Alzheimer Society
ALBERTA AND
NORTHWEST TERRITORIES

Care Planning Checklist for Young Onset Care Partners

Being diagnosed under the age of 65 presents unique challenges and there are many topics to consider, including, finances, children, employment, and health wishes.

Living with dementia can cause big changes in individuals and families future plans as many need to consider how life needs and wishes may change as a person's dementia progresses.

Your caregiving role is dependent on the needs of the person with dementia and your unique situation.

The following activities are for consideration only and offered as a guide so it may not fully cover everything that you need to consider in planning ahead for your individual and unique circumstances.

Remember, you do not need to do everything yourself!

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EARLY-STAGE PLANNING	Who/When/Comments
Education and support:	
Contact local Alzheimer Society for information. alzheimer.ca/ab/en/about-us/offices-alberta-northwest-territories	
Register for First Link® Connection session, or Seeds of Hope Learning Series.	
Register for support groups. Ask about Young Onset specific group options.	
Obtain list of community supports to be available as a reference. Ask for the regional Young Onset Dementia Resource from your local Alzheimer Society.	
Engage the person living with dementia in discussions when possible. Obtain the Young Onset Planning Ahead Checklist to discuss topics about planning ahead. Link to Young Onset Planning Ahead Checklist document	
Plan to talk or meet with other family members to share the care and keep everyone informed. First Steps: alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/first-steps-families-after-diagnosis	

Include young children and teens living in the home to get support and information. Set-up teachers and other trusted adults with resources. **Helping Children Understand**: alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/helping-children-understand-dementia **Helping Teens Understand**: alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/helping-teens-understand-dementia **Support Matters: A guide for young carers and their allies**: the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Support-Matters_AODA.pdf **Young Caregivers Association**: youngcaregivers.ca/	
Community support:	
Identify your support system, who you can contact for help, and link responsibilities to specific persons. **Asking for Help**: www.asantcafe.ca/learn/?session=15&part=4	
Create a weekly/monthly schedule including activities and appointments of the person living with dementia. Include your own “break times” into schedule.	

Make a list of personal contacts to call in an emergency and a list of professional contacts involved in care.	
Create a safety plan for living in the community and reducing risk of getting lost. **Living Safely With Dementia Resources**: findingyourwayontario.ca/living-safely-with-dementia/	
Register for **MedicAlert® Safely Home®** for the person with dementia at 1-800-668-1507 www.medicalert.ca/safelyhome	
Register with **Connect to Protect** or another Vulnerable Persons registry with your local police department www.medicalert.ca/Programs/MedicAlert-Connect-Protect	
Part of your plan might also include using locating technologies. Learn more about technology that might be able to help. findingyourwayontario.ca/locating-technology/	
Employment	
If person living with dementia is employed, consider how to support them in bringing up their diagnosis with their employer and seeking accommodation as available. **Rights to Accommodation**: www.albertahumanrights.ab.ca/employment/employer_info/accommodation/Pages/duty_to_accommodate.aspx	

Understand illness leaves and/or personal and employer insurance plans regarding long-term disability that may need to be used for yourself or the person living with dementia. **Long-term illness leave**: www.alberta.ca/long-term-illness-injury-leave.aspx **Disability Insurance**: www.canada.ca/en/financial-consumer-agency/services/insurance/disability.html#toc2 **Personal and Family Responsibility Leave**: www.alberta.ca/personal-family-responsibility-leave.aspx	
Legal issues:	
Enduring Power of Attorney (EPOA) for Property and Finances up-to-date and signed. Update to an immediate Enduring Power of Attorney for the person to provide permission for their named attorney(s) to support in monitoring and operating the account while maintaining the person living with dementia to continue having access to their account. **EPOA in Alberta**: www.alberta.ca/enduring-power-of-attorney.aspx	
Personal Directive for Personal Care up-to-date and signed. **Personal Directive in Alberta**: www.alberta.ca/personal-directive.aspx	

