

# Alzheimer's Disease: Helping Yourself Help A Loved One



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Caregiver stories are taken from:  
*Lessons Learned: Shared Experiences in Coping*. Participants of Duke University Alzheimer Support Groups, Edna L. Ballard, and Cornelia M. Poer. 1999. Durham, NC: Duke University Medical Center.

**As a caregiver you have so many things to do and think about, and most likely not enough time to do everything.** This workbook is designed to help you stay organized and get the information you need to take care of your loved one and yourself.

This workbook includes information and tools on preparing for health care appointments, making your home safe for your loved one, organizing legal and financial information, finding time for yourself, and more. Each section includes suggestions on how to use the worksheet or tool—but keep in mind that you can personalize this workbook to fit your needs. You may want to make copies of the worksheets and keep them in a binder with medical records and other important information. If you need blank copies, you can find them at [www.agingresearch.org](http://www.agingresearch.org). Once you have a binder or other organizational tool, keep it in an easy-to-find place so that others can get the information if you are not there.

As medical records, financial information, and medications start adding up, it's helpful to have one place to keep all of this information. Time is precious for both you and your loved one. Spending less time trying to find lost papers and getting ready for doctor's appointments gives you more time with your loved one and makes it easier to schedule time for yourself. Keeping track of your loved one's health and preparing for appointments will also help get your loved one the best care possible. We hope that this workbook will make your very important job as a caregiver a little bit easier.

*"I think this would have been so much easier if someone had told me earlier on what to expect, what I could do, what I shouldn't try. Maybe they did and I didn't hear."*

— Mr. Russell  
*Lessons Learned—  
Shared Experiences in Coping*

# Keeping a Health Journal

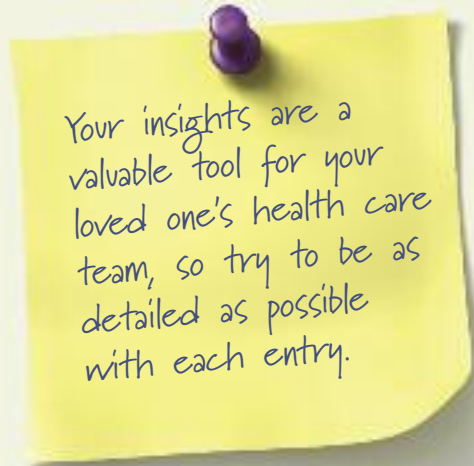
**It's useful to keep a health journal so you can ensure that your loved one's health care team is able to provide the best care possible.** By keeping track of day-to-day health information that only you may observe, you can provide valuable information to your loved one's health care team. A journal makes it easy to record information about Alzheimer's disease and other conditions your loved one may have, so you can make the most of your time at appointments and be sure not to forget anything.

You may want to keep a health journal in a separate notebook, or use the worksheet on the following page. For each entry, be sure to include the date, time and length of each event. Recording these will show any daily patterns or changes in behavior and symptoms. Since your loved one's health care team may want to make copies of your journal pages, write down dates and page numbers so you can keep the pages organized.

Your insights are a valuable tool for your loved one's health care team, so try to be as detailed as possible with each entry. All patients exhibit different symptoms, so it's important for you to keep a personalized record of which symptoms your loved one experiences. Remember that it may not be easy to write about what your loved one is going through, but your perspective is unique and important.

*"Now that I've done this for three years, there's so much I would do differently. I would be more patient. I would be easier on myself. I would let go—of old ideas, old expectations, old ways of doing things. I would bury shoulda, woulda, oughta, coulda. I would learn to appreciate the present. It was when I compared where we are, what we have, what he can do with the past that I got into trouble."*

— Alyce A.  
*Lessons Learned—Shared Experiences in Coping*



## Alzheimer's Disease: Helping Yourself Help a Loved One Health Journal

Loved One's Name: \_\_\_\_\_

Date	Time	Health event or change in physical or emotional health	Length of event or change	Other notes
3/6/08	2:15pm	Suddenly unable to walk without assistance	Lasted until bedtime	Regained his ability to walk the next morning

Journal Page #: \_\_\_\_\_

Start Date of Journal Page: \_\_\_\_\_

End Date: \_\_\_\_\_

# Preparing for Health Care Appointments

**Taking your loved one to health care appointments may become difficult at times.** If you prepare for appointments by writing down questions and scheduling the appointment at a good time for your loved one, you can make sure the appointment goes as smoothly as possible. Use the worksheet on the following page to record information about the appointment so it's all in one place.

