

Planning for the Future

Dealing with the day to day challenges of Alzheimer's disease or another form of dementia is overwhelming for many families. Thinking about the future can sometimes seem impossible – not only because caregivers are coping with the here and now, but also because thinking about what's ahead can bring up many difficult emotions. As dementia progresses, making decisions will become more and more difficult for the person you are caring for. Therefore, it is important for families to talk about the future while the person with dementia is able to play an active role in planning. This issue of In Touch provides information on planning for the future with regard to several different areas of life, including financial matters, health care decisions and driving. It also reviews some basic information on upcoming changes to the law in British Columbia. Please note that the information contained in this edition of In Touch is for informational purposes only and is meant to alert caregivers about some things to consider. This publication does not contain legal advice.



The importance of early planning

For families living with dementia, planning ahead can help avoid crises and make future situations more manageable. Planning for the future will mean different things for different people, as everyone's situation is unique. However, the overall goal of early planning is to honour the person with dementia by allowing them the opportunity to participate in making decisions about their own future. It is better to begin planning as early as possible, as waiting increases the risk that it will be difficult to have a process where the views and wishes of the person with dementia are made known. In addition, the person with dementia may be required to have 'legal competency' in order to sign several important documents related to planning. Most families will benefit from considering the following areas:

- Arranging for the management of the person's financial and legal affairs
- Understanding tax benefits that may apply to your family
- Making health care decisions
- Discussing the person's living situation, including decisions about moving to a long-term care facility
- Making decisions together about what to do when the person with dementia can no longer drive safely
- Making a will and funeral arrangements

Here is what some caregivers of people with dementia have said about planning:

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“If you have everything organized and express your wishes you can deal with everything better. This is something everyone needs; it gives the whole family peace of mind.”

“In my experience I’ve seen families fight, which is awful. So for us to be able to openly discuss everything ahead of time just makes the whole world easier.”

“What is a huge shock to people is that they don’t know about levels of care and DNR (Do Not Resuscitate), and those things blow people away. If you read about it and think about it – lots of people don’t do this – but if they have some information they are prepared.”

“You don’t sit down and put this information together in an hour, you sit down and study this information and think about it. It takes a great deal of thought. This is something we all need, but we cannot do it in a minute.”

New developments in the Alzheimer’s Drug Therapy Initiative (ADTI)

While the research intake phase of the Alzheimer’s Drug Therapy Initiative (ADTI) is ending, doctors will continue to be able to prescribe three cholinesterase inhibitor drugs – donepezil (Aricept™), galantamine (Reminyl™) and rivastigmine (Exelon™) – through the Pharmaceutical Services Special Authority process that has been in place through the course of the research study. The B.C. Ministry of Health Services provided PharmaCare coverage of the three drugs as part of the study.



This means that for families on the dementia journey, the purchase price of these drugs will continue to go towards their PharmaCare deductible, making the medications more affordable. The Alzheimer Society of B.C. and other members of the Project Advisory Committee for the ADTI recommended this result.

The ADTI was initiated in 2007 to address a clinical knowledge gap around the use of specific drugs for individuals diagnosed in the early to moderate stages of Alzheimer’s disease.

As of September 30, 2011, the ADTI will no longer enroll new people with dementia and their primary family caregivers in their studies. However, people with Alzheimer’s disease who are newly diagnosed and/or who are prescribed one of these medications by their physician and are eligible for PharmaCare coverage will still have their medication covered by Pharmaceutical Services until at least March 2012. At that time, Pharmaceutical Services will revisit their decision to provide coverage for these medications.

In the meantime, the Alzheimer Society of B.C. continues to advocate for full access to and full coverage of Alzheimer medications.

Fitness to drive in B.C.

*This is a **brief summary only**. Complete policies are available on the OSMV website at: www.pssg.gov.bc.ca/osmv/medical-fitness.*

Supporting a person with dementia as they lose the ability to function independently is challenging, and driving can be an especially tough issue. For caregivers, ensuring the safety of the person with dementia – and others – is an important concern. For people with dementia, losing the ability to drive can represent a significant loss of independence, mobility and even identity. A diagnosis of dementia does not mean that a person must stop driving immediately. Rather, the key to ensuring that individuals cease driving before becoming a risk lies in a process that includes clear communication, appropriate assessment and support.

