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HOPE
Hospice & Health Services

CareTalk

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Making Time for Self-Care

Anyone who provides substantial care to another person is at high risk of burnout and stress. This is especially true for those who care for people living with dementia because of how unpredictable each day can be. Caregiving is a hard job for family care partners and professionals alike. It is imperative to take stock of one's mental health and stress level, and to dedicate time to whatever rejuvenates you.

Self-care looks different from person to person. For some, it means getting a massage, taking a fitness class, or sitting quietly outside. For others, it's spending time with loved ones, going to church, participating in a book club, or listening to music while on a scenic drive.

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Hurdles to Self-Care

One life category sometimes gets in the way of allowing ourselves adequate time to recharge: chores and errands. When you're spending every daytime hour caring for another person, you tend to put your own needs aside, and these tasks pile up.

It can be hard to enjoy free time when laundry and mail is begging

(See "Self-Care" on page 4)

Assessing Agitation and Aggression

People who are experiencing cognitive decline may exhibit agitation at times, more so as the underlying disease advances. A person who is agitated may ignore someone who is speaking to them, grunt or have other verbal outbursts, refuse to eat, or resist regular tasks like bathing. Agitation can also present as anxious behaviors, such as pacing and fidgeting. There's always the chance that a person is simply having an off day. But usually, something in the body, environment, or routine needs to be addressed.

When a new behavior is observed, first consider pain that the person may be unable to express, illness, or a side effect of a new medication. If a doctor has ruled out a medical reason for the behavior change, the caregiver should look at the person's environment and routine. Agitation is usually related to an umet need. This could be itchy clothes, needing to use the bathroom, soiled undergarments, hunger/thirst, or being too hot/cold. Any alteration to routine can be problematic, such as irregular sleep, mistimed meals, too much noise/activity, or a change in who is providing care and how they do it (for example, changing the order of daily tasks or method of bathing assistance).

Sometimes, agitation is a result of mental health issues or psychotic conditions—either a diagnosed disease such as depression or schizophrenia, or general loneliness, boredom, and fear.

When Agitation Turns Into Aggression

If the person's needs remain unmet, frustration worsens and they may lash out at the caregiver. They may hit or spit. They may stiffen the body or tightly squeeze the caregiver's hand or arm. They may throw food, utensils, or other objects at the meal table. It's easy for a caregiver to take these actions

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Community-based and non-profit, Hope Hospice is accredited by The Joint Commission, certified by Medicare and Medi-Cal, and is a member of the National Hospice and Palliative Care Organization and National Partnership for Hospice Innovation.

Agitation

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personally. However, remember that these behaviors are almost always a patient's desperate attempt to communicate in the only way they can.

The ABC Method

When a caregiver observes unusual challenges in carrying out the daily routine, they should stop and think through some A-B-Cs:

- A means Antecedent. This is what happens just before an upsetting incident.
- B is the Behavior. This is the aggressive action that the patient does.
- C refers to the Consequence. This is what happens after the behavior.

Here is a story about people we are calling Mary and Robert. In this story, Mary is the caregiver for her husband, Robert, who has Alzheimer's disease.

A. The Antecedent. Mary overslept and now is in a hurry. She wants Robert to quickly get out of bed, eat, and get dressed before a driver arrives to take them to Robert's doctor's appointment. Mary yanks off the bed covers and yells at Robert to get up. He does not understand the words but reacts to her tone of voice. Mary gets angry when he pulls the bed covers back up. She yells at him and forcefully pulls him out of bed, then rushes through his dressing. Now he must balance on one leg rather than sit down to pull up his pants. This is not their usual routine when Mary takes her time helping Robert get ready.

B. The Behavior. Robert loses his balance because Mary is rushing him so much. He grabs her arm for support and does not let go. When she yells, he grabs even tighter. Robert is now digging his nails into Mary's arm.

C. The Consequence. Mary loses control and smacks Robert in the face (something she had never done before). He hits her back. Mary thinks he is fighting, though it may be that he is just afraid and doing to her what she did to him. Mary now worries that Robert will hurt her again. She questions whether she can care for him at home.

Let's re-evaluate this story with the ABC Method in mind.

- Mary will make a list of what happened just before Robert's upsetting behavior. She will look for causes of what went wrong.
- Mary can see that the problems started when she rushed and did not think of how Robert would react. Mary learned that because Robert has Alzheimer's disease, he cannot be rushed. While she should not feel guilty, she should realize how her actions made this worse.
- If Mary is ever late again, she will call the doctor's office and ask if they can come later in the day or make a new appointment.

