

Caregiver's Companion: A Practical Guide to Achieving Hannohy in Your Caregiving Role

By: Robin Weeks



Becoming the primary caregiver for my parent wasn't a calling... It was just what I did as the only daughter.



Caregiving is hard. It is lonely, and it is a roller coaster of emotions.

When I was a caregiver to my mom, it changed me.

Our journey together was the hardest thing I have ever done. I made a lot of compromises, and I made many mistakes along my path. Those years were some of the best and most heartbreaking.

I also learned so much... how to better care for myself, how to be prepared for the events that will happen and where to go for resources.

Yet something was always lacking.

I felt like I didn't know anyone who could relate. I didn't know where to go for support. I tried support groups, but they didn't offer the level of help and compassion I needed. I tried self-help books, but it wasn't more information I was after.

#### **Robin's Journey**



#### I needed a place where I could be open and candid, somewhere I didn't feel judged or labeled...

Trust me, I had enough self-imposed guilt that I didn't need or want anyone else dishing that up as well.

Yet no matter where I looked, I couldn't find a community that managed to nurture my emotional, social, and spiritual needs, nor one that provided the day-to-day insight I desperately craved.

After my mother passed, I decided to create something in her memory.

My Pivotal Point is an incarnation of that time.

I have taken my journals from those years, my memories, and my recorded conversations, and fused them with the training I have since taken, plus countless conversations with other caregivers, to create the PATH Program you are about to embark on.

My hope is that this feels like a loving place you can go -- free of judgment or criticism. A place that you can turn to for education, support, laughter, tears, and to have your questions answered.

Thank you for being here, and thank you for the hard work you do every day.

You are appreciated.

Letter to my readers



Dear Caregiver,

ドートリーンション

I am so glad to have you here with us on your caregiving PATH. You may have started some time ago or are just beginning in this role. I have information, education, resources, tips, and strategies for no matter where you are on your PATH.

This booklet is based on content from the Insights and Learning section of your membership. Inside, you'll find pages to journal and reflect on, pages for you to keep records, pages for you to learn from, and pages to inspire you throughout your journey.

Caregiving is hard. I won't tell you otherwise. It also can bring you moments of love, compassion, joy, and sadness. This is an opportunity to embrace these many emotions and feel true, deep compassion for another person. Even on the hardest days of caregiving, there is something rewarding about taking care of another person when they most need it...

## Letter to my readers contunued

My approach is proactive. I learned the long, hard way that taking a preparing, planning, and mindfulness stance helps you keep your life in balance and harmony. When stresses hit you (and they will), you can come to your Companion to write or find a resource and support.

Please note that while many of the resources listed within this Companion are U.S.-based, I certainly appreciate my international audience. I have tried to incorporate as many resources as possible from around the world; however, in the interest of brevity, I have focused primarily on the country where most members are located. I will continue updating this with global resources as soon as possible.

Know that I'm here to guide and nurture you on this PATH through caregiving. Please reach out if there's anything I can do to better support you!

With love, Robih Weeks

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## **GRATITUDE & GIFTS**



## Express Your Gratitude... to Improve Your Health

Caregiving has ups and downs. While it can seem like there are more downs than ups, it's important to teach your brain to recognize the gifts, the moments of happiness between you and your loved one. Writing 3 reasons for gratitude every day can shift your brain and make it easier to then handle the tougher moments.

Emotions can bottle up inside you, but you don't have to let them. You can master your thoughts, feelings, and emotions and learn to let them out in positive ways, so they don't cause you stress and harm.

One of the best ways to improve your health and handle your emotions is by expressing your gratitude. Yes, really!

Ask yourself: What are you thankful for? Who matters in your life? Even when life may not be going as planned, there are still many things to be grateful for.

Give Your Gratitude Away

No matter how much you appreciate someone in your life, that person may not have any idea about how you feel. Rather than just assume they know your thoughts and feelings, go ahead and speak up. Tell them how you really feel and what's in your heart. See the smile? It feels good, doesn't it? When you smile back, laugh, and even share tears of joy and love, it helps your heart, mind, and body thrive. It releases a flood of chemicals that your body just loves. It's a "feelgood" thing to do. That's true for both you and the receiver of your gratitude.

Maybe you're grateful for something you have, as opposed to a person. Did you ever think about sending a thankful message to the company that makes the products you love? They probably hear all about customer complaints, but how much gratitude do they get for the work they've done to make lives better or more convenient? Give them some of your gratitude and you'll spread joy all around!

Ways to Show your gratitude

Showing gratitude is something you can do quite easily and all it costs you is a little bit of time and effort.

Here are some ideas to get you started:

- Tell your loved ones you care for them.
- Hug a friend who's hurting.
- Smile at a stranger.
- Write to a company whose product or service you really love.
- Make time to listen to someone who needs to talk.
- Spend some time out in nature, appreciating the beauty of creation.
- Volunteer your services or help someone in need.

You can also show your gratitude just for being alive by treating others well and being kind to yourself. Relaxing and taking time to unwind from the stress of everyday life is very important, and you'll be happier and healthier because of it.

## Focus on What Really Matters

Many people are unhappy with their circumstances, and it's often because they feel they don't have enough money, a big house, or the ultimate car. These things are nice, but in the grand scheme of things, they don't really matter. After all, when you're on your deathbed, will you wish you had that red Ferrari? Or will you wish that you had more time with your loved ones?

Connect with what really matters by being grateful for all you've been given.

There will be obstacles and stumbling blocks in life, but there is joy all around you as well. When you tap into that joy, keep a positive attitude, and show how grateful you are, you'll prove that you're able to let go of unnecessary baggage. It's a great feeling, and one that you can give yourself, today, right now. What a wonderful thing to be grateful for!



# Reaping the Benefits of a Gratitude Journal

It might seem like a pipe dream that writing in a journal could be so beneficial. But the scientific evidence is in, and gratitude journals do benefit you in big ways if you keep one for the long term and use it daily. It's a mind shift. Thinking and writing about your gratitude creates new pathways in your brain that create a more positive view.

Experience Stronger & More Fulfilling

Relationships

It's so simple, but it can be hard to accept. You are the one who makes yourself happy with your own choices. Another person cannot make you happy or grateful. Only you can do that. But something amazing happens when you express gratitude often ñ your relationships simply open up and become better. Those that don't, you start to recognize what they are and let them go.

Become Physically Healthier

Being grateful for the ability to move and breathe will eventually cross over into wanting to ensure that you can always do that. Therefore, you'll be more motivated to go on walks, eat right, stay hydrated, and live in gratitude for every aspect of your life.



Therease your Mental Desterity

The ability to take lemons and turn them into that sweet, delightful state drink of Arizona can be gained by keeping a gratitude journal. The main reason is that you will learn on even a bad day to pick out the good in it. That requires a good imagination and creativity and thinking on your feet.

Feel less Aggression in your life

It's hard to feel aggressive if you are happy and grateful. It's okay to be angry about injustices in the world without being aggressive. But if you feel angry a lot due to your life, it's really due to not finding the things to be grateful about. There is almost always something for most people.

Act and Become More Empathetic

As you write more and learn to forgive yourself as you seek to fill your mind with thoughts of gratitude, you will start seeing others differently. You'll have more ability to put yourself in their shoes and see things from their way without judgment. It happens when you learn to forgive yourself.



Get More Restrul Sleep

If you're not anxious but go to sleep each night feeling thankful for everything you've experienced (or at least most of it), it's easier to sleep because you have less anxiety.

Get More Dohe Every Day

Due to feeling more rested, less stressed, and more grateful, you'll have a lot more energy to get things done every day. That is always going to make you feel even more thankful because good things happen due to productivity.

Feel Better About Vourself

You can't help but feel better about yourself when you have improved so many good qualities about yourself. Your self-esteem will go up when you express gratitude for what your mind and body can do for you.

If you want to be happier, get more done in life, and experience real joy, a gratitude journal can be the way to achieve it. The guiding thing to remember is that your thoughts cause your feelings, and you are the one in control of the actions you take once you accept your feelings. Accepting that you do have control is half the battle, and your journal will make it clear that you do.



Gratitude has been identified as one way for caregivers to cope with the stress of their duties. Write three things you are grateful for each day.

DATE:

#### TODAY I'M GRATEFUL FOR...



#### DATE:

#### TODAY I'M GRATEFUL FOR...



#### DATE:







#### DATE: TODAY I'M GRATEFUL FOR...

2.				
3.				

#### DATE:







#### DATE: TODAY I'M GRATEFUL FOR...

2.				
3.				

#### DATE:







## DATE: TODAY I'M GRATEFUL FOR...

2.				
3.				

#### DATE:



#### TODAY I'M GRATEFUL FOR...



#### DATE:

#### TODAY I'M GRATEFUL FOR...



#### DATE:



#### TODAY I'M GRATEFUL FOR...



#### DATE:

#### TODAY I'M GRATEFUL FOR...



#### DATE:



#### TODAY I'M GRATEFUL FOR...



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#### TODAY I'M GRATEFUL FOR...



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#### TODAY I'M GRATEFUL FOR...



#### DATE:

#### TODAY I'M GRATEFUL FOR...



#### DATE:



#### TODAY I'M GRATEFUL FOR...



#### DATE:

#### TODAY I'M GRATEFUL FOR...



#### DATE:



Gratitude & Gifts-

"Some days there won't be a song in your heart. Sing anyway."

**Emory Austin | Speaker** 



## HEALTH & SAFETY



## Make A Plan for Your PATH



Use this as a daily way to remind yourself of what you need. Prepare, Plan and Be Mindful

I AM GRATEFUL FOR:	I WILL TUNE INTO:
MY SELF-CARE INCLUDES:         Foods       Friends         Exercise       Family         Laughter       Hobbies/ Fun         Spirit       Foods	I WILL FORGIVE:

## My Care Plan

We need care plans for all sorts of situations. This worksheet is for you to create those plans so that when a situation occurs you can refer here and not panic for help or resources.

Important Documents Can Be Found Here:

In Case of An Emergency:





What do I need to do first?

Am I prepared with gas in the car, phone charged and charger with me?

Do I know where the important medical records are?

What is the name and phone number of my loved one's medical doctor?

How will I take care of my work?

Who will pick up the kids? Take care of my pets?

## My Plan for a Vacation, Break or Business Trip is:



Do I have all the important contacts stored on my phone?

Who is my backup in case of an emergency?

How will they reach me?

What level of responsibility do they have, or have I given them?

Which family members can help and what can they do?

Who are the neighbors I can rely on for help?

## My Plan if I Am Ill or Injured Is:



Who is my number one back up person?

What decision making limits do they have?

Who is my number two back up person?

How much responsibility are they willing to take on?

What will I need done for my parent, spouse, other?

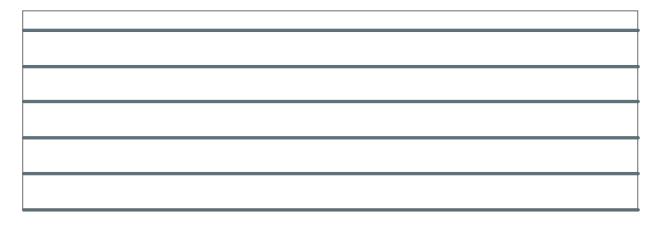
Who will take care of my family?



#### Who needs to be contacted?

Siblings?			 
Names:		 	
Numbers:			
_			
Neighbors	\$?		
Names:			
Numbers			
Friends?			
Names:			
Numbers:			

What Other Situations Will I Need to Plan For?



### **Easing into Caregiving**

There is one axiom that if your parents don't pass away young in life, you are going to watch them age. Now for the most part, this is a natural and nice part of life because mom and dad can slowly become grandma and grandpa which are nice roles for them after working so hard to raise you.

But a corollary to that axiom is that if mom and dad are going to age, at some point you are going to begin helping them with the daily affairs of life. And that occasional helping will escalate as their needs grow strong until you will become a full-fledged caregiver for an elderly person.

For many, the time when you suddenly become a caregiver is just that – sudden. It happens often after the death of a parent and the widowed parent suddenly becomes needy because of the loss they are experiencing. For married couples who have been together for decades, that loss is equivalent to the loss of a limb and far more devastating so that may be the time when you suddenly go from having few concerns for your aging parent to having many.

It might be strange to look at it this way, but the more you can ease into care giving, the more time you must get used to it, for your elderly parent or parents to get used to it and for your family, friends and coworkers to get used to it. And if you can step in and make some minor changes to the environment of your aging parent, you may be able to delay the time when they become very dependent on you. • Go through the house and make it easy for your parents to use. You can put in those walking and grab bars along the halls and in the bathtub and other places where your mom or dad might need the additional support. You can check the lights so there is plenty of visibility for what your parents must do.

To really take the preparation of your parent's living space for their ease of use and safety, look at pulling emergency pull ropes in every room. These units are used extensively in assisted care units, and they make it possible for your parent to pull that cord if she is in trouble and set off an alarm or call to you or to emergency care, should there be a sudden medical need.

