



ACR

**SUMMER
2006**

CARING

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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News from the Board

It was a little over a year ago that we held a strategic planning session and embarked on a quantum leap in technology that would update the tools and equipment critical to the work of ACR.

In December 2005, we held a launch party to celebrate the completion of our new website, Family Council Workshop and resource materials, and updated informational materials. Since December, we've put our new tools to good use and the response has been most positive. The word is spreading about family councils and the role they can play in enhancing the life and care of those in residential care facilities. And the word is spreading about ACR as we are receiving invitations to provide our informational materials at the CABC (Caregiver's Association of BC) Conference and AGM, and the AGM of the BC Aphasia Centre.

Now the time has come to look to the future. In May 2006, Board Members of ACR held a half-day retreat to review our goals for the coming year and consider how best to move forward. The goals agreed upon for the 2006/2007 year are:

- 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 ACR's profile through expanding the distribution of the newsletter and 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

The Board has identified activities to support the achievement of these goals and criteria to help us measure our success.

To achieve our goals, we need your help! For example, we'd like to develop a team of five or six trainers around the province to conduct Family Council Workshops in their local area. If you have experience with a family council and would be interested in spreading the word to others, we'd love to hear from you.

Improving the quality of care and quality of life in residential care facilities is a collaborative community issue and something ACR can't do alone. A common care concern expressed by families is the care of residents with specific diseases or conditions for which there are often disease-specific organizations. ACR is committed to exploring opportunities to work with these groups to encourage and support their presence and participation in residential care. Together we can promote improved standards of care.

As a small non-profit society we rely on our membership to fund our website, newsletter, Family Council Workshops and other information materials. If you are not yet a member or your membership has lapsed, please consider supporting us through membership or a donation. Our website (www.acrbc.ca) has downloadable new or renewal membership forms.

And, 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 as a consultant if you have specific expertise that you are willing to contribute. Our list of volunteer advisors is growing and in this issue we're pleased to include an article by one of them—Lori Amdam.

If you would prefer to read future newsletters online, we'd be pleased to send you an email when they are accessible on our website. Just contact us with your request and your email address.

Finally, a reminder that our AGM will take place on August 5th at 10.30am at Crossreach Adult Day Centre, located at 3348 West Broadway in Vancouver (between Blenheim and Waterloo). Perhaps we'll see you there?

On behalf of the ACR Board,
Gwen Roland
Kathleen Hamilton

Announcements

Please join us for the ACR AGM

August 5th 2006, 10.30am to Noon. Crossreach Adult Day Centre, 3348 West Broadway, Vancouver
To RSVP please call 604-681-7015

Abuse Prevention in Institutional Settings

A two-year collaborative project on the complex issues of abuse and neglect in congregate settings has been announced. It will involve the University of Toronto, six partner universities, and key community and long-term care stakeholders. The project will involve a national survey of key stakeholders and five regional forums. For information, please visit www.elderabuse.aging.utoronto.ca

Victoria Hospice Society Course

The next 'Psychosocial Care of the Dying and Bereaved' course conducted by the Victoria Hospice Society (in Victoria, BC) will be held October 23-27, 2006. For more information about this one-week course, contact Judy Martell, Victoria Hospice Course Registration Coordinator, at (250) 370-8283. The pdf brochure with information about the course is available at www.victoriahospice.org/PsychoSocBrochfall06.pdf

Family Council Update

Kudos

Family councils CAN make a difference!

Congratulations! ... to Lady Minto Hospital Extended Care Unit Family Council for successfully advocating for a palliative care room and air conditioning in the Extended Care Unit. We also extend our congratulations and sincere thanks to the management at Lady Minto Hospital for listening to the concerns of the family council and bringing about changes that improve the comfort and well being of the residents.

Congratulations to Wendy Searcy, Extended Care Unit Social Worker (wendysearcy@fraserhealth.ca), as well as to the Hospital Auxiliary, staff and family members of the Extended Care Pavilions at Peace Arch Hospital in White Rock, BC. Modeled after 'Body and Soul' carts developed at the New Vista Care Home (www.newvista.bc.ca), Wendy spearheaded a 'Comfort Cart' initiative to support end-of-life care in a residential setting. With funding from the Peace Arch Hospital Auxiliary, a custom-designed wooden trolley was created and fitted with items to provide comfort for families attending residents at end-of-life. As suggested by family members, volunteers, staff and White Rock Hospice Society counselors (www.whiterockhospice.org), the carts include a CD player and relaxation CDs, supportive readings, hospice information brochures, an electric candle, writing materials, a quiet fan, a soft reading light and massage lotions. The Comfort Carts are now in use and feedback cards have been distributed to receive input for ideas about additional supplies that could be included on the carts.

Please let us know about your facility and family council successes, big and small, so that we can share them and inspire others to make a difference in the quality of life of those living in residential care in British Columbia.

