



FALL/WINTER
2007

CARING

The Newsletter of the Advocates for Care Reform

ACR

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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News from the Board

Our 2006 AGM was held at the Crossreach Senior's Centre in Vancouver on August 5, 2006.

At the AGM, the resolution to amend the Constitution and Bylaws as passed by the Board on June 15, 2006 was approved by the membership. This amendment updates various administrative matters, re-orders contents by subject, includes a 'Table of Contents' and reflects ACR's Constitution and Bylaws in plain language.

The election conducted at the AGM confirmed the proposed slate of Board members, who will serve on the Board for a two-year term (2006/2007 and 2007/2008). The current Board members (Gwen Roland, Kathleen Hamilton, JoAnn Perry, Ray Roland and Dan Fairchild) will continue and we welcome new Board member Brad Birarda. Some Board vacancies remain. Board development and capacity building is ongoing as we seek to find new Board members through Board Match and other sources who have the knowledge, skills and enthusiasm that will help us move forward.

This year those attending the AGM were invited to participate in a dialogue on current issues in residential care. Dr. JoAnn Perry, a member of our Board and Associate Professor in the School of Nursing at the University of British Columbia (UBC), led the discussion. JoAnn is also a co-investigator at the centre for Research on Personhood in Dementia Care, funded by the Michael Smith Foundation. The opportunity to share information, experiences and concerns at the AGM was well received.

In October 2006, an ACR Board member attended a forum sponsored through a Michael Smith Foundation grant entitled "New Strategies in Dementia Care: A Knowledge Forum" that was presented by the Home and Community Care Research Network of BC. The Forum involved all health authorities, the Ministry of Health and a number of research institutions.

As we embark on a New Year, it is helpful to reflect on the ACR goals identified for 2006/2007:

- To promote and support the development of family councils in residential care facilities throughout BC and increase their number by 10%
- To advocate to improve the quality of care and life for residents of residential care facilities in BC
- To increase the ACR profile through expansion of the reach of the newsletter and increased awareness of the website
- To contribute \$500 towards a scholarship for the 2008/2009 academic year for graduate work relevant to residential care
- To secure funding and sponsorships for the newsletter, ACR outreach and projects
- To expand the Board

We have already made some great progress in achieving these goals, welcoming a new Board member who has a keen interest in fundraising!



And, with the New Year comes the time to consider joining or renewing your membership in ACR. Only a small proportion of those who receive our newsletter or participate in our Family Council Workshops support ACR through membership or donations. As a small, non-profit society, we rely on memberships and donations to fund our website, newsletter, Family Council Workshops and information materials – if you are not yet a member or your membership has lapsed, please consider supporting us by joining ACR or making a donation. Our website (www.acrbc.ca) has a downloadable new/renewal membership form. The larger our membership the stronger our voice!

Printing and mailing costs are a significant part of our budget. If you would be willing to access our future newsletters online to help us use our funds more efficiently, please contact us at info@acrbc.ca with your request and your email address. We'd be pleased to send you an email when the newsletters are available on our website.

If you have skills to share, consider joining us as a volunteer – for a committee, a project, as a Board member or 'ad hoc' advisor or consultant if you have expertise that you are willing to contribute. In this issue, we're pleased to include an article on Aphasia in Residential Care from volunteer author Jennifer Sweeney who is the Chair and Founder of the BC Aphasia Centre (www.bcaphasia.org). We look forward to future articles that address the particular concerns and care needs of those with specific diseases who reside in residential care.

We are also pleased to have had some response to our invitation to those who are interested in becoming part of a team of trainers around the province to conduct Family Council Workshops in their local areas. We would love to hear from others who have experience with a family council and who would be interested in taking an active role in helping expand the network of family councils throughout BC.

On behalf of the ACR Board,
Gwen Roland
Kathleen Hamilton



Announcements



1. Dementia Training and Education for Residential Care Facility Staff

Kudos to the Alzheimer Society of BC (www.alzheimerbc.org) for their development of the "Making The Connection" workshop, which incorporates an experiential portion – "The Dementia Experience" – to promote understanding of the nature of dementia as experienced by those with the disease and to provide practical tips on providing effective and compassionate care. The workshop was piloted for the first time in Vancouver in March 2005 and has since been offered in many facilities in the Lower Mainland. Although "Making the Connection" is presently focused on the Lower Mainland, it may be made available more broadly in the future. Please contact the Alzheimer Society of BC by phone at 604-681-6530 or 1-800-667-3742 or by email at info@alzheimerbc.org for more information and to discuss arrangements to have the program conducted for staff of residential care facilities or day programs. An information sheet on the "Making the Connection" program is available from the Alzheimer Society of BC.

