

Seattle Web Books

Alzheimer's/Dementia *Caregiver Tips*



Alzheimer's Resource Directory

Seattle & Puget Sound Area



Directory Listings for Alzheimer's Residences,
Adult Day Care, Home Care, Hospice, Care Management,
Legal Services and Support Groups

for free copy call:

206-999-7289

or e-mail

retirebart1@comcast.net

Welcome

Families provide 75% to 80% of the care for people with Alzheimer's disease. The benefits of a familiar setting and routine found in home care are many, but the debilitating nature of the illness imposes an enormous financial, social, physical and psychological/emotional burden on the caregiver.

This booklet provides a number of tips that can help you learn the necessary caregiving skills and strategies that ensure the best care for both your loved one and you. Remember, no two people experience Alzheimer's disease in the same way. As a result, there's no one right approach to caregiving. Experiment to find those tips and strategies that work best for you.

When you find you have questions or just need a little support, don't hesitate to call on the Alzheimer's Association at 1-800272-3900. If they can't help they will be glad to refer you to a source that can.

If you have a tip or strategy that you would like to share, please, email it to us (retirebart1@comcast.net) and we will be glad to include it in future editions of this publication.

We admire you for taking on the role of caregiver. There are few jobs that are more difficult and important. We hope this booklet in some small way can make your task a little easier.

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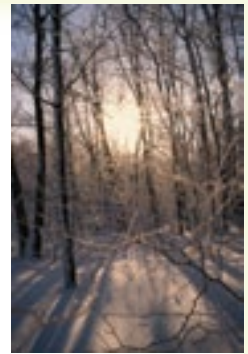
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First Things First

Learn as much as possible about the disease. The more you know and understand the easier it will be for you to cope.

Get the family together, preferably while the patient still has their mental capacity, to make some basic decisions on handling the road ahead. Get an inexpensive tape recorder to record these meetings for easy future referral.

Meet with an experienced expert who can give a realistic assessment on what's ahead.

Meet with an attorney who can advise you of the possible legal issues that may arise.

Two forms of advance directives you will definitely want to complete are: A living will and a durable power of attorney for health care. (In Washington, these forms can be download at no expense from www.caringinfo.org/files/public/ad/Washington.pdf

Be sure to keep the original on hand because you will need to make many copies as you go along.

Explore possible legal issues.

Begin a search for available resources.

Meet with a financial advisor to discover the best use of any monies over the course of the disease. If funds are limited, start a search for any help offered by private or government programs.

Meet with your pastor, priest or other spiritual leader that has been involved in the patient's life (if applicable). Advise them of the situation and see what help might be available as the disease advances.

Begin a search for available resources you will be needing as the disease progresses such as family help, both financially and physically, the closest Alzheimer's Association Chapter office, home care agencies, respite care services, adult day care services, facilities that accept Alzheimer's patients, social service agencies and neighbors that can help to mention a few.

Become familiar with programs offered to Alzheimer's patients such as "Stand by You" and "Safe Return".



Preparing the Home

Remove clutter to create spacious pathways between rooms especially between the patients room and the bathroom.

Keep a few sturdy familiar pieces of furniture for use by the patient.

Closets and drawers should be cleared of clutter and contain only essentials.

Consider removing all area rugs or at least securing them firmly to avoid tripping hazards.

Remove low furniture like coffee tables and small foot stools that are hard to see and may easily be tripped over.

Be sure all electrical and phone cords are out of the way to avoid tripping.

Install safety latches on cupboard doors where dishes or other breakables are stored.

Set up special cupboards and drawers through out the house that can be locked to keep sharp objects, cleaning materials, poisons, insecticides and other dangerous objects secure.