Family Council Workshops

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

- Arranglen Gardens (Qualicum Beach)
- Youville Residence (Vancouver)
- Fair Haven United Church Home (Vancouver)
- Sunrise (Vancouver)
- Holyrood Manor (Maple Ridge)

We are pleased to have been invited to these facilities and welcome the newly formed family councils amongst them to the growing network of family councils throughout the province. For a list of residential care facilities in BC with family councils, please visit the Family Councils section of our website at www.acrbc.ca

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.

Towards a New Understanding of Palliative Care

When most people hear the word 'palliative', they immediately think of death. For most of us, the term 'palliative care' elicits an emotional response—perhaps fear, denial or dread—because of its association with end-of-life care. Yet palliative care is an evolving practice that has come to encompass so much more than just end-of-life care. Much can be offered by a palliative approach to care, which works to address the total care of the *whole* person, rather than just the illness of the patient.

Currently, palliative care is neither fully understood nor consistently available within the context of residential care in British Columbia. Whether a resident is experiencing a chronic illness, such as advanced heart or respiratory disease, multiple sclerosis or kidney disease, or a terminal illness such as cancer, palliative care can help ease suffering and discomfort through pain and symptom management. Palliative care can improve the quality of life for residents of care facilities and allow them to live more comfortably *throughout* their life in care.

An evolving practice; new approaches to palliative care

The traditional view of palliative care as a medical specialty focused on the care of the dying and introduced only at the end of the patient's life has altered. Palliative care is now defined as the active and total care of patients whose disease no longer responds to curative treatment and for whom the goal is to achieve the best quality of life possible for them and their family. Under this modern approach, palliative care is an active discipline that includes assessing and treating pain and other conditions associated with a disease or illness on an ongoing and proactive basis, as well as compassionate care at end-of-life.

While end-of-life care is still a key and critical component of the specialty of palliative care, it is important to recognize that palliative care may be beneficial long before a patient reaches the end-of-life stage. Regrettably, the association with the traditional view of palliative care often scares people away from receiving pain or symptom management care that could greatly enhance their quality of life—at any age and at any stage of their illness.

Palliative care has evolved to become a specialty known for expertise in chronic pain management and symptom control, both of which can provide increased comfort to patients over long periods of an illness or condition.

The importance of providing palliative care services in the residential care setting

Multidisciplinary palliative care is not yet readily available in the majority of residential care facilities in BC. Offering palliative care as an integral part of care in residential care facilities provides the opportunity to ensure maximum quality of life for residents, throughout their life in care and as they experience end-of-life.

The benefits of integrating palliative care as a standard of care in residential care facilities are numerous and include:

- Reducing or eliminating the need to transfer residents to other facilities when they require specialized palliative care. Transfers can be traumatic for residents and family members alike.
- Ensuring that residents remain in comfortable and familiar surroundings, with staff they know and who know them, throughout the progression of their illness or condition.
- Reducing inappropriate use of acute care beds and referrals to palliative units or hospices, which are presently in short supply.
- Incorporating palliative care considerations during regular resident assessments and providing the opportunity for early palliative care interventions for pain and symptom management.
- Providing access to palliative care services over an extended period of time as the condition of the resident changes and progresses.
- Providing the opportunity to adapt palliative care programs to meet the needs of and respect the wishes of specific ethnic, cultural or religious groups.
- Increasing awareness of the benefits of palliative care. If palliative care is introduced as a standard of care and integrated with other care services, residents and families will be more aware of and receptive to how palliative care can help.

What is palliative care?

Palliative care is specialized care for individuals and families who are living with chronic or terminal illnesses where cure is no longer possible. What makes palliative care different is that it is care that is patient- and family-focused and includes total care that encompasses medical, physical, social, psychological, emotional, cultural and spiritual care.

The goal of palliative care is to promote maximum quality of life for the chronically or terminally ill by ensuring their comfort and dignity.

Important aspects of palliative care are:

- Pain management through medication or by other therapeutic means such as massage therapy, relaxation techniques, or therapeutic touch
- Symptom management to provide relief from conditions such as loss of appetite, nausea, weakness, shortness of breath, bladder and bowel problems and confusion
- Social, psychological, emotional, cultural and spiritual support that can include counseling services (e.g. Social Workers), culture or faith-specific volunteers (e.g. First Nations, Buddhist Priests), pastoral care workers, and palliative volunteers who can provide appropriate and compassionate care
- Family support and care to meet the psychological, social, cultural, emotional and spiritual needs of families of residents and to offer grief and bereavement support to the family, including follow-up bereavement support

Palliative care needs to be made available through all stages of an incurable illness and at all levels of the health care system.

