

Guide to Caregiving



Polk Family Caregivers

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Welcome

We admire you for taking on the role of caregiver. There are few jobs that are more difficult or important. Family caregiving is a role that is thrust upon most of us, not one we expected nor one for which any of us were prepared. We hope this booklet in some small way can make your task a little easier.

Families, not governmental services or social service agencies, provide 80% of the care for people with long-term chronic health problems. The debilitating nature of any long-term, chronic illness imposes an enormous financial, social, physical and emotional strain on the caregiver. For this reason, we have provided this guide containing a number of suggestions that will help you learn the necessary caregiving skills and strategies that ensure the best care for both your loved one and you.

No two people experience the caregiving journey in exactly the same way. As a result, there's no one correct approach to caregiving. You must find your own way. Experiment to find which ideas and strategies work best for you.

When you find you have questions or just need a little support, don't hesitate to phone Polk Family Caregivers. If we can't help, we will be glad to find someone from our network that can help.

Patience, Planning and Practice

National studies show that 46% of the people who are a primary caregiver had no preparation or instruction whatsoever for their role. Before you decide on a primary caregiver for your loved one, you need to consider who themselves is in reasonable health, lives close by, and already has an established, healthy relationship with your loved one. Caring for a family member or loved one takes patience, planning and practice, but it can be learned, especially with help from others.

Patience. People underestimate how difficult permanently caring for someone like a parent or mate is going to be. It impacts the entire family. Homework for younger children is neglected, appointments are missed, attendance on the job is impacted, job performance suffers, promotional opportunities suffer and financial problems cause tremendous stress.

Planning. You will need to follow through on doctor's recommendations, taking medications, watching nutrition and seeing to it that there is social interaction, otherwise your loved one can become withdrawn and depressed and descend into a steeper decline.

Practice. We do things 3 times before they become easier for us. Cut yourself some slack when attempting tasks that are new to you. If you have never balanced the checkbook, or had to be responsible for the car

maintenance, you already realize there is a learning curve. Whatever the task, in time, you can learn how to do it. It just takes patience!

On an average, where the family caregiver attends caregiving classes, the loved one is able to avoid long-term in-patient care, such as hospitalization or assisted living and remain at home 23-35 months longer than households where there was no caregiving instruction. With assisted living facilities costing over \$5,000 a month in Polk County; this is a saving of \$150,000 and that is without even considering the comfort of your loved one and all the emotional issues faced when someone is institutionalized.

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. Two heads

are better than one and a whole network is even better yet. Get the family together if possible to help make some basic decisions on handling the road ahead.

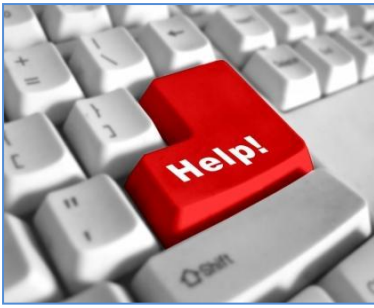


It is easiest to prepare for any situation before a crisis. Waiting until your house is on fire is not a good time to develop a plan. As

Set a clear course for the days ahead.

early as possible, meet with an experienced expert who can give a realistic assessment on what lies 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. Be sure to keep the original on hand because you will need to make many copies as you go along.



Search for Resources

Meet with some sort of professional financial advisor to discover the best use of any monies on hand over the course of the illness. If funds are limited, start a search for any help offered by private, nonprofit or government programs.

Search for resources relating to financial, physical and emotionally help, such as home care agencies, respite care services, adult day care services, facilities that deal with your loved one's specific condition, social service agencies and neighbors that can help, to mention but a few.

Begin a search for available resources.

Become familiar with programs offered that address your loved one's conditions. Most programs take time to understand and comprehend, apply for, and enroll in. Community resources are usually limited and requests for help may only get you placed on a waiting list. Get your loved one in the queue for services now, even before they really need them.

Preparing Your Home

No matter how much safer it is, most people are reluctant to change their home environment.



Preventing falls is a major issue in most long-term situations where someone's health is expected to deteriorate. Remove clutter to create spacious pathways between rooms, especially between the loved one's room and the bathroom. Keep only the larger, sturdier, familiar pieces of furniture. Closets and drawers should be cleared of clutter and contain only essentials. Consider removing all area rugs 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.

Many new aids and accessories will need a place in your home.

