Your Employee Assistance Program is a support service that can help you take the first step toward change.

Caring for Someone with Dementia

Not only is a diagnosis of dementia difficult for the person with the disease; it also poses significant changes and sources of stress for those who care for the person with the diagnosis. Most individuals with dementia have a primary caregiver - usually a spouse, partner, or adult child - and some people have secondary caregivers, such as other relatives or neighbors. The following coping skills are useful to both primary and secondary caregivers, but primary caregivers will find them the most relevant due to the way that their lives have changed:

- Learn as much as you can about the disease as soon as possible. Although you may be reluctant to do so, you will thank yourself down the road. You will be better prepared to handle the variety of challenges associated with dementia if you know what to expect and have some ideas about how other people have handled similar challenges.
- Adjust your expectations by imagining what your loved one is going through. People do not want to have dementia; it is not their fault that they developed the disease. Most of all, try to remember that the person's brain is not working properly. He or she is not engaging in this behavior on purpose, or to be difficult or annoying. Caregiving is a meditation on patience and understanding.
- Attend to your own physical and mental health. Make time for sleep, exercise, proper nutrition, socializing, and private time. If you are run down, exhausted, socially isolated, etc., you run the risk of becoming physically ill and overwhelmed and/or depressed yourself. You cannot help someone else without helping yourself first.
- Keep the lines of communication open with family and friends. Share your feelings about how you are doing in addition to how your loved one is doing. Those close to you most likely want to know what they can do to help, but they may not ask because they feel uncomfortable doing so, or do not know what to say. Even though it may be difficult, ASK FOR HELP when you need it. If people do not know how to help, think of some specific tasks that they can do. Try to tailor the request to the person offering the help. For instance, if neighbors are uncomfortable being around a person with dementia, ask them for help with getting groceries or running other errands, rather than pressing them to provide respite services (when someone spends time with your loved one so you can have a break). Similarly, if a friend enjoys a more "hands on" role, allow him or her to provide you with respite time to get away for a few hours or days.
- Make sure that legal and financial issues are in order, and include your loved one in the decision-making process as much as possible. Ideally, your loved one will initiate this process in the early stage of the disease while his or her decision-making abilities are still intact.
- Take an active role in your loved one's health care. Form a working alliance with a physician and other professionals who are experienced in issues related to dementia and other cognitive disorders.
- Plan activities with your loved one that you both enjoy and that can be adapted to the person's current level of functioning. Good examples of adaptable activities include walking, taking a drive, gardening, doing household chores, looking at pictures or magazines, watching movies or television shows, baking, listening to music, singing, dancing, and playing cards or other games.
- If your loved one can no longer participate in an activity like he or she used to, remember to relax the rules and definitions of what is "appropriate." For instance, if the person wants to help with household chores, let him fold a basket of laundry. Do not worry about whether things are folded correctly (or that the task is completed quickly). What is important is that he is participating in an activity that makes him feel useful. Likewise, if your relative enjoys playing cards but cannot follow the rules of poker anymore, try sorting a deck of cards into colors and suits instead.
- Monitor yourself for signs of caregiver burnout, such as anger, anxiety, irritability, depression (e.g., a loss of interest in normally fun activities, or feelings of worthlessness, guilt, or

suicidality), social withdrawal, denial about your loved one's diagnosis, denial about your role as a caregiver (e.g., you feel that your life has not changed dramatically even though you have left your job or given up most of your previous activities), extreme fatigue, sleep problems, and/or health problems such as ulcers, migraines, or high blood pressure. To prevent or address caregiver burnout, try joining a caregiver support group, which can provide education, emotional support, and connections to local resources that can help you meet your caregiving responsibilities. See the list of web resources at the end of this discussion for more information about support groups.

If self-coping methods are not working, seek mental health care from a professional who has expertise in addressing caregiver burnout, depression, and grief. If you are having difficulty dealing with some of your loved one's behaviors (e.g., suspicion, wandering), seek out mental health clinicians with expertise in behavior management techniques for individuals with dementia.