Create spacious pathways

*Take
pictures
down from
stairways*

- Place locks at top or bottom of doors where they will less likely be noticed by patient.
- Place easy to see decals on all large expanses of glass such as sliding doors.
- Be sure knobs on both electric and gas stoves can be easily removed and secured after use.
- Put a big clock with big easy to read numbers in a high traffic area.
- Keep just essentials available in bathrooms like soap and towels.
- Consider putting grab bars and non-slip mats in showers and tubs.
- You may want to keep a room or two off limits and secure with locks.
- Take locks off of bathroom doors to avoid patients accidentally locking themselves in.
- Make sure you can lock and secure windows and outside doors.
- Consider putting door alarms on outside doors to alert you if patient tries to leave.
- Take pictures down from stairways, as they can be a dangerous distraction.

- Make sure hallways and bathrooms are well lit at night with night-lights.
- Set water heater temperature to 135 degrees to avoid burns.
- Put a large picture of a toilet on the door of bathrooms for patient to easily identify.
- Make an emergency list and post it in a very visible place for helpers and other caregivers. Include the usual emergency numbers such as fire, police, ambulance and the patient's doctor, close family members, and maybe neighbors.

*Set water
heater
Temps
lower.*



Day by Day

Always, always treat the patient with respect and dignity. The patient deserves it and you will feel so much better about yourself.

*Try to
maintain
past
routines.*

Short-term memory usually goes first with the Alzheimer's patient. They can't remember what they had for breakfast but clearly recall events of 30 years ago. With this in mind:
Keep some old family albums handy.

Hang some photos from the past on walls in traffic areas (but not stairways).

Find a good "Oldies" radio station to play in the background or find some CD's that have music from the patient's early life that you can play.

Try to maintain the routine the patient has established over the years. ex. bathe in the morning, dinner at five, and bedtime at 10 pm.

Give the patient as much privacy as possible in carrying out their daily chores, especially in the bathroom.

Become the master of distraction when the patient has unusual requests. When the patient wants to go grocery shopping at 3 am distract them with:

- Food, like a couple of their favorite cookies, or a glass of their favorite drink.
- Bring out that photo album and start asking questions about some of the photos.
- Divert them with conversation about events they might remember.
- Ask them to put on some music before they leave or other activity.

Keep a daily diary to help identify patterns such as agitation that occurs at the time the patient used to leave for work. Then you can be ready with a distraction.

Use clothing and shoes that are easy to get in and out of such as jump suits and slip-ons.

You may need to acquire clothing that fastens in the back if the patient wants to frequently remove clothing.

Have emergency information sewn or written in cloths for wonderers

*Become a
master of
distraction.*



Activities

Always keep in mind patient's current capabilities and adjust activities accordingly.

Draw on the patient's likes and hobbies from earlier in life such as music, cooking, sewing, stamp collecting or sports. Try to gear some activities around these likes.

Choosing simple activities will help the patient avoid becoming frustrated and agitated.

Bring those photo albums out.

Activities from the past will be the easiest for the patient to remember.

Rent some old movies to watch.

Help with chores around the house as abilities allow.

If the patient played an instrument keep it handy.

Have the patient help in the yard with weeding, raking and other clean up activities.

Rent some old movies.

Set up a seat by a window.

Have the patient help in the kitchen with chores like setting the table or washing vegetables and sweeping the floor, keeping in mind their current abilities.

Show a person how to do a certain task or chore if they have trouble remembering.

Set up plastic boxes with different activities (get creative) such as:

- Checkers to sort by colors.
- Playing cards to sort in different ways you might suggest such as putting all the same numbers and face cards together, or separating by suits.
- Unsharpened wood pencils with rubber bands to bind them together in various groups, along with paper clips, small sheets of paper, notepads and possibly a rubber stamp or two.
- Different coins that can be counted and sorted.
- Keep boxes in several areas like bedroom, living room, bathroom, and car.

When boredom sets in try moving the patient to a different room, set up a seat by a window where they can watch street activity.

Set up bird feeders outside windows and fish tanks to draw attention.

Read aloud to the patient or if able have them read aloud to you.



Have a regular schedule.

The Bathroom

Make your tub safer with nonskid rubber mats or strips.

If needed provide a seat that goes across the tub.

