

Complimentary Resource

**52**

**Nonnegotiables  
for  
Family Caregivers**

*Presented by:*

**Deborah S. Greenhut, PhD**

**© 2024 Creative Room for Learning**  
*All rights reserved.*

# Introduction

- ▶ Before you take on the role of family caregiver, you have an opportunity to voice your own needs in the relationship you will form. Taking a rational approach like this will help you to think about what you will and won't agree to do or live with. People who do this can negotiate more effectively with family members and service professionals because these nonnegotiables create your much-needed bargaining chips.
- ▶ Remember: What you tolerate, you teach. If you permit people to exceed your healthy limits, in other words, they will learn that it's acceptable to do so. If you think about what this means for your future as a caregiver, you will recognize an overload from a distance and prevent it from happening. Many people are not aware of what it means to be a 24/7/365 caregiver, so you can forgive the ignorance, but you don't have to start off accepting that as your new lifestyle.
- ▶ First, let's look at areas of the caregiving life that create opportunities for negotiating. Here are what I consider six major considerations that create a foundation for a Rational Caregiver's Schedule:

- 1. Personal Health and Well-being:** Physical and mental health are essential to provide effective and sustainable care. A well-rested caregiver can perform their duties more efficiently and with a positive attitude. Post August 2, 2024
- 2. Quality of Care:** Highlight that a structured schedule allows caregivers to offer consistent, high-quality care, reducing the risk of errors and improving the overall well-being of the care recipient.
- 3. Preventing Burnout:** The rotary is a better model than the one-way street. Stress arises when there's no one to delegate too and no exit from a traffic circle, and this leads to burnout.
- 4. A reasonable schedule** helps prevent burnout, ensuring the caregiver remains capable of performing their duties long-term. Burnout can lead to mistakes and health issues, which ultimately affect everyone involved.
- 5. Time for Personal Goals:** Advocate for the necessity of personal time to pursue hobbies, education, or social activities. This balance enriches the caregiver's life and prevents feelings of resentment or frustration.
- 6. Flexibility and Adaptation:** Argue for a flexible schedule that can adapt to changing needs and emergencies, ensuring that the caregiver can manage unforeseen circumstances without compromising their health or the care they provide.

# A GUIDE TO PROTECTING YOUR WELLBEING

- *Next, I'll give you 52 Nonnegotiables that caregivers can include in caregiving agreements. There will be some obvious overlaps, but I list items separately in this much detail so that people can brainstorm about their individual circumstances.*
- It's wise to anticipate as much as possible as changes frequently happen in your caregiving journey.
- You may not get everything you want in an agreement, but reviewing this information can help a family or group understand the caregiving situation better upfront to avoid conflict later. Many people begin caregiving with the idea that they'll just add on to things they are already doing for themselves. They quickly find that taking care of another person involves a great deal more than "adding-on," and the feeling of being drained can result quickly.

# THE 52

- 1. Negotiation is necessary.** Working out and stating an understanding of what you will do and are expected to do is critical to the success of your caregiving assignment. Unspoken assumptions are potential minefields that a *pre-caregiving agreement* can disarm. It doesn't have to be adversarial, but it does need to be mutual, or it won't work.
- 2. Design a Schedule that Accommodates the Caregiver and the Loved One:** Surprises can happen any time, but the things you do not schedule can cost you time in the long run. This means gathering much information before you design your system.
- 3. Clear Expectations:** Define and agree on the scope of responsibilities and duties.
- 4. Fair Compensation:** Ensure fair and timely compensation for caregiving services. If the caregiving is being offered by one family member and funds are scant, how will others help out to make sure one person isn't sacrificing for everyone else?
- 5. Scheduled Breaks:** Provide regular and adequate breaks to prevent burnout.
- 6. Respite Care:** Arrange for backup or respite care to give the primary caregiver time off.
- 7. Training and Education:** Offer necessary training and education to perform caregiving tasks effectively. Caregivers are often asked to operate medical technology, deliver specialized medications, swap IV bags, and other paraprofessional tasks. What needs to be taught up front before the caregiving begins, and how will new tasks be scheduled for training in the future?
- 8. Work-Life Balance:** Respect the caregiver's need to balance work and personal life—this includes hobbies, exercise or recreation, visits with friends, other family, children and grandchildren.
- 9. Support System:** Provide access to a support system, including counseling and support groups. What support will non-caregiving or remote family members offer?
- 10. Health and Safety:** Ensure a safe working environment for the caregiver. What structural adjustments need to be made to the home? If the patient is suffering a mood disorder or dementia, how will behavioral changes be accommodated to protect the caregiver? What steps will be taken to monitor the emotional well-being of the caregiver?

**11. Communication Channels:** Maintain open and effective communication with the caregiver. Does the caregiver need training in technologies that can help? What are the voice and visual tools that can help? Can all parties operate smart devices or computers? If the caregiver is managing medical information, can she or he navigate the medical providers' portals, or do these need to be added to #7 above?

**12. Resource Access:** Provide access to necessary resources and tools for caregiving. Smart devices, subscriptions to information sources, technology, and money- and time-saving devices.