According to the Alzheimer Society of BC, an estimated 64,000 British Columbians have Alzheimer's disease or a related dementia. Those of us familiar with residential care in BC know well that the majority of residents now in residential care have a form of dementia. The provision of appropriate care has been a challenge for facility staff and a great concern for family members. Enhanced dementia care training and education for residential care facility staff is an important aspect of achieving the best quality of life possible for those living in residential care. ACR looks forward to the development of new standards of care, which integrate ongoing research findings in this area. For more information on research related to caring for persons with dementia, visit the website of the UBC Centre for Research on Personhood in Dementia at: www.crpdp.ubc.ca

2. Information Update – ACR Membership and Family Council Listings



We need your help! It's time for us to update (and confirm) our ACR membership information and our listing of family council organizations and residential care facilities throughout BC. We invite you to contact us with your current contact information: address, phone number, email address (and website address for facilities that have one). We hope to be able to distribute information of relevance to residential care electronically via email, so are especially interested in building our email database. Please note that we will respect the privacy of personal information and will not share your information without your permission.

Please get in touch with us to join or renew your membership with ACR, or to update your contact information:

- Use the new/renewal membership form available from our website at www.acrbc.ca
- 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

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



3. Palliative Care Training and Education

Victoria Hospice Society
3rd Floor, Richmond Pavilion
Royal Jubilee Hospital
1952 Bay Street
Victoria, British Columbia, V8R 1J8
www.victoriahospice.org



a. Psychosocial Care of the Dying and Bereaved (February 26–March 2, 2007 – Victoria, BC)

A full week course for physicians, nurses, social workers, counsellors, clergy members, and bereavement or hospice coordinators. The course is comprehensive and presents a psychosocial perspective on hospice/palliative care including self-care and team issues, disease transitions and holistic care, counselling and bereavement support.

b. Palliative Care – Medical Intensive Course (March 26–30 2007 – Richmond, BC)

A full week course for physicians, nurses and pharmacists. This course covers the basic and some advanced aspects of palliative care and is an excellent foundation in palliative care for nurses from home care and residential care facilities.

For more information, contact:

Judy Martell, Course Registration Coordinator (email: judy.martell@viha.ca; phone 250 370-8283)

4. Bill 32: Advance Directive Legislation (End-of-Life Care)

The BC Hospice Palliative Care Association is concerned that this legislation will restrict the ability of British Columbians to express their wishes for end-of-life care. For further information visit the BC Hospice Palliative Care Association's website at www.hospicebc.org, contact them by phone: 604-806-8821 or Toll Free at 1-877-422-4722 or via email: bchpca@cheos.ubc.ca





Family Council Update

In addition to ACR helping families and facilities establish family councils, we are often invited to hold 'tune-up' workshops for existing family councils, to help them learn new information and skills to revitalize their organization and sustain an effective family council.

Family councils need to continue to develop and grow over time. One of the ongoing challenges is to attract new members. Below are a few questions and tips family councils should consider to help address this challenge:

Are families of new residents informed of the existence of the family council and encouraged to join?

- Enlist the help of facility staff to encourage participation
- Ensure family council information is included in the facility admissions package

Do new families understand the role and benefits of a family council?

- Develop a family council brochure and make sure it is readily available to families visiting the facility
- Hold a yearly 'Open House' or information meeting for new families

Is there a place in the facility where family council activities and notice of meetings can be advertised?

- A dedicated family council bulletin board is ideal for advertising your family council and activities
- It is important that new families and friends of residents understand that everyone is welcome and encouraged to join

For more information and ideas, you can access the Family Council Handbook at www.acrbc.ca or call us at 604-732-7734

Family Council Workshops

Over the past several months Family Council Workshops have been held at the following facilities:

- Mission Hospital - ECU
- Langley Memorial Hospital – ECU
- Kiwanis Care Centre, North Vancouver
- Renfrew Care Centre, Vancouver
- Bear Creek Lodge, Surrey

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 email at info@acrbc.ca to book a Family Council Workshop.

Incontinence in Residential Care - *There is a lot we can do*

*Submitted by Lori Amdam, RN, MSN
Nursing Consultant, Gerontology*



Incontinence (the loss of bladder or bowel control) can be an embarrassing and difficult to discuss problem. It affects people of all ages but is most common in later years. Approximately one in four Canadians over the age of 65 experiences incontinence. For many, it is a problem that significantly decreases quality of life.

Many people believe that incontinence is a normal part of aging and therefore they do not seek help. This is a mistake because some types of incontinence are transient and reversible (i.e. related to an infection) and resources are available. If your loved one in care is experiencing incontinence, you should talk to their physician or visit a “Nurse Continence Advisor” – Registered Nurses with advanced education and training who work in some hospitals and health units. Ask if there is one in your area.

