Visit www.LLS.org/FamilyWorkbook to access all chapters and worksheets.



Once your child returns home from the hospital, there may be things you can do to make your child safer and more comfortable at home.

CARING FOR YOUR CHILD DURING TREATMENT

Preparing Your Home. Use this checklist to prepare your home. If you do not have time to prepare because your child starts treatment immediately after diagnosis, reach out to family members and friends to help you and provide them with specific instructions.

Move comfortable, easy-to-wear clothing to the front of your child's closet. If your child may lose their ha	ir
during treatment, find warm caps, hats and scarves to use to keep the head warm and protect the scalp	from
the sun.	

Keep throw blankets and extra quilts in an accessible location. Childre	en in cancer treatment may be more
susceptible to cold.	

If your child showers instead of taking a bath, use a nonslip bath mat, both in and outside the tub/shower. Add a safety bar or handle grips to reduce the risk of falls.

Add a shower seat and a handheld showerhead to make bathing easier, if needed.

Keep stairs and hallways well lit.

Get rid of slippery rugs that can slide or bunch up and cause a tripping hazard.

Find a safe place to keep medications so that none of the children in your home will be able to access them.

If financially possible, hire a maid service to clean your 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. Friends and family members may also be happy to volunteer to help with deep cleaning. (See *Cleaning the Home* on page 3.)

Buy disposable gloves.

Use nonbreakable dishes and cups.

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



Use Worksheet 11: Grocery List to begin with a fully stocked pantry.



LLS Health Manager™ App. With *LLS Health Manager™*, you can use your phone to manage your child's daily health by tracking side effects, medication, food and hydration, questions for the doctor, grocery lists and more. You can also set up reminders to take medications and to eat/drink throughout the day. Visit **www.LLS.org/HealthManager** to download.

Protecting a Weakened Immune System. Children in cancer treatment, especially those undergoing chemotherapy or a stem cell transplantation, are at higher risk for infection. White blood cells help fight infection and disease in the body. Blood cancers and cancer treatment can decrease the number of healthy white blood cells, making the immune system weaker. A child with a weakened immune system who catches a cold or virus or develops an infection will have a much more difficult time fighting it off. Talk to the healthcare team about ways to reduce risk of exposure.

The following tips can help you and your child avoid infections:

- Avoid friends or family members who are sick, including people who have a fever, runny nose, cough, diarrhea or rash.
- Avoid crowds of people. If you are leaving the house to go to a store, the movies or other location where crowds may be present, try to go on off hours when it's less crowded.
- Wear a mask in crowds and in an emergency room waiting area.
- Make sure to alert the emergency room staff that your child is a cancer patient and has a compromised immune system.
- Ask the healthcare team which vaccines or boosters your child needs. See Flu Shot and Immunizations on page 3.
- If your child (or siblings) attends school or day care, ask teachers and staff members to alert you if your child may have been exposed to chicken pox, shingles, pink eye, strep throat, lice or other illnesses. If your child has been exposed to chicken pox or shingles, alert the healthcare team immediately. Your child may need to be admitted to the hospital. Even if your child

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If someone in the home smokes, ask members of the healthcare team what precautions to take to protect your child from secondhand smoke. Talk to members of the healthcare team about the best way to bring up smoking cessation with persons who smoke. Visit www.smokefree.gov for resources.

received the chicken pox vaccine, chemotherapy may have decreased your child's immunity to the virus.

- If your children attend different schools, make sure that all teachers and staff know to alert you to possible exposure. If siblings have been exposed to illness, they may pass on the illness to their sibling at home.
- Talk to your child's teachers or school administrators about ways to reduce infection in the classroom, such as frequent handwashing, using gel or liquid hand sanitizers and wiping down desks and school supplies with disinfecting wipes.
- Make sure any person caring for your child, such as a teacher or a babysitter, has your correct phone number and the phone numbers of other emergency contacts. Give the people caring for your child a list of the reasons that they may need to call you and/or the healthcare team (for example, if your child has a fever or other signs or symptoms of infection). You can ask your child's healthcare team to help you make a list.
- O 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. If the wound is serious or if debris cannot be removed, see a doctor. If your child 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 your child at risk for cuts, injuries or falls.
- Take appropriate precautions around pets and animals. See **Pets** on page 8.
- Practice good hygiene and personal care. See Hygiene and Personal Care on page 5.
- Practice good food safety. Remind your child not to share utensils, drinks or take bites from anyone else's food.
- Properly care for and clean your child's central line or port, as instructed by the healthcare team.
- Regularly disinfect frequently touched items in the home including remotes, tablets, phones, faucets, light switches, doorknobs and railings.

