

# My Caregiver

## JOURNAL

*As a caregiver, people rely on your strength, your understanding, your knowledge and your dependability. But mostly, they count on your care. This journal will give you valuable tips and a place to record vital information, as well as a journal to write down your feelings and concerns.*





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**DISCLAIMER:** This book provides general information about caregiving and related issues. The information does not constitute medical advice and is not intended to be used for the diagnosis or treatment of a health problem or as a substitute for consulting with a licensed health professional. Consult with a qualified physician or healthcare practitioner to discuss specific individual issues or health needs and to professionally address personal medical concerns.

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## The power to care.

*Caring for someone is rarely easy. The balance between taking care of a loved one's health, safety and emotions can be overwhelming. This workbook will give you some tools and resources to help you care for a family member, a friend, a relative or patient.*

*The key is that when providing care, YOUR well-being should be top of mind. With your health, safety and emotions in check, you'll be better prepared to care for another. So, take care of yourself, give of yourself and define yourself with the power to care.*

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# Health Plan Information

*This is your workbook. Use it as a guide and resource for your general caregiving routine. Make the workbook your own by filling out this info.*



## Primary Health Insurance Provider Type:

Private       Medicare       Medicaid       Other

Company (if private): \_\_\_\_\_

Member Number: \_\_\_\_\_

Group Plan Number: \_\_\_\_\_

Member Services Phone Number: \_\_\_\_\_

Care Manager/Service Coordinator Name: \_\_\_\_\_

Care Manager/Service Coordinator Phone Number: \_\_\_\_\_

24/7 Nurse Advice Line Phone Number: \_\_\_\_\_

## Secondary Health Insurance Provider Type:

Private       Medicare       Medicaid       Other

Company (if private): \_\_\_\_\_

Member Number: \_\_\_\_\_

Group Plan Number: \_\_\_\_\_

Member Services Phone Number: \_\_\_\_\_

Care Manager/Service Coordinator Name: \_\_\_\_\_

Care Manager/Service Coordinator Phone Number: \_\_\_\_\_

24/7 Nurse Advice Line Phone Number: \_\_\_\_\_

# My Care Recipient's Information



Street Address: \_\_\_\_\_

City/State/ZIP: \_\_\_\_\_

Phone: \_\_\_\_\_

Email Address: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

Employer: \_\_\_\_\_

Employer Phone: \_\_\_\_\_

Primary Care Doctor: \_\_\_\_\_

Primary Care Doctor's Phone: \_\_\_\_\_

Specialist Doctor: \_\_\_\_\_

Specialist's Phone: \_\_\_\_\_

Specialist Doctor: \_\_\_\_\_

Specialist's Phone: \_\_\_\_\_

Attendant Care Provider: \_\_\_\_\_

Attendant Care Provider Phone: \_\_\_\_\_

Respite Care Provider: \_\_\_\_\_

Respite Care Provider Phone: \_\_\_\_\_

Pharmacy Name: \_\_\_\_\_

Pharmacy Phone: \_\_\_\_\_

Non-emergent Medical Transportation Name: \_\_\_\_\_

Non-emergent Medical Transportation Phone: \_\_\_\_\_

Emergency Contact Name & Phone: \_\_\_\_\_

Secondary Emergency Contact: \_\_\_\_\_

# The Basics of Caregiving

## CAREGIVER:

*Caregivers are broadly defined as family members, friends or neighbors who provide unpaid assistance to a person with a chronic illness or disabling condition.*



Maybe you've trained to be a caregiver, with completed coursework and professional certification. You may have a healthcare background and have made it your working life to tend to the needs of others.

Most likely you're new to the role of caring for a family member or friend who can no longer care for him or herself. If so, we hope you find this workbook helpful as it guides you through some of the concerns you might come across.

Providing care for a person is rarely easy. The time spent caring for someone who can't care for him or herself can drain you physically and emotionally.

But if you're the type of person willing to give of yourself to help someone else, this book might help.

## Who can be a caregiver?

- » A parent for a child
- » A child for an older or disabled parent
- » A spouse
- » A niece, nephew or grandchild
- » A family friend
- » A neighbor
- » A hired professional healthcare worker
- » You or anyone else

# Caregiver Basics

*As a caregiver, you may share in the responsibility of someone's well-being. You may provide basic functions for a person in need, such as making meals and feeding, bathing, grooming, walking or other daily routines.*



What is the care recipient's primary disability or chronic condition?

