

What is dementia?

Dementia is a medical term used to describe a group of symptoms related to a decline in cognitive abilities. These changes can be a result of a variety of different diseases which affect the brain. Some of the most common symptoms of dementia include memory loss, confusion and disorientation, impaired judgment and communication difficulties.

Figure 1. Causes and symptoms of dementia

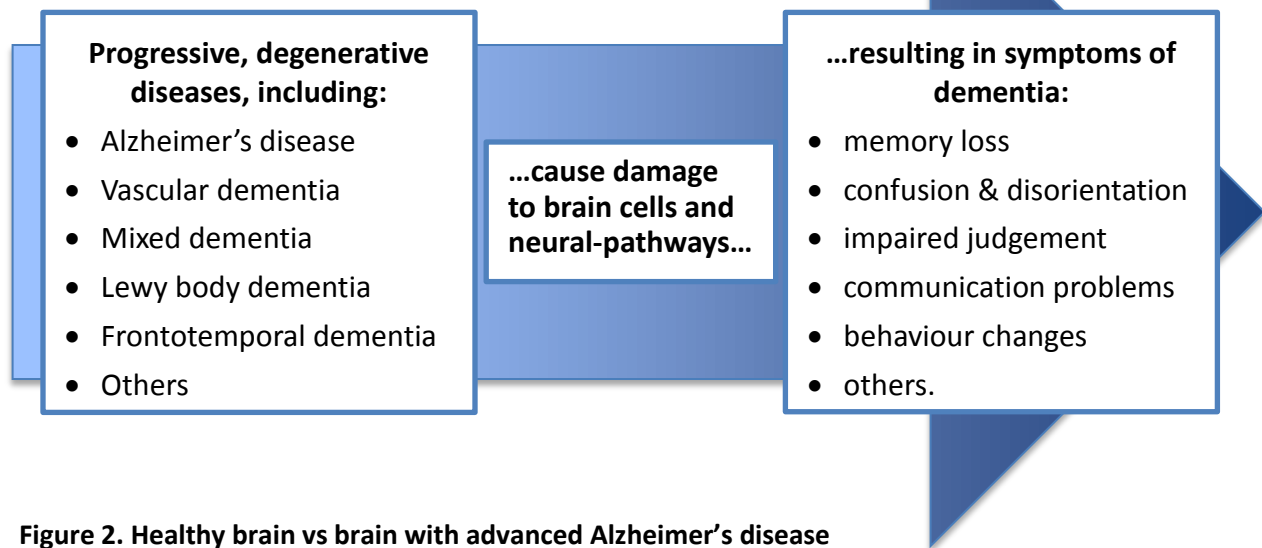
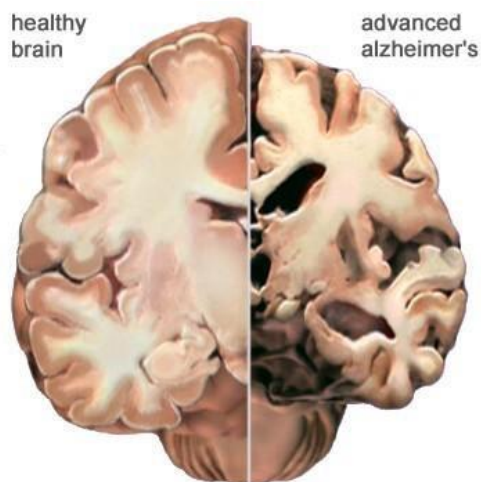


Figure 2. Healthy brain vs brain with advanced Alzheimer's disease



Brain damage due to advanced dementia is visible on the right side of this image.

Dementia leads to the death of nerve cells in the brain. As the disease progresses, these changes in the brain cause the symptoms of dementia.

Dementia is not a normal part of aging.

Learn more about dementia and how to live well on the dementia journey by contacting your local Alzheimer Society of B.C. Resource Centre or call the First Link® Dementia Helpline at **1-800-936-6033** or **604-681-8651**.

Personal Planning

Along the Dementia Journey



This resource offers information on important planning issues for you and your family to consider. It is an information resource only and does not provide legal advice. Please consult your lawyer, notary and/or financial advisor to ensure your financial, legal, health and personal care planning is appropriate for your needs.