Only run about 4 inches of water in tub and test to be sure it's a comfortable temperature.

Set out washcloths, soap shampoo brushes and towels in the order they will be used.

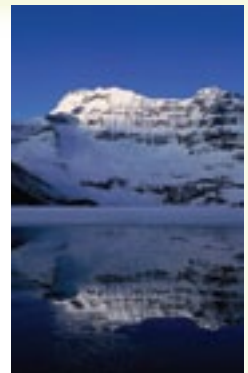
Alternate a sponge bath with regular baths.

Consider soap on a rope for easier use by the patient.

Have a regular schedule for the patient for taking baths and toileting.

Be sure to check with a doctor if the patient has trouble making it to the bathroom in time.

A commode at bedside can sometimes help if patient has trouble finding the bathroom during the night.



Set out one food at a time.

Meals

Most patients enjoy meals so make a big deal of it.

Keep eating area like tablemats, dishes and utensils free of patterns that can distract the patient.

Use bowls, spoons and non-spill cups as much as possible.

Plastic can help reduce breakage and provide easier cleanup.

Set out one food at a time so there is no confusion on what to eat.

Prepare foods you know the patient likes.

Demonstrate how utensils are used if patient gets confused.

Use finger foods and cut into small easy to chew pieces.

Keep healthy snacks on hand for between meal diversions.



Restlessness and Anxiety Problems

Sometimes agitation or anxiety in the patient is caused by basic needs that they are unable to express. The patient might just be bored, hungry or need to go to the bathroom.

***No caffeine
thank you.***

It could be a medication they are taking or need to be taking. Talk with your doctor.

Try to schedule exercise during the patients most restless time of day.

Make sure they are comfortable, not too hot or cold or clothing too tight.

Check to see if the person is hungry, comfortable or needs to go to the bathroom.

See if you can determine if it is being brought on by an illness or pain.

Keep the patient away from drinks with caffeine.

Confer with you doctor about medications that may cause or relieve symptoms.

Avoid noisy areas with lots of activity and stay in a less stressful environment.

Reassuring the patient throughout the day that everything is Ok can help relieve stress.

Exercise your talents as “master distracter” in helping the patient steer away from current thoughts and actions and calm them.

Look for clues at what might have caused outbursts and try to avoid them.

Frustration, anger, difficult and even violent behavior can be part of the disease so don't blame yourself.

Remain calm and reassuring during outbursts.

Stay in front of the patient with good eye contact speaking in clear understandable sentences.

If necessary, keep out of reach of patient and call a family member or neighbor for help. **DO NOT** try to restrain the patient unless absolutely necessary. This usually only makes matters worse.

If you fear for yours or the patients safety call 911.

***Look for
clues ...***



***Use the
patients
name ...***

Communication

Use the patients name when addressing them.

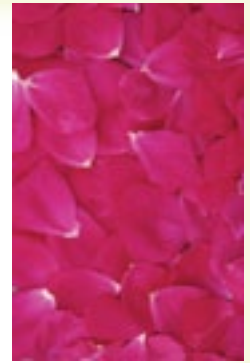
Be sure your instructions and questions are clear and simple.

You may have to repeat yourself several times. Maybe try another way to say the same thing if the patient is having trouble understanding.

If the patient starts to get upset or frustrated go on and try to come back to it later.

Reasoning rarely works with the patient so be prepared with a combination of reassurance and distraction.

Use touch and body language along with your speech to help patient understand your meaning.



Taking Care of the Caregiver

It's very easy for the caregiver to burn out quickly both physically and mentally which can only makes matters worse. Here are a few tips to prevent this.

Keep a sense of humor. Face the reality that your loved one will not be the same person you now know.

Become educated on what your future holds and prepare for it.

Do not be bashful to ask from help, especially from other family members.

Accept all help from family, friends and other resources you have developed. Do not face this experience alone.

Be ready to forgive yourself. Things are not always going to go as expected but you need to be ready to forgive yourself and move on, especially with that sense of humor mentioned above.