One way families can prepare for the future is by learning about how fitness to drive is determined in our province. In B.C., the Office of the Superintendent of Motor Vehicles (OSMV) is responsible for ensuring driver's licence holders are able and fit to drive. Below is a brief summary of the OSMV procedures currently in place for determining driver fitness.

Screening: The OSMV can review a driver's file at any time. However, screening is usually done in certain circumstances; for example, if a driver discloses a medical condition or fails a vision test for a licence renewal. Health care providers, family members or concerned citizens can send a report to the OSMV regarding concerns they have about a driver's ability to drive safely. Reports must be from a person with firsthand knowledge, be in writing, and give supporting reasons. The OSMV will not consider anonymous or verbal reports.

Assessment: This consists of two processes: the Driver's Medical Examination Report (DMER) and the OSMV assessment. Once the OSMV has identified a driver as having or possibly having a medical condition that may impair driving, the driver is sent a letter asking them to have their physician complete a DMER. For drivers who have or are suspected of having cognitive impairment, the physician conducts a test called the SIMARD MD and reports the score on the DMER along with any other pertinent information. The OSMV then reviews the DMER and decides if a driver fitness test is required. For drivers with a progressive cognitive impairment the standard test is called DriveABLE. The driver will be sent a letter by the OSMV directing them to call the DriveABLE Access Line to book an appointment within 30 days. The DriveABLE assessment includes a computer-based test to assess cognitive abilities and may include an on-road evaluation if necessary.

Determination: The OSMV reviews the results of all assessments to determine whether a person is fit to drive. If the OSMV determines the driver is not fit, a letter is sent letting them know the decision to revoke their licence. When a driver is found fit, no communication is sent by the OSMV. Drivers with a progressive cognitive impairment will be reassessed in one year or earlier if there is a significant change in their medical status.

Reconsideration: An individual can ask the OSMV to review a driver fitness determination. During the reconsideration the OSMV may request additional assessments.

Determining when driving is unsafe can be a stressful process. Planning ahead and involving health care professionals can help ensure the safety and wellbeing of everyone concerned. If the person you are caring for is still driving, consider contacting your local Alzheimer Society resource centre to obtain information and support to help you cope with these challenges.

Physicians are responsible for administering the SIMARD MD to patients when cognitive impairment is first suspected and every 6 months thereafter. They are also required to report to the OSMV patients who may be unfit to drive.

Enduring Power of Attorney and Representation Agreement

Enduring powers of attorney and representation agreements are two important legal documents that the Alzheimer Society of B.C. encourages families facing dementia to consider. Effective September 1, 2011, there will be changes to both the *Representation Agreement Act* and the *Power of Attorney Act* in B.C. Only basic information is presented below. Consulting a lawyer or notary is recommended.



Enduring Power of Attorney: A power of attorney is a legal document under the *Power of Attorney Act*. It is a way to appoint someone to act on your behalf for financial and legal affairs. The person who makes the power of attorney is referred to as the “donor” and the person appointed to act on the donor’s behalf is the “attorney”. An attorney can do things such as receive income and pay bills on your behalf, buy and sell property or assets that you own, and bring a legal action in your name. A power of attorney does not give your attorney the right to make health care decisions or to make decisions about where you will live. An enduring power of attorney clearly states that the agreement will continue to be in effect even when you are no longer able to make decisions for yourself. Making an enduring power of attorney is important for people with Alzheimer’s disease or another dementia.

Upcoming amendments to the *Power of Attorney Act* effective September 1, 2011 mainly clarify the duties and powers held under an enduring power of attorney. The *Act* will also now contain a provision that an attorney cannot make or change a will on behalf of the donor.

Representation Agreement: A representation agreement is the only way in B.C. to appoint someone to act on your behalf for health care and personal care matters. It allows you to authorize one or more persons to be your representative to make decisions in case of illness, injury, or disability. Most people appoint a spouse or partner, family member, or friend in their representation agreement. An appointed representative may live in another city, province, or country. There are many factors to consider when choosing who to appoint as a representative: your trust in them, their skills and abilities, their understanding of your wishes and values, and whether they will be available to act as your representative.