Legal Will updated and in place. **Wills in Alberta**: www.alberta.ca/wills-in-alberta.aspx	
Advance Care Planning discussion has taken place regarding wishes: **Speak Up Canada**: www.advancecareplanning.ca/	
Finances	
Once immediate EPOA is signed meet with the bank manager to have all the paperwork in order (a certified copy will be needed). Determine with the bank the process for access to monitor and support in banking activities, and to put safeguards in place on the account.	
Develop a list of household information: companies and contact information for utilities. Consider changing contact information to the spousal care partner for these services to reduce the number of services that need the EPOA to make changes in the future.	
Place person on National Do Not Call list to reduce telemarketing calls. **National Do Not Call List**: lnnte-dncl.gc.ca/en	

If eligible, apply for financial assistance programs for person living with dementia and/or spouses and children. Alberta Supports: myalbertasupports.alberta.ca/CitizenPortal/application.do AISH: www.alberta.ca/aish.aspx Income Support: www.alberta.ca/income-support.aspx Canada Pension Plan (CPP): www.canada.ca/en/services/benefits/publicpensions/cpp.html CPP Disability: www.canada.ca/en/employment-social-development/programs/pension-plan-disability-benefits.html CPP Children's Benefit: www.canada.ca/en/services/benefits/publicpensions/cpp/cpp-childrens-benefit.html	

During tax season, check and use tax benefits for persons living with dementia and care partners. **Canada Caregiver Credit**: www.canada.ca/en/revenue-agency/services/tax/individuals/topics/about-your-tax-return/tax-return/completing-a-tax-return/deductions-credits-expenses/canada-caregiver-amount.html **Disability Tax Credit**: www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html	
Getting organized:	
Develop a health information record including medications and keep updated. **Personal Health Record** myhealth.alberta.ca/myhealthrecords	
Keep an eye on driving capabilities and safety issues in the home. **Driving**: alzheimer.ca/en/help-support/im-caring-person-living-dementia/providing-day-day-care/driving-transportation **Safety at Home**: alzheimer.ca/en/help-support/im-caring-person-living-dementia/ensuring-safety-security/making-your-environment-safe	

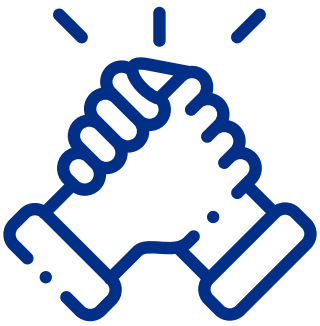
Consider living arrangements and start looking at options for getting help in the home and when to consider transitioning into a residential care home. Living Alone: alzheimer.ca/en/help-support/im-living-dementia/living-well-dementia/living-safely-independently Living Alone – Moving someone living with dementia in with you: alzheimer.ca/en/help-support/im-caring-person-living-dementia/long-distance-caregiving/inviting-someone-move-you Continuing Care – Home Care, Supportive Living, and Long-Term Care: www.albertahealthservices.ca/cc/page15328.aspx Continuing Care – Self-Managed Care: www.albertahealthservices.ca/assets/info/seniors/if-sen-self-managed-care-brochure.pdf Considering Long Term Care: alzheimer.ca/en/help-support/im-caring-person-living-dementia/long-term-care	

MIDDLE STAGE PLANNING	Who/When/Comments
Education and support:	
Contact your local Alzheimer Society. Register for information and education sessions and care partner support group.	
Learn strategies for coping with middle stage of dementia. **Ways to Communicate**: alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/communicating-people-living-dementia **Understanding Symptoms**: alzheimer.ca/en/help-support/im-caring-person-living-dementia/understanding-symptoms	
Adjusting to Changes:	
Update weekly schedule and ask for help from your support system.	
Plan activities for the person with dementia that are appropriate and promote satisfaction and achievement.	
Develop alternate driving/transportation plans if necessary. **Driving and Transportation**: alzheimer.ca/en/help-support/im-caring-person-living-dementia/providing-day-day-care/driving-transportation	