Incontinence should be viewed as a symptom, not a disease. A thorough assessment will determine the type of incontinence and provide the information necessary to design an appropriate treatment and management plan.

It is helpful to be aware of some of the common factors which can lead or contribute to incontinence, including:

- Caffeinated drinks, such as tea, coffee, some types of sodas and alcohol
- ‘Functional’ or mobility challenges, such as difficulty getting up and to the bathroom or being able to remove clothing in time
- Restricting fluid intake. It is not true that cutting back on fluids will improve the problem. Not drinking enough can actually make incontinence worse, and lead to constipation and urinary tract infections
- Laughing, coughing, sneezing or physical exertion that increase pressure on the bladder or bowels
- Nerve damage resulting from medical conditions such as Multiple Sclerosis, Parkinson’s Disease, Diabetes, dementia and stroke
- Medications that cause or worsen bladder or bowel problems

Treatment for incontinence depends on assessment findings. In some cases, medications are indicated. Sometimes, women are taught simple exercises (‘Kegals’) that strengthen pelvic muscles and help with urinary incontinence specifically. For other people, life style changes related to alcohol use and weight reduction are recommended.

For elders who live in residential care facilities, incontinence may be a longstanding problem; this is a very important consideration when planning care. It takes time and patience to identify challenges, and persistence may be required to determine the strategies that will be most helpful to the resident.

In many residential care facilities, a Registered Nurse or Licensed Practical Nurse initiates an assessment protocol when the elder moves in. Areas for assessment include:

- The time, type and amount of fluid or food the resident has daily
- Consumption of alcohol and caffeine
- Usual toileting patterns
- History of constipation or urinary tract infections
- History of medical conditions, medications or surgery that affect continence
- Any challenges such as difficulty with mobility or altered mental status



Based on assessment findings, the nurse develops an individualized plan of care for the resident. A key focus is to ensure the highest level of continence possible. Accordingly, the care plan often directs staff to offer the resident assistance to the bathroom at strategically scheduled times during the day. Staff will also assist the resident to drink and eat the recommended amount and type of fluid and food on a daily basis.

The care plan will also address safety concerns. Staff will ensure that the resident’s environment is uncluttered and pathways to the bathroom are clear to promote safety and independence. They will monitor the condition of the resident’s skin to prevent breakdown and may routinely check that urine and bowel movements are free from infection.

Families can play an important role. They are often the ones who note, and bring to the attention of staff, the subtle changes in behaviour that may signal constipation or a urinary tract infection. Tell the nurse if you observe sudden onset changes in behaviour, function or mental status in your loved one, as these are sometimes the first signs of an infection or other medical problem.

All interventions to promote continence reflect a commitment to ensure the resident's dignity. With dignity, he or she is able to remain connected with friends and family, feel comfortable to participate in activities and stay as mobile as possible.

It is important to remember that the language we use can promote or detract from dignity. For example, incontinence products are referred to as 'briefs' or 'liners' and are never called 'diapers'. As well, incontinence products vary in type and are selected according to individual need. It is important that those who remain independent are able to handle the garment in an easy and timely manner.

If you have questions or concerns about continence, talk to the resident's physician, nursing team leader or care coordinator. They should be able to answer your questions, and you may be able to offer additional information about the resident that will help staff to provide the best possible care.

Remember, also, to talk about continence with nursing staff in acute care if your loved one is admitted to hospital. The hospital environment may pose new and overwhelming challenges to continence, including intravenous lines, changes in medications and food, different beds, etc.

Efforts to promote continence are not always simple or easy, but are always worthwhile as they often make a significant contribution to improving quality of life.

Information Exchange



Aphasia in Residential Care Facilities

*Submitted by Jennifer Sweeney, M.S., CCC-SLP, S-LP(C)
Registered Speech-Language Pathologist
Founder and Chair, BC Aphasia Centre*

Working in the health care system, I have observed the difficulties people have in understanding the relationships between memory, thinking and language. This misunderstanding can result in an incorrect diagnosis, where people who have a primary deficit in language and the ability to communicate because of a stroke, known as aphasia, are thought to have the memory and thinking problems associated with dementia.

In many cases, I have seen a dementia care plan implemented for people with aphasia, and the consequence is improper care and unnecessary restrictions on freedom. Families often know that something is wrong with the care plan and they can be confused by the recommendations made by the care team. It is important for families to know that they are entitled to a second opinion if they have questions about a diagnosis. It is also important to understand what aphasia is and how it differs from dementia.

What is aphasia?