By working to make your parent's work area easy to use and safe, you can do a lot to put off the time when your mom or dad may have to move to a retirement village or nursing home. And you keep them independent which allows you to slowly ease into caregiving which is much easier on everybody.

If your parent or parents are still living in their own home, there are things you can do to make their living space more accessible and safe including...

- Create a lifestyle that is all on one level. Stairs can become a hazard for an elderly person. So early in your plans to adapt their living space, move them into a ground floor bedroom and put all significant rooms, including the kitchen, the pantry, the laundry room, and the living room on the same level.
- Take some of the work out of daily chores. Most local grocery stores will deliver food to the elderly so you can make those arrangements for your aging parent. You can also find services that work by the hour that come in and clean the house, do simple repairs and chores, and take care of the business of homeownership for your parents.
- You can decide with home health care professionals to drop by for an hour or two a week just to make sure your parents' medications are still safe to use, that all prescriptions have been filled and that your parents understand their medications and when and how to take them.
- Reorganize the kitchen so things your parents will use every day are on an eye level shelf and are easy to get to and to put away after washing. Make sure the toaster oven, microwave and other important appliances are also easy to get to and that your parents are comfortable with these units if the models that may have come with the assisted living center are not familiar to them.



### A Place To Go

When you first started working with your elderly mom or dad in helping them settle into their retired lifestyle, you exposed yourself to all kinds of services that can help take care of senior citizens. If you feel your parent could use being with people during the day but you are not able to be free to provide that support because of your job, the idea of an adult daycare is often suggested as a solution to the problem.

Of course, the phrase "adult daycare" can be upsetting because it only goes to reinforce the image of your adult parent becoming an infant and having to be treated as such.

So, when you suggest that you work together to find a place, they can spend time during the day, don't refer to it as an "adult day care" if you can. Immediately the senior citizen will feel that you are just "putting him away" somewhere so he won't be a nuisance to you. And you don't want him to get that idea.

But many seniors are open to going to a senior citizen's center or to a church program for the elderly that serves the same function. The best way to find the right adult day care situation for your parent is for you and your elderly parent to take a tour of what is available locally and make the decision together. To do that, you will want to come armed with some pertinent questions for you to get some peace of mind about letting your mom or dad spend time there each day.



### **Questions to Ask:**

- Do they provide transportation to the different assisted care facilities in town? Does that transportation continue to run all day? You don't want your parent going to the center and "getting stuck" there. If there is transportation, that won't happen.
- Do they have qualified medical people on hand should any problem come up?
- How many seniors are there on any given day? Too few implies that the center isn't providing good service. Too many and your parent could get lost in the shuffle.
- Do you provide food and beverages if the stay is all day? Are your food services sensitive to diet issues if your parent is diabetic or has other diet restrictions given to him by his doctor?
- What are the costs?

Of course, for your mom or dad, the activities that the day care center offers will be a big part of their willingness to go there. During football season, if the center just provides a place where elderly men can cheer for the game or have other sports programming available, that is a lot more fun for your dad than sitting alone in his apartment and watching those same sports.

If the day care center has a variety of activities that appeal specifically to each gender and then others that everyone can enjoy such as card games or puzzles, it could be an upbeat and fun place for your parent to pass the day.



By spending some time there, you can get a feel for the friendliness of the staff and the general atmosphere of the center to determine if this will be a warm and welcoming place where your parent will have some fun and meet new people or a place where he will feel alone and out of place.

But if you can find a good day care center for your senior citizen, it can take a big load off your mind. And if you know he is having fun each day and getting out with people, you know that will be healthy for him and be invigorating so he will eat better and sleep better that night. And that solves a lot of problems all at once. Take this list of questions with you when visiting an assisted living facility, nursing home, or adult family home.

- 1. What is included with your 'doctor care' service:
  - a. Does he/she actually see patients or just review records and give orders?
  - b. How often does the doctor see residents?
  - c. Can you meet with the doctor?
  - d. If you are POA, will you want to have approval of medications?
  - e. How quickly are you contacted in the event of an emergency, fall, or illness?
- 2. What is involved with your 'nursing care' service:
  - a. What can a nurse offer in terms of care?
  - b. What is the nurse's level of licensing?
  - c. What is the ratio of nurses to Certified Nursing Assistants?
  - d. What is the ratio of care staff to residents?
- 3. How frequently do you check on residents:
  - a. Coming to meals
  - b. Encourage them to participate in activities
- 4. If residents share a room and the roommate is not compatible, can they change?
  - a. YES
  - b. NO
- 5. Is there a social worker on staff?
  - a. ALWAYS
  - b. SOMETIMES
  - c. NEVER

## **Questions to Ask a Care Facility**

- 6. Do you provide the residents with your own transportation?
  - a. ALWAYS
  - b. SOMETIMES
  - c. NEVER
- 7. Do you rely on public transportation to transport residents?
  - a. ALWAYS
  - b. SOMETIMES
  - c. NEVER
- 8. Tell me about your laundry care:
  - a. Frequency?
  - b. Hot water and industrial tubs?
- 9. How do you monitor diets:
  - a. Is there a nutritionist on staff?
  - b. Do you offer flexible meal options?
  - c. What happens if a resident stops eating?
- 10. What is included in the monthly or annual cost:
  - a. TV?
  - b. Internet?
  - c. Phone?
  - d. Medication Management?
  - e. Entertainment?
  - f. Hygiene?
  - g. Meals?





- 11. What about housekeeping:
  - a. How often?
  - b. What is the scope of cleaning services included?
  - c. Are the housekeepers insured?
  - d. Are the housekeepers part of your normal staff or contracted out?
- 12. What sort of activities are offered and how often:
  - a. Are outings offered to those who are mobile?
  - b. Is mobility assistance available?
  - c. Is there an onsite Activities Director?
  - d. What types, and how many, activities are planned in a week?
  - e. How are residents informed of the activities offered?
  - f. Look at a sample schedule or ask to attend an activity.

13. How often do you hold family care planning meetings and how will I be notified when they take place?

14. What happens if my loved one experiences an emergency?

15. What else should I know?

### When Is It Time to Step In?

There comes a time in the adult lives of children and their parents when it dawns on you that you might have to step in and be more active in your parents' lives, not as a child but as a caregiver. For every family, that time seems to come as a shock.

It's strange because we all see reports on television about the transition that we go through when the parent becomes the dependent one and the child becomes the one making decisions in the relationship. And the hardest part of that transition may be the first time you have to step in and "stage an intervention" because there is an area of life that your parent needs to let go of and you know they won't want to. So what are the signs that it's time to step in and suggest or directly take action to make that change in your parents lives?

When it comes to driving, your dad or mom's doctor will be able to help by determining if your parents are physically able to drive any more. When the senior citizen's eyesight dims to where he or she cannot distinguish details in the distance or when depth perception is poor so he might not be able to judge where the intersection is or if he is stopped at the stoplight or in the middle of the intersection, the time is right for Grandpa to give up the keys and let someone else do the driving. The time to start the process of moving mom or dad out of their own home and into an assisted living facility may be more tricky to determine. As with driving, the senior citizen will mount every effort to appear to be competent to continue to live independently. That ability to live on our own, go where we want when we want to and take care of our own needs is so fundamental to who we are and to our self esteem that this transition from living on their own to living where everything is done for them is emotionally difficult to be sure.

So you as family members and as the caregiver for your parent need to watch for the signs that your parent's ability to take care of the house and of themselves living independently has come. Some of the symptoms of the need for change are...

- How is your mom or dad's health holding up? Are they eating well? Check the pantry and the refrigerator. Is it full of good things to eat, fresh foods and lots of supplies for cooking or is it sparse showing that going to the grocery store is a trial for your parent?
- Are your parents taking care of themselves? When you come over, do they look like they are sleeping ok? Are they groomed and clean and are their clothes clean and ready to use or is everything wrinkled because it's too hard to do the laundry and press shirts and blouses?
- How does the house look? Is it in good repair? Is it picked up and the kitchen clean with everything put away? If mom was always meticulous about her kitchen and now it's always a mess, she is having trouble keeping up with the housework.

• Does mom or dad stay home all the time? If they were normally outgoing and always up for a car trip, an outing to church or even just the grocery store or even an adventure, becoming a homebody signals that they don't want to go through the trouble of getting fixed up to go out.

Of all these symptoms, probably the one that signals the time to step in and take action is immediate if your elderly parent falls or goes to the floor and then cannot get up. If your mom or dad has to pass the night on the living room floor because they could not get up and had to sleep there until someone showed up to help them, that's an emergency situation that calls for immediate action.

Talk to your elderly parent about the risks of living alone, particularly in a scary thing like being unable to get up. By the time such a frightening incident happens, your parent may be suspecting the time to go somewhere where they can live with greater security and safety is here.

## Making a difference Together



There is something very self-absorbed about the caregiver to senior citizen relationship. By that, I mean that most if not all of the decisions you make, and subjects of concern focus either on the senior citizen and her needs or on the caregiver and the senior citizen and how you will work together to address her needs.

It's no wonder, then, when we think about what your elderly parent talked about all day, it tends to be one thing: himself! And by nature of their relationship, a conversation between caregiver and cared-for often circles around the needs of the one being cared for. As they age and their abilities slip away, their world slowly begins to downsize. The ability to drive, the ability to use the restroom, the ability to care for themselves... Their whole worldview shrinks just as yours is quite possibly getting larger.

But we know from raising children that having an ego-centric worldview can be unhealthy. It's easy to become a hypochondriac and overwhelmed when the world starts and stops at your doorstep.

Volunteer Activities to Do Together:

- Pick up trash on a slow walk
- Visit someone else in the retirement community that he or she knows is lonely and would enjoy company.
- Stuff envelopes or make phone calls for your church or a charity organization.
- Read to disadvantaged kids at the local library.
- Become a big brother or big sister and take a young person to a ball game or to the zoo.





- Volunteer vacations.
- Join gardening clubs.
- Life story exercises.

Most cities have a volunteer coordination agency that can match up your physical abilities with volunteer opportunities. Once you get your elderly parent involved in doing something for others, don't be surprised if their enthusiasm takes off.

The great feeling of making a difference for others can literally turn his or her life around. Enjoy the chatter that's sure to come. You'll soon realize just how much your loved one's life has transformed when requests for more time to volunteer start pouring in. And that's a good thing.

Protect Your Peace of Mind with Advance Health Care Directives and fiving Wills

Do you want to ensure that your loved one's wishes and beliefs are upheld with regard to medical care? Advance health care directives instruct others about your wishes concerning medical treatment, should they become unable to communicate those wishes themselves.

Documenting their plans can give them greater peace of mind and make decisions easier for everyone in potentially stressful situations. Here are some steps that will help you create these important documents.

### 1. Have your loved one's wishes and beliefs honored.

It's natural to feel uncomfortable thinking about physical incapacity and death, but it's comforting to know that you can exercise some control. Your loved one will feel more secure if you take every possible step to ensure that the medical care received is consistent with their personal values and beliefs.

### 2. Relieve your loved ones of unnecessary burdens.

It's difficult for your loved ones to know what you want unless you talk with them in advance. If your loved one is still able to, they can help family stay calm and united.

### 3. Help professional caregivers help you.

Doctors and nurses have demanding jobs. Make it easier for them to provide your loved one with the best care, even if that means referring out to a provider who better serves their needs.

### 4. Consider creating a Durable Power of Attorney.

This advance directive lets your loved one appoint another person who becomes their agent for making medical decisions if they are incapacitated. It's sometimes also called a Medical Power of Attorney. This power extends to all medical decisions unless you specify additional conditions.

### 5. Understand the limits of living wills.

A living will expresses your loved one's desires regarding life-sustaining or life-prolonging medical treatment. Practically speaking, their effectiveness is very limited, compared to a Durable Power of Attorney.

### 6. Decide on Do Not Resuscitate Orders.

One more directive is worth mentioning: Do Not Resuscitate Orders. These provide instructions to medical personnel if your loved one wishes to decline life-prolonging measures under certain circumstances.

### 7. Select a health care agent.

A health care agent can be your spouse or another close family member or friend. An agent may also be called a surrogate or attorney-in-fact. In any case, your loved one should select someone you trust with such a serious responsibility.

#### 8. Get the correct forms.

Facilities that receive Medicare and Medicaid payments are required to provide you with written information. You can also obtain forms from local hospitals, community agencies, medical societies, geriatric care managers, and many individual attorneys and physicians.

### 9. Follow local laws.

You may want to seek legal advice to ensure you comply with requirements such as notarization and witness signatures.

### 10. Distribute copies to key individuals.

An advance directive is more likely to be enforced if you give copies to all the key individuals involved. These include your family, your primary care physician, and hospital personnel.

### 11. Talk with your doctor and family.

Your loved one's doctor can help you understand medical implications and terminology to clarify the directive. Most of all, talk with your family about these sensitive issues.