- Do not undertake major home renovations during your child's cancer treatment. Talk to your child's healthcare team before any renovations are started.
- Do not let your child be near freshly laid mulch or play in piles of leaves or hay and limit time around campfires.

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
- Redness, swelling, tenderness or discharge from any cut, scrape or insertion site
- A sore throat
- Pain when urinating
- Frequent diarrhea or loose bowel movements

Flu Shot and Immunizations. Talk to your child's treatment team about what vaccines are recommended for your child. During cancer treatment, your child may need to delay getting certain vaccines. Some vaccines may need to be repeated or your child may need an additional booster.

Flu Shot. An annual flu shot is recommended for all children older than 6 months, even children receiving cancer treatment. Your child should receive the flu shot, which is made from the dead virus. Your child must not be given the nasal spray vaccine because the spray contains the live flu virus. The live virus can be dangerous for immunosuppressed patients.

Everyone in your home and people who spend time with your child should also receive the flu shot, **not the nasal spray vaccine.** By protecting everyone in your home from the flu, you further protect your child who has cancer. Ask the healthcare team what precautions you should take if someone in the home does receive a live vaccine or will not get the flu shot.

COVID-19 Vaccine. Talk to your child's healthcare team about the COVID-19 vaccine. Children who have a weakened immune system are more likely to have complications due to COVID-19. Everyone in your home and people who spend time with your child should receive the COVID-19 vaccine. By protecting everyone in your home from COVID-19, you further protect your child who has cancer.

Siblings. Siblings and other people in your home should continue to receive all their regularly scheduled vaccinations. However, tell the healthcare team if anyone will be receiving a live vaccine. Vaccines that contain a live virus include MMR (measles, mumps, and rubella), varicella (chicken pox) and the flu nasal spray. Ask what precautions you should take to protect your child with cancer.

Cleaning the Home. A clean home lowers the risk of infection for your child.

Cleaning Safety. Many household cleaners contain toxic ingredients. Always follow the directions on the product's bottle or box. Cleaners that aren't properly



Women who are pregnant should take extra precautions when caring for a child who is receiving chemotherapy. Let your child's healthcare team know if you are pregnant so they can give you instructions for the precautions you should be taking.

wiped or washed away could irritate the skin or be accidentally ingested. Strong fumes can irritate the eyes and make breathing difficult. Children undergoing chemotherapy may also be sensitive to the strong smells of cleaning products. Keep all cleaning products out of reach of children.

If your child is receiving chemotherapy or some other drug therapy, the drugs will leave their body through urine, bowel movements and vomit. (See *Septic Tanks* on page 4.) When you clean the toilet, change diapers 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 you may already have in your home, 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 of vinegar, ¼ cup of baking soda, and a ½ gallon of water.

The following tips will help to keep you (and your child) safe when you are cleaning your home:

- Avoid products with chlorine, ammonia, synthetic solvents and artificial fragrances and dyes.
- 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.
 - Keep warmers out of reach of children.
 - If your child is sensitive to smells or if strong odors trigger nausea, it may be best not to use any type of air freshener.
- Use unscented, gentle laundry detergent. Some detergents can irritate sensitive skin.

Septic Tanks. If your child 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 child's body will expel the drugs when using the bathroom. These drugs will collect in the septic tank along with the rest of the sewage. Septic tanks rely on "good" bacteria to break down 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 your child's 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.

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.

Make sure that anyone helping to clean knows all the safety "dos" and "don'ts" listed in the previous section.

Cleaning Toys. Cleaning toys can help reduce the risk of illness and infection. Clean toys:

- After your child (or someone in your home) has been ill
- After a playdate with other children
- If toys come into contact with bodily fluids, such as spit or vomit
- If there is visible dirt or grime on toys

Here are some suggestions for cleaning toys:

- Plastic toys can be washed with warm water and soap. You can also wash plastic toys in the top rack of the dishwasher. Or, spray toys with a mixture of equal parts of water and vinegar and wipe clean.
- For a more thorough cleaning, you can also soak plastic toys in a mixture of 1 tablespoon of bleach to 1 gallon of water. Rinse the toys and allow them to air dry.
- You can put most stuffed animals and plush toys in the washing machine. Check the tags for any special care instructions first.
- Sterilize pacifiers before the first use and after your child or anyone in your home has been ill. To sterilize, place them in a pot of boiling water for 5 minutes. Allow them to air dry and cool before giving them to your child. On a daily basis, washing with warm water and soap is sufficient.
- Be careful with electronic toys and toys with batteries. Wipe these toys clean, avoiding the batteries and electronic parts.
- Do not soak wood toys in water. Water can cause warping; wipe wood toys clean.

