

# Caregiver Confidence



A GUIDE TO CAREGIVING AT HOME

  
*Serenity First*  
HOSPICE CARE

Your Comfort, Your Legacy

# Introduction

It takes courage to be a caregiver. Providing care for someone who is seriously ill can be emotionally and physically draining. You may feel stressed or alone. You may not know what to expect. We are here to support you and your loved one.

This booklet lists steps for some common caregiving tasks. It may seem like a lot of information — try not to be overwhelmed. You'll get support and advice from a nurse, home care aide, or other healthcare professional. Reach out if you have questions.

The care needed will be different for everyone. We will help you figure out what your loved one needs. We can also give you tips for your loved one that may not be listed here. Use the blank spaces in this booklet to write notes.

We hope this booklet will help you build confidence as a caregiver. Use it as a tool. Fold page corners or use colored markers to highlight important information. Keep the booklet with you until you feel comfortable. When you feel confident, you can give better care.

“We may think of caring as simply having good intentions...but this is not enough. As caregivers, we must know the individuals we're looking after, their strengths and weaknesses. We must also know our own. And we must know how to respond to others' needs.”

— Rosalynn Carter, *Helping Yourself Help Others*

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## Creating a Safe Care Setting

This section lists common safety risks for your loved one. **SAFETY NOTES** are also marked with an **!** throughout this booklet. These are important, so pay careful attention when you see them. We may also speak to you about safety issues specific to your loved one.

### Avoiding infection

Always keep the room, your loved one, and yourself clean. Germs can spread easily during caregiving tasks. Your loved one may be at risk of getting really sick if their immune system is weak.

What you can do:

- Use disposable gloves when a task calls for it. Change gloves between tasks. Wash hands often with warm water and soap.
- Scrub soiled items and surfaces with soap. Wipe surfaces with bleach water (one teaspoon of bleach per gallon of water).

### Avoiding bed sores

Skin weakens with age or some medical conditions. A person with weak skin who sits or lies in the same place for a long time may get bed sores. Bed sores can be painful and cause infection.

What you can do:

- Massage pressure points such as knees, elbows, feet, hips, shoulders, and tailbone. Ask the nurse first. Some people may have skin that is too sensitive for massage.
- Ask the person to change position every couple hours. If they can't move, pad pressure points with pillows. Reposition often.
- Look for broken skin, red/dark marks, or scabs. Tell the nurse or aide if marks do not fade after taking pressure off of those spots.
- Check the person often if they have lost bladder or bowel control. Always keep the person clean and dry.

### Avoiding falls

Your loved one might be at a high risk for falls. Bad eyesight, weak muscles, or medication can affect balance. Falls can cause very serious injury. Do everything you can to prevent them.

- !** **SAFETY NOTE:** Call us immediately if the person falls and is injured or can't move. Falls can hurt you, too. Do not try to correct a fall. Ease the person to the floor only if you can. Get help to lift someone who has fallen. If the person can pull themselves up, put a sturdy chair nearby for support.

What you can do:

- Hearing aids/glasses should be worn, if the person needs them.
- Keep a cane or walker by the person at all times. Have them wear light, non-skid socks or shoes.
- Keep the home well lit. Use night lights when it gets dark.
- Pick up anything from the floor that might trip the person. Repair damaged floors. Put non-skid mats in slippery areas.
- Check stairs and steps for safety. Make sure handrails are sturdy. Put bright tape at the edge of each step.

### Managing medications

Your loved one might have to take a lot of different medication. Always review proper use with us. Avoid overdosing or missing doses. Giving medicines correctly will keep the person safe and comfortable.

What you can do:

- Keep a list of all medicines, vitamins, etc. Write down for each: **who** (the doctor who prescribed it), **what** (the drug's name and dose), **why** (what it does), and **when** (the time it has to be taken). Bring this list to all doctor visits.

- Give medicine exactly as prescribed. Always follow the doctor's orders, even if it doesn't seem like the person needs the medicine. This is especially true for pain management medicine. Do not crush or cut pills unless directed.
- Find out if the person's medicines have side effects. For example, pain medicines may cause itching, nausea, or constipation. Many side effects ease after the body adjusts to the medicine. But some, like constipation, do not and will need to be treated before they cause serious discomfort. Ask us about treatment options.
- Contact us if you have questions. Also consult us before giving over-the-counter drugs.
- Keep medications in a safe place if your loved one has dementia, is forgetful, or is confused.

