TIMELY RESOURCES CARE GUIDE SERIES:

COPING WITH THE STRESS

An informational workbook and
think-book for caregivers

How can you travel the caregiving journey and stay as healthy as possible?

Use this workbook to help you manage the stress that can come with caregiving.

This is YOUR workbook and think-book.

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INTRODUCTION

Do you provide help to an older relative or a friend? Do you find your caregiving responsibilities increasingly overwhelming? What is the state of your physical health? Your emotional health? Are you ignoring or setting aside your own health care needs because of the intensity of your caregiving?

What about your care receiver? How is your relationship? Is the care receiver compliant or argumentative, or somewhere in-between? What is going on in each of your lives? Each situation is different.

Primary caregivers frequently ignore their own physical and emotional needs. There may not be enough time for one more appointment. (*You may not have the energy for one more appointment*.) Finances may be prohibitive especially if you are helping to support your care receiver. Taking care of yourself while caring for others can be just too much to deal with.

Many caregivers find themselves virtually homebound by their duties, consumed by providing care to a loved one. The caregiver's only outlet may be to go to work, only to rush home afterward to resume providing care. They may need to stop at the care receiver's home or the caregiver and care receiver may live together. The after-work time may be reserved for grocery shopping, picking up prescriptions, care receiver appointments – any number of necessary tasks.

When this goes on for months and years, caregivers may ignore or set aside their own health care and emotional needs. (This is NOT good for us!) Research supports that a higher mortality rate exists for those caregivers who report stress, burden and depression that have resulted from their caregiving roles. Caregivers wear down. They become exhausted. Nutrition suffers. Health decline can spiral downward for the caregiver.

This booklet will discuss stress and how you can manage it while caring for a loved one. It is important to remember that caring for yourself is just as important as caring for your loved one. Ignoring your needs is not only harmful to you but also to your care receiver. Many nursing home placements occur because of the primary caregiver's exhaustion, failing health, illness or death.

Taking care of ourselves while we take care of others helps us get to the other side of caregiving in such a way that we can heal and move on.

Another factor in self-care is learning as much as you can about the care receiver's health, prognosis, supportive service options, and what resources can help you with your caregiving responsibilities.

Altenheim Resource & Referral Services is dedicated to empowering older adults, caregivers (family and professional), and their advocates through information, education, and support. We hope that the information contained in this booklet will help in that goal and offer guidance that will make the journey a little smoother.

I'd like to offer my thanks to my long-time friend and colleague Patricia L. Henderson, M.S., L.P.C. for proofing, editing, and making suggestions. It's not our first rodeo and the insight of her experience was invaluable.

For more information on caregiving or on community resources, contact Altenheim Resource & Referral Services through our website at https://www.altenheimcommunity.com

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POINTS TO REMEMBER

In general:

- ♥ The person that receives care may have physical, cognitive, or mental health challenges or any combination. They may have varied abilities. They may be any age. All of these factors and whatever else is in the care receiver's world, will impact the caregiver/care receiver relationship and the degree of challenge of caregiving.
- ♥ Accessibility, availability, appropriateness, and affordability of services are factors in the independence and safety of the care receiver, and the practicality of how long someone can age in place.
- ♥ Families often live too far away to help. This doesn't mean they are uninterested in their family but their circumstances may prevent them from helping in the way we want them to.
- ♥ A family member may not be able to do hands-on care but they may be able to do some other task that will be helpful to the primary caregiver. See if that's an option in your family.
- ♥ Some family members will not help and no amount of begging, pleading, or guilting will change that. Accept it and move on.
- ♥ Medical care is increasingly specialized and connecting all the medical information and specialists is more challenging. There is a need for communication overall in the health care system. Make sure your records are current. Many information systems are connected with the consolidation of medical systems (ie: WVU, UPMC).
- ♥ Quite often, the primary caregiver gets lost in the system. There is a need to recognize the caregivers who waited in the chair by the bedside of their loved one.
- ♥ There are caring, dedicated health care professionals and there are those who cause frustration and anxiety with caregivers and care receivers alike. Check on options for changing health care providers.
- ♥ Caregivers can smooth the transition into long term care by helping the staff learn who the care receiver is. This makes the transition less difficult for the caregiver, the facility caregivers, and the care receiver.
- ♥ Caregiving responsibilities change as the care receiver moves through life's journey
- ♥ Learning about the care receiver's disease and the services that are available can lessen your caregiving burden.
- ♥ "Hoping for the best, prepared for the worst, and unsurprised by anything in between" Maya Angelou

For caregivers:

- ♥ Be aware of a service's limitations, discharge policies, staff training, costs and billing processes.
- ♥ Keep a record of appointments, tests, health care professionals' contact information and specialties; know who your health care allies are (is it the doctor, the Nurse Practitioner or the office administrator?), and keep records of medications and pharmacy information. Take your documentation with you to health care visits. Keep documentation current. Make sure the office's records regarding the medical history is accurate.
- ♥ Have insurance information available (Medicare, Medicare Supplement or Advantage plan, Part D information)
- ♥ Talk to your care receiver about their end-of-life and care preferences.
- ♥ Make sure that legal arrangements have been made: medical and financial powers of attorney, living will, and will.
- ♥ When the care receiver goes to long term care, accept that you are no longer the hands-on caregiver. Your role will change to historian, health care advocate, social connection, and mediator for possible issues.

You will find a ♥ beside additional Points to Remember throughout this booklet.

It all begins with you.

If you do not care for yourself, you will not be strong enough to take care of anything in life.

*Quite often a "caregiver" does not self-identify as a "caregiver". They look at the job they are doing as their responsibility as a spouse or child. They are just "helping a friend or loved one". If you provide assistance to someone, you **are** a caregiver.*

WHO ARE CAREGIVERS?
WHAT DO THEY DO?

A *caregiver* may be a son or daughter, a spouse, a sibling, a grandchild. They may be a neighbor, a close friend or a distant relative. A caregiver may be young or older.

The *care receiver* may have physical challenges, cognitive challenges, mental health issues or they could have multiple diagnoses. They could have multiple challenges. The care receiver may be a parent, a child, a friend. They may be any age.

♥When you've seen one caregiver, you've seen ONE caregiver. When you've seen one care receiver, you've seen ONE care receiver. We are all different just as our situations are different.

Caregivers may have the responsibility of children, a job, a spouse, and maintaining a home in addition to caring for the care receiver. Older caregivers may be adjusting to age-related changes including retirement, reduced income, declining health, widowhood, or alternative housing arrangements. There may be grandchildren for whom the caregiver is responsible.

A caregiver may be a young person who helps a family member or they may be helping a parent who has issues with mental health or addiction.

A caregiver may have help or may be providing all the care by themselves.

At any age, there are most likely plans and goals that have been interrupted, postponed or given up due to caregiving responsibilities.

Caregivers may feel a loss of dreams. Caregivers may have been planning trips. They may have had educational goals or career goals. They may have anticipated time with children or retirement to a different area. So many caregivers have said, "It wasn't supposed to be this way." The changes that came about weren't anticipated. Whether it was a gradual decline or a catastrophic event, taking care of someone wasn't on their radar.

No matter the age, being a caregiver entails concessions and personal sacrifice to provide care for another person or other people. The caregiver may provide care because of love for the care receivers. Perhaps they feel obligated. Maybe it's a little of both.

Caregiving may alter your life, create areas of conflict, and cause high levels of stress.

Some caregivers find the "job" rewarding and satisfying. Other caregivers find the "job" burdensome, frustrating and overwhelming.

Regardless of how we approach caregiving, and how we react to our role – it is challenging and stressful.

Caregiving may come about slowly as our loved one's needs gradually increase or the job may come about suddenly in case of an illness or injury. A child may fall into the role of caregiver due to the parent's mental health issues.

The care receiver may live with the caregiver, they may live close, or it may be a long-distance caregiving situation. The care receiver may be physically challenged and / or mentally challenged (which may be a mental health issue or it may be a cognitive impairment such as dementia) or it may be a combination.

WHAT IS CAREGIVING?

Ask a caregiver what they do, and you'll get a variety of answers. Many caregivers would probably answer "EVERYTHING!". The job of caregiver entails many tasks, and is multi-faceted. It's being involved in many aspects of your care receiver's life.

The caregiver may be responsible for many different tasks. Being aware of your caregiving jobs gives you a more comprehensive picture of how involved you are. ***Fill in the circle***.

- ○ Providing care ranging from a few hours a week to providing round-the-clock assistance
- ○ Overseeing your care receiver's activities of daily living
- ○ Supervision and/or oversight of those who provide direct care
- ○ Shopping or taking your care receiver shopping for groceries
- ○ Shopping or taking your care receiver shopping for clothing, shoes, etc.
- ○ Personal care such as bathing, dressing and/or grooming
- ○ Managing incontinence
- ○ Managing financial affairs
- ○ Managing legal affairs
- ○ Providing social interaction
- ○ Supervising and/or administering medications
- ○ Arranging health care
- ○ Providing transportation to health care appointments
- ○ Providing transportation to hair care appointments
- ○ Providing emotional support
- ○ Meal preparation
- ○ Maintaining the care receiver's home
- ○ Outside chores, household repairs, lawn care
- ○ Assessing the care receiver's "norms" so you know when something is not quite right.
- ○ Social director for the care receiver, helping to maintain contact with friends, church members, and other family.
- ○ Historian: Making sure the primary health providers know the care receiver's medical history.
- ○ Care manager: managing all aspects of the care receiver's needs
- ○ Convening family meetings and/or facilitating the family awareness of the situation
- ○ Family negotiator when there are disagreements and conflict
- ○ What else do you do? Write your "jobs" below
- ○
- ○
- ○
- ○
- ○

In addition to the responsibilities of caregiving, we often have other responsibilities. Caregivers may still work. They may be parents. They may be single parents. They may be grandparents raising grandchildren. Look at the list below. What other responsibilities do you have? Fill in the circle.