## Scheduling the Appointment

Try to schedule the appointment for a time of day when your loved one is calm and alert. You may want to ask the office staff what time of day is the least crowded since a lot of people may make your loved one agitated or stressed.

## Preparing for the Appointment

Write down any questions you have for the health care provider. It can be very frustrating to remember a question after you leave. Put your questions in order by importance in case there isn't enough time to ask all of them. Doing this also creates a record of your loved one's treatment and medical history.

## Getting to the Appointment

If your loved one worries about medical appointments, you may want to wait to tell them about the appointment until the day of. Be positive and straight-forward when you do tell them—you may want to tell them it's just a checkup to reduce anxiety. Try not to show any negative emotions that you are having since Alzheimer's patients are very sensitive to others' feelings. Once there, try not to leave your loved one alone—if you anticipate that you will need to talk with the doctor separately, ask someone to come along to sit with your loved one.

## During the Appointment

Communication between you and your loved one's health care team is important, and you should feel like you clearly understand everything about your loved one's medical care. By taking notes and reading back anything you are uncertain of, you can clarify things such as unfamiliar words, and ask any further questions that you may have. At the end of the appointment, write down the date, time, and health care provider for the next one.

## After the Appointment

You may want to discuss the appointment with your loved one. Ask how he/she felt about the visit. It's good to stay positive about the doctor and visit when possible.



# Alzheimer's Disease: Helping Yourself Help a Loved One Health Care Appointment Form

Date: \_\_\_\_\_ Time: \_\_\_\_\_

Name of health care provider: \_\_\_\_\_

Questions for health care provider:  
(fill out in advance)

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Answers:  
(fill out at appointment)

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Notes/Additional questions:

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Next appointment date: \_\_\_\_\_ Time: \_\_\_\_\_

Health care provider: \_\_\_\_\_





# Making Your Home Safe

**Alzheimer's disease progresses differently in everyone, but eventually it will affect your loved one's independence.** The typical home environment may become unfamiliar and dangerous, but there are steps you can take to make the home less stressful.

Use the checklist on the following page to make sure that your loved one's residence is safe. If your loved one lives in your home, some of these changes may be inconvenient or undesirable to your personal taste. Try to maintain a balance between making your home safe, and having it suit your needs. Set aside a room or area of your home that is just for you, so you can arrange things they way you'd like them. If your home has more than one story, to reduce the risk of falls you may want to consider moving to a single-story home or arranging living quarters on the ground floor.

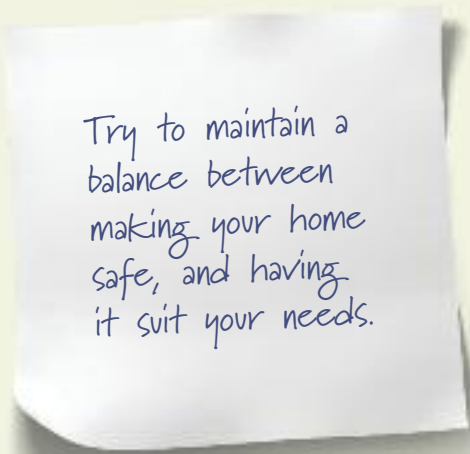
It may not be necessary to make all of these changes immediately. If you decide to wait on some, write a note on your calendar to check back later and re-evaluate whether you should take additional steps. Also, if you need help making these changes, ask family or friends or reach out to a local Alzheimer's community service organization for help.

## Leaving Your Loved One Alone

As your loved one becomes less independent, you will have to decide whether he/she can be left alone. While home alone, an emergency situation could arise that your loved one is not capable of handling. Ask yourself the following questions. If you answer yes to any of them, you may want to bring this issue to the attention of your loved one's health care provider.

### Does your loved one:

- Wander and forget where he/she is?
- Not know how to get help?
- Not recognize emergency situations like a fire or serious health symptoms?
- Show negative behavioral symptoms, like depression or anxiety, when left alone?
- Become confused or unpredictable when anxious?



## Alzheimer's Disease: Helping Yourself Help a Loved One Home Safety Checklist

### General Safety

- Place a list of emergency numbers near every phone; use an answering machine since your loved one may not be able to take messages when you're not there.
- Avoid extension cords if possible. Secure the one's you use to the floor or wall.
- Cover electrical outlets with childproof plugs.
- Make sure rooms are well-lit and use night-lights throughout the house.
- Securely carpet stairways if possible and make sure handrails extend to all steps.
- Lock medications and alcohol away in cabinets.
- Keep matches and lighters out of reach.
- Avoid clutter, such as newspaper, which could be tripping hazards.
- Put away plastic bags, because of choking or suffocating hazards.
- Get rid of poisonous plants—check with your local nursery for details.
- Password-protect your computer and Internet access.
- Keep fish tanks out of reach.
- Remove throw rugs, or secure them to prevent slipping.
- Consider an ID bracelet for your loved one. Many cities offer bracelets that include locating devices so you can find your loved one if they wander off.