### 12. Keep your directive updated.

It's a good idea to review the directive regularly to ensure it's compatible with your current life circumstances. Experts recommend that everyone 18 or over prepare a directive, so a lot can change over the years.

Advance health care directives can be simple to draft, but involve many complex issues. Get the guidance you need from medical and legal experts so you and your family will be prepared even in difficult circumstances.

Health and Gafety-

"During the 24/7 grind of being a carer, it's all too easy to forget the fact that the person you're doing so much for is and is obliged to be, more resourceful than you in many respects."

Naoki Higashida | Author



## **RECORD KEEPING**

Caregiver Stories

I learned one of the biggest lessons in letting go of control and accepting that Dad was free to make his own decisions in the early years of caregiving. Dad wanted to jump out of a plane for his 94th birthday. He brought it up every day with an insistence that triggered my angst. I wasn't sure how serious he was, but it agitated me. He knew it and seemed amused by it. I would actively discourage him, deflect his attention elsewhere, but mostly I just resisted the whole idea. Dad brought it up with his primary care physician, who said, "Why not?" It was one of those rhetorical questions that I could have answered with a monologue, but in shock, I just stammered, "Why not!" I was finally relenting and asking myself, "What the heck was all the fuss?".

Back at home, I asked Dad if he wanted me to arrange the jump. His friends and family were not happy. They were where I had been. They had not endured the months of daily drama. I did my best to help them catch up and understand that this was the request of an adult with a reasonably sound mind, and we would appreciate their support. My brother and his daughter decided to jump with Dad. We met at the location. Dad's friend, Bud even came along to watch despite being quite unhappy with me for "allowing" this to proceed. He did not hold back either, frequently whispering to me that I should put a stop to this madness. That morning Dad tried to back out, but I pushed him to go ahead as planned and would not call it off unless we were at the site, and he decided at that moment that he changed his mind. I had to ask myself, though, if this pushback was my way of continuing to wrestle for control?

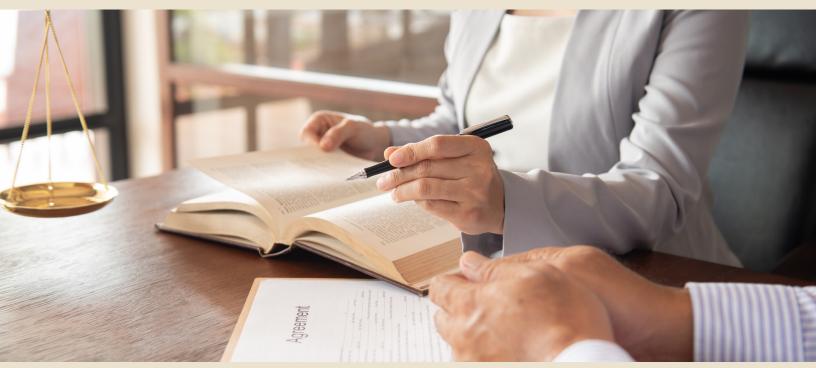
Dad met his jump partner, who said he could land a 94-year-old on his feet. The less risky alternative was to slide in. To me, this all still seemed like a terrible idea, but the release forms were completed so we settled in, watching others go up and come down while waiting for Dad's turn. I just wanted it to be over. I got my wish. The last group to land was a team of instructors who said that the winds had become too dangerous to continue. We were welcome to wait and see if things changed. Dad did not want to wait. We could reschedule or get a refund. Dad opted for a refund. His memory of the non-event doesn't include him trying to back out the morning of the jump. He only remembers that the wind foiled his plan, and that is not wrong.

I recalled this multi-month-long battle each time we butted heads in another clash of wills. Many "disagreeable" decisions that Dad had made could have had repercussions for all of us, and this goes along with the caregiving territory. Safety vs. independence can lead to the most epic battles and leave a path of destruction that takes ages to clear. I found it was better to shed the battle armor, even when your parent wants to jump out of a plane.

Theresa Wilbanks



## RECORD-KEEPING CHECKLIST



Record keeping for all of your legal and financial documents.

Location of Important Documents	Location of Will
Bank Accounts	Attorney
Monthly Bills	Certified Financial Planner or Other Investment Advisor
Investment and Accounting Documents	Insurance Information
Passwords	Bill Tracker



## **RECORD-KEEPING**

## CHECKLIST



Record keeping for all of your medical and health documents.

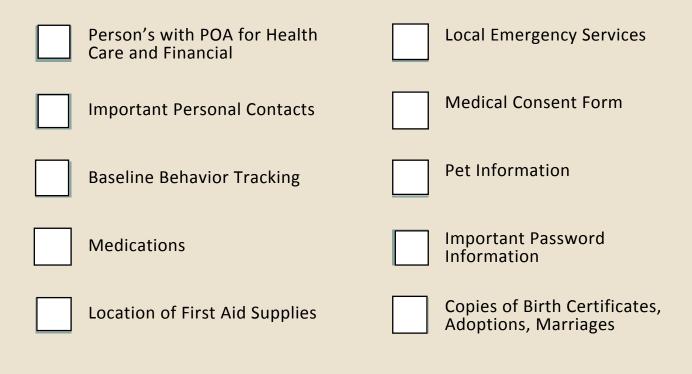




## RECORD-KEEPING CHECKLIST



Record keeping for all of your emergency information documents.





## RECORD-KEEPING CHECKLIST



Record keeping for all of your care provider documents.



## CAREGIVER'S CHECKLIST

Patient Name:	Date:							
Personal Care	Activities & Exercises							
	A	Duration						
Ω		Meals						
	Meal	Time	Amount					
Physical Therapy								
		Medicines						
	Medicine	Time	Dosage					
0		Bathroom						
Housekeeping								
		Supplies						
0								
Caregiver	Notes:							
Name:								
Signature:								

## MEDICATION TRACKER



WEEK 1								
Time	Medication	M	Т	W	Т	S	S	Dose
						Ο		

WEEK 2								
Time	Medication	M	Т	W	Т	S	S	Dose
					Ο	$\Box$		
			0					

WEEK 3								
Time	Medication	M	Т	W	Т	S	S	Dose
						0		
					$\Box$	$\Box$		

WEEK 4								
Time	Medication	Μ	Т	W	Т	S	S	Dose
			$\Box$					



## FAMILY DYNAMICS



## That Thing We Don't Talk About

Have you ever heard the phrase, "The 200-pound gorilla in the room"? It's a phrase that refers to a topic that nobody talks about, but it so dominates everybody's thoughts. Everyone knows the gorilla is there, but nobody gets anxious because, after all, you don't want to upset the gorilla.

There is a 200-pound gorilla in the room in any time being spent with a senior citizen. It is a topic that is blatantly pertinent to anyone in their golden years, but it is a topic that nobody talks about either because it's too upsetting, or nobody knows how to talk about it. But it is a topic that weighs on the mind of your senior citizen mom and dad virtually every day. The 200-pound gorilla in the room is death and the end-of-life issues that are ahead for every senior citizen at some point or another.

As the caregiver for your elderly mom or dad, you should be aware how heavily the topic we don't talk about weighs on the minds of your parents. If you have lost one parent, the surviving spouse is even more aware of the issue. But there are good reasons to remove the stigma from talking about end-of-life issues with your elderly parent. That is because there are numerous ends of life issues about which you must reach some decisions before that time comes along including:



- The condition of the Will.
- Do Not Resuscitate and other advance directive document decisions to give to end of life medical personnel.
- A review of insurance and the location of other financial documents that you, the executor of the Will or the person who has power of attorney will resolve.
- Any desires the senior citizen might have about funeral arrangements.

To be able to discuss the end of life and issues related to death, you will have to be at a point emotionally that you can deal with the topic yourself. Many of us bury our thoughts of death in a mental trick we play that seems like we think we will not have to go through this part of life. We do that perhaps because we prefer to think about life or because we are uncomfortable about discussion of the afterlife and religious ideas.

So, to get ready to be able to be a good caregiver and counselor to your aging mom or dad, you should sit down and get some peace and resolution about the topic yourself. If that means confronting your religious anxieties, well, that is part of adulthood and those who are depending on you including your aging parents and your children may be looking to you for some answers in that area. It will take some courage but face those issues so you can be ready to help your parents face them too. If you have a religious faith and your parents share that outlook, this is the time to review the afterlife assurances that come from your religious upbringing. By spending time with your mom or dad reviewing the doctrines of heaven and the comfort those religious texts bring, you can give them renewed hope and peace about the coming of death because they will know that passing from this life is not the end.

Don't let the 200-pound gorilla stay in the room. Confront the issue of death with your aging parent or parents and do so with compassion and kindness. If you do, you will help your parent reach a place of peace and acceptance about what is going to happen that will benefit them for the whole of their golden years remaining on this earth.



## **10 TIPS ON HOLDING A FAMILY MEETING**

- 1. Find a time that works for everyone. Best to do in person, but if not possible, try a zoom or other live video call.
- 2. Prepare an agenda or list of topics to be discussed ahead of time and share.
- 3. Avoid making anyone feel like it's an ambush.
- 4. Come with an open mind, leaving behind any old sibling or parental issues.
- 5. Set the intention for the meeting and desired outcome.
- 6.Come prepared with questions and curiosity, as opposed to opinions.
- 7. If you have research on things such as assisted living, in home care, or financial planning, bring that with you.
- 8. Set a time limit, don't make this about everything on your list. You may need to do a follow up meeting. Take breaks.
- 9. If the conversation gets tense or people shut down, either move on to a lighter topic, address the emotions in a calm way or reconvene.
- 10. Listen, don't judge, or form opinions or make assumptions.



To help you start to be more aware of your listening habits, complete the following listening self-evaluation. Answer each question thoughtfully and after you have answered all the questions turn to page 3 to score your self assessment.

Listening Habit	Almost Always	Frequently	Occassionally	Almost Never
1. Tune out people who say something you don't agree with or don't want to hear?				
2. Concentrate on what is being said even if you're not really interested?				
3. Assume you know what the talker is going to say and stop listening?				
4. Repeat in your own words what the talker has just said?				
5. Listen to the other person's viewpoint, even if it differs from yours?				
6. Learn something from each person you meet, even if it is ever so slight?				
7. Find out what words mean when they are used in ways not familiar to you?	/			
8. Form a rebuttal in your head while the speaker is talking?				
9. Give the appearance of listening when you aren't?				
10. Daydream while the speaker is talking?				
11. Listen to the whole message, what the talker is saying verbally and nonverbally?				

### A Practical Guide for Siblings Who Share Caregiving for Aging Parents

When you're caring for your aging parents, you can use all the help your siblings have to offer. Your brothers and sisters can provide a tremendous amount of support, but there may also be challenging family dynamics to manage.

Learn how to lighten your load and draw your family closer together by sharing caregiving responsibilities with your siblings. Try these strategies for working together as a team.

## Mahaging Logistics

- 1.Hold family meetings. Even if your family is spread out over long distances, try to gather in one place. Talking about how to care for your parents before an emergency arises allows you to approach the subject with a clearer head.
- 2. Assign roles. It's easy to drift into old patterns. The child who was labeled the responsible one growing up may automatically assume much of the decision making. Instead, each of you can look at your current capabilities and contribute accordingly.
- 3. Consult professionals. Ask family physicians, pastors, and social workers to help you find the resources you need. Engage a geriatric care manager to coordinate the process.



4. Share information. Talk with your brothers and sisters about what you learn as you research issues about aging and caregiving. Give each other updates after you call or visit your parents. Avoid making assumptions, assigning blame or guilt.

5. Maintain records. You may need to deal with some complicated medical, financial, and legal arrangements. Proper documentation can prevent misunderstandings and help you comply with applicable laws.
6. Encourage independence. It's important to remember that your mother and father want to maintain their independence for as long as possible. Look for ways to assist them that support their dignity. Installing safety bars around the shower is one adjustment that helps them to care for themselves. Look at other ways to help them be safe in their home. This can be a good family project.

7. Ask for help. Call on each other when you need a hand. Be tactful and specific. You can let your brothers and sisters know that you need them to cover part of a medical bill without trying to make anyone feel guilty.



### Mahaging Emotions

- 1. Think about aging. Watching your parents grow older may trigger uncomfortable thoughts about aging and death. Join a support group or read spiritual material that can help you to understand your feelings.
- 2. Sort out rivalries. You may find yourself competing for your mother's attention or reliving old memories about how your father took your brother camping without you. Decide to let go of past conflicts or talk them over with your siblings.
- 3. Respect differences. Each member of the family may have different opinions about the situation and unique ways of contributing. Accept that your sister may be more willing to pay for a gardener than to come over on weekends to do the yard work herself.
- 4. Establish realistic goals. It can be difficult to juggle caregiving on top of all your other responsibilities. If you're becoming overwhelmed, concentrate on the essentials.



