

The Clinic for **Alzheimer Disease & Related Disorders**

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Introduction

Approximately 364,000 Canadians over 65, including 83,400 British Columbians are affected by Alzheimer Disease and related dementing disorders.¹ As the number of elderly individuals increases, these numbers are also predicted to increase.

Unfortunately, there is no known cure for Alzheimer Disease or related disorders, but researches are beginning to understand the causes of these conditions and some of the symptoms can be treated effectively with medications. In addition there are many actions that can help if your loved one is experiencing memory and other cognitive losses. A visit to the UBC Clinic for Alzheimer Disease and Related Disorders will provide the following:

- Establishment of an accurate diagnosis.
- Information about the natural history and known causes of the diagnosed disorder (including both genetic and environmental factors).
- Information about available treatments for specific symptoms.
- Counselling for strategies for coping with the day to day difficulties which occur due to mental changes.
- Opportunities for involvement with research including clinical trials.
- Information for patients and caregivers regarding support groups, financial and legal issues (i.e. Representation agreements), care facilities, Adult Day Programs, and other support services such as the Continuing Care Program and the Alzheimer Society of B.C.

¹Canadian Study of Health and Aging Workshop Group (1994). Canadian Study of Health and Aging: study methods and prevalence of dementia. Canadian Medical Association Journal, 150(6), 899-913.

The Clinic

The establishment of the Clinic was initially possible through an operating grant from the Ministry of Health of British Columbia in November of 1983. To date it is the only clinic of its kind in British Columbia. Since the Clinic opened, it has provided assessments for many families throughout the province.

The Clinic's goals:

- To provide assessment and diagnosis, often a second opinion, for patients throughout B.C., who are referred by doctors.
- To co-ordinate information and to provide treatment and counselling for patients and to work with families who are caring for the referred patients.
- To be involved with research projects that look at:
 - the causes, course, characteristics and possible treatment of Alzheimer Disease and related dementias,
 - how best to provide care and support for the affected individual and his/her family.
- To work with various organizations to facilitate liaison for patients, and to assist with education activities and programs. These include Continuing Care, the Alzheimer Society of BC, and the Alzheimer Society of Canada as well as health professionals and lay persons.

Referral

Patients are typically referred to the Clinic by a doctor. Concerned individuals, family members, friends or other health care professionals may also contact the Alzheimer Clinic. However, for an assessment to be scheduled, a referral must be provided to the Clinic by a doctor.

There is a waiting list for assessment at the Clinic. This time allows all medical history reports to be obtained. An appointment for assessment is then made for the patient. A close family member(s) or friend is also asked to attend. It is important for a family member(s) or close friend(s) to come with the patient to the Clinic to provide historical information and also to give the patient support throughout the assessment.

Assessment

Over the course of one or two visits, patients undergo a thorough assessment. It is important to review the total health of the patient to find out if there are other factors contributing to the condition. Stress, grief and/or anxiety can cause memory loss and confusion. It can also be caused temporarily by other medical conditions or by an adverse drug reaction.

The Initial Assessment will include an assessment by some or all of the following:

Geriatrician or Neurologist

The doctor will complete a detailed neuromedical history and physical examination. Additional investigations may be requested, such as computed tomography (CT) head scan, magnetic resonance imaging (MRI), and/or laboratory (blood) tests.

Genetic Counsellor

The geneticist will take a detailed family history asking about the patient's parents, siblings, grandparents, aunts, uncles, nieces, nephews, children and first cousins. Information on the ages and health of these individuals will be needed. The genetic counsellor can provide information about the genetics of Alzheimer Disease and related disorders, recurrence risks for relatives and genetic testing.

Social Worker

The social worker will complete a comprehensive assessment regarding functioning in both the home and the community. The social worker is also available to provide counselling and education to the patients and their families. When necessary, the social worker will provide information about relevant community resources.

Other Clinic Team members

The neuropsychologist and/or psychiatrist may also be involved. These assessments will most likely follow the initial visit. On some occasions, it may be necessary to refer to another specialist.

Neuropsychologist

The neuropsychologist will provide a detailed evaluation of the patient's cognitive and emotional state. This assessment involves paper and pencil testing to evaluate different areas of cognition (i.e. memory, language, attention visuospatial skills and executive functions), as well as mood. Such detailed evaluation may require 2 to 6 hours of testing. Interviews with the patient and family are also included. Following the assessment, feedback is provided by the neuropsychologist regarding the results as well as coping strategies for managing cognitive issues (usually within two weeks of testing date).

Psychiatrist

The psychiatrist will provide an assessment of the patient's mood and behaviours, and when appropriate, the patient's competency. The patient and a family member or a close friend will be interviewed. Recommendations regarding optimising treatment from a psychiatric perspective will be made at the end of this assessment, and this will be relayed to the treating doctor in a written report. Ongoing management may include further follow-up visits with the psychiatrist.

Follow-Up

When the assessment and test results are available, the Clinic team meets to review diagnosis. A clinical summary is sent to the referring doctor and the family doctor.

The patient and family members, where appropriate, will attend a family conference with a member of the Clinic team. At this time the assessment results are reviewed including the patient's status and prognosis. This gives the patient and the family a chance to ask questions and listen to recommendations. Although an absolute diagnosis of Alzheimer Disease cannot be made (except at the time of an autopsy), experienced clinicians are accurate when making the diagnosis in at least 90% of the cases. The Clinic team can confirm the presence of a dementing illness and identify other physical disorders (such as depression or drug intoxication) that may be affecting the patient's symptoms.

Management plans for clinical problems are established with the cooperation of the family doctor. This may include initiation of available pharmaceutical treatment of Alzheimer Disease. As appropriate, patients may return to the Clinic for a reassessment and follow-up.

Ongoing Support and Initial Counselling and Information

The Clinic team try their best to make patients and families as comfortable as possible when at the Clinic. Some families seen in the Clinic have reached a point of desperation before having the assessment. This happens because they do not know their diagnosis and what they can do. Specialists at the Clinic can suggest ways to cope with some of the more distressing problems associated with the disease.

Many patients and families need help with the problems they face. The Clinic team can counsel family members and provide information about the disease as well as resources and support for the Alzheimer patient and their caregivers.

Research

If the patient and family are interested, they may be approached to participate in research projects. The types of projects include:

- Researching the course and characteristics of Alzheimer Disease and related dementias.
- Clinical drug trials that may decrease the rate of decline of dementia patients and improve cognitive symptoms.
- Research regarding the genetic and/or environment causes of Alzheimer Disease and related disorders.
- Research regarding patient care and support for caregivers.

The Clinic also has a computerized longitudinal database that not only helps to organize, record and access patient information, but it is also a vital part of all research projects and presentations. Members of the Clinic team and affiliated students from B.C.'s Universities use the database in accordance with strict patient confidentiality. The UBC Ethics Review Board must review all research projects before they are undertaken.

These critical research activities would not be possible without external funding by granting agencies, pharmaceutical companies, and donations. Many people have a strong interest in seeing that research in this area continues. Donations are gratefully accepted to enhance the activities of the Clinic, particularly the research directions.

To donate to the Clinic, cheques should be made out to:

Alzheimer Clinic

VGH and UBC Hospital Foundation

Vancouver Coastal Health
855 West 12th Avenue
Vancouver, B.C.
V5Z 1M9

For further information write or call:

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