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What supportive services or accommodations are needed?

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# Signs of the Times

*If you suspect that your care recipient may be at the point where he or she needs some extra care and attention, keep an eye out for these possible warning signs:*

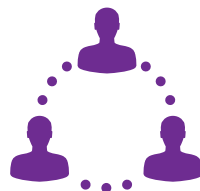


- » The house is messy and in a bit of disorder
- » Bills are unpaid, and mail is piled up
- » Dirty dishes are piling up in the sink
- » Food is spoiling or has expired in the refrigerator
- » Trash is piling up
- » Plumbing issues are causing odors

Issues like these could signal early signs of depression, dementia, vision and mobility problems. Look for these signs on your visits and get involved if any exist.

# Roles of a Caregiver

*As a caregiver, you wear many hats: doctor, nurse, lawyer, secretary, accountant, chauffeur, cook, housekeeper and social worker. Your duties may include:*



- » Keeping track of information on your loved one's condition, treatment and care
- » Monitoring your loved one's health
- » Helping your loved one with his/her needs
- » Helping your loved one make choices about his or her health
- » Handling your loved one's emotional needs
- » Keeping track of financial dealings on behalf of your loved one
- » Planning for your loved one's future care and treatment

# Relationship Issues



Getting to know your care recipient is important in providing the kind of care he or she needs. Your relationship may intensify during this time, in good and bad ways.

The secret to success is that it is really about the two people taking care of each other during a difficult time. It's all about give and take. Realizing this will lead to a relationship that thrives. Be gentle, be caring and be understanding.



## Why We Do It



Caregiving provides many positive experiences for the caregiver. We feel good about ourselves when we are useful, especially by helping others who cannot care for themselves. We may also see this care as a way of paying back our parents for taking care of us as we were growing up. We're motivated by the belief that we're doing the right thing. And we are.

Use the journal in the back of this book to explore your own reasons for caregiving and the feelings that go along with those reasons.

Caregiving isn't without challenges.  
When asked, caregivers give  
examples of stress like these:



- » Loss of privacy
- » Limits on free time or a social life
- » Less time for other family members
- » Giving up vacations, hobbies or favorite activities
- » Physical and mental exhaustion
- » Frustration with not making progress with care recipient
- » Financial strain



What do you think could become a problem  
for you during caregiving?

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# Communicate

*Your care recipient may worry about being a burden, taking up your time and asking too much of you.*



## **Create productive communication by doing these things:**

- » Show respect
- » Watch what you say – try not to use phrases like “You never...” or “You always...”
- » Listen to the feelings of your care recipient with compassion
- » Build and encourage two-way conversations
- » Allow him or her to show independence – your loved one has a right to his or her dignity, so allow him/her to do things in his/her own way
- » Speak in ways that support the abilities of your loved one
- » Be reassuring when talking to your care recipient
- » Notice fears and react in a positive manner
- » Work through disagreements to reach a solution
- » Set aside time each day when your care recipient knows you have the time and energy to listen

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# Respect Privacy



Imagine having to bathe and dress the person who bathed and dressed you when you were young. This role reversal can be hard when you're caregiving for your parent. Your elder may withdraw or become angry over the situation. You both may be embarrassed. Have a professional attitude when touching your older family member's body. Slow down and describe what you are about to do. Taking a more relaxed approach will feel less like you are invading personal territory.

# 10 Ways to Make Things Easier

- 1 GET READY:** Learn what is expected of you. Figure out your schedule and how much time you can devote.
- 2 GET ORGANIZED:** Organize medical and legal info and keep it up-to-date, in order and easy to find.
- 3 GET SUPPORT:** Seek information and advice from other caregivers and support groups.
- 4 GET TALKING:** Learn the best ways to communicate with the doctors and healthcare team.
- 5 GET HELP:** Take help from others who offer it. Don't be afraid to ask for specific tasks.
- 6 GET HEALTHY:** Take care of your own health so you are strong and well enough to care for another person.
- 7 GET REST:** A good night's sleep every night and regular breaks during the day will help you concentrate and have the energy to provide for others.
- 8 GET HAPPY:** Depression can be an issue when caregiving for another. Watch for signs and seek professional help if you need it.
- 9 GET THE LATEST TECHNOLOGY:** Caring can be easier if you're open to using technology. Personal computers, tablets and smartphones can keep you connected to information, healthcare teams, pharmacies and the health plan.
- 10 GET TO KNOW YOURSELF:** You're now doing one of the toughest jobs there is. Figure out what makes you tick and how understanding yourself can make you a great caregiver.