### Mahaging Emotions

5. Express compassion. This can be a challenging time for the whole family. Be gentle with yourself and your siblings as you take on new tasks. Let your parents know how grateful you are for the love and guidance they've provided.

6. Take a break. Taking time off will help you to sustain your strength. Ask your parents if they'd like to take senior aerobics classes at the local gym so you can spend Saturday morning with your kids.

As the average lifespan increases, you may be able to enjoy your parents' company for many more years than you expected. Advance planning and skillful communications will help you and your siblings to collaborate on caregiving to make this stage in your family's life more joyful and meaningful.

## **CONVERSATION STARTERS**



# These questions can help you hold those awkward conversations with your loved ones.

- I have something I'd like to discuss with you that I think will help us plan for the next few years.
- I'd like to talk about \_\_\_\_\_\_with you, but first I'd like to get your thoughts.
- I need you to help me so when you need my help, I can do it.
- I think we have different perceptions about \_\_\_\_\_\_.
   I'd like to hear your thoughts on this.
- I'd like to know what your wishes are should you not be able to choose for yourself.
- I'd like to know what your wishes are should you need care and who you would like to do that with you.
- I'd like to see if we might reach a better understanding about
   \_\_\_\_\_\_. I really want to hear your feelings about this and share my perspective as well.
- I have a friend whose parents had a medical crisis and she had to go help with everything from paying bills to arranging for in-home care and rehab. Because I am not so close, I'd like to talk about making a plan in case something like this happens.
- What are your concerns about aging and how can I support you?



## **CONVERSATION STARTERS**

Write some of your own conversational openings below.

Family Dynamics

"The day the roles reverse is foreign. It's a clumsy dance of love and responsibility, not wanting to cross any lines of respect. It's honoring this person who gave their life to you—not to mention literally gave you life —and taking their fragile body in your hands like a newborn, tending to their every need."

Lisa Goich-Andreadis | Author



# GETTING HELP & GETTING PAID

GETTING HELP & GETTING PAID

#### OUTER CIRCLE OF SUPPORT WORKSHEET

The outer circle of support includes people and professionals that you may be less involved with or have a more formal relationship with compared to your inner circle. This may include people you work with or go to church with. Your medical provider, the doorman at work, and other connections would be included here.

List your Outer Circle Network here. List as many people and organizations as you can think of. Include their phone number and email address.

Name	Phone	Email	Notes

#### YOUR CAREGIVING TEAM



Use this form to create your team.

You can use this for different situations where your team will shift. This should be a guide to help you reach out to team members.

Team Member	Relation	Role/Special Skills, Knowledge	Contact Info

#### **Caregiving Takes a Team**



This short assessment can help you to think through some potential situations so you can be prepared.

1. You have a family member living in another state. How do you make them a part of your team and why? What role can they hold in the team?

2. What other family members can you include and what role might they have?

3. Your loved one has had to go to the hospital. Who do you add to your team now and why? Who on your team do you reach out to for help, and what skills, knowledge, experience will they offer?

**4.** How do you communicate with hospital staff? How do you assess the "professional culture clash" of various experts to get the best information?



5. You have made the decision to move your loved one to a care facility (assisted, nursing, semi-independent living). Who is on this team? How do you lead this move for your team? How do you communicate this decision and who is included in it?

6. You can have different teams for different situations. What sort of situations might cause a change in your team? How would you shift your leadership and communications? Who will be on the shifting teams?

# For each of these programs, check your state or county as benefits and eligibility may vary.

#### VA Benefits

https://www.ebenefits.va.gov/ebenefits/learn/healthcare https://www.va.gov/health-care/family-caregiver-benefits/ https://www.va.gov/health-care/about-va-health-benefits/long-term-care/ https://www.va.gov/pension/ https://www.hsrd.research.va.gov/news/feature/caregivers2021.cfm https://www.hsrd.research.va.gov/research\_topics/caregiving.cfm

#### Medicaid

https://www.medicaid.gov/medicaid/home-community-basedservices/index.html https://www.medicaid.gov/medicaid/home-community-based-services/homecommunity-based-services-authorities/home-community-based-services-1915c/index.html

#### **Applied Self-Direction**

https://www.appliedselfdirection.com/

#### **Social Security**

https://www.appliedselfdirection.com/



#### **Database of Benefits Programs for Seniors**

https://benefitscheckup.org/

#### Area Agencies on Aging

https://eldercare.acl.gov/Public/About/Aging\_Network/AAA.aspx

#### **Elder Law**

https://www.naela.org//

#### **Cost of Elder Care**

https://www.genworth.com/aging-and-you/finances/cost-of-care.html

#### **Support for Outside Caregivers for Respite**

https://acl.gov/programs/support-caregivers/national-family-caregiversupport-program

#### **National Care Planning Council**

www.longtermcarelink.net

#### Long Term Care Personal Support Services Agreement Department of Health and Human Services, Office for Family Independence (2011)

www.maine.gov/dhhs/ofi/documents/LTC-Personal-Support-Agreement.pdf

Getting Help & Getting Paid

"My caregiver mantra is to remember: the only control you have is over the changes you choose to make."

Nancy L. Kriseman | Social Worker

Caregiver Stories

After the death of my father, my mother struggled with anxiety and depression and really started going downhill. She was not eating well and sleeping at odd hours, suffering from insomnia and losing weight, crying easily and constantly anxious. My brothers and I were very worried about her and very stressed trying to help her, to make her eat, to encourage her to sleep at night and not all day long, and to keep her spirits up. We were failing, and we could see that she was failing, too, and was not going to last long. I felt sure she was going to continue her downhill spiral and die.

My brothers and I had phone conference after phone conference, trying to figure out what else to do. We were at our wit's end. Then she said one day that she wanted to check out assisted living. We were so happy with this development and jumped on the idea, getting her on the waiting list and scheduling a tour and having many phone conferences about how to proceed.

Jah Hehcke

Caregiver Stories

I took her for a tour, where we visited with a sales person. We were both very impressed with the facility and the friendliness of the staff and residents alike. The apartments were very homey and comfortable. She agreed to move there and luckily only had to wait about a month before moving. Assisted living has saved her life, quite literally, and has relieved the tremendous pressure on my brothers and me. She is happy and healthy, and we are all delighted to have our mother back and to be able to enjoy her without worrying constantly about her daily wellbeing. What a gift!

Jah Hehcke



# **SELF-CARE**



SELF-CARE

# Caregiving Thoughts •••



I willingly took on the role as caregiver for my elderly mother after my father died. It was not a role I had ever planned on having. My parents had moved to a very nice retirement community one state away. I assumed all was taken care of for their elder years. Then my father became terminally ill and went into skilled care. After 64 years of marriage, my mother was in a fragile state. After spending a year going to check on her once a month, I moved her to an assisted living facility 25 minutes from my home.

> Caregiving is tedious: paperwork, prescriptions, 01 doctor appointments, etc.

Caregiving is about cultivating relationships: with physical 02 therapists, CNA's, nurses, administrators, doctors, activities directors, nutritionists, housekeepers, and other residents.

No one else cares about caregiving the way you do.

03

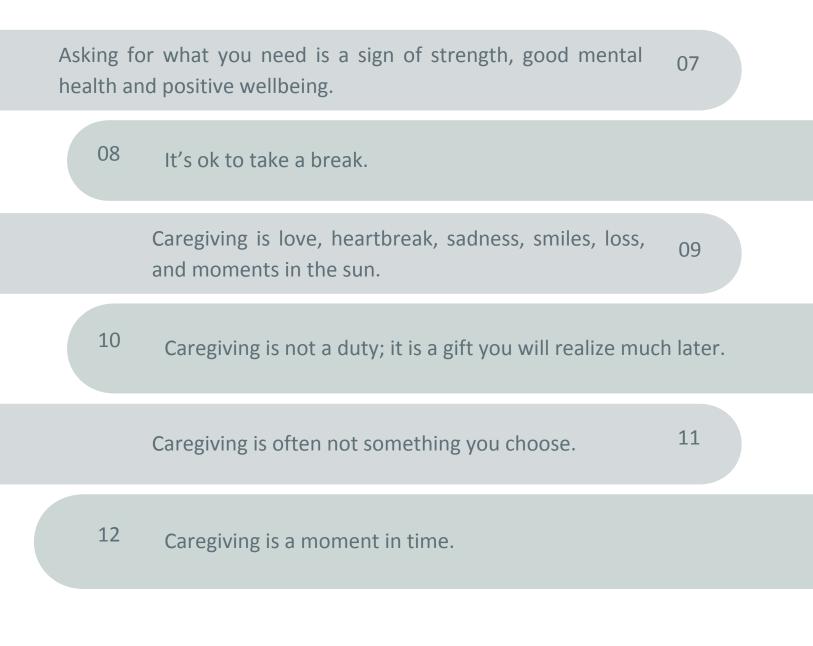
You are a caregiver when your senior parent needs you. You may 04 just be saying to yourself, it's my duty and responsibility, I'm helping out, and now you are a Caregiver.

Caregiving does not depend on where your loved one lives. It is 05 not location specific.

06 Caregiving is as much about you as them. Don't forget that!

# Caregiving Thoughts





"Compassion automatically invites you to relate with people because you no longer regard people as a drain on your energy." Chogyam Trungpa



The day we drove here to VA where she was to live, was a day that changed my life. My mother called me "my daughter/my mother." I did not have a clue what I was doing. I only knew that I needed to take care of her. I told her we would be "partners" in making decisions about what she needed. As she settled into her new life, those decisions became more and more all on me. As our roles shifted, I became more comfortable making decisions for her. My journey with her lasted 6 years.

Navigating the world of the elderly and their care is like being in a jungle without a map. I was constantly stressed, worried, and tired. And, frustrated, as she gave up more and more to me to take care of for her. Here are a few things I learned that I hope will help you on your journey.

Of all of these I would say, Be Involved!

	Always have your cell phone with you. Yes, you are on call 24/7!
14	You will miss work. You will give up some social activities, you will be tired, you will give up some of the things you love doing.
	Accept that your roles will be reversed and preserve their dignity and independence as much as you can. 15
16	Make sure you have Power of Attorney for your parent's healthcare and that the document is on file at their living facility, Dr.'s office, and local hospital.



Old people can be stubborn. You will sometimes have to just
make a decision and explain later. (One doctor's visit my mother did not want to go, so I bribed her with lunch out.)

Make sure they have an Advanced Directive and DNR if they so 18 desire.

19

Be prepared for the unexpected.

Know that things will always take longer and that a quick visit is 20 not ever going to happen. You can't just "drop by".

21 Don't try to do everything! If there are services like laundry provided and included, then use them.

If using services like laundry, be aware that it is done in HOT water, industrial machines and things will get lost, stolen and shrunk. So, if there are nice things, take care of them yourself.

23 Make sure you know what is in your parent's room. Things do go missing and sometimes it is just a lapse in memory.

Don't try to correct a false memory. Learn to live in 24 their moment.



Make sure to make time and be present. (One day I went to see my Mother and it was late in the day. I had worked all day and thought I would just check on her and come back the next day when I had more time. The activities person came to say there was going to be some piano and violin music, so we went. I stayed longer than wanted but we both enjoyed the music.)

Laugh! Sometimes the things that can frustrate you can be turned into a laughable moment.

Talk with the dietician. Elderly people don't eat very well, and you will have to make adjustments. It's ok if they want dessert for dinner!

It is ok to sit in the parking lot thinking you don't want to go into the building.

28

30

26

<sup>29</sup> It is ok to take a day for yourself.

Have a good cry!

31 Request that the first thing staff tell you when they call is that your loved one is okay (if it is true). You likely won't be able to hear anything else until you hear those words.

33



Every time your caller ID shows the number for your parent, your heart will skip a beat and your stomach will fall. It doesn't go away; it's part of the process.

Don't expect people who haven't gone through this process to understand. Their eyes are apt to glaze over if you go on at length. If you just need someone to talk to so you can unload, be very clear about those needs.

Understand what insurance covers -- and more importantly, 34 what it does. Rules change frequently.

35 Be pleasant, yet firm with healthcare staff. Ask lots of questions! Be there!

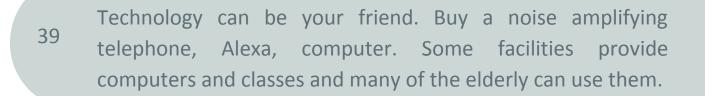
Know the baseline behavior and capabilities of your parent.

36

37 Emergency rooms and hospitals are not good places for recovery for the elderly. Do everything you can to be present.



Consider the healthcare staff at the assisted living facility your best allies. These people are your parent's friends. They will 38 come to love them. Know their names, the names of their kids, what they do after work. Take the staff gifts and goodies.



The older your parent gets, the smaller their world becomes. Old people can seem very self-centered and clingy, their world is very small.

