



Massachusetts Department of  
Developmental Services (DDS)



Massachusetts Councils  
on Aging (MCOA)



Center for Developmental Disabilities  
Evaluation and Research

## PRESERVING QUALITY OF LIFE

For individuals receiving services from DDS, there are six Quality of Life (QOL) Areas at the heart of the Individual Support Plan (ISP). For an individual with dementia, the ISP must be modified to reflect the shift in focus from learning and growth to support and comfort. However, the six QOL areas are still relevant to maintain the individual's dignity and quality of life.



### Rights and Dignity

- The individual will not lose any rights or supports as a result of their diagnosis. Programs and legal advocates, such as guardians, must uphold the individual's human dignity and rights. Decisions are made in accordance with the individual's wishes and preferences.

### Individual Control

- Caregivers must be skilled in facilitating the individual's decision-making and independence to the extent possible.

### Community Membership

- Community inclusion activities may be modified to allow the individual continued participation in preferred activities.

### Relationships

- Relationships with caregivers, family, and peers may change, but people in that social network will be important in providing support. Planning can ease transitions and prevent caregiver stress.

### Personal Goals and Achievement

- Facilitate independence and assist in maintaining the individual's skills for as long as possible. As dementia progresses, they may not be able to complete a full task. Focus on the part of the activity they can still engage in.

### Personal Well-Being

- The individual's health, safety, and economic security must be assured. If the person does not have a guardian, it may fall to the team to manage such affairs along with the Health Care Agent (HCA), if one has been appointed.
- If the individual has a guardian, a review of the guardianship decree may be indicated in order to assure appropriate authority exists for the guardian to address medical, legal and financial issues.

### TAKE ACTION:

Contact your **Service Coordinator** or **Area Office Nurse** through your [local Area Office](#) for guidance in any of the Quality of Life Areas listed below:

- If competent, the individual can name an HCA via a Health Care Proxy. If not, appoint a legal guardian, if needed. Create end of life plans in accordance with the individual's preferences. Review *End of Life Planning* in this series.
- Train caregivers in dementia care, including areas such as communication, and setting up the environment or routines to create opportunities for independence.
- The individual and the team can help determine activities that are preferred and meaningful. Use creative scheduling to optimize comfort and participation in groups, at home, day program, or community at large.
- Support peers, family and caregivers working to maintain social relationships with the person. Create ways of communicating, beyond words, including music, art, familiar foods or smells, and gentle touch.
- Support the person through consistent schedules, visual cues, and simple tasks. Maintain logbooks and records; keep open communication among caregivers, family and providers.
- Provide quality health care, including OT, PT, and Speech evaluations. Consider hospice at the end of life. Modify the home for safety. Consult with the [Human Rights Office](#), where the rights of the individual or others could be impacted.

### Useful Links

- [DDS/CDDER Aging with IDD](#), specifically the [Five Wishes](#) webinar, provide information on a wide array of topics on Aging and IDD
- [MassOptions](#) or call **844.422.6277** ask to speak with a Caregiver Specialist
- MCOA Senior Center [Information](#) or call **Massachusetts Council on Aging** at **413.527.6425**
- DDS [Family Support Center](#) or call DDS at **617.727.5608**
- DDS [Office of Human Rights](#) **617.624.7782**
- [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.