Alzheimer Society

ALBERTA AND NORTHWEST TERRITORIES

Young Onset Dementia

Resources for Edmonton and Area Families

FOREWORD

Young Onset Dementia is the term used to describe people under the age of 65 years who have been diagnosed with a type of dementia.

People under the age of 65 years are often still working, many are raising dependent children, and some are also caring for an elderly relative.

People with Young Onset Dementia have numerous decisions to make and a range of service options to consider as their dementia progresses.

They frequently report not knowing what services are available or how to access those services. This resource guide is one of several documents to give information and support to Young Onset families as they journey through the process of gaining supports and services that they need as they live with dementia.

This is a comprehensive guide to health, social, community, financial, legal services and resources which could be useful for people with Young Onset Dementia and their families. The guide is divided into sections making it easier for people to locate the service they are after at the time, as we know that everyone's journey is unique and each person may need different resources and services throughout this journey.

The advisory committee of people living with Young Onset Dementia and their family members have also included some of their own thoughts and stories throughout the document. They hoped that their stories would connect with those reading this document about the reality and hope of living well with Young Onset Dementia.

The Alzheimer Society of Alberta and Northwest Territories was funded by Alberta Health Services' Strategic Clinical Networks to develop a framework and resources aimed specifically at supporting those affected by Young Onset Dementia.

The Society would like to acknowledge that it is only through the generous knowledge and experience-sharing of Young Onset families in one-on-one discussions, focus groups, and the advisory committee that the framework for services and resources has been successfully developed.

We hope that as someone affected by Young Onset Dementia this booklet, along with the framework and other resources can connect you with beneficial services, resources, and supports throughout your journey.



PATHWAY TO A DIAGNOSIS

Everyone's pathway is unique.

Here is some information about important steps along the way.

CONNECT WITH THE ALZHEIMER SOCIETY

The Society helps you access programs and services so you can:

- Learn more about dementia
- Talk with like-minded people about your concerns
- · Learn how to live with the disease
- Connect with local resources that best suit your situation





ACCESS LOCAL RESOURCES

Depending on your situation, you may benefit from certain programs and services. Discuss these options with your support circle:

- Employment and financial planning
- Legal services
- Driving and transportation
- Community living
- Healthcare planning
- Information and support for rarer dementias





VISIT YOUR FAMILY DOCTOR

Tips:

- Have a family member or friend attend the appointment with you. They can help with taking notes and answering questions you may have later.
- Keep a diary to capture any changes in memory, function, mood, or personality and share these observations with the doctor.
- Ask the doctor for any reports and results to keep with your diary and keep all information in one place to look back on when needed.

CONNECT WITH A SPECIALIST

Your doctor may refer you to a specialist, such as a:

- Speciality Geriatric or Memory Clinic
- Neurologist
- Geriatrician
- Neuropsychologist
- Psychiatrist

You may also self-refer to some specialty clinics. Contact your local Society office for more information.



Recognizing and diagnosing Young Onset Dementia (YOD) can be complex. People may experience a long and difficult period with multiple referrals before a diagnosis. This may lead to frustration, but the Society can provide information and support during this process.

PATHWAY TO A DIAGNOSIS & SUPPORT

Changes in memory, language, judgement, behaviour, mood, personality, and/or initiative in a person under the age of 65 are often difficult to understand for family



members. When a person is noticing changes in themselves, a family member, or friend and becomes aware of problems at work or home these are often the keys to seeking a diagnosis and support. It can be difficult to start the process of seeking a diagnosis and for physicians, recognizing and diagnosing Young Onset Dementia can be complex and often requires referrals to specialists, making this process longer than diagnosing someone over the age of 65.

The Alzheimer Society is here to provide information and support no matter where a person is on the pathway. Some of the stepping stones on the pathway to getting a diagnosis include:

Visit your Family Doctor

Tip: Start a diary to capture any changes in memory, function, reasoning, mood, or personality and share with the doctor these observations/experiences.

