

Dignity and Self-Determination

Dignity is defined as a sense of worthiness or self-respect. It is important to help a person with dementia maintain their dignity throughout the course of the disease. Loss of control, increased dependence on others, and lack of reciprocity in relationships can damage the person's self-esteem and contribute to feeling like a burden on others. Though we all make decisions that compromise our own health and wellbeing, such as not sleeping enough or eating too much, we might find ourselves trying to protect people with dementia from anything that might compromise their health or wellbeing. Caregivers can be tempted to 'take over' or do more for the person with dementia than they really need. Perhaps the person does not do the task as well as they used to, or they take more time to do it and we lose patience. Maybe we worry about the person's safety and get frustrated when they refuse help. Navigating care decisions is challenging and complex. It is best to find a balance between risks we worry about and the person's wellbeing. Sometimes thinking creatively about the situation and the resources available can help us find a reasonable compromise.

	Factors to consider for the Patient	Factors to consider for the Caregiver	Strategies
Safety Risks	<ul style="list-style-type: none"> • Injury to self • Loss of function • Loss of insight and awareness 	<ul style="list-style-type: none"> • Responsibility for protecting the person • Property damage (for example, damage to the person's car) • Loss of resources (such as losing money due to a scam or financial mistake) • Threat to safety or wellbeing of others • Unpredictable changes in behavior and function 	<ul style="list-style-type: none"> • Investigate the person's individual risks • Talk with the person about what is important to them and what they think is acceptable • Try to make small changes in the environment that promote the person's independence and limits risks • Look for small ways to reduce harm • Ask the person to give something new a try for a limited time as a test • Educate yourself about the type of dementia the person has and the expected course • Develop a team of medical providers that you trust for advice and guidance • Seek guidance from an elder law attorney for financial and legal planning

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Impact on Wellbeing	<ul style="list-style-type: none"> • Loss of control and independence • Changes in relationship dynamics with family and friends • Compromised values and preferences (for example, the person attends a day program even though they might prefer to stay home alone) • Sense of embarrassment, loss of confidence, fear of being a burden • Uncertainty about the future 	<ul style="list-style-type: none"> • Changes in relationship dynamics • Sense of guilt, failure, or worry that you aren't handling things well • Disruption of the caregiver's own life • Trying to do it all and neglecting their own needs • Not knowing how to manage caregiving responsibilities • Uncertainty about the future 	<ul style="list-style-type: none"> • Work on maintaining connection and building trust with the person. Try to do enjoyable things together on a regular basis. Honor what is important to them (for example, if they value privacy in the bathroom but still need help, stand outside the door until they need your assistance). • Focus on the person's strengths and avoid drawing attention to their deficits • Modify the environment to help them maintain their independence and minimize safety risks (for example, reduce clutter, improve lighting, install grab bars, use monitoring or alert technology) • Find ways for them to contribute (tell their story, give their opinion or advice, offer affection/nurturing/humor, help with activity, express themselves through art) • Be discreet when helping • Avoid speaking or treating the person with dementia as if they are a child • Seek help from community services and programs for guidance, respite, and home modification