

CAREGIVING: Getting Organized

Developing a Plan



Caregivers – new and “experienced” – often feel overwhelmed by all that needs to be done. One caregiver described the caregiver role as “addressing a complex set of variables that change daily.” Another added that “I don’t even know what I don’t know, but, I DO know there is so much to do.”

There is a lot to know and do. And the stakes are high. In the balance are the health, safety and quality of life of both your loved-ones *and yourself!*

These next few pages offer you a process that many caregivers have found effective in managing caregiving responsibilities – over both the short- and long-term.

Develop a “master” chart – also known as a caregiving plan. The plan will not only help you secure a sense of control, it will also help you get and stay organized as caregiving responsibilities change.

Some have compared caregiving to taking a trip. “I sure don’t know where I am going, but I sure am getting there fast!” may adequately describe how one feels along the way! With the stakes so high, however, you may want to actually develop a caregiving plan for you and your loved-one.

Much the same with planning a trip, you can ask a professional to help you to get organized and plot out a route, gather ideas or seek guidance from friends and family, or you can develop the plan by yourself. The resulting document will serve as a valuable tool – a map – that will keep you on track, help you when you are lost, identify roadblocks and guide your decisions. With it, you can gain a valuable, practical perspective on how you can best care for your loved-one and yourself – both now and in the future.

A simple chart may contain the following headings:

1	2	3	4	5	6	7
TASKS	Levels of care	Frequency: e.g. # of times each day, each week, etc.	Loved-one can perform this task	I must perform part or all of this task.	Family, relatives, friends can perform part or all of this task.	Professional or paid help is needed to perform part or all of this task.

Column 1: Identify the most important (critical) tasks first.

Which are the most important ones? Think for a second about the personal tasks you routinely perform for yourself – brushing your teeth, preparing and eating a meal, getting in and out of a chair, taking a shower, getting dressed, and going to the bathroom. If you could not do these things, you may not be able to live an independent and healthy life.

The following is a list of tasks that **MUST** be performed:



- Bathing
- Dressing
- Meal preparation
- Mobility
- Transfer
- Laundry
- Shopping
- Body care / Personal hygiene
- Toileting
- Eating
- Positioning
- Housekeeping
- Medication management
- Travel to medical services

Look at this list. Definitions are provided on pages 15-16. Write those tasks that need to be done now on the chart on page 12.

Column 1: Identify other tasks too.

Consider including these less critical tasks too.

- Preparing light meals, snacks, soups, boiling water, etc.
- General home maintenance (change light bulbs, faucet gaskets, check smoke alarms, minor repairs, etc.)
- Yard work / maintenance
- Managing finances, paying bills, etc.
- Random errands



Can you think of others?

Columns 2 – 4: Assess how well your loved-one can or cannot perform each one of the tasks you have listed. This information will help you understand how much help may be needed to keep them living as independently and safely as possible. Page # 16 offers you definitions to “levels of care.”

Your loved-one may be able to perform all, part, or none of the tasks you listed. Take a moment to consider the “level of care” or the amount of care they need. Note that the level of care may change dramatically at any time. Use a 1-4 scale with level 1 representing “no help needed” and level 4 meaning “loved-one cannot perform at all.” Should a caregiver find a lot of 3’s and 4’s in the “level of care” column, this strongly suggests that the caregiver is faced with enormous demands. Such a case may necessitate professional help.

Level of care and frequency are related. How often a task must be performed, even if it is only a level 1, intensifies the time the caregiver needs to spend on this task. For example with toileting, let’s say your loved-one only needs cueing or supervision but has irritable bowel syndrome. In this case, the caregiver may be required to be available much of the day and night.

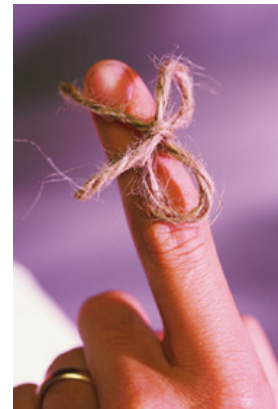
Column 2 and 3: Your loved-one’s “cognitive ability” must also be considered.

If your loved-one is forgetful, disoriented or has poor judgment, you will need to make adjustments to the care plan.

Cognitive ability is something that scares the heck out of family caregivers – why? Not only does cognitive ability influence how well our loved-ones’ cope with daily living, but also it is directly linked to personal safety. Just a few examples are: risk of scalding, wandering/getting lost, risk of setting a fire, ability to exit the home in case of an emergency, and properly storing foods.

Caregivers who live with their loved-ones will have a much better chance of knowing the answers to these questions. As you learn the answers, incorporate these findings into your plan:

- How good is their short-term memory?
- Are they easily confused?
- How good is their decision making? How about making decisions under stress?
- What kinds of decisions do they need to make every day...basic?...moderate?...involved?
- Do they have a sense of “routine?”
- How about their “common sense?” How “common” is it?
- How well can they communicate / express their needs? Can do this under stress?