- Look for changes related to the 10 Warning Signs of Dementia: alzheimer.ca/en/aboutdementia/do-i-havedementia/10-warning-signsdementia
- Consider Frontotemporal Dementia (FTD) or Lewy Body Dementia (LBD) which may have different early symptoms: FTD: alzheimer.ca/en/about-dementia/ other-types-dementia/frontotemporaldementia

LBD: alzheimer.ca/en/about-dementia/ other-types-dementia/dementia-lewybodies

- Preparing for your Doctor's
 Visit Checklist:
 alzheimer.ca/en/about dementia/do-i-have-dementia/
 how-get-tested-dementia/
 talking-your-doctor-about dementia
- Find a Family Doctor: albertafindadoctor.ca/
- Find a Physician (General or Specialist): search.cpsa.ca/ physiciansearch

Your Family Doctor may refer to specialists and/or you may ask for a referral to see a specialist. Possible specialist referrals may be to:

- Specialty Geriatric or Memory Clinics
- Neurologist
- Geriatrician
- Neuropsychologist
- Psychiatrist

Self or family referrals received from:

 Edmonton:
 Good Samaritan Seniors' Clinic gss.org/services/seniors-clinic/ Connect with your local
Alzheimer Society office for
information and access to
programs and services to help
you learn more about dementia,
talk about your concerns and
help you live well.

You will also be linked to local health services, community programs, and resources that best suit your situation.

- a. Your doctor or specialist may refer using the First Link Referral Program.
- b. Contact the Society directly Edmonton Phone: (780)-488-2266

Toll-Free: 1-866-950-5465 Email: <u>reception@alzheimer.</u>

<u>ab.ca</u>

Website: <u>alzheimer.ca/ab/en</u>

Programs and services discussed on Page 9 & 10

Find out about community programs and services that you may need:

Making Sense of the Diagnosis

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- · Alberta Health Services
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- · Grief Support

CONNECTING WITH THE ALZHEIMER SOCIETY

The Alzheimer Society of Alberta and Northwest Territories is working to change the face of dementia and improve the quality of life for those with the disease.

The Society offers education, information, and support services for those living with dementia and their care partners; brings awareness about Alzheimer's disease and other dementias; helps alleviate the personal and social consequences of the disease; and, promotes and funds research into the cause, prevention and cure.

LEGEND TO PROGRAMS AND SERVICES

- Highly Recommended by Young Onset Families
- 55 Available to Age 55+
- No Cost/Fee
- Fee Subsidized to Income Level
- Evening Programming/ Hours
- Regionally Available

Information Support Services 1-866-950-5465

Telephone, email, and in-person information and support for people living with dementia or care partners to speak directly and confidentially with staff regarding situations throughout their journey, including navigating the healthcare system. Find local contact information at:

<u>alzheimer.ca/ab/en/about-us/offices-alberta-northwest-territories</u>

Support Groups

- A support group provides the opportunity
- to meet others in similar situations. You
- have a chance to connect with others and share your experiences, while talking about any other topics or questions. Specific support groups may be

available for people living with young onset dementia, their partner/spouse, and children to meet others in a similar situation. This allows for sharing of day to day experiences, challenges, and successes with one another in an inclusive space. Connect with your local office for more information.

<u>alzheimer.ca/ab/en/about-us/offices-</u> alberta-northwest-territories

Information Sessions

There are different types of sessions for community members, people living with dementia, and care partners that may be offered. Connect with your local office for more information.

<u>alzheimer.ca/ab/en/about-us/offices-</u> alberta-northwest-territories

Education Sessions

The Seeds of Hope Family Learning Series is an education program that provides access to learn from experts in a variety of topics. This program may be offered in person or is available online to watch at your own pace.

www.asantcafe.ca/learn/program/3

Online Support & Information

The ASANT Café and DementiaTalk provide online gathering places for people living with dementia and their care partners to access information, education, and support within a virtual community. DementiaTalk provides a specific discussion space for Young Onset families to share their experiences, challenges, and successes. www.asantcafe.ca/discussions.dementiatalk.org/

I Live with Dementia provides stories from people living with dementia during Alzheimer's Awareness Month in January. Consider reading some of the stories of people from across Canada living with dementia.

ilivewithdementia.ca/read-our-stories/

The Alzheimer Society of Canada

partners with BrainXchange to provide engaging and meaningful webinar series and information online.

brainxchange.ca/

A particular webinar to consider viewing is "Living with young onset dementia: Let's have a conversation!" vimeo.com/186467135

Resource Library

Office libraries offer a comprehensive and diverse range of dementia-related books, pamphlets, videos/DVDs, and resources to borrow. Visit your local office and discuss with staff what types of information or resources could support you. alzheimer.ca/ab/en/about-us/offices-alberta-northwest-territories

Visit the website for online versions of the

alzheimer.ca/en/help-support/dementiaresources

pamphlets and brochures:

I really appreciate the openness and welcoming nature of the group, and it really helped alleviate the feeling of being alone, as much as is possible anyway. I didn't realize what a difference it makes talking to others who can actually come as close as possible as any human can to understanding what you're going through.