Due to changes in ability, your relationship with the person living with dementia may change and need to adjust. **How Relationships Change:** alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/understanding-how-your-relationship **Intimacy and Sexuality**: archive.alzheimer.ca/sites/default/files/files/national/brochures-conversations/conversations_intimacy-and-sexuality.pdf	
Safety issues:	
Register for **MedicAlert® Safely Home®** for the person with dementia at 1-800-668-1507 if not already done so. www.medicalert.ca/safelyhome	
Depending on how dementia is impacting a person's abilities, there may be changes to make to the household environment. **Making Your Environment Safe:** alzheimer.ca/en/help-support/im-caring-person-living-dementia/ensuring-safety-security/making-your-environment-safe	

Create or update safety plan(s) for you, the person living with dementia, and anyone else that may be impacted as changes occur with dementia. Consider who to call and supports for a number of scenarios including, the person living with dementia getting lost, an altercation occurring between the person living with dementia and a person in the community or with a care partner, etc.	
Community services and taking a break:	
Create an emergency plan of getting support and services in place if something were to happen to you as a care partner (i.e., illness, self-isolation, injury, etc.).	
Tell your own doctor that you are a care partner of a person with dementia so that your health can be monitored.	
Now is the time to assess your need to bring in appropriate community services to assist. **Finding Help:** alzheimer.ca/en/help-support/im-caring-person-living-dementia/looking-after-yourself/finding-help **Community Care Access**: www.albertahealthservices.ca/cc/Page15487.aspx **Reducing Stress**: alzheimer.ca/en/help-support/im-caring-person-living-dementia/looking-after-yourself/reducing-caregiver-stress	

Write up a life history including key facts about the person's life experiences that can be shared with care workers who come into the home. **All about me**: alzheimer.ca/en/help-support/im-living-dementia/managing-changes-your-abilities/helpful-routines-reminders	
Legal and financial issues	
Review income tax benefit options. **Family and Caregiving Benefits**: www.canada.ca/en/services/benefits/family.html	
Become familiar with the residential care home application process. **Designated Supportive Living**: www.albertahealthservices.ca/cc/Page15490.aspx	
Assess financial resources against cost of increasing in-home supports versus moving into a care home. **Care Home Costs:** www.alberta.ca/continuing-care-accommodation-charges.aspx	



Relocation to a care home:	
Assess living arrangements. Are there community supports that could be put in place? Should consideration be made to move into a residential care home? **Considering Long Term Care**: alzheimer.ca/en/help-support/im-caring-person-living-dementia/long-term-care	
Work with Alberta Health Services Case Manager through Community Care Access to determine when and where relocation will take place.	
Prepare person living with dementia for the move. **Moving Day**: alzheimer.ca/en/help-support/im-caring-person-living-dementia/long-term-care/moving-long-term-care	
To assist both you and the person living with dementia, review adjustments for the care partner, communicating and working with staff, and visiting. **Meaningful Visits**: alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/making-meaningful-visits **Long Term Care**: alzheimer.ca/en/help-support/im-caring-person-living-dementia/long-term-care	

LATE-STAGE PLANNING	Who/When/Comments
Education and support	
Contact your local Alzheimer Society for education related to late stages of dementia and a care partner support group. What to Expect: alzheimer.ca/en/help-support/im-caring-person-living-dementia/what-expect-persons-dementia-progresses#The_late_stage Finding Help: alzheimer.ca/en/help-support/im-caring-person-living-dementia/looking-after-yourself/finding-help	
Know that you will enter a new phase of grieving and that you will need support through this stage. Grief: alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/managing-ambiguous-loss-grief	
Care partner role	
Whether person is at home with 24-hour care or in a care home, your role is to inform, advise, recommend, and encourage person centered quality care.	
Provide the “All about me” history for care staff to read. Be sure it is up to date.	
Participate in activities with the person as appropriate and as you are able.	