☒ **Health care and personal affairs**

- ☐ Have conversations with your family and friends on how to provide support when current arrangements are no longer safe (e.g. living arrangements, driving a vehicle).
- ☐ Discuss plans to retire from driving now or in the future with your family. Explore alternative methods of transportation.
- ☐ Make and register a **Representation Agreement** (*Section 9 or Section 7, depending on your circumstances*) to name someone to make health and personal care decisions on your behalf.
- ☐ Complete a Medical Order for Scope of Treatment (MOST) form with your physician to help inform health-care providers about your goals for care.
- ☐ Speak with an Alzheimer Society of B.C. staff member about strategies to promote safety (e.g. wandering).
- ☐ Sign up for a support group and education with the Alzheimer Society of B.C. to learn more about dementia and planning, and to connect with others on the dementia journey.
- ☐ Explore options for home support, respite care, day programs, or long-term care by contacting your regional health authority's Home and Community Care office.
- ☐ Communicate end-of-life care choices to your representative (appointed through a *Representation Agreement*) and family.

☒ **Financial and legal affairs**

- ☐ Consult with a lawyer or notary and a financial planner.
- ☐ Make and register an **Enduring Power of Attorney** and **Will**.
- ☐ Inform your family of wishes/plans to avoid potential disputes. For example, make a list of personal items and who you would like to receive them.
- ☐ Review beneficiaries for life insurance, RRSPs, RRIAs, pensions, etc.
- ☐ Consider a charitable gift as part of your estate planning.
- ☐ Complete the T1013 *Authorizing or Cancelling a Representative* form to give permission for someone else to access your tax information.
- ☐ Apply for applicable tax credits.
- ☐ Review insurance needs (e.g. house, life, car or long-term care insurance).
- ☐ Ensure that someone you trust can access your bank account and safety deposit box.

Where to get more information:

- ◇ Nidus Resource Centre
- ◇ Lawyer or notary
- ◇ Bank or credit union
- ◇ Financial or investment advisor
- ◇ Canada Revenue Agency
- ◇ Family physician
- ◇ RoadSafetyBC
- ◇ Local health authority

Personal Planning

Tips and resources



Prepare a file with your important papers and information, such as:

- Your birth date and ID numbers (SIN, MSP, driver's license).
- Names of financial and legal advisors, executor(s) and individual(s) appointed through an *Enduring Power of Attorney* and *Representation Agreement* to act on your behalf.
- Phone numbers of family, your health care professionals (e.g. doctor, dentist) and other important people (e.g. home support worker, regional health authority contacts).
- Location of important planning documents, such as your *Enduring Power of Attorney*, *Representation Agreement*, *Will*, *Advance Directive*, and *Medical Order for Scope of Treatment (MOST)*.
- List of assets, deed(s), insurance policies.
- Bank account and investment account numbers, location of safety deposit box, security codes for home safe and credit card information.
- List of passwords (email, computer, voicemail, etc.).
- Location of where a duplicate set of keys are located. Ensure the keys are labeled.

Suggestions to consider:

- ◇ Planning early on with an **Enduring Power of Attorney** and **Representation Agreement** is the best way to avoid potential decision-making issues, uncertainties or disputes.
- ◇ If plans are not made or are inadequate, a **Temporary Substitute Decision Maker** may be assigned by a health care provider to make health care decisions. In some cases, the Public Guardian and Trustee of B.C. may be given authority to make health care, personal care, legal and financial decisions through **Committeeship**.
- ◇ Consider registering your legal documents with the Nidus Personal Planning Resource Centre and Registry.
- ◇ Remember, putting these documents into place takes time. Pick one item at a time to focus on and reach out to a professional (e.g. lawyer, notary, health authority, etc.) for help when it is needed.

