

Stress in Caregiving

The stress associated with being a primary caregiver, whether for a child or a parent, is a topic gaining deserved attention. In fact, finding the right healthcare for your loved one can leave you feeling like you need to visit a doctor as well. Caregiver strain is defined as the stress and problems that people experience when caring for a family member with health issues. The type of stress you may experience is dependent on the type of health care system you are dealing with.

Under managed care, caregiver strain was related to provider/payer related barriers to care. In the fee for service system, strain was linked to family perceptions about the care they were receiving and inconvenient appointment locations and times. Other things that affect both systems are barriers to care and poor service coordination.

Women traditionally take on the role of caregiving in our families. Usually when children have grown and are gone attention is usually turned to failing parents or relatives. Not every caregiver or “helper” feels she has a choice in taking in that parent or relative. By the same token, not every elder feels she has a choice about where she will spend her last years. Although adults in midlife may need to bring an aging family member under their roof, these individuals do have choices about how they will each handle this challenging situation. Taking care of an elder is really about the elder and helper taking care of each other through what can be a very difficult time. Those relationships that are able to thrive are the ones where people understand that there has been a cordial give-and-take. When people are gentle with each other, opportunities for love and understanding emerge and enrich the years they share.

There are a number of issues that are common to all such helping relationships: Communication is the key. Often elders don't communicate fully because they worry about being a burden or too demanding. Grateful to be cared for, they don't feel entitled to ask for what they feel they need. Other elders were never particularly good at communicating and find it even more difficult now that they have to depend on someone else. Often “helpers” tend to frustrate communication because they are in a hurry or they are overwhelmed. A successful caring relationship requires both parties make an effort to listen carefully, and state things clearly. Assumptions about meaning only lead to trouble. Seek first to understand, and then be understood.

People in helping relationships find themselves dancing around needs. The elder may feel so bad about imposing that she may not state what her needs actually are

or she may feel so bitter about needing that she becomes bossy. More confusing still is the elder that goes through the entire range of feelings. Some helpers assume they know what the elders needs are and are hurt when the elder isn't properly grateful. Others feel so helpless in the face of so much neediness and don't have a clue about what to prioritize.

Privacy is another issue. When an elder is cared for by an adult for whom they provided care during childhood, roles are embarrassingly reversed. It doesn't feel natural to either party for a child to bath, change, and dress a parent or older relative. The elder may withdraw or she may become angry at the whole situation. The "helper" may be embarrassed and awkward or may be overly rough in wanting to move through situations that create discomfort.

Lack of activity can also be a stressor if an elder is house and/or bed bound. Conversations are more difficult to keep going and conversations tend to center around health, food, and weather. It's no fun being the last to hear on news or what is going on around them.

In the intimacy of a caregiving relationship, it can be difficult to know where one person's responsibility ends and the other person's expectation begins. Boundaries should be set up and discussed so that each knows what can and cannot be done to make things go smoothly.

Elder and helper both will also have to deal with systems outside of the family structure, including the health care system, the Social Security System, and the various systems that need to be used for assistance. Often getting what is needed is challenging for the most educated and stouthearted. For those who are shy, overwhelmed, or simply confused by the complicated regulations and guidelines of these systems, getting help can be a daunting task.

For many families there comes a time when they question whether they can continue to care for their loved one at home. Simply contemplating this shift can cause feelings of ambivalence and guilt. Anticipating relief from primary caregiving can also trigger feelings of self-recrimination and grief. It's a normal but often unarticulated response.

When we are living a story that is not of our choosing or different from the one we have written in our head, it is time to grieve. There is grief for the elder who can no longer be at home and grief for the caregiver who may have reached new limits. If it has been your intention and life goal to care for your loved one in a family home until

the end of life, it is important to allow everyone to grieve this change when you realize home care is no longer possible. It may be necessary to mourn one dream in order to birth another one.

Before you initiate conversations with the elder, you may want to talk through the idea with siblings, professionals, and friends who can be there for you during this time of transition. Leaving and grieving home may require you to have additional emotional support and help in looking at what alternatives are available to you and your loved one.

