

Acute Care

Occupational Therapy

Home Caregiver Resources



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General tips for home caregivers

Encourage your loved one's involvement

Our goal is to help you provide a safe and comfortable living space for your loved one while supporting their independence as much as possible during self-care tasks. We want to encourage their involvement with activities of daily living (eating, dressing, cleaning, etc.), mobility (being able to move around), and meaningful activities as much as possible.

Design spaces and activities with your loved one in mind

Think of activities and items that are meaningful to your loved one, such as watching TV, reading books, listening to music, looking out a window, playing an instrument, painting, playing computer games, or looking at photographs. How can you set up their room to best allow for some of these activities? We know that it may not always be possible, depending on the space. Are there easy changes you can make to the room (such as changing the direction of the bed, bringing in a TV or stereo from another room, putting a table or shelf at the foot of the bed for photos, etc.)?

Expect and adapt to changes

At discharge, we will give you and your loved one some recommendations about the kind of help they currently need, adaptive equipment for activities of daily living, durable medical equipment, etc. However, a person's abilities and needs may change day-to-day, and even throughout each day. Please always put safety first and use your best judgment when making decisions about their care, especially about mobility and any activity that happens out of bed.

Take care of yourself, too

As a caregiver, we also encourage you consider your own self-care for your physical and mental health. There are resources in this guide to help you with

self-care, proper body mechanics (how to move in a way that protects your body and limits injury), and more. There may also be community resources available to you. Please don't hesitate to reach out to your healthcare provider for support.

Setting up your home

Rooms

When possible, choose a room to be your loved one's "home base." Set it up with a comfortable place to sit or a bed. Put any tools and materials that you'll need to use often in the room, as well as activities and items that bring your loved one joy (such as games, photographs, TV, books, music, etc.).

Bed materials

When setting up your loved one's bed, there are a few items you can use to help them with hygiene (staying clean) and mobility (moving around easily).

- **Draw sheet:** This is a flat sheet that will lay under your loved one (from around their shoulders to their knees) and untucked from the mattress. You can use this to help reposition your loved one if they aren't able to change their body position themselves. Typically, you'll need 2 people to reposition them using the draw sheet.
- **Incontinence pads:** These are disposable or reusable pads that will lay directly under your loved one (between their body and the draw sheet). They are easier to change or replace than bed sheets in the case of incontinence (loss of bladder or bowel control), and they can be very helpful for hygiene and skin protection.
- **Bed table:** Think about using a bedside table or lap tray. Try an internet search for "laptop tray" or "laptop table." If your loved one has trouble eating or participating in other tasks out of bed, this will make such activities much easier to complete at bed level.

Equipment

Try to keep materials that you and your loved one will need to use, like these listed below, in a place that's easy to get to. Depending on your loved one's needs, it may be helpful to keep some of the following materials and equipment

near their bedside, or where they will be spending most of their time. See the section on equipment later in this packet for more details on materials and equipment types and uses.

- Bed pan, urinal, or bedside commode
- Incontinence pads
- Plastic bin or “kidney” bin for oral (mouth) hygiene
- Body wipes or towels

Communication systems

Depending on the layout of your home, you may want to think about having a communication system, or a way for your loved one to get in touch with you if they need something. This could be as low-tech as a bell for your loved one to ring, or you could use a walkie-talkie or intercom system if needed. You may also be able to just use your cell phones!

Mobility recommendations

An occupational therapist will give your loved one recommendations for mobility (movement) at or near the time of their discharge. These recommendations will be recorded below. However, a person's needs may change from one day to the next, and they may even change throughout the day. Please continue to check on the needs of the person you're caring for, and reach out to your medical team as you have different needs or concerns. If you notice a change in function or the level of help they need, home occupational therapy or nursing and medical services staff may need to do more evaluation.

Can I do out of bed transfers (moving my loved one out of bed)? Yes No

Do any out of bed transfers and mobility with:

Supervision 1 person helping 2 people helping Mechanical lift
(someone watching)

Gait belt Walker Cane Wheelchair

Other: _____

Do any bed level mobility (rolling, sitting up in bed or on the edge of the bed, etc.) and activities of daily living with:

Supervision 1 person helping 2 people helping _____
(someone watching)

Recommended techniques or tips for transfers:

Where can I eat?