- Young Onset Spouse/Care Partner attending Alzheimer Society Young Onset Support Group

LIVING WELL WITH YOUNG ONSET DEMENTIA

It can be a long process to get a diagnosis, but once you do, often the next question is "What now?"

Due to being under 65, families are in different situations and there are many topics to consider, including, finances, children, employment, and health wishes. Living with dementia can cause big changes in an individual's and their family's future plans. You will need to consider how life needs and wishes may change as the dementia progresses.

MAKING SENSE OF THE DIAGNOSIS

Information about Dementia

alzheimer.ca/en/about-dementia

Young Onset Dementia:

alzheimer.ca/en/about-dementia/othertypes-dementia/young-onset-dementia

Alzheimer's Disease:

<u>alzheimer.ca/en/about-dementia/what-</u> alzheimers-disease

Other Dementias:

alzheimer.ca/en/about-dementia/othertypes-dementia

alzheimer.ca/en/about-dementia/othertypes-dementia/rare-types-dementia

Other Dementia-Related Support Organizations

Frontotemporal Dementia (FTD) www.theaftd.org/

Lewy Body Dementia (LBD) www.lbda.org/

O Down Syndrome

Edmonton Down Syndrome Society 780-944-4224 www.edss.ca/home

Parkinson's Disease

Parkinson's Association 1-800-561-1911 parkinsonassociation.ca/

Progressive Supranuclear Palsy (PSP)

www.psp.org/

Huntington's Disease

www.huntingtonsociety.ca/

Multiple Sclerosis

mssociety.ca/

Traumatic Brain Injury

www.braininjurycanada.ca/ www.alberta.ca/brain-injury-supports.aspx

Online Support Groups & Discussion Forums

DementiaTalk provides a specified discussion space for Young Onset families to share their experiences, challenges, and successes with one another, as well as share resources.

discussions.dementiatalk.org/

Dementia Alliance International (DAI)

offers peer to peer support groups run by people with dementia, for people with dementia. Groups are provided online through Facebook and Zoom. DAI also provides peer-to-peer mentoring, if you prefer one to one support, rather than joining a group.

www.dementiaallianceinternational.org/ services/online-support-groups/

The Young Caregivers Association

provides online support groups and programs, counselling services, and resources for children and young adults caring for a family member.
youngcaregivers.ca/

Genetic Counselling & Testing Services

Understanding Genetics and Alzheimer's Disease Brochure

alzheimer.ca/sites/default/files/documents/research_understandinggenetics-and-alzheimers-disease.pdf

Clinical and Metabolic Genetics Program:

www.albertahealthservices.ca/info/page15513.aspx

Find a Genetics Clinic:

geneticseducation.ca/genetics-centres/
canada/canadian_clinics/

Research & Clinical Trials

The Alzheimer Society website provides information on participating in research, as well as resources for finding projects to be involved in.

<u>alzheimer.ca/en/research/participate-research</u>

Although the experience of dementia is different for each person who has it, it is not uncommon for people with dementia to live a good quality of life for a long time.

Roger, person living dementia
 Read more at ILiveWithDementia.ca



EMPLOYMENT & FINANCES

Assured Income for the Severely Handicapped (AISH)

AISH provides financial and health benefits for eligible Albertans with a permanent medical condition that prevents them from earning a living. AISH is only available for people under the age of 65.

www.alberta.ca/aish.aspx

Income Support

Income Support can help with basic living costs and other necessities.

www.alberta.ca/income-support.aspx

Employee Rights

Employers have a duty to accommodate and employees have rights in terms of their employment, termination, and benefits that they receive. Find more information and resources:

www.cplea.ca/rightsatwork/

www.cplea.ca/wp-content/uploads/ ThingstoKnowJobLoss.pdf

www.alberta.ca/termination-pay.aspx

Private Pension Plans

Each person will be in a unique position of the retirement savings and private pension plans that they may or may not have from their employer.