## Keeping hydrated

The average adult needs about eight 8-ounce servings of water each day. The person could be at risk of dehydration. Be sure they get plenty of fluids.\*

- ! **SAFETY NOTE:** Contact us if the person has trouble swallowing. There may be a risk for choking. We may recommend thicker liquids.

What you can do:

- Always keep fresh water within the person's reach.
- Give liquids in different ways. Juice, milk, soups, fruits, and vegetables add variety. Avoid caffeine and alcohol.
- Give medications with a full glass of water.
- Do not limit liquids, even if the person has accidents. Dehydration can cause bladder infections.

\* There may come a time when the person won't need as much water. Give them ice chips or small amounts of liquid by dropper.

## Activities of Daily Living

Your loved one most likely needs help with activities of daily living, or ADLs. These include personal care tasks such as:

- Mobility and transfers
- Eating
- Mouth care
- Toileting
- Bathing and grooming
- Getting dressed

Some care tasks may be embarrassing. Realize this may be a tough time for your loved one. Allow the person to invite you to care for them, if possible, and always ask before giving help. Let them do as much as they can on their own for as long as possible.

Make a care schedule based on the person's usual routine. Be aware the schedule may need to change over time.

- ! **SAFETY NOTE:** Contact us before trying any task for the first time. A healthcare professional should show you how to do each task safely and correctly. Read the steps carefully. Prepare supplies before starting. Many of these steps are for someone who can be moved without pain. Contact us if your loved one is in pain.

## Mobility and transfers

Your loved one may struggle with mobility. That means they can't get around easily — or at all. You may have to help the person up from a chair, bed, or toilet. You may have to transfer them from one spot to another. You will need special training/equipment for transfers.

- ! **SAFETY NOTE:** A healthcare professional must show you how to do this safely. Have a walker or cane ready to support the person. Chairs should be sturdy and should not slide. Make sure wheelchair brakes are on.

## How to safely transfer a person:

- 1) Talk to the person through the whole process. They should tell you if they are in pain or dizzy. Stop if this happens at any point.
- 2) If the person is in bed, ask them to sit up or lift them into a sitting position. Swing their legs over the edge. Consider having them wear non-skid socks.
- 3) Have the person put both palms on the bed. (Use armrests if they are in a chair.) Their arm should never go around your neck. This can injure you both.
- 4) Stand close to the person, like you're going to hug. Their legs should be between yours. Their feet should be firmly on the floor.
- 5) Bend at your knees. Wrap your arms around their waist. If they can, have them rock front-to-back to assist. Count to three. On three, the person should push off as you lift.
- 6) Lift, keeping your back, neck, and shoulders in a straight line. Use your buttocks and legs to power the lift. If you feel strain, stop and get help.
- 7) Make sure the person is steady before backing away. Give them the walker or cane.
- 8) To transfer to a chair, do steps 1–6. While holding the person, turn their back toward the chair. Shuffle your feet to turn. Never twist. Shuffle until the back of their legs touch the chair.
- 9) Bend at your knees as you lower the person. Keep your back straight. Ask the person to use the armrest for support if they can. Slowly lower them into the chair.
- 10) Adjust the person in the chair for comfort. Make sure their skin isn't being pinched or rubbed.

 Notes for mobility and transfers:

## Eating

Most people connect food with caring. It can be troubling to see your loved one's eating habits change. A person might eat less if they are getting weak, feeling sick, or because of treatments. This can lead to weight loss.

If the person is very seriously ill, the body will weaken. Food is digested differently at this point. The person may lose even more weight. This doesn't mean the person is starving.

Try not to press the person to eat more. This may cause stress. Contact us for support. We may have special tips for your loved one's situation.

- ! **SAFETY NOTE:** Never force a person to eat. This can cause choking or inhaling of food. To prevent choking, the person should always sit up while eating. Have them sit up at least 20 minutes after meals.