Once you as the caregiver are clear that home care is no longer possible, it is time to initiate the conversation with the elder (if such conversation is possible). Talking honestly about the facts, the observations, and the concerns that you have as a caregiver enables the elder to hear why this move is necessary.

This is also a time to ask what the elder wants or needs and gives the person a chance to voice any fears or concerns. How can the elder be assured that being placed in a facility won't feel like abandonment? First you can review instances when you as the caregiver have responded to needs and wants in the past, and then you can reaffirm your commitment to doing so in the present and the future.

As the primary caregiver who chooses to initiate this shift, you may find it helpful to consider how the idea of home can be lovingly reframed. First of all, where a family member sleeps isn't the whole definition of home. Home is a word that can refer to the family we belong to as well as the building we reside in. When we speak of someone "coming from a good home," we aren't referring to the physical structure. So, creating home can also be a furthering of the relationships that have nourished us throughout our lives. Home can be created wherever someone lives.

As you look at the possibilities for different living arrangements such as assisted living facilities, nursing homes or hospitals, know that new opportunities will arise for co-creating as family. Co-creating means that you are asking, listening, responding, and then creating based on what you have heard.

When my father-in-law was placed in a nursing home his last nurse, Angel, told me how fortunate she was with her current case load because every resident had a family that was involved in their care. Angel said her job was so much easier and joyful when families found ways to stay connected, support and care for their loved ones even though they were in an institution. She pointed to the resident in the next bed. The elderly man's daughter had purchased a special phone with very large

numbers so that he could use the phone unassisted. Angel's face lit up as she talked about each family and their unique way of keeping connected with their elder. Predictable and frequent visits, small celebrations, massages, manicures and pedicures were some of the many ways she saw families nurturing their elders. I have found that nurses, aides, and caregivers relish telling stories that illustrate the power of family love and creativity.

Just because your loved one lives in a different building doesn't mean you will stop being a caregiver. When your elder is in a home or in an institution, you will have the opportunity to advocate for them and monitor their care. Your energy will continue to go to the elder but will also shift to include *intentionally developed relationships* with the caregivers in the institution. Relating to the new primary caregivers involves orchestrating a fine balance of being vigilant, saying what needs to be said, and honoring the jobs that they are doing. Establishing and maintaining good relationships with caregivers can greatly benefit those in their care.

Although home-based care might have been the goal for the last chapter of your elder's life, moving your loved one into a home or institution may prove beneficial for all concerned. With your loved one will receiving round-the-clock care, you will be free to give new kinds of support both to your loved one and to those ministering care.

Presented below are **20 Practical Tips** for finding the best residential care for your relative. These tips will help you focus your attention and your thoughts as you make your way through the process.

1. **Know your options.** To begin your search, educate yourself on the various levels and cost of care. In general, your options include Retirement Communities/ Independent Living, which may offer communal meals and activities for more independent residents; Residential Care Facilities (RCFEs); and Skilled Nursing Facilities (SNFs). Residential Care Facilities include small six-bed Board and Care Homes as well as larger Assisted Living Facilities. The RCFEs are licensed by Community Care Licensing through the State Department of Social Services, and provide, for the most part, nonmedical assistance. Nonmedical assistance includes help with activities of daily living (bathing, dressing, eating.); and "instrumental" activities of daily living (preparing meals, taking medications, etc.). Some care facilities include special units for people with dementia. Persons who qualify for Skilled Nursing Facilities typically require 24-hour nursing supervision and are confined to a bed for some portion of the day.

2. **Make Use of Resources.** FCA's Fact Sheet on [Residential Care Options](#) is a beginning guide to understanding care options, type of care provided and cost. For additional information on levels of care, cost, or how to evaluate a facility call California Advocates for Nursing Home Reform, (800) 474-1116 or visit their website (www.canhr.org). CANHR also has a comprehensive, up to date, online guide to over 7,000 facilities in California, including nursing homes and residential care facilities.

