



Care Partner Information

Tips for Providing Older Adult Care

Changing Life Roles with Dementia

Everyone has many roles in their life. For example, being a daughter, a shop owner, and a mom. These roles often change over time. Sometimes we choose to change our roles. Sometimes we don't have a choice. Older adults can have many role changes. Common role changes are becoming a grandparent and retiring from work.

Most older adults do well when their roles change. But some role changes are harder than others. The role changes that can come when a person gets dementia are hard for the person and their family. In dementia, a person's thinking and behavior can change. Some changes may be embarrassing and confusing for friends and family. Some changes may put the person's safety at risk. All of these changes may force the older adult and their family to change their roles.

Role changes in early stages of dementia

In the early stages of dementia, a person may no longer be able to go to work, pay bills on time, or drive. When these changes happen, sometimes the family wants to take away all of the person's independence. They do this because they think it will keep the person safe. The person and their family may have a hard time agreeing on what needs to change, and when. At times, the person living with dementia may not know how much they have changed. If it is safe, it is best to help the person with dementia to keep their independence for as long as possible. When help is needed, let the person with dementia do as much as they can on their own.

Role changes in later stages of dementia

When dementia gets worse, the person may not be able to take care of their basic needs, such as dressing, bathing or using the toilet by themselves. Often, a child or grandchild will take on the role of caregiver and help with these activities. It can be confusing for caregivers to know how to act toward someone who used to care for them. It is important to remember that the person living with dementia is still an adult. Never treat a person living with dementia like a child.

This Care Partner Information page is part of a series on older adult caregiving tips. They are written to help family and community caregivers, direct care workers and community health representatives care for older adults. Available in English and Spanish at www.aging.arizona.edu

Care Partner Information

Culture and changing roles

In some communities, the family may feel like the role changes that come with dementia break cultural norms. For example, in many American Indian and Alaska Native communities, the elder role has high social status and honor. Elders pass down cultural values, history, and traditional practices. The elder also make decisions for their family and the community. When dementia gets worse, the person's children may need to take on these roles and make more decisions for the family and the elder. Some families may ignore the signs that something is wrong so as not to go against the elder's role in the culture. Ignoring dementia can be more harmful. The person may not get the care or help they need.

It is best to find ways that the person with dementia can be respected and hold onto their status as an elder, even if they need more support. For example, the person may be able to continue to share the history, values and traditional practices until the last stage of dementia. These types of memories are often the last to go.

Below are several strategies that can help family and paid caregivers when roles change because of dementia.

Strategies to help with role changes in dementia
Respect the person's history and roles in their community. Continue to treat the person with high regard. Always speak to the person as an adult, even if it seems like they can't understand.
Include the person in decisions about their care for as long as possible. Speak to the person with dementia, even when their caregiver is present.
Paid caregivers can learn how the person's family and culture understands dementia. Include these values in the person's care.
Use foods, music and activities from the person's culture in their care. If possible, speak to the person in their native language.
Non-verbal communication, such as eye contact, means different things in different cultures. Learn the meanings of non-verbal cues and pay attention to them.

Caregivers who know very little about the person's culture can still provide good care by always treating the person with respect.

Written By: Jordan Lewis, PhD, MSW, CPG (Aleut) and Lauren Brooks-Cleator, MA

Care Partner Information ~ Tips for Providing Older Adult Care

Edited by an interprofessional team from the University of Arizona Center on Aging