- ○ Full time job
- ○ Part time job
- ○ School-age children at home
- ○ School-age grandchildren at home
- ○ Maintaining your home
- ○ Paying your bills
- ○ Doing your grocery shopping
- ○ Social or work responsibilities (chair of committees, parent-teacher events, conferences, business trips)
- ○ Single parent
- ○ Ill spouse/partner
- ○ Family member with substance use issues and/or mental health issues
- ○ Pets
- ○ Juggling time with family with caregiving responsibilities

There are a lot of situations that affect us. What other responsibilities do you have that aren't listed? List them below:

- ○
- ○
- ○
- ○
- ○
- ○
- ○
- ○
- ○
- ○
- ○

What else comes into play?

- ○ Long distance caregiver
- ○ Issues with family
- ○ Financial distress
- ○
- ○
- ○
- ○
- ○
- ○

The list goes on. The caregiver holds many positions. It's a tough job. Don't underestimate what you are doing!

You may be the primary overseer of your loved one's care while they live in their own home or you may be a full-time, round-the-clock caregiver. You may be directing the care provided by paid caregivers. You may be overseeing your loved one's care in a facility.

HOW MIGHT CAREGIVING AFFECT ME?

Regardless of whether you are providing direct care or are supervising, you are responsible for the care receiver's well-being. You may feel good about what you do. You may feel a sense of accomplishment, and feel a new level of closeness with your care receiver. You may also feel angry, depleted, resentful, or guilty. Even if the relationship is positive, caregiving almost always involves a degree of self-sacrifice and certain levels of stress.

What is Stress?
Stress is a body's response to what it perceives to be a threat. Your body reacts to these changes with emotional, physical, and behavioral responses. Stress can be caused by anything that requires you to adjust to a change in your environment, your routine, the structure of your life.

In itself, stress is not unhealthy. It's a survival response. In moderate amounts, stress challenges us to do our best so we can keep learning and growing. We are in a constant state of adaptation, whether we are caregivers or not. We adapt to our work environment and the changing workload each day. We adapt to the outside / inside temperature changes. We adapt to our environment in relation to what's going on around us, whether we're walking, driving, or are in our homes.

Caregiver stress – the emotional and physical stress of caregiving – is common among those providing care. There are risk factors for caregiver stress which include:

- ✓ Being a female
- ✓ Having fewer years of formal education
- ✓ Living with the care receiver
- ✓ Social isolation
- ✓ Having depression
- ✓ Financial problems
- ✓ High number of hours spent caregiving
- ✓ Lack of coping skills
- ✓ Lack of choice in being a caregiver

The Warning Signs of Stress
Too much stress has a negative effect on our minds, our bodies, our spirits, and potentially to those around us. When stress is chronic, it becomes *distress* and that is harmful.

♥There are signs and symptoms that indicate we are not dealing well with stress. Sometimes we may not acknowledge the stress (I'm fine, it's fine, everything is fine) but our bodies and actions tell a different story.

There are emotional, physical, and behavioral indicators. Stress can manifest in many ways. What are you experiencing? ***Fill in the circle(s).***

Emotional Warning Signs

- Emotional exhaustion
- Depression
- Anger
- Inability to concentrate
- Unproductive worry
- Sadness
- Frequent mood swings
- Catastrophizing (thinking the worst will happen)
- Focus on issues with an inability to move on
- Panic attacks

Physical Warning Signs

- Stooped posture
- Sweaty palms
- Tension headaches
- Physical Exhaustion
- Neck pain
- Chronic back pain
- Chronic fatigue
- Weight gain or loss
- Altered sleep patterns
- Increased blood pressure
- Rise in heart rate
- Changes in breathing
- Skin eruptions
- Stomach problems

Behavioral Warning Signs

- Marital problems
- Family problems
- Abuse of alcohol or other substances
- Conflict among life roles: spouse, caregiver, employee, parent, son / daughter
- Neglect or abuse of the care receiver
- Frequent job changes
- Withdrawing from relationships
- Acting on impulse
- Excessive “retail therapy” (on-line or in-store or both)

Other Warning Signs
You may have other warning signs that signal you've just about "had enough". What are some of YOUR warning signs? List them. Be honest in your evaluation. Ask a trusted friend to help with this. They can offer more objective information.

☹
☹
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☹

There is no wrong answer! You are YOU. Just as care receivers are different, so are caregivers. Our backgrounds are different. Our financial situations are different. Our families are different. Our health – physical and mental – may be different.

How have you reacted to changes in your life in the past? What has been your stress response?

As each of our situations differ so do our reactions. How have we reacted to stress in the past? What have our coping strategies been? Have they been effective? (How did that work for you?) If not, explore what you could have done differently.

Our past relationship with our care receiver may come into play. Were they loving and generous or were they cruel and abusive? Instances of physical, emotional, and/or sexual abuse can impact how a caregiver responds to their role and the responsibilities involved. The "abuser" care receiver may also respond according to past behaviors and perceptions of the caregiver.

Past relationships of the care receiver: If the care receiver had been the one who was abused, their reactions to personal care may be dictated by their long-ago memories of trauma.

All of these areas impact our caregiving and our health.

You may feel that there isn't enough time, there are too many expectations, you don't have enough energy – there isn't enough "me" to go around.

Unresolved, excessive or prolonged stress may result in "burn out". When challenges and demands are too heavy, our physical energy, time, health and money may be drained.

♥As caregivers, we need to be aware of stress and how it affects our lives. How we can combat it and be proactive with our well-being?

CAREGIVER STRESS SYNDROME (1)

Caregiver Stress Syndrome is a condition that is characterized by mental, emotional, and physical exhaustion brought about by a caregiver neglecting their own health because they are focused on caring for a loved one.

Caregiver stress can come about because of the constant demands of caring for someone.

Boundaries can be challenging.

Some caregivers have unrealistic expectations of themselves, their care receivers, or their perceived control over a situation. They may think they can do it all. They may not ask for help.

Finances may be an issue. The caregiver may have financial difficulties or the care receiver may have inadequate resources for their living expenses and/or care.

You may have work responsibilities, children or grandchildren responsibilities, your home, your care receiver's home, financial concerns, self-doubt over your caregiving abilities, issues with siblings or other family members that you think should be involved, the needs of your care receiver, and how you make it all come together.

Caregiver stress may lead to psycho-emotional issues such as anger and depression, and there may be physical manifestations as well such as high blood pressure, diabetes, and a compromised immune system.

The credited article "Caregiver Stress Syndrome" notes:

- *Caregivers report that they had not gone to their doctor as often as they should have*
- *Caregivers report that eating habits are worse than before they became caregivers*
- *Caregivers report chronic conditions including heart attacks, heart disease, cancer, diabetes, and arthritis*
    - *All of these may be exacerbated by the demands of caregiving*
- *Caregivers report that their role as caregiver has caused their physical health to decline*
- *Older caregivers (66yo – 96yo) have a higher mortality rate than non-caregivers of the same age*
- *Many caregivers suffer from depression (40% - 70%)*

Can you identify with any of those?

Caregiver Burnout

Caregiver burnout is when you feel like you are done. Through. Depleted. It's when you feel like you have given all you have to give.

Caregiver burnout comes about from trying to do it all. "Nobody can provide the same kind of care that I do" is often the fixed notion that leads to burnout. No – nobody will provide the same care. That doesn't mean that someone else can't help with the care, or if placement is needed, provide quality care. Informal caregivers need to remember that if their loved one needs to go to a long term care facility, there are several people doing medications, meals, laundry, housekeeping, and all the other tasks that you (and maybe you ALONE) have been doing.

Caregiver burnout comes from many situations: caring for more than one person, being in high intensity situations (long hours, little help), caring for medically complex care receivers. It comes from caregivers having difficulty coordinating care and dealing with the medical system and the insurance system. It comes from being placed in the role of caregiver with little or no preparation. It comes from the caregiver's compromised health.

There are risk factors for caregiver burnout with the following being more vulnerable:

- ☹ Those caring for a spouse
- ☹ Those caring for someone with dementia
- ☹ Those under financial stress
- ☹ Those who are juggling the care of an aging adult with raising a child (sandwich generation)

What is the combined effect when a spouse is caring for a partner with dementia, has a limited income, may have to consider a change in employment, and are raising a child or grandchild?

This is when there is a greater risk of placement.