3. **Consider what is most important to you and your relative.** For many families, being nearby is a major criterion in the decision making, so you can visit your loved one frequently and easily. Understanding the general atmosphere of a facility and services that are important to your relative is essential. For example, it might be important for your parent to bring his/her pet to the care facility. This is not an unusual request, and some facilities will accommodate it. Some people require a wide selection of daily activities to choose from, while others might not have this need. Narrow your search based on what is most important to you and your family member.

4. **Use your informal resource system.** First-hand information on residential care facilities and nursing homes is invaluable. Don't hesitate to ask friends or support group members if anyone can recommend a care home. Day care providers, hospital discharge planners, or community care nurses are also excellent referral resources.

5. **Contact a Private Placement Service.** A placement service can help you focus your search and recommend a few facilities that match your income and the needs of your relative. To locate placement services in your geographic area call Family Caregiver Alliance (800) 445-8106 or your CRC in California. Your local Area Agency on Aging or senior center may have information. There is no fee to you for a placement service, although they may collect a commission from the facility, and there is no obligation to move your loved one. Quality referral services are very familiar with the facilities that they list and are in contact with the families of the residents. This service provides you with another level of screening and facility accountability. Most placement services, however, only work with moderate to higher-cost facilities.

6. **Visit a few care facilities before you are in a crisis situation.** It's always best to be prepared. Knowing your care options before you are in a crisis situation is very helpful and might ease your fear about moving your loved one. You might also be pleasantly surprised at what you find!
7. **Make an appointment with the administrator.** Come prepared to your interview with lots of written questions. If you are interested in the facility, make a second, third and even fourth visit at different times of the day. You especially want to observe meal time, whether the food is appetizing and healthy, and how participants are accommodated. If you are not invited to visit at anytime, unannounced, you might want to rethink that particular facility. Most residences have an open-door policy for families and friends. For a comprehensive list of interview questions, call CANHR or visit their website. (See Tip 2 for [contact information](#).)
8. **Be prepared for a swell of emotions.** Your first visit to a facility might bring up a strong emotional reaction. Be prepared to see residents with varying levels of impairment. You might want to bring a friend or another relative with you for support and/or to help you remember the questions you would like to ask.
9. **Observe the general environment.** Is there a cheerful, warm interaction between the staff and the residents? Does the administrator know the residents by name? Do you feel welcomed? How clean is the facility? Do the staff and administrator seem comfortable with each other?
10. **Appearances aren't everything.** Spend time speaking with the staff, other family members and residents. Ask what they like most about living or working at the facility and what they like least. Recognize that if your relative moves to this facility, these are the people with whom you will be developing important relationships.
11. **Is the facility licensed?** Every facility must have their license displayed. The license lets you know they are registered with the State Department of Social Services and meet state requirements. There should also be an Ombudsman Program poster displayed. Each licensed facility is assigned a person from the state?an ombudsman?to investigate and try to resolve complaints made by, or on behalf of, individual residents.