40

41 Find your own personal space for quiet and decompressing time.

If siblings won't help, find others who will. 42

# Self Care for Caregivers<sup>®</sup> Support Ideas

# Find something positive.

Little things like saying thank you to someone for a small gesture such as holding the door, expressing your appreciation to a spouse/partner, coworker or child and writing thank you notes for gifts can make a difference for both you and the other person. Write down several things each day that you are grateful for or appreciate. It helps to identify three things at the end of the day that went well or left you feeling gratitude. (Included sheets)

• Find ways to relax.

Rest and relaxation are critical to managing stress and minimizing anxiety. Those who find it difficult to let go and relax may find yoga, breathing or stress management classes helpful. Regulating your breath has a calming effect on the mind and loosens tension held in the body. Sitting quietly at home for 5-10 minutes each day to simply be aware of your breathing can enhance relaxation. Try a meditation app such as Insight Timer, or HeadSpace.

# Self Care for Caregivers<sup>®</sup> Support Ideas

Move around every day.

Exercise and movement can include gardening, playing with your pets, dancing, stretching, Movement etc. improves cardiovascular health, flexibility, strengthens and improves mental health. muscles Exercise also oxygenates your body and brain providing clearer thinking and creativity. So many exercise programs are now available virtually, you can do it anytime.

• Engage in good conversation.

Spending time with good friends, even online or on the phone, and engaging in stimulating conversation with a neighbor is good for the soul (mind and body). When we share our thoughts with others, we establish an emotional and mental connection that can be refreshing and heartwarming.

# Self Care for Caregivers<sup>®</sup> Support Ideas

#### Get enough sleep.

Good sleep hygiene involves cutting out caffeine after 5 PM, turning off electronics two hours before bedtime, eating your last meal two or more hours before you turn in for the night, going to bed early enough to get 6-8 hours of sleep, darkening the room you sleep in. It is helpful to create a sleep habit of going to bed and arising at the same time everyday.

• Keep up with your medical needs.

Annual physicals, biannual dental checkups and cleanings, mammograms, pap smears, etc. are proactive habits for good health. Many advocate an annual mental health screening, which may be part of the annual physical at some point.

# Self Care for Caregivers Support Ideas

• Treat yourself regularly.	See a movie, eat dinner at a restaurant, sit in the park, get a massage, get a manicure/pedicure, buy yourself flowers – whatever you enjoy – do that for yourself. These are also ways to find respite from your duties.
• Engage in a hobby.	Build an airplane, play cards, get lost in good books, take up sewing or knitting – anything that relaxes you – do that.
• Eat healthily.	It's easy to stop and grab fast food when you are short on time or skip a meal. With so many fast casual restaurants (Panera,
	Chipotle, Zoe's, etc) it's easier to stop and grab a healthy meal. Or, cook something that will give you meals for a couple of days, like a good soup, or pot roast or roast a chicken and then make chicken salad. Keep fresh fruits handy. If your parent is in a care facility, take lunch to have with them.

#### (Adapted from Good Mental Health: Self Care)

# is Part of

# Taking Care of Yourself is Part of the Job

The job of becoming the primary caregiver for your aging parent is universally recognized as one of the most difficult transitions we will go through. To start with, it's hard to go through the reversal of parent and child. All your life, mom or dad were the strong ones. They were the ones you ran to for help and who were always there to tell you, "It's ok. Everything will be alright."

But now as your loved one ages and you have to witness their demise mentally and physically, you realize that everything may not be alright, especially if your loved one is going through a slow decline of a terminal illness. When the only outcome of what you are dealing with in your parent's life is death, that makes it tough to stay upbeat, creative and proactive about how to handle life's daily challenges.

The task of caring for an elderly parent is overwhelming. You have concerns about their finances, their medications, the progress of their disease if they are battling something terminal, their mental state, their diet and their emotional state as well. It's easy to begin to "hover" your senior citizen in an emotional attempt to block any more harm coming to him or her. This is a parenting instinct and one that your dad and mom probably won't resist because they want to be cared for.



### Keeping It At Arm's Length

Sometimes when you have a very consuming problem, it can so take over your life that you forget the rest of life's responsibilities and relationships. That is certainly a danger that caregivers are faced with. It is easy to become so wrapped up in the demands of being a good caregiver for your aging parent or loved one that the rest of the world seems to disappear.

This is never a healthy way to take on the challenge of caregiving. Not only would it be terrible for your family, job, and friends to see you vanish into the task of care giving and never be available for anyone else, it's also a bad idea for both you and your elderly parent for you to obsess that much.

This is a formula for caregiver burnout which can lead to medical problems, loss of sleep, eating disorders and maybe even a nervous breakdown. So, the healthy approach to being a caregiver is to keep the demands of that part of your life at arm's length so you can establish a balance between your life with your senior citizen and work and family life as well. One way to begin laying the groundwork for keeping that balance in right ratio to your life is to have an honest talk about the issue with your elderly parent who you are caring for. Sometimes the force draws you in to wanting to give it all to the task of caregiving. But if you talk about it in a rational way when both of you are rested and thinking calmly, your parent will see that she doesn't want you to give up your life to be her caregiver exclusively. Oh sure, sometimes when she is sad or lonely, she says things like "I wish you could stay here all the time." But that is not rational, and she knows you need to be a mature adult and take care of your job responsibilities and your spouse and children as well.

Another person you should have a frank discussion about the demands you are going through as a caregiver for your elderly parent is your boss at work. In the modern world, businesses need hard working and well-trained individuals like you. And this is a time when a lot of baby boomers are becoming "sandwich generation" people and have that additional demand of caring for an elderly parent along with home and work responsibilities. So, your work will want to work with you to get through this rather than lose you entirely. Your employer may be able to work with you to give you some flexibility so that if you must have time during the day to take your parent to the doctors or attend to some other need in your parents' life, you can make up the time or attend to your work in other ways. Many employers will even allow you to take work home with you and split your time between the office, your family life and your caregiving responsibilities. There are even extended leave programs that some larger companies have where you can take a few months off to care for your parent during a time when you must give her all your time. This is invaluable during time when you are moving her from her own home to the assisted living center or if your parent is terminally ill and you need to be constantly available in those last months of her life.

Above all, solicit the support and love of your spouse and kids. If mommy must be over at grandmas every evening for a few hours, it may call on the dad and kids to whip up some macaroni and cheese or just get in the car and go get some fast food to cut mom some slack to take care of the needs of that aging senior citizen. Your family, your work associates and your friends can handle giving you that time if you are open with them about what is going on and they see the need. But do make time to see them and be with others so the job of being a caregiver doesn't overwhelm you. You need them as much or more than they need you during this time.



Use this log to monitor how well your coping skills work. Rate the level of success 1-5, with 1 as the least successful and 5 being the most successful. Record any after thoughts about what might have worked better or why a specific skill worked/didn't work at that time.

Feeling	Coping Skills Used	Success	After Thoughts
Loneliness	Call Manuela & invited her out	4	l really need to remember to rely on the people closest to me more.

### The Coping Question Worksheet



Life can be overwhelming at times, especially when things are tough. Here are some suggestions for how to best cope.

1. Identify the Challenge. Be specific about different aspects of the problem.

2. Reflect On Previous Successes. What have you done in the past to cope with similar problems? (What did you do? Who did you call? Where did you go? What changes did you make to accommodate your needs?)

3. Consider Your Resources. What resources are available within your network to help you with this problem? Think of formal and informational resources (social services agencies, temporary agencies, day care centers, schools, etc.)

4. Remember Your Inner Resilience. List personal qualities of resilience that you possess to bounce back from difficulties in life.





### **Caregiver Stress Assessment**

Check any of the following that apply. You...

- Feel that you have to do it all yourself.
- **Feel that you should be doing more.**
- Spend less (or no) time with family and friends.
- No longer engage in activities that you once enjoyed.
- ☐ Worry about the person you care for their safety and wellbeing.
- □ Not sleeping or eating well.
- Feel anxious about money.
- Worry about making the right health care decisions.
- Minimize the impact of the disease, old age
- Deny how the disease, old age affects you and your family.
- Feel a sense of loss for the relationship you once had with the person you care for.

#### Check any of the following that apply. You...



**Feel frustrated or angry when caring for your loved one.** 



Experience feelings of resentment towards others.



Are beginning to experience mental or physical health effects.

(Adapted from Alzheimer's Association Caregiver Stress Check)

Scoring Count the check marks.

1-3: You are coping well – keep it up.

4-8: You are in dangerous territory – let's talk.

9 and above: You and your loved one are at risk – seek professional help.

Self Care

"Compassion automatically invites you to relate with people because you no longer regard people as a drain on your energy."

**Chogyam Trungpa | Meditation Master** 



# CHALLENGES & WINS

CHALLENGES & WINS



# 5 TIPS TO CREATE A PRESENT MOMENT MINDSET

Our lives are chaotic and busy, and we are so focused on the past and the future that we often forget to simply be in the moment.

The present is happening right now, yet so many of us take it for granted and don't appreciate the small elements of life that make it powerful and special.

You can train yourself to stop and be in the moment, thereby finding inner peace and tranquility, by following a few simple guidelines.

Try these tips to live more in the present moment:

- 1. Focus entirely on a specific action. Take some time to focus on a specific moment. Stop everything you are doing and concentrate on one thing only. This allows you to ground yourself in one task and completely clear your mind of everything but the present moment.
- For example, make a cup of coffee and consider how it tastes when you drink it. Concentrate on how the warm cup feels in your hands. Consider the blend of flavors. What's the temperature as it touches your lips?

• All goals, concerns, and objectives should leave your mind. By focusing on one action, you will be able to appreciate and enjoy the small, seemingly insignificant actions in life. You'll feel calmer, more at peace.

2. Switch off your phone. Screens are an integral part of our lives. But we are forever checking our emails or social media and are always connected. Take some time to switch off your phone and tablet.

• Disconnecting for a short time will allow you to focus on what you're doing in the present moment. Perhaps have coffee with a friend or engage in discussion, focusing on nothing but the conversation or the activity.

3. Go for a walk. A walk is one of the best ways to achieve a present moment mindset. It allows you to clear your head of unnecessary or intrusive thoughts and concerns for a short time.

- As you walk, consider where you are. Appreciate how the ground feels beneath you and what the temperature of the air might be.
- Think about the sounds of nature and isolate all other distractions. This will allow tranquil, calming thoughts to fill your mind as you enjoy being outside and concerning yourself only with what is around you.

4. Consider what you appreciate in the present moment. In our busy lives, we can forget what we are grateful for and what we enjoy. Take some time out to write, think about, or even record a list of things you appreciate.

- For example, you might appreciate your family, friends, your job, or your house. Did you get to eat a meal today?
- Consider what brings you joy in the present moment and this will allow you to feel a sense of positivity, warmth, and excitement.

5. Consider your senses. We take our senses for granted. Smell, taste, hearing, touch, and sight allow us to experience the joys of life.

- As you go for a walk, take in the surroundings around you. Take ten minutes of your day to sit still.
- Allow yourself to clear your mind, thinking of nothing but how your body and senses are responding to the world around you. This will allow you to be present in the moment, to fully experience that moment.

By taking some time out of your day to be present, you will find yourself happier, calmer, and more grateful for the smaller parts of life. We could all learn to take a moment to stop, think, and enjoy every second of our day.

#### **ROSES & THORNS**

Caregiving is a series of challenges and wins. One day you may feel like it is all challenges and frustrations, the next you may gain a win to something that was a struggle.

It is the PATH of caregiving to accept that you will have both. To recognize the wins is the harder part. It is important to acknowledge the wins, however small, so that you know that you have done the right thing at the moment.

- Were you able to get your parent to go to physical therapy? Can start as a challenge and end as a win!
- When you see them getting stronger it is an even bigger win.
- Did you take your parent to the Dr. Appointment?
- They were stubborn, saying they didn't need to go. Then you promised lunch out, WIN!
- Has your mom called you 6 times today to ask when you would be by to see her? Or any number of other requests? You are ready to scream because you were just there yesterday.
- But you stop by on your way home, and she gives you a big smile and tells you how happy she is to see you. WIN!

- Have you missed work because of a crisis with your parent? You're worried that your boss and colleagues will not understand.
- You decide to tell your boss about your increasing caregiving responsibilities and find that she is doing the same. WIN!

These are just a few examples of the daily challenges and wins when caregiving for an aging parent.

In the worksheets provided, list your challenges and wins. In doing so, you are shifting your mindset to see situations differently. You will still be challenged, but finding the win in the situation helps shift your perspective.



Some days feel like roses and others feel like thorns. This activity challenges you to recognize and celebrate each of those moments.

COLUMN 1: Recognize something that happened that sings to you and radiates beauty (a "rose"). It may be an unexpected smile someone offered, a shortcut on your way to work, overcoming an obstacle, or the quiet whistle of birds in your backyard.

COLUMN 2: Acknowledge something you're looking forward to for tomorrow (a "bud"). It may be something you long awaited or a simple joy you anticipate every day.

