

End-of-Life 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	✓
Talk to the Alzheimer Society in your area to find out what happens in the End-of-Life stage of dementia. They have helpful information.	End Stage Dementia: End of Life Care: https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care		<input type="checkbox"/>
Tell people that you trust about what you are going through. It's okay to let others know you need support.			<input type="checkbox"/>

Care partner role	Resource Links	Who/When/Comments	✓
Let the healthcare staff know the end-of-life wishes of your person.	End of Life Care: https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care		<input type="checkbox"/>
<p>The goal is to provide comfort to your person. Help to give comfort measures as needed. This can look like:</p> <ul style="list-style-type: none"> - Using physical touch to let your person know you are close by. - Talking to your person calmly and naturally. - Washing their skin gently and patting it dry. 	<p>Comforting the person: https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care/what-do-i-need-know-about-caring-person#Comforting the person</p>		<input type="checkbox"/>

<ul style="list-style-type: none"> - Apply lotion on their hands and feet. - Keep the lights low. - Move the head of the bed up using pillows if your person is having a hard time breathing. - Stay close to your person and make a connection using sense, like holding their hand or listening to music they love. 			
<p>Maintain the dignity of your person. Your person still needs you. Give them your attention through touch, music, and reading aloud.</p>			
<p>Talk about your favourite memories with them. Comfort them by:</p> <ul style="list-style-type: none"> • Saying “I’m here with you.” • Saying “You are safe with me.” • Holding their hand 			
<p>Give spiritual support based on your person’s wishes and life history. This can look like:</p> <ul style="list-style-type: none"> - Setting up visits from faith leaders - Praying with them - Listening to music 			
<p>Let the staff know if you see that your person is in pain or looking uncomfortable.</p>	<p>Understanding pain management: https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care/what-do-i-need-know-about-caring-person#Understanding_pain_management</p>		

Give regular updates to family members and friends. Let them know how your person is doing.			<input type="checkbox"/>
<p>If a brain autopsy has been asked for, make sure to notify:</p> <ul style="list-style-type: none"> - the doctor - Care home - Funeral home 	<p>Brain donation and/or autopsy https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care/what-decisions-will-i-need-make#Brain donation and/or autopsy</p>		<input type="checkbox"/>

Caring for yourself	Resource Links	Who/When/Comments	✓
Ask friends or family to help take care of the person. Get others to spend time with them.			<input type="checkbox"/>
Remember to plan some physical exercise daily for yourself.			<input type="checkbox"/>
Consider joining a grief support group. It can be helpful to open up about your emotions with others who may be going through something similar.			<input type="checkbox"/>
Celebrate the person's life you've been looking after. Be proud of your hard work because you've helped make their life better.	<p>How do I care for myself and my family? https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care/how-do-i-care-myself-my-family</p>		<input type="checkbox"/>

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



Alzheimer *Society*

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