Sources: Alzheimer's Association, Teepa Snow, National Institutes of Health, Comfort of Home for Alzheimer's Disease (CareTrust Publications, 2007)

The Art of Slowing Down

Someone with dementia will struggle to process language. That's both the language coming in (what they hear) and language going out (what they speak). This challenge worsens as the underlying disease progresses. Care partners can make a few simple changes to improve communication.

Limit sentences to one request/action.
Use hand signals.

Here's an example: *John, you've finished your breakfast. Was it good? Let's go to the bathroom for a shower.*

This interaction has three parts: Finishing breakfast, a question about if he liked it, and going somewhere for a shower. That's too much for John to process, and he'll probably just stare at his caregiver in confusion.

Improved communication: *John, you've finished your breakfast – great job!* Remove the plate and return before starting next topic. *John, now it's time to take a shower.* Make hand gestures that show soaping up and washing hair. Pause, and let John compute. *Come with me to the bathroom for your shower.* Repeat washing signs and hold out your hand to John.

Explain what you are going to do before you do it.

It takes extra time for a person with dementia to process what someone is saying to them. Especially when providing personal care, caregivers need to go one step at a time and explain what is about to happen. For example, Sherry needs her daily oral care. The caregiver says, *Sherry, it's time to brush your teeth,* and points to her own teeth and then to Sherry's mouth. The caregiver readies the toothbrush with paste and shows it to Sherry, demonstrating the motion again near her own mouth. Sherry can use the toothbrush on her own with help, so the caregiver gently assists in guiding it to Sherry's mouth.

Source: Teepa Snow

QUICK QUIZ

Read the issue and answer True or False to the questions below.

1. Agitation usually has a trigger.
True or False

2. Fidgeting and pacing can be signs that a patient is agitated.
True or False

3. Someone with dementia may struggle to process what you are saying.
True or False

4. Depression does not cause agitation.
True or False

5. Changing up a routine can cause someone with dementia to become agitated.
True or False

6. Solo activities are the best types of self-care for all people.
True or False

7. Use simple hand gestures that match your speech to help a person with dementia better understand you.
True or False

8. When performing personal care, get the job done as quickly as possible to avoid confusing the patient.
True or False

9. Care providers should consider how their own actions may have caused an upsetting incident involving the patient.
True or False

10. Unusually excessive noise in the home can cause a person with dementia to become agitated.
True or False

Find the quiz answers at the bottom of page 4.

Self-Care

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for attention, there's grocery shopping to be done, the dog needs bathing, and kids' school projects need supervision. In this case, there are only two solutions: pay for help or ask for help.

Anyone who must pinch their pennies will frown at fees associated with restaurant delivery, online grocery shopping, laundry service, and professional housecleaning. But when your mental health is at stake, will that inspire you to budget for some of these services once in a while? Think of what you could do for yourself with the time you save by hiring help in some areas.

If your budget doesn't allow for paid relief, build your own helpful community. Seek out a few friends/neighbors with a shared situation and discuss ways to help one another find time for self-care. This might look like trading hosting duties for kids' playdates to ensure each parent gets a free Saturday off. Are there common errands you can knock out? Is one person a good seamstress for the group while another can cook bulk meals in advance?

Support Groups

Support groups are helpful for many because they connect people who have a shared experience. If a friend has tried to show sympathy to you and you felt like saying, "You just don't understand," you may benefit from attending a support group. Hope Hospice has a group specifically for family caregivers of loved ones with dementia. You can also find groups through MeetUp.com, a senior center, the Family Caregiver Alliance, and the Alzheimer's Association.

Senior-Care Education

Hope Hospice is committed to helping our community offer the best care to seniors. Our experts are available to present complimentary educational seminars to professionals in the medical field and to the public. If you oversee a team of care providers who would benefit from a refresher on such topics as hospice, best practices in dementia care, or any of the other subjects listed at right, please connect today to discuss your needs. We can tailor certain lectures to the layperson and conduct seminars for residents of senior living communities, church groups, and the like. We are available to present in-person at your facility or over Zoom.

Fall Prevention

Hope Hospice is a 501(c)(3) non-profit organization.

Available Topics

- Agitation/terminal restlessness
- Advance healthcare directives
- Body mechanics
- Dementia care
- Fall prevention
- Hospice education
- Infection control
- Medication administration
- Nutrition for seniors
- Pain in the elderly

Connect With Us

Contact Delinda Brown, Director of Outreach, to discuss your group's needs. (925) 829-8770; delindab@hopehospice.com.

Answers to Quiz on page 3: 1) T; 2) T; 3) T; 4) F; 5) T; 6) F; 7) T; 8) F; 9) T; 10) T