

Supporting Families on the Caregiver Journey

A Guide for helping families through communication, resources, and support.



NCCDP In-service Toolkit



Understanding the Family Experience



- Families may feel guilt
- Families may feel exhaustion
- Families may feel frustration
- Families may experience stress
- Families may experience feeling overwhelmed
- Every family will be at a different place in their journey of understanding and acceptance

Approaches to Utilize When Communicating With Families



- Utilize empathy and reflecting listening
- Ask open ended questions to allow families to express their emotions
- Have another team member with you to provide support if needed
- Identify how often the family would like to be provided updates even if there is no change of a condition
- Share all information along the journey positive and changes or needs they should be made aware of

Family Support Considerations



- Learn about support groups in your area or host a support group for your families on a monthly basis
- Host family education nights on various care topics
- Host family social events for opportunities for enjoyment when with their loved one
- Learn about various simulation experiences that are available to understand what is like to live with dementia

Family Resource Center



- Provide free education materials provided by the National institute of aging at [NIA Publications | Publication Ordering System and Contact Report System](#)
- Provide activity supplies for visitors to use to engage with their loved one when they visit
- Make light refreshments and coffee and other drinks available for visitors
- Provide private comfortable sitting areas for uninterrupted visits with their loved one
- Provide other caregiver books that families can access

Consider Family Ambassadors



- Identify current family members who are farther along on the caregiver journey who may be able to assist newer families for support
- Provide training and resources for families who will serve in this capacity
- Discuss with families if they would like to be paired with another family member for conversation and guidance on the family caregiver journey

Providing Tip Sheets and Tools for Families to have Successful Visits



- Provide tip sheet on how to decorate their loved one's room or apartment with personal touches and what is regulatory requirements
- Provide tip sheets on topics like how to have a good visit
- Create a list of conversation prompts for the season or upcoming holiday for families to utilize
- Provide a list of department head leaders and their email and phone number for contact needs

Provide Local Resources And Phone Numbers for After Hours Support Needs

- www.alz.org
- Provide the 24 helpline phone number for families
1-800-272-3900
- Friendship hotline for elderly
1-800-971-0016



10 Absolutes of Communicating through Alzheimer's

- 1** Never argue, instead agree
- 2** Never reason, instead divert
- 3** Never shame, instead distract
- 4** Never lecture, instead reassure
- 5** Never say "remember," instead reminisce
- 6** Never say "I told you," instead repeat/regroup
- 7** Never say "you can't," instead do what they can
- 8** Never command/demand, instead ask/model
- 9** Never condescend, instead encourage/praise
- 10** Never force, instead reinforce



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Key Takeaways



Important to have ongoing family support and education offerings along the caregiver journey

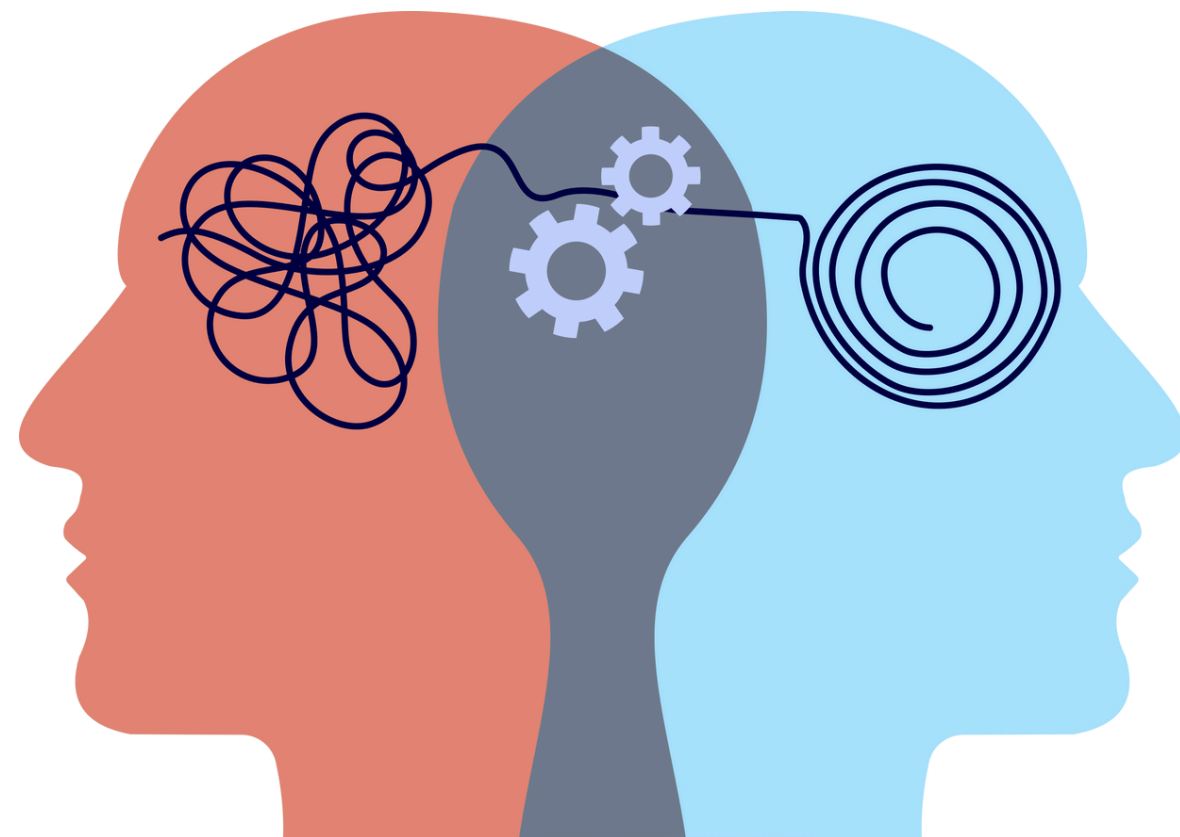
Providing information and updates along the way can alleviate family concerns

Pro active and ongoing communication is a best practice to partner in caring for person with dementia

Continue to evaluate and get input on family needs and availability as you plan offerings for them

Remember this is an emotional journey for family members and empathy and compassion go a long way

Certifications & Additional Information



National Council of Certified Dementia Practitioners (NCCDP)

www.nccdp.org

- ADDC Alzheimer's Disease and Dementia Care curriculum
- CDP Certified Dementia Practitioner
- CADDCT Certified Alzheimer's Disease and Dementia Care Trainer
- CDCM Certified Dementia Care Manager
- CDSGF Certified Dementia Support Group Facilitator
- CFRDT Certified First Responder Dementia Trainer

International Council of Certified Dementia Practitioners (ICCDP)

www.iccdp.net

- CMDCP Certified Montessori Dementia Care Professional
- CDP Certified Dementia Practitioner