What you can do:

- Let the person help plan meals, if possible. Be aware that they may no longer want the same foods they used to like.
- Let your loved one decide when they want to eat. Give them plenty of time to eat. Try small meals served more often.
- Let the person eat on their own for as long as possible. Sectioned plates, two-handled cups, bending straws, and forks/spoons with larger handles can help. Finger foods (like sandwiches), soups, or liquids may be easier to handle.
- Never comment that the person is not eating enough. Adjust portion sizes as the person's needs change.

 Notes for eating:

## Mouth care

Mouth care should be done in the morning, after eating, in the evening, and as needed. Disposable toothbrushes can be used after meals. This will help prevent mouth sores, problems with teeth, and other discomforts. Good mouth care can add to overall health.

What you can do:

- Let the person brush their own teeth, if they can. Use a large-handled toothbrush. A foam roller or tape around the handle may help.
- Help the person to the bathroom to brush for as long as possible. If the person is bedbound or can't brush their own teeth, follow the steps below.
- Gently wipe the mouth clean and pat dry as needed. Use lip balm to keep lips from chapping. If the person is unable to drink water, keep the mouth and lips moist with wet swabs.
- Follow the same cleaning schedule for dentures. Check dentures often for damage. Store them properly when not in use.

### How to brush a person's teeth:

*You will need...*

- |   |   |
|---|---|
| <input type="checkbox"/> Non-latex medical gloves | <input type="checkbox"/> Soft-bristled toothbrush |
| <input type="checkbox"/> Water                    | <input type="checkbox"/> Toothpaste/baking soda   |
| <input type="checkbox"/> A small basin, if needed | <input type="checkbox"/> Dental floss             |
| <input type="checkbox"/> Hand towel               | <input type="checkbox"/> Flavor-free lip balm     |

! **SAFETY NOTE:** Contact us if the person cannot swallow. Use a pea-size amount of toothpaste to prevent choking.

- 1) Put on gloves. Ask the person to rinse their mouth with water, if possible. Use the basin to catch the rinse if the person is in bed.
- 2) If they can't rinse, wet the toothbrush and use it to swab the mouth. Dry spills with the towel as you go.

- 3) Gently brush the person's teeth. Use either toothpaste or baking soda and water.
- 4) Have the person rinse (or swab the mouth with a wet toothbrush) until all traces of toothpaste are gone.
- 5) Wipe the mouth and chin clean. Pat dry with a towel. Gently floss once a day. Apply lip balm if needed.



Notes for mouth care:

## Toileting

Incontinence is the loss of bladder or bowel control. You may have to help your loved one go to the bathroom. Helping with toileting can be uncomfortable for you both at first.

! **SAFETY NOTE:** Contact us if there are a lot of accidents. It could be a sign of infection. Sometimes incontinence can be treated. We may be able to give you treatment options.

What you can do:

- Let the person know it's okay. Always be calm and reassuring.
- Make a schedule. Set bathroom trips every 2 or 3 hours. This will keep them from having to ask every time and reduce accidents. If the person asks, take them right away.
- Help the person walk to the bathroom to use the toilet for as long as they are able.
- Move the bed as close to the bathroom as you can. A bedside toilet may help.

- Leave the room if it's safe to leave the person alone. If not, turn away. Respect their dignity by giving plenty of time and privacy.
- You may need to use disposable briefs or bed pads. Always keep the person dry and clean. Change soiled clothing and sheets right away (see page 15).
- You will need to use a bedpan or urinal if your loved one can't get out of bed. See below.

### How to use a bedpan:

*You will need...*

- |   |   |
|---|---|
| <input type="checkbox"/> Bedpan/portable urinal   | <input type="checkbox"/> Washcloths, water, mild soap   |
| <input type="checkbox"/> Baby powder              | <input type="checkbox"/> Towels                         |
| <input type="checkbox"/> Non-latex medical gloves | <input type="checkbox"/> Disinfectant soap              |
| <input type="checkbox"/> Bed pad                  | <input type="checkbox"/> Toilet brush (just for bedpan) |
| <input type="checkbox"/> Toilet paper             | <input type="checkbox"/> Bleach                         |