Caregiving and PTSD or PTCG

Pre-existing conditions or those conditions that existed before you became a caregiver may influence your susceptibility to Post Traumatic Stress Disorder. Those caregivers who had depression or anxiety before starting caregiving and those caregivers who experienced adverse life experiences are more prone to the negative effects from caregiving. Is there unresolved loss or trauma? According to professionals, more research needs to be done with the link between PTSD and caregiving although there is the recognition that chronic stress can lead to PTSD. (2)

Many caregivers had no preparation time. They were thrust into caregiving based on a catastrophic event or a life-altering diagnosis. Perhaps the caregiver is experiencing unwanted, upsetting memories or nightmares or emotional distress brought on by reminders. This may be referred to as 'post traumatic caregiving' or PTCG. (3)

Regardless, the stress of caregiving is very real and very damaging. Effects can be long-lasting and have a serious impact on the caregiver's mental, emotional, and physical health. Work on self-care. Establish a habit of self-care. (Establishing a habit takes several days of repeating the action. It doesn't have to take a long time. Try 5 minutes.) Work to avoid stressors in the first place. What can you avoid or delegate that serves as a stressor? (4) Learn about tips to take care of yourself. Seek social support. Pay attention to your health. (5) Try to keep your expectations realistic. Read Albert Ellis' Irrational Beliefs. (6)

When you experience an unusual level of stress, certain warning signs occur. Answering the following questions will increase your awareness of the warning signs.

Take the "**CAREGIVING STRESS – SYMPTOMS AND CAUSES**" quiz. Be aware of your answers and what they mean to your well-being.

CAREGIVING STRESS – SYMPTOMS AND CAUSES

The Warning Signs of Stress

YES	NO	WARNING SIGNS
		Do you feel a loss of energy? A loss of interest in life?
		Do you feel like you are out of control? Are you exhibiting emotions or actions that aren't like you?
		Do you lack interest in people or things that were formerly pleasant for you?
		Do you feel like the isolation is closing in on you?
		Are you consuming sleeping pills, alcohol, other substances, cigarettes? Is there a change in your consumption?
		Do you have difficulty falling asleep, difficulty getting back to sleep, are you awakening too early, or sleeping excessively?
		Are there appetite changes?
		Have you lost or gained weight?
		Do you have problems with concentration or with memory?
		Are you increasingly irritated, impatient with others, intolerant of others?
		Do you have thoughts of suicide?
		Are you withdrawing from others?
		Are you having problems with your place of employment or your job?
		List other symptoms that are stress indicators for you:
		☹
		☹
		☹
		☹
		☹

A "yes" answer to even some of these questions may indicate stress that has become debilitating.

Talk to your health care provider or a mental health provider about your warning signs and stressors. Take this questionnaire with you when you discuss your symptoms.

Recognizing the source of this stress is the next step in dealing with the destructive effects of stress.

The quiz on the next page will help you identify <u>what</u> stresses you.

The causes of stress vary with the responsibilities and the caregiver. What creates stress for one caregiver may not create stress for someone else.

THE CAUSES OF STRESS

There are some common sources of caregiving stress. Are these stressors for you?

YES	NO	CAUSES OF STRESS
		Are you experiencing multiple demands on your time, energy, or money? What are they? ☹ ☹ ☹
		Do you feel that your responsibilities conflict? Which ones? ☹ ☹ ☹
		Do expectations differ among family, employer, care receiver, and yourself? What are they? ☹ ☹ ☹
		Do you understand the care receiver's physical and/or cognitive diagnosis?
		Do you understand the prognosis / course of the disease(s) for the care receiver?
		Do you have difficulty meeting the physical needs of your care receiver?
		Do you have difficulty meeting the emotional and social needs of your care receiver?
		Does the care receiver place unrealistic demands on you?
		Are there financial obligations that are difficult to meet? For yourself or the care receiver?
		Do you feel trapped? Do you feel a loss of freedom?
		Is the situation with family members challenging? How? ☹ ☹ ☹
		Do you feel that other family members aren't doing their share to help?
		Do family members have negative attitudes?
		Is there disagreement among family members?
		Are there unresolved issues with family members? What are they? ☹ ☹ ☹
		Is there open communication among all involved?

THE CAUSES OF STRESS (con't)

YES	NO	CAUSES OF STRESS
		Is there an observable decline in the care receiver that is difficult for you? The family?
		Do you feel helpless about the care receiver's decline despite your best efforts?
		Do you feel like you work harder but it's not enough?
		Do you feel like you need to quit your job to fulfill your caregiving responsibilities?
		Are there other problems with family? Marriage? Employment? ☹ ☹ ☹
		Are there other issues? What are they?
		☹
		☹
		☹
		☹

Look at your "yes" responses and the items you listed as stressors.

Focus your attention on these specific sources of stress.

You may feel that there are too many expectations, not enough time, not enough energy. You may feel like you are spread too thin. Unresolved, excessive or prolonged stress may result in "burn out". When challenges and demands are too heavy, our physical energy, time, health, and money are drained. As caregivers, we need to be aware of stress and how it affects our lives.

What do you need to work on? Keep these sources of stress in mind as you work out an action plan.

Determining and identifying our sources of stress can help us figure out an action plan. In order to make changes and improve our situation, we need to be aware of what bothers us, name it, and decide what we can do. It is important to realize that there are things we can't change. Equally important is the realization that there are things we can change. Perhaps the change lies in us. We can't always change what happens but we can change our reaction to it.

MAKING A PLAN: STRATEGIES FOR MANAGING STRESS

Usually something can be done to decrease stress. ♥ Evaluate your situation and that of your care receiver. Keep in mind that managing your caregiving responsibilities more efficiently means less stress for you.

Once you identify and are attuned to your stressors, you need to determine which ones you can do something about and which ones area beyond your control. Successful coping involves accepting what you cannot change. It also means letting go of unrealistic expectations.

- ♥ You will not be able to change the care receiver who has always been demanding and inflexible, but you can change the way you react and respond to those demands.
- ♥ You can't change past hurts and abuses. You can forgive and move on.
- ♥ You can't force your family to be involved in your loved one's care but you can work on alternative supports to help ease your caregiving burden.
- ♥ You cannot change the care receiver's progressively debilitating illness but you can develop skills for caring and coping with the changes brought on by the illness.

What do you need? Evaluating your needs and making an action plan can help you feel that you are more in control of your situation which can help lower your stress levels.

Think about **A – P – I – E**.

Assess: What will help? What do you need? What does your care receiver need? Identify needs. Make a list.

Plan: What can be done? What help is available – formal and informal. Make a plan to address those needs. What might help with the needs? Talk to a professional about the options that may be available. There are a lot of services for care receivers and caregivers.

When developing a plan, you need to keep the following in mind:

Availability of services

What is in your area? Can you get what you / your care receiver need?

Accessibility to services

Can you / your care receiver get to the services or can the services get to you / your care receiver?

Affordability of services

Can you / your care receiver afford to pay for the services?

What financial assistance may be available?

Appropriateness of services

Does the service meet your / your care receiver's needs?

Intervene: Implement the plan. It may be hiring help. It may be obtaining services. It may be a family meeting. It may be a discussion with the health care provider.

Evaluate: How did the intervention work? Was it too much help? Too little? Enough? If it was successful, keep it up. If not, go back and evaluate what other action you may take.

Care Receiver concerns (Example)

Assess (Identify concern)	Plan (What can we do?)	Intervene (Do it)	Evaluate (How's it going)
Ie: Transportation to doctor	Son Jordan takes her	Arrange appointment w/ doctor and confirm w/ Jordan or have Jordan make the appointment so it fits his schedule	Worked well Need alternate in case Jordan is not available
Ie: Transportation to doctor in case family is unavailable	Local agencies that offer transportation	Call agencies for eligibility requirements and make application	TBD but applications with agencies completed
Ie: Doesn't understand stove, leaves burners on	Get home delivered meals (hdm)	Check on hdm availability with county senior center, other agency, or online service and arrange delivery	Easy to get Mom on the hdm meal program. Mom likes them, thinks she is getting room service

Caregiver concerns

Assess (Identify concern)	Plan (What can we do?)	Intervene (Do it)	Evaluate (How's it going)
Ie: I wake up with a million things going through my mind.	I need to focus, to get centered. Deep breathing	Each morning, I will take 5 deep breaths and "see" my happy place in my mind. I will enjoy all of the sensory experience of being in my happy place. Ie: hear the seagulls and the waves, feel the heat of the sun, see the horizon, smell the salt air	Helped me get centered and focus on the tasks at hand.
Ie: I can't get it all done!	Obtain services to help when I can't be there	Look into available areas of support. Ask a friend to sit with Mom while I go to the bank. Make a list of what I need and who might help.	Friends are so willing to help! Being specific in my needs has helped define what friends can do

You can work out a chart on paper, on your phone, or on your computer / tablet. What helps you focus on the specifics of the problem, the possible support, what to do to get started, and determine how it worked? Develop what works for you or use the above format.

You may want to add a column to designate who will be responsible for the particular interventions / arrangements.

When you're evaluating the situation, look at all areas.

Think about these areas for yourself as well as your caregiver. Check off possible needs & comment:

Area of concern	Caregiver	Care Receiver
Physical needs		
Emotional needs		
Environmental concerns / housing repairs: Modifications, adaptability, stairs, bathrooms		
Neighborhood issues: Is the neighborhood safe? Is it too rural?		
Financial situation		
Legal concerns		
Social needs		
Support needs		
Spiritual needs		
Other dependents: Minor children, grandchildren, adult dependent children		
Distance: Are you a long distance caregiver? Are other family members long distance caregivers?		
Service needs: In home assistance, transportation, meals, shopping, home health		
Other – list:		

Getting help for your care receiver can help YOU – the caregiver. Getting help for yourself benefits your care receiver.