As of September 1, 2011, amendments to the *Representation Agreement Act* will come into effect. One of the key amendments relates to the context under which the document must be signed and witnessed. For example, as of September 1 you will no longer be required to consult a lawyer to make a representation agreement that includes broader powers.

Both enduring power of attorney and representation agreements are powerful legal documents and it is a good idea to talk to a lawyer before you make one. The Lawyer Referral Service, operated by the BC Branch of the Canadian Bar Association, can assist you with finding a lawyer. Call 604-687-3221 (Lower Mainland) or 1-800-663-1919.

Sources: Nidus Personal Planning Resource Centre and Registry; Public Guardian and Trustee of B.C.

Advance care directives

What is an advance care directive?

An advance care directive allows you to predetermine what health care you may wish to have, or not have, at a later time when you are no longer capable of giving instruction. Advance care directives mainly focus on decisions about end-of-life care, but the document can also be used to express your wishes regarding specific types of treatments.

Upcoming changes to the law

In the past, advance directives have not been legally binding. However, effective September 1, 2011, individuals will be able to make advance directives in which, subject to a few restrictions, they can give or refuse consent to any health care described in their document. Unlike in the past, a validly executed advance directive that is relevant to the circumstances can be used on its own as consent or refusal of medical care without the involvement of a substitute decision maker. This is the key change resulting from the new law to be introduced in British Columbia.

Making an advance care directive

To make a valid advance directive, an individual must be capable of understanding the nature and consequences of the directive, including the scope and effect of the health care instructions they give. They must also understand that health care providers may give medical treatment without choosing a temporary substitute decision-maker (if no representation agreement is in place) who might otherwise consider the current circumstances. The document must be drafted, signed and witnessed in a particular manner. There are some instructions that cannot be included in an advance directive, such as anything that is prohibited by law or certain experimental health care procedures.

Advance directives and representation agreements

It is still highly recommended that individuals make a representation agreement in addition to an advance care directive. You cannot use an advance care directive to authorize a person to speak on your behalf if you should become incapable. The only way to authorize someone to speak on your behalf for health and personal care matters is to make a representation agreement.

An advance directive is **not** an alternative to a representation agreement. If a person has both an advance directive and a representation agreement, health care providers must seek consent from the representative. The instructions in the advance directive will be treated as wishes expressed while capable and an advance directive will be legally binding if the representative cannot ascertain the current wishes of the adult. Any current wishes known by the representative will override instructions provided in an advance directive.



More information about upcoming changes to the legislation regarding incapacity planning in B.C. can be found on the Ministry of Attorney General website at: www.ag.gov.bc.ca/incapacity-planning

Choice in Supports for Independent Living (CSIL)

Choice in Supports for Independent Living (CSIL) – pronounced “SEE-sul” – is an alternative way for people to receive home support services in British Columbia. CSIL was developed to give British Columbians with disabilities and high-intensity care needs more flexibility in managing their home support services.

Individuals who qualify for the CSIL program become “employers”. They receive funds from their local health authority to purchase their own home support services. CSIL employers manage, coordinate, hire, train, schedule and supervise home support workers. People with disabilities who are unable, or not always able, to direct their own care can obtain CSIL funding through the formation of a client support group or a representative designated through a valid Representation Agreement. The client support group or representative takes on all the responsibilities of an employer. CSIL funds go directly to them to purchase home support services on behalf of the client.

There are a number of CSIL eligibility requirements to be aware of. For example, eligible clients:

- have a disability and high-intensity care needs;
- require daily personal assistance;
- have the ability to direct all aspects of their care or have a client support group to do so or an individual designated as a representative through a valid Representation Agreement; and
- have demonstrated the ability to manage care services.



The BC Paraplegic Association, in partnership with the Ministry of Health, developed a workbook on how to apply for and manage CSIL. It also reviews the pros and cons of CSIL to help you determine whether the program could be right for you and your family. The workbook can be downloaded at www.bcpara.org (under “We Can Help”).

To read further on how the CSIL program works, and to learn more about eligibility criteria, visit the BC Ministry of Health’s website at www.health.gov.bc.ca/hcc/csil.html. You can also contact your local health authority’s Home and Community Care department for more information about CSIL.