Financial and legal resources:

- ◇ **Nidus Personal Planning Resource Centre and Registry:** www.nidus.ca
- ◇ **People's Law School:** www.publiclegaled.bc.ca
- ◇ **Public Guardian and Trustee of B.C.** www.trustee.bc.ca, 1-800-663-7867
- ◇ **Bar Association Lawyer Referral Service** www.cbabc.org/For-the-Public/Lawyer-Referral-Service, 1-800-663-1919
- ◇ **Canada Revenue Agency:** www.canada.ca/en/revenue-agency.html

Health and personal care resources:

- ◇ **Alzheimer Society of B.C.** www.alzheimerbc.ca, 1-800-667-3742
- ◇ **B.C. Ministry of Health:** www.gov.bc.ca/health
- ◇ **Your local health authority:** Visit <https://www2.gov.bc.ca/gov/content/health/accessing-health-care> for contact information.
- ◇ **Seniors First B.C.** www.seniorsfirstbc.ca
- ◇ **RoadSafetyBC:** 1-855-387-7747

PROVINCIAL RESOURCES

The following services and resources are often available in BC communities.
We have provided province-wide contact information where it is available.

Alzheimer Society of B.C.		
First Link® Dementia Helpline – English (Monday to Friday, 9 a.m. to 8 p.m.)	1-800-936-6033	info.helpline@alzheimercbc.org
First Link® Dementia Helpline - Chinese (Monday to Friday, 9 a.m. to 4 p.m.)	1-833-674-5007	info.chinese@alzheimercbc.org
First Link® Dementia Helpline - South Asian (Monday to Friday, 9 a.m. to 4 p.m.)	1-833-674-5003	info.southasian@alzheimercbc.org
Health Authority		
Accessing Health Care To obtain a case manager and initial assessment to home support, day programs, respite, facility placement, etc.		www2.gov.bc.ca/gov/content/health/accessing-health-care
Support and Health Services		
BC Housing Offers programs such as SAFER & the BC Rebate for Accessible Housing. Income eligibility required.	1-866-465-6873	www.bchousing.org/home
BC Mental Health Support Line (24 hours) For emotional support, information, and resources	310-6789 across BC - no area code	www.crisislines.bc.ca
BC211 (24 hours) Source for local community centers, seniors' centers, transportation options & other social and government services.	Phone/Text 2-1-1	www.bc211.ca info@bc211.ca
Better At Home A United Way program that helps seniors with simple non-medical, day-to-day tasks *Not available in all communities		www.betterathome.ca
Crisis Centre of BC (24 hours) Crisis intervention and suicide prevention center.	1-800-784-2433	www.crisiscentre.bc.ca
Family Caregivers of BC Access to information, education, and a toll-free support line that enables caregivers to feel successful in their role.	1-877-520-3267	www.familycaregiversbc.ca
HealthLink BC (24 hours) Non-emergency health information line in 130 languages. Speak with a nurse, pharmacist, or dietician.	Phone 8-1-1	www.healthlinkbc.ca
KUU-US Indigenous Crisis Response Service Provides 24/7 culturally aware crisis support to Indigenous people in BC	1-800-588-8717	www.kuu-uscrisisline.com

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DISCLAIMER: The Alzheimer Society of B.C. does not endorse or assume responsibility for the resources or services mentioned in this document. The list is simply a tool to help with personal research and access to information.

Support and Health Services (cont'd)		
PharmaCare for BC Residents PharmaCare helps B.C. residents pay for eligible prescription drugs, designated medical supplies, and some pharmacy services	604-683-7151 (Lower mainland) 1-800-663-7100 (Rest of BC)	www2.gov.bc.ca/gov/content/health/health-drug-coverage
Red Cross Health Equipment Loan Program Short term equipment rental such as wheelchairs, walkers, and bathroom aids. Ask if longer terms available.	1-800-418-1111	www.redcross.ca
Seniors Distress Line	604-872-1234	www.crisislines.bc.ca
(S.U.C.C.E.S.S.) Chinese Help Line (10 a.m. to 10 p.m.)	604-270-8233 604-270-8222	(Cantonese) (Mandarin)
Safety and Medical Alert Services		
Lifeline A personal response service	1-866-594-7420	www.lifeline.ca
MedicalAlert® Medical ID bracelets	1-800-668-1507	www.medicalert.ca
Telus Livingwell Companion A personal response service with fall detection, GPS tracking, automatic fall detection and more.	1-855-909-2250	https://www.telus.com/en/personal-health/livingwell-companion
Meal Delivery Services		
Better Meals Program Meal service provider delivering healthy meals *Not available in all communities	1-888-838-1888	www.bettermeals.ca
Transportation		
BC Transit Transit options available in your community. Includes seniors' fare discount, Bus Pass program and HandyDART services	250-382-6161 (Head Office)	www.bctransit.com transitinfo@bctransit.com
Hope Air Providing free flights to people who cannot afford the cost of an airline ticket for specialized medical care outside their home community.	1-877-346-4673	www.hopeair.ca
RoadSafetyBC Responsible for road safety including assessing medical fitness of drivers.	1-855 387-7747	www2.gov.bc.ca/gov/content/transportation/driving-and-cycling
Sparc BC Parking permits for persons with disabilities.	1-888-718-7794	info@sparc.bc.ca www.sparc.bc.ca
Travel Assistance Program (TAP BC) Helps alleviate some of the transportation costs for eligible BC residents who must travel within the province for treatment.	1-800-663-7100	www2.gov.bc.ca/gov/content/health/accessing-health-care/tap-bc