Talk, talk, and talk. Get your feelings out.

***Don't be
bashful ...***

Join a support group. Call 1-800-272-3900 to find the Alzheimer's Chapter for your area and they will link you with a group closest to you. According to the Alzheimer's Association their support groups can give you an opportunity to:

- Share your experiences.
- Increase your feelings of self-worth.
- Decrease your sense of isolation.
- Learn from others in your situation.
- Learn about resources available to you.
- Receive encouragement and moral support from other caregivers.

Take Be sure you get some kind of exercise every day.

advantage of Prepare healthy meals and get plenty of sleep.
even small

breaks ... Take advantage of even small breaks like watching your favorite TV show or a quick refreshing shower or bath.

Keep in contact with friends and family by phone or through e-mail.

Don't be afraid or ashamed to seek professional help if the load starts to become too much.



Signs of Caregiver Stress

Too much stress can be damaging to both you and the person you are caring for. The following stress indicators, experienced frequently or simultaneously, can lead to more serious health problems. Learn to recognize signs of stress in yourself. Taking care of yourself will help you be a better caregiver.

Denial about the disease and its effect on the person who's been diagnosed
I know mom's going to get better.

Anger at the person with Alzheimer's or others; angry that few treatments and no cure currently exist and that people don't understand what's going on.
If he asks me that question one more time I'll scream!

Social withdrawal from friends and activities that once brought pleasure.
I don't care about getting together with the neighbor's anymore.

Learn to recognize signs of stress ...

I'm too tired for this.

Anxiety about facing another day and what the future holds.

What happens when he needs more care than I can provide.

Depression begins to break your spirit and affect your ability to cope.

I don't care anymore.

Exhaustion makes it nearly impossible to complete necessary daily tasks.

I'm too tired for this.

Sleeplessness caused by a never-ending list of concerns.

What if she wanders out of the house or falls and hurts herself?

Irritability leads to moodiness and triggers negative responses and reactions.

Leave me alone!

Lack of concentration makes it difficult to perform familiar tasks.

I was so busy; I forgot we had an appointment.

Health problems begin to take their toll, both mentally and physically.

I can't remember the last time I felt good.

If you experience several of these symptoms on a regular basis, consult a physician.

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Some suggestions on combating stress ...

Seek out a support group. Spending even a short amount of time with others in the same situation sharing feeling of frustration, guilt and helplessness can be very healing. These groups can also be an invaluable source of information on all sorts of subjects.

Bring in outside help. Don't hesitate to call on relatives or friends who are willing to help. There are also several in-home care agencies that specialize in this type of help that will come into the home and provide a few hours of relief.

Adult Day Care Centers can be a tremendous help. Most specialize in care of Alzheimer's/dementia patients and provide a safe, secure and welcoming break for the caregiver.

Short term respite care. Some assisted living, home care and skilled nursing communities offer safe, secure short-term respite care for an hour a day or week or two.

To get more information on where the above-mentioned services are offered in your area contact the sponsor of this booklet closest to you or call for a free copy of Retirement Publishing's *Alzheimer's Resource Directory* at 844-393-1698.

In-home care agencies can help.

A Caregivers Bill of Rights

It is all right to:

Be Angry. Turn this energy into positive action. Clean closets, take a walk or talk with someone

Be Frustrated. Stop the present activity, take a deep breath and begin a different activity.

Need time alone. A favorite chair in a quiet room, a trip to the store or out with friends.

Need and ask for help. Explore family, friends, local agencies for services needed. A good place to start is with the sponsors of this booklet.

Trust your judgment. Relax, you are doing the best you can.

Recognize your limits. You are a valuable person, take care of yourself, too!

Make mistakes. So, who's perfect? This is how we learn.

Grieve. This is a normal response to a loss. You may be sad over the loss of the way things used to be.

Laugh and love. It can seem out of place, but your capacity to feel is not gone and can occur unexpectedly.

Hope. Tomorrow, the day may go smoother, a friend may call or a cure may be found.

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