

Managing from Day to Day

Creating a safe and workable environment

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An illness like Alzheimer's disease causes steady decline in the patient's abilities. As a caregiver, you will be called on to deal with many problems posed by the impaired person's declining skills. As more and more skills are lost, you will need to take over more and more.

Just what will you need to do? As caregiver, you need to actively manage the person's daily life. At first, you may only have to make daily events simpler. Later, you may need to restrict them. This may well be easier said than done. You also need to look closely at your home setting. Does it make life easier or harder for the person (and for you)?

You have several concerns. You need to see that the impaired person is safe and happy. You need to make sure your caregiving tasks work well for you. You also need some strength and time left for yourself.

This pamphlet deals with controlling the impaired person's physical surroundings and managing the daily routine. Both are important parts of creating a safe and workable environment for the impaired person, for you and for everyone else involved. In talking about these issues, the subject of finding help when you need it comes up too. You can't be alert and on-the-job day and night. You will need to find ways to cope with the increasing need to watch over the impaired person. Family members or social and health agencies might be sources of help.

Assess and modify your home

Conduct a survey of your home to see what you might change or store away while you are caring for this person. Look at your home in great detail to see what might be harmful. Then take steps to prevent harm. The goals of your home survey should be to reduce needless choices, confusion and danger.

If you ever had to "childproof" your home, the process is somewhat the same. The survey requires you to look at your home and to observe the impaired person in it. Pretend you are a stranger in your home. Put aside your feelings so you can look at your household as a stranger might. Does it make life easier or harder (even dangerous) for the impaired person? Does it help you in your caregiving or not?

Your family and friends, especially members of an Alzheimer's support group, can help you with ideas. You can also get outside help from experts in checking the safety and efficiency of the home. Public health nurses (visiting nurses) and occupational therapists are especially good at sizing up a home and suggesting ways to make it work better for an impaired person. Carpenters and handymen may have good, practical tips too.

A safety survey should be made in every room of your home. The kitchen and the bathroom are most important. Be sure you check the laundry, workroom, garage and outdoor areas too. Use these general guidelines:

Open up the spaces Your work should leave rooms more open. There should be space for wandering and clear pathways from room to room. The fewer things the impaired person runs into, trips over or feels blocked by, the better. The person shouldn't have to walk around tables or chairs to get from one place to another. Remove items the person could trip over like coffee tables, floor lamps, standing vases or phone and electrical cords. If you need access to these things, at least move them back out of the impaired person's pathways.

Prevent slips and falls. Do the floors provide good traction for walking? Make sure the floors aren't too slick. If you keep linoleum or vinyl floors polished, use a non-skid wax. Or allow the floor's surface to become dull. (Wash it, but don't wax it, and use a cleaner that doesn't include a waxing agent.) Follow the same routines with wood floors. Are the rugs in your home secure? Do edges stick up so the person could trip? Do you have throw rugs that could slip out from under the person? If so, fasten them down or store them away. Are the surfaces of the bathroom floor and tub or shower slippery? Rough textured strips or decals can be purchased cheaply. They are easy to apply and greatly improve traction. Properly installed grab bars in the right places can make the bathroom safer too.

Offer clear contrasts. Can the impaired person tell easily where the floor stops and the wall begins? Where the wall stops and the doorway begins? If you observe the impaired person having problems like walking into walls or being surprised by a doorway, try to make such areas clearer. A number of experts suggest using tape or paint in a contrasting color around borders. Start out with a small experiment to see if the results would be worth the effort and expense to make this change throughout the house. Your neighborhood hardware store can be a resource for you in such projects. Describe what you want to do, and ask for help and suggestions.

Remove distractions Take away anything you can that seems to upset the impaired person needlessly or to interfere with tasks that must be done. Knickknacks, magazines, mirrors, even certain fabrics or rugs with busy or too bright patterns can be confusing. Some things (like the magazines) are easily removed. Try doing so and see what happens. Other things, like carpeting, drapes and upholstery, are very expensive. You may not be able to consider changing them. You may suspect that a certain chair or drape pattern is causing problems. Remove the item or use a slipcover for a while to see if you are right. You can then weigh the possible benefit against the expense.

Another problem may be needless glare off the floors or walls. Not waxing floors (or using a non-skid wax) and using "flat" rather than "high gloss" or "semi-gloss" paint will reduce glare. As you replace light bulbs, try the "soft light" kind (in the same wattage). Be sure no bare lightbulbs are exposed. Draw the drapes if sunlight is too bright. Also, be aware that having the radio or TV on too often or too loud may be stimulating or distracting the impaired person too much.