# 5 WAYS TO Keep Yourself Healthy

*Without guilt, you must take care of yourself. If you are not well-rested and healthy, you cannot tend to the healthcare needs of others. The people who count on you want you to be fit and well. Follow these steps to keep your own health and well-being as an important part of your caregiving plan.*



## SLEEP WELL

Don't cut back on your sleep schedule. Trying to get more done by sleeping less rarely works. You need more sleep than you think you do. Eight hours a night is normal. Cheating yourself of this precious downtime means:



- » Your mood could change
- » Your energy level may reduce
- » Your productivity could go down
- » Your stress may be greater
- » Your ability to handle stress may weaken

### Sleep Chart:

DAY / DATE	HOURS SLEPT	HEALTH / MOOD <i>the following day</i>

*Make copies of this chart or use a journal page to continue.*

## 2

### EXERCISE & STAY ACTIVE



Exercise has many benefits. Relieving stress and making moods better are a couple of the benefits. It may be hard to motivate yourself to exercise after a demanding and stressful caregiving shift, but it will help you feel better. Regular exercise will boost your energy level and may help you be less tired.

Try to exercise for at least 30 minutes each day. Find time in your schedule. It may be when you get up in the morning, during a lunch break, before dinner or later in the evening.

## 3

### EAT WELL

Fuel your body with the best things to give you lasting energy:

- » Fresh fruits
- » Vegetables
- » Whole grains, like brown rice or oatmeal
- » Lean proteins, like fish, chicken, eggs or beans
- » Healthy fats like nuts and olive oil



Sugar and caffeine may seem like they provide energy, but they don't last. The energy rush crashes quickly, leaving you more tired.

### Healthy Foods Chart:

DAY / DATE	TIME	HEALTHY FOODS EATEN

## 4

## SEE YOUR DOCTOR

Make it a point to keep all of your doctor appointments, follow his or her instructions and take your prescribed medicine and vitamins. Know your boundaries and don't try to do too much. To care for a loved one, you first have to get your own health in order.

Work with your doctor to fill out this wellness chart. Compare your current numbers to your ideal numbers and work toward getting closer to those ideals.



### Wellness Chart:

My ideal blood pressure:	My current blood pressure:
My ideal LDL cholesterol:	My current LDL cholesterol:
My ideal HDL cholesterol:	My current HDL cholesterol:
My ideal triglyceride level:	My current triglyceride level:
My ideal weight:	My current weight:
My ideal amount of time staying physically active:	My current amount of time staying physically active:
My ideal number of fruits and vegetables each day:	My current number of fruits and vegetables each day:



## 5

## RELAX AND MEDITATE

Setting aside a time to unwind and meditate can be a great stress reliever. If you don't have a block of time, even just a few minutes in the middle of your day can get stress levels under control. Practice a routine of deep breathing, clearing your mind and focusing on positive thoughts. Consider adding yoga or stretching to relax even more.

Repeating phrases or mantras may help you reduce stress and bring yourself back to calm. Here are some examples to get you started:

- » In every moment, peace is a choice.
- » All is well.
- » I did well. I don't have to be perfect.
- » I will stay calm and carry on.
- » I surrender and let go.



# Keep Safety in Mind

*Safety for your care recipient and yourself should always be a main concern. For frail older adults and those with Alzheimer’s disease and dementia, everyday things can pose problems.*



**Check that elderly care recipients are wearing appropriate shoes with non-slip soles.**

**Help your older adult prevent falls by making sure he/she:**

- » Exercises regularly.
- » Asks the doctor or pharmacist to check for medications that may cause side effects, such as dizziness or drowsiness.
- » Sees an eye doctor at least once a year and updates his/her eyeglasses prescription.
- » Takes out all tripping hazards from the home.
- » Improves lighting in the home and adds grab bars and rails.