Aphasia is a problem with language. By using language we are able to understand what others are thinking and tell others what we are thinking. Language includes using words in speech, understanding speech, reading and writing. More specifically, aphasia is an impairment of the power to use or understand words as the result of an injury to the brain.

Why are people with aphasia diagnosed as having dementia?

A person with aphasia may appear to have memory problems if evaluated using an assessment tool that requires the use of language. Performing poorly on such an assessment does not necessarily mean there is a problem with memory or thinking. The best analogy is to think about yourself in a country where you don't speak the language. You can think and you can remember – but how would you be able to prove it when interviewed or questioned in a language you don't know?

Differentiating communication problems of dementia and aphasia

When using a screening tool as a diagnostic tool, the communication problems of aphasia may be mistaken for those that occur in dementia. However, key factors help clinicians differentiate the disorders. First, the onset of aphasia is typically abrupt and related to a stroke or other acute neurological event; in Alzheimer disease, the most common cause of dementia, the onset of language problems begins slowly and cannot be tied to any one event (such as a stroke).

Second, the *course* of the language problems also differentiates aphasia from dementia. A person who has a stroke declines suddenly and will improve in function over time. This is true for language functions as well as physical movement. Dementia begins slowly and progresses and worsens over time.

Sometimes dementia can occur as a result of multiple strokes (vascular dementia) or, more rarely, a very large single stroke that affects multiple areas of the brain.

A diagnosis of any kind of dementia requires that individuals have multiple cognitive deficits that affect their ability to function in everyday life and to care for themselves. Often, behaviour and personality changes also occur with dementia – these are not typical in individuals who were functioning at a normal level before a stroke caused their aphasia.

Speech-language pathologists have specialized training in diagnosing and treating aphasia, and differentiating it from the types of communication problems that occur in dementia, yet it is uncommon to have a speech-language pathologist involved in residential care facilities in BC.

Why does the diagnosis matter?

Aphasia is not a primary medical diagnosis. In BC, only a medical doctor can make a primary diagnosis. Aphasia is a secondary diagnosis associated with a primary diagnosis, such as a stroke. Understanding the cause of any language or communication problem is critical in order for the most appropriate, effective plan of care to be implemented.

Communication strategies

The major difference in communicating with a person who has aphasia caused by a stroke is that you can build a relationship and continue discussions from day to day as they will remember recent events. For a person with dementia, conversations about recent events that they don't remember can be distressing.

Some basic strategies work well when communicating with any person who has a communication disorder, including one related to hearing loss. For example, you should:

- Treat the person with respect as a competent adult
- Minimize distractions – turn off the TV, go to a quiet place to talk
- Use gestures, facial expressions, differing tones of voice
- Take your time
- Be honest when you don't understand



The most difficult type of aphasia to work with – and the type of aphasia that is most frequently confused with dementia-related communication problems – is known as 'fluent' or Wernicke's aphasia. People with Wernicke's aphasia speak a great deal and make no sense. In addition, they have trouble understanding what other people say. If you are working with someone like this you will need to use additional strategies to be understood, such as:

- Drawing pictures or using pictures
- Writing key words
- Using gestures and 'acting' to get a message across
- Asking questions to clarify that your message was understood

A person with this type of aphasia does not always realize that the words they say make no sense. You will need to encourage them to help you understand with the same strategies.



All behaviour is communicative

For any person who has difficulty communicating, it becomes much more important for families and caregivers to become observers of behaviour. The truism “actions speak louder than words” comes into play from both directions. A person who is ‘combative’ or ‘non-compliant’ may be telling you something that you need to know. And if your behaviour is disrespectful, condescending or threatening, the person with aphasia will respond to that as well. If you are afraid to talk to the person with aphasia, or avoid them because of this difficulty, it is important for you to know that the person with aphasia is aware of your fear and avoidance.

If you have any questions about the care of a person with aphasia, seek help from your local health authority and ask for a second opinion from a specialist in language and cognition.

Thank you to Dr. Tammy Hopper, Ph.D., CCC-SLP, R-SLP (Alberta), Assistant Professor, Faculty of Rehabilitation Medicine, Department of Speech Pathology and Audiology at the University of Alberta for reviewing this article and providing input.

Acknowledgements

We would like to thank 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 facilities in BC.

A special thank you to Brad Birarda for his generous donation and commitment to ACR, and we are honoured to have received an in-memorial donation in memory of Beatrice Hamilton.

We also thank those who have contributed in other ways to the work of ACR:



Our heartfelt thanks and appreciation go to Lori Amdam for her continuing support, providing us with advice and information, and generously donating her time and energy to prepare informative articles for our newsletter.

Welcome and thank you to Jennifer Sweeney for her article on Aphasia in this issue.

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.

