

## **Update to Public Input Submission for Alzheimer's Disease Therapeutic Initiative Drugs (ADTI)**

To protect the privacy of members in your group, please do not include in your response names of individuals or companies, locations, or any other information that might identify them or anyone else.

The following drugs were investigated by the ADTI:

- donepezil (ARICEPT<sup>®</sup>),
- galantamine (REMINYL<sup>®</sup>), and
- rivastigmine (EXELON<sup>®</sup>).

### **Contact Information**

Your organization's contact information will only be used to retrieve your submission if you submit a request under the Freedom of Information and Protection of Privacy Act (FOIPPA). It will not be used for any other purpose.

Your organization's name, however, will be included as part of your submission to the Drug Benefit Council.

### **Patient Group Name and name of representative completing this questionnaire:**

- Alzheimer Society B.C.  
Submitted by Rebecca Morris, Provincial Coordinator of Advocacy & Public Policy

### **Organization's Address**

- 300 – 828 West 8<sup>th</sup> Avenue, Vancouver B.C.

### **Postal Code:**

- V5Z 1E2

### **Conflict of Interest Declaration**

To make sure the Drug Review process is objective and credible; everyone who provides input has to tell us about any possible conflicts of interest.

A conflict of interest exists if you, an immediate family member or your organization might benefit from the outcome of the review. For example, if you or your family own stock in the company that makes the drug, there could be a financial benefit IF PharmaCare decides to cover the drug. If your organization receives funding from the drug company, there could be a

financial benefit (such as ongoing or increased funding) IF PharmaCare decides to cover the drug.

Examples of conflicts of interest include, but are not limited to, financial support from the pharmaceutical industry (e.g., educational or research grants, honoraria, gifts and salary) as well as affiliations or commercial relationships with drug manufacturers or other interest groups.

Even if you or an immediate family member, or your organization, has a conflict of interest, your input will still be considered as long as you declare the conflict of interest in your answers to the questions.

All information you provide is protected under the Freedom of Information and Protection of Privacy Act.

**Do you have any Conflict(s) of Interest to declare?**

The Alzheimer Society of B.C. receives a very small percentage of our overall operating budget from pharmaceutical partners (see previous Patient Input for ADTI submission from the Society). Funds are unrestricted and are used to partially cover the cost of delivering dementia education.

If you answered yes to the above, describe any Conflict(s) of Interest below.

- Please see above.

## Questions on Drugs in the Alzheimer Drug Therapeutic Initiative (ADTI)

**Describe how the condition or disease for which this drug is used affects the day-to-day life of patients in your group.**

Symptoms of Alzheimer's disease include the loss of memory, impaired judgment and changes in behaviour and personality. Alzheimer's disease is progressive, terminal and is the most common type of dementia accounting for almost two-thirds of dementias in Canada today. Alzheimer's disease is a debilitating disease which affects the person as well as the family and friends who are their informal caregivers. Alzheimer's disease is one of the most feared diseases for Canadians as they age. Early on in the disease progression people with dementia are able to participate in many of their usual activities with limited support. However, the need for support increases as the disease progresses and eventually the person's need for caregiver support is almost constant. For many, caregiving is a 24-hour-a-day job which takes a toll on a person's finances, health and psychological well-being. People with dementia often become high users of health care services as the disease progresses, accessing primary health care, home and community care, adult day programs and eventually residential care. Delaying the progression of Alzheimer's disease through medication can result in lower service use.

As part of three focus groups that were facilitated with 1) people with dementia, 2) family caregivers and 3) Alzheimer Society of B.C. staff (who provide direct, ongoing support and education to families through workshops, caregiver support groups and one-on-one support meetings). Participants were asked to describe how Alzheimer's disease impacts their lives/the lives of people living with the disease. Participants noted the following themes.

### *Focus Group One: People with dementia*

- Profound and life altering changes in:
  - Social interactions
  - Ability to travel
  - Memory problems, (short-term memory loss, losing train of thought)
  - Speech problems (word finding, altered speech)
  - Their ability to be independent.

- Personality changes (examples of experiences: "moody", "cranky", "outbursts of anger", "apathy")
- Ability to plan for the future (e.g., retirement plan changes).

*Focus Group Two: Family members and caregivers of people with dementia*

- Caregivers and family members feel that dementia:
  - Has turned their lives "upside-down".
  - Resulted in a loss of independence for both the person with dementia and the care-partner.
  - Resulted in the person with dementia no longer being able to do the same everyday tasks they once did routinely (e.g., personal care, driving, finances, and recreational activities like baking, as well as other activities that gave the person meaning/purpose).
  - Altered their dreams, resulting in a feeling that the future was lost for both partners (e.g., retirement plans change).
  - Meant that they, and the person they are caring for, are no longer able to plan ahead and "have a strategy", instead they report living "day-to-day."
- Caregivers often reported that the person with dementia developed an increased dependence on them. As a result:
  - Caregiver stress increases.
  - The person with dementia feels as if he or she is a burden.
- Caregivers note that dementia means that all relationships in the family change:
  - Dynamics change between the person with dementia and other family members.
  - Role reversals occur (traditional caregiver is now cared for, and vice versa).
  - The care-partner/spouse "lives the life" of the person with dementia and care-partners/spouses are left feeling like their life has become secondary.