(3) Canadian Pension Plan (CPP)

The CPP retirement pension is a monthly, taxable benefit that replaces part of your income when you retire. To qualify you

must be at least 60 years old and have made a valid contribution to the CPP. www.canada.ca/en/services/benefits/publicpensions/cpp.html

Canadian Pension Plan Disability (CPPD)

CPPD benefits are designed to provide partial income replacement to eligible CPP contributors who are under age 65 with a severe and prolonged disability. www.canada.ca/en/employment-social-development/programs/pension-plan-disability-benefits.html

Canadian Pension Plan Children's Benefit

The CPP children's benefits provide monthly payments to the dependent children of disabled or deceased CPP contributors. The child must be either: under age 18; or under age 25 and in full-time attendance at a recognized school or university.

www.canada.ca/en/services/benefits/ publicpensions/cpp/cpp-childrensbenefit. html

Canada Caregiver Credit (CCC)

The CCC is a non-refundable tax credit that may be available to those supporting a spouse or common-law partner with a physical or mental impairment.

www.canada.ca/en/revenue-agency/
services/tax/individuals/topics/aboutyour-tax-return/tax-return/completing-atax-return/deductions-credits-expenses/
canada-caregiver-amount.html

Disability Tax Credit (DTC)

The DTC is a non-refundable tax credit that helps persons with disabilities, or their supporting persons reduce the amount of income tax they may have to pay.

www.canada.ca/en/revenue-agency/ services/tax/individuals/segments/ taxcredits-deductions-persons-disabilities/ disability-tax-credit.html

Alberta Aids to Daily Living (AADL)

AADL helps Albertans with a long-term disability, chronic or terminal illness to pay for basic medical equipment and supplies.

www.alberta.ca/alberta-aids-to-dailyliving.aspx

© Community Housing and Rent Supplement Programs

This government of Alberta program provide access to affordable housing options.

www.alberta.ca/affordable-housing-

www.aiperta.ca/affordable-nousingprograms.aspx

Métis Housing

Métis Housing programs provide affordable rental housing to low- and moderate-income Métis and other indigenous families in Alberta and have support programs for home repair, down payment assistance, and rental supplement.

www.metishousing.ca/mtis-housing-home-page/

Emergency Needs Allowance

The Emergency Needs Allowance provides financial assistance for unexpected emergencies.

www.alberta.ca/emergency-financial-assistance.aspx

Care Home Costs

Whether a person is considering moving into a care home soon or into the future, it is important to consider the possible costs that will be incurred to plan for the future. www.alberta.ca/continuing-care-accommodation-charges.aspx

Grants for Respite Care

Home Instead Senior Care facilitates grants for respite care hours. Eligibility criteria includes the person living with dementia residing at home and their primary care partner(s) are facing financial and emotional hardship.

www.helpforalzheimersfamilies.com/gethelp/hilarity-for-charity/



LEGAL SERVICES

Enduring Power of Attorney (EPOA)

An EPOA allows you to name a person to make financial decisions on your behalf if your capacity is impaired.

www.alberta.ca/enduring-power-ofattorney.aspx

Personal Directive (PD)

A PD allows you to name someone to make personal decisions for you if your capacity is impaired.

www.alberta.ca/personal-directive.aspx

Office of the Public Guardian and Trustee (OPGT)

The OPGT provides services, tools and support for personal and financial matters to vulnerable Albertans and their families. www.alberta.ca/office-public-guardian-trustee.aspx

Guardianship

When an adult does not have a PD and isn't capable of making decisions the court gives legal authority to a guardian to make personal decisions for them.

www.alberta.ca/adult-guardianship.aspx

Trusteeship

When an adult does not have a EPOA and isn't capable of making decisions the court gives legal authority to a trustee to make financial decisions for them.

www.alberta.ca/trusteeship.aspx



Speak to your bank about any extra checks you want them to make in case you might get defrauded. Do it soon!

A Tip from Dementia Tip-Share website

Check out Dementia Tip-Share at dementiatip-share.org.uk/

For more great tips from people living with dementia for people living with dementia and share your own tips as well!