### Kitchen

- Place childproof door latches on drawers and cabinets with dangerous items such as knives, scissors, matches, and cleaning products.
- Install an automatic shut-off switch for the stove or remove stove knobs.
- Dismantle the garbage disposal if your loved one may place foreign objects, or even their hands, in the disposal.

### Bedrooms

- Use an intercom device to alert you of calls for help from your loved one.
- Do not use space heaters, and try to keep fans out of reach.
- Consider a bed that can be electronically raised or lowered to the floor.

### Bathroom

- Don't leave your loved one alone if they are severely impaired.
- Remove the bathroom lock so your loved one doesn't get locked inside.
- Use a non-skid product on the bathtub/shower floor to prevent slipping
- Use bathroom carpeting to prevent slipping.
- Install handrails by the toilet seat and in the bathtub/shower.
- Use a foam faucet cover to prevent serious injury if your loved one falls.
- Set the water heater at 120° or lower to avoid scalding water.

You may wish to **survey your home** to see if there are other areas you might be able to improve to increase the safety of your loved one.

# Financial & Legal Planning

By starting the financial and legal planning process now, you can make sure that your loved one is cared for as their diseases progresses. It's important for you to start this process early, because Alzheimer's disease will gradually make it harder for your loved one to participate in planning.

Take the time to sit down with your loved one and talk about finances and legal planning. Keep in mind that this conversation is probably extremely difficult for your loved one. Not only are they discussing their own death, but also giving up financial control—which begins their gradual loss of independence. This conversation could also be hard for you, but remember that it will help you to finance your loved one's care, make well-informed decisions about health care, and honor their wishes when making end-of-life decisions.

The checklist on the following page can help you work through the financial and legal planning process. As the disease progresses, your loved one may hide or misplace these papers. Original copies of documents should be stored in a fire-proof box in your home, and/or a safety deposit box. If you need additional help, use the list of resources below:

## Find Benefits

### BenefitsCheckUp®

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

A free service provided by the National Council on aging that matches seniors with appropriate state and federal assistance programs.

### Department of Veterans Affairs

[www.va.gov](http://www.va.gov)

(800) 827-1000

### Medicare

[www.medicare.gov](http://www.medicare.gov)

(800) 633-4227

### Social Security Administration

[www.ssa.gov](http://www.ssa.gov)

(800) 772-1213

### Together Rx Access

[www.TogetherRxAccess.com](http://www.TogetherRxAccess.com)

(800) 250-2839

Provides a free savings card for eligible individuals without prescription drug coverage.

## Find Local Professional Assistance

### Agency on Aging

[www.eldercare.gov](http://www.eldercare.gov)

(800) 677-1116

### Alzheimer's Association

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

(800) 272-3900

### National Academy of Eldercare Law Attorneys

[www.naela.com](http://www.naela.com)

## Learn More About Insurance Options

### America's Health Insurance Plans

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

## Other Resources

### Alzheimer's Association

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

(800) 272-3900

### Family Caregiver Alliance of Aging

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

(800) 445-8106

### National Institute on Aging

[www.nia.nih.gov](http://www.nia.nih.gov)

(800) 438-4380


# Alzheimer's Disease: Helping Yourself Help a Loved One Financial & Legal Checklist

## Finances

- Take inventory.** Locate and review financial documents and assess your loved one's financial situation. Documents to look for include:
  - Monthly bills
  - Financial statements (savings, checking, brokerage, investments)
  - Debts & liabilities (credit cards, loans, etc.)
  - Mortgage paperwork
  - Insurance policies (life, disability, health, long-term care, etc.)
  - Pension and retirement paperwork
  - Social security or other benefit summaries
  - Property deeds
- Determine your role.** Will you be paying bills, handling insurance claims, managing paperwork, filing tax returns, etc.? Will you need to help finance the care of your loved one?
- Review your financial situation.** If you will be providing financial assistance, be sure to take inventory of your own assets. If necessary, increase your insurance coverage in the event that something happens to you.
- Estimate costs.** Put together a list of short-term and long-term costs, including: healthcare, insurance, housing, personal care supplies, ongoing medical treatments, prescriptions, adult day care services, and in-home services.
- Explore insurance and other benefits.** In addition to health insurance benefits, your loved one may be eligible for other assistance including Medicare (if over 65), Medicaid, Social Security, and veterans' benefits. You should also learn about your eligibility for tax deductions and credits as a caregiver. Make sure you appeal if you feel insurance benefits have been unfairly denied.
- Consult a financial advisor.** They can help you identify resources, address tax issues, and make good investments.