Advocacy/Protection from Abuse		
Alzheimer Society of B.C. Self-advocacy strategies webpage with several “Fact Sheets”		www.alzheimerbc.org >> search “advocacy” in the search bar
Office of the Seniors Advocate of BC Information for BC Seniors	1-877-952-3181	www.seniorsadvocatebc.ca/
Patient Voices Network A community of patients, families and caregivers working together with health care partners to improve B.C.’s health care system.	1-877-282-1919	patientvoicesbc.ca/
Public Guardian and Trustee of BC Helps adults who need support for financial and personal decision making.	1-800-663-7867	www.trustee.bc.ca
Seniors Abuse and Information Line (SAIL) Seniors First BC	1-866-437-1940	www.seniorsfirstbc.ca
Financial/Legal Assistance		
Access Pro Bono Provides legal services to clients who meet the income eligibility criteria. A free online 15-minute lawyer consultation is available.	1-877-762-6664	www.accessprobono.ca/our-programs/lawyer-referral-service
BC Seniors Supplement 65+ low income, GIS, OAS	1-866-866-0800	www2.gov.bc.ca/gov/content/family-social-supports/seniors
Canada Benefits Overview of all government benefits programs & services for individuals.	1-800-622-6232	www.canadabenefits.gc.ca
Canada Revenue Agency Information on tax returns, including tax benefits and disability. Tax Certificate (T2201).	1-800-959-8281	www.canada.ca
Canadian Centre for Elder Law (CCEL) Conducts research, outreach, and public legal education on elder law legal issues.		www.bcli.org/sectors/ccel
Clicklaw BC This is a self-help on-line resource with easy access to information on various legal topics.		editor@clicklaw.bc.ca www.clicklaw.bc.ca
Legal Aid BC Provides legal aid, legal resources and publications for very low-income clients who meet the income eligibility criteria.	1-866-577-2525	www.lss.bc.ca/legal_aid/legalinformationOutreachWorkers
Nidus Personal Planning Resource Centre Personal planning resources and assistance Phone appointments can be requested by email.		www.nidus.ca info@nidus.ca
Service BC (Government Services) They will direct you to the appropriate service or department.	1-800-663-7867	www.servicebc.gov.bc.ca
Service Canada Canada Pension Plan (CPP), Guaranteed Income Supplement (GIS), Old Age Security (OAS), OAS Spousal Allowances.	1-800-622-6232	www.servicecanada.gc.ca
Veterans Affairs Canada Provides veterans and their families with services and benefits	1-866-522-2122	www.veterans.gc.ca

Grief Support Services

BC Bereavement Helpline Provides telephone support and connects to grief and support services.	1-877-779-2223	contact@bcbh.ca www.bcbh.ca
BC Hospice Palliative Care Association Membership in BCHPCA is open to individuals	1-877-410-6297	www.bchpca.org
Canadian Virtual Hospice Information and support on palliative and end of life care.		info@virtualhospice.ca www.virtualhospice.ca

SUGGESTED WEBSITES

Updated July 2022

Dementia / Alzheimer's Disease Organizations

<p>www.alzheimerbc.org Alzheimer Society of B.C.</p> <p>alzheimer.ca Alzheimer Society of Canada</p> <p>theaftd.org Association for Frontotemporal Degeneration</p> <p>www.brainstreams.ca British Columbia Brain Injury Association</p>	<p>www.alzint.org Alzheimer's Disease International Contains links to Alzheimer organizations throughout the world.</p> <p>lbda.org Lewy Body Dementia Association</p> <p>www.parkinson.ca/ Parkinson's Disease</p>
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Research, Treatment and Medications