**Getting calcium and vitamin D from food or supplements, doing weight exercises and getting screened for osteoporosis can help lower the risk of hip fractures.**



## **BRIGHT IDEA**

*Put in motion-sensor lights in the bathroom, hallways, stairways and bedrooms.*



# Safety Check



## AT HOME SAFETY CHECKLIST:

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### All Rooms and Hallways

- Electrical cords out of the way and secured to walls
- Walkways free of furniture and clutter
- Carpeting and rugs secured with non-slip backing
- All light bulbs and switches working

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### Bathroom

- Grab bars mounted in shower and near toilet, if needed
- Shower/bath has non-slip bathmat, secured with suction
- Nightlight
- Bathroom rug or mat with non-slip backing
- Free of clutter with enough room to move around
- Shower bench or chair

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### Bedroom

- Bedside table with a secured lamp
- Clear walkway from bed to bathroom
- Sturdy chair to sit in while dressing

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### Kitchen

- All needed items reachable without using a stool
- Place to sit when making food
- No cracks or edges in kitchen floor
- Electrical cords away from water sources

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### Stairs

- Free of clutter
- Room to move at top of stairs
- All carpeting secured on steps
- Handrails secured and at the right height
- Well-lit stairways with switches at top and bottom

# Other Safety Tips



- » When not in use, store clothing, bedding and other items where they can be reached with ease.
- » Place brightly colored tape on the edge of each step. This will signal you're at the drop-off point.
- » Make sure all floorboards are even.
- » Put a liquid soap dispenser in the shower. Slips and falls can happen when trying to pick up a dropped bar of soap.
- » Make sure the water is set at a safe temperature (120°F or lower).
- » Make sure items used often are placed within reach.
- » Lock up cleaning supplies or flammable liquids.
- » Keep a first aid kit in an easy to find place.



## **BRIGHT IDEA**

*Make sure a lamp and phone are beside the bed of your care recipient.*

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# Keeping It All Together

*As a caregiver you will need to keep all forms and info organized and at your fingertips at all times. Fill out these forms and keep them with you. Keep this info private, to be shared only with your care recipient's healthcare team and close family members.*



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## MEDICATION LOG

Use this log to keep track of your care recipient's medicine schedule. Share this list with your loved one, family members and healthcare team so all know of the medicines taken and the schedule for taking them.

Patient Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

Local Pharmacy Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Pharmacy Address: \_\_\_\_\_

Mail Order Pharmacy: \_\_\_\_\_

Mail Order Pharmacy Phone/Website: \_\_\_\_\_

### Over-the-Counter Medications

Allergy Relief/Antihistamines: \_\_\_\_\_

Antacids: \_\_\_\_\_

Aspirin/Other Pain or Fever Relief: \_\_\_\_\_

Cold/Cough Medicines: \_\_\_\_\_

Diet Pills: \_\_\_\_\_

Herbal Supplements: \_\_\_\_\_

Laxatives: \_\_\_\_\_

Sleeping Pills: \_\_\_\_\_

Vitamins/Minerals: \_\_\_\_\_

Other: \_\_\_\_\_

# Prescription Medications



	MEDICINE 1	MEDICINE 2
MEDICINE NAME		
DOSE		
WHEN TO TAKE		
WHY IS IT TAKEN?		
START DATE		
END DATE		
PRESCRIBED BY		
SIDE EFFECTS OR DANGER SIGNS		

	MEDICINE 3	MEDICINE 4
MEDICINE NAME		
DOSE		
WHEN TO TAKE		
WHY IS IT TAKEN?		
START DATE		
END DATE		
PRESCRIBED BY		
SIDE EFFECTS OR DANGER SIGNS		

# Prescription Medications



	MEDICINE 5	MEDICINE 6
MEDICINE NAME		
DOSE		
WHEN TO TAKE		
WHY IS IT TAKEN?		
START DATE		
END DATE		
PRESCRIBED BY		
SIDE EFFECTS OR DANGER SIGNS		

	MEDICINE 7	MEDICINE 8
MEDICINE NAME		
DOSE		
WHEN TO TAKE		
WHY IS IT TAKEN?		
START DATE		
END DATE		
PRESCRIBED BY		
SIDE EFFECTS OR DANGER SIGNS		

# Health History



Check the items that apply to your care recipient's past or present state of health.