- 1) Dust powder on the rim of the bedpan. This makes it easier to slide. (Use a portable urinal if appropriate.)
- 2) Close doors/curtains for privacy. Put on gloves. Help the person pull clothes down and out of the way.
- 3) Ask the person to lay flat and lift their hips off the bed. Place a bed pad under their buttocks. (If the person can't lift their hips, see step 5 on page 16 to place the bed pad.)
- 4) Get the bedpan. Ask the person to lift their hips again. Support their lower back with one hand and slide the bedpan in place. If they can't lift their hips, roll the person to one side. Put the bedpan on the pad, next to the buttocks. Carefully roll them onto the bedpan, holding the bedpan in place.

**!** **SAFETY NOTE:** When rolling a person on their side, put up side rails or stable chairs at the side of the bed. This will prevent a fall. Be sure the chairs do not slide.

- 5) Help the person into a sitting position. Prop them up with pillows or raise the bed. Bend knees if possible.
- 6) When they are finished, help the person lay flat. Have them roll to one side (or roll them) off of the bedpan. Put the bedpan on the floor and cover it with a towel.
- 7) Keep the person on their side and wipe the buttocks with toilet paper. Private parts need to be wiped and cleaned separately. For women, wipe front to back to avoid infection.
- 8) If needed, clean with a washcloth, warm water, and soap. Look for skin irritation. Dry washed areas and remove the bed pad.
- 9) Empty the bedpan in a toilet. Fill the bedpan with hot, soapy water. Scrub with the toilet brush. Empty the pan into the toilet again and rinse. Pour five capfuls of bleach into the bed pan. Rinse with hot water. Let dry.
- 10) Throw away the gloves. Wash your hands with soap and water.

 Notes for toileting:

### Bathing and grooming

A bath can be a way for your loved one to exercise and increase blood flow. It also gives you a chance to check for skin problems. The face, hands, and private areas should be washed daily: morning, night, and as needed. Full baths can take a lot of energy and can be given as needed. Taking the time for extra grooming can add to comfort and self-esteem.

**!** **SAFETY NOTE:** Put non-slip mats inside and outside of the bath. Consider using a shower chair and installing grab bars.

## What you can do:

- Give baths when the person has the most energy. Keep baths relaxed and enjoyable. Adjust room temperature before baths.
- Wash the hair another day if the person is easily tired. (If they can't get out of bed, see page 16.) You could use dry shampoos or shampoo caps between washings.
- Getting out for a haircut and style can be a nice boost. Some hairdressers may make house visits. We may have recommendations or you can search for "mobile salons" online.
- Use an electric razor for shaving. Start on the neck and work up.
- Your loved one will probably want to use the tub or shower for as long as possible. But if the person can't move from the bed, you'll have to give a bed bath. See below.

## How to give someone a bed bath:

*You will need...*

- |   |  |
|---|--|
| <input type="checkbox"/> Non-latex medical gloves | <input type="checkbox"/> Washcloths                    |
| <input type="checkbox"/> Sheet or blanket         | <input type="checkbox"/> Baby oil or lotion (optional) |
| <input type="checkbox"/> Basin of warm water      | <input type="checkbox"/> Disposable briefs, if needed  |
| <input type="checkbox"/> Mild soap                | <input type="checkbox"/> Clean clothes                 |
| <input type="checkbox"/> 2 large towels           |  |
- 1) Put on gloves. Close doors/curtains for privacy. Remove soiled clothes and disposable briefs (if using). Cover the person with a blanket.
  - 2) Use warm (not hot) water. Change it often to keep it warm and clean. Use mild soap to keep the skin from drying.
  - 3) Uncover and wash one body part at a time. Place a towel under the part being washed. Rinse and pat dry. Cover each part again before you move to the next one.
  - 4) Start with the face and work down. Skip the private areas and wash the legs. Roll the person to one side to wash the back.

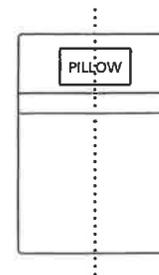
! **SAFETY NOTE:** When rolling a person on their side, put up side rails or stable chairs at the side of the bed. This will prevent a fall. Be sure the chairs do not slide.

