CAREGIVING DURING TREATMENT

Visit <u>www.LLS.org/CaregiverWorkbook</u> to access all chapters and worksheets.

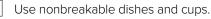
Preparing the Home. During and after cancer treatment, your loved one may find life at home becomes increasingly challenging. Make changes to the home that will make life easier and safer if your loved one is experiencing mobility issues, peripheral neuropathy, pain and/or weakness after treatment.

Home Changes Checklist. Check off the changes as you implement them around the home to make it more comfortable and safer for a patient who will be undergoing cancer treatment.

- Put items in easy-to-reach places. For example, put clothing in baskets or drawers instead of on high shelves or in closets.
 - Lower the patient's bed or get a step stool to make getting into and out of bed easier.
- Keep stairs and hallways well lit.
- Get rid of slippery rugs that can slide or bunch up causing a tripping hazard.
- Add a shower seat and hand-held showerhead to make bathing easier.

Use nonslip bath mats, both in and outside the tub/shower. Add a safety bar or hand grips to reduce the risk of falls.

Find a raised toilet seat or commode.



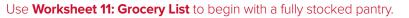
Depending on your loved one's diagnosis, treatment, and health, you may need professional help to make larger or structural changes to his or her home. For example, if your loved one is wheelchair bound, you will need to add a ramp to the entrance of the home. You may also need to widen doorways and install handrails in some locations.

Other Things You Can Do to Prepare the Home. Follow these tips to prepare your loved one's home.

Stock the pantry, fridge, and freezer with healthy food choices.

Move comfortable, easy-to-wear clothing to the front of the closet.

Keep throw blankets and extra quilts in an accessible location. Cancer patients can be more susceptible to cold.



FACT

Peripheral neuropathy results from damage to the nerves in the arms, legs, hands or feet which can cause numbness, tingling, burning, coldness or weakness in the affected area. It can be a side effect of some cancer treatments. Peripheral neuropathy can also lead to mobility issues. **Protecting a Weakened Immune System.** Cancer patients, especially those undergoing chemotherapy or a stem cell transplantation, are at higher risk for infection than healthy people because their immune systems are weaker. A patient with a weakened immune system who catches a cold or develops an infection, will have a much more difficult time fighting it off.

The following tips can help you and your loved one avoid infections:

- Avoid crowds and friends or family members who are sick.
- Wear a mask in crowds or in an emergency room waiting area.
- Make sure to alert the emergency room staff that your loved one is a cancer patient with a compromised immune system.
- Clean cuts and scrapes immediately. Rinse the wound under running water. Wash the skin around the wound with soap. To avoid irritation, do not use soap on the wound. Remove any debris in the wound with tweezers that have been cleaned with alcohol. If the wound is serious or if debris cannot be removed, see a doctor. If the patient has a low platelet count and is at risk for bleeding issues, ask the healthcare team to explain how to care for cuts in the correct way.
- Avoid activities that put the patient at risk for cuts or injury.
- Practice good hygiene and personal care.
- Practice good food safety.
- Ask the healthcare team which vaccines or boosters the patient needs.
- The caregiver and other people living in the home with the patient should get a flu shot and updated vaccines, if needed, too.
- When they get the flu vaccine, cancer patients, caregivers and the other people living in the home who have contact with the patient should receive the flu shot, which is made from the dead virus. They must not get the nasal spray vaccine because the spray contains the live flu virus. The live virus can be dangerous for immunosuppressed patients.
- Anyone who has received a live vaccine should not be near the patient for a period of time.
- Properly care for and clean the patient's central line or port.

Contact the healthcare team immediately if you notice any of the following signs and/or symptoms of infection:

- A fever of 100.4°F or higher
- O Chills
- Persistent coughing
- Tenderness at a site prone to infection, such as the area around the anus or the nasal sinuses
- A sore throat
- Pain when urinating
- Frequent diarrhea or loose bowel movements.

Read Hygiene and Personal Care on page 4.



Use Worksheet 9: Immunization Record.

Cleaning the Home. You may need to help to keep the house clean. A clean home lowers the risk of infection for the patient.

Cleaning Safety. Many household cleaners contain toxic ingredients. Always follow the directions on the product's bottle or box. Cleaners that aren't properly wiped or washed away could irritate the skin or be accidentally ingested. Strong fumes can irritate the eyes and make breathing difficult. Patients undergoing chemotherapy may also be sensitive to the strong smells of cleaning products.

If your loved one receives chemotherapy or other drug therapy, the drugs will leave his or her body through urine, bowel movements and vomit, if vomiting occurs. When you clean the toilet or wipe up bodily fluids, wear disposable gloves to protect yourself from exposure to the drugs. Dispose of gloves, sponges, or paper towels that come into contact with bodily fluids in two sealed plastic bags. Wash clothing and linens that come into contact with bodily fluids separately from other laundry.