In bed Sitting on the edge of the bed At a table _____
 or in a chair

Where can I do grooming activities (brushing teeth or hair, shaving, doing makeup, etc.)?

In bed Sitting on the edge of the bed In a bathroom _____
 or in a chair

Where can I do toileting activities (peeing and pooping)?

In bed (using pads, Using the bedside In a bathroom _____
briefs, or bed pan) commode

Where can I do bathing activities (showering, taking a bath)?

In bed Sitting on the edge of the bed In a bathroom _____
 or in a chair

Where can I get dressed?

In bed Sitting on the edge of the bed _____
 or in a chair

Activities of daily living

With activities of daily living, the goal is always to support your loved one to be as independent (able to do things on their own) as possible. It is okay to help them, and also to encourage them to participate when possible. Use the tips below to support their independence and safety.

Eating and feeding

- Your loved one will find it easier to participate in eating – and be safer – with proper positioning.
 - Help them sit up as much as possible in bed or in a chair. Make sure they have back support.
 - If your loved one has decreased strength or body coordination issues (like having trouble reaching or holding onto objects), you can use arm supports (such as placing pillows or blankets) under their elbows.
- There are many pieces of equipment, or simple changes that you can make, to make eating and drinking easier for your loved one. Here is a short list of equipment that you could look at to see if it would help. You can also talk with an occupational therapist for more recommendations and problem solving.
 - Cups with handles and lids
 - Straws that bend, or long straws
 - Built-up handles
 - Scoop dishes
 - Partitioned dishware (such as plates with dividers)
 - “Nosey” drinking cups
 - Universal cuffs
 - Suction plates and bowls
 - Flexible utensils

- Use a large napkin or towel on your loved one's chest to protect their clothes and skin from any food or drink.
- Use good lighting so your loved one can see what they are doing.
- If eating in bed, use a lap tray, bed table, or bed desk to practice eating at a regular table as best you can.

Grooming

- Help your loved one sit up in bed or in a chair so they're as upright as possible while grooming. Making sure their torso (stomach area) is supported will make it easier for them to use their arms during grooming tasks, such as brushing and flossing teeth, brushing hair, putting makeup on, etc.
- Use arm support, such as pillows or blankets under their elbows or armrests, to help them save energy and reach needed areas.
- Think about using adaptive and medical equipment to make grooming tasks easier. Your loved one's occupational therapist can recommend specific equipment based on their needs. Here is a short list of items that could be helpful:
 - Grooming tools with a large grip (or adding built-up handles to a toothbrush, brush, etc.)
 - Grooming tools with long handles (or using everyday materials to make handles longer)
 - Portable mirror
 - Tray table
 - Basin
- Make sure the room has good lighting.
- Place all items within their arm's reach (consider using a tray or lap table).

Toileting

- If your loved one has issues with incontinence (leaking pee or poop), here are supplies that can help:
 - You can buy incontinence pads online or from a medical supply store. These are useful in bed to protect sheets and skin.
 - You can use briefs (such as Depend®) for out-of-bed tasks or for trips outside the home. Avoid having your loved one wear a brief in bed or for longer than 2 hours, as this can cause issues with their skin.
- If your loved one experiences some incontinence, do hygiene checks (looking to see if they've had incontinence) every 2 hours. Read the "Pressure relief and skin protection" section for more information.
- Sometimes setting a schedule for toileting - called "timed toileting" - can reduce incontinence. For example, have your loved one use their preferred toileting equipment every 2-3 hours during the day, even if they don't think they need to. Providing opportunities for toileting can help your loved one get on a schedule.
- Here is some toileting equipment your loved one might use, and suggestions for how to use it:
 - **Bed pan:** Have your loved one roll to one side for placement and removal of the bed pan. You can use an incontinence pad under or even over the bed pan to protect the bed and your loved one's skin.
 - **Urinal:** You can use a urinal at bed level or chair level. There are urinals for all genders. However, bed pans may be easier for people without penises to use who are peeing at bed level.
 - **Bedside commode:** Only use a bedside commode if your therapist has recommended this. Complete the transfer to the commode using the techniques your therapist taught you. If your loved one is unable to transfer to the commode, use the other techniques described (briefs, pads, pans, or urinals) for toileting.