Evaluating both caregiver and care receiver needs will show you what areas need addressed, and give you a better idea of how to make an action plan.

When you sit down to evaluate your needs and develop your action plan, there are basic strategies that will help you.

BASIC STRATEGIES TO HELP CONTROL STRESS

1. Set realistic goals and expectations
    a. Identify problems / stressors that need addressed. Prioritize.
    b. Plan achievable goals.
    c. Develop realistic expectations.

2. Establish your limits. "Know" and "No" your limits.
    a. Be aware of how much you can handle.
    b. Say "no" to what you can't do.

3. Ask for and accept help.
    a. Learn about services.
    b. List your needs.
    c. Know who is in your support system.
    d. Know who is not someone you can count on.
    e. Know who the allies are in your health care professionals' offices.
    f. If someone offers to help, pull out your list and ask about a specific task.
        i. Do not EXPECT family to help if they've not been involved. You can't make them do anything.
        ii. They may, however, be willing to help with things that are more agreeable to them. For example, if they can't do personal care perhaps they can do grocery shopping or banking.

4. Involve other people
    a. Hold a family meeting.
        i. It is important to remember that you can't force other people to be involved. You cannot make your siblings / family take care of your care receiver but you can keep them informed. What caregiving task(s) may they be willing to handle? They may not want to be involved in hands-on care but they may help with other tasks.
    b. Seek professional assistance.
    c. Use community resources.

5. Take care of yourself – you're the only one who can!
    a. Express your feelings honestly and objectively.
    b. Maintain your health.
    c. Take time for yourself.

Some ideas for quick self-care

*Disclaimer: Check with your health care professional before doing the stretching, chair exercises, or self-massage. There are medical conditions in which these may be contraindicated or done with caution. Ask your doc!

☺ Stretching (Check with your physician)
Stretching and Flexibility Exercises | American Heart Association
https://www.heart.org/en/health-topics/cardiac-rehab/getting-physically-active/stretching-and-flexibility-exercises

☺ Chair exercises (Check with your physician)
You don't have to be a "senior" to benefit from these exercises
21 Chair Exercises for Seniors: Complete Visual Guide (californiamobility.com)
https://californiamobility.com/21-chair-exercises-for-seniors-visual-guide/
Best chair exercises for seniors: Safe and easy workouts (medicalnewstoday.com)
https://www.medicalnewstoday.com/articles/chair-exercises-for-seniors

☺ Self-massage (Check with your physician)
Check out these resources for self-massage.
Self-Massage Techniques
https://backintelligence.com/self-massage-techniques/
Self Massage: 17 Tips for a Soothing Massage | The Healthy
https://www.thehealthy.com/home-remedies/self-massage/
DIY massage: Give yourself a neck, back, shoulder, foot rub (today.com)
https://www.today.com/health/how-give-yourself-one-heck-killer-massage-t74581

☺ Deep breathing
- Sit with your feet on the floor. Arms comfortably on your lap. Inhale for a count of 5, exhale for a count of 5. Repeat 5 times.

☺ Pray or meditate

☺ Read
- Even a chapter or two will give you a little down time.

☺ House plants or container gardening
- This doesn't take much time and helps you get in touch with nature

Not only do you need to understand your needs, your limitations, your strengths and weaknesses, you also need to be cognizant of how the illness or disability affects your care receiver.

SETTING REALISTIC GOALS AND EXPECTATIONS

Identify your most pressing concerns

In order to set realistic goals and expectations, you need to determine what issue(s) you are addressing. Look at your causes of stress. Evaluate your care receiver's needs. What do you need to work on?

Plan achievable goals

What do you want to accomplish? What do you NEED to accomplish? Our basic goal of caregiving is to assure the safety and comfort for our care receiver. Quality of life is an important goal, as much as our care receiver's condition will allow. Consider the options for achieving these goals.

When you are setting goals, consider how caregiving is impacting other areas of your life.

- How is your health?
- Is the relationship with your partner and / or children affected?
- What other demands and obligations do you have?
- Are you still employed?

Preventing caregiver burnout starts with accepting the limitations of what you can accomplish!

Learn what you can about your care receiver's diagnoses and issues.

- What is likely to occur medically and behaviorally now and as time goes on? Behaviors may be a consequence of the disease process (especially if you are caring for a loved one with dementia).
- Seek information on your care receiver's health issues. What is the "normal" progression for the primary diagnosis and any co-morbidities?
- Are there complications that may arise?
- Are there other concerns?

Select goals that are specific and achievable. Select problems, and set *short-term* goals specific to those problems. Focusing on larger, long-term goals may be frustrating and cause more stress.

A few things to think about as you determine goals:

- ♥ What is your definition of "long term"?
- ♥ Long-term goals can change very rapidly

When you're setting goals, you need to think about the care receiver's personality and capabilities. Focus on the care receiver's strengths. They may not be able to do an entire task, but they do parts of a task. Make accommodations part of the 'plan'.

Some caregivers see their job as making the care receiver happy. Is this a realistic goal? Probably not. Can we make someone else happy? Probably not. We can add enjoyment to their days. We can create moments of joy. But, more often than not, "making someone happy" is not an achievable goal.

[Depression is very real! If you suspect that you / your care receiver is suffering depression, please talk to your health care professional.]

Making a list of problems, goals, and an action plan can help clarify what you are experiencing, what you hope to accomplish and how you might do that.

- What are the problems you are facing?
- What goals might you set for your caregiving?
- How might you accomplish those goals?
- Who can help? Family? Friend? Agency?

Name the Problem Chart: Use this chart to get started. It will help you prepare for the Discussion Guide.

PROBLEM	GOAL	ACTION PLAN	WHO CAN HELP
Example: Isolation	**Increase socialization**	**Call friend** **Online support group**	**Best friend** **FB**

Develop realistic expectations

Are your expectations realistic? Do you think if you did more, things would be better?

Do you fall prey to others' expectations of us?

Do you hold onto the notion that "Mom took care of me when I was little, I should be able to do this!" Have you considered that when Mom took care of you, that you were young, you were smaller, you were growing and developing, that you were the CHILD?

You will always be the child. Your parent will be the parent even when they are dependent on you. That family dynamic will not change.

Caregivers often struggle with what they expect of themselves, and what they can really do. We often expect too much of ourselves which leads us to a huge let-down because we can't live up to those expectations. Do you fall prey to the "shoulds" of life? Do you think you can do everything yourself? We often interpret our inability to do it all as "failure" which is totally unrealistic! Don't fall into this 'expectation trap'! We are human. We have limitations.

What about making promises? Promises get in the way of objectivity and impair our ability to make sound decisions. Did you promise to "never put Dad in a nursing home"? Perhaps you made that promise when Dad was healthy and you had different responsibilities. Don't make promises you may not be able to keep! We are not super-humans, and we are aging as our care receiver's age. That promise may be totally unrealistic now. Instead, tell your loved one that you will make sure they are cared for. You will do your best to keep them comfortable and safe. We may need to place a loved one as their health issues become more medically complex, and having made a promise about future care may no longer be realistic.

Establish your limits

You have the right to set limits on what you will do. It is important that you "KNOW" your limits as well as "NO" your limits. This can be hard to do and can entail difficult choices. There are times that we all go beyond our limits.

When you set limits, it is important to communicate them to your family and to the care receiver. Your care receiver may not understand this or they may be resistant. They may try to guilt you. They may test those limits. Failing to set limits and sticking to those limits will only result in increased stress. When you are establishing those limits, offer options as to how the needs will be met.

You may not be able to take Dad grocery shopping every Tuesday at 1:00 pm but there is an agency in town that can take him. It's not the same as if you are doing this, but you have offered a reasonable solution. Offer to help with the grocery list or help putting the groceries away.

What limits can you set? What can you say "NO" to? What do you "KNOW" you can no longer do?
1.

2.

3.

There are times that you will go beyond those limits. There are times that even though you ***KNOW*** you need to say ***NO***, you will still fall to the pressure (self-imposed or presented by someone else) or the situation will necessitate you flex. Be cautious about how much you put on your plate!

Make it your goal to be consistent and firm with your convictions. Constantly backing down and making concessions won't help.

Ask for and accept help

You can't do everything! All too often, we think we can do it all. We think that nobody can provide the quality of care that we provide. Our culture emphasizes "independence" and doing tasks all by ourselves. What will people think if we have to get help with Mom? We view asking for help as a sign of weakness or failure. Actually, the opposite is true. ♥*Knowing that you need help and asking for assistance is a sign of strength.* It helps ensure quality care for your care receiver and less stress for your – the caregiver.

Do you refuse help, and then become resentful or exhausted because no one comes to your aid? Do you hold on to the notion that you "should be able to this alone"? Being a martyr helps no one. Refusing help does not make you a better caregiver. It makes you tired, irritable, frustrated and unfocused.