Look for objects that might be dangerous Cigarettes, cigars or pipes may be very unsafe for a forgetful person. In the kitchen, the stove poses the biggest danger. The impaired person could be burned or could start fires. Knives and other pointed utensils such as large meat forks are dangers too. Small appliances like the toaster, toaster/oven, food processor, blender, mixer, can opener, waffle iron and microwave oven all can be very dangerous.

In the rest of the house, are there any other electrical appliances (space heaters, electric fans) that might pose a threat? Keep in mind that electric appliances must be used with great care around water. There may be a number of items in the bathroom (hairdryer, electric razor, radio, dock, even a telephone) which the impaired person should not use alone. Look carefully at personal grooming items, too. Razors, nail files and clippers, small scissors and such may require more skill to use than the impaired person still has. Are there other sharp or pointed objects lying out in sight like scissors, letter openers or decorative items? Are there fragile objects like a hand mirror which might be broken, leaving jagged pieces which might injure someone?

Is any of the furniture easily pulled over or toppled (for instance, a tall, unsecured bookcase)? Are there items like stools or stepladders on which the person might climb? Do you have places like stairs where the person might fall? Are there any storm doors or low windows that might be broken? Is the water heater temperature so hot that the water could scald someone? Are there any guns or other weapons in the house?

Dispose of dangerous objects Throw away old paint thinner or old drugs, for instance. Sell or give away any guns, other weapons, or extra sharp tools. Substitute safe items for dangerous ones whenever possible. Bathroom glasses can be replaced with paper cups or unbreakable plastic glasses. Glass in storm doors or low windows can be replaced with plexiglass or safety glass. Find a safe storage area for dangerous items that you must keep but don't need often. Store such supplies as lawn fertilizer, insect poisons and gasoline there. If you must keep any guns or other weapons, they should also be locked up (unloaded), and you should have the only key. Be sure to lock up any ammunition too. Your storage area may be a garage or outside shed. You may use a room or area of the house like the attic or basement that you are sure the impaired person can't reach. Or you may simply use a locked storage closet. You can even try just putting items out of reach (on a top shelf, for instance) if you are sure the impaired person can't climb up to get them.

Secure items that might be dangerous In each room of the house secure any items that might be dangerous but which you need often. Speak with your local utility company about ways to make the stove safe. For instance, a hidden on-off switch or a cover with a lock may be used. Small appliances which might be misused should be stored in a cupboard or closet with a secure latch on it. Lock up such items as scissors, knives, or pointed kitchen utensils. You can use "childproofing" devices on cabinets and use hooks that are hard to open (or oddly placed) on closet doors. Inexpensive locks can be installed on drawers and cabinets holding especially dangerous items.

Store household cleaning supplies safely. Detergents, polishes, drain and toilet bowl cleaners, shower and tub cleansers are all potential poisons. These should be removed or stored safely. You might want to collect all the household cleaning materials and store them in one secure place where the impaired person could not get into them. At the very least, make sure you have a secure cabinet in each room where you store such items.

Lock up all over-the-counter and prescription drugs Off-the-shelf pain relievers like aspirin or Tylenol are quite dangerous in large doses. An overdose of a laxative may not have as serious results as an overdose of Valium, but you don't need either problem. Find a way to lock the medicine cabinet or else remove dangerous items to a locked drawer or closet.

Consider putting away personal hygiene and grooming supplies Mouthwash, toothpaste, cologne, after shave lotions, rubbing alcohol, soaps and shampoos all look and smell good enough to eat or drink. The impaired person may do just that and become ill. Control access to liquor and even food. A forgetful person may consume more alcohol than is healthful. At times impaired persons may hoard food and become ill from eating an item which has spoiled.