- |  |  |
|--|--|
| <input type="checkbox"/> Alcoholism                  | <input type="checkbox"/> Arthritis               |
| <input type="checkbox"/> Asthma                      | <input type="checkbox"/> Cancer                  |
| <input type="checkbox"/> Diabetes-Type I             | <input type="checkbox"/> Diabetes-Type II        |
| <input type="checkbox"/> Emphysema                   | <input type="checkbox"/> Glaucoma                |
| <input type="checkbox"/> Heart Condition             | <input type="checkbox"/> Hemodialysis            |
| <input type="checkbox"/> Hepatitis A                 | <input type="checkbox"/> Hepatitis B             |
| <input type="checkbox"/> High Cholesterol            | <input type="checkbox"/> High Blood Pressure     |
| <input type="checkbox"/> Kidney Disease              | <input type="checkbox"/> Intellectually Disabled |
| <input type="checkbox"/> Rheumatic Fever             | <input type="checkbox"/> Seizures                |
| <input type="checkbox"/> Stomach/Intestinal Problems | <input type="checkbox"/> Stroke                  |
| <input type="checkbox"/> Thyroid Disorders           | <input type="checkbox"/> Tuberculosis            |
| <input type="checkbox"/> Tumor                       | <input type="checkbox"/> Other: _____            |



# Lifestyle



- |   |   |
|---|---|
| Smoking: <input type="checkbox"/> Yes <input type="checkbox"/> No | Alcohol: <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Packs per day: _____  | Drinks per week: _____  |
| Number of years: _____  | Number of years: _____  |



# Allergies



List all food, medication, environmental and other factors to which your care recipient may be allergic.

ALLERGEN	REACTION	LAST INSTANCE	TREATMENT

## The most common allergy triggers:

- Animal dander
- Dust mites
- Mold
- Certain foods
- Insect stings
- Pollen
- Certain medications
- Latex

# Advance Directives

Explanations of these terms can be found on pages 36-37.



## HEALTHCARE PROXY

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Cell: \_\_\_\_\_ Work: \_\_\_\_\_

Agent Address: \_\_\_\_\_

Agent Work Address: \_\_\_\_\_

Document Location: \_\_\_\_\_

Document Contact Name: \_\_\_\_\_ Phone: \_\_\_\_\_

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## LIVING WILL

Document Location: \_\_\_\_\_

Document Contact Name: \_\_\_\_\_ Phone: \_\_\_\_\_

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## POWER OF ATTORNEY

*(Fill in the information for the person with Power of Attorney)*

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Cell: \_\_\_\_\_ Work: \_\_\_\_\_

Agent Address: \_\_\_\_\_

Agent Work Address: \_\_\_\_\_

Document Location: \_\_\_\_\_

Document Contact Name: \_\_\_\_\_ Phone: \_\_\_\_\_

# Fitness for You

*Caring for someone else can be time-consuming and exhausting. Spending your free time exercising might seem like the last thing on your list. But it just might be the best thing for your body. Exercise can:*

- » Keep you from getting sick
- » Help you sleep better
- » Give you energy to last through the day
- » Lower blood pressure and cholesterol
- » Lower stress
- » Make you a better caregiver



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*If exercising feels more like a chore, you're much less likely to do it. The good news is: exercise can be easy and fun. It doesn't have to be a full gym workout five times a week.*

## **FIND A FITNESS FRIEND**

Pick a friend who has a lot of energy and you enjoy being around. Motivate each other to develop a fitness routine and stick to it. Have fun while you walk, jog, bike or work out.

## **TRY A GROUP FITNESS CLASS**

Many parks and community centers have fitness activities. Look for classes that teach yoga, tai chi, swimming, step aerobics and even martial arts. You'll meet new people, learn new things and improve your overall wellness.

## DANCE

Dancing can keep you active and fit. Try ballroom dancing, square dancing or salsa dancing. Dance helps your balance and builds your endurance. And it's fun.

## GET ACTIVE WITH THE KIDS

Grab your kids and go for a hike, play basketball, get to the park and be active. They need exercise as much as you do. Hold friendly competitions each week and get everyone involved.

## TRY A TEAM SPORT

Softball, bowling, volleyball and tennis teams form regularly. Join one and stay active as you compete.

## TURN CHORES INTO FITNESS

Activity comes in many forms. Gardening, raking leaves, mowing the grass, shoveling snow, grocery shopping and washing the car burn calories and keep you active and moving.