Working to include palliative care as an integral component of quality care in residential care

Recognizing the need, some initiatives are underway to promote the integration of palliative care as a standard of care in residential care facilities in BC. For example, the Board of a non-profit society that runs a residential care facility has developed a 'Palliative Care Protocol' for their facility. In addition, as part of their ongoing effort to improve the quality of life and care for residents, another family council has begun work to define what a palliative care program at their facility might look like. The information below is from the family council's 'work in progress' towards achieving this goal.

The Family Council regards the provision of specialized palliative care as a basic and integral part of quality care and caring for residential care facility residents.

We understand that a quality and comprehensive palliative care program would:

- Be proactive, active and visible. Families and residents would be informed and advised of the nature and role of palliative care and have access to information and contacts.
- Ensure that residential professional staff, including nurses, social workers, rehabilitation staff and therapists, pastoral staff and care aides, have current training in palliative care and have attained the requisite knowledge and skills.
- Provide for ready access to specialists in palliative care including physicians, nurse practitioners and clinical nurse specialists for consultation and care of residents, and for the continuing education and training of facility staff.
- Provide access to comprehensive palliative care at all times—24/7.
- Embrace a multidisciplinary team approach to palliative care that includes medical, pastoral and rehabilitation staff (e.g. music therapists, occupational therapists, physiotherapists) who can offer skills, expertise and support.
- Welcome and support trained 'palliative volunteers' to provide comfort and support to both the residents and their families.
- Provide palliative care space that is conducive to the care and comfort of palliative residents and their families.
- Respect the culture, religion, values and wishes of residents and families.
- Provide current information on end-of-life, loss, grieving and bereavement and ongoing compassionate and non-judgmental support to families.

Palliative care resources

Canadian Hospice Palliative Care Association

Cambridge Street North, Ottawa, Ontario, K1R 7A5
Telephone: 1800 668 2785

A national association, which provides leadership in hospice palliative care in Canada. www.chpca.net

International Association for Hospice and Palliative Care

Provides access to an extensive collection of information and resources, including a free online newsletter. www.hospicecare.com

Canadian Virtual Hospice

An interactive network for people dealing with life-threatening illness and loss offering information for individual patients, family members and friends, health care professionals and volunteers. www.virtualhospice.ca

Living Lessons

A national initiative to increase awareness of hospice palliative care and end-of-life care services in Canada, presented in partnership with the Canadian Hospice Palliative Care Association (CHPCA) and The GlaxoSmithKline Foundation. www.living-lessons.org

Palliative.org

The regional palliative care program in Edmonton, Alberta; the website includes academic research and information, as well as resources for the general public. www.palliative.org

Victoria Hospice Society

3rd Floor, Richmond Pavilion, Royal Jubilee Hospital
1952 Bay Street, Victoria, BC, V8R 1J8
Telephone/24 hours: (250) 370-8715

Offers educational resource materials and palliative courses for health care professionals and others as well as free monthly Hospice & Palliative Care Information Evenings on the third Tuesday of each month. www.victoriahospice.org

Medical Care for the Dying (4th Ed.)

A helpful textbook about palliative care. Available to order from: www.victoriahospice.org/ed_publications.html

Transitions in Dying and Bereavement - A Psychosocial Guide for Hospice and Palliative Care

An award-winning book for counsellors and others working with those facing death and bereavement. Available to order from: www.victoriahospice.org/ed_publications.html

Information Exchange

Thank you to Lori Amdam, RN, MSN and Gerontology Nursing Consultant for contributing the following article.

Restraint-Free In Residential Care - A Worldwide Goal

For the last many decades, restraints have been used routinely in most residential care facilities. Now, nurses and other members of the interdisciplinary team in Canadian residential care homes are joining a worldwide movement to eliminate their use on elderly, frail residents. Research has shown us that there are better ways.

Restraints defined

Restraints refer to devices used on individuals to restrict their movement or in some way 'control' their behaviour. Restraints can be physical/mechanical, chemical or environmental.

Physical or mechanical restraints are devices that restrict the person's freedom of movement and/or normal access to body parts, and which they are unable to remove or unlock themselves. These include 'safety' jackets, limb restraints, mitts, back closing lap belts, tilted recliner chairs and wheelchair table trays. It is important to note that this definition does not apply to 'positioning' or seating devices recommended by an Occupational or Physical Therapist.

A chemical restraint is any medication given in response to a 'problem' behavior or to restrict a person's movement that is not needed to treat medical or psychiatric symptoms. Such medications include sedatives, anti-psychotic and anti-anxiety medications, among others.

Environmental restraints include any physical barriers that impede free movement around the unit or facility. These include half doors, 'isolation' rooms and cords placed across doors.

Best practice

The philosophy of care in every residential care facility should mandate a 'No Restraint' or 'Least Restraint' policy. Families should have access to, and information about, the facility's restraint policy.