Hygiene and Personal Care. Good hygiene and personal care help to lower the risk of infection in immunosuppressed children, such as those receiving cancer treatment.

Wash your hands with soap and warm water frequently. Your child should also wash their hands frequently, especially before eating, after the using the bathroom, after playing with other children or pets or playing outside. Encourage other people in your home and anybody else who interacts with your child to do the same. You can also use either liquid or gel hand sanitizer to keep hands clean.

Your child may also need to modify their hygiene habits. Depending on your child's age and how well they are feeling, you either may or may not need to help them with hygiene and personal care. You may only need to help with certain tasks. Follow these guidelines and/or share them with your child.

Skin Care. Caring for the skin can lower the risk of infection from minor cuts and scrapes. To care for the skin:

- Take a warm (not hot) bath or shower every day with unscented soap or body wash.
 - Check the water temperature to prevent scalding.
 - Children under 1 year of age do not need a bath every day. Three baths a week may be enough. Bathing can dry out an infant's sensitive skin.
 - Never leave an infant or toddler alone in a bath.

TIP: Favorite toys that your

child plays with every day may need to be cleaned often. Bath toys should be cleaned once a week to prevent mold. Other toys do not need to be cleaned as frequently.

TIP:

Teach your children to wash their hands with warm water and soap for 20 seconds by counting to 20 slowly or singing the ABCs.

- 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.
- Avoid direct sunlight. The American Academy of Dermatology recommends the use of a broad-spectrum, waterresistant sunscreen with a sun protection factor (SPF) of 30 or higher for all children older than 6 months. Reapply every 2 hours.
 - \odot For children under 6 months, ask members of the healthcare team about methods of sun protection.
- If your child is old enough to shave, provide an electric shaver instead of a razor to prevent cuts and reduce the risk of infection.
 - Remind your child that using cologne or body spray immediately after shaving can sting and irritate the skin.

Hair Care. Hair loss is a common side effect of cancer treatment. Hair loss is upsetting and can affect your child's selfconfidence. Be sensitive to these feelings. To care for your child's hair:

- Wash the hair and scalp every 2 to 4 days with fragrance-free shampoo and conditioner. Rinse well and pat dry with a soft towel.
- Continue to comb 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 shaving the head or getting a short haircut before treatment begins if hair loss is a likely side effect of treatment.
- 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.

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. To care for your child's nails:

- Keep nails clean, dry and short because nails may darken, crack or become brittle as a result of treatment.
- Do not allow your child to bite their nails.
- 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.
- Ask members of the healthcare team about wearing nail polish. Nail polish can help strengthen and may protect nails. However, if your child is an inpatient, the healthcare team may prefer to be able to see your child's nail beds to check blood circulation. To take off polish, use an oily remover to prevent drying.
- To protect toenails, have your child wear comfortable, loose-fitting shoes with cushioned socks.

Dental and Mouth Care. Teach your child good mouth and dental care.

- If possible, take your child to the dentist before treatment begins in case they need any dental work done.
- Before beginning any dental work, clear it with the members of the child's cancer healthcare team first. Dental
 work may not be safe for your child during cancer treatment or extra precautions may be needed if dental work is
 necessary, especially if blood cell counts are low.
- Braces may need to be removed before treatment to reduce the risk of infection.

- Teach your child to brush their teeth twice a day using toothpaste and a toothbrush with soft bristles. Brush for 2 minutes and make sure to brush every tooth. You may need to help with dental care until your child can manage it alone.
- Ask your child's doctor if it is okay for your child to floss. If your child's platelet counts are low, flossing may increase the risk of bleeding. If your child's white blood cell count is low, flossing may increase the risk of infection. If the doctor approves, your child's teeth can be gently flossed every day.
- Rinse your child's mouth several times a day with plain water or a mixture of 1/4 teaspoon of baking soda and 1/8 teaspoon of salt in 1 cup of water.
- Tell the doctor if your child's gums bleed or if there are white patches in the mouth. Both can be signs of infection.
- Teach teenagers to avoid tobacco use, which also irritates the mouth. If your teenager smokes, ask members of the healthcare team about smoking, "vaping" and tobacco cessation resources.



For more information about childhood dental care, visit the **www.mouthhealthy.org** from the American Dental Association.