Family, friends and neighbors are often willing to help. Sometimes people are reluctant to ask because they don't want to offend the caregiver. They may be frightened of the illness, feel uncomfortable around the care receiver, or perhaps their offers have been refused in the past. Perhaps you fake it really well, and potential helpers think you have everything under control!

From a faith-based perspective, the Judeo-Christian tradition has extended the idea of receiving God's grace – that is, accepting His love and blessings and reciting prayers of thanks upon awakening and before meals – to graciously accepting the love and blessings of fellow human beings. It is a gift to the giver to thankfully receive the blessing they are offering. There is giving in receiving. Accept help with graciousness and gratitude and then you make it a joyful gift from the giver.

If we do ask for help, we may not be specific enough for potential helper to know exactly what we want. We expect people to 'read our minds', to know what we need.

1 - List your needs & those of your care receiver

You are in a better position to explore services when you know what the needs are, and, people are best able to help you when they know specifically what they can do.

What are your needs? What does the care receiver need? What will be helpful? Be specific. You have options of community services, paid services, and informal supports (family and friends).

What are you willing to delegate? Sometimes we have tasks that we prefer to do ourselves.

For formal caregivers:

Community services or paid services have more defined parameters. There may be limits to what agencies can do. Be sure you understand these limits. If you hire someone privately (not connected to an agency, check references and check background), negotiate a work contract, be specific about needs, determine experience with your care receiver's condition, etc.

For family and friends:

Make a list and when someone asks how they can help – pull out your list! Help from family and friends may be a little more flexible. Tasks unrelated to caregiving may be easier for some people while others do well with visiting or sitting with the care receiver. Ask what time is best for your "assistant".

For all of your care partners:

Show appreciation! Say thank you. Let your helpers know how much their help means to you.

People are less likely to respond to requests that are demanding, manipulative or guilt-provoking. (We may be more inclined to take this tact with family members, especially if we think they aren't doing their part or pulling their caregiving weight!)

We sometimes think family or friends "should KNOW I need help!" or "they should KNOW what I need!" People aren't mind-readers. Just as people may not know what all we have on OUR caregiving daily life plates, we may not be aware of the situations or obligations of others.

What do you need help with? The Discussion Guide on the next page will help you identify needs.

A DISCUSSION GUIDE: WHAT DOES THE CARE RECEIVER NEED?

In what areas does your care receiver need help? Make a check and note who can help: family, friend, agency, etc.

TASK	WHO CAN HELP? (Friend, family, paid caregiver)	INDEPENDENT (No assistance needed)	NEEDS ASSISTANCE OR NEEDS CUED (Some help or supervision)	DEPENDENT (Total Care)
Bathing / showering				
Hair care				
Dressing				
Personal care				
Eating				
Shopping				
Meal preparation or bring in a meal				
Light housekeeping				
Laundry				
Medication: Oral: set up meds Injections				
Financial management				
Banking				
Take care receiver for a walk				
Take to medical appts				
Pick up prescriptions				
Take to grocery store				
Grocery shop for care receiver				
Clothing shop for care receiver				
Take care receiver for a ride				

A DISCUSSION GUIDE: continued

TASK	WHO CAN HELP? (Friend, family, paid caregiver)	INDEPENDENT (No assistance needed)	NEEDS ASSISTANCE OR NEEDS CUED (Some help or supervision)	DEPENDENT (Total Care)
Calling care receiver				
Send care receiver a card				
Other:				

What kind of help can you get for these tasks? Who can help?
Perhaps you are the primary caregiver who performs some of these tasks, but where might others help?
What other tasks do you do where others could help?

Who might be able to help? Friends? Family? Do you need paid assistance or an agency?

List people or agencies who might be able to help with the preceding tasks.

1.

2.

3.

4.

5.

6.

7.

8.

9.

10.

Helper caregivers need "orientation" and paid caregivers need "trained" as well. Where are the supplies? Where are the care receiver's personal items? What areas are off-limits?

Regardless of whether it's family, friends or paid assistance, caregiver helpers need to learn about the care receiver, the home, where supplies are kept (as needed). Make sure to acquaint your helpers with your home, and with the person they are assisting.

CARE RECEIVER ORIENTATION GUIDE: Offer the following information to help in the home:

_____ Where is underclothing

-
-

_____ Where are everyday clothes: pants, tops, skirts, etc

-
-

_____ Where are personal care items: soap, shampoo, lotion, deodorant, toothpaste, denture cleaner

-
-

_____ How to use the microwave and the stove

-

_____ Is there a pantry or other area where additional food supplies are kept

-

_____ Where are cleaning supplies

-
-

_____ How to use the washer and dryer

_____ Is the helper driving the care receiver? Whose car is being used? If the helper is driving your car, where are the keys? Where is registration? Where is the insurance card? Who is the insurance carrier? (Make your policy covers other drivers!!)

-
-
-

_____ If shopping is being done, how is payment made? (Request the receipt. Be cautious about giving credit cards to helpers.)

What are the preferences and dislikes of the care receiver? Help them get to know your care receiver.

GETTING TO KNOW YOU…INFORMATION ON CARE RECEIVERS

Basic information on our care receivers can be helpful to paid caregivers and also friends or family who fill in and help. If your loved one needs to go to a facility, staff can use this sheet to get to know your loved one. Adding personal information can help personalize care and interactions. Information on the care receiver's likes and dislikes can guide caregivers to provide care with a focus on individual quality of care. Our family member may like to be called by a certain name or nickname, and they may no longer recognize that they are "Mom" or "Dad".

Following is some information that you may want to share with other caregivers to help them become acquainted with your loved one.

CARE RECEIVER INFORMATION

Name	
Nickname **What do I like to be called?**	
Spouse's name **Spouses' names**	
Date of birth	
Where was care receiver born	
Where they lived as a child	
Where they went to grade school	
Where they went to high school	
Where they went to college	
Who were childhood friends	
Parents' names	
Siblings' names	
Pets' names & what (dog, cat, etc)	
Animal experiences – good and bad	
Favorite foods	
Least favorite foods	

CARE RECEIVER INFORMATION
(continued)

Usual bedtime	
Awakens when?	
Bath or Shower?	
Usual time for bath / shower	
Strange behaviors or idiosyncratic behaviors	
Things that may agitate	
Things that may calm	
Likes	
Dislikes	
Special skills	
Favorite activities, hobbies or interests	
Food intolerances	
Special dietary needs	
Family history issues Incidents that may evoke a catastrophic reaction or other negative emotion. This may be abuse or trauma.	
Other:	

Having this information can make the care receiver more at ease. For those who have memory loss, this information can be especially helpful.

2 – Learn what services are available to you

You're ready and willing to get help. Maybe you don't know exactly who can provide assistance or where to find what you need. Where can you get general information about the services in your area?

Think about what you and your care receiver need, and if you don't know the name of the service, you can describe it.

Take notes: what agency did you call, who did you talk to, what do they offer, what are the eligibility requirements, can they send you information, are there fees, is there any financial help available. See the sheet on the following page to help you organize your information.

You can become a better caregiver by becoming familiar with the services that are available to you and your care receiver.

Local, state, and national resources

Altenheim Resource Services

We are here to answer your questions on aging and caregiving resources no matter where you live.
www.altenheimcommunity.com

Senior Centers

Senior Centers usually offer services that can include in-home assistance, congregate and home delivered meals, transportation, and some offer support groups.

Hospital social service departments or discharge planners

Various state and federal resource programs

Aging & Disability Resource Networks, WV Navigate or Bridging Resources WV, Ohio's Help4Seniors, or 211 (United Way's Community Resource number)

National organizations

Alzheimer's, Parkinson's, Heart, etc.

Special events

Local health fairs or senior expos offer opportunities for caregivers to explore services, talk to the agencies represented, and gather information on local services.

Some areas are more service-rich than others. Metropolitan areas may have more formal services than rural areas. Think about Availability, Accessibility, Affordability and Appropriateness.

Just remember that getting help can take off some of the burden and help decrease some of the stress.

[A word of caution: Internet searches are great tools to familiarize yourself with services but it is imperative that you make sure that the site is reputable, and that their information is up-to-date and correct. One on-line site told their caller to contact the Yellow Pages, and said "You do know how to find the Yellow Pages, don't you? Go to yellowpages.com". Not exactly the information they were looking for. The person was not helpful, and their lack of assistance and attitude just added to the caregiver's frustration and stress. These sites are advertised on all media, but that doesn't mean they are helpful, reliable or compassionate. Become acquainted with what is available on-line but contact local agencies, reliable agencies or state departments on aging for information specific to your needs and your location. Ask friends or family about their experiences. Who might they recommend? Who should you avoid?]

EXPLORING OPTIONS FOR ASSISTANCE

Use this sheet to help you as you (or a helper) make calls for resource information

Name of agency:

Phone number or email address:

Who am I speaking with?

What services do you offer:

-
-
-

Is there a waiting list for services? For all or for some?

Does your agency serve my area?

Is there a fee?

Is there financial assistance?

What are eligibility requirements?

- Age
- Income
- Medical assessment

Can you send me information and/or an application or how do I apply for services?

Dynamics differ in every family. Some family members WANT to be involved. Other family members are content to get information, and not be active caregivers. Still other family members, want NOTHING to do with the caregiving. We also hear about the 'seagull' caregivers: they swoop in, make a mess of things, then swoop out. How can you discern which family members fall into which category?