### ***REMEMBER: Exercise is vital for caregivers.***

*Set a goal of 30 – 40 minutes of moderate exercise three or more times a week.*

*Always talk to your doctor or healthcare team before starting any exercise program.*



# My Exercise Log



DAY / DATE	TIME OF DAY	EXERCISE	LENGTH OF TIME (REPETITIONS)



# Dealing with Stress

*As a caregiver, there are a lot of demands on you physically, mentally and emotionally. You may feel the pressure and stress of your situation, and think you are in over your head with little or no control. Watching for the signs of stress can help you better handle it.*

## SIGNS OF CAREGIVER STRESS

Check the ones you've experienced yourself since serving as a caregiver:

- |  |   |
|--|---|
| <input type="checkbox"/> Anxiety           | <input type="checkbox"/> Depression                           |
| <input type="checkbox"/> Irritability      | <input type="checkbox"/> Tiredness/run down feeling           |
| <input type="checkbox"/> Sleep problems    | <input type="checkbox"/> Short temper                         |
| <input type="checkbox"/> Problems focusing | <input type="checkbox"/> Resentful feelings                   |
| <input type="checkbox"/> Drinking more     | <input type="checkbox"/> Smoking more                         |
| <input type="checkbox"/> Eating more       | <input type="checkbox"/> Neglecting duties                    |
| <input type="checkbox"/> Health problems   | <input type="checkbox"/> Cutting back on free time activities |

What other signs of stress have you experienced?

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# Rest, Relax, Recharge

*It's essential to switch off your caregiver mode and relax. Stress and burnout are real risks.*



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It's easy to find ways to relax that won't cost a lot of money. There are many little things you can do to reduce caregiver stress:

- » Take a long bath
- » Take a walk
- » Bake a favorite dish or dessert
- » Read a relaxing book
- » Browse the library
- » Go see a movie
- » Plant some flowers or do some gardening
- » Practice yoga
- » Talk to a friend
- » Listen to soothing music in a low-lit and comfortable place

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What other relaxing activities do you enjoy that serve to de-stress you?

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# Ask for Help

*You can't do this alone. And you shouldn't have to. Trying to tackle all the duties and burdens of caring for a loved one on your own won't work.*

- » Let those around you know you need help.
- » Spread out the duties and get as many family members involved as you can. Delegate duties: someone to shop for food; someone to see to the finances; someone to set up appointments; someone to oversee medical concerns, etc. Set up a schedule and assign times and tasks.
- » Don't say no to help when offered by a family member or friend. Many people will want to help, and you'll feel better by taking it.
- » You can't control every part of your care plan. Let people help and don't micro-manage their efforts. That can harm their desire to help.
- » Make a contact list of those you think will be willing to help.
- » Create a schedule and document your loved one's likes and dislikes and regular routine.

## My helper resources:

NAME	PHONE	TASKS

# Take a Break

*You owe it to yourself. Your loved one most likely needs the break, too. Add breaks to your schedule and see that you take them. You'll be a better caregiver by giving yourself rest and time to do the things you need and want to do for yourself.*

- » Set aside at least 30 minutes of “Me Time” each day. This is time to do what makes you feel good, relaxed and unstressed. Enjoy this time without guilt and make it a priority in your day.
- » Raise your spirits while you lower your blood pressure. Take a long candle-lit bubble bath. Read a magazine. Anything that relaxes you and makes you feel special will go a long way in defeating stress.
- » Laughter is a known stress buster. Watch a funny movie or TV show. Read a funny book. Talk to a friend who knows how to bring out your smile.
- » Go shop with a friend. Go for a walk or a drive while others are caring for your loved one.

Make a list of places close by that you enjoy visiting:

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# Calling the Care Manager/ Service Coordinator

*The Care Manager/Service Coordinator is there to support you and is an important part of your care recipient's care team.*

While there are many reasons to call, here are some to keep in mind\*:

- » Change in condition or available support needs
- » ER visit
- » Hospital admission
- » Fall
- » Urinary tract infection (UTI)
- » Significant injury
- » Attendant Provider not providing the agreed upon services
- » New diagnosis or medication
- » Assistance with finding a provider or changing providers
- » Difficulty getting an appointment with a provider
- » Potential change in living or work arrangement for the care recipient
- » Need for additional caregiver task training
- » Durable Medical Equipment (DME) broken or in need of repair