Don't forget the laundry room, utility room and workshop. You should lower your water heater setting to prevent accidental scalding. Laundry products such as bleach, detergents and fabric softeners are poisonous if consumed. At the very least, they must be used properly to avoid damaging fabrics or even the washer or dryer. Hide or lock up such products safely. A workshop area may be full of materials which could be very dangerous. Check over the electrical equipment and power tools. Remove what you don't need and make sure that what remains is secure. Remove cutting edges from standing tools

such as a band saw, jig saw or drill press. Paints, paint thinners and other solvents may be poisonous. Many hand tools can cause injury when used by someone whose coordination or judgment is impaired. Lock up all of these. Check outside as well. The most dangerous item outdoors is the car. There may also be other things in the garage that could pose a threat (lawn mower, snowblower, chainsaw, axe, charcoal lighter, gasoline, hedge clippers, ladder, etc.) You should carefully control the person's access to all of these. If your home has a swimming pool, you need to be aware that this poses a serious threat. Especially if the person is up and about at night while you sleep, you must be sure he or she can't get out to the pool. Fence off the pool area, and keep the gate locked.

Post emergency phone numbers by each phone. Keep numbers for the doctor, fire department and police handy. A good idea is to call the fire station to let them know you have a person at home who might not be able to get out alone in case of a fire. In those areas using the "911" emergency call number, contact the service to inform the staff that an impaired person lives in your home. Then this information will be instantly available in any emergency. Another useful idea is an alert system. An alert system can be used to call certain numbers automatically. As the caregiver, you might carry an electronic paging type of device which will allow you to call for emergency help even if you can't use the telephone. The call may be pre-planned to go to several locations: neighbor, family members, or (in some places) the police or other emergency service. The alarm will continue to repeat its message until such time as someone turns off the system.

Managing the daily routine

Managing the daily routine for the impaired person involves three parts. You must simplify, you must structure, and you must supervise.

You want to simplify and structure your care routine as well as the impaired person's activities. To do this you must reduce the number of choices to be made each day by each of you. You must also keep in mind what the impaired person really can do and cannot do. And you must set up priorities for yourself. What really matters? What can you give up? You will need to be ready to compromise your standards in many cases to avoid needless conflict. But you also need to know when to stand firm (about safety issues, for instance).

Simplifying activities

Reduce the number of choices the impaired person must make. Instead of asking "What do you want for dinner?" you might offer just two choices. If you know there really isn't any choice, don't bring up the subject. You want to allow and encourage the impaired person to make choices, but make sure the choices are within the person's powers. These powers will decline as the disease goes on. If you are aware of changes, you can adapt the choices offered as you need to.

Respect the impaired person's likes and dislikes. Be prepared to compromise when need be. This is especially true for the events which must be done each day (eating, dressing and grooming). If the person becomes attached to a certain plate, cup, glass or placemat or a certain chair at the table, don't interfere. Even if what the person has chosen is the least attractive old thing you have, this is not a point worth arguing. Compromise will be easier on everyone than needless conflict.

Encourage the impaired person to continue self-care as long as possible, but be realistic about the person's ability. This will save you work and help preserve the person's self-esteem. If, for instance, you see that the person has trouble cutting food and using a fork, set the person's place only with a spoon and pre-cut the food. If the person has trouble using a spoon, let the person use his or her fingers. Expect spills and messiness at mealtime. Tie a large napkin around the person's neck, or use a large bib. Use a plastic table cloth (or a plastic cover) and paper napkins. You may even want to put a large plastic dropcloth under the person's chair. Or think about eating in a room with a vinyl floor rather than one with carpeting.

As long as the person can dress alone, encourage this. As time goes by, the task may take longer and longer. You will then need to help select clothes or remind the person of what to do next. If the person is unsteady, have him or her sit on a chair or use the bed when putting on pants and underclothes. Consider using a tub seat or bench and grab bars to assist the person in moving into the tub or on and off the toilet.

Make sure the person's wardrobe suits his or her needs. Scale down the person's wardrobe. This will make choosing something to wear easier. A closet full of clothes on hangers and shelves can be more of a challenge than either of you needs. As the person becomes more and more impaired, a few changes of comfortable and easily laundered clothes are all he or she will need. Ask a friend or a family member to help you choose these, if you like. Don't forget to include the impaired person in making such choices, if possible.

Choose clothes that are practical. Comfort and ease of use are big issues. The clothes you choose should be easy to put on, shouldn't be tight, and should be easy to take off for toileting, bathing and changing for bed. Two-piece outfits are easy to change, for instance. Consider clothes with elastic waist bands, over-sized pullovers, front closing shirts or blouses, tube socks, reversible shirts, pre-tied, clip-on ties, elastic shoe laces or velcro fastened shoes. Footwear needs vary with the course of the illness. Running shoes offer good support and traction for the person who does a lot of pacing. If the person is less active, slip-on shoes that fit well will be easier for you when the person is less mobile. If the person prefers bedroom slippers, make sure they have good traction and don't come off easily.