You don't have to spend a lot of money for safe cleaning supplies. Vinegar and baking soda are nontoxic items that most of us already have in our homes, and they make effective and affordable cleaners. Mix baking soda and water into a paste to clean the oven and tackle toilet stains. Clean and shine mirrors, windows and floors with a vinegar and water mixture. Make your own safe, green cleaner with ½ cup vinegar, ¼ cup baking soda, and ½ gallon of water.

The following cleaning tips will help to keep you and your loved one safe:

- Avoid products with chlorine, ammonia, synthetic solvents and artificial fragrances and dyes.
- Use fragrance-free laundry detergent.
- Avoid aerosol cans.
- Wear gloves when cleaning.
- Open windows and doors while cleaning or run a fan to let out strong fumes from cleaning products.
- Do not mix bleach with ammonia or vinegar. This can produce deadly gases.
- Instead of aerosol air fresheners, use oils or wax warmers instead.
 - If the patient is sensitive to smells or if strong odors trigger nausea, it may be best not to use any type of air freshener.

Chore Chart. To stay on top of household chores, make a cleaning schedule. It's easier to clean a little bit every day than it is to try to clean a whole house in a few hours. Here is an example of a chore chart to keep you on task.

	Done	Chore
Monday	~	Take out the trash
	~	Wipe down bathroom counters
	~	Clean bathroom mirror
Tuesday	~	Water the plants
	~	Laundry
		Vacuum living room

Use Worksheet 12: Chore Chart to create your cleaning schedule.

If there are other people living in your household who can help, delegate chores to them as well. Hang the chart on your refrigerator as a reminder.

If financially possible, hire a maid service to clean the home. Even if a regular house cleaner isn't an option, it may be helpful to have the house cleaned thoroughly before treatment starts so that all that you will need to do is light cleaning, as needed. If you can't afford a cleaning service, look for free or discounted cleaning services for cancer patients, or ask friends and family to help.

Make sure that anyone helping to clean knows all the safety "dos" and "don'ts" listed on in *Cleaning Safety* on *page 3*. You may want them to use your cleaning supplies rather than letting cleaners bring their own preferred cleaning products into the patient's home.

Septic Tanks. If your loved one receives chemotherapy or some other drug therapy, you may need to take special precautions to care for the home's septic tank. After drug therapy, your loved one's body will expel the drugs naturally when he or she uses the bathroom. These drugs will then collect in the septic tank along with the rest of the sewage. Septic tanks rely on "good" bacteria to breakdown waste. Strong medications, such as the drugs used in cancer treatment, can kill these good bacteria so that the septic system is less able to manage waste. This can lead to sewage backups or even system failures. Plan to have the septic tank pumped soon after treatment ends. Consider using a product to boost the number of good bacteria in the septic tank. Call your septic service provider to discuss the best way to maintain your septic system.

Hygiene and Personal Care. Immaculate hygiene and personal care helps to lower the risk of infection in immunosuppressed patients.

As a caregiver, wash your hands with soap and warm water frequently, especially before handling food or assisting your loved one with any tasks. Encourage visitors to the home or people interacting with the patient to do the same. You can also use either liquid or gel hand sanitizer to keep hands clean.

Your loved one may also need to modify his or her hygiene habits. Here are guidelines to share with your loved one.

Skin Care. Caring for the skin can lower the risk of infection from minor cuts and scrapes. Encourage your loved one to

- Take a warm (not hot) bath or shower every day with unscented soap or bodywash.
- Pat skin dry instead of rubbing with a towel.
- Use unscented lotion for dry skin to prevent cracking.
- Use lip balm for dry or chapped lips.
- Use an electric shaver instead of a razor to prevent cuts and reduce the risk of infection.
- Avoid direct sunlight. Use a broad-spectrum sunscreen with SPF 30 or higher and reapply every 2 hours.

Nail Care. Taking proper care of fingernails and toenails can lower the risk of infection from minor wounds or cuts around the nails or cuticles. Advise your loved one to

- Keep nails clean, dry and short because nails may darken, crack or become brittle as a result of treatment.
- Avoid manicures, pedicures, and artificial nails.
- Avoid picking or pulling at cuticles or loose skin around the nails.
- Soaking hands in natural oils, such as olive oil, may be helpful.
- Wear comfortable, loose-fitting shoes with cushioned cotton socks.