*Focus Group Three: Alzheimer Society of B.C. staff*

- A diagnosis of dementia impacts all day-to-day aspects of a person's life (e.g., activities of daily living like feeding, dressing, or bathing oneself), but it also impacts:
  - Familial relationships
  - Self-esteem and dignity
  - Finances

- Dementia is not just a diagnosis of the very old. This is a disease that can strike earlier in life than most people are aware. People as young as 50 years-old are frequently diagnosed with dementia. It impacts the lives of younger people in different, and possibly more profound ways:
  - People can be forced into early retirement and sometimes people are let-go from their jobs. Therefore, a diagnosis can have repercussions for a person's career and ultimately their pensions.
  - Significantly affects finances, particularly for those without a good long-term disability plan. Even with a good plan, people are unable to save as well due to increased costs related to the disease.

To summarize, all three groups felt that there "*was nothing this disease didn't change*". From acts of daily living, to physical problems like gait, to psychological well-being, this disease profoundly affects those who are on the Alzheimer's disease journey.

## **If you had experiences with drugs, what have you noticed? What impact have they had? Side-effects?**

As with many medications cholinesterase inhibitors are experienced differently by different people. While participants did sometimes note challenging reactions or side-effects (which sometimes resulted in a change or discontinuation of the medication) families and people with dementia were overwhelmingly grateful for the opportunity to try the medications. Families, staff, and people with dementia acknowledged that these medications are not a cure and that they do not work for everyone, however, many noted that in some cases the person experienced less confusion and more confidence in managing their day-to-day activities, or an overall feeling that the medication was slowing the progression of the disease.

### *Focus Group One: People with dementia*

#### Positive experiences on medication

- A “plateau” in the disease progression.
- Changes in memory/thought process:
  - Improvement in recall memory.
  - Improvement in cognitive clarity (“it removed the fogginess”, “I was able to think more clearly”, “I was more alert”).
- Improvements in mood, disposition and impulse control.
- Psychosocial changes:
  - Improved coping abilities.
  - Aided independence.

#### Medication side-effects

- Most often, reactions to medications occurred when the dosage was increased. For example, people with dementia experienced:
  - Increased “crankiness”.
  - Aggressiveness.
  - Physical discomfort.
  - Chest pains.
  - Challenges with gait.
- With the support of their doctors, individuals often adjusted the medication dosage to find a dosage that was right for them and their ability to tolerate side effects.

#### Experiences stopping medication

- Worsening memory.

- Apathy.
- Lack of clarity.
- For some individuals these symptoms were reduced once the person started the medications again.

### *Focus Group Two: Family members and caregivers of people with dementia*

#### Positive experiences on medication

- Improved symptoms (e.g., able to complete acts of daily-living again, no longer repeating questions, reading comprehension improved, no longer having angry outbursts, etc.).
- Cognitive decline reported to have stabilized.
- Perceived “slowing” of the disease.
- For some, there were no negative side-effects.

#### Medication side-effects

- Gastrointestinal issues.
- Visual disturbances (seeing “lights”).
- Increased need for sleep.
- Skin irritation from the patch.
- One report of accelerated deterioration.

#### Experiences stopping medication

- Some caregivers reported a decline when the medication was stopped.

#### Other factors

- Some families also report that they are making healthy lifestyle choices to delay the progression of the disease (e.g., healthy eating, exercise, going to Minds in Motion) along with taking medication. In some cases they are not sure what role these choices have had in the well-being, and sometimes improvement, of the person with dementia.

### *Focus Group Three: Alzheimer Society of B.C. staff*

#### Positive experiences on medication

- Gives people with dementia and caregivers a sense of hope.
- Can create a “re-bound effect,” whereas the person’s functioning improves considerably.

### Medication side-effects

- Some clients report that the side-effects are so bad that it is not worth taking the medication, even if there are good effects.
- Side-effects include:
  - Gastrointestinal issues.
  - Leg cramps.
  - Sleeping issues (disturbing dreams).
  - Skin irritation with patch.
  - Nausea, dizziness and balance issues.
- Many people who experience side-effects from the pill form of the drug are unaware that other forms of the medication (patch) are available.

### Experiences stopping medication

- Staff were in consensus that sometimes clients do not realize the potential benefits of being on the medication, until they experience negative effects after stopping the medication. Some of these negative effects include:
  - Hallucinations.
  - Agitation.
  - Decline.
- In some cases, if medication is re-started, clients are unable to regain what they lost when they went off the drug.