INVOLVE OTHER PEOPLE

Hold a family meeting

Caregiving is often provided by a primary caregiver, however it is important for all family members be involved in the planning and continued support. A family meeting is a good way to determine how to share the caregiving responsibilities and to keep everyone current on the care receiver's status.

A family meeting should be held when the caregiving needs become apparent. The meeting gives family members the opportunity to discuss caregiving concerns, identify potential problems and solutions, negotiate the sharing of caregiving tasks, and determine the strengths and preferences of the family. The meeting may clarify expectations and minimize misunderstandings.

Include everyone

Everyone who is concerned and may be affected by care decisions should be involved in the family meeting. Siblings, spouses, other relatives, significant others / housemates, close friends, "children"-in-law, and the care receiver should be involved. If illness prevents the participation of the care receiver, his or her input should be provided and he or she should be kept informed of the outcome of the meeting. The care receiver needs to maintain as much control as possible.

The family may want to provide information to long distance family members. Telephoning distant relatives and seeking their input will keep them informed and feeling like part of the process. Involvement of all family members in developing a caregiving plan ensures greater success and support for the plan, and helps prevent later undermining or arguments about the decisions.

♥***A word of caution***

Although primary caregivers may seek to include everyone, everyone may not want to be included. It is not unusual for only a few members of a family to be primary caregivers and other family members only assisting in certain areas or choosing to become involved in only the most minor way.

Do not expend your energy "wishing" they would help or resenting their lack of involvement. There is no magic wand to "make my family member become involved". It is most valuable for you, the primary caregiver, to adapt to this stressor, work with other caregivers in achieving goals, keep the "uninvolved" family member informed and do what is necessary for you and your care receiver.

We cannot dictate others' behaviors. We can choose to respond positively and move on.

Consider two-step meetings

The first step is meeting without the care receiver to air ideas and feelings, identify concerns, look at information that is needed, and discuss responsibilities for family members. The purpose is not to make concrete decisions nor to gang up on the care receiver.

A second meeting is then held with the care receiver to actively work out a plan of action.

♥Keep the care receiver's cognitive status in mind when planning.

Plan for success

When planning a family conference, pay attention to the following:

- Before the meeting, ask family members to list their concerns and tasks that they are willing to do.
- Holding the meeting in the care receiver's home will give a greater sense of control or hold the conference in a neutral location.
- Create a feeling of support and confidentiality.
- Keep the meeting focused on the current concerns rather than on other issues or past conflicts.
- Allow everyone the opportunity to express feelings, voice preferences and offer suggestions without undue criticism.
- Focus on the positive. Identify what each person can do but encourage everyone be honest about their limitations. Sharing information about other responsibilities can help others understand why the support is limited.
- Prepare a written plan listing what each person will do and when they can do it. A written plan can prevent later disagreements about who agreed to do what and can better assure that needed tasks will be completed. It also helps you remember. You may not be able to remember all of the arrangements.

A professional may help you gain some insight and put things in perspective. Don't be afraid to seek assistance and don't wait until you are overwhelmed to do so. Getting help is a sign of strength not weakness, and will enable you to become a better caregiver.

Realize there may be conflicts

A family meeting isn't always easy and in some families, it's almost impossible! It's most difficult for families who have not discussed concerns or other family issues, and those families who have poor communication habits. If there is already conflict, don't expect this to change in light of caregiving. Old conflicts, hurts and resentments can emerge or re-emerge in regard to family relationships, control, family roles, expectations and/or inheritance issues.

Family members may not recognize the care receiver's needs, the best options for providing care, the division of caregiving tasks, how money should be spent and how much, and who makes these decisions.

Family members may disagree on what is "best" for the care receiver. One family member may insist that the care receiver remain in the home while another family member is adamant about placement. Don't hesitate to enlist the opinion of the primary health care professional about the best care options. Consulting the medical professional offers a third opinion focusing on what is in the best interest of the care receiver.

Don't overlook the care receiver's right to autonomy. Involve them in the decision-making process and respect their decisions. Do they understand what is happening? Can they communicate their wishes?

Another issue with families is 'end-of-life care' especially if the care receiver has not expressed their wishes (hopefully they have with the completion of advanced directives) and sometimes, even if they have. What constitutes life-prolonging measures may create heated arguments. Talk to a palliative care or hospice program to determine the best course of action and to learn about the physical process when someone is at the end of life. Learn what different interventions entail. Ask about CPR, intubation, and/or tube-feeding.

Family conflicts often stand in the way of problem-solving. Obtain professional guidance to help.

It is helpful to have an agenda for family meetings. Without structure, these meetings can get out of hand and not focus on the needs of the care receiver, the caregiver and other family members.

The Agenda

Think about setting up your agenda around the following topics:

1. The latest information from the primary health care provider(s)
    a. What is the primary / are the primary diagnosis(es)?
    b. What are comorbidities?
    c. What tests are on the schedule?
2. What are the daily caregiving needs?
    a. Is help needed with personal care? Meals? Housekeeping? Laundry? Shopping?
3. What help is needed with medical appointments?
    a. Who is liaison with health care providers? (Think about advance directives - #8)
4. What are the care receiver's preferences for care?
    a. Are there preferences realistic? Achievable? Appropriate?
5. Should the care receiver live alone?
    a. Should they move in with the caregiver?
    b. Should they move to assisted living or a nursing home?
        i. The primary care physician may have input on this.
6. What are financial concerns?
    a. Can the care receiver afford in-home assistance?
    b. Is financial assistance available?
        i. State programs
        ii. Veteran's assistance
        iii. UMWA assistance
7. Is the primary caregiver working? Missing work?
    a. How much work can the primary caregiver miss?
8. Who will make decisions – financial, medical, hiring assistance?
    a. Have legal concerns been addressed or arranged by the care receiver?
        i. Medical Power of Attorney

        ii. Durable Power of Attorney
        iii. Will
        iv. Transfer on death deed (Inclusions depend on your state)
    b. Is legal counsel needed?
        i. Advance directives
        ii. Medicaid planning
        iii. Formal caregiver contract
9. What are the end-of-life wishes of the care receiver?
    a. Are there Advance Directives?
        i. Living Will
        ii. Medical Power of Attorney
        iii. DNR or Physician's Scope of Treatment
    b. Does the care receiver want hospice care?
10. What type of support does the primary caregiver need?
    a. Assistance with activities of daily living
    b. Respite / time away – short term – a break from caregiving
    c. Respite for events (graduations, weddings, vacation, etc) – longer term
11. What are the primary caregivers feelings about caregiving? About the decline of the care receiver? About the continuation of the role as primary caregiver?
    a. About the care receiver's dying? Death?
    b. About being overwhelmed?
    c. About what will happen to the family after the care receiver's death?
    d. About feelings of sadness, guilt, inability to cope / decline in coping abilities?
12. Who in family can help?
    a. What can they do?
    b. How much time does each family member have?
    c. What tasks are they willing to do?
    d. What tasks are they unwilling to do?
    e. What support can they offer?
        i. To the caregiver
        ii. To the care receiver
13. Who else might be able to help?
    a. Neighbors
    b. Church family
    c. Others
14. How will caregiving and support needs change as the care receiver declines, if an emergency comes up, if there is a fall or other catastrophic event such as a fall, or if there is an acute illness?
15. How do we schedule regular updates?
16. Take notes and have a summary of the meeting.
    a. List tasks
    b. Have a written summary of what each person has agreed to

You will probably not address all of your concerns in one family meeting. Make notes about additional concerns or situations specific to your circumstances. Schedule other meetings. You can do these in person, through a telephone conference, via Skype or Facetime, or through Zoom or Cisco meeting apps.

Set a timetable with a beginning and end time. Try to stick to the timetable. If meetings are too long, participants get tired. Minds may wander. Fatigue sets in. People may be reluctant to attend other meetings.

You may want to create a record of family meetings, and have a notebook for those records.

As caregiving goes on, keep a list of new concerns. Comment on what might help. Keep problem solving ideas on hand so you're prepared to discuss your concerns and ideas.

Family meetings can be extremely helpful on a lot of levels. You – as the caregiver – will discover what kind of help other family members are willing and/or able to provide. You may discover that your beliefs about a family member's ability to help are wrong. They may have items on their "plate" that you didn't know about, and have perfectly legitimate reasons for their limitations.

You will probably find out who you can rely on and who you can't. You can't force cooperation, help or understanding. You can't make a family member help. You can't change them. You can learn. You can accept. You can move on. Realizing these limits, and accepting that people won't be what you want them to will be beneficial to your emotional health, and can decrease the stress of unrealistic and unrealized expectations.

The family member may insist on a certain course of intervention (Mom needs to remain at home with no placement, for example) but what will their involvement be in that decision? If family members refuse to participate or help, this may be your 'permission' to move forward and make the decisions you need to make. If your decisions are criticized, give them one of your caregiving tasks to do. What is their reaction?

Seek professional assistance

Professional guidance is another way of involving others to help. A professional therapist may help you deal with some of your stressors by helping you understand the stressor and reframe the situation. If you – the caregiver – can learn to adjust your thinking, you may feel more positive and in control. If you find yourself in the following circumstances, you may want to consider seeking professional guidance.