<p>the-ria.ca/programs/murray-alzheimer-research-education-program-marep/ Murray Alzheimer Research and Education Program (MAREP) Provides current research and information.</p> <p>alzinfo.org Fisher Center for Alzheimer's Research Foundation Overview of treatments, research, clinical trials, caregiver information and online community.</p>	<p>ismp-canada.org/beers_list Institute for Safe Medication Practices in Canada <i>Choose 'Potentially Harmful Medications' on the top menu bar</i> List of medications that could be potentially inappropriate for the elderly.</p> <p>clinicaltrials.gov ClinicalTrials.gov Registry of clinical trials.</p>
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Caregiving and Support

<p>www.alzheimerbc.org Alzheimer Society of B.C. <i>Choose 'Living with Dementia' on the top menu</i></p> <p>www.familycaregiversbc.ca Family Caregivers of BC Canadian resources, information and online support.</p> <p>bcbereavementhelpline.com BC Bereavement Helpline Telephone support and grief support services</p> <p>livingwithdementia.uwaterloo.ca Living With Dementia - Resources for Living Well Comprehensive resources on dementia</p>	<p>thiscaringhome.org This Caring Home Tips for home safety for people with dementia.</p> <p>nia.nih.gov/health/topics National Institute on Aging <i>Click on 'S' for safety tips</i></p> <p>caregiver.org Family Caregiver Alliance Information for caregivers providing care at home.</p> <p>helpguide.org Helpguide <i>On the left side menu, under 'Aging Well Topics' choose 'Alzheimer/Dementia'</i></p>
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[Suggested-Websites-July 2022 MasterCopy.docx](#)

Alzheimer Society of B.C. Provincial Office

300 - 828 West 8th Ave.

Vancouver, B.C. V5Z 1E2

Toll-free: 1-800.936.6033

www.alzheimerbc.org

firstlink@alzheimerbc.org

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Long Distance

nia.nih.gov National Institute on Aging <i>Type 'long distance' in the search box</i>	alzheimer.ca Alzheimer Canada <i>Type 'long distance' in the search box</i>
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Transportation and Travelling

health.gov.bc.ca Ministry of Health –Travel Assistance Program <i>Type 'travel assistance' in the search box</i> sparc.bc.ca SPARC BC Parking permits for persons with disabilities. easterseals.ca Easter Seal Disability Travel Card <i>Type 'travel card' in the search box</i>	www.bctransit.com BC Transit Transit options in your community. Includes seniors' fare discount, Bus Pass program and HandyDart, services. otc-cta.gc.ca Canadian Transportation Agency <i>Type 'Take charge of your travel' in the search box</i> A guide to help travellers with disabilities plan and prepare their trip by air within Canada.
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Driving

thehartford.com/alzheimers The Hartford Suggestions to start family conversations about dementia and driving. www2.gov.bc.ca/gov/content/transportation/driving-and-cycling/roadsafetybc RoadSafetyBC	alz.org Alzheimer's Association (USA) <i>Type 'driving' in the search box</i> Information and videos on how to start a conversation about driving. seniorsdriving.caa.ca BCAA Mature Drivers Tips for seniors and their loved ones.
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Chat Rooms for Caregivers and/or People with Dementia

ftdsupportforum.com Frontotemporal Dementia Support Forum For caregivers and people with Frontotemporal Dementia.	alztalk.org Fisher Center for Alzheimer's Research Foundation Online community where caregivers can chat, post messages, pictures and favorite links.
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Websites for Children/Teenagers