'No Restraint' policies direct members of the interdisciplinary care team to:

- Minimize or eliminate the use of restraints on frail, elderly persons;
- Find creative and respectful alternatives to the use of restraints; and,
- Thoroughly assess the causes of symptoms such as anxiety and restlessness because there are often contributing factors that can be easily resolved without medication or the use of restraints.

Why are 'no restraint' policies being implemented worldwide?

There is a worldwide movement to reduce or eliminate the use of restraints in residential care facilities for a number of reasons. One reason is that research has proven that traditional beliefs about the need to use restraints are inaccurate. For example, restraints do not decrease the risk of falling for elders. In fact, they increase the risk. In addition, injuries from falling while restrained may be more serious.

A second reason is related to growing awareness of the possible complications related to the use of restraints. These include:

- Skin breakdown
- Pneumonia
- Pain
- Sensory deprivation
- Withdrawal, anxiety
- Increased confusion
- Incontinence (loss of bladder and/or bowel control)
- Nerve injury
- Consequences of immobility (i.e., weakness)
- Fear, depression
- Agitation, emotional trauma
- Death

Research has shown that restraints also damage the elder's sense of 'personhood', resulting in loss of dignity and freedom of choice. Being restrained causes fear, confusion and aggression and makes most elders feel humiliated, powerless and angry.

Psychotropic medications (such as sedatives and anti-psychotics) are sometimes given for behavioral symptoms of dementia, including pacing and calling out. These drugs generally do not help and carry with them risks of side effects and adverse reactions. As an alternative, providing 'person-centered care' and removing environmental hazards has proven to be the better approach.

When can restraints be used?

Except in rare emergencies, restraints should only be used as a last resort and only on a temporary basis after all alternatives have been considered and found inadequate. In all cases, the use of restraints requires a physician's order. Decisions about restraint use should involve the elderly person, family, physician and interdisciplinary team members.

Specialty areas where emergency use of restraints may be necessary (for example in the emergency department or in a mental health setting) require protocols that address how restraints are approved, used, discontinued and how restrained persons are monitored and cared for.

Restraints should not be used before a comprehensive assessment of a 'challenging' behavior is completed.

The behavioural assessment identifies:

- The cause(s) of the behavior;
- Factors that contribute to or trigger the problem;
- Patterns such as timing of the behavior; and,
- Approaches that could prevent or reduce the behavior without the use of restraints.

Being alert to 'delirium'

It is important to know the difference between the confusion and disorientation commonly associated with Alzheimer's disease and what is called 'delirium'. Delirium is the sudden onset of changes in the thinking, mood, functioning and behavior of an older adult. When these changes happen over a period of hours or days, the cause is not dementia. (Keep in mind that a person with dementia can also develop delirium.)

An elder experiencing delirium will have trouble paying attention; they may have hallucinations and be fearful or aggressive. Less commonly, but equally dangerous, is a form of delirium in which the elder becomes lethargic, withdrawn and quiet.

There are many causes of delirium – some common ones include reactions to medications, infection (often a urinary tract infection or pneumonia), pain, dehydration and acute illness. Seniors can also develop delirium following a general anesthetic. Delirium is considered a medical emergency; the cause(s) must be investigated quickly and treatment implemented.

Physical restraints should not be used for delirious elders as these could increase confusion and restlessness. Likewise, chemical restraints should be avoided because some medications can actually make delirium worse. Families can help by sitting with their loved one in the care facility or in hospital and assisting him or her to stay safe, comfortable and hydrated.

How can families support restraint-free care?

There are many alternatives to the use of restraints. By employing creative and compassionate approaches to care, we respect the personhood of elders. Staff who embrace a philosophy of ‘person-centered care’ welcome the involvement of families in the care of loved ones. Staff and families who form caring partnerships ensure the elder’s voice is heard and that he or she enjoys maximum quality of life.

Talk to care facility staff about how you and others who visit your loved one can support restraint free care. Here are some questions you may wish to consider discussing:

- What strategies are in place to prevent falls?
- How should you approach your loved one during times of agitation or disorientation?
- Would it be helpful to bring in an audiotape that staff could play for your loved one in between your visits?
- If your loved one is restless, would it help for you to walk outdoors with him or her?
- If your loved one is admitted to the hospital, can you sit with him or her and help to prevent interference with tubes, intravenous lines, dressings, etc.?
- Can you suggest an alternative bathing method if your loved one is afraid of the tub?

We all want to improve the quality of life for elders who reside in care facilities. Caring, creativity and teamwork are critical to achieving this goal. As the “Eden Alternative” (www.edenalt.com) reminds us:

“Residents don’t live in our workplace – we work in their home.”

If you have questions or comments about this article, please email ACR at info@acrbc.ca

Acknowledgements

ACR 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 in BC. Thank you.

A special thank you to the Royal Bank of Canada Employee Volunteer Grant Program for their generous donation.

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.