COLUMN 3: Identify something that you need help with or that feels heavy during your day (a "thorn"). It may be an event that will have long-lasting effects, or something that just bothered you for a moment.

COLUMN 4: Remark on a way you will try to turn your thorn into a rose ("transform"). It may feel insurmountable at the moment, in which case you can leave this column blank, but if you're able to find something, that will help you move forward.

ROSE	BUD	THORN	TRANSFORM

#### **Roses and Thorns**



ROSE	BUD	THORN	TRANSFORM

Challenges & Wins

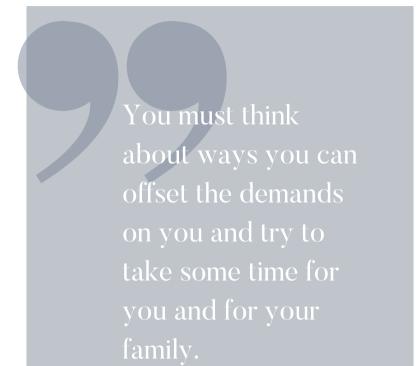
"The disease might hide the person underneath, but there's still a person in there who needs your love and attention."

Jamie Calandriello | Home Health Aide



## MINDFULNESS

### giving thanks for being a caregiver

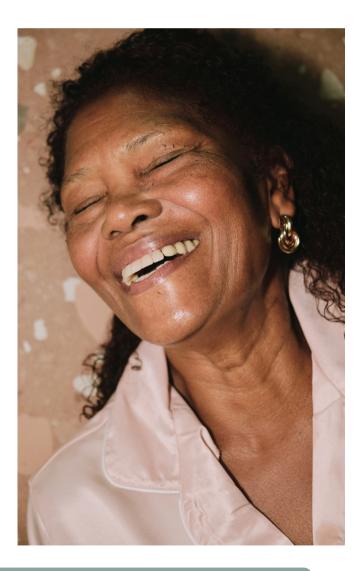


Much of the adjustment that goes into being a caregiver for your aging parent goes into dealing with the stress and the emotional drain that role can bring.

In addition to the issues of how to care for her in the best possible way, there are the emotions of anger when programs don't work right or when the facility she is in has problems. There is resentment at other siblings or even at your aging parent because of the demands this job has on you personally. There are other adjustments that are a huge drain on you emotionally.

Balancing work, home, and private life with the demands on your time being a caregiver is a juggling act that will involve as many "dropped balls" as successes before you ever get it right.

And about the time you do get a good balance, the demands of your elderly parent might change, and you are again pulled back into that stressful situation.



## giving thanks





I knew it would work if I kept trying.

But there is one emotion you may wish to foster and dwell on as much as you can to offset the worry, the anxiety, the anger, and the resentment. That is the emotion of thankfulness.

Now it may seem impossible to even ponder how thankfulness could become part of your emotional reaction to this demanding situation you find yourself in.

But if you can find ways to be thankful that you are the caregiver for your parent, that positive emotion can do wonders to drive out those negative emotions in your heart. And when you think about it, there are quite a few great things you can be thankful for BECAUSE you are the primary caregiver for your aging parent. Some of those are...

- You can give back a bit of the sacrifices they made to raise you. You can say, "Thank you for raising me and never giving up on me. And now I am not going to give up on you."
- There would be anxiety if you were not there. By being close, you can get the facts quickly and get them right.
- You always know what's going on. They need someone that can say, "It's alright. It's under control" to them. That someone is you.





# giving thanks

You are needed and you are important to your elderly mom or dad. If ever there was a time when you felt needed not just every so often but every day and every hour of the day, it is when you are there to help your parents through this tough time of their lives.

Celebrate those little times of laughter and joy.

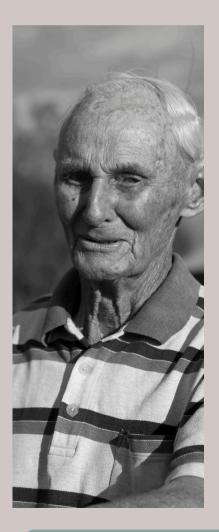
Celebrate when you enjoy a movie together or laugh at those "insider" family jokes that always bring a smile.

Those times will be precious to you when your parent dies.

And even after your parent dies, you will be able to look back on those months when you gave all you could to make those final months of her life happy and peaceful and you will be able to say, "I did the right thing."

And that is one feeling that is irreplaceable and something you will be able to be thankful for forever.

### does grandpa like himself?



Few of us think about our own self esteem. But how we feel about ourselves, our work, our relationship to family and the community and our place in the world is the cornerstone not only of your ability to function and be productive in life but of your mental and physical health as well. That is a basic concept of human psychology for everyone and that need for self esteem doesn't go away when you become a senior citizen.

When you think about it, this episode of being a caregiver for your aging parent is not your first crack at caregiving. You were the caregiver and to some extent still are for your children as they were growing up. You took care of their every need including their emotional and psychological needs. And any good parent learns early on that a child's self esteem is vital to their success in school and in life.

Now you are in that relationship with your mom and dad and while you are not "raising them", you have taken on the caregiver role which means in addition to worrying about their finances, their physical health, their diet and their living arrangements, their mental health and self esteem are things for you to consider as well.

## does grandpa like himself?





99

A grandfather is someone with silver in his hair & gold in his heart.

Because it's not us going through it, it's hard for us to empathize with the huge changes going on in the life of your aging mom and dad and the massive impact those changes have on their self esteem. For a parent, your sense of self worth comes from your independence, your ability to take care of your kids, do your job and be useful to others in society. In the senior years all of that disappears in what seems like an instant. In the eyes of the senior, they go from being the hero to their kids to being a pitiful old man or woman being taken care of like they were the child.

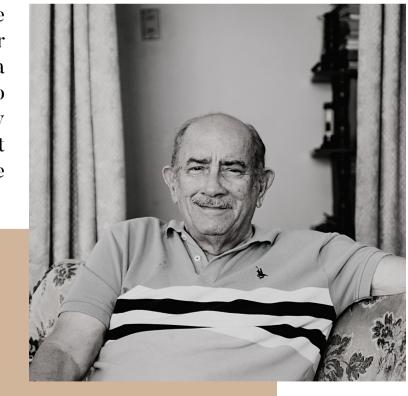
feeling of useful Their being vanishes and is replaced by a feeling being unnecessary of and а nuisance. The "things" that they invested themselves in that are symbols of their success which includes their house, their ability to drive and their work all go away in rapid succession one after the other. wonder Small senior citizens undergo a tremendous drop of self esteem. And when you go from thinking highly of yourself to not liking who you are at all, that is a formula for disaster.

## does grandpa like himself?



It's a dangerous mental condition to stay in because without self esteem, the natural response is to turn to unhealthy thoughts of alcohol or drug abuse or in the most extreme cases, suicide.

As a caregiver, be aware of the self esteem of your aging parent and the huge impact moving out of their home and losing their spouse and ability to drive is having on them. The symptoms of poor self esteem is your parent doesn't take care of himself like he used to, repeats stories over and over because those stories remind him of a time when he liked himself and seem to launch on desperate adventures to try things he really should not take on just to get a feeling of being someone again. You can do a lot to build that self esteem back up in your aging parent. Help him get in touch with family and old friends. Encourage him to talk about the old times and pour praise on him about those days. And above all, let him have lots of time with the grandkids. Those little angels could love anyone into liking themselves. So let them use a little of that magic on Granddad so he can like himself again as well.





## listening to your parents

#### -- even now

Have you ever had that aggravation that you go over to your aging parents' apartment or house to help with the housework and get some serious "care giving" done and the senior himself seems to be bent on stopping your progress? You no doubt came over with a list of things to do at the apartment to help your parent live a clean and healthier life by getting the place into shape.

You know that part of your job as caregiver is to take care of chores and do the things your aging parent cannot do any more or just doesn't do because of fatigue or general lack of attention to detail. So, when your parent wants you to forget all that work and just sit and talk, what is aggravating to you may be very important to your parent, maybe even more important than the apartment getting cleaned up.





No matter how old a girl gets, she never stops needing her mom.

### listening to your parents

#### even now

It's good for you to think about your role as caregiver because you really are not just called to be a maid, chauffeur and cook. Anybody could do those things. The reason you are perfect for the caregiving role is you are close to the heart of your aging parent, and you are the one that will understand when she talks about things she is thinking or feeling that day.

So don't downplay the value of just being a companion to your parent during your visits. The emotional and family support you provide to your parent is central to his self esteem and feeling of who he is in the world. He will be storing up dozens of little anecdotes and stories to share with you when you come over. So, to let him get all of that sharing "out of his system", it's important for you to be a good listener.







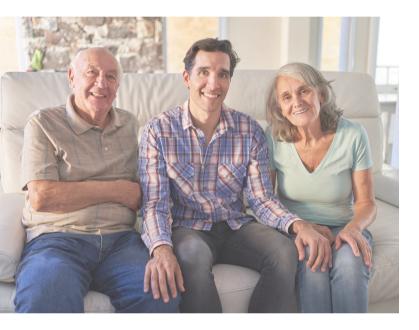
# listening to your parents

A good listener doesn't just let the other person talk and say "uh huh" every so often. If you are just tolerating your parent as she shares little things with you, that will become apparent and be worse than if you didn't talk to her at all. The best way to fit your fellowship and relationship time around work time is to start out each visit with some time together just to talk.

Perhaps you might make it a habit that every time you come over, you and your parent will sit down and just talk for about a half hour over coffee, a snack or tea. That is when you can focus all your attention on what mom or dad have to say. Listen with focus and attention so when something is funny, you laugh, and you can ask questions and explore the concept or situation being discussed in some depth.

Be patient, elderly people repeat themselves and often dwell in memories. The memories are opportunities for you to capture their stories, ask questions you always wondered about and keep a journal.







# listening to your parents

Then at an appropriate time, you can say, "Gee Mom, I would like to tidy up those dishes. Can you sit at the table, and we can keep talking while I do that?" That is a nice easy transition to starting your work and keeping the lines of communication open. And you can continue to let your mom or dad "follow you around" as you do chores chattering away the whole time.

Don't censor the topics or insist that what you talk about are only the important things. You should know from talking to your kids that you must be ready to talk about the trivial things in their lives to prime the pump of communication about the hard issues and ones that will take some mature understanding to deal with. So be patient and open with your aging mom and dad and once they know you have good listening ears, they will open about important things going on in their lives. And that is when your listening skills will really pay off.

#### MEDITATION FOR GIVING AND RECEIVING CARE

Close your eyes and focus your attention on the present. Scan your body and notice any sensations you're feeling.

What do you hear? What do you smell?

Simply observe your experience in the present. Now bring your attention to your breath. Feel the air going in and out.

In. Out.

Notice your chest rising and falling. With each inhale, feel yourself taking in acceptance. With each exhale, feel yourself letting go of self-judgment.

You breathe in love. You breathe out self-criticism.

Continue breathing like this for a few moments. Inhale peace. Exhale anxiety.

Now breathe in and give yourself forgiveness. Breathe out and release resentment.

#### MEDITATION FOR GIVING AND RECEIVING CARE

Now visualize yourself with those you love.

With each breath in, take their pain and frustration. With each breath out, give love and acceptance.

Visualize yourself radiating compassion toward those around you. Inhale their pain. Exhale forgiveness and joy to them.

As you care for yourself, your peace and happiness increases. As you care for others, they too experience deep rest and joy.

Continue this practice of receiving and giving love for a few moments. Then let your breathing return to normal.

Open your eyes.



As you transition into being a caretaker, it's helpful to consider the values that will shape your journey. In this exercise, I'd like you to reflect on the principles or standards of behavior that you consider most important in life.

Keep in mind that there is no right or wrong. There is no judgment in this space.

STEP 1: Go through the list below and mark the values that most resonate with you when it comes to your role as a caretaker.