Hair Care. Hair loss is a common side effect of cancer treatment. Hair loss is upsetting and can affect your loved one's self-confidence. Be sensitive to these feelings. Avoid saying things such as "it's just hair," "it will grow back," or "you look better with short hair." Although these comments are all well-intentioned, they can undermine the patient's valid feelings. If your loved one is dealing with hair loss, encourage him or her to

- Wash the hair and scalp every 2-4 days with a fragrance-free shampoo and conditioner. Rinse well and pat dry with soft towel.
- Continue to comb his or her hair, even if hair loss begins.
- Use hats, scarves, caps, or bandanas to keep the head warm and to protect the delicate scalp from sunburns when outdoors.
- Use mineral oil or coconut oil to moisturize the scalp, if dry.
- Consider purchasing a wig; match it to a lock of hair.
- Consider shaving his or her head or getting a short haircut before treatment begins.
- Avoid perms, chemical relaxers, permanent hair dyes and bleach which may damage hair and irritate the scalp.
- Do not put hair in tight braids, cornrows or pony tails which can cause breakage. Do not use clips or ties that hold the hair tightly.
- Use a makeup pencil to draw on eyebrows, if desired.

TIP:

Homemade Mouthwash Recipe Mix ¼ teaspoon of baking soda and ⅓ teaspoon of salt in a cup of warm water.

Dental and Mouth Care. When treatment is not urgent, patients should visit a dentist at least 4 weeks before treatment starts. A pretreatment oral evaluation will identify problems, such as cavities, fractured teeth, loose crowns or fillings, or gum disease.

To address these problems and reduce the risk of complications during treatment patients should

- Use a toothbrush with soft bristles to brush teeth and gums two to three times a day.
- Rinse the mouth several times a day.
- Avoid using a mouthwash that contains alcohol (especially if the patient is experiencing sore mouth as a side effect of treatment). Alcohol makes a sore mouth worse.
- Clean dentures well and remove them when not eating to ease the discomfort of a sore mouth.
- Tell the healthcare team about bleeding gums or white patches in the mouth. Both can be signs of infection.
- Avoid tobacco use, which also irritates the mouth.
 - \odot Visit www.smokefree.gov for smoking and tobacco cessation resources.

Bisphosphonate Treatment and Dental Health. Bisphosphonates are drugs that prevent or minimize bone loss that are sometimes prescribed to blood cancer patients. Bisphosphonate treatment can cause a rare but serious side effect called "osteonecrosis of the jaw (ONJ)." Osteonecrosis of the jaw causes part of the jaw bone to die, which can lead to pain, open sores, risk of tooth loss and abcesses. Patients should have a dental checkup before starting treatment with this class of drugs and address any dental problems before treatment begins. Doctors will stop the bisphosphonate treatment if ONJ occurs.



For more information about dental and oral complications of cancer treatment, visit www.LLS.org/booklets to view, print or order the free LLS booklet *Dental and Oral Complications* of *Cancer Treatment Facts*. **Sleep.** Difficulty sleeping or insomnia can be a side effect of cancer or its treatment, but sleep is an important part of recovery and allows the body to heal. The following tips can help your loved one to maintain a good sleep schedule:

- Create a relaxing sleeping environment.
 - Provide comfortable bedding.
 - \odot Turn off lights, TV and electronics when it is time for bed.
 - O Silence cell phones.
 - \odot Try a fan or a white-noise machine to drown out distracting sounds.
- Set your loved one up to sleep through the night.
 - Go to bed and wake up at the same time each day.
 - Limit daytime naps to no more than 30 minutes.
 - \odot Use the restroom right before going to bed.
 - Avoid caffeine before bed.

Pets. Talk to the healthcare team about any pets in the patient's home. Being around animals, including pets, may increase the risk of infection for your loved one. You may need to take special precautions to reduce this risk.

While your loved one is going through cancer treatment, follow these basic guidelines:

- Clean up after pets for your loved one by cleaning the litter box or changing dog pads. If the pet has an accident, be sure to disinfect the area. Wash your hands well afterwards.
- Keep litter boxes away from the kitchen and dining room.
- If the pet is sick—is vomiting, has diarrhea, or is sneezing—take the pet to the vet right away. The pet may have an infection that could be passed on to your loved one (who may have a weakened immune system).
- Avoid scratches. Keep the dog's or cat's nails trimmed to minimize the risk of scratches. If your loved one does get scratched, clean the scratches well and check frequently for signs and/or symptoms of infection. Let the healthcare team know about scratches.
- Keep pets up-to-date on vaccines and heartworm prevention and use flea and tick medications and shampoo on pets to reduce the risk of the diseases parasites carry.
- Do not adopt new pets or take in strays during cancer treatment since the animal's health status is unknown.
- Avoid reptiles, chickens, ducks, and rodents, all of which can carry salmonella and other germs that may cause infection. Salmonella can lead to severe diarrhea, which can be especially dangerous for cancer patients.
- Find a good pet sitter. If your loved one has to spend time at the hospital for surgery or treatment and you are not available, make sure there is a reliable pet sitter lined up to take care of the pet.

As long as you are communicating with the healthcare team and are taking the appropriate measures to reduce the risk of infection, pets can often stay by your loved one's side during cancer treatment. Pets can offer benefits, too. Patients' pets provide companionship, improve their mood, and motivate them to stay active.

Caregiving During Treatment Notes

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