- 5) Wash the private area and buttocks last. Remove all body waste.
- 6) Gently massage baby oil or lotion onto the skin if it is dry.
- 7) Put new disposable briefs on the person, if needed. Dress in clean clothes.
- 8) Change the bed sheets if they are soiled. If the person can't get out of bed, see below.

## How to change sheets for a bedbound person:

*You will need...*

- 2 clean, flat sheets (no fitted sheet)
- Bed pads
- Plastic bag or hamper
- Extra blanket, if needed
- Clean pillowcases



- 1) Imagine the bed divided in half lengthwise, like the picture above. Have the person roll onto their side (or roll them) onto one half of the bed.

! **SAFETY NOTE:** When rolling a person on their side, put up side rails or stable chairs at the side of the bed. This will prevent a fall. Be sure the chairs do not slide.

- 2) Untuck the dirty sheet from under the mattress on your side. Roll it lengthwise towards the center of the bed until the roll rests by the person's back.
- 3) Take a clean flat sheet and fold it in half lengthwise. Put it on the bed with the fold running down the center.

- 4) Roll the top half of this sheet to the center of the bed. Tuck the unrolled half of the sheet under the mattress. Smooth out all wrinkles.
- 5) Add a bed pad, if needed. Fold the pad in half, put the fold at the center, and roll the top half to the center.
- 6) Ask the person to lie flat on their back (or roll them) to the center of the bed. They should be laying on top of the rolls.
- 7) Put the opposite side rails up/move the chairs to the other side. Ask the person to roll over (or roll them) to the clean half of the sheets. Remove the dirty sheets completely. Put them in the plastic bag/hamper.
- 8) Unroll the clean bottom sheet (and bed pad, if using) from the center of the bed. Stretch the sheet and smooth out all wrinkles. Tuck the bottom sheet under the mattress.
- 9) Cover the person with the second sheet. Tuck it in, if they prefer. Add an extra blanket if they want one. Change the pillowcases and adjust the pillows.

### How to wash someone's hair in bed:

*You will need...*

- |   |  |
|---|--|
| <input type="checkbox"/> A large trash bag            | <input type="checkbox"/> A plastic cup         |
| <input type="checkbox"/> 5-6 large towels             | <input type="checkbox"/> Mild shampoo          |
| <input type="checkbox"/> 2-gallon basin of warm water | <input type="checkbox"/> Hair dryer (optional) |
| <input type="checkbox"/> A washcloth                  |  |
- 1) Open the trash bag. Roll the sides down until the bag looks like a bowl. Line the inside of the bag with 2 or 3 towels to catch water. This helps keep the bed dry.
  - 2) Cover the pillow with a towel. Roll up another towel and place it under the person's neck.

- 3) Put the trash bag under the head. The rolled towel under the neck should be inside the bag.
- 4) Fold the washcloth in half. Place it over the person's eyes. They may want to hold it in place.
- 5) Use the cup to wet the hair. Keep water off of the person's face. Cover the forehead with your free hand.
- 6) Gently massage shampoo (about the size of a quarter or less) into the hair and scalp. Lift the head gently to massage underneath.
- 7) Rinse with the cup until all traces of shampoo are gone.
- 8) Remove the bag. Carefully unroll it to keep the water inside.
- 9) Dry the hair with a hair dryer or a towel. Remove the towel from the pillow when the hair is dry.



Notes for bathing and grooming:

### Getting dressed

Dressing for the day helps keep routines feeling normal. There could come a time when it may be better to use a hospital gown. But you will want to help the person dress in everyday clothes for as long as possible. Helping the person to get dressed can maintain dignity and boost self-esteem.

- ! **SAFETY NOTE:** Be careful with weak limbs and joints when dressing and undressing.

What you can do:

- Let the person choose outfits, if possible. Give them two or three options to pick from.
- Choose comfortable, loose clothes that are easy to remove. Look for clothes with snaps, zippers, Velcro, and elastic.
- Let the person dress and undress themselves as much as they can. Hand them one item at a time.
- If the person has a weak side, put the clothes on that side first. When undressing, take the clothes off the weak side last.