- Accountability
- Accuracy
- Achievement
- O Adventurousness
- Altruism
- Ambition
- Assertiveness
- 🔘 Balance
- $\bigcirc$  Being the best
- O Belonging
- Boldness
- $\bigcirc$  Calmness
- Carefulness
- Challenge
- Cheerfulness
- Clear-mindedness

- ) Commitment
- Community
- Compassion
- Competitiveness
- Consistency
- Contentment
- Continuous Improvement
- Excellence
- Excitement
- Expertise
- $\bigcirc$  Exploration
- Expressiveness
- Fairness
- 🔵 Faith
- ) Family
- $\bigcirc$  Fidelity

- Fitness
  Fluency
  Focus
  Freedom
  Fun
  Generosity
  Goodness
  Grace
  Growth
  Happiness
- ) Hard Work
- ) Health
- Helping Society
- 🔵 Holiness
- ) Honesty
- Perfection



- Pietv Positivity Practicality Preparedness Professionalism Prudence Quality-orientation Reliability Resourcefulness Restraint **Results-oriented** Rigor Security Self-actualization Self-control Selflessness Self-reliance () Sensitivity ○ Serenity Service ) Shrewdness ○ Simplicity  $\bigcirc$  Soundness Contribution Control Cooperation Correctness
- Courtesy Creativity Curiosity Decisiveness **Democraticness** Dependability Determination Devoutness Diligence Discipline Discretion Diversity Dynamism Economy Effectiveness Efficiency Elegance Empathy Enjoyment Enthusiasm Equality Honor Humility Independence Ingenuity **Inner Harmony**

- ) Insightfulness
- ) Intelligence
- ) Intellectual Status
- ) Intuition
- ) Joy
- ) Justice
- ) Leadership
- Legacy
- $\bigcirc$  Love
- 🔵 Loyalty
- ) Making a difference
- ) Mastery
- ) Merit
- ) Obedience
- ) Openness
- Order
- ) Originality
- ) Patriotism
- ) Speed
- Spontaneity
- ) Stability
- Strategic
- ) Strength
- Structure
- ) Success
- ) Support
- ) Teamwork



- Temperance
- Thankfulness
- O Thoroughness
- O Thoughtfulness
- $\bigcirc$  Timeliness
- Tolerance
- $\bigcirc$  Traditionalism
- $\frown$  Trustworthiness

- Truth-seeking

  - Uniqueness
- 🔘 Unity
  - Usefulness
  - Vision
    - 🔵 Vitality

STEP 2: Now, narrow that list down to the 10 most important values. Write them below.



STEP 3: Finally, par your list down to the absolute most important 3 to 5 values that you want to guide your life as a caretaker.

### VALUES & MINDSET



Now that you've narrowed your list to the most important values guiding your caregiving journey, it's time to go a little deeper.

After selecting your most important values, think about the following:

- Which values influence how you provide care for your loved one?
  - If you don't currently provide care, which values are the most important in how you will provide care?
- Which ones would you like to be more intentional in practicing?
- What would greater intentionality look like?
- When are your values most challenged as a caregiver? Has this changed over time?

VALUE I WANT TO FOCUS MORE ON:	WHAT WOULD GREATER INTENTIONALITY LOOK LIKE?	WHEN ARE YOU MOST CHALLENGED WITH THIS VALUE?
MY FIRST PRIORITY VALUE TO FOCUS ON:		
MY SECOND PRIORITY VALUE TO FOCUS ON:		

#### VALUES & MINDSET



VALUE I WANT TO FOCUS MORE ON:	WHAT WOULD GREATER INTENTIONALITY LOOK LIKE?	WHEN ARE YOU MOST CHALLENGED WITH THIS VALUE?
MY THIRD PRIORITY VALUE TO FOCUS ON:		
ANOTHER VALUE I'D LIKE TO PRACTICE AS A MINDSET IS:		
ANOTHER VALUE I'D LIKE TO PRACTICE AS A MINDSET IS:		



### Values Reflection Questions

Caregiving requires us to live up to our values. This exercise is to help you determine the values that are most important to you in this role. It's vital to think about values and mindset as what you can truly practice (or already are) and how you might use them in each situation. These questions may also help you rank your selections.

- What are your top 3 values? What do these mean to you?
- If you could live one of these daily, which one would it be? How would it show up?
- Are these values you would be proud to share with your caregiving team, friends, family?
- Do they represent things that you would support despite challenges, or unpopularity or putting you in the minority?
- Are there gaps in what you say you value and what you do? Why and what do you do about it?

Mihdfulhess

"I am seeking, I am not lost. I am forgetful, I am not gone."

Koenig Coste | Family Therapist

Mom and I used to always tell everyone we were best friends. We had a running joke about who would call first in the morning, and I normally won, since I lived on the east coast and she was an hour behind in Texas.

Then my dad passed away and things began to change.

Caregiver Stories

The calls got fewer and farther in between. When we did have them, they were only about dad. When I tried to talk about my life or another of my siblings, she would just pull the conversation back to my dad. Then the panicked phone calls started.

Her electricity was turned off. She was fighting with her neighbor – a woman who had been her close friend up until now. Someone was in her backyard in the middle of the night. Someone kept turning off her computer. She couldn't find her keys, her bridge, her anything. We soon realized that she could no longer live alone and moved her to an independent living community. Then Covid happened.

Caregiver Stories

I could no longer check in on her, and she decided that she no longer needed to take her medication. She went downhill very fast. When we finally were able to get to see her, it was like something out of a horror story. She was starving herself and wouldn't let anyone into her apartment to clean or help her.

Over time, she has become belligerent and violent. Every time I go to visit her, I'm greeted with a snarl. And then the abusive language and yelling starts. It has been devastating. Fortunately, I have reached out to friends, and they have pointed me to resources. I discovered the different ways that dementia shows up, and also found out that I was not alone.

I think that's one of the biggest things we need to realize when we are dealing with this insidious disease – not to take it personally, and not to "tough it out" thinking you can handle it alone. You really can't – or shouldn't. Caregiver Stories

Emotionally it is hard to have a mother you love start to go "Linda Blaire" on you. At times I have felt that she is possessed. But that's part of the disease. Your rational mind can sometimes be your worst enemy as oftentimes it's totally negated by the emotional response you have as "mommy" is no longer mommy anymore. Even at 68+ I still want my mommy from time to time. I want my best friend. I want to be validated. But "mommy" shows up rarely, if at all, and I have had to learn about self-care.

Self-care without feeling guilty about not seeing her every day. Not feeling guilty about putting up boundaries. About not taking the verbal abuse, while remaining loving and kind. This is hard for me because I am a pleaser but – and this is a big but - I also have a temper. So, part of the self-care I am learning is not to lash out. It accomplishes nothing, and only leads to guilt and not feeling good enough. It becomes a self-perpetuating state of inadequacy and shame. Canegiver Stories

So now when I go to see her, I prepare myself. I am very much into creative visualization and meditation, and I have several exercises that I have learned to do to prepare myself. I sit in my car outside of her facility and get in my heart. I go to a time when mom and I were still very close, and I remember how that felt, the love that was there between us. I remember mom the way she was and try not to allow my own insecurities to color my emotions. I allow the glow of that love that a mother and daughter can feel flow throughout my entire body – and I smile.

I always try to bring her something to make her smile too, although that doesn't always elicit the response I want. So, I am also learning to let go of expectations and to be with Mom in the moment – to meet her where she is at and to just hug her. Caregiver Stories

One of the positive aspects of Alzheimer's is that short-term memory can be your friend. So as long as I don't respond to her with anger or frustration, she will be in a different place in a few minutes. I hold onto that. She will change, and I can help her change by being present for her. I can help her change by loving her – unconditionally. Because after all, isn't that what love is?

Rebecca Nagy



## **EMPLOYERS**

For most of your working life, you'll probably juggle your responsibilities at home and the office, but sometimes personal issues demand your full attention. Caregiving can be one of those things that creates enough of a disruption that a leave of absence may be appropriate.

A leave of absence can be the ideal solution for such major life events. However, it's important to take precautions so you'll be able to resume your career when things settle down.

After all, life is full of uncertainties. One day you're paying for monthly parking, and the next you could be considering taking an extended break from your job. Use these ideas for taking time off without sacrificing future opportunities.

Planning your Leave of Absence

 Save money. Unless you're on disability, you probably won't receive any pay while you're away from work. Build up your cash reserves in advance. Reduce your housing expenses if possible. Cook at home instead of dining out. Cut membership fees.

- Research your rights. You may be legally entitled to some forms of leave, depending on the country you reside in. Check your employee manual or speak with your HR department.
- Weigh the consequences. Clarify what level of job protection you're provided. With mandated leave, there's usually a guarantee you'll be reinstated. With voluntary leave, you could be terminated if there's no suitable opening available when you return.
- Cover your responsibilities. Assure your boss that you care about your job. Present proposals for how to cover your tasks while you're out.
- Give prompt notice. Let your employer know about your plans as soon as possible. Cooperating on a smooth transition will help everyone to adapt to the changes.
- Ask for Part Time or Flex Time work. Cross train a colleague to help with your work if you need to be absent.

#### Taking your Leave of Absence

- Provide updates. Keep your boss in the loop. Tell them about any developments in your caregiving role or other circumstances that would affect your return to work.
- Remain accessible. Of course, your situation will impact your coworkers as well as your boss. If you're able to stay in touch, give a trusted team member your contact information so you can answer questions as they come up.
- Stay active. Look for ways to minimize gaps on your resume. If your situation allows, do volunteer work, or take on consulting assignments. Join a committee at your professional association.
- Protect your health. For some workers, staying home can be more stressful than keeping up their usual 9 to 5 routine. Pay extra attention to eating a balanced diet, exercising daily, and sleeping well. Spend time with family and friends. Find a support network to talk about your caregiving role.

Returning From Your Leave of Absence

- Contact your employer. Thank your employer for accommodating you and let them know that you're eager to be back on the job.
   Discuss what would be the most productive way for you to catch up.
- Modify your job. In some cases, you may need to make a phased return to work. Ask your employer about altering your hours or responsibilities or adapting your workspace.
- Negotiate offers. What about job hunting after a leave of absence if you decide to move on or your employer needs to terminate you because there's no immediate openings? Find out what salary range is appropriate for your skills, and rehearse a brief explanation of the situation that you can deliver with confidence when you go on interviews.

Preparing for emergencies gives you peace of mind and more control over your future. Collaborate with your employer so you can maintain your professionalism while taking off the time you need for personal obligations.

Employers

"Doctors diagnose, nurses heal, and caregivers make sense of it all."

Brett H. Lewis | Author



## **REFLECTIONS JOURNALING**

**REFLECTIONS JOURNALING** 

# journaling for personal growth

Journaling is a powerful tool that few people take full advantage of. It can seem like a silly waste of time to some. However, journaling provides a ton of benefits and a surprising number of highly successful people make journaling a daily habit.

You can learn a lot about yourself and gain a lot of insight into your life. There's something magical about writing that thinking alone just doesn't have. While you can type your journal into your computer, most people find it more effective to use actual paper and write.

Use these tips to take advantage of journaling to gain insight into your mind and your life:

- Review your day. Take a look at your day and make some notes.
  - What happened?
  - How can you use this in the future?
  - What did you learn?
  - What mistakes did you make?
  - How can tomorrow be better than today?
- List progress toward your goals. Think about your goals and list the progress you made toward each. If you failed to do anything to make progress toward one or more of your goals, note that, too.





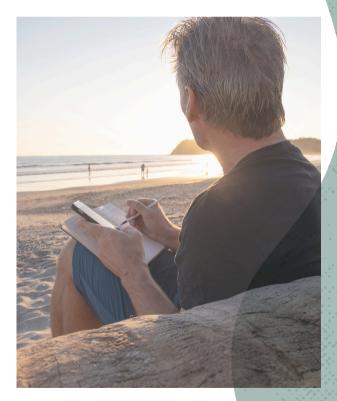
- Be proud of the progress you've made.
- Become more determined by the progress you failed to make.
- Address your fears. Write about your fears. What are you afraid of? Why do you think you're afraid of those things? How do your fears impact your life? What is your plan to address those fears?
- Choose one way to enhance yourself. Pick something you want to work on and work on it. Write about it in your journal. Perhaps you want to lose 10 pounds or strengthen your communication skills. Just be sure to select something that would enhance your life and write about your thoughts, plans, and progress.
- List your goals each day. Writing down your goals each day is a powerful way to stay focused on them. Write your 10 most important goals each day and notice how they evolve over time.





- List five things that make you feel grateful. What are you grateful for? Make a list of several items each day and notice how your perspective on life changes.
- Write about the obstacles in your life. What's standing in your way? List the obstacles in your life that you believe are blocking you from happiness or achieving your goals.
- Make a plan for the future. Aside from your specific goals, what does your dream life look like? How are you planning on getting there? Think about it and sketch out a plan.
- Write about what is causing you to feel negative emotions. What is getting you down? What are the situations, people, habits, and beliefs that are causing you the most grief? Why do these things bother you? What can you do about it?





- List the best thing and the worst thing that happened today. What are these two things and what was so great or terrible about them?
- Use journaling prompts. There are literally thousands of journaling prompts online you can choose to use at any time. Here are a few examples to get you started:
  - Make a travel bucket list.
  - List five things you appreciate about each member of your family.
  - Describe your ideal day.
  - If I could speak to my teenage self, I would say...
  - I wish that others knew I...
  - I wish I could say no to ...

Journaling each day can take some time, but it's time that's well spent. Develop a routine that incorporates journaling into your life. It won't be long before you begin noticing the benefits. Do what the most successful people in the world do and write about your thoughts and your life.





# making a routine



#### MAKE IT EASY

The simpler it is, the easier it will be to get done.





#### **CHOOSE A TIME**

The best times for most people to the journal are early morning or the last thing before you go to bed.