<p>faculty.washington.edu Neuroscience for Kids <i>Type 'Neuroscience for kids' in the search box</i></p> <p>youtube.com What Is Alzheimer's Disease? <i>Type 'What Is Alzheimer's Disease' in the search box</i> Three minute video suitable for teens.</p> <p>hbo.com/alzheimers Grandpa, Do You Know Who I Am? <i>Choose the American side</i> Video suitable for the whole family.</p> <p>www.grievingchildrencanada.org/ Comox Valley - Youth as Caregivers Information and short videos for teens and about teens who are caregivers of adults.</p>	<p>alz.org Alzheimer's Association (USA) <i>Type 'kids and teens' in the search box</i> Resources for kids, teens and parents.</p> <p>alzheimer.ca Alzheimer Canada <i>Choose Help and support, Dementia Resources, National resource library, Kids and teens. '</i></p> <p>nia.nih.gov National Institute on Aging <i>Type 'Children and teens resource list' in the search box</i> Bibliography of books, videos and websites.</p>
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Housing and Government Links

<p>bchousing.org BC Housing Information on housing options, how to apply, home adaptation subsidies and tenants' rights.</p> <p>seniorsbc.ca SeniorsBC B.C. resources and education for seniors and caregivers.</p> <p>www.canada.ca/en/employment-social-development/campaigns/seniors.html Seniors Canada Government of Canada's information source for seniors, caregivers and families.</p> <p>seniorsservicessociety.ca Senior Services Society Information on housing options and support services, including meals, listed by communities.</p> <p>www.seniorsadvocatebc.ca Seniors Advocate Office Residential Care Facilities Quick Facts Directory</p>	<p>healthlinkbc.ca HealthLinkBC Offers information on 5,000 health topics, plus a search engine to locate health services in your community.</p> <p>veterans.gc.ca Veterans Affairs Canada Programs for veterans and their families.</p> <p>health.gov.bc.ca British Columbia Ministry of Health <i>Type 'Regional Health Authorities' in the search box.</i> Links to regional health authorities.</p> <p>www2.gov.bc.ca/goiv/content/health/health-drug-coverage PharmaCare for BC Residents PharmaCare helps BC residents to pay for eligible prescription drugs, designated medical supplies and some pharmacy services.</p>
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Legal Matters, Planning and Advocacy

<p>www.alzheimerbc.org Alzheimer Society of B.C. <i>Type 'Personal Planning' in the search box</i></p> <p>www.Advancecareplanning.ca Advance Planning in Canada: Speak UP Advance Care Planning is a process of thinking about and sharing your wishes for future health and personal care.</p> <p>www2.gov.bc.ca BC Ministry of Health <i>Type 'Advance Care Planning' in the search box</i> Comprehensive information and resources on how to create an advance care plan.</p> <p>notaries.bc.ca BC Notaries Find a Notary Public office in your community</p>	<p>nidus.ca Nidus Personal Planning Resource Centre & Registry Information on personal planning tools, including representation agreements and power of attorney.</p> <p>www.peopleslawschool.ca/ People's Law School Booklets on Power of Attorney, Scams to Avoid, Choosing an Executor and Writing Your Will. Publications available in several languages.</p> <p>www.seniorsfirstbc.ca Seniors First BC – SAIL: Seniors Abuse and Information Line</p> <p>www.trustee.bc.ca Public Guardian and Trustee of BC</p>
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Information in Other Languages

<p>https://alzheimer.ca/bc/en Alzheimer Society of B.C. <i>Choose 'Help and support, Dementia Resources Information in other languages'</i></p> <p>fightdementia.org.au Alzheimer's Australia <i>Choose 'Understanding Dementia and Memory Loss' on the top menu, select 'information in Other Languages' Information in over 30 different languages</i></p>	<p>alz.co.uk/other-languages Alzheimer's Disease International List of international dementia organizations offering services in 50 different languages.</p> <p>www.peopleslawschool.ca/ People's Law School Booklets on Power of Attorney, Scams to Avoid, Choosing an Executor & Writing Your Will. Publications available in several languages.</p>
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Products

Note: ASBC does not necessarily endorse these products or assume responsibility for the websites mentioned in this document. This list is simply a tool to help with personal research and to access information.

<p>store.best-alzheimers-products.com Best Alzheimer's Products Assistive devices, books, DVD, games, activities and clothing for people with dementia.</p> <p>redcross.ca/what-we-do Red Cross Health Equipment Loan Program <i>Short term equipment rental such as wheelchairs, walkers and bathroom aids.</i></p>	<p>alzstore.ca The Alzheimer's Store Products adapted for people with dementia.</p> <p>www.cdsboutique.com Concept du Sablier Activity products for people with dementia.</p>
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