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**The Alzheimer Drug Therapy Initiative
Caregiver Appraisal Study**

Now that the BC government has agreed to cover some of the cost of drugs for people with Alzheimer's disease (AD), a University of Victoria gerontologist is asking caregivers whether they think the drugs are effective.

Cholinesterase inhibitors (ChEI's), the class of medications being covered, are perceived to be beneficial for treating AD; however, existing studies have shown the drugs to have limited effectiveness and have only looked at short-term effects. In addition, previous research has focused on clinical effectiveness and overlooked changes in day-to-day functioning and quality of life, effects which are observed on a regular basis by informal caregivers to people taking these medications. The specific medications in question are donepezil (Aricept), galantamine (Reminyl), and rivastigmine (Exelon).

In an effort to understand the caregiver perspective about the benefits and limitations of ChEI's, UVic's Dr. Neena Chappell is collecting information on the experiences of caregivers to people with dementia who qualify for Fair PharmaCare coverage of these three medications. She is asking for 2000 volunteers—from across the province—to participate in interviews with trained researchers. Interviews have started and will carry on into mid-2009.

Pharmacists are being asked for their assistance in the recruitment of caregivers by giving an information sheet about the study to those clients who have a prescription for donepezil (Aricept), galantamine (Reminyl), and rivastigmine (Exelon). Those Pharmacists who wish to assist the study by passing on this information should contact Chelsie Kadgien at the UVic Centre on Aging at 250-472-4169, or ckadgien@uvic.ca. The Centre on Aging can provide postings and hand-outs upon request.

Caregivers interested in participating in the study should contact the Survey Research Centre, University of Victoria toll-free at 1-866-511-2594 (ALZH).

PharmaCare is funding the "Alzheimer Drug Therapy Initiative, Caregiver Appraisal Study," until December 2010.

BACKGROUND INFORMATION

Research Project: Alzheimer Drug Therapy Initiative, Caregiver Appraisal Study

Funding Partner: Ministry of Health, Pharmaceutical Services Division

Context

Alzheimer's Disease, one form of dementia, is a progressive degenerative disease without known cause or cure. Although there is no cure, there are some drug treatments available to people with dementia that may help slow the progression of the disease in the early stages. One class of medications, cholinesterase inhibitors (ChEI), are believed to have beneficial outcomes on certain aspects of dementia, such as memory loss and difficulty performing normal daily activities. Although many provinces across Canada fund the coverage of these medications, until recently there was no coverage provided by the Province of British Columbia. This was due to gaps in our knowledge about who receives the most benefit from medication, as well as limited or inconsistent knowledge about the clinical effectiveness of the medications and how long they are effective for.

On October 22, 2007, the Provincial Government of BC began the Alzheimer's Drug Therapy Initiative (ADTI) – a province-wide project to help fill the gaps in our knowledge about cholinesterase inhibitor treatment for dementia, including Alzheimer's Disease. Coverage of these medications is being provided over an initial three-year period for patients who qualify under the Fair PharmaCare program. At the same time, the Province is funding several research projects looking into the benefits and limitations of the medication over a longer time-frame, and from different perspectives than most previous research. The goal is to provide a much better understanding of who will benefit from the medication and how long those benefits will last.

The specific medications being covered are donepezil (Aricept), galantamine (Reminyl), and rivastigmine (Exelon). Physicians must submit a Special Authority form to PharmaCare for each individual to apply for approval of coverage under the Fair PharmaCare program. From this initial submission patients must receive an assessment by their MD every six months in order to continue to qualify for coverage.

The Research – Caregiver Appraisal Study

One of the innovative research projects funded by the Initiative is the Caregiver Appraisal Study being led by Dr. Neena Chappell at the Centre on Aging at the University of Victoria. The project's goal is to discover the benefits and limitations of ChEI's from a perspective no researcher has taken before – that of the caregiver. Most research focuses on the clinical effects of the medications, measured by standardized tests given to patients when they visit their MD. The Caregiver Appraisal Study hopes to open up an untapped, but very important, source of information about the day-to-day effects of these drugs by asking the informal caregivers to people with dementia about their experiences with these three medications over the course of a year.

Caregivers are generally privy to intimate details about the person for whom they provide care which few others have the opportunity to see or understand. This provides them with an insight regarding the benefits, limitations and/or side-effects of the medication that cannot be measured by clinical assessments. The changes that may occur in the patient's daily functioning and quality of life are extremely important when assessing whether or not a medication is beneficial, but are often overlooked. In addition, caregiving can be a stressful role with many implications for the caregivers themselves. With that in mind, the Caregiver Appraisal Study also hopes to uncover the benefits and drawbacks of ChEI's for caregivers and their families.

We are hoping to speak with around 2000 informal caregivers to people with dementia who have experience with cholinesterase inhibitor medications. We need volunteers to participate in structured face-to-face interviews that will be scheduled throughout 2008 and into 2009. We are hoping to be able to accommodate caregivers across the Province of British Columbia, including more rural and remote areas.

At this time, we are inviting caregivers to contact the Survey Research Centre, UVic to indicate interest, 1 866 511-2594 (ALZH). All participation is voluntary and calling will not enrol the caller in the study. Involvement in the study will not impact PharmaCare coverage of the medication. Callers will receive a return phone call with more detailed information about the study and will be asked at that time if they wish to participate.

In order to recruit a broad sample of caregivers from across the province, we are asking for the assistance of pharmacists in distributing information about the study. Any pharmacists interested in passing information along to clients with prescriptions for donepezil (Aricept), galantamine (Reminyl) or rivastigmine (Exelon), are invited to contact Chelsie Kadgien at the Centre on Aging, University of Victoria at (250) 472-4169.

Contact Information

Chelsie Kadgien, Centre on Aging, University of Victoria
(250) 472-4169
ckadgien@uvic.ca

Caregivers interested in the study should be directed to contact the Survey Research Centre, Centre on Aging, UVic.
1 866 511-2594 (ALZH)

You may contact the researchers through Carren Dujela, the Project Coordinator, at the Centre on Aging, University of Victoria at (250) 472-4464. You may verify the ethics approval of this study or raise any concerns you may have by contacting the Human Research Ethics Assistant, Office of Research Services at the University of Victoria (250) 472-4545. The members of the research team are Dr. Neena Chappell (principle investigator), Dr. Malcolm Maclure, Dr. André Smith, Dr. Karen Kobayashi, Carren Dujela, and Chelsie Kadgien.