## Legal Documents

- Take inventory.** Locate and review legal documents, including:
  - *Will:* Records your loved one's wishes for distributing their possessions and estate when they die.
  - *Living will:* Records your loved one's wishes for their end-of life care.
  - *Durable power of attorney—estate & financial management:* Appoints someone to make financial decisions when your loved one no longer can.
  - *Durable power of attorney—health care:* Appoints someone to make health care decisions when your loved one no longer can.
  - *Do not resuscitate form:* Instructs health care professionals not to perform certain life-saving measures if your loved one doesn't want them.
- Determine your role.** If you are going to handle your loved one's finances or health care decisions, make sure they designate you in their durable power of attorney.
- Consult an Eldercare or Estate attorney.** Legal advisors can help you with estate planning and creating documents such as a will or power of attorney.



It's important for you to start this process early.

# Taking Care of Yourself

**As Alzheimer's disease progresses, your loved one will need more and more care.** While you may feel that you don't have time to think about yourself, it is important to remember your own health and well-being. By exercising, thinking about your health, and giving yourself time to relax, you will stay healthier and be able to spend more time with your loved one.

Use the log on the following page to keep track of your own appointments and leisure activities. Include health care appointments, exercise schedule, social engagements, etc. Challenge yourself to find a few hours each week that are just for you. Use the log to record the event and any hurdles that kept you from it. Identifying these challenges allows you to adjust your schedule in the future by finding a time that works better.

*Caregiving that demands all of you requires a perspective that says, "This is one part of my life." The other parts of you need attention: affection and nurturing; positive feedback from family and friends; time off; and self-care that includes rest, good nutrition, exercise, and routine consultation with your physician.*

*Lessons Learned—  
Shared Experiences in Coping*

## Accept Offers of Help When Needed

Caregiving is one of a number of responsibilities in your life. Create a network of caring and responsible people who can help you when you need it. More information can be found in the Forming Your Support Network section of this workbook.

## Schedule Your Own Health Care Appointments

Stay on top of your own regularly scheduled check-ups. If you have someone who can take care of your loved one while you are gone, you may want to schedule multiple appointments close together to make the most of your time.

## Stay Fit and Relaxed

Try to work in cardiovascular exercise as well as more relaxing exercises such as pilates or yoga. Here are some tips that can help you incorporate a workout into your busy schedule:

- **Workout Early**—research shows that morning exercisers tend to stick to their schedule better than others.
- **Break it up**—the daily recommended 30 minutes of exercise (5 days a week) can be broken up into smaller chunks throughout the day. Keep a pair of athletic shoes in your car in case you have extra time while you're away from home.
- **Step swiftly**—quicken the pace when doing chores. You'll finish faster and get some exercise.
- **Use your TV time**—lift weights or use stationary equipment while you watch TV.
- **Join a club**—scheduling a sports class with a friend can help you get out the door each week.
- **Write it down**—add consistency and motivation to your exercise program by keeping a log of what you have accomplished.
- **Do something for you**—Look for other fun activities that interest you, such as art classes. Social activities are also good for your emotional health.

## Alzheimer's Disease: Helping Yourself Help a Loved One

# My Personal Schedule

Month: \_\_\_\_\_

### Week 1

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Appt./Task: \_\_\_\_\_

Able to keep appt./task?  Yes  No

Notes: \_\_\_\_\_

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Appt./Task: \_\_\_\_\_

Able to keep appt./task?  Yes  No

Notes: \_\_\_\_\_

### Week 2

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Appt./Task: \_\_\_\_\_

Able to keep appt./task?  Yes  No

Notes: \_\_\_\_\_

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Appt./Task: \_\_\_\_\_

Able to keep appt./task?  Yes  No

Notes: \_\_\_\_\_

### Week 3

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Appt./Task: \_\_\_\_\_

Able to keep appt./task?  Yes  No

Notes: \_\_\_\_\_

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Appt./Task: \_\_\_\_\_

Able to keep appt./task?  Yes  No

Notes: \_\_\_\_\_

### Week 4

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Appt./Task: \_\_\_\_\_

Able to keep appt./task?  Yes  No

Notes: \_\_\_\_\_

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Appt./Task: \_\_\_\_\_

Able to keep appt./task?  Yes  No

Notes: \_\_\_\_\_





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Made possible by a grant from

