we are laying the groundwork for our own future too. We will one day need help, and we have an opportunity now to affect changes while we still have a voice.

Tips for family members to help ease the transition to residential care

1. Anticipate Change

- We know change will occur - we just don't know how and when. Trying to anticipate the course of action as events occur can help you prepare for change.

2. Seek Out Information

- Proactively look for information about health care services and community resources available to help prepare you for what to do if and when a family member can no longer cope on their own.

3. Seek Support

- Do not try to face the change alone. Seek support, for both your loved one and yourself, from whatever sources you find helpful. Once placement has occurred, seek out and get involved in the facility's family council as soon as you can. Remember that your participation will benefit you and your loved one.

With communication, knowledge and participation, we can demystify the transition to living in residential care for our loved one and for ourselves. We can help make this new home a desirable place to be, and we can help make this stage of life the best that it can be.

Information Exchange



Fraser Valley Family Council Conference

On September 22, 2007, ACR together with the Fraser Health Family Council Task Group sponsored the Fraser Valley Family Council Conference. More than 50 participants attended the event, including family members, staff, management and board members of facilities throughout the Lower Mainland. This was the largest and most diverse gathering to date in BC of those associated with and interested in family councils. Holyrood Manor in Maple Ridge generously provided the venue, as well as refreshments and lunch for the full-day conference.

The purpose of the conference was twofold:

- To promote the idea and possibilities of management and families working together to deliver the best possible care for our loved ones, and,

- To provide an opportunity for existing family councils to come together and share experiences, ideas and best practices, and demonstrate how family councils can work to support quality care.

A panel discussion in the morning entitled “The Move to Residential Care – Collaborating for a Smooth Transition” explored the transition to residential care from the different perspectives of a family member, an administrator, a social worker and a nurse. Our distinguished panel included: Karen Baillie, Executive Director, Haro Park Centre, Vancouver; Leanne DeRomeri, Social Worker, Czorny Alzheimer Centre, Surrey; Cherry Harriman, Manager, Health Services, Peace Arch Hospital – Extended Care, Surrey; and Gaby Marcano, Family Council Member, Holyrood Manor, Maple Ridge.

The panel provided insight, observations and suggestions and reiterated the necessity of open communications, ongoing dialogue and mutual understanding among the various participants involved in residential care. The panel also spoke of the importance of working together to improve the quality of care and quality of life in residential care facilities.

We are pleased to include in this newsletter information from Gaby Marcano’s presentation to the panel. Gaby’s presentation was a powerful description of the emotional journey of placing a loved one in residential care. We hope to provide an edited video of the panel discussion on our website in the future.

In the afternoon participants were divided into focus groups to share ideas and best practices on “The Role of Family Councils in Making the Experience of Living in Residential Care the Best it Can Be”. Topics discussed among the groups were:

- Recruiting and maintaining family council members;
- Conducting effective meetings and keeping meetings positive;
- Building a collaborative relationship with management; and,
- How family councils can support family members and friends living in residential care.

We invite you to have a look at the ideas and suggestions from the focus groups that have been compiled and are available on our website (click on the link on the homepage at www.acrbc.ca).

We would like to thank all participants for their involvement in the conference, and for their valuable feedback and suggestions for future events.



Acknowledgements



Our heartfelt thanks to all those who contributed to the success of the Fraser Valley Family Council Conference:

- **The Fraser Health Family Council Task Group** representing family councils in the Fraser Health Authority and the Chair, Lynn Christie, Social Work Consultant, Fraser Health.
- **Ken Lylack** whose vision it was and who volunteered many hours of planning the conference, undertaking the designing, printing and assembling of the folders, name tags and signage and a myriad of other details.
- **Gaby Marcano** who contributed many hours in the planning and also kindly agreed to provide a voice for families on our panel and to share her story in this newsletter.
- **Ann MacMillan**, Executive Director of Holyrood Manor, Maple Ridge, who generously provided the venue plus refreshments and lunch for over 50 participants. Thanks also to her staff for setting up the room, serving the refreshments and working around the intrusion of their workday.
- Our distinguished panel: **Karen Baillie**, Executive Director, Haro Park Centre, Vancouver; **Cherry Harriman**, Manager, Health Services, Peace Arch Hospital – Extended Care, Surrey; **Leanne DeRomeri**, Social Worker, Czorny Alzheimer Centre, Surrey; and **Gaby Marcano**, Family Council Member, Holyrood Manor, Maple Ridge.



Our thanks also to:

Lyne England, Chair, Saanich Peninsula Hospital – ECU Family Council and Chair, Regional Family Advisory Council, for her efforts in promoting family councils on Vancouver Island.

Lexie Leitz, for volunteering her time folding and stuffing newsletters.

The HYDRECS Fund and the **Royal Bank Retired Employees Volunteer Grant Program** for their generous donations.

A special thank you to **Brad Birarda** for his very generous donation and commitment to ACR.

And thank you to our new and renewing members for their support by way of membership and donations. Your contribution allows us to further our work to support family councils and create awareness around the issues of care and quality of life in residential care in BC. We couldn't do it without you. Thank you.

Disclaimer

This newsletter contains material that is meant to be informative, thought-provoking and promote dialogue. Articles are 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 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.

Submissions for the newsletter, including articles, creative writing, photos, links and topic ideas are most welcome. However, the editors reserve the right to edit material and to withhold material from publication. Although ACR make every effort to ensure accuracy, reliability and currency, we cannot guarantee the information contained in this newsletter.