#### **DRINK & EAT**

Make sure you're fed and hydrated.

#### **REWARD YOURSELF**

When you have been diligent for a month writing in your journal, take some time to read what you wrote, then reward yourself for doing it.





It's easier to get into your thoughts if you're comfortable and not thinking about how bad your tailbone hurts.

# journaling as a way to deal with the stresses of caregiving

Caregiving is stressful, no doubt about it. Journaling is one way to cope with stress. Congratulations for recognizing it and wanting to do something about it. Here are some effective ways to journal to combat your stress.



#### Write Daily for 5 to 15 Minutes

The thing about journaling that is important is you need to do it daily long term for it to really work. It takes a lot of writing and insight to figure out why you're dealing with stress and how to overcome it.

#### Write About Your Worries

Go straight to the problem and write about your worries. Describe them from every angle you can come up with. The more descriptive, the better. Go back to the first time you felt this feeling regarding this topic so that you can get to the bottom of it.

# 03

#### Describe What's Happening Now

Put out of your mind what you did, what someone else did, or what can be done - right now write about precisely what is happening right now and where you stand with the issue causing your stress. If it's generalized stress, try to make a list of things that might be contributing.

# journaling as a way to deal with the stresses of caregiving



#### Document the Worst That Can Happen

As you look at the situation, one thing that often causes stress is the unknown. Describe this worst thing but make it realistic. For example, don't make up something like an airplane falling on your wedding party. That isn't realistic.

#### Document the Best That Can Happen

Let's get serious by thinking about and writing about the very best (realistic) outcome of the situation you're stressing about. Include potential steps and tactics to achieve this best-case scenario so that you can see it to fruition if you so choose.

#### **Document What Is Really Happening**

Let's get serious by thinking about and writing about the very best (realistic) outcome of the situation you're stressing about. Include potential steps and tactics to achieve this best-case scenario so that you can see it to fruition if you so choose.



#### Write a Counter-Argument to Yourself

A really good way to overcome some stress about a situation is to argue with yourself. First, tell your story as a letter to yourself about what is happening. Then write a letter back to yourself, turning it into positivity. If your best friend wrote that, how would you reply?

Reflections Journaling

"You can't explain what it's like to mourn someone who is still alive unless you've experienced it firsthand."

Jessica Seay-Soto | Therapist



## RESOURCES

RESOURCES

- Aging Life Care Association (you can hire a geriatric care manager to find resources, develop care plans, complete an assessment of your aging relative): <u>www.aginglifecare.org/</u>
- American Association of Homes and Services for the Aged: 202-783-2242 or
   <u>www.aahsa.org</u>
- ARCH National Respite Network and Resource Center <u>www.archrespite.org</u>
- Assisted Living Federation of America: 703-894-1805 or <u>www.alfa.org</u>
- Benefits CheckUp (you can search to learn about services that may help):
   <u>www.benefitscheckup.org</u>
- Caregiver Action Network: <u>www.caregiveraction.org/</u>
- Center for Medicare Advocacy (helps you with Medicare appeals):
   <u>www.medicareadvocacy.org</u>
- ElderCare Locator (will refer to your local Area Agencies on Aging): 800-677-1116
- Family Caregiver Alliance <u>www.caregiver.org</u>
- Five Wishes (a wonderful handbook to document end-of-life care wishes): <u>www.agingwithdignity.org</u>
- Financial Planning Association: 800-322-4237 or <a href="https://www.fpanet.org/">www.fpanet.org/</a>
- Medicaid: <u>www.medicaid.gov</u>
- Medicare: 1-800-MEDICARE (1-800-633-4227) or www.medicare.gov

My Medicare Matters provides step-by-step help to choose a Medicare plan for the first time, reassess coverage each year during open enrollment, and answer common questions about:

- Medicare and what it covers) www.mymedicarematters.org
- National Academy of ElderLaw Attorneys: 520-881-4005 or <u>www.naela.org</u>
- National Adult Day Services Association: 877-745-1440 or <u>www.nadsa.org</u>
- National Library of Medicine (terrific research resource): <u>www.nlm.nih.gov/</u>
- National Association for Home Care and Hospice: 202-547-7424 or <u>www.nahc.org</u>
- National Hospice and Palliative Care Association <u>www.nhpco.org/</u>
- National Association of Senior Move Managers: 877-606-2766 or <u>www.nasmm.org</u>
- National Aging and Disability Transportation Center (works to increase transportation options for older adults and enhance their ability to live more independently) <u>http://www.nadtc.org/</u>
- Next Step in Care website (the website offers a range of guides and checklists
   —most intended for family caregivers of persons with serious illness, with
   some specifically for health care providers—designed to make patients'
   transitions between care settings smoother and safer)

www.nextstepincare.org.

- Social Security Administration: <u>www.ssa.gov</u> or 1-800-772-1213
- U.S. Administration of Aging: <u>www.aoa.gov</u>
- U.S. Department of Veterans Affairs Caregiver Support: <u>www.caregiver.va.gov/</u> or (toll-free) 1-855-260-3274
- https://prepareforyourcare.org/en/covid-19

This is a booklet and videos to help you create all the necessary documents.

<u>https://get.caringboost.com/covid/?</u>
 <u>utm\_source=Daughterhood&utm\_medium=facebook&utm\_campaign=covid</u>
 <u>&fbclid=IwAR1VER9YTr6P0CQdgazOVNhzEMS\_7bZA55VHHmUWTI-</u>
 <u>5n54XGnohHVHokrQ</u>

Good resource for caring for someone at home, lots of medical tips.

• https://fivewishes.org/#

Information and guides for having end of life conversations

 <u>https://www.ncoa.org/age-well-planner/medicare/coverage-</u> <u>costs/understanding-medicare-costs/learn?</u> <u>gclsrc=aw.ds&utm\_campaign=14497063106&utm\_term=&adgroup=13154191</u> <u>0527&utm\_source=google&utm\_medium=cpc&gclid=EAIaIQobChMIwKmvj</u> <u>ruL9AIVzWxvBB2L1gN8EAAYASAAEgLZBfD\_BwE</u>

### Caregiving Websites

- <u>AARP.org/caregiving/</u>
- <u>Caring.com</u>
- <u>Caregiver.com</u>
- <u>CareYearsAcademy.com</u>
- <u>DailyCaring.com</u>
- <u>TheCaregiverSpace.org</u>
- <u>CaregiverAction.org</u>

For each of these programs, check your state as benefits and eligibility may vary.

- VA Benefits
  - https://www.ebenefits.va.gov/ebenefits/learn/healthcare
  - <u>https://www.va.gov/health-care/family-caregiver-benefits/</u>
  - <u>https://www.va.gov/health-care/about-va-health-benefits/long-term-</u>care/
  - <u>https://www.va.gov/pension/</u>
  - <u>https://www.hsrd.research.va.gov/news/feature/caregivers2021.cfm</u>
  - <u>https://www.hsrd.research.va.gov/research\_topics/caregiving.cfm</u>
- <u>Medicaid</u>
  - <u>https://www.medicaid.gov/medicaid/home-community-based-</u> services/index.html
  - <u>https://www.medicaid.gov/medicaid/home-community-based-</u> <u>services/home-community-based-services-authorities/home-community-</u> <u>based-services-1915c/index.html</u>
- <u>Applied Self-Direction</u>
  - <u>https://www.appliedselfdirection.com/</u>
- <u>Social Security</u>
  - <u>https://faq.ssa.gov/en-US/topic/?id=CAT-01094</u>

- Database of Benefits Programs for Seniors
  - https://benefitscheckup.org/
- Area Agencies on Aging
  - <u>https://eldercare.acl.gov/Public/About/Aging\_Network/AAA.aspx</u>
- Elder Law
  - https://www.naela.org//
- Cost of Elder Care
  - <u>https://www.genworth.com/aging-and-you/finances/cost-of-care.html</u>
- Support for Outside Caregivers for Respite
  - <u>https://acl.gov/programs/support-caregivers/national-family-caregiver-</u> <u>support-program</u>
- National Care Planning Council
  - <u>www.longtermcarelink.net</u>
- Long Term Care Personal Support Services Agreement
- Department of Health and Human Services, Office for Family Independence (2011)
  - <u>www.maine.gov/dhhs/ofi/documents/LTC-Personal-Support-</u> <u>Agreement.pdf</u>



# **IMPORTANT TERMS**

As a caregiver, you will encounter a lot of acronyms and clinical terms. It can be very confusing when healthcare and care facility staff talk using these terms. If you hear something and are unsure of its meaning, it's best to speak up right away.

Explore this glossary for an extensive list of terms you're apt to hear among medical staff, care facility employees, social workers, and others who speak "industry lingo." Keep in mind, however, that this is not a comprehensive list.

### **Common Acronyms**

- HHA Home Health Aid
- PCS Personal Care Services
- PERS Personal Emergency Response System
- RPM Remote Patient Monitoring
- VA Veterans Administration
- VDC Veteran Directed Care
- VAMC Veteran Medical Center
- PCAFC Program of Comprehensive Assistance for Family Caregivers HCBS Home & Community Based Services
- CDC Consumer Direct Care
- CHAMPVA Civilian Health and Medical Program
- ADL Activities of Daily Living
- SSI Supplemental Security Income
- SSDI Social Security Disability Insurance

- AAA Area Agencies on Aging
- ALF Assisted Living Facility
- CCRC Continuing Care Retirement Community
- DNR Do Not Resuscitate
- POA Power Of Attorney
- FMLA Family and Medical Leave Act
- MSP Medicare Savings Program
- NFCSP National Family Caregiver Support Program CNA Certified
   Nursing Assistant

### Further Explanation Activities of Daily Living (ADL)

Basic personal care tasks, including bathing, grooming, dressing and undressing, eating, toileting, transferring from a bed or chair, range-of-motion exercising, taking medications and getting around the home; these self-care tasks are used to measure the functional impairment level that determines eligibility for some assistance programs.

Acute care. Medical care given for a short time to treat a specific illness or condition. This includes some doctor visits, short hospital stays or surgery.

Adult care home, also called an adult family-care home (AFCH) or group home. A small assisted living residence where employees provide care for disabled adults or older adults who need help with certain tasks but want to remain as independent as possible.

### Adult Day Program

Adult day programs provide a safe, structured environment for seniors, adults with physical or mental disabilities and other adults who live in the community, providing socialization for the participant and respite for the caregiver. These programs offer different levels of care, ranging from medical models that provide a high level of care, specialized care for people with Alzheimer's disease or other forms of dementia, and programs that offer social and recreational activities, some assistance with ADLs, support services, meals, and transportation.

### Advance directives

Written statements that communicate individuals' medical preferences if they become unable to make their own health care decisions. Two types are possible:

1. A living will that outlines the types of medical treatment someone wants at the end of

life if they are unable to speak for themselves.

2. A health care proxy, which identifies a health care agent or attorney-in-fact to serve as

spokesperson for medical decisions for an individual who has lost the ability to communicate.

### Assisted living facility (ALF)

Housing for those who may need help living independently but do not need skilled nursing care. The level of assistance varies among individuals and may include help with bathing, dressing, meals, and housekeeping.

Congregate Housing - A shared living environment designed to integrate the housing and services needs of elders and younger disabled individuals to maintain their privacy and independence with supportive services in a residential setting.

### Conservator

A person whom a court appoints to handle someone's affairs when that person cannot do the job. Usually, a conservator handles only finances.

### Discharge planner

Someone who assists patients and their families in developing a method of care for a patient following a hospital or nursing home stay.

### **Councils on Aging (COA)**

Councils on Aging are local volunteer organizations that offer information and direct services to seniors, their caregivers and other people with aging concerns. COAs are part of the local government, and work with other senior agencies and city and town departments to provide social, recreational, health, safety and educational programs for seniors in their communities.

### Do Not Resuscitate Order (DNR)

An advance directive that is to be followed when a person's heart or breathing stops and they are unable to communicate their wishes to refuse cardiopulmonary resuscitation (CPR).

### **Durable Power of Attorney**

A legal document that gives someone the authority to act financially, legally and medically in your place if you become incapacitated and unable to handle matters on your own. It remains in effect until the person who grants it either cancels it or dies.

### End-of-life Doula

Also known as a death doula. An individual who provides nonmedical comfort and support to a dying person and their family. This may include education and guidance as well as emotional, spiritual or practical care.

### **End-of-Life Care**

Care that helps those with advanced, progressive, incurable illnesses to live as well as possible until death.

### Guardianship

A court-sanctioned legal relationship in which a person is given legal authority over another when that other person is unable to make safe and reasonable decisions regarding his or her person or property.

### Home Health Aide

A person who provides non-medical health care to people at home, usually assisting with activities of daily living, managing medications and performing household tasks.

### **Licensed Practical Nurse (LPN)**

A person who has completed nursing or vocational training and obtained a state license that authorizes the person to take care of basic duties in settings such as hospitals, nursing homes and long-term care facilities.