- Use toilet wipes or baby wipes to keep your loved one clean, if needed.
- When toileting in bed, have your loved one roll to the side and replace their incontinence pads as needed.
 - To replace a pad at bed level, roll and tuck the used pad underneath your loved one while they are rolled to one side. Roll out the new pad halfway and tuck it underneath the soiled pad that you just tucked. Have your loved one roll to the opposite side to remove the soiled pad and fully roll out the new pad.
- If you are helping your loved one clean themselves after using the commode, use the mobility recommendations from your therapist (written in the “Mobility recommendations” section).

Dressing

- If your loved one has limited mobility and it is hard for them to stand to put on their pants, consider putting on pants while they are lying in bed.
 - Have them roll side-to-side (or help them roll) to pull their pants up over their butt.
 - You can also have them bridge (bend their knees with their feet flat on the bed and lift their butt off the bed) if they are able to.
- When helping your loved one, keep them as close to you as possible to avoid reaching too far and to protect your back. If possible, raise the height of the bed or sit down to get yourself or them in a better position. See the “Transfers and mobility” section for more guidance on safe movement.
- Have your loved one wear loose-fitting and stretching clothing. This will be more comfortable and easier to take on and off.
- If regular clothes are hard for you or your loved one, consider getting adaptive clothing or specialty gowns.
 - Lots of adaptive clothing is available to buy online (such as open back tops, seat-less pants, or clothing with Velcro® or magnet

closures). Some people have friends or family with sewing skills who can change their clothes to add Velcro®, snaps, zippers, etc.

- You can buy hospital style gowns online (you can also use the search terms “labor and delivery gown”). They are often available in many different styles, fabrics, and colors. You can also try “open back gown” or “adaptive gown” when searching online.

Bathing

- If you are doing bed level bathing, set up all your materials before you start (including a plastic basin or bucket, washcloths, plenty of towels, and rinse-less soap). Have a table at their bedside so everything is in reach.
 - Let your loved one do as much of the bathing themselves as they can. You can use pillows or blankets as support under their elbows if they have trouble reaching their face.
 - You might want to have another person help you with rolling or moving your loved one to clean their back, butt, and genitals area.
- If your loved one is showering, you might want to use a shower chair or a tub bench (depending on your home set-up and your loved one’s current abilities). Shower wheelchairs are another possibility, but they can be harder to find and don’t work in all showers. Your occupational therapist in the hospital may give you some basic equipment recommendations.
 - An occupational therapist or another home health provider may also be able to do a home safety evaluation to give you equipment recommendations.
- At discharge, your occupational therapist may give you recommendations about either bathing at bed or chair level or showering. Due to the risk of falls and difficulty of bathing in a shower, you may need to have a skilled provider help your loved one in the shower (instead of a family member or friend helping).

Transfers and mobility

When repositioning your loved one in bed or helping them to get out of bed, be aware of your own body position to avoid hurting yourself. Follow the tips below and get more advice from an occupational or physical therapist.

- Let your loved one to do as much of the work while moving as possible. This not only reduces your effort, but also helps them to be more independent.
- Lift using your legs (not your back) and keep your legs shoulder-width apart.
- Keep your back straight and your knees slightly bent to avoid locking your knees when lifting or moving someone.
- Tighten your stomach muscles to protect your back from taking on too much strain.
- If possible, raise the height of the bed to be at waist level when doing bed mobility.
- Keep your loved one - or whatever you are lifting - as close to your body as possible. If possible, lower the bed rails or remove other items you typically would have to reach over.
- Try to avoid twisting your spine. Use your legs to turn or pivot as needed.
- Have another person help you if you need to, or if you have any concerns about being able to reposition your loved one on your own.
- Keep the room (or workspace, floor, etc.) free of clutter, cords, and other obstacles.
- Use equipment (draw sheets, gait belts, adjustable beds or chairs, etc.) to reduce your effort and to keep you and your loved one safe.
- When rolling your loved one in bed, roll them toward you (not away from you).
- Before rolling them, have your loved one bend one or both knees. This will make it easier to roll them.

- Before doing any transfers out of a bed or chair, be sure that all equipment is locked in place (like wheelchair or bed brakes) or stabilized (make sure items like bedside commodes are sturdy on all legs and won't tip).