If your loved one's condition involves any type of dementia, brain injury, Alzheimer's Disease, Parkinson's Disease, head trauma or other condition that may impair judgment, install safety latches if needed on cupboard doors where dishes or other breakables are stored. Set up special cupboards and drawers throughout the house that can be locked to secure sharp objects, cleaning materials, poisons, insecticides and other dangerous objects. Place locks at top or bottom of doors where they will less likely be noticed by loved one. Be sure knobs on both electric and gas stoves can be easily removed and secured after use. Consider putting door

alarms on outside doors to alert you if your loved one tries to exit. Put a large picture of a toilet on the door of the bathroom for your loved one to more easily identify where they need to go.

Place easy to see decals on all large expanses of glass such as sliding doors.

Put a giant 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.

If your loved one is going to be in a wheel chair, hang towel racks at lower heights. Use remote controls for ceiling fans, light switches, TV sets wherever they are helpful to control without walking or standing to use.

*Prepare your
home
environment
to match your
new
situation.*

You may want to keep a space off limits primarily for yourself where environmental changes have not been made. Somehow it helps to have an unaltered space where you can retreat to when you need to be alone.

Take locks off of bathroom doors to avoid your loved one from accidentally locking themselves in. Make sure you can lock and secure windows and outside doors. Take pictures down from stairways, as they can be a dangerous distraction and fall from walls easily if bumped.

Make sure hallways and bathrooms are well lit at night with night lights.

Set water heater temperatures to 135 degrees to avoid burns.

Make an emergency list and post it in a very visible place for helpers and other caregivers.

Be sure you have an ICE card (In Case of Emergency) listing usual emergency



numbers such as fire, police, ambulance and your loved one's doctor, close family members, as well as those who have either house or car keys. Sample ICE cards are available for downloading on the www.polkcregivers.org website.

Also, under ICE on any relevant cell phone, list the number of whom to contact in an emergency. It is a common national practice of law enforcement to look for an ICE listing on cell phones in the event of an emergency.



Facing Each Day

The three keys to caregiving are understanding that for your loved one, it is about a personal loss of dignity and respect, loss of their independence and loss of their self-identity and who they have been. Always, always treat your loved one with respect and dignity. They deserve it and you will feel so much better about yourself.

Impaired memory due to medical conditions and medication effects is common in long-term care situations. Reactions like depression and withdrawal should be expected. There is going to be a certain amount of grief by your loved one over changes that are beyond their control. Try to keep them connected and cheered up by:

Hanging recent photos on walls in areas where they spend much of their day, such as the bedside;

Finding a good radio station or television audio only channel to play soothing background music, or use IPOD downloads or CD's that have music dear to your loved one, to help fill their time;

Trying to maintain the routine your loved one has established over the years, such as bathing in the morning, dinner at five, and bedtime at 10 pm;

*Try to
maintain
familiar
routines.*

Giving your loved one as much privacy as possible in carrying out personal daily hygiene, especially in the bathroom and

Letting your loved one continue whatever chores they feel they can accomplish.

*Become a
master of
distraction.*

Learn about distractions like a couple of favorite cookies, a glass of favorite drink, or the daily newspaper, but focus on positive current events. Divert them with conversation about how poor they feel. Keep a daily diary to help identify patterns such as anxiety or increased pain. Then, be ready with an activity of 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 your loved one has dementia, diminished mobility or an impaired range of motion. There are wonderful “paper” clothes, that feel and look like cloth and can be thrown away if bathroom accidents occur. Have emergency information sewn or written in all clothes.

Activities

Always keep in mind your loved one's current capabilities and adjust their activities accordingly. Draw on your loved one's likes and hobbies such as music, cooking, sewing, stamp collecting or sports. Try to gear some activities around these likes. If your loved one played an instrument, keep that instrument handy.



It is important when you are ill to still feel useful. Choosing simple activities that contribute to the family workload will help your loved one avoid becoming frustrated and agitated and promote self-sufficiency and independence. Repetitive tasks such as folding clothes are calming to most people. Help with chores around the house as abilities allow. In the yard, have your loved one help with gardening or other simple clean-up activities if their condition allows.

Watching sunsets is a good daily ritual.

Encourage your loved one to help in the kitchen with chores like setting the table or washing vegetables or sweeping the floor, keeping in mind their current abilities. Simplify as much as possible. For instance, if stove top cooking is somewhat unsafe, perhaps microwaving still works.

Simplify necessary daily activities, such as dressing. If all the socks are the same color and match most daily clothing decisions, arguments and time-consuming choices are reduced.

Show a person how to do a certain task or chore using new strategies if at all possible.

Set up plastic boxes with different activities (get creative) such as playing cards.