Sleep. Sleep is an important part of healthy childhood development. See the chart below for recommendations from the American Academy of Pediatrics for how much sleep children need by age.

Age	Recommended Hours of Sleep per Day
4-12 months	12-16 hours (including naps)
1-2 years	11-14 hours (including naps)
3-5 years	10-13 hours (including naps)
6-12 years	9-12 hours
13-18 years	8-10 hours

Source: American Academy of Pediatrics

Even if your child slept well before the cancer diagnosis, some cancer treatments can cause difficulty sleeping. The following tips can help your child (and you) maintain a good sleep schedule:

- Create a bedtime routine.
 - \odot Go to bed and wake up at the same time every day.
 - Follow the same routine each night to set the stage for bedtime. For example, take a bath, put on pajamas, brush the teeth, use the bathroom and read a story.
- Create a relaxing sleep environment.
 - Provide comfortable bedding.
 - An infant should be placed on their back on a firm sleep surface such as in a crib or bassinet with a tightfitting sheet. There should not be any soft bedding, blanket, pillows or toys in the crib. Ask members of the healthcare team for safe sleep guidelines.
 - Let your child (with the exception of infants) sleep with a favorite comfort item such as a blanket or stuffed animal.
 - \odot Turn off lights, TV and electronics when it's time for bed.
 - □ A small night-light is okay if your child is more comfortable with a dim light in the room.
 - O Silence cell phones.
 - \odot Try a fan or white-noise machine to drown out distracting sounds.
 - \odot Encourage everyone in your home to keep noise to a minimum.

- Set your child up to sleep through the night.
 - \odot Be sure they use the bathroom right before going to bed.
 - Do not allow your child to eat foods containing caffeine and/or sugar and limit the amount of liquids they drink before bed.

Bed-Wetting. Bed-wetting is common among preschool-aged children. Children usually outgrow it. If your child wets the bed, use a plastic mattress cover and have extra sheets available for quick cleanup. If your child hasn't wet the bed for 6 months or longer but begins wetting the bed again, talk to members of the healthcare team for strategies to help cope with bed-wetting. Stress can sometimes cause children to start wetting the bed again, and cancer treatment can be a stressful time. Remember that wetting the bed is not your child's fault. Bed-wetting may cause your child to feel embarrassed or anxious so take care not to shame your child.

Play. Play is an important part of a child's development. Children learn, explore and process their emotions through play. Play can also be a source of exercise and a way for your child to socialize with other children. Throughout treatment, allow and encourage your child to continue to play and to do any of the things they enjoy and can do.

Bear in mind, though, that during treatment, the ways in which your child plays may change or certain activities may need to be modified or avoided. Talk to members of the healthcare team about what precautions to take during playtime. Examples of the sorts of issues that can affect your child's playtime include:

- Fatigue or other side effects from treatment. This may mean your child doesn't have as much energy for playtime as usual.
- A low platelet count that puts your child at an increased risk of bleeding. Activities that increase the risk of cuts and bruises may not be safe for your child.
- A low white blood cell count that puts your child at an increased risk of infection. Your child will need to avoid playdates with children who are sick.

If your child is hospitalized for treatment, continue to offer opportunities for your child to play. Many children's hospitals have a recreation or playroom with toys and activities for patients and their families.

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

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

- Do not have your child clean up after pets. If the pet has an accident, be sure to disinfect the area. Wash your hands well afterwards.
- Tell your child to avoid the pet's feeding area and litter box or dog pad. If your child encounters animal waste while playing outside, tell them not to touch it.
- 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 child (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 child does get scratched, clean the scratches well and check frequently for signs and/or symptoms of infection. Let the healthcare team know about scratches.



A child receiving a stem cell transplantation may need to follow stricter guidelines when around pets. Ask the healthcare team what precautions to take regarding pets and other animals.

• Keep pets up-to-date on vaccines and heartworm prevention. Use flea and tick medications and shampoo on pets to reduce the risk of diseases carried by parasites.

- Do not adopt new pets or take in strays during your child's 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 children in cancer treatment.
- If you live on a farm, your child may need to take antibiotics to prevent infections.
- Find a good pet sitter. If you will not be available while your child is receiving treatment, make sure there is a reliable pet sitter lined up to take care of the pet. Taking care of pets can often be a good task for family members and friends who want to help.

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 child's side during cancer treatment. Pets can offer benefits, too. Pets provide companionship, emotional support and motivation to stay active.



For more general information on parenting and health and wellness for children, visit **www.healthychildren.org** from the American Academy of Pediatrics.

Coping With a Childhood Cancer Diagnosis Notes