CSIL is a unique program that is not suitable for everyone. It may meet the needs of some families living with dementia who satisfy the eligibility requirements and who are willing and able to spend time and effort on the responsibilities associated with being a CSIL employer. The Alzheimer Society of B.C. would like to hear about how the CSIL program is working for people with dementia. If the person you are caring for is using this program, or if you have experience with the CSIL application process, we would appreciate hearing your story. You can contact Barbara Lindsay, Senior Manager of Advocacy and Public Policy for the Alzheimer Society of B.C., at 604-742-4918 (toll-free 1-800-667-3742 extension 4918) or by email at blindsay@alzheimerbc.org.

Special thanks to Paul Gauthier for his assistance with this article on CSIL.

Planning resources

The **People's Law School** is a non-profit charitable society which has been providing free and impartial public legal education to British Columbians since 1972. The People's Law School strives to improve access to information for diverse groups such as: youth, students, adults, seniors, newcomers and others with distinctive needs.



The People's Law School publishes a number of plain language booklets and fact sheets on a variety of legal topics. Some of these booklets and fact sheets on topics related to future planning, such as *Power of Attorney* and *Writing your Will*, are available to download from the People's Law School website at www.publiclegaled.bc.ca. A selection of People's Law School publications are also available in hard copy from your local Alzheimer Society of B.C. resource centre.

The People's Law School
150-900 Howe St.
Vancouver, BC, V6Z 2M4
Tel: 604-331-5400
Fax: 604-331-5401
www.publiclegaled.bc.ca

Nidus Personal Planning Resource Centre and Registry

The **Nidus Personal Planning Resource Centre** is a non-profit, charitable organization that provides information to British Columbians about personal planning. They also operate a centralized Registry for personal planning documents. The mandate of the Nidus Personal Planning Resource Centre is to provide education, support, and assistance to British Columbians with personal planning for the purpose of:

1. enabling adults, who need help with decision making today, to use Representation Agreements as a legal alternative to adult guardianship.
2. enabling adults who want to plan for the future to use Representation Agreements and Enduring Powers of Attorney, in the event of mental incapacity due to illness, injury, or disability.

The Nidus office is located in the 411 Seniors Centre in Vancouver:
411 Dunsmuir St.
Vancouver, B.C. V6B 1X4
Tel: 604-408-7414
Toll free: 1-877-267-5552
Fax: 604-801-5506
Email: info@nidus.ca Website: www.nidus.ca

Notes and events

DEMENTIA HELPLINE

Alzheimer Society
BRITISH COLUMBIA

1-800-936-6033

(Lower Mainland 604-681-8651)
Tuesday to Friday, 10 a.m. to 4 p.m.

Helping people with dementia, their friends, and their family members to build the confidence to maintain quality of life when facing dementia.



Our Vision

Our ultimate vision is to create a world without Alzheimer's disease and related dementias.

Our Mission

The Alzheimer Society of B.C. exists to alleviate the personal and social consequences of Alzheimer's disease and related dementias, to promote public awareness and to search for the causes and the cures.

In Touch is published by:

Alzheimer Society
BRITISH COLUMBIA

#300 – 828 West 8th Avenue
Vancouver, B.C. V5Z 1E2

Tel: 604-681-6530

Toll-free: 1-800-667-3742

Fax: 604-669-6907

Email: info@alzheimerbc.org

Website: www.alzheimerbc.org

Free Telephone Workshops



September 8th, 2011, 7:00pm (PST)
The State of Brain Research in Canada

Guest Speaker: Dr. Max Cynader

Dr. Cynader is a world leader in the field of brain research. As the founding Director of the Brain Research Centre, he has built a multidisciplinary team to create one of the world's top neuroscience centres. He is a Member of the Order of Canada and a Member of the Order of British Columbia.

Dr. Cynader will explain in plain language the state of brain research and its implication for people living with dementia. Following the presentation Dr. Cynader will answer questions about brain research.



To see a list of the upcoming workshops or to register, go to www.alzheimerbc.org and click on ***We Can Help.***

You can also register toll-free at 1-866-396-2433 (Mon-Fri, 6am to 2pm P.S.T.)