Fill in the circle if:

- You find that you're using alcohol or other substances to forget your problems, relieve stress, fall asleep or get going in the morning, or get through the day.
- You become depressed.
- You are having thoughts of hurting yourself or your care receiver.
- You find yourself feeling resentful and losing emotional control or neglecting, humiliating or becoming physically rough with the care receiver.
- You are being physically or emotionally abused by the care receiver.
- Your family cannot resolve problems or reach agreement on care decisions.

Don't be afraid to seek assistance and don't wait until you're overwhelmed to do so.

Use community resources

Long term care involves a range of services for the care receiver and the caregiver. These services may be provided in the home, in the community or in a facility. Some services provide care for the care receiver but the service that is provided offers some respite for the caregiver.

- ♥ Learn what's available before you get overwhelmed. Learn what options there are before you are rushing to address a crisis. Learn what Medicare covers and (importantly!) what it does NOT cover. (Medicare does not cover long term care in a nursing home and covers very little of in-home support services.

Prices for long term care have a broad range. Services are available in some areas but not in others. State programs vary.

Some services are free or donation-based. Some services are provided on a sliding-scale fee, and others are offered at a fixed rate. Some programs have age, income and/or asset requirements.

Find out what is available for you and for your care receiver. Contacting agencies requires time and energy, and requires that you have an opportunity to talk. This may be a task that a family member or friend can do, or perhaps they could care for the care receiver while the caregiver makes the contacts.

All of this adds up to self-care.

TAKE CARE OF YOURSELF

Do you have someone with whom you can talk openly? Having a sounding board is important in coping with the caregiving role.

Caregivers experience a variety of emotions. It is difficult to watch someone you love decline. You may experience conflicting, confusing, and ambivalent emotions. You may feel love, sadness, frustration, dislike, repugnance, guilty, grief, fear, resentment, hopelessness or despair. You may feel angry at the care receiver's dependency; frustration at your lack of control over the situation; guilt at the anger you feel toward the care receiver; resentment at the life you no longer have; and/or despair over the seemingly never-ending caregiving.

Feeling unappreciated is another difficulty for the caregiver. Some care receivers are unable to express gratitude; some are contrary, angry, have never been people to say "thank you" or only express displeasure or negative feelings.

The range of emotions that accompany caregiving is normal. They are neither good nor bad nor do they reflect the degree of your caring. Feeling angry doesn't mean that you love the care receiver any less. What is important is how you deal with these emotions. Learning to channel this energy, deal with the tensions and expressing the emotions in constructive ways is critical to the caregiver's emotional and physical health.

Stress has fewer negative effects for those who can acknowledge their feelings and act on them constructively. Acknowledging and understanding your emotions gives you control. Repressing or denying feelings takes energy that can be better used elsewhere. Irritability, depression and/or physical issues may result from "holding it in". Your feelings also influence your judgment. Your caregiving abilities also decline if your health declines, if you are exhausted, if you are angry and not addressing that anger.

Sometimes it is hard to express your feelings to someone else. If you want to punch a pillow – punch a pillow! Exercise. Write your feelings in your personal journal.

<u>Use assertive communication</u>

This doesn't mean that we are expressing our feelings in a manipulative, unkind way. It doesn't mean that we are projecting anger or hostility. What it does mean is that we are being firm in relaying our needs, and those of our care receivers.

When conflicts arise, discuss the issues with those involved. Own your feelings. Use "I" statements and be specific about what is bothering you. Avoid "you" or blaming statements that sound accusatory which tend to create defensive arguments and can provoke others to react rather than discuss and see solutions. Avoid "always" and "never".

Assertive communication encourages problem solving. Sharing your feelings with other family members allows for brain-storming to seek options for difficult situations. It also allows for constructive expression of feelings.

Support groups or therapists

Support groups can be extremely valuable for caregivers. They allow free expression of feelings in a safe environment. There are often great suggestions for interventions as the people in the group share the common experience of caring for someone. Support groups can offer a new perspective on a situation as the caregiver is often too close and too invested in a situation to be able to view it clearly.

Support groups are available in some areas and provide support for various concerns such as dementia, grief, Parkinson's disease, stroke, and others. There are also on-line, social media, and virtual support groups.

Many caregivers find that support groups help them feel less alone, give an opportunity to share with others, provide new techniques for care and coping, and provide opportunities for giving and receiving information.

Caregivers may want to contact the group facilitator about the group process (educational and/or support, peer or professionally led). Is the group open and continuing or a time-specific group?

Some caregivers opt for one-on-one support with therapy. There may be deeper issues or the individual support may be more comfortable. Some insurances cover therapy.

Maintain your health

If you – the caregiver – don't take care of yourself and mind your own health, you will not be able to provide effective care for your care receiver. Neglecting your health has long-range negative consequences, and will ultimately wear away at your emotional health and coping abilities. You can become ill, chronic illness can result, and at worst – your situation may decline more quickly than that of your care receiver.

Proper diet, sleep, exercise, regular check-ups, and attention to health problems are essential! Keep up with dental care, annual preventive tests such as mammograms, prostate exams, and lab work. Take your medications. Be pro-active with your health and well-being!

Without adequate nutrition and rest, the caregiver will become exhausted, discouraged and depressed. You can become more susceptible to illness, and your immune system may become less strong. If adequate sleep is a problem, see assistance from overnight helpers.

Exercise has benefits beyond physical fitness. It can promote better sleep, decreases tension and depression, lifts spirits and increases energy. It can lower cholesterol and help with overall health. If you can't go to a gym, incorporate exercise in your daily routine. Take a walk with the care receiver. Check out an exercise or yoga program on TV or get a DVD to follow. Find something you enjoy and can do daily.

In addition, relaxation exercises help reduce tension. Try yoga. Do meditation exercises. Deep breathing doesn't take long and can help your focus and help you get centered.

Don't forget the value of humor! Humor is a powerful medicine for stress. Laughing quickens the pulse rate, stimulates blood circulation, activates muscles, increases oxygen intake, releases endorphins, and fosters physical relaxation. Those are just short-term effects. Over the long term, laughter can improve your immune system, relieve pain, increase personal satisfaction, and improve your mood.

Take time for yourself

What do you do for yourself? What do you do for a personal reward? Do you save some time for yourself each day? OR – are you so involved in caregiving that you have little or no time for yourself?

It is all too common for caregivers to place their needs at the very END of the list. Caregiving may be all-consuming but it is critical that you have (MAKE!) some time to do something for you.

What can you do for YOU? You may have limited time. Any of us who have been caregivers understand that there are not enough hours in the day. But – think about activities that are just for you.

- Read a little
- Spend a little time on social media (Be careful! It's easy to go down a rabbit hole!)
- Take a shower or a bath
- Do a 5-minute meditation
- Sit on the porch listen to the birds, or if you're a bird-watcher, see what birds you can identify
- Listen to a book on your phone or listen to a podcast
- What can you do / what can you work into your schedule that will give you a break but not make you stressed? Write down a few things:
-
-

Plan to take breaks from caregiving. If you wait until you're burned out, breaks will not be enough. Make a "date" or plan for a break. Allow alternative care, set the day / time / place – and follow through!

Finding assistance can take time. Check with a family member (add this to the 'needs' list for your family meeting!), ask a friend, call an agency and set up a regular time for service.

In home respite can be provided by an agency 24/7/365. The care receiver remains in familiar surroundings with supportive care.

Caregivers often don't want to give up ANY of the care for a care receiver. "No one can do it like I do!" or "What if something happens while I'm gone?!" become the caregiver's mantras. Try to objectively evaluate the situation. Others can provide adequate care while the caregiver is out – at least for a short time. If you are reluctant to leave, think about the worst case scenario, and plan for that. Write those plans down, as well as your contact information so the 'substitute' caregiver can contact you in case of an emergency.

Caring at a distance can make caregiving more difficult and more stressful.

LONG DISTANCE CAREGIVING

Receiving calls about the care receiver from concerned friends and neighbors is disconcerting, and it's difficult to determine needs without being close.

Establish a network

Establish a network of friends, neighbors, church family and professionals that can help assess the care receiver's needs and arrange for services.

Think before you move the care receiver

Perhaps you're thinking about moving the care receiver close to you. Only children, those caregivers who have the primary responsibility of care, or caregivers who have no relatives living close may need to make decisions regarding the care receiver's living arrangements. Carefully weigh the advantages and disadvantages of such a move. Consider the implication for the present as well as the future. Consider the advantages and disadvantages for both the care receiver and the caregiver.

ADVANTAGES	DISADVANTAGES

Consider medical care, getting new physicians, insurance coverage (does coverage extend to the area where the care receiver would be moving?), change in routine for the care receiver, change of supports for care receiver, housing, etc. How will this impact your family? Your partner?

A move can separate the care receiver from established roots. A move can precipitate increased dependence on the caregiver for social, spiritual and recreational outlets. This can be more difficult if the care receiver doesn't make friends easily, can't get out without assistance, or is unable to initiate the action necessary to create new relationships.

A move needs to be considered in regard to the past relationship with the care receiver. Relationships that were difficult in the past will not be eased with this change. You may want to explore services in the care receiver's current location to see if your loved one can remain in their own home in their own area. Perhaps assisted living in their home area would be a preferable solution.