 Notes for getting dressed:

“Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring...”

— Leo Buscaglia, *Love: What Life Is All About*

## Changes in Behavior

It doesn't happen all the time, but many caregivers struggle when their loved one's personality starts to change. This can happen because of illness, dementia, frustration, or age. Sometimes medications can affect behavior, too.

Someone who used to be loving may turn mean. Someone who was always fussy may get even more difficult. Someone who used to be cheerful may get depressed. It may be hard for you to stay positive. The emotional stress added to caregiving duties can be a lot to handle.

What you can do:

- Check with us first. We will see if the changes are because of medical reasons.
- Understand that anger toward you may really be anger at the situation. Try not to take anger personally.
- Don't downplay the person's feelings. Take time to talk if they are upset. Ask them what's wrong. See what can be adjusted.
- Identify bad-attitude patterns. Are they in a bad mood at night? Do they lash out before meals? Patterns may give clues to what is causing the behavior.
- Clearly state how the behavior makes you feel: “When you (*describe action*), I feel (*state how you feel*), because (*how action affects you*). What I need from you is (*describe behavior you want from the person*).” Saying “I'm sorry” also helps.
- If it's safe to do so, leave the room if you start to lose your temper. Come back when you can talk to the person calmly.
- Call us right away if you feel like you're being abused. You should never have to suffer through abuse. Also reach out if you have thoughts of harming the person.

## Improving Quality of Life

Losing independence is a big loss for many people. For most of our lives, we do things on our own. If we want to eat, we eat. If we want to go somewhere, we get in the car and go. Having this freedom taken away is a huge change. A person may start to feel lonely, “stuck,” or depressed.

Quality of life is how a person feels day to day. It includes physical, emotional, and spiritual wellness. It’s important at every stage of life.

Help your loved one continue doing things they enjoy. Pick activities that are at their skill level. Do some of the activities with them. This could be a good time to bond. Taking small steps to add joy to each day can do a lot to improve quality of life for you both.

What you can do:

- Ask us if there are simple exercises the person can do. Stretches or short walks may be suggested.
- Do things to exercise the brain for as long possible. Read, listen to audiobooks or music, play games, or do puzzles. Write letters, look at family photos, or call loved ones.
- Include the person in tasks around the house, if possible. Ask them if they want to sit close by while you make meals or fold laundry. Some people may even be able to help with easy chores.
- If the person can’t get out of bed, move family time to their room. Plan visits for when the person has the most energy. Watch movies or eat dinner sitting around the bed. Follow their cues to know when to leave and let them rest.
- If your loved one is religious, keep up their faith traditions. If you can’t go to a service, watch one on TV. Pray at home together. Or contact us to see if we have a chaplain on staff who can visit. If your loved one isn’t religious, try meditation.

## Caring for Yourself

Your quality of life is important, too. Many caregivers get overwhelmed with caregiving duties. You may feel like everything you’re doing still isn’t enough. You must take care of yourself to be a good caregiver. It’s hard to take care of someone else when you feel worn out and stressed.

What you can do:

- Keep in touch with family and friends. Ask for their help. Invite them over or talk to them online or on the phone.
- Ask us if respite care is available to give you a short break from caregiving.
- Try to stay positive and keep your sense of humor. Reach out to people who make you happy. Watch an uplifting show or movie.
- Exercise, drink plenty of water, eat well, and get sleep.
- Take each day one step at a time. **Call us if you need help. We’re here for you.**

### Caregiver’s Bill of Rights

I have the right to take care of myself. This is not selfish. It makes me a better caregiver. I do a lot for this person. I can do things just for myself.

I have the right to make a life for myself. I know there may come a time when my loved one no longer needs my full-time help.

I have the right to get help from others even if my loved one doesn’t want me to. I know there are limits to what I can do alone.

I have the right to get angry, be depressed, and express all feelings.

I have the right to not be controlled by my loved one through guilt.

I have the right to receive respect, love, forgiveness, and acceptance from my loved one for what I do. I will offer these things in return.

I have the right to give myself credit for all that I do. It takes courage to be a caregiver.

— Adapted from *Caregiving: Helping an Aging Loved One*, by Jo Horne