*\* Nothing within this book should be viewed as medical advice. In the case of a medical emergency, contact your healthcare provider or call 911.*

# Managing Caregiving & Work

*Millions of Americans juggle the challenges of caregiving with a full-time or part-time job. This struggle for balance can lead to emotional fatigue, physical exhaustion and distraction.*

*This reality of life has led many employers to be more generous with allowing their workforce to accommodate these demands. Some companies even help with finding community resources, counseling, legal and financial aid and support groups for caregivers. Many offer flex time or leave for their employees caring for a family member in need. If you have a full or part-time job, look into the options your company offers.*

## Tips for Managing Work and Caregiving:

**1 LEARN THE COMPANY POLICIES**  
Read your employee handbook or speak with someone from Human Resources (HR) to find out the company’s policy regarding time off for caregiving. Your company may have an Employee Assistance Program (EAP) that provides benefits for caring for an elderly parent or relative.

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**2 KNOW YOUR RIGHTS**  
The federal Family and Medical Leave Act (FMLA) provides eligible workers with 12 weeks per year of unpaid leave for family caregiving. You can’t lose your job security or health benefits during these times. Ask your HR department for more info.

3

### TALK TO YOUR MANAGER

Tell your manager about your caregiving duties and demands. Ask about changing your work times if your caregiving calls for being away from your job. Be honest about this demand on your time and let your manager know you're willing to work other hours to make up for time lost while caregiving.

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### ASK ABOUT FLEX-TIME

Ask your manager about altering your work schedule, going from full-time to part-time or working earlier or later shifts to accommodate your caregiving needs.

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5

### STAY ORGANIZED

Try to manage your time as best as you can. Write to-do lists and use calendar reminders. Make a list of priorities and address those first. Don't be afraid to assign tasks to others in the family to help with the caregiving.

.....

6

### APPRECIATE

Be thankful and appreciative of your coworkers and managers who help out with your job duties while you are going through these tough times. Offer to take on extra work when you can and help others who may find themselves in a situation like yours.

# Legal Matters

*Caregiving comes with legal and financial concerns. Make sure you have a working knowledge of these concepts that are put in place to ensure the wishes of your loved one are met.*



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## ADVANCE DIRECTIVES

Advance directives are legal documents that a person writes to tell the healthcare team what medical care and treatment he or she wants or doesn't want. When a person can't speak for him or herself or is too sick or unable to make decisions, these documents make wishes known.

Having advance directives in place for your loved one will make sure he or she gets the care desired, or forgoes the treatment not wanted.

### Advance directives cover two types of info:

- » The kinds of treatment wanted or not wanted by the family member
- » The person put in charge of making healthcare decisions if the family member isn't able to

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## HEALTHCARE PROXY

This form of advance directive allows someone to name a healthcare substitute. This substitute will make legal healthcare decisions for the person.

**Healthcare Proxy Form:** A form filled out that gives another person the right to act on healthcare matters for another person. Each state has its own laws and rules about this decision making process. Contact your state's Department of Health to learn the laws and obtain the form that applies for your state.

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## LIVING WILL

This is a written account of what healthcare treatment a person wants or doesn't want in the future. Again, this document makes sure a person's wishes and decisions are followed, in the event that he or she is not able to make them. Healthcare teams and family members must abide by these legally-binding wishes.

## DO NOT RESUSCITATE (DNR) ORDER

This document makes sure the wishes of a person who doesn't want CPR or other life-sustaining methods used if his or her heart or breathing stops are met. Here are some things to keep in mind:

- » The DNR order must be signed by a doctor
- » If you are a family member caregiver, you may also need to sign the order
- » The DNR order will still be in effect, even if no healthcare proxy has been chosen
- » There is also an Out-of-Hospital DNR Order that tells emergency staff not to perform CPR if your family member's heart fails while at home. This order must also be signed by a doctor.

Many states have POLST (Physician Orders for Life-Sustaining Treatment) forms that allow for DNR orders to be followed when patients are taken from one healthcare setting to another. See [POLST.org](http://POLST.org) for more information and to learn about the laws in your state.

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## LEGAL HELP

It's wise to speak to a lawyer about these documents and certain financial concerns. A lawyer can help you set up a will or estate plan, as well as give advice on key matters in the life of your care recipient. Legal assistance may be available in your community. Care Managers/ Service Coordinators may be able to connect you to a resource.



