

Early Stage Planning

Living with dementia can cause big changes in individuals and families' future plans. Care partners must 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.

Use this checklist as a guide to help plan ahead. Each activity is a suggestion. This guide may not fully cover everything that applies to your own circumstances.

- Use the “who/when/comments” column to write down anything you need.
- This can be reminders, information, appointment details, etc.
- The “✓” column is a checkbox for you to fill out when you finish the task.
- Click on the links in the Resource Links column to access additional information and resources.

This will help you keep track of your progress.

To navigate through the checklist, use your mouse to hover over the item in the Table of Contents that you wish to move to, then click to proceed to that item.

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Glossary:

Here are some common terms that will be used throughout the document. You can refer to the top of the document to understand terms used. Below are common terms used in the checklist. You can refer to these when you need reminders of the definitions.

***Enduring Power of Attorney (EPOA)** is a legal document that gives another person the control to make financial decisions on your behalf.

***Personal Directive** is a legal document that gives another person the control to make personal, non-financial decisions on your behalf.

***Legal Will** is a legal document that allows you to name your representative who is in charge of distributing your property, following instructions on your will and naming the guardian of your minor children at the time of your death.

***Respite care** options give care partners a break or time to rest. This helps care partners take a short time away from their care responsibilities. In the early stages, it can be provided by family or friends. As the disease progresses, there might be formal services in your area.

***Advance care planning** is how you discuss, plan, and document your wishes for the health care you want to receive now and in the future.

***Green Sleeve:** In Alberta, you can store your important Advance Care Planning documents (such as Personal Directives, Goals of Care Designation) in a green plastic pocket. You should take your Green Sleeve any time you access the Alberta Healthcare system.

* **Supported Decision-Making:** Even if an adult is capable of making decisions, there may be times when they need someone to help them make personal decisions not related to financial matters. This is called supported decision-making.

Education and Support	Resource Links	Who/When/Comments	✓
<p>Contact your local Alzheimer Society. Through the Alzheimer Society you can sign up for:</p> <ul style="list-style-type: none"> • First Link® Connection session • Seeds of Hope Learning Series 	<p>Contact your local Alzheimer Society https://alzheimer.ca/ab/en/about-us/offices-alberta-northwest-territories</p> <p>First Link https://alzheimer.ca/ab/en/help-support/programs-services/first-linkr</p>		
<p>Register for support groups.</p>	<p>Community Support</p> <p>Call 1-866-950-5465 for more information and to reserve your space in support groups https://alzheimer.ca/en/help-support/programs-services</p> <p>Finding help: https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/looking-after-yourself/finding-help</p>		
<p>Consult 211 to identify the community resources available in your area. Create a list for yourself.</p>	<p>211 Alberta: https://ab.211.ca/</p>		

<p>Plan to talk or meet with other family members. Talk about who wants to do what. Share the plan for care and how to keep everyone informed.</p>	<p>Family support</p> <p>First steps for families after diagnosis: https://alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/first-steps-families-after-diagnosis</p> <p>Reducing caregiver stress Alzheimer Society of Canada</p> <p>Helping Children Understand: https://alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/helping-children-understand-dementia</p> <p>Helping Teens Understand: https://alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/helping-teens-understand-dementia</p> <p>Support Matters: A guide for young carers and their allies: 14YCW001_Cpt1_v4b.indd (the-ria.ca)</p> <p>Young Caregivers Association: Young Caregivers Association - Empowering Young Caregivers</p>		
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Community Support	Resource Links	Who/When/Comments	✓
<p>Identify your support system and what they specifically can do to help.</p> <p>Asking for help can be difficult. Many people want to help but don't know how. The Alzheimer Society of Alberta and Northwest Territories can help with timely tips.</p>	<p>Call 1-866-950-5465 for more information and to reserve your space in support groups</p> <p>https://alzheimer.ca/en/help-support/programs-services</p> <p>Finding help: https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/looking-after-yourself/finding-help</p> <p>211 Alberta: https://ab.211.ca/</p>		
<p>Create a weekly or monthly schedule. This helps you plan activities and appointments for the person living with dementia. It is important to include time for yourself in the schedule. Consider respite care* options.</p>			
<p>Make a safety plan. This reduces risk of getting lost.</p>	<p>Finding your way: Living safely with dementia – Finding Your Way (findingyourwayontario.ca)</p>		
<p>Make a list of everyone you can call in an emergency. Write down their contact information. Include contact information of the health professional that works with the person living with dementia.</p>			

