



Massachusetts Department of
Developmental Services (DDS)



Massachusetts Councils
on Aging (MCOA)



Center for Developmental Disabilities
Evaluation and Research

CAREGIVER SUPPORT

Being a caregiver for an individual with dementia can be demanding both physically and emotionally. It takes planning and daily effort to maintain the individual's routines, quality of life, and health. Relationships may change as the individual becomes more dependent. And as the disease progresses, caregivers may feel the stress of dealing with a terminal disease.

Burnout and stress have negative impacts on everyone. Caregivers struggle to provide quality care when they're fatigued and stressed. Fatigue may lead to absences from work, which put other staff members under

greater strain. Direct support staff and supervisors should pay attention to the negative effects of stress. It's important that caregivers take care of themselves, and reach out for support if they need it.

Family caregivers can experience all the same stresses as paid caregivers, and face additional challenges when there is disagreement within the family about the course of care.

Peers in the residence may experience fear, sadness, jealousy of additional attention, and loss of a friend. Listen to and support them.



TAKE ACTION:

Get educated:

Learning more about dementia and the specialized needs of individuals with dementia can help caregivers improve and adapt their approach to care and may help reduce stress and frustration. Start by talking to your Service Coordinator, who you can locate through your local [Area Office](#).

Additional Resources:

- Alzheimer's Association [care training resources](#)
- DDS/CDDER [Aging with Intellectual and Developmental Disability](#) webinar series
- Executive Office of Elder Affairs [caregiver help and information](#)

Expand the Network of Support:

- Within the group home setting, supervisors could explore increased staffing if there is evidence of need. Other options are using shorter shifts and scheduling relief breaks for respite. Staff should document any increased needs of the individual to help residential directors anticipate changing support needs.
- Within caregiving teams, encourage open communication to create a supportive environment, which respects and acknowledges feelings and frustrations. Include the family as part of the team. Discuss and document future support needs at the Individual Service Plan (ISP) meeting.
- Seek out [caregiver support groups](#) through the Alzheimer's Association or call their 24/7 helpline at **800.272.3900**
- Visit [Memory Cafés](#) that offer socialization and structured activities at meetings for individuals with dementia and their caregivers. Many groups include people with and without IDD.
- Contact Massachusetts Councils On Aging for information about [Memory Cafés](#) or [Senior Centers](#)

- Families caring for someone at home should ask their Service Coordinator about **respite care** or they can contact the DDS [Family Support Center](#) in their area. Don't forget natural supports such as friends, neighbors and religious group members.
- Family caregivers may also contact [MassOptions](#) or call Mass Executive Office of Elder Affairs **844.422.6277** and ask to speak with a Caregiver Specialist.
- [National Task Group on Intellectual Disabilities and Dementia Practices](#) is a coalition that advocates for services and supports for people with IDD and Alzheimers disease and related dementias.