Capacity Assessments

A capacity assessment is done to see if an adult can make personal or financial decisions and can understand the consequences.

www.alberta.ca/capacity-assessment.aspx

Wills

A properly prepared Will allows you to direct where your property will go after your death. A Will can help relieve stress from your family and loved ones during a time of grief and can ensure your last wishes are followed.

www.alberta.ca/wills-in-alberta.aspx

Free/Affordable Legal Assistance

Legal Aid Alberta

1-866-845-3425

For Albertans who qualify under the eligibility guidelines, legal representation is offered through an assigned lawyer. www.legalaid.ab.ca/Pages/default.aspx

Community Legal Clinics

Edmonton: 780-702-1725

www.eclc.ca

- Student Legal Assistance & Services
- © Edmonton: 780-492-8244 www.slsedmonton.com

Law Central Alberta

Offers free access to family law resources in Alberta including information about Powers of Attorney, personal directives, wills, estates, elder abuse, and grandparents' rights.

www.lawcentralalberta.ca/en

Do not hesitate to get an enduring power of attorney and personal directive. Get it as soon as possible. It will save you lots of pain and time.

– Jenn, spouse





DRIVING & TRANSPORTATION

Insurance & Dementia

Having a diagnosis of dementia does not automatically mean that a person is unable to drive. It is important to inform the insurance company of the diagnosis to ensure that if an accident were to occur that you are still covered. Find more information about driving and transportation with dementia: alzheimer.ca/en/help-support/im-living-dementia/managing-changes-your-abilities/driving-dementia

www.ualberta.ca/medically-at-risk-drivercentre/media-library/mard-publications/ medical-conditions-and-drivingbrochure-2016.pdf

Driving Assessment & Cessation

Determining when a person is no longer safely able to drive is important to watch and have conversations about other options for transportation. Here are some resources on driving assessment and cessation.

alzheimer.ca/en/help-support/im-caringperson-living-dementia/providing-dayday-care/driving-transportation

www.ualberta.ca/medically-at-risk-driver-centre/index.html

• DriveABLE is an organization that a physician may refer a person to for assessment of how cognitive changes may be affecting someone's ability to drive safely.

impirica.tech/driveable/

Alternative Transport Options

MARD's Online Listings is a searchable databases of alternate transportation providers (both for-profit and not-for-profit) in Alberta.

www.ualberta.ca/medically-at-risk-drivercentre/resources/forseniors/alberta-listing. html

O Specialized Transit Services

Many communities have specialized transport services for persons who cannot use regular transit for some or all of their travel needs, due to a physical or cognitive impairment. Some communities and programs include:

Edmonton's Disabled Adult Transport Services (DATS)

www.edmonton.ca/ets/disabled-adult-transit-service.aspx

Carry a card to show all that you come in contact with that [yourself or] your partner has dementia. I couldn't have imagined how helpful this was.

Tip from Spouse/Care Partner
 For a template consider the editable ActOnAlz Awareness Notification
 Cards:

actonalz.org/sites/default/files/documents/ACT-DementiaCards.docx

St. Albert Transit Handibus

stalbert.ca/city/transit/handibus/

Strathcona County Mobility

www.strathcona.ca/transportation-roads/ transportation/strathcona-countyaccessible-transit/

Leduc Assisted Transportation Service (LATS)

www.leductransit.ca/lats

Spruce Grove & Stony Plain Accessible Transportation Service (ATS)

www.sprucegrove.org/services/accessible-transportation-service-ats/



Transportation Companion Programs

WestJet offers a variety of assistance services to assist guests with special needs. If you are not self-reliant you may be accommodated to have a personal attendant travel with you for a base fare of \$0 (applicable taxes and airport fees must still be collected) within Canada.

www.westjet.com/en-ca/travel-info/special-needs/personal-attendant

Air Canada offers a variety of assistance services to assist guests with special needs. If you are not self-reliant you may be accommodated to have a personal attendant travel with you for a base fare of \$0 (applicable taxes and airport fees must still be collected) within Canada or at a special rate for flights outside of Canada. www.aircanada.com/ca/en/aco/home/plan/accessibility.html#/home:

LIVING AT HOME

Family, Community, Senior Services

Collaborative Online Resource & Education (CORE) Alberta is a knowledge hub for seniors serving organizations, allied agencies and individuals in Alberta. corealberta.ca/



O Edmonton (SAGE) provides information and support services in many areas of life for seniors and their families. www.mysage.ca/

Seniors' Centre Without Walls provides

😘 a variety of interactive telephone-based social and health programming, free of charge.

www.edmontonsouthsidepcn.ca/classeshealth-resources/seniors-centre-withoutwalls/

211 is a helpline and online database of Alberta's community and social services. 211 is answered and updated by highly trained specialists.