Columns 4 – 7: Decide who is willing or able to help with caregiving tasks for your loved-one... starting with your loved-one.

Most caregivers have said they have limits to what and how much care they are willing or able to perform. But, for these same caregivers, they admit that asking for help was loaded with feelings of guilt, failure and even disgrace.

Who said you have to do it all? The fact is, in most cases, it is a healthier situation for you and your loved-one when others are involved in caregiving.

Columns 6 – 7: Getting support from other sources.

The last two columns of the chart provide you with space to write down who else can help to get these tasks done.

Pages 17-18 will offer you strategies in getting help.

Last words from other caregivers: How you approach caregiving makes all the difference. These suggestions may be helpful:

- “I learned very fast that my loved-one wanted to maintain his independence – so I let him do as much as he could for himself and reminded him how terrific that was. Skills not used are forgotten!”

- “I learned that being busy and wanting to hurry up my helping tended to interfere with honoring my loved-one’s dignity and respect. It was hard to learn how to balance my needs with hers.”
- “I learned that small changes can make a big difference.”
- “Perfection is enemy of good.”
- “A day without denial is day you have to face.”
- “I made a promise on my Dad’s deathbed that I would always take care of Mom forever, in my home, by myself, until the end of her life. I learned that this was a mistake because her care needs were far greater than what I could provide. By renegotiating this promise (with myself, Mom and the family) it became easier to get the quality of care Mom really needed and deserved.”

ACTIVITIES OF DAILY LIVING

Bathing: includes getting in and out of the tub, lathering, washing, and rinsing the body and hair.

Body Care: includes managing skin care such as application of non-prescribed ointments or lotions, changing dry bandages or dressings when professional judgment is not required, and trimming finger/toenails. Body care also includes physical exercises.



Personal Hygiene: includes care of hair, teeth, dentures, shaving, filing of nails, and other basic personal hygiene and grooming needs.

Dressing: includes dressing/undressing, and managing difficult tasks such as tying shoes and buttoning.

Toileting: includes getting to / from the bathroom and on / off the toilet, handling incontinent briefs and other protective aids, and managing bedpan routines. It also includes clothing adjustment, washing hands, wiping, and cleansing.

Meal Preparation: includes planning meals (also special diets), meal preparation, cleaning up after meals, and proper food storage.

Eating/Feeding: includes carrying food to the loved-one, assisting with difficult tasks such as cutting food or buttering bread, and feeding when the loved-one is unable to feed his or herself. It also includes standby assistance for gagging, choking, or swallowing difficulty.

Mobility: includes walking (or propelling a wheelchair) from place to place, in or outside, with or without the help of a mechanical device; maneuvering uneven surfaces; and climbing stairs.

Positioning: includes assuming a desired position when chronically in bed or in a chair, turning and positioning to prevent secondary disabilities.

Transfer: includes getting in / out of a bed or wheelchair or on / off the toilet or in / out of the bathtub.

Housework/Housekeeping: includes those periodic and essential tasks to maintain a safe and healthy environment such as cleaning the kitchen and bathroom, sweeping, vacuuming, mopping, cleaning the oven, and defrosting the refrigerator.

Laundry: includes washing, drying, ironing, and mending clothes and linens.

Medication: includes all aspects of managing medications prescribed by attending physician such as knowing when it is time to take prescribed medication, opening a container, laying out the medications and/or organizing them.

Essential Shopping: includes shopping to meet health care or nutritional needs such as food, medical necessities and household items required specifically for health, maintenance, and well-being. It also includes driving and/or using public transportation, getting to / from as well as in / out of the transportation vehicle.

Travel to Medical Services: includes transportation to a physician's office or clinic in the local area in order to obtain medical diagnosis or treatment. It also includes driving and/or using public transportation, getting to / from as well as in / out of the transportation vehicle.



LEVELS OF CARE:

Your loved-one's ability to self-manage tasks may range from (1) independent, to (2) minimal help needed, to (3) substantial help needed to (4) total dependency. These explanations may be useful to "quantify" the need.

Level 1 = loved-one is able to perform and manage all tasks by self and on a regular basis, with or without assistive devices.

Level 2 = loved-one requires oversight, supervision, instruction, guidance, cueing or reminding in self-performance some of the time, or requires occasional and limited physical assistance like steadying, or requires stand-by assistance for safety or encouragement around some or all of the tasks.

Level 3 = loved-one always requires physical assistance to perform tasks, or requires substantial assistance with part of the tasks. Loved-one can cooperate/participate to assist the caregiver.

Level 4 = loved-one always requires physical help and is dependent on others to perform tasks.