### Other factors

- Whether or not a client engages in other options for maintaining their well-being can differ depending on the health and age of the client at the time of their diagnosis. Some clients are dealing with a complex combination of health issues and are less able to participate in beneficial activity such as exercise or eating well.
- Some caregivers report that it can be difficult to get a person with dementia involved in other activities and therefore rely solely on the medication.
- Clients compliment medications with other approaches, including:
  - Physical activity (Minds in Motion program, exercise).
  - Healthy eating and alternative medications.
- Some physicians and pharmacists are not offering/discussing the medication with clients due to lack of knowledge about the medication or perceived ineffectiveness of the medication.

**What drugs or other treatments have the patients in your group used, or are currently using, for the condition or disease for which this drug is used? Please list all of the drugs and tell us about the experience of the patients in your group with each treatment.**

Other medications are not available for individuals who are in the early to moderate stages of dementia. This makes it even more important that these medications are listed on the provincial formulary for those who need them.

## **Do you feel this drug should be covered? Why or why not?**

Do we want to insert general ASBC position here?

Consistently, all people with dementia, caregivers and Alzheimer Society of B.C. staff who were consulted in this process agreed that the medications used to treat the symptoms of Alzheimer's disease (known as cholinesterase inhibitors – donepezil (Aricept®), galantamine (Reminyl®) and rivastigmine (Exelon®)) should receive PharmaCare coverage in British Columbia. The following themes emerged from the discussion.

### *Focus Group One: People with dementia*

#### Cost

- If this medication was not covered, people on lower incomes would not be able to afford the medication. This may resort in cost-cutting measures (taking medications every other day, cutting pills in half, having to choose to pay for essential items such as groceries and housing or medications).
- For those able to afford the medication, they would continue to take it.

#### Independence

- The medications help some people to maintain their independence and live at home longer. This potentially delays the use of government programs/ resources and other forms of support and care (e.g. long-term care facilities, caregivers). One person with dementia in particular said: "if it helps a lot of people then there will be less people in care homes. If they are still able to function in their individual homes, with the medication they could still do their everyday life in their home. In the long run it will be cheaper for the government because they will not have to access other government critical care facilities".

#### Care partner/caregivers

- It can decrease stress for the caregiver if the person with dementia is doing better on the medication.

#### Other considerations

- Participants felt that coverage of these medications should be extended for people with other dementias (Lewy Body, frontotemporal dementia, Parkinson's disease etc.).

### *Focus Group Two: Family members and caregivers of people with dementia*

### Cost

- Participants felt that the medications should be covered. They felt that if the medications were not covered, some people may have to make choices between other expenses (e.g. food) and medications.
- Participants felt that a decision to not cover the medications would mean that lower-income seniors would be unable to afford them, an outcome which they thought unfair.

### Quality of life

- Participants felt that these medications contributed to an improved quality of life, and should be covered for the following reasons:
  - “If it improves the quality of life for the person, it should be covered.”
  - It improves the quality of life for the family and caregiver as well.
  - It gives hope.
  - “Wouldn’t you want the best healthcare for your loved one with dementia? And if it included medication coverage, I’m sure the answer would be yes.”

### *Focus Group Three: Alzheimer Society of B.C. staff*

### Cost

- Staff reported that:
  - If not covered through Pharmacare, some clients would not be able to continue taking the medication due to the cost.
  - Some clients would take cost-saving measures (taking half the prescribed amount).
- For the clients who report benefits from the medications, it is potentially keeping them in the home and community longer which decreases the need and use of other resources.

### Equity

- Staff felt that:
  - The option to take the medication should be available to all, without barriers.
  - Because the current cohort of people with dementia was able to have this drug covered, it would be unjust not to offer this medication for persons with dementia in the future.
  - People shouldn’t have to choose between paying for necessities (e.g. groceries) and paying for the medication.

- Treatment options are offered to other terminally ill patients to improve their quality of life, why shouldn't treatment options be available for people with dementia?

## Conclusion

Dementia is a debilitating and fatal disease, robbing people of their memory and their independence over the many years of disability it causes. More people in B.C. than ever before are either living with this disease or are caring for a person who has dementia. Families have reported that these medications can work to slow or improve symptoms of dementia. At this time there are no tests to determine how a person with dementia will respond to these medications. Access to these medications is a health equity issue and all people diagnosed with Alzheimer's disease should have the opportunity to determine efficacy in their individual situation. Those who do not report benefits note that they are appreciative of the opportunity to try the medications to see if they help. Listing these medications with concomitant evidence based prescriptions guidelines provide physicians with tools to help people manage at home longer and to ensure that the medications are prescribed appropriately. If these medications are not to be listed on the provincial formulary it will have a large and direct impact on the finances of many people in B.C. affected by dementia. Some will be forced to choose between medications that may be of benefit, or financing their basic living needs. The decision as to whether or not to list these medications is an issue directly related to the well-being of people affected by dementia - a disease which impacts 1 in 11 Canadians over the age of 65.