Computer games are another way to entertain oneself, so are renting old movies.

Set the junk drawer in your loved one's lap and let them clean and sort.

Roll coins for deposit in the bank if your loved is wheelchair bound.

Keep extra boxes or baskets in several areas like bedroom, living room, bathroom, and car, where many items can be scooped up at once and transported to other rooms to be put away.

When boredom sets in, try moving your loved one to a different room. Set up a seat by a window where they can watch the street activity.

Set up a seat by a window.

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

Pets are great companions and help fill hours when other people must be busy or away.

Read aloud to your loved one or, if able, have them read aloud to you.

Get audio books from the library to listen to, or use the library's free delivery of "books for the homebound" services to save you time.



The Bathroom

Have an in-home assessment of durable medical equipment done that will acquaint you with all the equipment that can make family caregiving easier.

Make your tub safer with nonskid rubber mats or strips or line with an extra towel before bathing. 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 your loved one.

***Keep a
regular
routine.***

Have a regular schedule for your loved one for taking baths and toileting. Be sure to check with a doctor if your loved one has trouble making it to the bathroom in time. A commode at bedside can sometimes help if your loved one has trouble finding the bathroom during the night.

Meals and Eating

Changes in eating habits can cause health problems.

Not eating enough or getting the right nutrients can lead to a broken hip, make diabetes worse or cause memory loss.

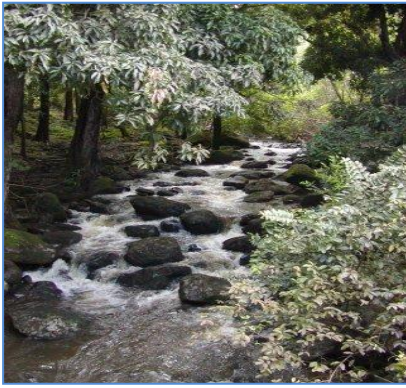


How can you tell if your loved one isn't eating enough or getting the vitamins they need? Weight loss is one sign, but other signs may include, poor healing, bleeding gums and brittle fingernails.

*Keep healthy
snacks
available and
on display.*

Food is always the best way to get nutrients, but if you are worried about good nutrition, a standard dose supplements may also help. There are also many liquid supplements on the market, like Ensure. Physicians can also give prescriptions to enhance appetite. However, loss of appetite is common in illness and eating does decrease as chronic illness advances.

Use bowls, spoons and non-spill cups as much as possible. Plastic can help reduce breakage and provide easier cleanup. Keep healthy foods out where they can be seen and are appealing. Prepare foods you know your loved one likes. Demonstrate how utensils are used if your loved one gets confused. Use finger foods and cut into small, easy to chew, pieces. Keep healthy snacks on hand for between meal diversions.



Behavior Changes

Medications and advancing illness often cause insomnia, restlessness, anxiety or other behavior changes. Your loved one could just be bored, hungry, or need to go to the bathroom and unable to express their wishes. It could be the results of a medication they are taking or need to be taking. Talk with your doctor.

Try to schedule activities like exercise during your loved ones most upbeat 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.

*Avoid
caffeine and
alcohol.*

See if you can determine if the changes are from illness or pain.

Keep your loved one away from drinks with caffeine or alcohol.

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

Avoid strange, new or noisy areas with lots of activity and keep to a less stressful environment.

Reassuring your loved one throughout the day that everything is okay can help relieve stress.

Exercise your talents at distraction in helping your loved one steer away from depressing thoughts and radical actions and calm them.

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

Look for clues...

Frustration, anger, difficult and even violent behavior can be part of many diseases so don't blame yourself if your loved one's behavior goes out of control. Remain calm and reassuring during outbursts. Stay in front of your loved one, making good eye contact, speaking in clear, understandable sentences. If necessary, keep out of the reach of your loved one and call a family member or neighbor for help.

DO NOT try to restrain a person unless absolutely necessary, such as when balance becomes an issue. Even when you feel the person is a danger to their self by their poor choices, restraining anyone usually only makes matters worse. If the situation turns uncooperative, someone can fall or get hurt.

A note about falling: Many caregivers make the assumption that 9-1-1 is there to respond if you can't help your loved one up should they fall, roll out of bed, or be unable to stand. This is NOT what 9-1-1 is for and it is important that you use other means in these situations, such as a gait belt to help with transfers. Otherwise, make advance arrangements with a friend or neighbor if you need help lifting.

Communication

Don't start talking about your loved one as if they weren't in the room and unable to speak for themselves. Don't fall into the habit of saying "We" as in "We are going to take our medication now". It is irritating.