Pressure relief and skin protection

Pressure relief

If your loved one has difficulty or is unable to reposition themselves, be sure to change their sitting or lying position regularly to prevent **pressure wounds** (also known as **bed sores**). This can be as simple as helping them roll from one side to another and using a pillow for support, or raising and lowering the head of their bed to change the pressure on their butt. If they are able to get in and out of bed, help them spend time out of bed during the day as they're able.

Skin checks

Be sure to check your loved one's skin for signs of pressure wounds. Remember that they may not be able to tell you if they're in discomfort or pain, so it is up to you to look at their skin every day. Look for:

- Color changes or marks on the skin (impressions or indentations) that don't go away after about 10 minutes
- Color or texture changes
 - Depending on their skin tone, skin that is developing a pressure wound may look red, blue, purple, or darker than usual. Skin may also look shiny or feel harder than the area around it.
- Swelling
- Broken skin (skin that is scraped, torn, cut, punctured, bleeding, etc.)
- Areas of skin that feel colder or warmer than the rest of their body
- Skin tenderness or pain

Keep in mind that pressure wounds usually start under the skin, in the deeper layers of tissue. If you think a pressure wound is starting, do not wait for visible signs. **Report any skin or pressure wound concerns to your care team.**

Skin hygiene (cleanliness)

Keeping your loved one's skin, clothing, and bedding clean is a great way to protect their skin and reduce the risk of infection. Bathing and changing or checking the bedding every day also gives you a good opportunity to do skin checks and to make sure there are no items (including food crumbs, extra clothing, etc.) laying under your loved one.

- If your loved one experiences incontinence, you may need to do skin and hygiene checks more often, as incontinence highly increases the risk of skin damage.

Useful equipment

Here is a list of equipment or materials that may make things easier while you care for your loved one. You can buy most of these items online (such as through Wal-Mart or Amazon), at a medical supply store, or at a standard pharmacy or drug store.

- Draw sheet (you can buy this or use a flat bed sheet)
- Incontinence pads*
- Briefs*
- Urinal*
- Bed pan*
- Kidney bin*
- Pink or grey bucket*
- Reusable cup with straw
- Gait belt*
- Bed table, bed desk, or lap table
- Baby wipes*
- Hospital gowns (also called “labor and delivery” gowns)
- No-rinse soap*
- Communication system (such as a baby monitor, cell phone, walkie-talkie, or intercom system)

*These items may also be present in your loved one’s hospital room. You can take home any of these items that have been used or opened from the hospital room.

Bathroom equipment

Here are some examples of bathroom equipment, so you have a better understanding of the types of products that we may recommend or that may be useful for you and your loved one:

Toilet safety frame



Raised toilet seat with arms



Bedside commode



Shower seats



Tub transfer bench



Caregiver burnout

Becoming a caregiver for a loved one can be a challenging change for everyone involved. We've included some practical ideas below to make the job of caregiving just a little easier. Don't feel the need to do everything on this list - just use what works for you!

- Continue participating in other hobbies and activities. Keeping your social connections and interests is so important for both your physical and mental health. The healthier you are, the better you will be able to care for your loved one.
- Make a list of questions to bring to medical appointments. This way, you will feel prepared for appointments rather than overwhelmed.
- Prepare meals on weekends or slow days (when you don't have a lot of things to do) to make your busy weeks a little easier. Leftovers or frozen meals are just as good as fresh meals!
- Use a daily pill organizer to keep track of your loved one's medications. This makes it easier on busy days or days with strange schedules.
- Teach other family members and friends about your loved one's needs. They may be able to help you with some caregiving duties so you can have some personal time.
- Encourage your loved one to be independent - if they can do something, let them! It may be harder for them or take more time, but it will help them to be more independent and reduce your stress.

Respite care and other resources

Respite care may be available to your loved one (this could be planned respite care or care in an emergency) to give you a short break as a caregiver. There are often community-based organizations that provide these services or resources. Search online for services in your area or use the ARCH National Respite Network and Resource Center website as a starting point: archrespite.org

The American Occupational Therapy Association (AOTA) has a great collection of links, handouts, and resources that can support caregivers with self-care and the care of their loved ones. Visit this website to read their Caregiver Toolkit:
www.aota.org/About-Occupational-Therapy/Patients-Clients/Caregivers.aspx

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Authors: Maggie Sutherland, OTR/L, Kristina Smith, COTA/L
Reviewer: Melissa Williams, OTR/L
Edited by: Brittany Batell, MPH MSW CHES®

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