**13. Legal Protections:** Ensure the caregiver is protected by appropriate legal agreements and insurance. If instruments like Powers of Attorney or Guardianship are needed, these should be developed and assigned as soon as possible. Liability, health, and life insurance for the caregiver and loved one should be considered. Education on what's covered by health insurance policies is essential.

**14. Conflict Resolution:** Establish clear procedures for resolving conflicts and grievances. Plan ahead to have a process that protects everyone's interests. Are there conditions that the caregiver finds unacceptable? How might these be resolved? If other family members disagree with a caregiver's decisions, how will these disagreements be resolved? A caregiver should consider what they will tolerate and what not. Certainly, hospital bedside conflicts (about treatments, when to stop curative treatments, DNRs, and the like) can be upsetting and counterproductive. How will the family resolve potential religious or ethnic conflicts about treatments or palliative care or funeral customs? Is the caregiver aware of what the loved one wants? If he or she is the health care proxy, it's best to know the patient's wishes, for the proxy will have to represent these interests to the medical providers. What if the conditions can't be met?

**15. Respect:** Show respect and recognition for the caregiver's efforts and contributions. This is an area where many families fall short. What signs of respect would the caregiver recognize? Some suggestions: inclusion in medical and social decision-making discussions; consideration of the caregiver's time and energy when making requests; appropriate notice for changes, and so on.



**16. Emotional Support:** Provide emotional support and understanding to the caregiver. What does the caregiver want and need? Be available to listen and provide emotional support to the caregiver. Who in the family will take on the role of comforter?

**17. Workload Management:** Ensure the caregiver's workload is manageable and not overwhelming. This system especially should be developed from the caregiver's point of view.

**18. Health Monitoring:** Monitor and support the caregiver's physical and mental health. Allow for time and transportation (if necessary) to make the necessary medical appointments for the caregiver.

**19. Professional Development:** Encourage opportunities for professional development and growth. These can be about caregiving skills or keeping the caregiver's other professional skills and licenses current if the caregiver is working or plans to return to the workforce.

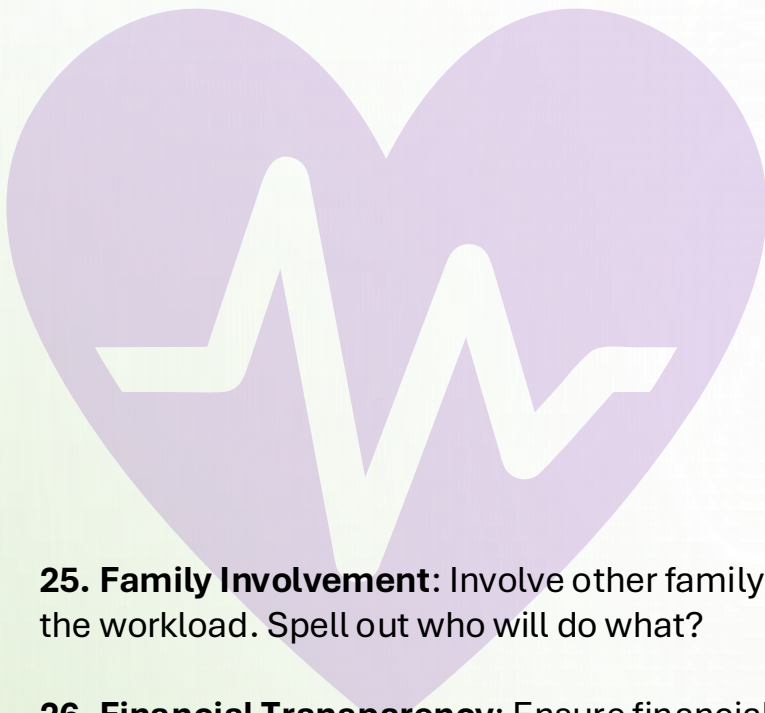
**20. Flexible Scheduling:** Offer flexible scheduling to accommodate the caregiver's needs. Even with the best-laid plans, illness and disability, along with car maintenance and other household emergencies can compete with getting things done. Backup is necessary and accommodating healthcare professionals need to be chosen wisely. Will someone else in the family step in if the caregiver is unable to keep all or part of the schedule on a given day?

**21. Privacy and Boundaries:** Respect the caregiver's personal privacy and boundaries. The caregiver is neither a possession of nor a servant to the family. Caregivers deserve protection for their own space, time, and feelings.

**22. Emergency Protocols:** Have clear protocols in place for emergencies involving the caregiver. These can range from household to health emergencies; clear explanations of responsibilities for the loved one in an emergency should be spelled out as well.

**23. Feedback Mechanisms:** Establish regular feedback mechanisms to address concerns and improvements. How will the family communicate to avoid misunderstandings or worries about performance?

**24. Role Clarity:** Clearly define the caregiver's role and responsibilities to avoid misunderstandings. Caregivers cannot do everything round the clock; their primary role is to manage the "everything" so that it all gets done. Who else is on the team, and what are their roles?



