

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.

This will help you keep track of your progress.

▶ - **Each flag has a number beside it to guide you to the specific resource in the resource link document. Use the QR code below to access the links:**

Open the camera function on your cell phone or tablet.

Hold it over this QR code. Click on the yellow link that appears to access the document.



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	Who/When/Comments	✓
<p>▶¹ 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.</p>		
<p>Tell people that you trust about what you are going through. It's okay to let others know you need support.</p>		

Care partner role		✓
<p>▶¹ Let the healthcare staff know the end-of-life wishes of the person.</p>		
<p>▶² The goal is to provide comfort to the 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. - 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 the 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 		

Care partner role (continued)		✓
<p>Give spiritual support based on the 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>▶³ Let the staff know if you see that the person is in pain or looking uncomfortable.</p>		
<p>Give regular updates to family members and friends. Let them know how the person is doing.</p>		
<p>▶⁴ 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 		

Caring for yourself		✓
<p>Ask friends or family to help take care of the person. Get others to spend time with them.</p>		
<p>Remember to plan some physical exercise daily for yourself.</p>		
<p>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.</p>		
<p>▶⁵ 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>		

Adapted from Alzheimer Society of Alberta and Northwest Territories
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Alzheimer *Society*

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