Think carefully about the implications of a move – for you, your family, and the care receiver.

Long distance caregiving may mean that you have paid help or support from friends or family who live close to the care receiver. Make sure to offer support to those who are helping!

Support the local caregiver

If you live at a distance, it is important to support those who are providing daily support. Perhaps the care receiver takes out their frustrations on the day-to-day caregiver. The care receiver may "perk up" or seem OK to the visiting family (which probably takes a great deal of energy on behalf of the care receiver). The day-to-day caregiver sees the care receiver frequently but the visiting family doesn't have the same perspective.

Local caregivers may need to compromise with the care receiver or follow the lead of the care receiver. The care receiver may adamantly refuse to let the day-to-day caregiver do certain tasks or help with household chores. Make sure to encourage an open line of communication about these situations. You need to know if the care receiver is setting these limits for the day-to-day caregiver!

Be prepared for changes

If you are unable to visit regularly, you may be surprised by changes in the care receiver. You may think that you haven't been given accurate reports of how the care receiver is doing. But, you need to keep in mind that the day-to-day caregiver is with the care receiver regularly and adjusts to those changes whereas you haven't seen the care receiver as frequently and have a different frame of reference for those changes.

For the day-to-day caregiver, try to understand the out-of-town caregiver's perspective. Keep the long distance caregiver informed and involved indecisions. What are the needs? What specific help is needed? What changes have been noted with the care receiver?

PLACEMENT IN A CARE FACILITY

There may come a time that the care receiver needs more than can be provided in home, or the caregiver can no longer provide that care whether it's the emotional toll or the physical toll. It is important to note that while the home caregiver may be the only person providing care in the home, the facility has numerous people taking care of the resident's needs. There is housekeeping, dietary, laundry, registered nurses, licensed practical nurses and certified nursing aids.

A move to a facility does not mean that your caregiving days are over! Your role has changed but you are still a caregiver. You are now a link to the community, a link to the church family. You are a member of the health care team that is caring for your loved one and you will be participating in planning care, assisting the staff in understanding the care receiver's needs, and monitoring the care that they are receiving. You are a historian, helping the staff get to know who your loved one is. You are an advocate for your loved one.

The potential benefits of placement for your loved one include increases social contact, recreational and social activities (with their peers) and rehabilitation services. You will be better able to help meet some of the emotional and social needs as you are no longer devoting so much time to the hands on care.

Talk to the health care professional about the level of care needed. Does the care receiver need assisted living or nursing home care?

What facility should you choose? If at all possible, go visit.

When you go – Walk in and stop.

- Take a sniff. What's the facility smell like? Hopefully, it smells clean and "neutral" with no strong smells of cleaners and disinfectants, urine or feces.
- Look around. What do you see? Are residents out of their rooms and engaged?
- Listen. What do you hear? Do you hear residents and staff interacting? Do you hear laughter? Do you hear cries and screams?
  Go unannounced and schedule an appointment for a tour. Go to the admissions office and ask to schedule a time to talk and take a tour. I firmly believe that we need to stop in but we need to be considerate and not expect staff to drop everything just for us.

When you go for a tour, talk to the residents. Do they seem happy or content? How is the food? (This is usually an area where residents complain most!) How is the staff? Are they kind? Are they attentive? Is there enough help?

If your care receiver is able to help with the decision, engage them in the search. Can they go with you to look at a facility? Perhaps the facility has a virtual tour option so even if the care receiver can't go to the facility, the facility can come to them! Just as each of our homes is different and reflects our individual tastes, so do nursing homes. Décor is different. Layout is different. Room arrangements are different. Do your homework!

You can research facilities through their web pages. You can go to www.medicare.gov and see how the facility has performed on recent surveys. The site will allow you to compare facilities of your choosing.

You can also request to see the survey results at each facility.

When you have narrowed down your choices, talk to the Admissions Director about their application process. Is there a waiting list? If so, how long is it? Can you complete an application? Is there an admission fee?

If you will need financial assistance through Medicaid, talk to Admissions about the process for Medicaid applications. In addition, your health care professional will need to complete a Pre-Admission Screen. This is required of all potential residents.

Placement is a difficult decision for families but there often comes a time that we need to make that decision. We do it for the care receiver when we can no longer meet their needs, and we do it for us – the caregiver – when care is becoming too challenging, too difficult, or too stressful.

You will still be a caregiver. Your tasks will have changed. There will now be several departments to take care of the things that you may have done alone. Housekeeping will keep the room clean and do laundry. Dietary will prepare and serve meals. Nursing staff will administer meds and contact the physician as needed. Activities will plan events.

You will visit. You will be the historian helping the staff get to know your loved one. You will be the connection to family and concerned friends.

You will have adjustments to make. Shifting caregiving responsibilities will be challenging.

CONCLUSION

A great deal of information in this booklet involves the care receiver. The caregiver's life and health is interwoven with the life and care of their loved one. What happens to the care receiver or caregiver impacts the caregiver or care receiver in some way. Working out the care concerns of your family member helps put your 'stress house' in better order.

Caregiving cannot be based exclusively on the wishes and demands of the care receiver. We all want to stay in our own homes. We would like to retain our youth, our strength, our independence. Most often, we do not stay as we were in our youth. Despite exercise and taking care of ourselves, our bodies age and change. Chances are good that we WILL need help as we age, and we WILL lose some of our independence.

Consequences of caregiving decisions must be considered for the primary caregiver, other family members and the care receiver.

Caregiving is not only providing care for the care receiver, it also involves the on-going well-being of the caregiver(s).

During the time you are providing care, not everything will be as you like or want. There will be times you wish you'd done things differently. There will be times that you are making choices between "bad" and "not as bad". If you make a mistake, admit it, look for ways to minimize the damage and move on. There is no advantage to staying on a guilt trip.

♥Don't let irrational thoughts take over your mind. Don't fall prey to the "I should have" or "I shouldn't have". Don't think you should know everything there is to know about caregiving.

Caregivers often focus on what they have not done well. Think instead of where (and how often!) you've done a good job! Ask yourself: what are my personal strengths? Am I making a difference in the life of the care receiver? Am I improving the care receiver's quality of life? What do I feel good about? How do I hope to come out the other side of this journey?

♥Don't neglect yourself.
♥Don't fail to give yourself credit.
♥Take care of yourself!
♥You're doing a hard job!

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God grant me the serenity to accept the things I cannot change,
The courage to change the things I can,
And the wisdom to know the difference.

~Reinhold Niebuhr~

Sources:

(1) Source: Today's Caregiver, "Caregiver Stress Syndrome", Ron Ingber, JD, https://caregiver.com/articles/caregiver-stress-syndrome/ , May 12, 2021

(2) Source: Forbes, "Can Caregiving Cause PTSD?", August 21, 2020, https://www.forbes.com/sites/nextavenue/2020/08/21/can-caregiving-cause-ptsd/ https://www.caminorecovery.com/blog/why-family-caregivers-are-likely-to-develop-ptsd/

(3) Source: "Coping with Post Traumatic Caregiving", Mike Verano, LPC, LMFT, https://www.psychologytoday.com/us/blog/confessions-of-a-psychological-first-responder/202312/coping-with-post-traumatic-caregiving

(4) Source: Forbes Health, "Caregiver Burnout: 8 Ways to Avoid It", Marissa Conrad, Rufus Tony Spann, PhD, LPC, www.forbes.com/health/healthy-aging/how-to-avoid-caregiver-burnout, 06/23/2022

(5) Source: Mayo Clinic, "Caregiver Stress: Tips for Taking Care of Yourself", Mayo Clinic Staff, https://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/caregiver-stress/art-20044784

NOTE: Credits are listed for known sources. Most of the information is from a long career in geriatric social work working with older adults and caregivers. The information has been pieced together from many sources, a lot of years of experience, and from the shared experiences of those with whom I've worked.

(6) Read more about "Irrational Beliefs: 12 Irrational Beliefs", Albert Ellis, The Emotional Intelligence Training Company, https://selfdefinition.org/psychology/Albert-Ellis--12-Irrational-Beliefs.pdf

APPENDIX

Locating community resources

To help you find resources to help with your caregiving needs, contact the following:

Altenheim Resource & Referral Services
304 243-0996 or akoegler1995@gmail.com
Hospital discharge planners
County senior centers

Find state specific information
Area Agency on Aging
State office on Aging
Aging & Disability Resource Networks

Locating Support Groups

To find a support group that addresses your needs, contact the following:

Altenheim Resource & Referral Services
304 243-0996 or akoegler1995@gmail.com
Local hospital
Check with social services department, discharge planners, or pastoral care
Area Agency on Aging office or Senior Center
Funeral homes, churches, hospice organizations
Grief support
Specific organizations
Alzheimer's Association
Parkinson's Foundation or Parkinson's Association
American Cancer Society
Family Caregiver Association

Locating professional assistance

To find a professional to help with your caregiving needs:
Altenheim Resource & Referral Services
304 243-0996 or akoegler1995@gmail.com
Area Agency on Aging
Find your Area Agency on Aging and other state resources by contacting Altenheim Resource & Referral Services or check out this search tool.

To find a professional to help you cope with your caregiving situation:
Mental health facility
Private therapists
Emergencies: Dial 911
Suicide & Crisis Lifeline: Dial 988