12. **Does the facility have a dementia waiver or hospice waiver?** Residential care facilities are not required by state law to have a dementia waiver. Facilities with a waiver, however, are required to train staff on care for individuals with dementia to safeguard against accidents and wandering. If your loved one has dementia, it might be very important to you to look for a facility that has a dementia waiver. More and more residential care facilities are now licensed to have hospice services come into the facility to care for a resident who is terminally ill. In this way, care is not disrupted and you and your relative do not have to adjust to a change in environment. This is a wonderful new development and benefits both the care receiver and the caregiver.
13. **Cost.** In addition to the average monthly cost for an RCFE (which can range from \$1800 - \$4,000+ a month), the family is responsible for incontinence and personal care products. There are also usually add-on costs, which might include help with bathing, dressing, eating or incontinence. You might want to ask how often the rates are increased; how much notice is given before an increase; and how it's determined when someone is to be advanced to the next level of care. Typically, there is a change in cost when the next level of care is needed. RCFEs are "private pay" only?which means they do not qualify for Medi-Cal coverage. Most SNFs, on the other hand, accept Medi-Cal for qualified individuals. Medicare only pays for a short-term nursing home stay for rehabilitation purposes. The average cost for a nursing home in California is approximately \$4500 per month for a private room; some cost even more. Your family consultant can help with a referral to an elderlaw specialist to discuss planning Medi-Cal eligibility in case a nursing home is necessary in the future. (See FCA's Fact Sheet [Legal Issues in Planning for Incapacity.](#))
14. **Be up-front about your situation.** If your mother sometimes refuses her medication or a shower, let the administrator know. This is also an opportunity for you to ask how the staff might handle these behaviors. Remember, your role is to try to make the transition for you and your family member as easy as possible. If the facility's philosophy of care does not agree with your philosophy, this is probably not the right facility for your family.
15. **Staffing Patterns and Staff Retention.** A good staff ratio during the day shift in an RCFE is one direct staff person to eight residents. This does not include the activity coordinator, program director or on-call nurse. Fewer staff are needed on evening and night shifts. In a small Board and Care Home, the

required ratio is two staff to six residents. However, Board and Care Home staff are usually responsible for cooking and cleaning as well as resident care. To get a sense of the satisfaction level of the staff, you might want to ask how many employees have been with the facility for more than one year.

16. **Is there a perfect situation?** Personal care and attention to individual needs should be a major priority in choosing the care home for your relative. If you find something lacking at a facility (outside of personal care), it might be possible for you to supplement what is missing. For example, you could take your relative out to a beauty shop if there isn't one on-site, or volunteer to call bingo if you believe there are too few activities. Typically, more expensive facilities will have more amenities and special features.
17. **Changing your care home.** Sometimes caregivers discover that their first facility choice is not a good match for their relative. Now that the family knows what is most important to their relative, they can be more successful when choosing another site. Although we recommend you work with staff to help your relative adjust to their living situation, we also encourage you to trust your instincts. If you believe there is a better living situation for your loved one, make the move.
18. **Helping your relative adjust.** Although there is a brief social history of your relative taken during the intake process, you should supplement this information with your own "Personal Profile." Include information about the care receiver's occupation, place of birth etc., as well as information on the care receiver's parents and siblings. Don't forget to include what has made them unique in the family; their special attributes, hobbies and contributions. You might even choose to create a wall poster with pictures from your relative's past, with brief subtitles under each picture. Staff will then become familiar with your relative's history in a positive way. Knowing someone's past is the key to developing rapport and a trusting relationship with the staff. When trust is established, your parent is more likely to feel comfortable at his or her new home. Also provide staff with a written description of your relative's typical day. Write down your relative's daily schedule including sleep time, bathing schedule and preference for time of bath and meals. Also let staff know if your relative would prefer a male or female caregiver to provide personal care.
19. **You are still the caregiver.** Even after you move your loved one, you are still the caregiver. If the administrator and/or staff suggest you no longer need to

be involved in care decisions, ask yourself if this is the environment you want. Remember, you might not be providing the hands-on care (although you should still have the option of doing this if it is important to you), but you will always be your relative's advocate and care manager. Your role shifts, but is still vital to the health and well being of your loved one.

20. **Take Care of Yourself.** Although everyone's experience is different, moving a relative to a care facility might be the most difficult decision you will have to make as a caregiver. When making the transition from home to a community setting, reach out to people who understand and will support you. Don't hesitate to call Family Caregiver Alliance to speak with your Family Consultant, join a support group, or contact a private counselor or clergy member. Try to rest, eat well, exercise.

Research suggests that the first months may be the most difficult, but once your relative is situated and you have developed a relationship with his or her caregivers, you will experience a long over-due sense of relief. Keep in mind that often the care receiver does very well with the move. After all, their social and physical needs are being accommodated 'round-the-clock. You have the opportunity now to enjoy spending time with your relative in a new way, free of the 24-7 demands of caregiving.