**25. Family Involvement:** Involve other family members in caregiving duties to share the workload. Spell out who will do what?

**26. Financial Transparency:** Ensure financial transparency in caregiving expenses and compensation. Who will contribute to financing the effort? How much? How often? Who will cover unexpected expenses? Compensation? Health or accident insurance for the caregiver and the loved one? Food? Clothing? Housing? Respite care for the caregiver? Relocation of the loved one to a facility if circumstances warrant?

**27. Regular Reviews:** Conduct regular reviews of the caregiving arrangement to make necessary adjustments. What checklist will be used? Who will conduct the review?

**28. Provide Respite Care:** Offer to take over caregiving duties to give the primary caregiver a break. Who can be counted on to take over? Who will finance a break for the caregiver?

**29. Financial Assistance:** Contribute financially to caregiving expenses or pay for specific needs like medical supplies or services.

**30. Meal Preparation:** Cook and deliver meals for both the caregiver and the care recipient. It helps to decide ahead of time if the caregiver is providing meal service or not and be sure prep, serving, and cleaning up time are included in the schedule.

**31. Household Chores:** Assist with cleaning, laundry, and other household chores. Again, are these chores part of the caregiver's schedule?

**32. Transportation:** Provide transportation for medical appointments or errands. Whose vehicle will be used? Will transportation be reimbursed? Is public transportation safe? Are there services in the town or county that can help? Are there at-home services that can be used? Telemedicine? Are they covered by healthcare insurance?



**33. Sharegiving:** An evolution of family caregiving that includes a circle of help rather than a one-way street without houses. There are plenty of on-ramps for people to provide intentional acts of kindness at the caregiver's discretion. If we don't share the labor this time, we're at risk for not having caregivers when we need them.

**34. Errands:** Run errands such as grocery shopping, picking up prescriptions, or other necessary tasks. Who can agree to help, say, weekly or on short notice?

**35. Medical Appointments:** Accompany the care recipient to medical appointments and take notes. These need to be added to the schedule.

**36. Social Engagement:** Spend time with the care recipient to provide companionship and reduce the burden on the caregiver. Who in the family will offer more than a short visit? How much notice would the caregiver be given to protect the schedule?

**37. Financial Management:** Help manage finances, pay bills, and handle insurance paperwork. Will the caregiver manage these? If so, time should be allowed in the schedule—these cannot be an add-on or “overtime” consideration.

**38. Home Maintenance:** Assist with home repairs and maintenance tasks. Who will help or how will these tasks be compensated?

**39. Care Plan Meetings:** Participate in care plan meetings and decision-making processes. These need to be scheduled at convenient times for the caregiver.

**40. Education and Training:** Educate themselves about the care recipient's condition and care needs. Other family members need to be kept up to speed on changing conditions, not to “police” the caregiver but to make appropriate suggestions.

**41. Specialist Appointments:** Arrange and attend specialist appointments if needed. Beyond routine appointments, if these are the home caregiver's responsibility, who will help by attending and communicating new routines or medications as necessary?

**42. Advocacy:** Advocate for the care recipient's needs with healthcare providers and other professionals. Who will be the primary link—the caregiver or another family member? How will developments be communicated to the caregiver and other family members?

**43. Legal Matters:** Assist with legal paperwork and matters such as powers of attorney and wills. Does the caregiver have a legal background? If not, is there another family member who does, or will an attorney be hired to help the family? If funds are limited, what resources are available to help the family?

- 44. Technology Assistance:** Set up and manage technology for the care recipient, like medical alert systems or communication devices. Is there a family member available to help if caregiver is not tech-savvy, or someone else who can be hired?
- 45. Organize Support:** Help organize and coordinate support from other family members, friends, and community resources.
- 46. Exercise and Activities:** Help the care recipient with physical activities or recreational pursuits. Is this a particular strength of the caregiver, or should it be delegated?
- 47. Monitoring Health:** Share in monitoring the care recipient's health and well-being.
- 48. Crisis Management:** Be prepared to step in during emergencies or crises.
- 49. Childcare:** Provide childcare for the caregiver's children if needed.
- 50. Grocery Shopping:** Regularly take care of grocery shopping or order groceries online.
- 51. Information Sharing:** Keep other family members informed about the care recipient's condition and needs.
- 52. Appreciation and Recognition:** Show appreciation and recognize the hard work and dedication of the primary caregiver.

***\*\*\*These contributions can significantly reduce the burden on the primary caregiver and ensure a more balanced and supportive caregiving environment.***

**For best results, spell out your working conditions in a pre-caregiving agreement.**

**You won't be sorry if you state them all up front. If the family can't agree to everything, you still have a choice about taking the job, but no one can say you didn't explain your needs if you cannot do it all.**

**THE BEST TIME TO NEGOTIATE IS WHEN YOU BEGIN CAREGIVING.**



**Complimentary Resource**

## **52 Nonnegotiables For Family Caregivers**

*Contact:*

Deborah S. Greenhut, PhD

Call: 323-510-8816

Website: [www.deborahgreenhut.com](http://www.deborahgreenhut.com)