Employment	Resource Links	Who/When/Comments	✓
<p>Does the person living with dementia currently have a job?</p> <p>Consider talking with their employer about their dementia. Find out if their workplace can provide services and accommodations.</p>	<p>Rights to Accommodation: www.albertahumanrights.ab.ca/employment/employer_info/accommodation/Pages/duty_to_accommodate.aspx</p> <p>Alberta information on work and dementia: https://www.dementiaalberta.ca/</p>		
<p>For both care partner and person living with dementia:</p> <p>It is important to know about work policies. Illness or personal leaves may apply to your situation in the future.</p>	<p>Long Term Illness Leave: www.alberta.ca/long-term-illness-injury-leave.aspx</p>		
<p>Ask questions about employer insurance plans regarding long-term disability and government programs.</p>	<p>Government programs: www.canada.ca/en/financial-consumer-agency/services/insurance/disability.html#toc2</p> <p>Alberta specific programs www.alberta.ca/personal-family-responsibility-leave.aspx</p>		

Legal Issues	Resource Links	Who/When/Comments	✓
<p>Enduring Power of Attorney *(EPOA*) for property and finances are up-to-date and signed.</p>	<p>EPOA in Alberta: https://www.alberta.ca/enduring-power-of-attorney</p> <p>You can update to an immediate EPOA 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.</p>		
<p>Personal Directive* is up-to-date and signed.</p>	<p>Personal Directive in Alberta: https://www.alberta.ca/personal-directive</p>		
<p>Legal Will* is updated and in place.</p>	<p>Wills</p> <p>Wills in Alberta: https://www.alberta.ca/wills-in-alberta</p>		
<p>If appropriate, Advance Care Planning* discussion has taken place regarding wishes.</p>	<p>Advance Care Planning https://compassionatealberta.ca/plan-ahead/advance-care-planning</p> <p>My Wishes Workbook: https://compassionatealberta.ca/plan-ahead/my-wishes-alberta-workbook</p>		

Finances	Resource Links	Who/When/Comments	✓
<p>Obtain a certified copy of the Enduring Power of Attorney (EPOA) for the bank.</p>	<p>EPOA in Alberta: https://www.alberta.ca/enduring-power-of-attorney</p> <p>You can update to an immediate EPOA 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.</p>		
<p>Set a meeting with the bank to talk about:</p> <ul style="list-style-type: none"> - monitoring and supporting banking activities. - to ensure the account is safe. 			
<p>Make a list of household information such as utility companies/organizations you are using.</p> <p><u>Consider changing the main contact information under the care partner's or designate's name.</u></p>			
<p>Register the person living with dementia on the National 'Do Not Call' list. This will reduce telemarketing calls.</p>	<p>National Do Not Call List https://lnnte-dncl.gc.ca/en</p>		

<p>Apply for financial assistance programs.</p>	<p>Alberta Supports: https://myalbertasupports.alberta.ca/CitizenPortal/application.do</p> <p>Assured Income for the Severely Handicapped (AISH): https://www.alberta.ca/aish</p> <p>Income Support: https://www.alberta.ca/income-support</p> <p>Canada Pension Plan (CPP): https://www.canada.ca/en/services/benefits/publicpensions/cpp.Html</p> <p>CPP Disability: https://www.canada.ca/en/employment-social-development/programs/pension-plan-disability-benefits.Html</p>		
<p>Check and use tax benefits.</p>	<p>Canada Caregiver Credit: https://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</p> <p>Disability Tax Credit: www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html</p>		

Getting Organized	Resource Links	Who/When/Comments	✓
<p>Keep a record of all health information, including a list of medications. You can add it to your green sleeve* or a Capsule of Life®.</p> <p>Update it regularly and store it in an accessible place. On top of your fridge is a common suggested place.</p>	<p>Personal Health Record</p> <p>Alberta: myhealthrecords (alberta.ca)</p> <p>Northwest Territories: https://www.hss.gov.nt.ca/en/services/accepting-correcting-personal-health-information</p> <p>Advance Care Planning and Green sleeve: https://myhealth.alberta.ca/advance-care-planning/keep-advance-care-planning-documents-in-a-green-sleeve</p> <p>Capsule of Life®. https://emsfoundation.ca/what-we-do/caring-programs/capsule-of-life-2/</p>		
<p>It can be difficult to understand everything your physician or nurse tell you.</p> <p>Discuss with your person if they would be interested in Supported Decision Making*.</p>	<p>Alberta Supported Decision-Making: https://www.alberta.ca/supported-decision-making</p>		

<p>Observe the person's ability to do activities of daily living. This includes activities such as: driving, cooking, cleaning, etc. The changes of dementia may create safety issues.</p>	<p>Safety Considerations</p> <p>Driving: https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/providing-day-day-care/driving-transportation</p> <p>Safety at Home: https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/ensuring-safety-security/making-your-environment-safe</p> <p>Living Alone: https://alzheimer.ca/en/help-support/im-living-dementia/living-well-dementia/living-safely-independently</p> <p>Living Alone – Moving someone living with dementia in with you: https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/long-distance-caregiving/inviting-someone-move-you</p>		
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Adapted from Alzheimer Society of Alberta and Northwest Territories

“Care Planning Checklist for Young Onset Care Partners” 2022



Alzheimer*Society*
ALBERTA AND
NORTHWEST TERRITORIES

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