www.ab.211.ca/

Alberta Supports can help you access more than 30 programs and 120 services for seniors, people with disabilities, job seekers, 🚯 Edmonton Seniors Coordinating parents and families, homelessness, financial assistance, and more. myalbertasupports.alberta.ca/ CitizenPortal/application.do

Volunteering

Volunteer Alberta

provides services and learning for volunteers and organizations. volunteeralberta.ab.ca/



Volunteer Connector is a website database to connect volunteers to organizations across Canada. www.volunteerconnector.org/who-we-are

Recreation & Leisure

Staying active and engaged is important for everyone. The Alzheimer Society website has some ideas and tips for maintaining an active and meaningful life. alzhe<u>imer.ca/en/help-support/im-living-</u> dementia/living-well-dementia

Living and Celebrating Life through

Leisure is a "By Us For Us" Guide for people living with early stage memory loss about meaningful leisure and quality of life.

the-ria.ca/wp-content/uploads/2018/11/ BUFU-Guide-Living-and-Celebrating-Life-Through-Leisure_AODA.pdf

- Council's Recreation and Wellness **Directory** provides information on arts, fitness, technology, health, and recreational activities.

www.seniorscouncil.net/recreationdirectory

Minds in Motion® is a fitness and social program for people experiencing early symptoms of Alzheimer's disease or another dementia and a friend, family member or care partner.

alzheimer.ca/ab/en/help-support/programs-services/minds-motion

Travel Alberta provides information on attractions, events, and places to go and engage in the community.

www.travelalberta.com/ca/

Community leagues provide a great opportunity to socialize, join recreation and leisure groups, and get to know your neighbours. Find the community league in your area through the Edmonton Federation of Community Leagues directory map: efcl.org/league-directory

Home Adaptations & Safety

For safety and independence, some changes may need to be considered in the home. **The Alzheimer Society** website has resources and tips for things to consider.

alzheimer.ca/en/help-support/im-caringperson-living-dementia/ensuring-safetysecurity/making-your-environment-safe I use my Google Home for everything...at 9am every morning it tells me my reminders for the day...and if I am having trouble finding a word I can always say 'Hey Google, what is ...' and it tells me the word.

- Tip from Person Living with Dementia

Consider using technologies for assisting with reminders, calendars, answering questions, and more. **AGE-WELL** is a Canadian network of industry and researchers developing technologies and services for healthy aging.

agewell-nce.ca/

Good Samaritan TeleCare® provides monitored home safety devices, telephone support and personal emergency response services to improve your quality of life and bring you peace of mind.

www.goodsamaritantelecare.com/

The Alzheimer's Store Canada provides products designed for people with dementia and their care partner's for safety and security, entertainment, and comfort.

www.alzstore.ca/

The Canadian Red Cross Health Equipment Loan Program provides loans of up to 6 months of medical and health equipment aids.

www.redcross.ca/in-your-community/ alberta/health-equipment-loans Life goes on despite dementia. Enjoy your friends and hobbies so you have experiences besides dementia in your day.

- Tip from Person Living with
 Dementia and their spouse
- Residential Access Modification Program (RAMP) provides low-income Albertans with mobility challenges financial grants to modify their home.

 www.alberta.ca/residential-access-modification-program.aspx

Adaptability Canada's Age at Home Loan provides assistance to those modifying their home and leverages all relevant subsidies and tax credits as part of the process to offset the cost of borrowing and the interest.

adaptabilitycanada.com/solutions/financial/

Occupational Therapy Services for Chronic Disease Management offers assessment and intervention for activities of daily living, home safety and adaptations, fall risk and prevention, and chronic disease management.

www.albertahealthservices.ca/findhealth/service.aspx?ld=1018171&facilityId=1025102

Walking and Risk of Getting Lost Safety When Out and About is a "By Us For Us" Guide for people living with early stage memory loss and their care partners about planning ahead to reduce the risk of getting lost and staying safe in the community.

the-ria.ca/wp-content/uploads/2018/11/ BUFU-Guide-Safety-When-Out-and-About_AODA.pdf

The Alzheimer Society of Canada resources provide a checklist for considering different identification and locating technologies for people living with dementia who may be at risk of getting lost in their community. alzheimer.ca/en/help-support/im-caring-person-living-dementia/ensuring-safety-security/locating-devices

MedicAlert Safely Home is a 24/7 emergency hotline that provides families and emergency response teams critical information for those that are at risk of getting lost. Important information is engraved on the MedicAlert® and worn at all times by the person with dementia. www.medicalert.ca/safely-home

Finding Your Way® helps people living with dementia, their families, and communities to recognize the risk of going missing, be prepared for incidents of going missing, and ensure that people with dementia can live safely in the community. Finding Your Way also provides a database to compare locating technologies.

findingyourwayontario.ca/

Look for help before the changes, which will help you adjust when [those changes] come.

