



The
**Dementia
Society**
Ottawa and Renfrew County

CARE PLANNING CHECKLIST FOR CAREGIVERS LATER STAGES



Your caregiving role is dependent on the needs of the person with dementia. In the later stages, a person with dementia has significant challenges performing tasks. The person might need help with almost all their care needs. They may have severe cognitive impairment and difficulty communicating their needs. At this stage, preparations for end-of-life care are made. This is when that **advanced care plan** you made is put into action. The focus of care is now on comfort and sensory connection.

The following suggestions are for consideration only and offered as a guide. Remember, you do not need to do everything yourself!

Education and Support

- Contact the Dementia Society. Register for **Caregiver Support Groups** – [Click Here](#)
- Speak with your **Dementia Care Coach**. Discuss strategies for connecting with your loved one.
- Know that you will enter a new phase of grieving. You will need support through this stage. Ask your coach about grief support and resources in the community.

The Caregiving Role

- If you have not yet made an advanced care plan, [Click Here](#) to learn more.
- If your loved one has moved into a care home, you may wish to visit often at first. As the person adjusts to their new environment, your visits may occur less often.
- No matter where the person lives, your role is to inform, recommend, and encourage the best quality of care.
 - The goal is comfort care. Assist in providing comfort measures as appropriate.
 - Maintain dignity of the person.

- ❑ The need for companionship remains:
 - ❑ Stay calm and attentive
 - ❑ Communicate through sensory experiences like touch, music, reading aloud, reminiscing, etc.
 - ❑ Re-assure: I'm here with you, you are safe. Use a therapeutic touch, hold their hand.
 - ❑ Spend positive time with the person. Reminisce or recall humorous experiences.
 - ❑ Find comfort in the silence.
 - ❑ Communicate according to the abilities of the person. Be a good listener.
- ❑ Provide spiritual support in line with the person's wishes and life history. Arrange pastoral care or faith leader visits if appropriate.
- ❑ Communicate regularly with family members and friends on how the person is doing.
- ❑ If the person is in a care home, make the environment home-like.
- ❑ Decorate the room with seasonal decorations and appropriate articles from home.
- ❑ If a brain autopsy has been requested, tell the doctor, the Retirement or Care Home, and the Funeral Home.

Working with Healthcare Staff

- ❑ Get to know the staff, maintain regular contact with them.
 - ❑ Give positive feedback.
 - ❑ Make sure that health care staff know the person's wishes for end of life care.
 - ❑ Communicate with staff any signs of discomfort.
- ❑ Provide the life history for care staff to read. Make sure it is up-to-date.
- ❑ If the person is in a care facility, attend care conferences. Help in the development of the care plan.
- ❑ Use effective communication skills when talking to staff about any concerns you have.
 - ❑ **After the Move: Working and Communicating with Staff** fact sheet available – [Click Here](#)

Caring for Yourself

- ❑ Share the care. Enlist others to sit with the person. Plan a schedule for visiting with family and friends.
- ❑ Make sure you schedule some self-care such as physical exercise each day. Reconnect with pleasurable activities you once did.
- ❑ Participate in grief support.
 - Learn about dementia-related grief such as Grief Characteristics – [Click Here](#)
- ❑ Take satisfaction for the role you have played to promote quality of life.

If Your Loved One Passes Away

- ❑ Reach out to your support network.
- ❑ Review a checklist of what to do after someone passes away – [Click Here](#)
- ❑ Reminisce about the person's life, accomplishments, and their life story. Celebrate the life of the person.
- ❑ Feel the emotions that come up. It's okay to feel pain or to feel relief that the journey is over. Recognize the significance and the challenges that come with closure.

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