

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

Five biggest issues that sabotage the family caregiver

The family caregiver has a very important role be it taking care of children, elderly parents, or any relative. It’s often easy to discuss how they receive little appreciate for the tasks they do and emphasize self-care, which are important topics to cover. It is far more challenging to discus some of the challenges that come with being the caregiver and the struggles that many face.

Finding ways to take care of yourself is absolutely important, but it is often necessary to understand what it is that leaves you feeling so burnt out all the time. Especially when you’re taking care of someone you love and it truly can be such a fulfilling experience in so many ways, that it is hard to see where the challenges may be coming from.

Paula Spencer Scott has identified a few common issues in an article she wrote for caring.com.

Sore point #1: Lack of privacy

Everyone in a caregiving family needs privacy -- the freedom to exist in their own space.

Having physical privacy means having boundaries that let everyone in the house get away from 24/7 interactions. It's especially challenging in small living spaces or when the live-in elder has dementia. The disinhibition (loss of social appropriateness) that can be part of a dementia like Alzheimer's can lead a loved one to barge into bedrooms and bathrooms, for example.

Having mental privacy means being able to continue some version of long-established family time and traditions. While it's important to weave a live-in guest into family life, this needs to be balanced against the risk of alienating kids and spouses who may miss old routines or come to feel ignored.

Lack of privacy: Solutions

- Make necessary home improvements to allow the live-in elder to have his or her own space, not just for sleeping but also for living: a TV set and comfortable chair, a desk, opportunities to get out of the house.
- Establish household rules everyone agrees on for the use of the TV, the kitchen, and other possible points of conflict. Keep in mind, though, that in the case of dementia, rules become less realistic as the disease progresses.
- Remain conscious of maintaining one-on-one time with other family members. Your live-in elder doesn't always have to come first with you; use respite care or other relatives to supplement care.
- Don't put vacations, school or sports events, or other previous family activities on indefinite hold.
- Use locks and a low-key response to help manage disinhibition; explain it to kids so they're not frightened.

Sore point #2: Ignoring sleep deprivation

Sleep problems are often dismissed by caregivers for two common, misguided reasons, says geriatric psychiatrist Ken Robbins. First, they assume that poor sleep is part of aging or of dementia, and that nothing can be done about it. Second, they fear that addressing sleep problems is "selfish," only for their benefit.

In fact, resolving runaway sleep problems helps everyone. The elder whose sleep issues are addressed will experience better mood, more energy, and less pain; sleep is closely connected with all three conditions. And the caregiver who makes his or her own sleep a priority will be better able to cope with caregiving stresses and will have more energy for every part of life.

Ignoring sleep deprivation: Solutions

- First make sure your loved one's basic "sleep hygiene" is in order: No stimulating beverages or activity late in the day. A quiet, dark room. Proper clothing for sleep (elders sometimes nod off in their day clothes). No TV or electronics used in the bedroom at night. Use of a proper, comfortable bed, not a lounge chair. (An elder may "turn in" but never actually get in bed.)
- Next, make sure your own sleep habits are similarly healthy. That 5 p.m. coffee crutch or after-dinner drink…not a good idea.
- If you've done everything you can to create a healthy sleep environment, discuss sleep issues with your loved one's doctor. A mixed-up sleep-wake cycle is not a normal part of aging. It is a feature of dementia (because brain changes can mess up circadian rhythms), but it can often be remedied by a good household routine and by addressing the person's fears to reduce anxiety.

Sore point #3: Lone-soldier syndrome

Caregivers too often fall into "lone-soldier" mode thinking without even realizing it. Feeling responsible for a loved one, they assume the full burden, marching forward without regard to their own emotional needs. Eventual result: one badly wounded soldier who's not much good to anyone.

In reality, it takes a whole army to manage caregiving effectively. Failing to have emotional outlets where you can vent and "be yourself," and failing to let others share the practical burdens, results in a surefire recipe for falling down -- or giving up.

Lone-soldier syndrome: Solutions

- Let go of old ideas that asking for help is a sign of weakness. If ever you needed other people in your life, it's now.
- Join a caregiver support group. Groups offer a level of emotional support and group-think problem solving and idea sharing that's different from what a mental health counselor provides in one-on-one sessions.
- See a counselor if you're experiencing signs of depression. It's no stigma to get help; caregivers (and especially dementia caregivers) are in fact at higher risk for depression.
- Arrange monthly or, ideally, weekly respite breaks.

Sore point #4: Not anticipating what's coming next

Like firefighters, caregivers tend to stomp out one flaring crisis after another. Unfortunately, it's an exhausting way to live and fuels the stressful feeling that your life is at the mercy of an unpredictable force in your home.

"Feeling a lack of control comes in part from a lack of knowledge about what to expect," geriatric psychiatrist Ken Robbins says. "Especially with dementia, being able to step back and see a bigger picture can help you make appropriate plans and then feel more on top of things."

Not anticipating: Solutions

- Make contingency plans. "Live in the moment" is good advice to help you manage stress, but don't do so at the expense of a little advance planning. Once a week, devote an hour to focusing on "if this, then this" scenarios.
- Make lists of your options, or of places and people you can contact to solve potential problems common to your situation.

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- Learn as much as you can about your loved one's condition(s) and how it/they typically progress. Caregivers are sometimes reluctant to "read too far ahead" for fear they can't relate to later disease stages. They're also prey to fear of "jinxing" -- worrying that if they think about something, it might come true.
- Consider a support group. These help caregivers visualize future problems, as they're expressed by other group members.

Sore point #5: Overwhelming care tasks

Perhaps the most difficult home-care deal-breakers are practical matters that go beyond the caregiver's ability to manage. Chief among these: incontinence, heavy lifting, wandering behaviors in someone with dementia. Both urinary incontinence and fecal incontinence, for example, are among leading causes of nursing-home placement. A small or frail wife of a big man who needs help is another tough scenario.

Overwhelming care tasks: Solutions

- Be sure there's been a through physical exam to see if a problem, such as incontinence, is fixable. Adult diapers and toileting schedules, or a change in medications, may make incontinence more manageable, for example.
- For behavioral issues such as wandering, learn the basic ways to address the problem (for example: floor alarms, locks, reducing anxiety) and see if they make a difference.
- Explore whether bringing in more help, such as personal care assistants or nurse aides, can buy time and get you through difficult challenges (such as bathing and dressing).
- Make sure you're not trying to solve the problem alone. Brainstorm possible solutions with other family members, a social worker or geriatric care manager, doctors, and friends -- including virtual ones -- who may have experienced similar issues.

If you’re in need of some outside care taking assistance please take a look at the Eldercare and Childcare Searches provided on this site or call you EAP for further Eldercare or Childcare Search options.