- Karen, spouse



Meals, Groceries, & Shopping

Food and Mealtimes is a "By Us For Us" Guide for people living with memory loss and their care partners about changes around food and mealtimes and keeping everyone involved in activities related to food.

the-ria.ca/wp-content/uploads/2018/11/ BUFU-Guide-Food-and-Mealtime_ AODA.pdf

- Free Food in Alberta is an AHS website directory about where to find free food including food banks, food hampers, and free meals.

 www.albertahealthservices.ca/nutrition/Page16163.aspx
- Meals on Wheels provides hot and fresh or frozen meals delivered to your home. mealsonwheelsedmonton.org/

Meal Kits are a subscription box that delivers all the ingredients for you to make a fresh meal at home.

mealkitscanada.ca/

• Grocery delivery services can be helpful to order ahead and get fresh products to your house without having to go to the store.



HEALTH & WELLBEING

Mental Health Support & Counselling

Mental Health Help Line

1-877-303-2642

alberta.cmha.ca/getting-help/help-right-now/

Canadian Mental Health Association (CMHA) Distress Lines

Edmonton and Area: 780-482-4357 Rural Distress Line: 1 (800) 232-7288 <u>alberta.cmha.ca/getting-help/help-right-now/</u>

First Nations and Inuit Hope for Wellness Help Line & Online Chat

1 (855) 242-331 www.hopeforwellness.ca/

Kids Help Phone

1-800-668-6868 kidshelpphone.ca/

Find a Psychologist/Counsellor

Psychology Today:

www.psychologytoday.com/ca/therapists/alzheimers/alberta

Theravive:

www.theravive.com/cities/ab/

There are many psychologists throughout the city, here are just two that the Alzheimer Society has utilized for presentations and supporting people on this journey.

Thamarai Moorthy

www.resolvepsychology.com/

Rochelle Major

www.redtreepsychology.com/ YWCA 780-423-9922

Support services and counselling for women and girls.

ywcacanada.ca/find-your-ywca/

Dental

Find a Dentist:

www.dentalhealthalberta.ca/visiting-your-dentist/find-a-dentist/

Dental Care and Oral Health Information:

alzheimer.ca/en/help-support/im-caringperson-living-dementia/providing-dayday-care/personal-care/dental-care

The Importance of Oral Hygiene for People Living with Dementia

This webinar provides information on oral health and tools for supporting someone with oral care.

www.asantcafe.ca/learn/ event/259?=The+Importance+of+Oral+Hygiene+for+People+Living+with+Dementia. html

Alberta Health Services

- Dementia Advice Line via Health
- Link 8-1-1 responds to the immediate needs of persons with dementia living in community settings and their care partners, who require health related advice, education, information on community resources, and emotional support.

 www.albertahealthservices.ca/info/

www.albertahealthservices.ca/info/ Page15482.aspx

- Continuing Care Services provides services based on an assessment of unmet health care needs, including, Home Care, Adult Day Programs, Designated Supportive Living, Long Term Care, Palliative and End of Life Care, or the Medication Assistance Program (MAP).

 www.albertahealthservices.ca/cc/
 Page15487.aspx
- Self-Managed Care and Invoicing are
- alternate methods of service provision
- to provide financial resources to pay for and manage personal care and home care services.

www.albertahealthservices.ca/assets/ info/seniors/if-sen-self-managed-carebrochure.pdf

The Indigenous Health Program partners

with Indigenous peoples, communities and key stakeholders to provide accessible, culturally appropriate health services for First Nations, Métis and Inuit people in Alberta.

www.albertahealthservices.ca/info/ Pagell949.aspx

- Community Geriatric Psychiatry Services
- provide individualized assessment and advice on strategies and interventions for care partners and people living with dementia who are experiencing behavioural and psychological symptoms associated with dementia.

 www.albertahealthservices.ca/findhealth/service.aspx?ld=1001408
- Occupational Therapy Services for Chronic Disease Management offers assessment and intervention for activities of daily living, home safety adaptations, fall risk and prevention, lower leg edema management, medically-at-risk drivers, and chronic disease management.

