ADVOCACY FACT SHEET 3

Getting a Diagnosis

Example Story

Dan is a single man in his late 60s. He has a heart condition, but he takes medication and his health is otherwise fine. Lately he's been losing things and having memory problems. A few times when he went to the store, he couldn't remember where he parked. For a long time he didn't want to face up to it, but finally he asked a couple of good friends and they agreed that his memory is getting worse.

Dan asked his regular doctor to test him for Alzheimer's disease. The first time he asked, his doctor just said "don't worry about it." The second time, the doctor asked him a few general questions and then dismissed his concerns, saying, "You're just getting older."

But Dan doesn't think this problem is just age. He thinks he may have the beginnings of dementia, and he wants to know for sure so he can plan his future. What should he do?

In B.C., family doctors are the gatekeepers for the medical system. Without a referral from your family doctor, you can't see a specialist.

Unfortunately, some doctors minimize their patients' concerns about dementia. There are a lot of different reasons for this. Many General Practitioners (GPs) have little training in diagnosing dementia, and also may not be aware of the programs and resources available in the community. Doctors may not notice any symptoms to be concerned about during a short check-up, and they may think that further testing is unnecessary. And doctors are human, too—they

may be reluctant to deliver news that they know will be very upsetting.

But with a diagnosis, individuals and their families can begin the process of planning and putting their legal affairs in order while the person with dementia is still capable of making decisions.

It's also important to remember that not everybody with memory problems has dementia. Similar symptoms may be reversible and might be caused by other medical conditions such as depression, infection, thyroid problems, or side effects of medication. Alzheimer's disease is diagnosed through a process of elimination, so it's very important to get proper medical tests.

Here are some tactics Dan can try:

- He can write down a list of symptoms that have worried him, with specific times/dates and other details, so that he's prepared with information to give his doctor.
- He can take a friend or family member to the doctor's office to confirm his concerns.
- He can call the Alzheimer Society of B.C. for advice and assistance. For example, the Alzheimer Society might suggest that Dan tell his doctor about the Cognitive Impairment

This is one of 10 Advocacy Fact Sheets prepared by the Alzheimer Society of B.C. These fact sheets offer tips on advocating for a family member with dementia. We suggest you read through the series, and then use the resources provided to find more specific information.

Guidelines for B.C. This is a document for physicians that tells them how to screen for dementia. It sets out appropriate treatments and provides information about care issues.

- Dan can ask for a referral to a specialist or a specialized clinic (see below).
- If all else fails, Dan could see another doctor.
 Some people want to be "loyal" to their longtime doctors, but your health is important.
 It is your right to get a second opinion.

For people with dementia, it's a great benefit to have a family doctor you trust and can depend on. Doctors don't always have the time or knowledge to coordinate health care and services for their patients. However, when doctors do provide this assistance, they can be very helpful in getting patients the care they need when they need it.

Also, doctors do a lot of important paperwork. For instance, if you need to apply for CPP disability benefits, or for the federal disability tax credit, your doctor must sign the forms. This is why having a family doctor can be very helpful, as opposed to clinics where you might not see the same doctor again.

If you can't get a family doctor, you can try to see the same doctor each time you visit a clinic.

Younger People with Dementia

For people under 65, it is vital to get a diagnosis if you are experiencing memory concerns or unexplained difficulty doing a job you know well. People with dementia may display odd or erratic behaviour. In some cases, for people still working, this can result in a person losing their job before anyone realizes they have a medical problem.

Most people with dementia have to leave work

earlier than planned, with serious consequences for themselves and their families. Retiring early can have a big financial impact, including the loss of extended health coverage. It's important that people under 65 with dementia get registered for government pension and financial aid programs such as disability benefits, so they can access critical support services.

Specialists Who Diagnose Dementia

The following specialists deal with dementia: geriatric mental health workers, geriatricians, gerontologists, geriatric psychiatrists, neurologists, and neuropsychologists. There is an Alzheimer Clinic at the University of B.C. A number of B.C. hospitals have geriatric clinics.

RESOURCES

More details on dementia screening tests is available in a brochure on the ASBC website: <u>Getting a Diagnosis.</u>

Alzheimer Society of B.C. Dementia Helpline, toll-free 1-800-936-6033 (Lower Mainland 604-681-8651) Tuesday to Friday, 10 a.m. to 4 p.m.

The Alzheimer Society of Canada has a brochure on <u>Preparing for Your Doctor's Visit</u> at www.alzheimer.ca.

<u>UBC Alzheimer Clinic</u>: http://vch.eduhealth.ca/.

<u>Cognitive Impairment Guidelines for BC</u> www.bcguidelines.ca/guideline_cognitive.html.

College of Physicians and Surgeons of BC: Find a Family Physician https://www.cpsbc.ca/.

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