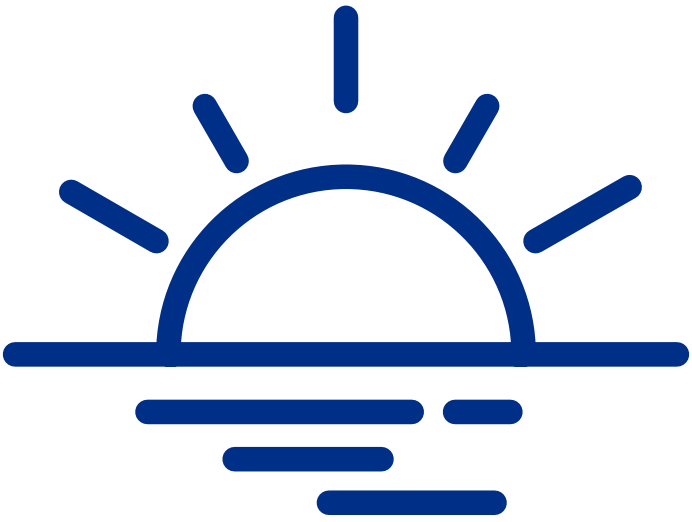
If person is in a care home, make the environment home-like. Decorate the room seasonally, with familiar and appropriate non valuable articles from home.	
Spend positive time with the person: reminisce, recall humorous experiences, find comfort in the silence.	
Communicate according to communication abilities of the person. Be a good listener. Communication Strategies: alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/communicating-people-living-dementia#Tips_for_communicating_with_a_person_with_dementia	
Working with health care staff	
Get to know the staff, maintain regular contact with them, see if you can participate in some activities, give positive feedback.	
If person is in a care home, attend Family/ Resident care conferences and participate in development of plan of care.	
If you have a concern about the care being provided, use effective communication skills when discussing with health care staff. End of Life Care: alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care/what-do-i-need-know-about-caring-person	

Adjustments	
Initially you may wish to visit often and then as the person adjusts to new environment, your visits may become less often as trust builds with staff.	
Enlist the help of your support system to sit with the person so that you can take a break, perhaps a hired or volunteer companion.	
Plan a schedule for visiting with family and friends.	
Know that your life will change, and you need to stay physically active and reconnect with pleasurable activities that you once enjoyed	

END STAGE PLANNING	Who/When/Comments
Education and support	
Contact your local Alzheimer Society and gather information about end stage dementia and what to expect. **End of Life Care**: alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care	
Let others know what you are going through and seek support.	
Care partner role	
Make sure that the end-of-life wishes of the person are communicated to health care staff. **End of Life Care**: alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care	
Goal is comfort care. Assist in providing comfort measures as appropriate. **Comfort Care**: alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care/what-do-i-need-know-about-caring-person#Comforting_the_person	
Maintain dignity of the person.	

The need for companionship remains. Stay calm, attentive and communicate through sensory experiences such as touch, music, reading aloud, reminiscing. Reminisce – talk about favorite memories, play favorite music. Re-assure – "I'm here with you", "You are safe"; use touch as in holding their hand.	
Provide spiritual support in line with person's wishes and life history; i.e. arrange pastoral care or faith leader visits; recite or play favorite readings, prayers, music.	
Make sure that health care staff know the person's wishes for end-of-life care.	
Communicate with staff any signs of pain/ discomfort. **Understanding Pain Management:** alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care/what-do-i-need-know-about-caring-person#Understanding_pain_management	
Communicate regularly with family members, friends on how person is doing.	
If a brain autopsy has been requested, ensure that the doctor, care home and funeral home are aware. **End of Life & Brain Donation:** alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care/what-decisions-will-i-need-make#Brain_donation_and/or_autopsy	

Caring for yourself	
Share the care. Enlist others to sit with the person.	
Make sure you schedule in some physical exercise daily.	
Participate in grief support.	
Celebrate the life of the person you have been caring for and take satisfaction for the role you have played to promote quality of life. Caring for Yourself & Family: alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care/how-do-i-care-myself-my-family	



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