 www.albertahealthservices.ca/findhealth/service.aspx?ld=1018171&facilityld=1025102

The Alberta Health Advocate & Mental Health Patient Advocate provide education about the Alberta Health Charter and patients' rights set out in the Mental Health Act, and connect people with health and mental health services, programs and resources.
780-422-1812

www.albertahealthservices.ca/findhealth/service.aspx?Id=1018171&facilityId=1025102



Doctors

Find a Family Doctor:

albertafindadoctor.ca/

Find a Physician (General or Specialist): search.cpsa.ca/physiciansearch

Preparing for your Doctor's Visit Checklist:

alzheimer.ca/sites/default/files/ files/national/tip-sheets/tipsheet_ preparingforyourdoctor_e.pdf

Emergency Room Visits

Be Ready for an Emergency Department

Visit is a series of handy checklists and forms for a person with dementia to fill out with a family member, friend, or care partner. Complete these forms before a trip to the hospital is necessary, so everything is ready to go. alzheimer.ca/en/help-support/im-caring-person-living-dementia/ensuring-safety-security/disaster-emergency#Be_ready_for_an_emergency_department_visit

Advanced Care Planning Toolkits

The Alzheimer Society website has information and resources for planning ahead in terms of legal, financial, medical, and lifestyle choices for the future. alzheimer.ca/en/help-support/im-living-dementia/planning-your-future

Advance Care Planning Canada provides an online program to think through and create your own advance care plan. The workbook goes through what are your medical wishes, as well as who to talk to about those wishes.

www.advancecareplanning.ca/

My Health Alberta provides information and resources on advance care planning in Alberta and communicating wishes to family, friends, and your health care team. myhealth.alberta.ca/HealthTopics/Advance-Care-Planning

Alternative Living Arrangements

When a person living with dementia needs full time support, moving to a long-term care home may be the next step for you and your family. The Alzheimer Society website provides many resources for moving into a care home.

alzheimer.ca/en/help-support/im-caring-person-living-dementia/long-term-care

Alberta Health Services' Continuing Care Services provides many services including assessing, designating, and transitioning a person to move into Designated Supportive Living, Long Term Care, or Palliative and End of Life Care.

www.albertahealthservices.ca/cc/
Page15487.aspx

End of Life Care

This Alzheimer Society resource is for a family member supporting the person living with dementia to help prepare for end of life, make some of the difficult decisions you may face, and cope with the grief and loss you might experience. alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care

- Canadian Virtual Hospice offers information and support on palliative and end-of-life care, loss, and grief. www.virtualhospice.ca/en_US/ Main+Site+Navigation/Home.aspx
- The Alberta Hospice Palliative Care
 Association (AHPCA) has developed a
 resource directory to provide palliative
 patients and their care partners with
 information about services and resources
 specific to Alberta's palliative care.
 ahpca.ca/ahpca-resource-directory/

Alberta Health Services palliative and end-of-life care services are listed by zone on their website.

www.albertahealthservices.ca/info/
Pagel4778.aspx

The Palliative Coverage Program

benefits.aspx

provides subsidized benefits to Albertans who are diagnosed as palliative and remain in their home or in a hospice where access to publicly funded drugs, diabetic supplies and ambulance services are not included.

www.alberta.ca/palliative-care-health-

Grief Support

- Pilgrims Hospice Society provides supportive and compassionate family centred care to enhance the quality and dignity of life for those diagnosed with a progressive, life-threatening illness as well as support to those who are bereaved. pilgrimshospice.com/
- The Edmonton Healing Centre for Grief
- **& Loss** serves those touched by loss.
- They offer workshops, presentations and courses for anyone who mourns. Both support groups and one-onone counselling services are available throughout the year. www.jfse.org/ehc/

Canadian Virtual Hospice can help you understand grief and work through some of the difficult issues you may be facing. www.mygrief.ca/

The Alzheimer Society website provides information and resources regarding grief for the person living with dementia and care partners.

alzheimer.ca/en/help-support/i-havefriend-or-family-member-who-livesdementia/managing-ambiguous-lossgrief For further resources please reach out to your local Alzheimer Society office or visit our website's Young Onset page:

<u>alzheimer.ca/en/about-dementia/other-types-dementia/young-onset-dementia</u>



Alzheimer *Society*

ALBERTA AND NORTHWEST TERRITORIES

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