Reduce and simplify grooming tasks. Consider using the shower instead of the tub for bathing. Have the person's hair cut in a way that is easy to wash and comb. If you are caring for a man who cannot shave himself, shave him with an electric razor rather than a safety razor. If you are caring for a woman, consider being less concerned about hair on the legs and underarms. If need be, use an electric razor. Trimmed but unpolished nails are quite adequate. Make-up, if used, can be quite simple. Ask family members or friends to help with some of the special grooming tasks. Have someone come in on a regular basis to give the person a shampoo or to trim the person's nails. If the expense is not too great, a local barber or beauty shop could do a regular shampoo. This combines a pleasure outing with a basic need.

Plan menus for a week or two at a time. Set up a menu pattern that you can follow over the course of a week or two and then repeat. Take into account food likes and dislikes. This may avoid struggles to get the person to eat. Your own tastes also count. Planning meals ahead will make it easier for you to come up with a shopping list. Then, if you need to, you can ask someone else to shop for you. If you are just learning how to plan and prepare meals, the limited menu is doubly helpful. You can ask family members or friends to help you set up the pattern.

Encourage the impaired person to help with household tasks when possible. Simple, repetitive tasks are best. Perhaps the impaired person can still dry dishes even if cooking is too hard. Folding laundry might take the place of doing the wash. Or perhaps raking leaves would be a form of yard work which would still be safe, even when mowing the lawn might not be. Structuring activities To structure the day for the impaired person and yourself, you want to come up with a schedule. This, of course, will always depend on the impaired person's abilities. As the disease progresses and these abilities decline, the schedule and what will work may change. At each stage, though, having a repeating pattern of tasks and routines can help both you and the impaired person.

You will need to observe, analyze and organize the impaired person's activities. This task may require expert help. Consult an occupational therapist or visiting nurse for guidance. Here are some guidelines:

Observe your days. Start by keeping track for a week or so of what you and the impaired person do on an hour-by-hour basis. Keep track of events and outcomes. What went well and what didn't? When did you feel under strain? When did the impaired person seem upset? When did you feel relaxed? When did the impaired person seem at ease? Are there times of the day when things go well and times when they don't? Are there certain activities that succeed and others that cause a fuss. Are some events such as bathing and getting out of the house happening less often than you wish? Were there any special "high spots?" Were there trouble spots? Were there times when there was little to do, and, if so, how did these times go? Did all the necessary events (eating, dressing, toileting, bathing) take place on time and with as little fuss as possible? How much help did you need to provide so that the person could safely do an activity without becoming confused or upset? For instance, could the person still bathe alone if you drew the bathwater? Or could the person put on clothes alone if you selected them?

Collect your notes and analyze them. Look for patterns. See if you already have a schedule and if it is working for you. Ask for help in examining what you have observed. Your health care team, family members or friends may be more objective. Set up a schedule. The next step is to write out a daily schedule. You must be flexible and keep in mind the impaired person's abilities and interests. The impaired person needs more time than usual to do things. Don't aim for a tight, minute-by-minute plan. Include some "free" time periods too.

Try to reach a point where you know in advance what will happen each hour of the day. Aim for a regular pattern for each day. Regularity makes things simpler for the person for whom you provide care and for you. The person may not "learn" the pattern of activities, but he or she may be more comfortable and less often surprised in a patterned environment. A patterned day also allows you to spend less time and energy trying to figure out what to do from minute to minute. A patterned day also simplifies the process of using a substitute caregiver once in a while because you can coach that person about what to expect and what to do. Your schedule may, in fact, simply summarize what you are already doing. You might include changes that you have observed. For instance, you may note that the evenings are times when the impaired person is most likely to become upset, while the mornings seem like the calmest times. You may also see that you have often done some activity like bathing in the evening, leading to a lot of fuss. You may decide to switch that activity to the morning, keeping the evenings more calm and pleasant.

Looking over your notes may also suggest when might be the best time to add a new activity. You will want to try something new during the calm times. Have someone stay with the person while you leave, or try an outing with the impaired person. Try following your schedule for a week. Keep a written record of how it works and what problems arise. Then you can make changes, if need be.

Plan ahead how you will handle those events which occur fairly often but not daily. Think about those events like doctor's visits which occur fairly often but not daily. Plan out how you will handle these too.