Everyone likes to be called by name, it is one of the earliest responses we learn and it is helpful when you need your loved one to focus and cooperate. 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 loved one is having trouble understanding. Have them repeat instructions back to you to be sure they are clear. If your loved one starts to get upset or frustrated, or appears to be in too much pain to track on what you are saying, try to come back to it later.

Reasoning rarely works with people who are ill if they are uncooperative about requirements such as medications, regular intake levels of food, liquids or other requirements. Be prepared with a combination of reassurance and distraction. Use touch and body language along with your speech to help your loved one understand your meaning.

Make allowances. Try to remember that your loved one is not acting differently on purpose. Don't take it personally. Many illnesses cause erosion in the way one expresses themselves.

Show interest. Maintain eye contact and stay near your loved one so that he or she will know you're listening and paying attention. It is an effort to talk when you are seriously ill. The least you can do is listen.

Avoid distractions and noise. Good communication is difficult, if not impossible, against a background of competing noise like television and running dish washer. Eliminate unnecessary noise when possible.

Keep things simple. Use short sentences and plain words. Avoid complicated questions or directions with too many options. When communicating a task or request, break it down into single steps.

*Use your
loved one's
name...*

Don't interrupt. It may take longer for your loved one to respond. Avoid criticizing, hurrying, correcting and arguing.



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 in asking for 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.

*Don't be
bashful about
asking...*

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

Join a support group. Log on to www.polkcaregivers.org to view a listing of caregiver support groups in your area or call the Polk Family Caregivers' Care Line at 863-603-9110 if you do not have internet access. Support groups can give you an opportunity to:

- Share your experiences and ventilate your frustrations,
- 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 support from other caregivers.

Be sure you get some kind of exercise every day.

Prepare healthy meals and get plenty of sleep.

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 your loved one who has the disease or anger that there are few treatments or 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 neighbors anymore.*

Anxiety about facing another day and what the future holds. *What happens when he needs more care than I can provide.*

Learn to recognize signs of stress...

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!

*I'm too tired
for this.*

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.



Some suggestions on caregiving ...

Seek out a support group. Spending even a short amount of time with others in the same situation and sharing feelings 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, usually called "respite" that will come into the home and provide a few hours of relief.

Adult Day Care Centers can be a tremendous help. Some are county services, some are privately owned, most specialize in care of Alzheimer's/dementia loved ones, but all provide a safe, secure and welcoming break for the caregiver.

In-home care agencies can help.

Short-term respite care. Some assisted living and adult family senior homes offer safe, secure short-term respite care for a week or two.

To get more information on where these services are offered in your area contact Polk Family Caregivers Care Line, 863-603-9110, the Elder Helpline, 1-800-963-5337 or United Way of Central Florida Referral Information, 2-1-1.



A Caregivers Bill of Rights

It is all right to:

Be angry, be depressed or express other difficult emotions.

Seek time alone to maintain outlets and interest on your own just as you would if your loved one were healthy, and not lose yourself in providing care.

Seek help from others, even though your loved one may object. Recognize the limits of your own endurance.

Trust your own judgment, relax and do the best you can.

Recognize your own limits and know you do not have to do everything perfectly and completely all the time

Make mistakes. This is how we learn.

Grieve, which is a normal response to any loss and be sad over the loss of the way things used to be, are now, or what might have been.

Take care of yourself. This is not an act of selfishness but will instead enable you to better care for your loved one.

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

About Polk Family Caregivers

Polk Family Caregivers is a Florida incorporated 501c3 charitable origination that exists to be a public voice for family caregivers, illuminating the daily challenges they face, offering them the assistance they need, and championing their cause by helping them to become better prepared to be good caregivers.

Polk Family Caregivers achieves these goals by providing information, insight, assistance and support for the thousands of people in Polk County who struggle to care for a loved one that has become ill, frail or disabled.

Polk Family Caregivers provides several services including a:

- Care Line telephone service that connects caregivers to vital community resources,
- Welcome Wagon home delivery bag of samples and products useful to new caregivers,
- Workshops, seasonal conferences and caregiving classes,
- Support groups such as “Caring for Your Parents,”
- Speakers Bureau of experts available to address social and civic organizations.

If you need help because you have been thrust into the role of caring for a loved one, please feel free to contact Polk Family Caregivers at any time.

For additional copies of this guide, please contact Polk Family Caregivers. For additional helpful information about family caregiving, visit us on the web at www.polkcaregivers.org