### DID YOU KNOW?

*You may be eligible for tax benefits as the caregiving relative to an older adult in the form of tax breaks or financial help. Check out [irs.gov](http://irs.gov) or call 1-800-829-1040 to learn more.*

# Support Groups

You can't go it alone. But sometimes finding friends, allies and emotional outlets nearby can be a challenge. That's where support groups come in. They're great resources to lean on when you're:



- » First becoming a caregiver.
- » Learning about caregiving.
- » Dealing with the stress of caregiving.
- » Sharing your stories and concerns with others who have similar experiences.

Support groups listen to your concerns and problems, giving expert answers to your questions and offering advice. You also listen to others who have issues and need advice. In time, you'll be able to offer advice to others in need. The first thing you'll learn pretty quickly is that you aren't alone in this. Others are in the same situation, with similar problems and challenges.

Some of these groups may be found locally. Others you'll be able to reach online.

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## HOW SUPPORT GROUPS WORK

Local in-person groups:

- » Group members live nearby and meet regularly.
- » At each session, you make new friends and speak face-to-face about your concerns while listening to others.
- » The meetings offer a social outlet, a chance to get out of the house so you don't feel all alone.
- » In most cases, the meetings will be held at a set time and place. Attending regularly will help you get the most out of these support group sessions.
- » Learn about local resources from the other local group members. These may include doctors and specialists, health and financial programs or other outlets that could be of help to you.





## ONLINE SUPPORT GROUPS

- » Group members are from all over the world, meeting online to talk about their concerns.
- » You can find these groups online through email, websites, message boards, social media or through recommendations from healthcare providers.
- » If you're short on time or can't leave the house, these online support groups may be ideal.
- » These groups are most likely easy to reach at any time, offering help when you need it.
- » Help will come from a variety of online participants, so finding answers to even your most unique questions and concerns is likely.

You can find a community support group by checking the local phone book, by dialing the United Way at 2-1-1, by asking your doctor or hospital or by calling your Care Manager/Service Coordinator.



## MY LOCAL SUPPORT GROUP

Name of Group: \_\_\_\_\_

Dates/Times: \_\_\_\_\_

Location: \_\_\_\_\_

## MY ONLINE SUPPORT GROUP

Name of Group: \_\_\_\_\_

Web Address: \_\_\_\_\_























# Resources for Caregivers

## **AARP**

[aarp.org](http://aarp.org)

## **Eldercare Locator**

1.800.677.1116

[Eldercare.gov](http://Eldercare.gov)

## **CAN**

### **(Caregiver Action Network)**

[Caregiveraction.org](http://Caregiveraction.org)

## **POLST**

### **(Physician Orders For Life-Sustaining Treatment)**

[POLST.org](http://POLST.org)

## **Stroke**

[Stroke.org](http://Stroke.org)

1-800-STROKES (787-6537)

## **Brain Injury**

### **Association of America**

[www.BIAUSA.org](http://www.BIAUSA.org)

## **Serious Mental Illness**

[NAMI.org](http://NAMI.org)

1-800-950-NAMI (6264)

## **Medicare**

[Medicare.gov](http://Medicare.gov)

## **Medicaid**

[Medicaid.gov](http://Medicaid.gov)

## **Disability**

[Disability.gov](http://Disability.gov)

## **U.S. Living Will Registry®**

[uslivingwillregistry.com](http://uslivingwillregistry.com)

## **MedlinePlus:**

### **End of Life Issues**

[medlineplus.gov/  
endoflifeissues.html](http://medlineplus.gov/endoflifeissues.html)

## **Dementia/Alzheimer's**

[ALZ.org](http://ALZ.org)

1-800-272-3900

## **Family Caregiver Alliance**

[Caregiver.org](http://Caregiver.org)

1-800-445-8106

## **NASUAD (National Association of States United for Aging and Disabilities)**

[nasuad.org](http://nasuad.org)

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# My Caregiver Journal

## SOMEBODY NEEDS YOU.

*Caregiver roles can vary, but all exist because someone needs help and care. To support you in your important role, this journal provides tips, resources and tools to assist you in looking after your care recipient and yourself.*

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### Topics in this book include:

- » Caregiving basics
- » Safety
- » Your health and fitness
- » Dealing with stress and burnout
- » Organization
- » Legal and financial matters
- » Support groups and resources
- » And more

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