Keep in mind a few "back-up plans" you can use when a planned activity doesn't seem right. You may need alternatives to scheduled activities for those times when the impaired person becomes balky. For instance, if bath time arrives and the person is fussy, try just washing him or her with a washcloth. Offer a milkshake instead of a lunch the person dislikes. If the person won't nap, try a quiet activity instead.

Finally, keep a written list of simple diversions you can use if you need to distract the impaired person. This is especially important when the person seems to be getting upset. Often you can draw the person out of this mood if you can offer something he or she enjoys doing. For instance, you can offer a cup of tea or coffee or a snack. You might offer to rub the person's neck or back or offer to go with the person on a walk. On your list keep track of activities the person can do (and enjoys doing) alone. This might include such things as playing solitaire, listening to music (especially old favorites), watching TV, knitting, looking through picture magazines or albums, pacing, or even doing a large, simple jigsaw puzzle. Add a list of activities you and the impaired person both can enjoy together. Some of these may be at home, and some may be outings. Don't automatically stop going out to public places. Some activities you might use include taking a walk, doing simple chores together, watching TV together, going to a drive-in movie, going to a local coffee shop for a doughnut or playing simple card games. (Keep in mind that the impaired person may not remember the rules or how to play. You might have to be creative to let the person win from time to time.)

If you find that you can't think of enough things to keep the person occupied and interested, ask for suggestions from a member of your health care team, members of a support group, the director of a senior citizens program or an activity director or recreational therapist at a nursing home. You could call them, or have someone stay with the impaired person and go visit the nursing home. Supervising activities Even after you have simplified and organized everything you can, you will still need to watch over the impaired person's activities. You may even have to take over or restrict certain activities altogether. Once you have determined that an activity is no longer safe for the impaired person, or poses a threat to others, you have the responsibility and authority to restrict the person's activities, hard though it may be for the person to accept. Here are some suggestions for dealing with typical problems that may arise as the impaired person's powers decline. Be prepared to supervise even very personal activities. For instance, bathing alone may become too difficult or dangerous for the impaired person. You will have to take charge more and more. You will want to consider just how often the person needs to bathe. Are there changes in the routine that would help you? You may have to provide help in the form of prompting the person by telling or showing what to do. You may need to help more directly by actually washing the person. As the disease progresses, the person's sensitivity to temperature declines. You will have to adjust the water so it will not burn him or her. As coordination and balance decline, you will have to judge whether the person can safely get in and out of the tub or safely stand, unsupported, in a shower. You will need to decide if special equipment like supporting bars or a shower chair might help. At some point you will need to decide if a shower or bath is worth the effort and if it is still safe. Perhaps you will want to switch to sponge baths.

Be prepared to ban the most dangerous activities. Most experts in the care of dementia patients stress the importance of stopping the patient from driving very early in the disease. Driving is one of the most complex activities most people attempt. Accidents cause an enormous number of deaths and injuries every year. Impaired people should not drive. Other dangerous activities include working with power tools or using firearms. Smoking poses a very real fire hazard. You may want to dispose of all smoking materials. At the very least, the impaired person must be supervised constantly when smoking.

Be prepared to have the impaired person resist your efforts. You may find that certain events such as bathing always upset the person. This may be a task that someone else could handle with less stress. At the very least get someone to help you so no one is injured.

Another problem comes up when the person is still alert enough to get around any measures you may use in trying to prevent a certain activity. For instance, the person may be able to figure out how to start the car by reattaching a wire, but he or she may not have the skills to drive safely. In such a case, you must find some other way to keep the impaired person from the activity. How you do this will vary from person to person and will depend on how much the impaired person is able to understand. You may be able to explain, very simply, that the activity is no longer safe and that the person must not attempt it. You may have to deny access by locking up rooms or equipment and hiding the keys. Or you may have to enlist outside help. Have the doctor, for instance, tell the patient that a certain activity is no longer allowed. The authority of other family members, a health care expert, a police officer, or a clergy member may convince the impaired person he or she is no longer allowed to do something. Sometimes a note from the doctor stating that the person is no longer allowed to do a certain activity may work.

Be prepared to seek help in supervising the impaired person's activities, around the clock if need be. Family and friends can help you, or you may want to look into the option of hiring help, either in your home or in a care facility. Be sure to seek help early, before you become exhausted or a crisis occurs.