

## Late 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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Education and Support	Resource Links	Who/When/Comments	✓
<p>Contact your local Alzheimer Society. Register for the following:</p> <ul style="list-style-type: none"> <li>- Information and Education Sessions</li> <li>- Care Partner Support Group</li> </ul>	<p>What to Expect in Late-stage dementia:  <a href="https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/what-expect-persons-dementia-progresses#The%20late%20stage">https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/what-expect-persons-dementia-progresses#The late stage</a></p> <p>Finding Help:  <a href="https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/looking-after-yourself/finding-help">https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/looking-after-yourself/finding-help</a></p> <p>Seeds of Hope Family Learning series:  <a href="https://www.helpfordementia.ca/seeds-of-hope/">https://www.helpfordementia.ca/seeds-of-hope/</a></p>		
<p>In late-stage dementia, care partners often share they experience different feelings of loss and grief. This is normal and happens to many people going through a similar situation. Reach out for support during this stage.</p>	<p>Managing grief:  <a href="https://alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/managing-ambiguous-loss-grief">https://alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/managing-ambiguous-loss-grief</a></p> <p>My Tools for Care – In Care:  <a href="https://www.helpfordementia.ca/courses/my-tools-4-care-in-care/">https://www.helpfordementia.ca/courses/my-tools-4-care-in-care/</a></p>		

Relocation to a care home	Resource Links	Who/When/Comments	✓
Prepare person living with dementia for the move.	Moving into long-term care: <a href="https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/long-term-care/moving-long-term-care">https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/long-term-care/moving-long-term-care</a>		<input type="checkbox"/>
To assist both you and the person living with dementia: <ul style="list-style-type: none"> <li>- Review adjustment for the care partner</li> <li>- Communicate and work with staff</li> <li>- Ask the care home about visiting information</li> </ul>	Meaningful Visits: <a href="https://alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/making-meaningful-visits">https://alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/making-meaningful-visits</a>		<input type="checkbox"/>

Adjustments	Resource Links	Who/When/Comments	✓
At first you might want to visit often right after the move. Over time, the person living with dementia may adjust to their new home. Also, their trust in staff at the new location may build up. When this happens, your visits might become less frequent.			<input type="checkbox"/>
Make a list of your support system that can assist you when you take a break. Consider hiring someone or a volunteer companion.			<input type="checkbox"/>
Plan a schedule for visiting with family and friends.			<input type="checkbox"/>
Know that your life will change during this process. But it's still important to take care of yourself. You still need to stay physically active. Spend time to reconnect and do activities that you have done and enjoyed in the past.	My Tools for Care – In Care: <a href="https://www.helpfordementia.ca/courses/my-tools-4-care-in-care/">https://www.helpfordementia.ca/courses/my-tools-4-care-in-care/</a>		<input type="checkbox"/>

Care partner role	Resource Links	Who/When/Comments	✓
<p>You can make sure other people are giving quality care by:</p> <ul style="list-style-type: none"> <li>● Helping care staff get to know the person</li> <li>● Give advice on the type of care they prefer</li> <li>● Give ideas or solutions</li> <li>● Encourage others to give quality care</li> </ul> <p>This applies at any location that the person living with dementia is living in.</p>			
<p>Update the “All About Me” document regularly. Help the staff to use the information provided in how they connect with the person.</p>			
<p>Take part in activities with the person. Join the activities when you’re able to and when it’s appropriate.</p>			
<p>If the person is in a care home, make the environment home-like. Decorate the room seasonally, with familiar and appropriate non valuable articles from home.</p>			
<p>Spend positive time with the person living with dementia. Some examples are:</p> <ul style="list-style-type: none"> <li>● Reminiscing (talk about past experiences)</li> <li>● Recalling funny experiences</li> <li>● Finding comfort in the silence together</li> </ul>			
<p>Adjust your communication approach based on the communication ability of the person. Be a good listener.</p>	<p>Communication Strategies:  <a href="https://alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/communicating-people-living-dementia">https://alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/communicating-people-living-dementia</a></p>		

Working with health care staff	Resource Links	Who/When/Comments	✓
Tips to develop positive relationships: <ul style="list-style-type: none"> <li>• Get to know the staff.</li> <li>• Maintain regular contact.</li> <li>• Check if you can participate in some activities.</li> <li>• Give positive feedback.</li> </ul>			
If your person is in a care home, attend Family/Resident care conferences. Participate in the development of a plan of care. This can be a safe space for you to suggest anything to improve the person’s quality of care.			
If you have a concern about the care being provided, discuss with health care staff using effective communication skills such as: <ul style="list-style-type: none"> <li>- Clear and even tone</li> <li>- Active Listening</li> <li>- Maintain eye contact</li> </ul>	End of Life Care: <a href="https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care/what-do-i-need-know-about-caring-person">https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care/what-do-i-need-know-about-caring-person</a>		

Adapted from Alzheimer Society of Alberta and Northwest Territories  
 “Care Planning Checklist for Young Onset Care Partners” 2022

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